Identifying & Addressing Developmental-Behavioral Problems: A Practical Guide for Medical and Non-Medical Professionals, Trainees, Researchers and Advocates

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INTRODUCTION

This book is devoted to primary care issues in the early detection, prevention, care coordination and intervention for families whose children have suspected developmental or behavioral problems (the latter also meaning mental health or social-emotional issues). We focus on the practical concerns facing physicians and nurses in private practice or public health, address their needs for brief, accurate techniques, and explain how these actually save time. We cover how to train others (or self-train) on the many issues of early identification, explain results to families, provide developmental promotion, how to find and collaborate with referral resources, and how to implement all these tasks in a way that is efficient, effective and do-able in primary care. The basics of child development and developmental disabilities are defined for nursing and medical students, residents, and other trainees.

We emphasize evidence-based methods of early detection, and hold that the process of screening and surveillance can and should rely on the same sets of tools.[1] For this reason, we often refer to the process as "screening/surveillance." Most providers, when exposed to options among tools, choose screens that rely on information from parents.[2] Such tools are more efficient, are as accurate as hands-on measures, and are decidedly more useful in busy clinics. So we promulgate in this book screening/surveillance tests that parents can usually complete on their own.

Clinicians tend to think of early detection in binary terms—should this child be referred or not? But a broader view is crucial. Early detection and intervention are preventive services of three different types:

> **Primary Prevention**—meaning that we spot harbingers of problems not yet manifest, and so address "the handwriting on the wall," by intervening with issues likely to cause problems in the future;

> **Secondary Prevention**—meaning we quickly spot mild delays, intervene, and restore children to developmental-behavioral health where possible;

> **Tertiary Prevention**—meaning we promptly treat those with manifest problems, and in so doing, prevent children's and families' difficulties from proliferating in even more problematic ways.

All this means that early detection is anything but binary. Rather, the measures we use must help us parse children who are:

(a) Typically developing and lacking psychosocial or biological risk factors—meaning we can reassure these families that their children are doing well and that parents are parenting well;

(b) Typically developing, lacking risk factors but whose parents need our advice and our vigilant monitoring of how well our advice worked, so that we can quickly decide when more help is needed;

(c) Typically developing or mildly delayed but with risk factors—meaning we must often marshal services other than specialized programs for children with disabilities in order to prevent future problems or further declines;

(d) Substantially delayed, with or without biological or psychosocial risk factors, and thus in need of specialized interventions.

So rather than think in simple terms, such as whether to refer/not refer to special services, instead we must think about gathering "the big picture"—using different types of evidence to more carefully decide what children and families need. The range of decisions we make requires a thoughtful recognition that early intervention is more than just special needs services. Early intervention includes:

(a) our efforts in primary care to carefully promote development and behavior;

(b) parent-training programs (when we recognize our brief advice is ineffective);

(c) community services such as Head Start, Early Head Start and quality daycare;

(d) mental health and social work services for families;

(e) specialized services provided by the Individuals with Disabilities Education Act (IDEA) for children with disabilities and private therapies.

This book also covers developmental promotion in primary care, information about the wide range of services available to our families, and how IDEA works (including terms you'll need to know). Needless to say, we view early detection and intervention as a collaboration among medical and non-medical providers, i.e., clinicians are not alone in this process. Health care is the fundamental starting point in early detection, but working effectively with interventionists is essential for doing the best we can for children with disabilities, those with risk factors who are not yet delayed, and for helping parents do their best at promoting their children's development.

For trainees—medical and nursing school students, pediatric and family practice residents, to those in developmental-behavioral or neurodevelopmental fellowship programs, and their preceptors—we devote space to explaining the nature of child development and its various domains. We lean heavily on the work of Lev Vygotsky to explain how children progress, i.e., via positive, joyful interactions between parent and child. To aid preceptors, we devote a chapter to training young professionals wherein the focus is on "over-training," i.e., learning to administer measures hands-on (instead of via parent-report) in order to make the constructs of child development meaningful and real, and to aid trainees in learning to manage children and families during testing—a skill that generalizes to medical care. Included is a detailed table of milestones helpful for training. Given our evidence-based bent, we include a pre-/post-test that can be used to measure learning.

Several chapters focus on unique populations and how to work with them effectively. There is a chapter on working with families with various cultural backgrounds (e.g., Latinos, American Indians, Asians, and Middle Easterners), how these families view child development, and implications for early detection and intervention. We also cover the issues of school-age children and present an algorithm for triaging their needs. The unique challenges of premature children and those in foster care are addressed with a focus on efficient but thorough measurement and follow-up. Another chapter is devoted to psychosocial risk and what to do about it. Within, we focus heavily on language development because it is the best indicator of various types of problems and the best predictor of future success in school.

Otherwise, you won't find much in this text on the specifics of various disabilities. There are many valuable books on these topics, described in the resource sections of relevant chapters. Our rationale for not focusing on specific conditions is that in primary care we are reasoning from the information we've gathered to come to a basic, non-diagnostic conclusion: a probability of a problem, its probable causes, and how to select optimal interventions. Rarely do we need to arrive at a definitive disability diagnosis, except at times, for specific health-related conditions. But even then, many health diagnoses, just like developmental-behavioral diagnoses, require help from medical subspecialists and/or non-medical professionals. This approach may feel like the antithesis of what we learned in medical training but given that "development develops and developmental problems do too" it often takes a long time, lots of information gathering, and many "eyes on the prize" to figure out the exact type of problem.

Back at the ranch that is primary care, our questions are more basic and in many ways more profound because we are "where the children are." It is our duty to assist families with needs, but this challenging job begins by learning to recognize the likelihood of problems, however vaguely defined these may be. And so our questions are broader than just a diagnosis. Does evidence suggest we need to refer? If so, where should we refer? If not, what kind of developmental-behavioral promotion is likely to be most effective? Are there other ways to best help families do the best for their children? We must gather a range of information and synthesize it in functional ways, i.e., how best to help. If all this smacks of Hegel's theory of dialectical materialism and Kant's synthesis of conceptual unification and integration, well, that's where we learned this too!

Okay, off our high horse! Meanwhile, research issues in early detection are many, and we cover these in a chapter devoted to test psychometry, optimal methods for studying existing measures, how to develop new items for research protocols, and how to translate existing measures into other languages and cultures. We also highlight directions for future research focused on the many issues in early detection and intervention in need of further study.

Other chapters concentrate on national and international models for optimal early detection and intervention, and describe initiatives in North America and world-wide. Included are projects in

developed nations such as Australia and Iceland, where there is an enormous infrastructure for promoting children's development. But we also cover efforts in countries with numerous economic and environmental challenges, such as Haiti, where parents and providers, despite earthquakes, homelessness, cholera, and limited access to safe drinking water, are still vitally interested in children's development and well-being. These initiatives serve as invaluable examples of approaches that could be adapted in North America—given our own extremes of wealth and poverty.

We conclude with two chapters on advocacy, including a personal perspective (from a professional whose experiences span Federal, State, and local lobbying, along with grass-roots initiatives to coordinate care and improve early detection). At the end, we summarize our thoughts and recommendations in a chapter called, *"Flying Off Into Sunny Skies."*

Best viewed as a "how-to" manual, this text is sprinkled with case examples to vividly illustrate the issues at hand and how to resolve them. We used pseudonyms and stock photography when talking about children and families, except when parents prefer to speak for themselves. We've tried to make this book as jargon-free as possible, and so we often write in the first or second person in hopes that this book feels like a conversation with you.

Please note that this book comes with a website, *www.pedstest.com/TheBook* wherein we house, chapter by chapter, downloadable materials useful for training and implementation. These documents are designed to be adapted as needed. Included on the site are live links to referral services, resources for life-long learning and training, templates for referral letters, well-child visit forms that remind us of the essentials of screening/surveillance, implementation work sheets, etc. Links to specific documents housed on the website are shown in each chapter.

Finally, because all of us (and this book) are "works in progress," please contact us through the site via *www.pedstest.com/ContactUs* wherein you can send us suggestions...and hopefully praise too!

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HOW TO NAVIGATE WITHIN THIS BOOK

We hope you read this riveting text from start to finish, but in case you are looking for specific information, below is a guide to what's within and how to find it. We also list the specific web pages for chapters with links to websites for professional and parenting resources and downloadable materials.

IF YOU WANT TO LEARN ABOUT:	*GO TO:*	*WEB PAGE WITH SUPPORTING MATERIAL:*	*WEBSITE CONTENT*
Early Intervention, Federally-mandated programs, eligibility requirements, glossary of terms in intervention, highlights of American Academy of Pediatrics policy on early detection	CHAPTER 1	*www.pedstest.com/TheBook/ Chapter1*	Links to sites with information on special services, enrollment rates state-by-state, etc.
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Measuring development and behavior including available tools	CHAPTER 4	*www.pedstest.com/TheBook/ Chapter4*	1. Downloadable list of quality measures for early detection with links to publishers 2. Downloadable surveillance-only measures focused on parent-child interactions and psychosocial risk
An efficient algorithm for screening and surveillance in the birth to 6-year age-range including what to do and when	CHAPTER 5	*www.pedstest.com/TheBook/ Chapter5* *www.pedstest.com/TheBook/ AppendixA*	1. Links to referral resources 2. Downloadable referral letters focused on two-way consent 3. Longitudinal screening/ surveillance checklist 4. Well-child visit forms showing staggered tasks for screening and surveillance across the 0 to 18-year age-range

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Triaging likely problems in school-age children: academic, developmental, mental health, etc.	CHAPTER 9	*www.pedstest.com/TheBook/ Chapter9*	1. Sample letter to schools requesting records 2. Downloadable directive for medications administered at schools 3. Referral resources for school-age children 4. Downloadable screens for mental health and academic achievement
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Training professionals in practice, including self-training, group-training, cross-training (with non-medical professionals), tips/ resources for training-the-trainer, and for life-long learning	CHAPTER 15	*www.pedstest.com/TheBook/ Chapter15* *www.pedstest.com/TheBook/ AppendixB*	1. Links to training materials including pre-/post-tests, implementation planning, and slide shows for presentations 2. Information on options for Continuing Education credits 3. Downloadable and modifiable certificate of attendance/ participation/mastery
Implementation issues and solutions for detecting and addressing developmental-behavioral problems in primary care	CHAPTER 16	*www.pedstest.com/TheBook/ Chapter16*	1. Sample clinic work-flow templates 2. Downloadable implementation planning worksheet 3. Information on reimbursement 4. Links to videos and slide shows on implementation challenges and solutions

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Well-child visit forms for birth to 18-years that identify and stagger screening and surveillance tasks	Appendix A	*www.pedstest.com/TheBook/ AppendixA*	1. Guide to well-visit tasks 2. Downloadable age-specific encounter forms
Measuring training outcomes	Appendix B	*www.pedstest.com/TheBook/ AppendixB*	Downloadable questions for use in training
Milestones for teaching and learning child development and behavior, including social-emotional and mental health	Appendix C	*www.pedstest.com/TheBook/ AppendixC*	Milestones charts for birth to 8-years-old

CHAPTER 1: WHY EARLY DETECTION IS CRUCIAL: INTERVENTION OUTCOMES AND SERVICES

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CHAPTER HIGHLIGHTS

IN THIS CHAPTER WE ADDRESS:

- The economic and social benefits of early intervention, whether through services for children with special needs, or through programs such as Head Start that focus on children with psychosocial risk factors;

- Federal policy on services for children with delays and disabilities, including eligibility requirements;

- Terms (and abbreviations) you need for understanding federally mandated intervention services;

- Terms you need to know for working with early detection and American Academy of Pediatrics policy;

- Programs dealing with children who don't qualify for special needs services but still have problems in need of intervention;

- Common questions about policy and early detection raised by primary care providers.

INTRODUCTION

Our goals, whether we are parents or professionals, are to prevent, detect, and intervene with developmental-behavioral problems as early as possible. For children with severe and life-long disabilities, as well as with those whose development is likely to be derailed by psychosocial risk factors (such as limited parental education, problematic parenting skills, parental depression, poverty, etc.), intervention helps and helps enormously. In providing intervention, we facilitate children's success in life, whether academic or vocational. If we can help children do well in something (although facilitating mastery of school skills is invaluable), they are far more likely to circumvent health risks (such as smoking and drug abuse), graduate from high school and hold jobs, and less likely to engage in teen pregnancy and criminal behavior or take steps toward suicide.

There is a strong consensus among researchers who study high-quality early childhood intervention (of which there are many different kinds of services), that these programs have substantial payoffs. Early detection and intervention confer not only enormous social benefits but also save tax payers enormous amounts of money. For every $1 we spend on early intervention, we save between $3.78 (Abecedarian study) to $17.07 (Perry preschool study), well above the 1:1 ratio needed to justify such programs.[1] If every low-income 3- to 4-year-old-child in the USA (about 20% of the U.S. population is classified as low-income) received two years of a quality early child development program, this 'investment' is predicted to generate a 16% annual return rate in cost savings to society.[1] Early child development programs provide economic benefits to society by decreasing elementary school remediation rates, frequency of high school drop-out, tobacco use, alcohol and drug abuse, teenage pregnancy and criminality. Early childhood development programs provide economic benefits by decreasing the chance of childhood abuse and neglect (and therefore, the number of children in foster care). Over time, such benefits translate into less poverty, less welfare dependency, a more educated work force, a higher national gross domestic product and a more stable U.S. economy.

Even economists who are skeptical about government programs make an exception for high-quality early childhood services. Well-respected economic analysts like Rolnick and Grunewald concluded that "Future proposed economic development should have early childhood development at the top."[1,2] A publicly financed, comprehensive early childhood development program for all children from low-income families (e.g., Head Start without a waiting list) would cost billions of dollars annually, but would create much larger budget savings over time. By about the 17-year mark, the net effect on budgets for all levels of government combined would have a positive return on investments. Within 25 years, if a nationwide program were started next year, the budget benefits would exceed costs by $31 billion (in

2004 dollars). By 2050, the net budget savings would reach $61 billion.[1]

In addition to Head Start and Early Head Start, America is fortunate to have enacted, in 1976, what is now known as the Individuals with Disabilities Education Act (IDEA). IDEA guarantees a free and appropriate education for children with disabilities starting at birth until age 21. IDEA is divided into two age-groups: Part C addressing services for children birth to 3 years of age and is commonly referred to (with capital letters to distinguish it from other types of intervention such as Head Start), as Early Intervention (EI); and Part B covering services for children 3 to 22 years of age, which is commonly referred to as special education, and in general involves public schools.

Overall, IDEA ensures that children with disabilities are guaranteed a free, appropriate, public education, just as for children without disabilities. The education of children with special needs is designed to address their unique learning requirements while preparing them for further education, employment and independent living.

In addition, the Americans with Disabilities Act (ADA, now ammended to ADAAA) and Section 504 of the Rehabilitation Act guarantees "right to access." ADA and Section 504 are responsible for services such as wheel-chair ramps, tape-recorded and large print books for children with visual impairment and reading disabilities, and behavior management programs in regular education classrooms (e.g., to help children with attention-deficit disorder succeed at grade level).

Below is a glossary of terms in early detection, intervention and federal mandates. It is designed to help you get familiar with the tenets of federal policy and with the terms used throughout this book to describe the early detection and intervention process.

Table 1-1. Glossary of Terms in Detection, Intervention and Policy

Term/Abbreviation	*Definition/Description*
IDEA	Individuals with Disabilities Education Act is the US federal law mandating a free and appropriate education for children with disabilities from birth to 22 years of age. IDEA has two submandates, Part B and Part C.
Part B of IDEA (special education)	Refers to services for conditions covered by IDEA for children 3 years to 22 years of age through the public schools, and is generally referred to as special education.
Part C of IDEA (EI or Early Intervention)	Serves children from birth to 3 years of age and is often referred to as Early Intervention (EI). As with Part B, different States have slightly different eligibility criteria. But, nevertheless, all IDEA programs provide free evaluations to determine whether a child qualifies.
Individual Family Service Plan (IFSP)	An ISFP is created within IDEA birth to 3 programs (aka Part C) to delineate specific services, goals, objectives and time frames for children's and families' progress. The goal of an IFSP for a child is to provide services, aligned with the goals of the family.
Individual Education Program (	Individual Education Program is used in IDEA programs for children 3 years to 22 years (aka Part B or special education) to delineate specific services, goals, objectives, and time frames for determining child's progress. An IEP differs from an IFSP in that it focuses only on the child's needs, not the family's needs (although families have input into goal-setting via the multidisciplinary meeting where the IEP is created and approved by all).

table continues...

Table 1.1. Cont'd

Least Restrictive Environment (LRE)	Maintaining children in the Least Restrictive Environment is the goal of IDEA programs which strive to keep children with special needs integrated with typically developing children as much as possible.
Early Intervention (EI)	EI, when capitalized, means services under IDEA Part C, but when appearing without capitalization refers to any service designed to promote healthy development and behavior for children who do not qualify for IDEA programs (e.g., Head Start, Early Head Start, Triple P: Positive Parenting Program, etc.).
ADAAA/Section 504	Americans with Disabilities Act Amendments Act (ADAAA) and Section 504 of the Rehabilitation Act, ensure right to access (e.g., wheelchair ramps, large print books for students with low vision, behavior modification in the classroom for students with ADHD).
Medical Risk Factors and Conditions	Many states ensure eligibility for IDEA services on the basis of health and biological conditions (e.g., extremely low birth weight, genetic conditions associated with a high probability of a developmental delay, in-utero exposure to a teratogenic substance, a significant health or physical impairment, traumatic brain injury, etc.).
Psychosocial Risk Factors	These are issues sometimes associated with developmental delay but otherwise are harbingers of delays in the future. Psychosocial risk factors include parents who have not graduated from high school, single or teen parents, parents with mental health problems (including depression and anxiety), housing/food/or employment instability, parents who don't speak English, lack social support, and most significantly, parents who lack skills in positive parent-child interactions and who may not promote development effectively. Children with risk factors are not likely to qualify for IDEA services but still need other forms of intervention.
Developmental-Behavioral Protective Factors or Resilience	Protective factors are positive parent-child interactions that enhance development such as frequent book sharing, parent-child conversations, vocal play, etc.
Development	Refers to all aspects of children's learning across all domains, including receptive and expressive language, fine and gross motor, cognitive, adaptive/ self-help. The term "development" is also inclusive of behavior, social-emotional and mental health domains. At times, the term "developmental-behavioral" is used merely to emphasize that development includes social-emotional, behavior and mental health.
Developmental-Behavioral Screening and Surveillance	Screening is the use of accurate, validated tests to indicate the probable presence or absence of difficulties. Surveillance is a flexible, longitudinal, continuous and cumulative process whereby knowledgeable providers detect and address current problems, as well as predictors of potential problems not yet manifest. Accurate surveillance depends on screening tests and other validated measures to ensure evidentiary support for decisions. This means that the same measures can and should be used over time for both longitudinal surveillance and for immediate decision-making via the results of screens, physical exam findings, etc.

table continues...

Table 1.1. Cont'd

Developmental-Behavioral Promotion	Developmental-behavioral promotion means addressing parents' concerns (e.g., about disciplinary methods) and actively teaching parents skills associated with typical development, such as how to talk and share books with children. Developmental-behavioral promotion is a critical part of early detection and should be provided at every well-visit.
Medical Home	Per the American Academy of Pediatrics, the "Medical Home" is where primary care providers establish centralized, comprehensive care for children with disabilities and chronic illness (whose care would otherwise be fragmented across services and thus absent the "big picture" of family's and children's needs and issues). The Medical Home coordinates care across subspecialists and services, communicates with agencies, maintains all records, and helps plan needed interventions.
HIPAA	The Health Insurance Portability and Accountability Act of 1996 protects the privacy of individually identifiable health information and sets national standards for the security of electronically gathered health data.
FERPA	The Family Educational Rights and Privacy Act protects the privacy of students' education records. Schools must have written permission from the parent (or the student if 18 years or older), in order to release any information from a student's education record. Parents and families have the right to inspect records and make corrections if they deem them misleading.
EPSDT	The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program is the child health component of Medicaid, required in every state, and designed to improve the health of low-income children. Screening services "to detect physical and mental conditions must be provided at established, periodic intervals (periodic screens) and whenever a problem is suspected (inter-periodic screens). Screening also includes a comprehensive health and developmental history, an unclothed physical exam, appropriate immunizations, laboratory tests, dental, vision, and hearing screens, and health education.
CAPTA	The Child Abuse Prevention and Treatment Act provides Federal funding to States in support of prevention, assessment, investigation, prosecution, and treatment activities for children who are maltreated, born to substance abusing mothers, who are homeless, etc. CAPTA grants establish reporting requirements for healthcare, education, and other agencies.

EARLY INTERVENTION ENROLLMENT RATES AND THE ENORMOUS PROBLEM OF UNDER-DETECTION

Although the effectiveness of early intervention is well established and services are available, most States' Early Intervention enrollment rates are about 50% less than the prevalence figures established by the Centers for Disease Control, *www.cdc.gov*, (which are 2% by age 1 year, 4% by age 2, and 8% by age 3). Public school special education enrollment is about 30% less than prevalence figures (which are 12% by age 5, and 16 – 18% by age 9 and older). This means that early detection and referral to IDEA is hugely problematic: Half of all children with special needs are not detected until kindergarten or later. Thus they've lost opportunities for earlier intervention—intervention that would have either eliminated or ameliorated their problems and facilitated school success.

Although IDEA legislation includes child-find services such as free screening for children suspected of problems, IDEA programs do not have access to all children in the way healthcare providers do. Since health care is "where the kids are," many States mandate that healthcare providers improve the methods by which they identify children with difficulties. In general, these mandates take the form of increased reimbursement when quality screens are administered, along with a list of approved (and non-approved, non-reimbursable) measures. Class action suits (e.g. against Cigna for failing to reimburse for screening in health care) are compelling private payers to comply. Meanwhile, the advocacy arm of the American Academy of Pediatrics is battling (in Congress, State legislatures, and with private payers) for appropriate reimbursement for screening–*at all well-visits*.

Several States (e.g., Tennessee, North Carolina, Hawaii, Massachusetts, Texas, Connecticut, Oregon, Minnesota) established their own mandates dictating the use of quality screens along with initiatives to train providers. Note that States' IDEA programs have differing eligibility requirements and some are far more stringent than others. Nevertheless, States with strong training initiatives, mandates, and reimbursement plans that cover the costs of early detection, clearly have higher enrollment rates than do States without such efforts. Table 2 shows examples using data from 2007 (*www.ideadata.org*).

Table 1-2. *State Enrollment in IDEA Part C (0 - 3-years) Eligibility Criteria by Presence or Absence of Mandates/Initiatives**

STATE	CRITERIA	MANDATES/ INITIATIVES*	ENROLLMENT RATE (FOR BIRTH TO THREE)
Hawaii	broad	yes	6.94%
Mississippi	broad	no	1.34%
Rhode Island	moderate	yes	4.61%
Louisiana	moderate	no	1.78%
Connecticut	narrow	yes	3.35%
Washington, DC	narrow	no	1.19%

* Initiatives include Help Me Grow (Connecticut), AAP State Chapter (Hawaii), KidsCount and other programs (Rhode Island).

Clearly, States with mandates for use of quality screens in primary care have more than three times the enrollment rate in IDEA programs than do States without mandates. But honestly, with or without mandates, we should do the right thing by families and children, i.e., use effective methods to detect problems and refer whenever we find difficulties. We'll guide you in subsequent chapters on how to best detect problems, but we know that one obstacle to referral is not knowing much about what's available. So for now, we continue with information on how IDEA works and how to obtain services for your patients.

THE PROCESS OF OBTAINING IDEA SERVICES

IDEA's Part C Programs (birth to 3-years) do not require a specific diagnosis. Instead, children receive a general classification of "developmental delay." This fact can present a conceptual challenge for healthcare providers who are accustomed to making a diagnosis before devising a treatment plan. But treating first and diagnosing later makes sense when it comes to young children because new delays can emerge with time and the defining characteristics of disabilities may not be evident immediately. For example, a delay in language development may be a precursor to deficits in cognitive skills that are not yet fully manifested. Time, intervention, progress tracking, and further evaluations will eventually identify the specific type of problem(s).

Even so, autism spectrum disorders (ASD) is one condition that should be diagnosed as early as possible so that highly focused interventions can be implemented. The diagnosis of ASD typically requires a multidisciplinary team, which often includes a physician, a developmental psychologist, and a speech-language pathologist. So when you suspect ASD, first refer to IDEA services (so that children receive prompt intervention even while waiting for a diagnosis), but simultaneously refer to ASD specialists (e.g., developmental-behavioral pediatricians, neurodevelopmental pediatricians, pediatric psychologists, speech-language centers, audiologists, autism subspecialty services of which many are within teaching hospitals' developmental evaluation clinics). Note that many such private services have lengthy waiting lists, so again, it is essential to get children enrolled in EI and treated while they wait (typically 4 to 9 months or longer) for a diagnostic evaluation.

    Eligibility criteria for EI (which varies across States) is generally determined by:

    (a) the presence of a condition that places a child at very high risk for future developmental challenges (e.g., a chronic or fixed health condition like Down Syndrome) and/or;

    (b) the degree of delay across domains (e.g., a 25% delay in two domains, or a 40% delay in one domain).

    See *www.ectacenter.org* for links to IDEA programs and their eligibility requirements, State by State.

    Here's what providers need to know and do:

    1. When a high risk medical condition is present, refer to IDEA via a referral letter in which you document findings, identify known or suspected conditions, and include suggestions for follow-up evaluations (e.g., speech-language, physical therapy). Refer also to subspecialty medical services when indicated.

    2. In the absence of medical contributors to the delays you've identified via screening/surveillance, document the results of measures you've administered, your clinical observations, suggested avenues for further evaluations, and then refer to IDEA.

    3. In either of the above situations, you will need to document vision and hearing status. IDEA programs can provide audiological and functional vision evaluations if recommended. But they are understandably reluctant to test a child who, for example, has an unrecognized hearing deficit, that might lead to a false conclusion that intellectual disabilities are present.

In any case, primary care providers don't need to make a definitive diagnosis most especially in the absence of known health conditions. Also, providers don't need to define the percentage of delay (in the case of birth to 3-year-olds). Children referred to IDEA programs will receive free evaluations to determine eligibility according to State standards. So, a primary care referral is simply a request that IDEA services provide further evaluations to determine whether delays or disabilities are present and eligibility criteria are met.

With Part C (birth to 3 programs) children receive an evaluation to determine whether delays are extensive enough to meet entrance criteria. Part B services (3- to 22-years), in contrast, require and provide more detailed evaluations, usually via a multi-disciplinary team assessment that, in turn, lead to a broad range of diagnoses (e.g., language impairment, intellectual disabilities, etc.). For some conditions (e.g., physical or health impairment, autism spectrum disorder, traumatic brain injury) documentation from healthcare professionals is a needed component of multidisciplinary team evaluations. States vary in terms of which professionals are needed to make a diagnosis, but all States have voluminous manuals defining which tests are approved for which condition and which types of professionals are needed to confirm a diagnosis. In Chapter 2, where we describe child development, its domains, and what promotes or deters it, we also describe common disabilities with a focus on those leading to eligibility for IDEA Part B programs.

REFERRING TO IDEA SERVICES: INTAKE TIME FRAMES, SUBSEQUENT EVALUATIONS AND PROGRAM PLANNING

- To find local IDEA (Part C, birth to 3 programs) follow links to *www.ectacenter.org* for contact information. There are usually toll-free numbers for each State;

- For IDEA Part B, i.e., children 3-years and older, you will need to identify the county (or city) school system in which the family resides, and contact the Director of Special Education or Psychology. The website for each school identifies where referrals should be made. Again, *www.ectacenter.org* includes contact information for Part B referrals;

- It is most effective if a clinician's office makes a referral and better still if you participate in a system-wide care coordination program, like Help Me Grow. Using this approach, families are far more likely to keep appointments. Advice for clinicians when families do not follow through with referrals is provided in Chapter 8;

- IDEA programs have 30 – 45 school days during which they are required to provide testing and establish an individual service plan. IDEA Part C will ensure a smooth transition to public school special education services, i.e., that diagnostic assessment is conducted and an Individual Educational Program (IEP) is in place. Nevertheless, Part C personnel may be understandably reluctant to provide testing for children who are close to turning 3-years of age—yet another incentive to detect children early. Refer to EI anyway but expect discussion about whether a school system referral would be more efficient;

- Once a referral is received, the intake process for IDEA whether Part B or C starts with in-depth screening or assessment, as well as observation, most especially if a child is enrolled in daycare, Head Start, or grade school education. In the latter cases, IDEA personnel first consider modifications to the existing program to determine whether, with supportive services, a child can remain in his or her current placement. These modifications can include behavior management, large print or recorded textbooks, auditory trainers, etc. If a child is not enrolled or when modifications are not effective, assessment is the next step;

- results are problematic and eligibility evident, IDEA professionals, parents, and other involved professionals, establish an Individual Family Service Plan (IFSP) for children 0 to 3-years or an Individual Education Program (IEP) in the case of public schools. The IFSP or IEP includes goals,

objectives, and instructional methods/materials, time frames, persons responsible, the supportive services each child will receive (e.g., speech-language therapy), the setting or program in which services will be delivered, and an annual date for re-evaluation in order to view progress and determine continued eligibility. Table 1-3 shows the range of supportive services available.

Table 1-3. Supportive Services Within IDEA Programs

Speech-language Therapy
Physical Therapy
Occupational Therapy
Behavior Management
Medications/Healthcare interventions at school
Special Materials in the Regular Classroom
Aide in the Regular Classroom
Aide on the School Bus
After-School Services
Summer School

RANGE OF PLACEMENTS

IDEA programs must strive to keep children in the least restrictive environment (LRE) due to federal mandates based on research showing that children tend to progress faster when exposed to typically developing peers. Table 1-4 shows the program placement options from least to most restrictive environments.

*Table 1-4. Cascade of Services from Least to Most Restrictive Environment**

Least Restrictive	Regular classroom with special materials or special education teacher consultation to the regular classroom teacher;
	Regular classroom with specific therapies provided but without pulling the child out of class for services, i.e., special educators come to the child for services (usually 30 – 45 minutes for each type of therapy);
	Regular classroom with an aide who works with one or more children throughout the school day;
	Regular classroom but child is pulled out for ancillary services (e.g., child leaves the class to go to speech-therapy);
	Special education classroom with some opportunities to interact with typical peers (e.g., gym, library, etc.). Some classrooms include children without disabilities who serve as role models;
	Special School (e.g., the child attends a full-time special education school). Most special schools arrange opportunities for typically developing children to visit and interact with special needs children;
Most Restrictive	Residential Placement (a 24-hour program, usually offered only short term, e.g., for a few weeks) devoted to intensive behavioral interventions, medication management, etc. followed by transition support for subsequent home and public school placement.

*Costs of services increase substantially as services become more restrictive.

ADVOCACY ISSUES IN IDEA SERVICES AND CHALLENGES IN NEGOTIATING

IDEA's educational plans (IFSPs and IEPs) are negotiated by group consensus. The group includes parents (but can include extended family and individuals who provide family support, such as a friend or mentor with a special needs child, and sometimes students themselves) and professionals (both those working with IDEA as well as outside professionals such as healthcare providers, private therapists, former teachers, etc.). Together, the group collectively determines the best plan for services, goals, etc.

Meanwhile, IDEA's budget is limited (Congress has only funded the mandate at roughly 40% of projected costs). School systems and IDEA programs are financially strapped, increasingly so given the current economy, and so schools continue to bear the brunt of costs for special services. Between the mandate for least restrictive environments and the fiscal challenges of providing expensive services, IDEA personnel tend to recommend minimalist approaches to intervention. That may well be reasonable, but it is helpful to know that the IEP and IFSP must include times for the group to reconvene, review progress, reassess, and determine whether more intensive services should be added.

The balance between least restrictive services and the expense of more intensive programs, means that parents' ability to advocate for services is a critical part of the process. Chapter 20 covers advocacy issues and how to get help for parents who need support. Also included is information on how the AAP's Medical Home model helps, information on the surrogate parent or guardian ad litem role (e.g., for foster children), due process under the IDEA mandate, and services to help parents advocate effectively for their children.

THE VALUE OF COLLABORATION BETWEEN HEALTHCARE AND IDEA PROVIDERS IN FACILITATING REFERRALS

It is essential to establish a referral relationship with IDEA services but anticipate that negotiating how best to collaborate will be needed. The non-medical professionals to whom healthcare providers refer, don't always respond in the way that the ideal sub-specialist medical provider would (e.g., call you back, explain findings, create a joint treatment plan, etc.). Clinicians need to take the lead in collaboration. Chapters 5 and 16 cover this issue (e.g., best ways to communicate, what information to share, two-way consent forms, etc.).

Non-medical providers often need clinicians' authorization for services such as physical or occupational therapy. So, you will definitely want to receive prompt assessment results detailing the recommendations from IDEA evaluations (and thus avoid the sense that IDEA programs create a "runaway train" wherein you are asked to prescribe services without adequate explanation).

Information sharing is a two-way street. You need information from IDEA services on how children are doing, and IDEA providers need your advice about children's healthcare issues especially when these require intervention at school (e.g., gastrostomy tube or ventilator care, administration of medications, health risks related to various conditions such as cardiac problems in Turner Syndrome or avoiding somersaults in patients with Down syndrome). We discuss how to communicate with programs and establish two consent forms (in which parents agree that information can be shared between your clinic and IDEA personnel) in Chapter 5.

DELAYED, AT-RISK, BUT NOT ELIGIBLE FOR IDEA SERVICES

It is immensely frustrating for healthcare providers to screen, document results, and refer, only to find that patients don't follow through or don't qualify for IDEA programs. Marks et al[3] studied 1427 moderate risk children at a large, pediatric group setting in Lane County, Oregon. Routine practice was to administer a general developmental screening instrument (the Ages & Stages Questionnaire) to children at their 12, 24 and 36 months well-child visit.[3] All pediatrician-generated referrals to IDEA programs were diligently tracked these over a 2-3 year period. Sadly, due to a myriad of reasons (e.g., family lost to follow-up, questionable delay and thus placed on a monitoring list, screened out, no parental concerns or refused services, etc.), nearly 50% of children who were referred with suspected delays were not enrolled in IDEA programs. So, it is important to know that:

1. IDEA programs focus on intervention, not prevention; and on substantive delays but neither on mild to moderate delays nor on elevated risk for delays in the future;

2. Children with delays but found ineligible for IDEA are not truly false-positives (meaning development is normal, but they just had a bad day, and so did not demonstrate the full complement of their skills). Rather, most children who do poorly on screens but don't qualify, have numerous psychosocial risk factors and mild to moderate delays. A substantial body of research indicates such children are likely to fall further and further behind without some kind of intervention, even if not through IDEA.[4,5] As disturbing, are recent findings suggesting children with risk factors are also likely to acquire various health problems.[6] So for these delayed, at-risk, but non-IDEA qualifying children, it is definitely time to think about early intervention in broader terms;

3. Children found to be ineligible for IDEA still need intervention and so providers need to cast a wider net and refer to other services (e.g., quality daycare, Head Start, parent training, etc.);

4. Children ineligible for IDEA, even when enrolled in other services remain at risk. Careful monitoring of developmental-behavioral progress is always needed but it is helpful to know that programs such as Head Start routinely monitor progress (and should be asked to share information with you);

5. In all cases, whether a child is referred or not, we still need to view developmental promotion as a preliminary approach to intervention. While promotion is hardly intensive, parents, whether their children need referring or not, still want and need guidance on how to parent well.

Although developmental promotion is invaluable, it is also essential for providers to recognize that a few minutes of advice at annual well-visits may not constitute intervention of sufficient intensity. So, it is important to monitor the effectiveness of developmental promotion and refer promptly to alternative services that may well prevent problems if not rectify them. Suitable programs include: Early Head Start, Head Start, quality daycare or preschool programs, parent training, social work services, after-school tutoring such as Boys and Girls Club, summer school, etc. For this reason your list of referral options should include a range of programs. See Chapter 5 for more information, resource links, etc.

So what to do for non-qualifying children with risk factors or delays? All of the following:

- Don't give up--continue to refer all children with suspected delays to IDEA services;

- If your patients don't qualify, find out why and then refer to other services that can help (e.g., Early Head Start, quality preschool/daycare programs, parent training, etc. See Chapter 5 for referral options);

- Offer developmental promotion suggestions to parents. (See Chapter 7 for various approaches and materials.);

- Determine whether your State's IDEA program offers monitoring (meaning they will check periodically on children's progress and reconsider eligibility in the future);

- If your State's IDEA program does not offer monitoring, you'll need to vigilantly check on children's progress (e.g., have families return between the usual well-visit appointments for re-screening, and encourage non-IDEA services to provide progress reports). See Chapter 5 for monitoring methods, problem checklists, etc;

- Document carefully in your health records, your findings and recommendations. Ideally, ensure there are "triggers" in each patient's record to identify when to rescreen (and as a reminder to check on whether families have followed through with your recommendations). See Chapter 5 and Appendix A for documentation suggestions including well-visit forms that help you capture information over time;

- Get to know your service community, establish feedback mechanisms between your clinic and referral services, so that you can collaborate on monitoring, information-sharing, and joint decision-making about other needed referrals;

- See the website for this book for live links and downloads (*www.pedstest.com/TheBook*);

- You can use the Notes pages at the end of the book to list local resources and contact information.

Chapter Comments*: Knowing that services are available and how to work well with non-medical providers (and establishing how they can best work with primary care providers) offer a comforting first step in willingness to detect problems and make referrals. We explain the "how-to's" of detection in subsequent chapters but we start in Chapter 2 by describing the nature of child development and what we are looking for in our efforts to discern children with typical development from those with difficulties.*

INTERNET RESOURCES ON IDEA ENROLLMENT AND PREVALENCE

Individuals with Disabilities Education Act (IDEA) *www.ideadata.org*
Provides State-by-State information on enrollment rates in IDEA programs [both Early Intervention for children from 0 to 3 years (also known as Part C) and Special Education for children 3 to 21 years (known as Part B)].

National Education Technical Assistance Center *www.ectacenter.org*
Houses links to Part C and Part B services State-by-State, and county-by-county.

Centers for Disease Control *www.cdc.gov*
Provides federal disability prevalence data (search the site for developmental screening and developmental disabilities).

Kids Count *www.aecf.org*
Within is information, state-by-state, on rates of children at risk (e.g., whose parents are unemployed, in poverty, in single-parent households, without health insurance, etc.).

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CHAPTER 2: WHAT IS CHILD DEVELOPMENT?

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INTRODUCTION

Delineated in this chapter are the domains that define development—an all-encompassing term that embraces many emerging skills including behavior, mental health, and social-emotional skills. For development to proceed age-appropriately, skills across domains must work together and so case examples by various ages are presented as examples. Just as development develops, developmental problems develop, and difficulties can be enormously varied. Definitions of delays and disabilities are described along with common causes including psychosocial risk. Features of resilience are also specified, as children can display resilience in the face of adverse events instead of exhibiting the downward trajectory that often accompanies psychosocial risk.

DEFINITIONS OF DOMAINS

First let's start by defining our terms. **Development** is a series of domains. Each domain typically has several subdomains (which are underlined below). These include:

1. **Cognitive (also called intellectual) skills** covers: rate of learning and short- and long-term memory (for what a child has seen, heard and learned including sequences required to complete tasks); information processing (ability to incorporate and integrate new learning) and most especially problem-solving—meaning how a child figures out ways to overcome challenges; work around things that are hard to do with creative ideas for fixing conundrums (e.g., No knife to cut a pizza? How about scissors instead?).

2. **Language** includes two broad subdomains, each of which has sub-subdomains that are preferably measured separately:

   (a) Expressive skills, i.e., the ability to communicate and be understood by others including facility with articulation of sounds and pragmatic skills or social use of language, which involves initiating, maintaining and terminating a conversation that embraces the listener's perspective and interests, and;

   (b) Receptive skills, meaning the ability to understand words, sentences and passages (and follow commands) when heard.

3. **Motor** includes two subdomains (that are preferably measured separately):

   (a) Gross motor, meaning the use of large muscles in the neck, arms, legs, back and torso to move around effectively, and;

   (b) Fine motor, includes the use of hands, fingers, and wrists to execute refined tasks such as using utensils to eat, ability to draw, write, and eventually use tools like screwdrivers, keyboards, needle and thread, DVD players, etc.

4. **Preacademic/academic** covers knowledge of shapes, colors, and eventually letter names, words in print, comprehension of written words and passages; ability to spell and write words on his/her own; and eventually to create "talk written down," i.e., express himself/herself in writing. In older children, academic skills become more diverse and include:

   (a) Math (often subdivided into computational, and applied or word problems);

   (b) Reading (usually subdivided into word attack (phonics); sight word vocabulary; and reading comprehension (which itself is typically subdivided into literal, meaning recall of content, and inferential, meaning drawing conclusions);

   (c) Written Language (divided into spelling skills and ability to write sentences, paragraphs, and eventually essays); and

   (d) Knowledge (broken out into science, social studies, and humanities).

5. **Self-Help** (sometimes called **adaptive behavior** or **personal-social**), covers acquisition of basic skills with hygiene, dressing, explaining where he/she lives, knowing phone numbers, and eventually household maintenance: Cooking, cleaning, home repair, running errands, etc.

6. **Behavior,** includes two subdomains: <u>Behavior</u> (often referred to as "conduct") and <u>Social-Emotional/Mental Health</u>. The two subdomains overlap considerably. For example, complying with rules and turn-taking (behavior) also depends on respect for others and knowledge of social conventions (social-emotional).

The <u>Behavior</u> subdomain includes:

(a) Willingness to comply with rules when asked, understand why complying with rules is wise, ability to remember rules and conform to rules (even when no one is watching);

(b) Ability to be still long enough to focus on the tasks at hand;

(c) An age-appropriate attention span to facilitate taking in new information.

The <u>Social-Emotional/Mental Health</u> subdomain includes:

(a) <u>Sense of well-being</u> or self-esteem (e.g., a positive outlook on life with an increasingly realistic sense of one's own strengths and weaknesses);

(b) <u>Relating</u> to siblings, parents and close relatives, ideally with joy and affection;

(c) <u>Interest</u> in less than familiar people, new events and objects, but with appropriate wariness of strangers, novelty, and especially dangers;

(d) <u>Emerging respect</u> for others including their well-being, rights, and property (e.g., increasing self-restraint with decreases in stealing or lying);

(e) <u>Empathic responses</u> to others (e.g., refrains from bullying or teasing in a way that is unkind, hurtful or cruel, and is increasingly tolerant of diversity;

(f) <u>Understanding social conventions</u>, with demonstration of at least some compliance with social norms—noticing and imitating how others behave, dress, what they are interested in, etc.—although adolescent rebellion is common, healthy, and a typical developmental phase (e.g., long hair, quirky clothes, etc.);

(g) <u>Adjusting to life's challenges</u>, learning to regulate and cope with difficult emotions, such as anger, disappointment, fatigue, etc., and bringing these skills back into the behavior/conduct domain so as to behave in increasingly mature ways (e.g., fewer outbursts);

(h) <u>Acquiring a shared perspective</u> on life and the world, i.e., a communal reality that in general, makes sense to others (e.g., decreasing nightmares and night-terrors, and no hallucinations).

Now, back to the domains we've listed above. If you've noticed an enormous overlap among the various domains and subdomains of development, you are so right! For a child to have typical development, skills across the many domains/subdomains have to work together. Several examples are described below.

How Domains Work Together

Example 1. If you ask a child to pick up toys, this requires that she understand the request (*receptive language*), remember what was asked (the *cognitive* skill of short-term memory), have the ability to move to where the mess is (*gross motor*), locate the appropriate container where toys should be stored (cognitive, i.e., long-term memory), pick up and then release the toys (*fine motor*), and the attention span and the willingness to comply with requests (*behavior* and *social-emotional* skills). She also needs to be able to hear and see well enough, and to have the necessary energy that good health provides.

Example 2. When we ask a child to get dressed without prompting, this requires a willingness to comply (*behavior* and *social-emotional* skills), an ability to recall routines such as time of day and memory for the necessary sequences in which tasks need to be executed, such as knowing that he has to put his pants on before his shoes and socks (various kinds of *cognitive* skills). Next, the child has to be physically able to pull on his shirt, pants, coat, etc. (*gross motor*). Then he has to deal with many kinds of fasteners like buttons, zippers, and shoe laces (*fine motor/self-help*).

We also hope children notice what other people wear, care at least a little about their appearance, and so figure out that plaids and polka dots don't go together, and that it isn't desirable to wear stained and dirty clothes (the *social-emotional* skill of interest in others). So success with this task requires skills across myriad domains, and as usual, visual and auditory acuity, and overall good health and energy.

Example 3. Domains and subdomains overlap even more when it comes to infants. For example, when a baby is fussing in her crib and then hears her dad's voice in another room, she will most likely quiet a bit because she remembers his voice, associates his voice with a soothing and pleasant experience, and anticipates his coming to play with her (*cognitive*/memory+*receptive language*+the *social-emotional* skill of relating to family).

But if a stranger appears, the baby will probably stop smiling for a bit and just stare (*cognitive*, i.e. memory for what is familiar and what is not+the *social-emotional* skill of interest in others but also wariness about the unfamiliar).

In contrast, if her dad walks in, she will likely smile in recognition (*cognitive*/memory + the *social-emotional* skill of relating to family). Next, she will probably coo or make other sounds [*expressive language + social-emotional* skills].

She will surely wriggle, reach out her arms, and if her dad picks her up, she may try to grab his glasses or his hair (*gross motor+social-emotional+fine motor*). He'll wince and gently say "No" as he tries to extract his glasses and hair from her fist. She'll notice that wince and with time will learn that people aren't too crazy about having their hair and glasses pulled, and so she'll eventually stop doing it (*cognitive*/memory+ *social-emotional+behavior*). With time she will also learn the meaning of "No" (*receptive language*).

Hopefully, her dad will talk to her and ask her about her day (even though she can't understand his words quite yet) and he'll also imitate the sounds she is making in response. She'll repeat her own sounds after her dad imitates her and she'll smile at this game (*cognitive/*memory+*receptive language*+*expressive language+social-emotional*).

Then, he might make a new sound for her such as "da-da-da-da" and then smile and point to himself. She'll start to associate that sound with him (*cognitive*/memory+*social-emotional+receptive language*).

Day after day, he'll keep playing enthusiastically with that sound and offer her ones that sound more like "da-da-da-DY." She'll imitate that with a social-emotional response, i.e., excitement. Her dad will get excited too. As they repeat this game over time, she'll eventually say, "Daddy!" when her dad is in front of her and encouraging her imitations (*expressive language+receptive language+cognitive*/memory+*social-emotional*) and she'll receive an even more enthusiastic responses from her dad. So his excitement at her efforts helps her learn that some sounds have unique meaning that get a unique and positive response.

Eventually, whenever she sees him, she'll say "Daddy" which means that "Daddy" is slowly becoming a word with specific meaning (*expressive language+receptive language*). She will surely over-generalize for

a while and call other adult males "Daddy." But eventually she'll figure out that's not quite right and doesn't get the same happy response as it gets from her dad (*cognitive*/memory+*receptive language*+*expressive language*+*social-emotional*). With experience, and as her memory skills improve with age, she'll only say "Daddy" to her dad, and later she will be able to hold onto a mental image of him that she associates only with the sound "Daddy."

"Daddy" is now a real word! And very soon, she will call for him even when she can't see him, and most especially if her Mom isn't giving her exactly what she wants (*behavior*+*social-emotional*+*self-help*+ *cognitive*/memory+*problem-solving*+*expressive language* skills)!

Comment on Developmental Domains: *The interplay of various domains is critical for new learning. And in infancy, indeed throughout childhood and adolescence, social-emotional engagement, together with communication opportunities (meaning chances to listen and chances to be heard) drive most of a child's learning. The association between positive warm interactions with parents: Adults who notice and respond to a child's interests, point out new things, and communicate, is often referred to as a "mediated learning experience" (sometimes also called the "transactional nature of learning," "cultural mediation" or "social reciprocity"). These terms all mean that children's behaviors and interests should shape parents' responses, and that parents' responses, interests and activities should shape children's behaviors. Such interchanges are the core of new learning.*

We include in Appendix C, a detailed table of milestones across all domains from birth to age 8. The table was compiled by many developmentalists in order to offer support to trainees, clinicians and possibly parents. Under no circumstances should this table be used as a screening tool—the milestones are set at the 50th percentile (meaning half of all children will not be able to do these tasks) and the items are insufficiently defined for quality measurement. Rather, these milestones serve only as a guide for observing and teaching child development. You can also download the milestones checklist on the website for this book: www.pedstest.com/TheBook/AppendixC.

DEFINITIONS OF DELAY VERSUS DISABILITY

The term "delayed" is often a catch-all phrase for children whose development is behind that of their peers. "Delayed" is a helpful professional term for children for whom a diagnosis has not been made, i.e., when a screening test reveals that a child is behind. But terms like "delayed" or "slower learner" can be confusing for parents because it connotes ability to "catch up." Although some children do catch up, one-time administration of screening tests does not give us information on rate of progress over time. (See Chapter 8 for recommendations on explaining results to families). Finally, "Developmentally Delayed" also has an official meaning because it is used by used by IDEA (Part C) for children birth to three-years who are eligible for services, i.e., as a general diagnosis—even when a child has a condition likely associated with a disability (e.g., Down Syndrome).

Starting at three-years of age, when children are eligible for IDEA (Part B), the term "disability" is used and thus reflects more discrete diagnoses (as described below). Even so, some children who are far behind their peers are not found to be eligible for special education. Thus the term "delayed" is also used to describe children who are failing in school, held back in grade, etc. Below is additional discussion about the meaning of developmental delay and disabilities. Definitions and typical determination criteria are provided in Table 2-1.

Developmental Delay occurs in about 25% of children and refers to weaknesses in one or more domains of development, i.e., performance is below average (e.g., less than the 25th percentile for school-aged children, or more often, less than the 16th percentile compared to peers of all ages)—meaning that 75% - 84% of same-age children do lots better. While performance around the 16th percentile may not strike you as problematic (it is indeed fine for height, weight, and head circumference), when it comes to school skills, the 16th or even the 25th percentile is not a happy place to be. In a classroom of 20 children,

there may be only one child who is that far behind. He or she will quickly notice performance deficits and this often leads to frustration, misbehavior and diminishing self-esteem.

A child with delays who has not had intervention will come into kindergarten already behind (e.g., can't name letters of the alphabet when she sees them). Teachers, meanwhile, aim instruction toward the middle of the class, meaning that a child with delays will not understand much of what is going on. And that's bad because it means a child with delays isn't learning much: It is hard to learn from instruction (e.g., sounds of letters) if you don't have enough prerequisite skills such as ability to recognize the shapes of letters. All this means we want to catch delays early, even in infancy. If we can identify and intervene with delays, we have a chance of helping a child catch up before he or she has a miserable school experience. Still, not all children with delays can catch up even with the best of help. Some remain "slower learners." Some delays progress to disabilities. But in all cases it is definitely worth intervening early so that delays and their social-emotional comorbidities can be prevented or at least ameliorated.

<u>Disabilities</u>. The Centers for Disease Control states that 16% – 18% of the 0 – 18-year-old population has a developmental disability (*www.cdc.gov*). For adults, this jumps to ~ 22% mostly due to added mental health issues (*www.surgeongeneral.gov*). Because there is overlap between disabilities and delays, overall about 22% of our population faces challenges—challenges that are evident most immediately when children are faced with school tasks. While this figure may seem high, we are talking about the most sophisticated of human aptitudes—communication, literacy, vocational skills and employment, organizational ability (e.g., to balance a checkbook, pay bills on time, cook nutritious foods, navigate in cities, etc.). So it is actually surprising that about 80% of us can actually do all these things well, and thus understandable that 20% or more have significant trouble, and trouble in various ways.

Below we describe the conditions that qualify a child for special education services. Entrance criteria are stringent and many children with problems do not qualify. IDEA programs serve only about 12% of the population of children in the 0 to 22-year age-range—not the 16% - 18% or more who struggle with unidentified disabilities (including those with substantial deficits but who are ineligible under various State criteria); and certainly not the full 22% with mental health and/or developmental disabilities, given that mental health issues are the single most under-served problem in children, youth, and adults. Only about 5% of children with mental health problems are served under IDEA.

IDEA is a good start, even if we still have to figure out what to do for children with problems but who are not eligible. Determining that a child is disabled or delayed enough to qualify for IDEA requires careful evaluation—far more than can be accomplished with the brief measures appropriate for primary care. Each State has eligibility requirements that identify the various types of professionals needed, the measures they can use, and the criteria they must apply to various test results before deciding on the type of disability (or extent of delay). Typically, the determination of an exact type of disability is deferred until children are 3-years or older—meaning that, sometimes and confusingly, 0 – 3-year-old children in IDEA programs are usually referred to as "delayed" even if they have syndromes or other conditions that will likely lead to a disability determination later on.

So what are the various types of impairments? Which ones are most common? What should we look out for? Not that a screening test should ever be used to make a diagnosis but, it is important to know what we are looking for when we screen, i.e., what are the most common difficulties. Too often we focus on motor disorders, which as you can see, in the table below, are much less frequent than speech-language disabilities. And, we need to remember that most disabilities, especially in young children, are very subtle and require measurement before we can discern a likely problem. When we hear the word "disability" we are likely to picture a child with major motor impairments or syndromes—who look different from most kids. Not so! Only about 15% of all children with disabilities have an observable syndrome or condition, meaning that 85% appear physically normal. Again, disabilities are usually imperceptible without measurement and we must screen with quality tools if we are to identify probable problems.

Table 2-1. Categories and Prevalence of Disabilities Under Part B*[1-17]

Category	Typical Eligibility Criteria under IDEA	Prevalence*
Speech-Language Impairment (e.g., receptive, expressive, and phonological/ articulation deficits and disorders)	A significant discrepancy between expected performance based on IQ and actual performance in language (i.e., language skills 1 – 1 ½ standard deviations (sds) below IQ, or determination by a speech-language pathologist of disordered language (e.g., words are out of order when speaking; difficulty repeating /paraphrasing/ understanding language as well as their peers do;) or disordered articulation/ vocalization (e.g., presence of a lateral lisp; stuttering with repetitions of the initial sound in a word such as "m-m-m" rather than the typical "mom-mom-mom"; unusual sound substitutions such as the guttural consonant "g" for labial consonant "b").	~ 7% (up to 17% if including children with delays, i.e., performing 1 to 1 ½ sds below average)
Emotional/ Behavioral Disturbance (e.g., depression, anxiety, disruptive behavior disorder, schizophrenia, etc.)	A school, clinical psychologist or psychiatrist must identify academic deficits along with the presence of a mental health condition that characterized by: (a) substantial difficulties with learning that cannot be explained by intellectual, sensory, or health factors; (b) substantial difficulties with building or maintaining satisfactory interpersonal relationships with peers and teachers; (c) Inappropriate types of behavior or feelings under normal circumstances; (d) A general pervasive mood of unhappiness or depression; (e) A tendency to develop physical symptoms or fears associated with personal or school problems.	~14% - 22% (increasing with age and often overlapping with developmental problems)
Learning Disabilities (e.g., various types of reading, math, written language or processing problems)	A significant discrepancy between expected performance based on IQ and actual performance in one or more academic skills (e.g., reading comprehension or decoding skills) usually 1 - 1½ standard deviations below IQ, or determination by a school psychologist that processing deficits are present.	~7%
Attention-Deficit Hyperactivity Disorder (ADHD)	Requires a statement from a physician plus observation in the classroom often by a school psychologist. Children with ADHD alone do not qualify for special education but can receive help under Section 504 which can offer behavioral management programs in the regular classroom, teacher consultation, administration of medications at school, etc.	5% - 10%
Intellectual Disabilities (formerly called mental retardation)	A developmental or school psychologist is required to test IQ and adaptive behavior. In most States, both quotients need to be < 74	~ 1%

<div align="right">table continues…</div>

Table 2-1. Cont'd

Autism Spectrum Disorder	Requires a statement from a physician and most often diagnostic testing from a speech-language pathologist and developmental psychologist.	0.7% - 1.1%†
Orthopedic Impairment (e.g., cerebral palsy, motor coordination disorder)	Requires a diagnosed motor disability plus substantive academic and self-help deficits. Enables students to use augmentative communication systems (also the case for those with oral-motor disabilities) and other adaptive equipment, etc.	~ 2%
Hearing Impairment	Requires a diagnosis from an audiologist plus confirmation of academic deficits. Enables students to receive modified teaching materials (e.g., sign language, total communication, speech-language therapy) and special curricula.	< 1%
Vision Impairment	Requires a diagnosis from an opthamologist and a functional vision specialist plus verification of academic delays. Enables students to receive modified teaching materials (e.g., large print, books on tape) and special curricula (e.g., orientation and mobility training).	< 1%
Traumatic Brain Injury	Requires a diagnosed brain injury along with proven deficits in academics. Provides curricular modifications for children who may need to be out of school for long periods, administration of medications, nap times, as well as special education instruction.	< 1%
Other Health Impairment (e.g., seizure disorders, chronic illness)	Requires a diagnosed chronic health problem along with deficits in academics. Provides curricular modifications for children who may need to be out of school for long periods and in homeschooling in the interim, administration of medications at school, nap times, as well as special education instruction.	< 1%

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Note that IDEA programs have a category of special service for children who are gifted or talented [defined as performance 2 or more standard deviations above the mean for IQ, academic skills, or other talent (as defined by a panel of teachers, psychologists, etc.] Prevalence for gifted and talented is < 1%.

† 2013 studies found prevalence closer to 2% but with remission or diagnostic reassignment in 32% to 40% of cases. See Fein D et al. Optimal outcome in individuals with a history of autism. <u>Journal of Child Psychology and Psychiatry</u>. 2013; 54(2): 195-205; Blumberg et al. Changes in prevalence of Parent-reported autism spectrum disorder in school-aged US children: 2007 to 2011-2012. <u>National Health Statistics Reports</u>. 2013;65:1-7.

DISABILITIES AND CO-MORBIDITIES

Disabilities often co-occur and children may acquire additional problems over time. For example, it is hard to be a child with trouble communicating and so it is none too surprising that secondary behavioral-emotional problems may develop (e.g., depression or anxiety, acting out in frustration, limited attention due to difficulties understanding what is being said). The same goes for children with cognitive deficits: They can usually tell that other kids do things much better. Unfavorable self-comparisons may be depressing or anxiety-provoking and so such children may actively avoid challenging tasks (e.g., don't want to go to school, don't like to read, don't get as much practice as others, and thus fall further and further behind). When children don't understand what is being taught or if they can't hear or see well enough, they are more likely to daydream or fidget (e.g., show signs of attention-deficit hyperactivity disorder, even when ADHD is not the root of the problem). Secondary emotional problems are common and add to the burden of children with existing disabililties. Thus we must do our best to prevent "co-morbidities." Chapter 9 describes in more detail the challenges facing school-age children and the common co-occurrences of developmental and mental health disabilities. Many co-morbidities are not secondary but rather co-occur. Be especially alert to the fact that problems with speech-language are:

1. The most common type of delay or disability;

2. A main feature of other disabilities too (e.g., autism-spectrum disorder, intellectual disabilities, motor disorders and sometimes learning disabilities)—all meaning that we must use tools that do a good job tapping speech-language skills (while not short-shrifting measurement of other domains), and;

3. Sadly, speech-language impairments are the least diagnosed of all disabilities. Even when spotted there is a huge tendency to "defer, defer, defer" rather than "refer, refer, refer." Wrong and wrong! We need to do better than this—early prevention and intervention work—and that's the reason we need to screen well, early, and often. Chapter 10 describes issues of language development, its manifestations in a range of disabilities, and how and why to look very carefully at bilingual/dual-language learners and those with psychosocial risk factors.

Although we never diagnose problems from screening tests, we do want to make sure that when we refer children for additional testing or services, we review performance patterns on screens, add our clinical observations, spell out in our referral letters the types of evaluations that seem needed, and note vision and hearing status. Chapter 5 includes examples of referral letters that serve as templates for describing your findings and for recommending the possible foci for subsequent evaluations.

Comment on Types of Disabilities: *To most parents and providers, the term "disabilities" connotes life-long impairment. But life-long disabilities are not always the case. When it comes to IDEA services and their eligibility criteria, the central goal is helping children unable to thrive with the usual school curricula. Many children with substantial disabilities do well once they graduate, (e.g., will hold jobs, earn a living, live independently, marry, own a home), although they may have ongoing trouble balancing a checkbook, reading technical training manuals or filing tax forms. Others will need supervised living to help with food preparation, eating or hygiene. But for most children, school is or will become, the first and most challenging aspect of their lives. We must to do our best to help them and to prevent secondary co-morbidities. This mission includes identifying potential problems as early as possible, intervening with likely causes and facilitating needed interventions.*

CAUSES OF CHILDHOOD DELAYS AND DISABILITIES

We won't dwell much on health-related or inborn conditions (syndromes, metabolic errors, birth trauma, injury, etc.). These are well-known predictors of delays and disabilities and their detection depends on a quality neurological exam with attention to neuromotor, genetic markers, and behavioral variables (as highlighted in Chapter 5). We often think disabilities are consistently observable (e.g., Down Syndrome, Williams Syndrome, etc.), but that is rarely the case. Overt dysmorphology (meaning physical characteristics obvious to the naked eye) is only apparent with ~ 15% of all children with disabilities—meaning that ~ 85% of children with disabilities will look for all the world like typical children, and that means, we can't spot them just by physical exam and visual inspection.

Even if we could do sophisticated imaging to see how brains or bodies fail to work optimally, all that enormous expense won't do much to solve children's problems. So, given that biological causes are hard to detect (although must make sure that all children are as healthy as possible, hear well, see well and don't have any untreated but treatable medical conditions), we should always conclude that early educational intervention is the best, optimal course. But that still leaves us to ponder whether some problems might be deterred or ameliorated. So what else should we look for?

THE MOST COMMON CAUSE OF DELAYS: PSYCHOSOCIAL RISK

Psychosocial risk is the leading cause of developmental delays in early childhood. Psychosocial risk refers to external factors that contribute heavily to weaknesses in the better predictors of school success: Language development, pre-academic/academic skills, and cognitive skills. There are many contributors including: Parents with less than a high school education, who are single parents, are unemployed, have mental health problems (of which depression and anxiety are particularly common), housing/food instability, three or more children in the home, limited facility with English, limited literacy in any language, being among an ethnic minority, and most particularly a problematic parenting style. Four or more of these psychosocial risk factors lead to performance at or below the 16th percentile, which is fine for height, weight, and head circumference, but is not fine when it comes to school preparedness and likelihood of success in school.[18] Children who enter kindergarten with skills below the 25th percentile are walking in the door well behind their more advantaged peers. They tend to fail, be retained in grade, and to drop out of high school—and thus is repeated the "cycle of poverty."

We can do lots to prevent such troubling outcomes if we identify risk factors early—and preferably well before delays are observable. For example, we can vigorously promote development, ask social services to assist in finding mental health counseling for parents, housing, drug abuse treatment, domestic violence shelters, job training and employment. We can also assist by understanding, recognizing and intervening with one of the most important contributors to delays: Parenting skills that do not propel optimal developmental-behavioral outcomes.

Parents, as those of us who are parents well know, are rarely trained in the challenges of child-rearing. Some of us lack role models for how to share the joys of communication or how to discipline our children in a way that teaches them better ways to behave. We need to spot and intervene with families in need of better parenting skills—pronto—and well before delays (or potential maltreatment) are evident.

There are two worrisome types of parenting styles:

1. **Neglectful**. This style is sometimes (but not always) a cause of infants' failure to gain weight, apparent in signs of child abuse and hygiene problems, and in parents who don't come for visits with an extra diaper, food or toys for their children or who just don't respond to their child's efforts to communicate (e.g., a parent may only talk to their baby when she cries, but not when she is calm, attentive and facing the parent). Such parents are often overwhelmed and depressed. Mental health interventions and/or housing/food/child care assistance for such parents are usually needed. Parent training is essential. Referrals to protective services are needed in the case of abuse or neglect.

2. **Authoritarian** (also called punitive). This style is visible in parents who mostly yell "No" at their children but don't engage their child in conversation, don't talk with their children about the safe things they are touching or playing with; and don't praise their children for good behavior. These parents often don't know how to communicate with their child, are unskilled at parenting, and are almost always overwhelmed and anxious. Parent training is much needed as is assistance helping families address and cope with life stressors. Referrals to protective services are needed when parenting is exessively punitive.

Both types of problematic styles are characterized by limited back-and-forth communication between child and parent. We know that for optimal language learning, children must have lots and lots and lots of conversations (including parent-child sound play as babies). Orders barked at children don't do much to promote communication and well-being. Watching TV doesn't do much either. Parent-child interactions have to be a conversation, and without that there will inevitably be a delay in learning language skills that, in turn, creates an enormous risk for delays in learning pre-academic skills. These delays in turn lead to school failure, high school dropout, unemployment, etc.

Better parenting styles, those less associated with problematic outcomes, are:

1. **Permissive.** This approach to parenting allows children to "rule the roost," interrupt adult conversations, climb all over the furniture and… sometimes make the rest of us crazy. But these parents are clearly attentive and verbal with their children, as their children are with them. So, while the children of permissive parents may seem "out of control," such children are learning well (although some declare understandable preferences for a bit more structure via excessive demandingness).

2. **Authoritative** (not to be confused with the _Authoritarian_ style). Authoritative parents pick up on their child's interests, point out new things, and engage in two-way communication. But they also lay down some clear rules for what is acceptable behavior and what is not.

RESILIENCE (ALSO KNOWN AS PROTECTIVE FACTORS)

Some children have psychosocial risk factors that would ordinarily suggest a likelihood of developmental-behavior delays. But despite such risk, some children thrive and do well. How does this happen against the odds? There is much research on resilience factors showing that these facilitate success in school and in life.

Resilience factors for young children include:

- Positive parenting styles, i.e., permissive or authoritative, wherein parents actively and age-appropriately teach children new things, label objects of interest, talk with children at meals, share books with their children, perceive their child as sooth-able, and as interested in conversing (including back-and-forth sound play in infancy, playing peek-a-boo, etc.);[18,19]

- Parents who have good mental health (are not depressed, anxious, etc.).[18,19]

Resilience factors for older children include:

- A responsive and interested parent;

- Good mental health in parent and child;

- A child's own success in something…anything! Success helps prevent mental health problems because it brings self-confidence, and increases interest in learning and working;

- Success in school is optimal, of course, but even if a child is not the best of students, then success (and pride) in other accomplishments also works well (e.g., in music, sports, art, fixing things, helping others, etc.);

- Having an encouraging mentor or a supportive parent is also critical. When outside mentors are needed, it is wise to refer to programs like Boys and Girls' Club, volunteering, after school clubs, scouting, etc.

INTERVENING WITH PSYCHOSOCIAL RISK AND PROMOTING RESILIENCE

There is much that can be done to prevent the adverse impact of psychosocial risk and encourage resilience. Identifying both risk and resilience requires measurement and skilled observation—informal tools are not sufficient (as discussed in Chapter 3). In Chapter 4 we present measurement options including tools to identify risk and resilience. Chapter 5 shows how to detect difficulties during a brief primary care encounter. Chapter 7 describes methods for brief intervention in primary care and what to do if advice to parents is not effective. Chapter 10 goes into greater detail on the impact of psychosocial risk on language development (inarguably the most critical and predictive domain of development in preschool age children) and how to tease apart the impact of psychosocial risk and language delays in the face of bilingual/dual language learning. Chapter 10 also houses effective tools downloadable on *www.pedstest.com/TheBook/Chapter10*.

Chapter Comments: Child development is an intricate system of interrelated domains promulgated by parent-child interactions. Observing and measuring a child at a single well-visit is a momentary snapshot. Development develops. Developmental problems do too. We need to repeatedly measure development, as well as risk and resilience. The adverse impact of psychosocial risk coupled with a lack of resilience becomes increasingly manifest during the early childhood years. For instance, the medical risk factors (which might predict substantive developmental problems) of prematurely born children are often eclipsed by psychosocial risk and lack of protective factors. Psychosocial risk is also associated with increased health risk—asthma, obesity, high lead levels, to name a few. So, our efforts at early detection and intervention must be nuanced and thoughtful. When it comes to young children we have two tasks: (a) to figure out those who have current delays, however subtle, and direct them to specialized intervention; and (b) to determine those children who, while not delayed at present, may acquire deficits in a not too distant future especially when parent-child interactions are unlikely to promote typical development, i.e., absence of resilience factors. When we make these distinctions carefully, the types of services we should recommend become clear. Early intervention is not just for those with disabilities: Early intervention embraces our efforts in primary care to promote development and address parenting skills, monitor the effectiveness of our advice, and help families seek a range of community services when needed. Nevertheless, evidence is required to make accurate decisions, and so in Chapter 3 we describe why informal methods don't work well.

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Chapter 3: The Problems of Informal Approaches

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INTRODUCTION

Research on informal methods of early detection speaks consistently to its extraordinary inability to detect children with disabilities. Research from Great Britain revealed that only 45% to 55% of children with developmental problems are detected prior to school entrance.[1,2] U.S. research on this topic is equally disturbing. Pediatricians examining children for the first time were asked to estimate the standard deviation into which children's IQs fell. Sixty-seven percent of children with IQs below 80 were not identified.[3] In another study in which pediatricians examined their own patients, previous contact did not improve the accuracy of IQ estimates.[4] Pediatricians were found to significantly underestimate IQ in chronically ill children and overestimate IQ in children with intellectual disabilities. Detection of behavioral and emotional problems via informal methods suffers a similar fate. Fewer than half of children with diagnosable conditions were identified.[5,6] Now if you are looking at the research we've cited, you'll see it dates back to the 1960's to 1990's. Have things changed since then? The sad answer is, "no."[7-9]

In contrast, periodic use of screening tools in primary care identifies two to six times more children with suspected delays than a pediatrician's surveillance alone.[10-14] In turn, periodic screening leads to substantial increases in needed referrals to programs for children with special needs.[10-14] Even in foster care populations, where providers were apprised of children's high-risk status before the encounter, use of screening tools doubled detection rates for suspected developmental delays. Periodic screening for social-emotional instruments led to a six-fold increase in the detection of suspected social-emotional delays/ disorders, when compared to informal surveillance.[12]

Nevertheless, pediatric practitioners have a tendency to dismiss the need to refer, despite problematic results on quality screens. In a national screening and surveillance implementation project involving seventeen diverse practices in fifteen states over a nine-month period, practices referred only 61% (range = 78% in September, 48% in January) of children with troubling screening results. Providers were particularly reluctant to refer based on an accurate screen relying on parents' concerns, despite all manner of supporting results.[7] It seems likely that providers override evidence with informal approaches that lack empirical support and over-value non-validated data. To date there is no evidence that a practitioner's informal methods should ever over-rule the results of screens or avoid a referral when indicated.

This is not to say that clinical acumen should be ignored. In fact, in about 20% - 25% of cases of children with problems, parents don't raise predictive concerns and/or children do well on screens, but providers wisely suspect difficulties are present.[10,15] But 75% - 80% of the time screens identify children with a high probability of problems. We need to take that seriously. While not all will qualify for IDEA services, almost every child with troubling screening results needs help—and help that's beyond brief primary care advice on developmental promotion. Clinical acumen is most needed when: (a) children pass screens (but lack resilience factors that suggest a likelihood of emerging problems); (b) when children fail screens (for deciding what kinds of help are needed); and (c) for making refined decisions about the types of evaluations needed.

So what is meant by informal measurement and why is it so problematic? There are three broad approaches with inherent challenges.

TYPES AND CHALLENGES OF INFORMAL APPROACHES

1. Milestones Checklists

Such checklists are commonly found on age-specific encounter forms including those imbedded in electronic records. So what is wrong with that?

Consider this typical example of items at the 4-year level :

- Uses hungry, tired, thirsty
- Climbs stairs without holding on
- Stacks 12 blocks
- Knows colors
- Dresses self completely
- Plays games with rules

Now try asking yourself and a group of colleagues questions like these:

- If a 4-year-old child can't do one of these six tasks, would you refer?
- How about if a child can't do two of the tasks? Would you refer?
- How many here would refer if a child couldn't do three?
- Four?
- Five?

You will inevitably find very different thresholds for referral. Clearly we all have wide range of decision-making criteria Who is correct? Who knows!

Similarly, what if your four-year-old can do all these tasks, do we know he or she has typical development? No!

Now consider the different ways providers administer the items. For example, if you asked each colleague how they test for "Knows Colors," you'd find that some only require a point (e.g., "show me something red."), while others require a child to name colors. Very few include "purple," "black," "white," "pink" or "brown"—all terms we expect a 4-year-old to be mastering. Clearly we are not administering this task in the same way and that means we cannot confidently compare one patient's performance to that of others around the country. Without identical administrations of tasks we cannot tell who is doing well for age and who is not. And without validation we don't know whether naming lots of colors is even an important predictor of overall developmental status.

So the content of our informal measures is a major issue. In the above checklist, where are items about alphabet knowledge—one of the best predictors of future school success? How many letters should a child know? What differences should we expect from a 4-year-1-month-old versus a 4-year-11-month-old? Informal milestones checklists not only lack content proven to be predictive, but also fail to provide essential criteria for making informed decisions.

Comment on Informal Measurement of Children's Skills: *Informal checklists lack proof and as a consequence, their content is often incorrect. In fact, the items shown above were taken from the original Denver Developmental Screening Test, which failed to detect 70% of children with language impairments, 50% of children with intellectual disabilities and 90% or more of children with learning disabilities—the three most common diagnoses. So it is very likely that a child with special needs would not be detected by such a checklist.*

But again this is only a guess. Why are we guessing? Development is a measurable phenomena and we measure everything else anthropomorphic: Cholesterol levels, PKU, galactasemia, head circumference, temperature, height, weight, etc. So why are we so casual about one of the most important aspects of a child's life—his or her development?

Quality measurement is sorely needed—meaning questions that tap skills proven to be age-appropriate, predictive of developmental status (preferably both current and future), have clear scoring criteria, and provide uniform cutoffs to determine when a child is truly behind. Developmental problems are extremely subtle in young children. We can't discern those who are doing well from those who are not without careful, accurate measurement.

2. Informal Including (Trigger) Questions to Parents

Healthcare providers almost always ask parents about their concerns at every visit. Common questions include: "Do you have worries about your child's development?" or "Do you think he has any problems?"

What is wrong with such questions? They don't work. Research shows that only 2% of families respond. Why? The words "worries" and "problems" are too strong. When families are first noticing but aren't sure, they are reluctant to endorse such questions. The word "development" itself is only understood by about 50% of families.[16,17]

Similarly, asking only a few questions doesn't work well either. The AAP's 2006 Policy Statement suggested the use of these questions: "Do you have concerns about your child's development? Learning? Behavior?" A recent study revealed that only a fraction of parents responded. Given that most parents don't understand the word "development," it was not surprising to find that parents only answered with comments about behavior and did not address language, social-emotional, motor or other concerns.[18]

Meanwhile, what we really want to do is encourage parents to think through all developmental domains. Yes, behavior is the first and most salient domain parents notice. But we need parents to consider whether behavior problems may be related to skill deficits in talking, hearing, seeing, understanding, motor, social-emotional and cognitive, i.e., whether children are able and willing to comply with requests. Unless we ask carefully, we won't get parents to think fully about performance in each developmental domain.

And, if we don't ask well (or at all) many parents won't tell us about their concerns. Parents with limited education often don't realize that developmental-behavioral issues are a critical component of a well-child visit. So, we must ask and ask well. Quality measures are essential—meaning tools using questions to parents that have been tested for clarity of communication and accuracy in early detection.[19-21]

3. Clinical Observation and Judgment

Although clinical reasoning is essential for making thoughtful decisions about the range of services needed, it is problematic to rely only on clinical opinion when it comes to detecting developmental and behavioral problems—most especially if the information gathered during the process is derived from faulty informal milestones checklists and ineffective questions to parents.

Clinical Impressions and Judgment Heuristics: When we form clinical impressions we select among a vast array of sometimes competing information. Because human short-term memory is limited, we use judgment heuristics to sort relevant from irrelevant information and group data into meaningful clusters of symptoms.[22-26] Judgment heuristics are derived from providers' unique experiences with similar children, and from our beliefs and attitudes about specific conditions and treatments. Differences in the content of judgment heuristics may explain why some children with disabilities are identified while others are not. The following illustrates how the eight common judgment heuristics may interfere with the formation of accurate impressions, especially when clinical decisions are not grounded by the results of accurate measures.

(a) **Representativeness** is the expectation that children with a particular diagnosis will resemble the "classic" case. Often the classic case, such as those used in medical texts, is one that is relatively severe in order to illustrate a wide range of symptoms. Representativeness is also tied to the human tendency to categorize or even stereotype. For example, a genetic condition often serves as the classic case of intellectual disabilities. Nevertheless, most individuals with intellectual disabilities do not have Down syndrome. Professionals who rely on the classic case may fail to notice developmental delays in children lacking dysmorphology, i.e., the majority of patients with developmental disabilities are not dysmorphic or even very obviously delayed. Similarly, if the classic case of emotional/behavioral disturbance is represented by psychosis, children with more subtle difficulties such as depression or anxiety may be missed.

(b) **Anchoring** is the use of an initial hypothesis for evaluating the importance of subsequent observations. Anchoring is critical for effective reasoning (and much aided by the results of quality screening tests), but it can be impeded by "primacy effects" through which the information collected earliest during an encounter tends to be more memorable than information obtained later. Anchoring an incorrect diagnosis is abetted by the fact that parents rarely list complaints in their order of importance: The most predictive data are as likely to be last as first.[27] Similarly, excessive expectations of continuing normal development may interfere in the detection of developmental problems since children often appear normal at earlier ages but may acquire disabilities in later childhood (e.g., when the impact of an adverse environment increases).[28]

(c) **Adjustment** involves assigning probabilities to a potential diagnosis based on known prevalence estimates. If a condition is believed to be rare, it is likely to be disregarded in the differential diagnosis. For example, providers who consider the prevalence of developmental disabilities to be 2% to 3% may be less likely to look for and recognize problems than providers who are aware of current prevalence estimates of 16% to 20%.[29]

(d) **Justifiability** is the tendency to search for a medical cause to explain the findings of developmental problems. Conditions for which the underlying causes are not well understood are less frequently diagnosed. For example, gastrointestinal pathology is more likely to be diagnosed than is the competing psychosomatic condition of nonorganic recurrent abdominal pain. Similarly, over-emphasis on genetic contributors to developmental problems may cause providers to overlook developmental deficits in children whose etiology is largely psychosocial.

(e) **Ego bias and overconfidence** can produce selective forgetting, remembering or attending to various symptoms. For example, the professional who holds an anchoring diagnosis of normal development may disregard an important parental concern predictive of developmental problems. Similarly, excessive confidence in the effectiveness of advice given to parents may militate against appropriate referrals for a child with risk factors associated with developmental delay.

(f) **Value-induced bias** and **wishful thinking** involve the over-estimation or under-estimation of a diagnosis because of its perceived adverse impact on children, families or on healthcare professionals themselves. For example, a pediatrician may delay a diagnosis of cerebral palsy to avoid distressing parents or limiting parents' joy about their infant. Value-induced bias can take the form of the "augmentation principle" in which even professionals are known to be excessively and positively prejudicial about the capacities of individuals with some types of disabilities (e.g., blind people are often thought to hear better than normally sighted people).[8] This may lead to under-detection of developmental or emotional disabilities in children with physical or sensory impairments.

(g) **Passive Expectancies** involve the suppression of uncertain information and the over-valuing of commonly occurring events because these are more easily perceived than rare ones. For example, when a child behaves well during an office visit, providers may give less credence to parents' and teachers' concerns about attentional and behavior problems. The frequency with which clinicians deal with viral illness that without treatment diminishes over time, may lead to a passive expectancy that developmental problems will follow a similar course. This is sometimes referred to as the "flu model" of development and is characterized by "temporizing" (meaning "wait and see") a subtle developmental or behavioral problem, with "watchful waiting," but without stimulation suggestions, developmental measurement or necessary referrals.

(h) **Miscellaneous** heuristics include the adverse influences on judgment brought on by fatigue, distractions, information overload, peer pressure and time factors. For example, many physicians find they deal differently with a complex psychosocial issue raised at the beginning versus the end of the day or even within an encounter. Early childhood professionals working in classrooms containing many high risk children may come to regard their performance as typical or average, when in fact, performance is well below that of children with fewer risk factors. Another example is when parental insistence prompts professionals to recommend or initiate treatments or services that they would not have otherwise recommended.

Chapter Comments: *Human beings don't think in the same linear way as computers. The quality of our clinical judgment depends on the quality of information we have at hand. Informal milestones and informal questions to parents do not work well at raising our hackles about possible problems. Screening is for the asymptomatic—those children we think, at first glance, are doing OK—but via a deeper, evidence-based look, our data may indicate problems. The proof in early detection rests with accurate measures. We should not over-ride evidence with our hopes and wishes that things are going well when screens suggest otherwise. We are scientists. We do not ignore findings from blood work or urine samples. And we should not ignore the evidence provided by developmental-behavioral screening tests (or fail to use quality measures). Instead we should capitalize on screening results to hone our invaluable clinical acumen and thus recommendations for needed services. We must do better by our patients and their families than rely solely on clinical judgment.*[30, 31]

And so we should (and explain how in Chapter 5):

1. *Rely on evidence-based (i.e., psychometrically sound) developmental-behavioral screens;*

2. *Measure risk factors in families: Parents might look "perky" during an encounter and children may behave well. But all that may just be a momentary masking of enormous life stressors, significant behavior problems, parental depression, etc. Such does not bode well for optimal child development; careful screening of risk factors is needed;*

3. *Search for and promote resilience factors, monitor effectiveness and intervene when needed;*

4. *Consistently and routinely refer when screens are failed;*

5. *Over-ride the results of a successful screen, in the presence of risk factors that predict developmental declines with time. In these cases we should refer to social services, mental health services, quality daycare, Head Start, parent training, etc.;*

6. *Use screening/surveillance results as a prompt for a particularly detailed physical exam and exploration of child and family medical history;*

7. *Incorporate our clinical observations, including longitudinal knowledge of family and child medical history to determine treatment plans;*

8. *Offer developmental promotion and guidance at each visit but also recognize the limits of a few minutes of advice;*

9. *Follow up on the effectiveness of advice given. If, for example, a discipline problem is not resolved by in-office counseling, we should "ratchet up" the intensity of intervention (e.g., refer to parent training programs).*

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Chapter 4: Measurement Approaches and Options Among Tools

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INTRODUCTION

After reading Chapter 3, we hope you have been thoroughly disabused of relying solely on informal measurement approaches to early detection—including taking items from other measures to create checklists. Using measures that are thoroughly investigated and supported by evidence provides the fundamental scaffold for making accurate decisions about children's needs. This doesn't mean that clinical opinion is useless: It is essential. Clinical acumen is far more honed and precise when supported by the valid evidence of developmental status that screens provide. An accurate screen, when failed, alerts us to look further, i.e., to provide a more thorough physical exam, to carefully observe parent-child interactions, to carefully explore medical history, to remember the importance of assessing sensory and health status, and to consider family psychosocial issues—and address potential problems therein. And even when screens are passed, we still want to identify and intervene with risk factors, well before delays become manifest. The combination of accurate screening and surveillance (meaning an accurate way of gathering an array of clinical information) enriches decision-making about how best to address the needs of children and families.

In this chapter we present:

1. Approaches to measurement recognizing that different methods are needed for information gathering, and with the recognition that providers have preferences among measurement methods;

2. How screening and surveillance work together (often with the same set of tools);

3. A table of accurate, validated screening/surveillance tools together with a list of assessment-level tools useful in follow-up (e.g., NICU monitoring, IDEA intake). We present the latter so that primary care providers understand the types of tests patients are likely to receive when a referral is made and to aid subspecialists in selecting quality tools that are economical to use;

4. Measures in progress that we hope will have proven accuracy in the future;

5. A case example of screening and surveillance.

After reading this chapter, you may well feel overwhelmed by the range of measurement issues and options. But please read on! In Chapter 5 we explain how screening/surveillance can work easily, including making use of the same tools for both tasks, and by staggering tools across visits so that measurement of developmental-behavioral issues can be accomplished within the time-constraints of well-child care. We also explain how, over time, you can gather a complete picture of children's and families' needs and how best to address them.

MEASUREMENT METHODS IN CHILD DEVELOPMENT

Tools have different approaches to defining probable developmental status. That's a good thing because providers have different preferences for how to measure development. Some are comfortable gathering information from parents, but within that, some prefer to work from parents' concerns while others prefer parents' reports about specific skills. Some like to interview families or observe children, while others prefer hands-on measurement, i.e., directly eliciting skills from children. So, it is helpful that across well-constructed tools, there are measurement options, although each approach has pros and cons.

Hands-On

With hands-on measures (also referred to as direct-elicitation), an examiner asks the child to perform various tasks. Most diagnostic tools rely on this approach [with the exception of mental health and self-help skills since these require information from a child or parent (e.g., we are rarely able to have a child demonstrate how he/she takes a bath, adjusts water temperature, washes hair and body, picks out clothes

to wear, brushes teeth, etc.)]. But otherwise, hands-on measurement allows us to watch a child carefully and discern the quality of responses. For example, we can view whether a child is frustrated with certain tasks and tries to avoid them, has difficulties working systematically from left to right and top to bottom, etc. The ability to observe children at work is always a part of diagnostic testing, wherein specialists bring to an evaluation, not only skills in administering measures, but also rich clinical observations honed by experience and enormous background knowledge in a specific domain of development.

There is much we need to know in order to administer tools hands-on to children, even with brief primary care measures. Chapter 14 (Training Trainees) describes the skills needed to accurately elicit from children the skills they possess. And, there are times in primary care, when it is useful to administer tests hands-on, most especially under these circumstances:

1. A child is newly placed in foster care and so the new caretaker doesn't know much about what the child can do;
2. The accompanying parent isn't a knowledgeable caretaker (e.g., a teen mom whose parents or relatives provide most of the child's care);
3. The examiner feels the caretaker isn't a reliable reporter of a child's skills. Examples are a parent who is obviously abusing substances, is mentally ill, or extremely defensive—as sometimes happens if testing occurs during the process of determining whether a child should be removed from the home;
4. When we want to teach young professionals about child development and to acquire skills that are generalizable to well-child or sick visits (e.g., in managing children's behavior, building rapport, etc.).

Otherwise, hands-on administration of tools in primary care, has mostly disadvantages:

1. Children may not be cooperative (especially infants and toddlers—who may well be asleep, hungry, unaccustomed to strangers, not feeling well, or just in a very oppositional phase and so none too compliant with requests to perform);
2. Hands-on testing, given the inconsistency of children's performance, even under the best of circumstances, does not ensure an accurate assessment of children's skills—measurement via multiple methods is still needed;
3. Providers need much practice to develop requisite skills in eliciting children's performance (as described in Chapter 14) including how to: Manage challenging children during testing, build rapport, advise parents before testing (e.g., not to prompt or criticize their child's performance), position infants and children with motor disabilities during testing, etc. For hands-on evaluation, providers need abundant familiarity and lots of practice with test materials and questions—so as to ensure an administration that has fidelity to standardized directions. Clinicians must learn how present items swiftly without fumbling for stimuli or scoring directions (and thus potentially losing a child's interest, attention, and compliance);
4. Ultimately, hands-on administration of tests takes more time than other approaches.

Observation

Observation (sometimes referred to as play-based assessment) enables examiners to score items by simply watching a child's behaviors and skills. Often a display of tempting materials is needed (e.g., setting a bit of cereal in front of an infant or toddler enables us to watch the type of pincer grasp used, whether chewing involves gumming or chomping, how well a child swallows and maneuvers his or her tongue, etc.). If we follow an eating task by offering a cup of water, we can then note how well a child holds and controls the cup, and whether the water is sucked out, or instead, poured into the mouth in small amounts as older children and adults do. We can also see how the child conveys an interest in getting more food (e.g., gazing at cereal out of reach, looking at the examiner and then back at the food, vocalizing while looking at the examiner, using single words like "more" or phrases like "want more," and whether he or she names the food like "Cheerios" etc.). We can also observe how well a child sits

unsupported, reaches for things, uses a spoon, etc. Observation-based assessment is often used with very young children (and with older children when measuring interactions with others, i.e., social-emotional and behavioral skills).

Advantages of observational measurement are that we can take note of many child and parent behaviors in only a few seconds (e.g., how parents interact with their children, whether there are troubling interactions during a physical exam, etc.).

Disadvantages are that observation methods don't work well when a child is tired, asleep or reluctant or when we need to look at a child's ability to name or understand specific words, read, write, etc. For measuring such skills we need to use hands-on measurement, information from parents or a combination of the two approaches.

Information From Parents

There are two different methods for gathering information from parents—*parent report* and *parents' concerns.* Each approach offers different kinds of information:

Parent Report. This measurement approach presents parents with descriptions of milestone-type tasks that most children of the same age can perform. Parents are asked to read (or sometimes listen) to a description of a skill and then asked to tell to what degree their child can perform (or not) such tasks. Parents by virtue of the substantive time they have to observe their children can be quite accurate reporters of current skills. Some examples of parent-report measures are: *Ages and Stages Questionnaire*, the *Modified Checklist of Autism in Toddlers, PEDS: Developmental Milestones*, etc.

 The disadvantages/challenges with parent-report measures may include:

1. **Literacy problems.** Parents who don't read well can almost always read response options on multiple choice tests (e.g., "yes" or "no"). As a consequence, they may just circle answers randomly to "save face." Obviously, literacy barriers, if unidentified, severely threaten the validity of test results. It is critical to gently prompt for reading ability with a question such as, *"Would you like to complete this on your own or have someone go through this with you?"*;

2. **Length.** Some parent-report measures (although not all) exceed the span of time we allocate for parents to answer questions (e.g., the time we expect them to spend in waiting/ exam rooms or the time we expect to spend during a home visit). When tools aren't completed in the anticipated time frame, this complicates work flow, lengthens visits, etc. Briefer measures or asking parents to come to appointments 10 – 15 minutes early to complete tools can circumvent problems with tool length;

3. **Time and expense.** Parent report tools must present varying sets of items at various ages and so some tests (but not all) require photocopying and also retrieving different forms for different ages (e.g., copying in pink for one age, orange for the next, etc.). This incurs material and labor costs (for photocopying, organizing copies, allocating storage space, and for making sure examiners have the correct form for the child's age). Measures that come laminated offer a way to circumvent the time and expense of photocopying, but if laminated copies are not provided by the publisher, providers will need to check with publishers to make sure that adding lamination does not infringe on copyright;

4. **Reporting accuracy.** Parents often report success with skills that are only emerging but not yet mastered (meaning neither fully generalized nor demonstrable in unfamiliar settings). This is particularly problematic for measures that only offer two response options such "yes" or "no," wherein parents are likely to select "yes" even though their child has not fully established the skill in question. Quality parent report tools circumvent over-reporting by offering at least three-

response options (e.g., "rarely—sometimes—most of the time");

5. **Ability to capture disordered development.** Although skill-focused multiple-choice questions are helpful in teaching parents and providers about child development, they may not capture disordered development (e.g., a child may be using age-appropriate three-word utterances, but if he is just saying "Wheel of Fortune" over and over, that's a problem that might not be detected by skill-focused tools);

6. **Restricted information about unique challenges.** Skill-focused questions do not give parents an opportunity to describe their specific developmental-behavioral challenges (e.g., bed-time or eating problems). In the absence of feedback about parents' unique issues, professionals are less able to respond with focused advice and specific referrals. As a consequence, true parent-professional collaboration and communication is limited, and thus encounters may lack relevance to families. In turn, this may diminish parents' willingness to return for visits or follow through with recommendations;

7. **Limited flexibility.** Some parent-report tools are restricted to self-report/interview and lack a hands-on administration option. This is a problem when professionals worry about the veracity of parent-reporting and wish to switch to direct elicitation. Test items written only for parent report do not offer clear directions for evoking performance. Attempting to create a facsimile question is problematic: Consider how a question such as, "How many words does your child use?" could be converted to hands-on measurement. How would you prompt a child to speak? How would you know you had an accurate vocabulary count? Ad hoc conversion of a parent-report tool to hands-on measurement violates standardized administration and renders less than useful results, i.e., inability to determine whether a child performs below average. It is optimal to use measures normed for both parent-report and hands-on administration. If unavailable within the same tool, professionals need to switch to a different measure.

Nevertheless, the advantages of parent-report measures, especially in primary care, are many because they:

1. Are **accurate** as hands-on measures (if quality tools are deployed and literacy barriers are eliminated);

2. Often require **less time** than hands-on or observation measures;

3. Are **easy to administer** (since we don't have to grapple with children's behavioral issues, fatigue, hunger, etc.);

4. Are known to **help parents learn** about age-appropriate skills (information in which parents are highly interested);

5. Can usually be **completed before an encounter**, enabling professionals to enter the exam room fully armed with information (including referral options if indicated);

6. Are **useful for tracking** with milestones' progress per AAP recommendations.[1] Early childhood programs, for example under IDEA or Head Start, also require progress indicators as do research projects involving follow-up studies wherein we want to see that children are learning and acquiring skills.

Parents' Concerns. This approach to early detection involves eliciting parents' observations and child-rearing issues in their own words and then addressing those specific concerns with referrals, parenting information, etc. All of us appreciate being asked our opinions, having them listened to, and taken seriously. Parents are no exception. Eliciting and addressing parents' concerns is the most collaborative of approaches to early detection and an AAP recommended component of each well-visit.[1] Even so, this

measurement method has advantages and disadvantages, particularly when asking ad-hoc questions (meaning wording that has not been tested for its effectiveness), i.e.,

1. Use of informal non-validated questions that may not "speak to parents." For example, the word "worries" doesn't encourage families to talk (since they may not be sure yet that they are in fact worried. Maybe parents are just noticing difficulties and thus simply concerned);

2. Use of professional terms that are often unfamiliar to parents (e.g., "development," "gross motor," "expressive language");

3. Translations, if poorly done, often use questions that don't work in other languages and subcultures. For example, the word "concerns," which is prominent in *Parents Evaluation of Developmental Status (PEDS),* didn't work in Somali (because it turned out to be a popular warlord slogan, i.e., "we are concerned about you," and parents thought providers were spying on their families back home)! Careful, careful vetting of translations among providers and families is essential and that's one of the things validated measures offer;

4. With informal questions, professionals inevitably flounder with accurate decision-making. In such cases, they tend to under-refer and "wait and see," and so will miss ~ 70% of children with problems. With the evidence validated tools offer, providers are shown when it is better to refer.

But even validated approaches to eliciting/addressing parents' concerns have challenges as well:

1. Parents' concerns do not offer a detailed way to track children's progress in learning new skills. Decreases in parents' concerns over time may reflect satisfaction with services and sense of improvement, even though disabilities may be ongoing;

2. Order effects can occur. For example, if parents' concerns are elicited after they've been asked to report on children's skills, parents sometimes think they themselves are being tested on knowledge of child development. Thus parents may raise needless concerns. It is important to elicit parents' concerns before administering other measures;

3. Professionals often have distinct preferences for measurement methods. Some professionals, no matter how much they are shown the validity of parents' concerns, much prefer skill-focused tools, and so may mistrust the value of parents' concerns thus over-riding evidence with non-validated clinical opinion;

4. Parents may not have thought about development as professionals do, i.e., as a range of domains. They may not feel comfortable revealing their concerns especially to a stranger the first time they are asked. Nevertheless, on subsequent administrations, parents have usually contemplated and observed more carefully and so are better able to answer;

5. It is sometimes necessary to confirm parents' concerns with a milestones-focused screen, particularly when a concern's measure calls for additional screening. Again, the AAP 2006 policy statement calls for eliciting and addressing parents' concerns plus viewing milestones trajectories, meaning that viewing developmental-behavioral issues in various ways is needed.[1]

The strengths of eliciting and addressing parents' concerns, if using a standardized, validated screen, are many:

1. Questions are proven to work and professionals are, with some tools, guided into an optimal response based on evidence;

2. Professionals come to understand parents' unique child-rearing issues and are better able to discern disorder from delay (e.g., a child may well pass a fine motor item about ability to pick up

a Cheerio, but only the parents' own description will alert you to the presence of a concerning tremor). Similarly, only if we ask parents will we hear their concerns about fatigue, misbehavior, frequent illnesses, odd syntax and other critical indicators that something isn't right;

3. Parents learn that their observations and parenting questions are truly of interest to professionals and a routine part of well-child care. Parents with limited education, who tend not to raise concerns (or even know that developmental-behavioral issues are a part of health care) are more willing to raise important concerns they might not otherwise express;[2]

4. When parents have a chance to express their concerns they are far more likely to keep their appointments (e.g., for well-visits and parent-teacher conferences);[3]

5. Questions about concerns, if carefully written, probing all domains and proven to work (i.e., standardized, reliable, and validated) help parents think about development as professionals do—as relatively discrete skill areas;

6. Eliciting parents' concerns in advance of the visit, saves time by reducing "oh by the way concerns" by an average of 3 minutes—minutes that can be devoted to advising parents, facilitating referrals, and other aspects of developmental-behavioral promotion;[4]

7. Given parents' precise worries, professionals are better able to focus child-rearing advice and referral recommendations on parents' and children's unique needs.[4,5]

Comment on Measurement Methods: *There are many different ways to accurately measure child and family issues: Structured observation; eliciting parent's concerns; parent-report/interview; versus direct elicitation of children's milestones-related skills. Meanwhile, providers often have decided preferences among measurement methods. Some providers feel comfortable relying on parents' concerns for both screening and surveillance while others prefer to rely on milestone-focused tools based on parent report. Still other clinicians prefer hands-on elicitation of children's skills. So it is helpful to have quality tools relying on different measurement methods, i.e., "different strokes for different folks."*

Even so, a combination of measurement methods is best and much needed for evidence-based compliance with AAP policies:[1,6,7] We must ask parents about their concerns, use parent-report or hands-on testing to gather information about children's milestones, and observe parent-child interactions and children's behavior and health status during physical and sensory exams, etc. The triangulation of information collected by various methods ensures that we capitalize on the strengths of each approach and in so doing, gain crucial insight into children and their families.

In the next section, we describe the specifics of screening and surveillance tools. We focus on evidence-based measures that aid us in making accurate decisions about children's and families' needs.

SCREENING: PURPOSE AND MEASUREMENT

Developmental screening is the use of brief validated tests to sort children who probably have developmental problems from those who probably do not. Observation alone alerts us that we need to refer a 2-year-old who isn't walking or talking. We don't need screens to guide us in such cases. Observation fails us when it comes to detecting most problems because these are extremely subtle in young children and difficult to detect in a short visit in which medical issues may take priority. As with blood pressure, blood sugar, and temperature, evidence-based tools are needed to identify problems not obvious to the naked eye. The subtle cases are also where we get the "biggest bang for the buck" when it comes to intervention; most especially for children who don't have delays (yet) but whose psychosocial risk factors suggest there will be problems in the future. Even so, children with life-long disabilities also greatly benefit from early intervention. We can't cure them but we can lessen the severity of their symptoms and help them become productive citizens. Even adults with moderate to severe intellectual

disabilities may hold jobs from which society benefits greatly, for example, sorting recyclables or stuffing envelopes for mass mail-outs—efforts that may be less rewarding for adults with typical intellectual development. To ensure that children (including those with subtle problems) receive early intervention, we need to use screening measures with proven accuracy in early identification.

Screening is for the asymptomatic—for the nearly occult conditions that we would not otherwise recognize. If you don't think there is a problem, that is precisely when to screen. For this reason, screening tests tend to rely on active, not observational, measurement methods such as eliciting parents' concerns, or gleaning information on specific skills by asking children to demonstrate them or by asking parents to report to us.

Screens are not diagnostic instruments. They contain error and reflect only a probability, albeit a high probability, that a problem exists. They do not indicate exactly what is going on with a child and family but simply convey that something is not right. For example, it is tempting to think that a child whose parents have concerns about speech-language or who does poorly on speech-language items within a screen, actually has a speech-language problem. However, that may not be the case at all. The problem could be an intellectual disability, a motor disorder, hearing impairment or autism spectrum disorder. Therefore, we never make a diagnosis on the basis of screening test results. We should hypothesize to ourselves (and possibly colleagues) about what might be going on and explore various possibilities with our now heightened awareness (e.g., medical history, a more detailed physical exam, sensory screening, psychosocial risk factors, etc.). This is what surveillance brings to screening—more information about the possible types of problems so that we can decide what types of confirmatory evaluations are needed and which referrals we need to make. Even so, surveillance measures should also be evidence-based.

Surveillance: Purpose And Measurement

Surveillance brings in the broader picture of what might be the source of a problem, what problems might arise in the future, and also what is going well. To the pass/fail sorts of scores provided by screening tests, surveillance encourages us to look at the "big picture" of a child's life. Surveillance encourages us to expand our clinical thinking, consider a wide range of variables that may be potentially explanatory, and ensure that the interventions we select address contributors to problems. Most importantly, surveillance helps identify issues that may create difficulties in the future. For example, if a child is delayed and the parent is depressed, we make different recommendations than we would if the child is delayed but risk factors are absent.

Surveillance is an information-gathering process that occurs in part at each visit, and in full across visits. The reason for longitudinal surveillance is that just as development develops, developmental problems can too. A child can be typically developing at six-months, but via surveillance we may find that parents aren't talking much to their child. From this information we can surmise there will be developmental delays in the future, and that we need to teach parents how to promote development. And we must also very carefully monitor how such children are progressing. Even substantive conditions (e.g., acoustic neuroma, Fragile X Syndrome, autism spectrum disorder) have mild if invisible manifestations early in life. These infants may pass screening tests, but by eliciting parents' concerns, noting observations from the physical exam plus hearing/vision screening, and by viewing these results over time, we begin to see a pattern of issues in need of varied types of attention. So at times, surveillance can spot problems missed by screening tests.

Surveillance And Screening In Consort

For the most part, failed screens are the trigger for looking more carefully at a child and family because test results provide most of the evidence for early detection and the need for referral. Without screens we miss the majority of children with problems. But it is important to note that sometimes surveillance activities can themselves be the trigger for looking further (e.g., a parent who tells us *"something isn't*

right" even when their child passes a screen). Surveillance, especially if it relies on informal methods, should never override a problematic screening result. However, if a screen is passed, but surveillance activities spot a problem, surveillance trumps a negative (meaning passed) screen. Figure 4-1 illustrates the basics of decision-making:

Figure 4-1. Decision-making with Screening and Surveillance Information

SCREEN RESULTS		SURVEILLANCE		DECISION
If Screen(s) Failed	⟹	But Surveillance suggests Child is OK	⟹	Refer
If Screen(s) Failed	⟹	And Surveillance indicates problems	⟹	Refer
If Screen(s) Passed	⟹	But Surveillance indicates problems	⟹	Refer
If Screen(s) Passed	⟹	And Surveillance suggests Child is OK	⟹	No referral needed

Surveillance is much aided by use of evidence-based tools. These help structure our observations, and make sure we've considered all the issues at hand. There exist quality measures that: Detect psychosocial risk, resilience, elicit and address parents' concerns, assess hearing and vision, and offer helpful guidance for a thorough physical exam. Note that screening and surveillance can often be accomplished with the same tools. For example, we can use the same measure to monitor milestones over time AND screen for current developmental problems. We can use the same measure to elicit/address parents' concerns AND screen for developmental problems. Efficiency in accomplishing the tasks of early detection means we should use the same measures for multiple purposes whenever possible. In Table 4-1 we note when screens can also be used for longitudinal surveillance. Following Table 4-1 is a description of two surveillance tools that do not function as screens (i.e., provide cutoff scores indicating when a referral is needed), but offer important information about child and family needs—information that if problematic helps us decide whether to advise parents and monitor vigilantly or refer even if a screen is passed.

EVIDENCE-BASED MEASURES FOR SCREENING/SURVEILLANCE

Highlights and selection criteria for the tools shown in Table 4-1 include the following:

1. Many tools can be used simultaneously for both screening and surveillance. It is rarely necessary to use separate tools for both processes;

2. The screening tools selected meet standards for screening test construction (described further in Chapter 19). All correctly identify at least 70% of children with disabilities, referred to as sensitivity or co-positivity, while also correctly identifying at least 70% children without disabilities, referred to as specificity or co-negativity. All listed measures were standardized on national samples (including ethnic minorities, varying levels of parent education and income, and child gender— all in proportion to their prevalence as identified by the US Census Bureau). All measures are proven to be accurate for English and Spanish-speaking families (and often with other language groups within and outside the US), proven to be reliable in various ways (test-retest, inter-rater, and internal consistency), and all have been validated against a range of diagnostic measures. As a consequence, information on psychometrics is not detailed in this table, although accuracy by age and types of disabilities detected is described (for screening tools);

3. Three tools used exclusively for surveillance (of psychosocial risk factors and resilience) are included. All were heavily researched and proven to identify variables predictive of successful development or future delays;

4. Selected assessment-level tools are also listed. Assessment measures are deployed after a problematic screening result and are used to monitor progress with a high risk group of children. Assessment measures are rarely used in primary care due to their length but instead by referral resources (e.g., IDEA intake and in NICU follow-up). We include descriptions of these measures so that primary care and other providers have information about the tests most likely to be used by the specialists who receive referrals. The assessment-level tools were selected because they can be completed by parent-report and have abundant psychometric support, i.e., validation research supporting the close relationship between subtest results and performance in the same domain on diagnostic measures (e.g., high correlations or unique performance patterns across various types of disabilities);

5. Tools are sorted into those most feasible in health care versus early childhood or similar settings where there is more time and, for educational programming purposes, a greater need to observe and directly test children during the process of screening;

6. Tools are further sorted by their breadth of focus. Broad-band screens measure most or all domains of development, i.e., cognitive/academic, language, motor, self-help) although some do not cover emotional/behavioral/mental health—meaning that when a screen measuring only some areas is failed, we may need to measure the remaining domains with separate measures;

7. We also include several condition-specific or narrow-band tools. These typically focus on a single domain of development, behavior/social-emotional or mental health or a specific condition (e.g., autism spectrum disorder). These tools are useful when a broad-band screen indicates a problem, when clinical observation suggests more information is needed or in the case of autism spectrum disorder, timing recommended by the AAP.[1,6,7] Note that narrow-band tools should not be used as the sole indicator of developmental-behavioral status—they will miss the majority of children with difficulties in other domains because of their limited focus;

8. Not included are measures such as the Denver-II, DIAL-III, ESP or E-LAP because they fail to meet test standards (limited standardization, absent validation, and no proof of accuracy); screens such as the CAT-CLAMS (because they were not standardized on general populations); and/or measures of a single developmental domain (e.g., language or motor), because these are best deployed by specialists;

9. Diagnostic measures are not listed, such as the Vanderbilt Diagnostic ADHD Scales, because such tools should only be used after a broad-band screening test indicates the need for detailed assessment. In the case of attentional difficulties, many conditions (e.g., depression, anxiety, conduct disorders, learning disabilities) masquerade as ADHD when in fact the real problem is elsewhere—hence why a broader screen is needed to sort those with problems other than ADHD and direct them to appropriate treatment;

10. Table Headers:

    (a) The first column provides publication and contact information, the cost of purchasing a specimen set as of 2013, and the training options available;

    (b) The "Purpose/Description" column indicates the type of measure [screening, surveillance (or both)], versus assessment, and the overall coverage. Also presented are measurement methods (e.g., parent report, interview, or direct administration). For parent-report tools, the "Description" column includes information about readability for parent-report measures and shows grade-level reading requirements;

(c) The "Scoring" column indicates the results provided. Although all scores are essentially cutoffs for deciding which children need referring and which do not, screening test results are rendered in various ways with some tests providing a range of results helpful for deciding when to refer, monitor, screen further, advise parents, or reassure;

(d) The "Accuracy" column shows the percentage of patients with and without problems identified correctly, i.e., sensitivity and specificity. When available, these figures are shown first as a range embracing accuracy across age levels (thus describing how well a measure predicts concurrent performance on diagnostic measures with younger versus older children). Following is information on discriminant validity, meaning how well specific performance on screening tests predicts performance on diagnostic measures [viewed by developmental-behavioral domain and/or by specific conditions studied (e.g., learning disabilities or autism spectrum disorder)]. Authors/researchers do not always study measures for discriminant validity but when they do, results may take the form of correlations, sensitivity/specificity within a relatively high-risk sample, or sensitivity alone (determined by selecting those children who performed poorly on a screening test and then viewing the types of disabilities they were found to have). Thus a range of data, when available, is included in the Accuracy column.

Note 1: Positive predictive value/over-referral rates are not presented because the majority of children who fail screens but are not found eligible for special services, still have delays and psychosocial risk factors for which non-IDEA services are needed.

Note 2: False-negatives/under-detection rates are not presented because repeated screening at subsequent well-visits detects these cases.

(e) The "Time Frame/Costs" column shows the time required for scoring, associated expense for professional time (using an average salary of $60.00 per hour), and price of materials per administration [meaning the cost of purchasing test forms or photocopying (if permissible) at $0.06 cents per page]. When parents can complete screens independently, the "Total (Self-Report)" figure reflects the total costs to providers. Below "Total (Self-Report)" is the time required for an interview, its associated costs, plus the expense for scoring and materials, summarized as "Total (Interview)." For measures that elicit skills directly from children, "Total" reflects the amounts associated with administration time, scoring, and materials. Time/cost estimates do not include expenses associated with report writing or making referrals.

11. Information about electronic options is included at the end of the table. Electronic applications can reduce human error via automated scoring, generate referral letters, provide procedure and billing codes, and aggregate results across patients/clients/students—helpful for program evaluation and quality improvement initiatives. While somewhat more expensive than print tools, electronic options offer time-savers that offset the costs of hand-scoring, writing referral letters, etc.;

12. A brief description of measures in progress is also provided. These tools are under contruction, but we list them here as measures to keep an eye on because their authors are actively working to establish psychometric support and may substantiate their screens in the future.

Table 4-1 Tools for Screening, Surveillance and Assessment (Meaning Long-term Monitoring of Outcomes with High-risk Children).

SCREENS FOR PRIMARY CARE

BEHAVIORAL AND/OR DEVELOPMENTAL SCREENS RELYING ON INFORMATION FROM PARENTS	AGE RANGE	PURPOSE AND DESCRIPTION	SCORING	ACCURACY	TIME FRAME/COSTS*
Ages & Stages Questionnaire, 3rd ed. (ASQ-3) (2009). Paul H. Brookes Publishing Co., Inc., P.O. Box 10624, Baltimore, MD 21285. (800-638-3775) *www.agesandstages.com*. ($295.00) **Training Options:** DVDs for purchase, case examples, and live training **Electronic Options:** See below.	1 – 66 months	**Purpose:** Screening and surveillance of developmental milestones **Description:** Parents indicate children's developmental skills on 30 items plus overall concerns. The ASQ has a different form (5-7 pages) for each age interval. Written at the 4th – 6th grade level. Can be used in mass mail-outs for child find programs. Manual contains detailed instructions for organizing child-find programs and includes activity handouts for parents. The ASQ-3 is available in English, Spanish, with the ASQ-2 also available in French and Korean with additional translations underway.	Cutoff scores set at 2 SDs below the mean, in 5 developmental domains: Indicate need for referral or monitoring,	**By age,** Sensitivity: 82% - 89% Specificity: 77% - 92% **By domain,** Sensitivity: 83% Specificity: 91% **By disabilities,** i.e, CP, visual and Hearing Impairment, Sensitivity: 87%	Scoring time: 2 min Scoring cost: $2.40 Materials: $~0.36 - $0.48 **Total Self-Report: $2.76 - $2.88** Interview Time: 12 min. Interview Cost: $14.40 Scoring/Materials: $2.76 - $2.88 **Total Interview: $17.28**
Parents' Evaluations of Developmental Status (PEDS) (2013). PEDStest.com, LLC, 1013 Austin Court, Nolensville, TN 37135 (615-776-4121) *www.pedstest.com* ($36.00) **Training Options:** offers through its website self-training/train-the-trainer support via downloadable slide shows with notes, case examples, pre-post-test questions, FAQs, participant handouts, website discussion list (covering all screens), short videos, with some live training available. **Electronic Options:** See below.	Birth to 8 years	**Purpose:** Screening/surveillance of development/social-emotional/behavior/mental health via parents' concerns. **Description:** 10 questions eliciting parents' (and providers') concerns in English, Spanish, Vietnamese and many other languages. Items written at the 5th grade level. Longitudinal Score and Interpretation Forms, assign risk levels, track decision-making and offer specific guidance on how to address concerns. Provides screening, longitudinal surveillance and triage for developmental as well as behavioral/ social-emotional/mental health problems. PEDS can be used in conjunction with the PEDS:DM (below) for compliance with AAP Policy on screening as well as surveillance, i.e., eliciting and addressing parents' concerns and monitoring milestones.	Identifies when to refer and what types of referrals are needed: Advise parents; Monitor vigilantly; Screen further (or refer for screening); or Reassure.	**By age:** Sensitivity: 91% - 97% Specificity: 73% - 86% **By disabilities,** i.e., learning, intellectual, language, mental health, and autism spectrum disorders, Sensitivity: 71% - 87%	Scoring time: 1 min. Scoring cost: $1.20 Materials: $0.39 **Total Self-Report: $1.59** Interview Time: 2 min Interview Cost: $2.40 Scoring/Materials: $1.59 **Total Interview: $3.99**

Table 4-1 Cont'd

PEDS: Developmental Milestones (PEDS:DM) (Screening Version) (2008). PEDStest.com, LLC, 1013 Austin Court, Nolensville, TN 37135 (615-776-4121) *www.pedstest.com* ($275.00) **Training Options:** offers through its website self-training/train-the-trainer support via downloadable slide shows with notes, case examples, pre-post-test questions, participant handouts, FAQs, website discussion list (covering all screens), short videos, with some live training available. The PEDS:DM manual includes extensive suggestions for training medical students, residents, and nurses. **Electronic Options:** See below.	Birth to 8 years	**Purpose:** Screening/ surveillance of developmental and social-emotional/mental health milestones **Description:** PEDS-DM is designed to replace informal milestones checklists (such as key items from other measures) with evidence. It consists of 6 – 8 items at each age level. Each item taps a different domain: fine/gross motor, self-help, academics, expressive/receptive language, social-emotional. The PEDS:DM provides screening, triage, and surveillance via a longitudinal score form for tracking milestones progress. Written at the 2nd to 3rd grade level and can be completed by self-report, interview, or administered directly to children. Forms are laminated and completed with a dry erase marker. Supplemental measures focus on AAP policy include the M-CHAT, Family Psychosocial Screen, Pictorial PSC-17, the SWILS, the Vanderbilt ADHD scale, and the Brigance Parent-Child Interactions Scale. When combined with PEDS, ensures full compliance with AAP policy. In English, Spanish, Chinese, Portuguese, and Arabic with other languages in process.	Pass/Fail cutoffs tied to performance above and below the 16th percentile for each item and its domain.	**By age,** Sensitivity: 70% - 94% Specificity: 77% - 93% **By developmental domain,** Sensitivity: 75% - 87% Specificity: 71% - 88%	Scoring time: 1 min Scoring cost: $1.20 Materials: $0.02 **Total Self-Report: $1.22** Interview Time: 3 min Scoring/ Materials: $1.22 **Total Interview: $3.82** Direct Admin: 4 min Scoring/ Materials: $1.22 **Total Direct Admin: $6.10**

table continues...

Table 4-1 Cont'd

Parent-report narrow-band screens (for social-emotional/behavioral/ mental health, psychosocial risk, and autism spectrum disorder). These are valuable adjuncts in primary care and in other settings but only when preceded by a broad-band screen. Narrow-band tools should not be used as the sole measure of developmental-behavioral status).

NARROW-BAND SCREENS RELYING ON INFORMATION FROM PARENTS	AGE RANGE	PURPOSE AND DESCRIPTION	SCORING	ACCURACY	TIME FRAME/COSTS*
Modified Checklist for Autism in Toddlers (M-CHAT) (1999). Freely downloadable in multiple languages along with the Follow-up Interview at *www.mchatscreen.com* Also included in print within PEDS: Developmental Milestones. Commercial software vendors must pay a licensing fee. **Training Options:** the site contains a guide to the needed follow-up interview for missed items, and houses research papers and reviews on ASD screening. **Electronic options:** See below.	18 –47 months	**Purpose:** Screening for autism spectrum disorders—*cannot be used as a broadband screener* **Description:** Parent-report of 23 yes-no questions and written at 4-6th grade reading level. Downloadable scoring template and .xls files for automated scoring. Requires a follow-up interview for failed items (which can be requested by referral sources). Available in multiple languages.	Pass/fail scores based on failing at least 2 critical items, or 3 or more non-critical items.	**By age and disability,** i.e, autism spectrum disorders: Sensitivity: 90% Specificity: 99%	Scoring Time: 2 min Scoring costs: $2.40 Materials: $0.06 **Total (Self-Report): $2.46** Interview Time: 5 minutes (excluding follow-up on any failed items) Interview Cost: $6.00 Scoring/Materials: $2.46 **Total (Interview): $8.46**
Brief-Infant-Toddler Social-Emotional Assessment (BITSEA) (2006). Pearson/Psych Corp, Inc., 19500 Bulverde Road, San Antonio, Texas 78259 (800-627-7271) *www.pearsonassessments.com* ($113.75) **Training Options:** none **Electronic Options:** none	12 – 36 months	**Purpose:** Screening and surveillance of milestones in social-emotional and mental health **Description:** 42-item parent-report measure (with separate forms if clinical observation is needed). Identifies social-emotional/ behavioral. problems and delays in competence. Written at the 4th – 6th grade level. Can be followed by the more detailed ITSEA. Available in Spanish, French, Dutch, Hebrew. Has a CD-ROM for ease of scoring and generating reports and referral letters.	Cut-points based on child age and sex show present/absence of problems and competence.	**By age and disability,** i.e, internalizing, externalizing, and autism spectrum disorders, Sensitivity: 80% – 95% Specificity: 80%	Scoring Time: 3 minutes Scoring costs: $3.60 Materials: $1.56 **Total (Self-Report): $5.16** Interview Time: 6 minutes Interview Costs: $7.20 Scoring/Materials: $5.16 **Total (Interview): $12.36**

Table 4-1 Cont'd

NARROW BAND SCREENS RELYING ON INFORMATION FROM PARENTS	AGE RANGE	PURPOSE AND DESCRIPTION	SCORING	ACCURACY	TIME FRAME/COSTS*
Infant Toddler Checklist (ITC) (2002). Paul H. Brookes Publishing Co., Inc., P.O. Box 10624, Baltimore, MD 21285 (800-638-3775) *www.brookespublishing.com* ($99.95) **Training Options:** live training and research support, downloadable slide shows, abstracts, videos, and references at (*http://firstwords.fsu.edu*) **Electronic options:** none	6 - 24 months	**Purpose:** Screening and surveillance of language and social milestones **Description:** Parents complete the ITC's 24 multiple-choice questions. Focuses on screening for language, social communication. Examiners are encouraged to observe child to verify parents' answers via brief observation. Reading level is ~ 3rd grade. Can serve as an entry point into the assessment-level, CSBS and also as a monitoring tool. Does not screen for motor milestones. In English, Spanish, Slovenian, Chinese, and German.	Cutoff scores for each domain: Social, speech and symbolic.	**By age and by disability,** i.e., developmental disabilities, Sensitivity: 78% Specificity: 84%	Scoring time: ~ 10 minutes (by hand), ~ 3 with CD-ROM Observation time: ~ 5 minutes Scoring Costs: $3.60 - $12.00 Observation Costs: $6.00 Material Costs: $0.12 **Total (Self-Report/Observation)**= $9.72 -$18.12 Interview Time: 8 mins Interview Costs: $9.60 Scoring/Materials + Observation: $9.72 - $18.12 **Total Interview Costs:** $19.32 - $28.72
Ages & Stages Questionnaires: Social-Emotional (ASQ:SE) (2002). Paul H. Brookes Publishing Co., Inc., P.O. Box 10624, Baltimore, MD 21285 (800-638-3775) *www.agesandstages.com* ($225.00) **Training Options:** training DVD live training, webinars, supporting research on website **Electronic options:** See below.	3 – 66 months	**Purpose:** Screening and surveillance of milestones in social-emotional and mental health **Description:** Companion measure to ASQ-3. ASQ:SE consists of 8 age-specific forms (each 4-6 pages long) with 22-36 items. Items focus on self-regulation, compliance, communication, adaptive functioning, autonomy, affect, and interaction with people. Readability is 5th – 6th grade. Includes activities sheets for families. In English and Spanish.	Single cutoff score indicating when a referral is needed.	**By age and disability,** i.e., social-emotional problems, Sensitivity: 71% - 85% Specificity: 90% - 98%	Scoring Time: 2 mins Scoring Cost: $2.40 Material Costs: $0.24 - $0.36 **Total (Self-Report):** $2.64 - $2.76 Interview Time: 10 mins Interview Cost: $12.00 Scoring/Materials: $2.64 - $2.76 **Total (Interview):** $14.64 - $14.76

Table 4-1 Cont'd

DEVELOPMENTAL SCREENS RELYING ON ELICITING SKILLS DIRECTLY FROM CHILDREN/ ASSESSMENT LEVEL MEASURES: These tools are recommended for early childhood, NICU follow-up, referral clinic triage, etc. All require more time and skill than is typically available in primary care—although clinics with nurse practitioners or developmental specialists, i.e., professionals who are adept at hands-on testing, may find any of the below helpful as a follow-up measure for children at risk.

HANDS-ON SCREENS AND ASSESSMENT TOOLS	AGE RANGE	PURPOSE AND DESCRIPTION	SCORING	ACCURACY	TIME FRAME/COSTS
Bayley Infant Neurodevelopmental Screen (BINS) (1995). San Antonio, The Psychological Corporation, 555 Academic Court, San Antonio, TX 78204 (800-228-0752) *www.pearsonassessments.com* ($215.00) **Training Options:** training tape and detailed guidance in the Bayley-III and BINS Manuals **Electronic Options:** none	3 - 24 months	**Purpose:** Screening and surveillance of neuromotor and cognitive milestones **Description:** Uses 10 - 13 directly elicited items per 3- to 6-month age-range (six forms in all) to assess: neurological processes (reflexes, and tone); neurodevelopmental skills (movement, and symmetry) and developmental accomplishments (object permanence, imitation, and language). In English only.	Categorizes item performance into optimal/ non-optimal with overall cut scores of low, moderate or high risk.	**By age, disability,** i.e., cognitive delay and neurological/motor impairment, Sensitivity: 75% - 86% Specificity: 75% - 86%	Admin/Scoring Time: ~ 10 mins Admin/Scoring Costs: $12.00 Materials $1.88 **Total = $13.88**
Brigance Screens-III (2013). Curriculum Associates, Inc. 153 Rangeway Road, N. Billerica, MA, 01862 (800-225-0248) ($1058.00) *www.curriculumassociates.com* **Training Options:** live workshops, webcasts, videos, listserv **Electronic Options:** See below.	0 months through 1st grade	**Purpose:** Screening and surveillance of milestones in most domains **Description:** Nine separate forms, one for each 12-month age-range. Taps speech-language, motor, readiness and general knowledge at younger ages and also reading and math at older ages. Uses a combination of direct elicitation and observation. In the 0 – 2-year age-range, can be administered by parent interview. Includes longitudinal tracking, progress indicators plus separate psychosocial risk cutoffs for children in Head Start type programs who need "the gift of time" before referral decisions are made. In English and with Spanish directions.	Cutoff, quotients, percentiles, age equivalent scores in various domains and overall.	**By age, disabilities,** i.e., language impairment, LD, intellectual disabilities, physical impairment, ASD), Sensitivity: 73% - 100% Specificity: 72% - 94% **By age, giftedness/ academic talent,** Sensitivity: 81% - 100% Specificity: 70% - 94%	Admin/Scoring Time: 10 - 15 minutes Admin/Scoring Costs: $12.00 - $18.00 Materials: $~1.25 **Total = ~$13.25 - ~ $19.25**

Table 4-1 Cont'd

ASSESSMENT TOOLS	AGE RANGE	PURPOSE AND DESCRIPTION	SCORING	ACCURACY	TIME FRAME/COSTS
PEDS: Developmental Milestones (Assessment Level) (PEDS:DM-AL) (2008). PEDSTest.com, LLC., 1013 Austin Court, Nolensville, TN 37135 (615-776-4121) *www.pedstest.com* ($275.00) **Training Options:** 2 minute movie on website, plus slide shows with notes, case examples, FAQs, audience handouts, some live training, and a discussion list. **Electronic options:** See below.	0 – 8 years	**Purpose:** Follow-up monitoring, assessment and surveillance of milestones in all domains for high risk children and surveillance **Description:** PEDS:DM-AL uses the same items as the Screening Version but presents more at once in each domain (about 35 total, depending on age and skills) for: fine motor, gross motor, self-help, academics, expressive language, receptive language, and social-emotional). Items are administered by parents, or skills can be elicited from children by professionals. Items are written at the 2nd to 3rd grade level. The Assessment Level booklet is reusable with each child and includes a longitudinal score form to track progress. Includes the same supplementary measures (e.g., of mental health, ASD, parent-child interactions, academic measures, psychosocial risk) as the Screening Version. In English, Spanish, etc.	Cutoff, quotients, percentiles, age equivalent scores in various domains and overall. Age equivalent scores, percentage of delay/progress along with the same cutoffs, sensitivity/ specificity as the PEDS:DM Screening Version.	**By age, disabilities,** i.e., significant deficits in each domain of development on diagnostic measures, Sensitivity: 75% - 94% Specificity: 71% - 93%	Scoring time: 5 mins Scoring Costs: $6.00 Materials: $3.00 **Total (Self-Report): $9.00** Direct Admin Time: ~ 10 min. Direct Admin Costs: ~$12.00 Scoring/Materials: $9.00 **Total (Direct Admin): $21.00**
Battelle Developmental Inventory (BDI-2) and the **Battelle Developmental Inventory Screening Test (BDIST-2)** (2006). Riverside Publishing Company, 8420 Bryn Mawr Avenue, Chicago, Illinois 60631 (800-323-9540) *www.riversidepublishing.com* ($371.50) **Training Options:** live workshops, website FAQs, online training/webcasts **Electronic options:** See below.	0 - 95 months	**Purpose:** Screening, Follow-up monitoring, assessment and surveillance of milestones in all domains for high risk children **Description:** For the BDIST-2, Items (at least 6 are needed per domain) use a combination of direct assessment, observation, and parental interview to provide separate scores in adaptive behavior, personal-social, communication, motor, and cognitive domains). Used only to decide whether to administer the full BDI-2 (an assessment level tool that takes about 1 ½ - 2 hours to complete). Includes links to the Hawaii Curriculum and to the BDI-2 Curriculum. In English and Spanish.	Age equivalents and cutoffs at 1.0, 1.5, and 2.0 SDs below the mean in each of 5 domains	**By age:** not available **By disability:** The BDIST-2 was compared to the BDI-2 and accuracy was computed on a select sample with 50% of children qualifying for special services—making the following figures likely to be inflated when compared to other tools. Sensitivity: 72% - 93% Specificity: 79% - 88%.	Admin/Scoring time for the BDIST: 10 – 30 minutes Admin/Scoring costs: $12.00 - $36.00 Materials: $1.94 **Total = $13.94 - $37.94**

Table 4-1 Cont'd

ASSESSMENT TOOLS	AGE RANGE	PURPOSE AND DESCRIPTION	SCORING	ACCURACY	TIME FRAME/COSTS
Developmental Profile-3 (DP-3) (2006). Western Psychological Services, 625 Alaska Ave. Torrance, CA 90503 (800-648-8857) *http://portal.wpspublish.com* ($240.00) **Training Options:** none **Electronic Options:** Scoring CD	0 - 13 years	**Purpose:** Follow-up, monitoring, assessment and surveillance of milestones in all domains for high risk children **Description:** Measures physical, self help skills, social, academic and communication. Involves an interview or self-report with a primary caretaker.	Percentiles, age-equivalents, stanines	**By age:** not available **By disability:** not available	Admin/Scoring time: 20 – 40 minutes Admin/Scoring costs: $24.00 - $48.00 Materials: $3.00 **Total = $27.00 - $51.00**

PSYCHOSOCIAL RISK and RESILIENCE TOOLS: Not all measures below are screens (meaning they do not provide definitive cutoffs but instead assess a broad array of environmental risk and protective/resilience factors that may affect children's developmental/mental health trajectory—well before delays become obvious. Lack of resilience factors or presence of risk factors, even if all aspects of development are typical at the moment, serve as a call to lower thresholds for referral and to consider a wide-range of community services (e.g., Head Start, parent-training, parent mental health programs/parents' own healthcare providers, social services, etc.).

SURVEILLANCE TOOLS FOR RESILIENCE, RISK AND MENTAL HEALTH	AGE RANGE	PURPOSE AND DESCRIPTION	SCORING	ACCURACY	TIME FRAME/COSTS
Family Psychosocial Screen (FPS) (2000). Included within the AAP Pediatric Intake Form (*www.brightfutures.org*), within PEDS:Developmental Milestones, and freely downloadable at *www.pedstest.com/TheBook/ Chapter10* **Training Options:** none **Electronic Options:** none	Parent	**Purpose:** Screening and surveillance of family psychosocial risk **Description:** A two-page clinic measure of psychosocial risk factors associated with developmental problems, often used for clinic intake. More than four risk factors is associated with developmental delays. The FPS also includes: (a) a four item screen for parental history of physical abuse as a child; (b) a six item measure of parental substance abuse; (c) a four item screen for domestic violence; and (d) a three item measure of parental depression. Can be used along with the Brigance Parent-Child Interaction Scale to view parenting risk and resilience. Readability is 4th grade. In English and Spanish.	Refer/no refer to available community resources for each of the four screens' risk factors.	**By condition,** i.e., parental depression, substance abuse, etc. Depression (3 items): Sensitivity: 100% Specificity: 88% Parental Substance Abuse (7 items): Alcohol abuse, Sensitivity: ~90% Drug abuse, Sensitivity: ~88% Parent history of abuse as a child (4 items): Sensitivity: 92 - 95% Specificity: 87 - 92%	Scoring Time: 3 mins Scoring Cost: $3.60 Material Costs: $0.00 (laminated)- $0.00 (photocopied)- $0.12 **Total (Self-Report):** **$3.60 - $3.72**

table continues...

Table 4-1 Cont'd

SURVEILLANCE TOOLS FOR RESILIENCE, RISK AND MENTAL HEALTH	AGE RANGE	PURPOSE AND DESCRIPTION	SCORING	ACCURACY	TIME FRAME/COSTS
Brigance Parent-Child Interaction Scale (BPCIS) (2002). PEDStest.com, LLC. The BPCIS is included in PEDS:Developmental Milestones and in the Brigance Screens-III. It can be freely downloaded at: *http://www.pedstest.com/TheBook/Chapter10*	0 – 30 months	**Purpose:** surveillance of parenting behaviors associated with resilience versus psychosocial risk **Description:** administered by parent-self report or examiner observation, the 18 – 19 multiple choice items tap whether parents read and talk with their child, enjoy talking with their child and perceive him/her as interested in communication, whether parents actively teach their child new things, etc. Certain items are associated with resilience while others are associated with accumulating delays (which start to become visible at 6-months of age and are striking by 12 – 18-months).	Item analysis-discrete sets of items reflect resilience factors associated with typical development while others items reflect limited resilience associated with future or current delays	Not applicable	Scoring Time: 1 minute Scoring Costs: $1.20 Materials ~$.06 **Total (Self-Report):** $1.26 Interview/Observation Administration time: ~ 5 minutes Interview Admin Costs: $6.00 Materials/Scoring ~$1.26 **Total (Direct Admin):** = $7.26
Strengths and Difficulties Questionnaire (SDQ) (1997). *www.sdqinfo.org* Freely downloadable in multiple languages **Training options:** none **Electronic options:** none	4 – 17 years	**Purpose:** Resilience and psychosocial risk for mental health/social-emotional, behavioral skills. **Description:** 25 items (youth self-report versus parent or teacher report) tapping positive and negative attributes. Generates indicators for conduct problems, hyperactivity, emotional symptoms, peer problems and prosocial behavior. Produces a total strengths versus total difficulties score. Guidance is available on how to aggregate results for epidemiological and needs-assessment studies. Cross-cultural research and translations are abundant and norming studies have been conducted in Great Britain, the United States and otherwise in European countries.	Comparison of factors	Not applicable	Scoring Time: 5 minutes Scoring Cost:$6.00 Materials: ~$.12 **Total (Self-Report):** $6.12 Interview time: ~5 minutes Interview Admin costs: $6.00 Materials/Scoring: ~$0.12 **Total (Direct Admin):** = $12.12

table continues...

Table 4-1 Cont'd

SCREENS FOR OLDER CHILDREN (these screens focus on academic skills and mental health, including ADHD screening)

SCREENS FOR OLDER CHILDREN	AGE RANGE	PURPOSE AND DESCRIPTION	SCORING	ACCURACY	TIME FRAME/ COSTS
Safety Word Inventory and Literacy Screener (SWILS) (2013). From PEDStest.com, LLC with items courtesy of Curriculum Associates, Inc. The SWILS is included in PEDS:Developmental Milestones (PEDS:DM) and is freely downloadable at: *www.pedstest.com/TheBook/Chapter9* **Training Options:** none **Electronic Options:** none	6 – 14 years	**Purpose:** Screening and surveillance of academic skills **Description:** Children are asked (by parents or professionals) to read 29 common safety words (e.g., High Voltage, Wait, Poison) aloud. The number of correctly read words is compared to a cutoff score. Results predict performance in math, written language and a range of reading skills. Test content may serve as a springboard to injury prevention counseling and can be used to screen for parental literacy. Because even non-English speakers living in the US need to read safety words in English, the measure is only available in English.	Single cutoff score by age, indicating the need for a referral	**By age/academic deficits,** Sensitivity: 73% - 88% Specificity: 77% - 88%	Scoring Time: 1 minute Scoring Costs: $1.20 Materials ~$.06 **Total (Self-Report): $1.26** Admin time: ~ 7 minutes Admin/Scoring Costs: $8.40 Materials/Scoring ~$1.26 **Total (Direct Admin): = $9.66**
Pediatric Symptom Checklist (PSC) (1991). Freely downloadable in multiple languages in its 35-question version at: *http://psc.partners.org* **The Pictorial PSC** is useful with low-income Spanish and English speaking families and is included in its 17 item factorable version in PEDS: Developmental Milestones and on *www.pedstest.com/TheBook/Chapter9* **Training Options:** none **Electronic Options:** See below.	6 - 18 years	**Purpose:** Screening and surveillance of emotional/mental health, and conduct. Serves as a necessary prescreen for sorting attention problems from competing conditions. **Description:** Administered by youth/ parent self-report or by interview, the PSC/Pictorial PSC are 35 short statements of problem behaviors capturing various mental health challenges. The PSC-17/Pictorial PSC-17 are 17 item versions producing cutoffs for attentional, internalizing (meaning depression or anxiety) and externalizing problems (conduct, impulsivity, etc.) Readability is ~ 2nd grade. In English, Spanish, Portuguese, Chinese, Dutch, Filippino, French, Somali, and several other languages.	For the PSC, a single score, refer/nonrefer score, for the PSC-17/Pictorial PSC-17, cutoffs for attention, internalizing, and externalizing factors	**PSC/Pictorial PSC by disability,** i.e., mental problems of any kind, across numerous studies: Sensitivity: 80% - 95% Sensitivity: 68% - 100% **PSC-17/Pictorial PSC-17 by specific disability,** i.e., ADHD Sensitivity: 58% Specificity: 91% Internalizing Disorders, Sensitivity: 52% - 73% Specificity: 74% Externalizing Disorders, Sensitivity: 62% Specificity: 89%	Scoring time: 3 minutes Scoring Cost: $3.60 Materials ~$.06 **Total (Self-Report): $3.66** Interview Time: 3 minutes Interview Cost: $3.60 Materials/Scoring: $3.66 **Total (Interview): $7.26**

Table 4-1 Cont'd

SCREENS FOR OLDER CHILDREN	AGE RANGE	PURPOSE AND DESCRIPTION	SCORING	ACCURACY	TIME FRAME/ COSTS
CRAFFT (Car, Relax, Alone, Forget, Friends, Trouble) (2009). Freely downloadable from the Center for Adolescent Substance Abuse Research *www.ceasar-boston.org* and at *www.pedstest.com/TheBook/AppendixA* **Training options:** none **Electronic options:** none	Adolescents (11 to 21 years)	Purpose: to identify substance use (tobacco, alcohol or other drug abuse) in adolescents. Description: self/youth-report questionnaire of six items	Scores 0 - 1: Brief advice Scores 2 - 4: Brief assessment Scores $\geq$ 5: Refer to treatment Note: the AAP has published a recommended algorithm for substance abuse screening, assessment and intervention. Must be completed by youth confidentially.	Sensitivity: 76% - 93% Specificity: 76% - 94%	Scoring time: 1-2 minutes Scoring cost: $1.20 - $2.40 Materials ~$0.6 - $2.40 **Total (Self-Report): $1.26 - $2.46** Interview time: 3 mins Interview cost: $3.60 Materials/Scoring: $3.66 **Total (Interview): $4.86 - $6.06**

table continues…

Table 4-1 Cont'd

Electronic Records Options for Screening and Surveillance with Quality Tools

Essential definitions are:

Tablet PC—approaches that typically require a stylus to select among multiple choice answers only;

Keyboards –approaches enabling users to select multiple choice responses but also type in text-based answers to questions;

Touch-screens applications—these often allow parents to listen to questions and response options and then touch a simple response box (e.g., yes/no) thus reducing literacy demands;

Online –meaning hosted on a website and thus requiring an internet connection, preferably high speed;

PDA –personal digital assistant such as a Palm Pilot or Blackberry usually requiring users to be online, with or without a keyboard;

CD-ROM—offline but still electronic, and requiring installation on the user's computer;

Parent Portal —online applications wherein parents can complete measures but do not see results. Rather these are sent to a different office computer for retrieval/inclusion in electronic records;

Telephony –automated calling, often along with appointment reminder systems through which multiple-choice screens can be administered;

Data Aggregation—almost all electronic applications create a database either online or on individuals' computers (in the case of CD-ROMs) where all administered screens can be viewed, overall results summarized, etc. Some web-based scoring services provide exported files (e.g., EXCEL compatible) to allow users to view overall results. In all such applications, an administrator of multiple sites can view all results;

Webcasts/webinars—These are training options online, either live on a specific day and, eventually constantly available on publishers' websites.

COMPANY/OFFERINGS	TRAINING/SUPPORT OPTIONS	DESCRIPTION AND PRICING
CHADIS (*www.chadis.com*) ASQ, M-CHAT, PSC and over 75 measures online for touch-screen, tablet PCs, keyboards, telephony, smart phones and parent portal methods). Spanish language applications coming soon.	Downloadable guides, live training at exhibits, and other training services on request. Includes options for MOC, QI credit, and e-chapters for clinicians.	CHADIS includes decision support for more than 75 measures, both diagnostic and parent/family focused, such as the Vanderbilt ADHD Diagnostic Rating Scale, and various parent and adolescent depression, substance abuse, domestic violence and other inventories. CHADIS offers integration with existing EHRs, works with a range of equipment/applications, and automatically generates reports plus creates a virtual baby book for parents. Pricing is via site license and ~ $695 per year per full-time provider, although some measures incur per-use fees.
PEDS Online (*www.pedstest.com/online*) PEDS, PEDS:DM, M-CHAT online (for keyboards) in English and Spanish	Slide shows, website FAQs, email support, online videos, discussion list	This site offers PEDS, PEDS: Developmental Milestones, and the Modified Checklist in Toddlers for keyboard applications (allowing for actual comments from parents). Offers a parent portal (wherein families do not see the results), etc. Scoring is automated as are summary reports for parents, referral letters when needed, and ICD-9/procedure codes. In English and Spanish. HL-7/HPPA/FERPA compliant integration with electronic records is available as is data export and aggregate views of records. $2.00 - $2.75 per encounter (depending on volume).
Patient Tools (*www.patienttools.com*) (M-CHAT, ASQ, ASQ:SE and other measures online for tablet, i.e., touch-screen PCs)	Webcasts/webinars, live support by phone, email	Patient Tools offers the ASQ (w/audio option), ASQ:SE (w/audio option), MCHAT, PEDS (in a survey version, i.e., closed-ended questions), PSC, the Vanderbilt ADHD Scales and a wide range of behavioral/mental health measures in multiple languages for adolescents and adults. A practice-based approach provides access in the office via dedicated Survey Tablet equipment, wireless tablet PCs and kiosk PC; or online from home with results available in the office. Access fees are $58.00 per month for ongoing hosting, data storage, reporting, custom programming, telephone technical & installation support. Uses clients PCs or alternately Survey Tablet equipment including rented, lease-purchased or purchased docking stations. $15.25 plus licensing fees for certain measures.

table continues...

Table 4-1 Cont'd

COMPANY/OFFERINGS	TRAINING/SUPPORT OPTIONS	DESCRIPTION AND PRICING
ASQ-3 and ASQ:SE (*www.ASQonline.com*) online administration and separately on a CD-ROM for offline administration with keyboards and tablet PCs.	Live training, online training	Web-based management system offers automated scoring, reporting, referral tracking, and customizable letters for parents/providers for ASQ-3 and ASQ:SE. ASQ Pro is designed for single-site programs ($149.95 annual subscription, plus quarterly billing for screens used) and ASQ Enterprise is designed for multisite programs ($499.95 annual subscription, quarterly billing for screens used). Online questionnaire completion available through ASQ Family Access ($349.95 annual subscription plus $79.95 for annual support). ASQ Family Access provides programs with a secure, customizable website for parent completion of questionnaires, i.e., a parent portal.
Brigance Early Childhood Screens-III. (*www.cainc.com*) Online for keyboards	Live training, online training, email and phone support, customer suggestion box	This web-based service provides clickable data sheets which automatically calculate chronological age, and test scores including age equivalents, quotients, progress indicators, at-risk cutoff scores quotients etc. Aggregated reports and administrative access are available through the online service. $4.00 per child per year.
Battelle Developmental Inventory Screening Test-2 (*www.riverpub.com*) online via keyboards, PDAs, and/or CD-ROM	Website FAQs, email support, live workshops, webcasts/webinars	Scoring services include report writing via a web interface, ~ $378.50 per year plus $76.50 annual renewal fees. Also offers mobile phone data management software priced separately.

PROMISING TOOLS UNDER CONSTRUCTION

All tools, whether screening, surveillance or assessment measures are always works in progress. Even those with national standardization and proven accuracy need to be updated at least every ten years because populations change rapidly [e.g., the frequency with which different languages are spoken, variability of socioeconomic status and psychosocial risk, children's exposure to different media, and the impact of initiatives such as "Back to Sleep" (which altered the ages at which infants acquire motor milestones, etc.)]. So, even tools with abundant psychometric support need regular updates.

Meanwhile, there are promising tools in the works and these are worth watching as they progress from pilot research to, we hope, fully validated, accurate measures. We describe several of these below along with suggestions for authors:

> **Surveillance of the Wellbeing of Young Children (SWYC)** *www.theswyc.org* is an effort to create a freely downloadable package of tools that address all aspects of developmental-behavioral/mental health and autism screening, as well as surveillance/screens for psychosocial risk. The SWYC is designed for children birth to five-years of age. Readability is at the high first to second grade level. Pilot studies compare various SWYC components mostly to other screening measures although there is one comparison study with the Child Behavior Checklist. The studies are promising and suggest that with further validation against diagnostic measures, accuracy standards may be met. Translations into Spanish and cross-validation studies across national samples are ongoing. Suggestions for authors focus on the sustainability of measures offered freely, i.e., how, without income from test purchases, will authors have enough salary support to help researchers, collaborate with electronic healthcare vendors, update standardization and validation, and ensure quality translations? In any case, it is important to recognize that all tests incur costs to providers including duplication of paper forms and the time required for administration and scoring.

> **Strengths and Difficulties Questionnaire (SDQ)** *www.sdqinfo.org* The SDQ measures resilience and psychosocial risk for mental health/socio-emotional, behavioral skills. It includes twenty-five items across various versions (youth self-report, parent or teacher report) tapping positive and negative attributes. Generates indicators for conduct problems, hyperactivity, emotional symptoms, peer problems and prosocial behavior and produces a total strengths versus total difficulties factor score. Guidance is available on how to aggregate results for epidemiological and needs-assessment studies. Widely used in research, cross-cultural studies and translations are abundant with norming studies conducted in many different nations. Currently the SDQ is an aid to clinical judgment and a helpful surveillance measure but as a decision support tool, it still requires clear indicators of sensitivity and specificity. We encourage the authors and researchers to consider such efforts.

> **Parent Screening Questionnaire (PSQ)** *www.umm.edu* was developed by the SEEK project, which aims to reduce child maltreatment. The PSQ is a twenty-item measure with a yes-no format. There are six separate screens within the PSQ including: Parental depression, parental substance abuse, intimate partner violence, family stress, corporal punishment and food insecurity. Of the five published studies, only the depression screen achieves appropriate levels of sensitivity and specificity. So more work is needed, including revising the format to embrace a "sometimes" response option (thereby reducing the likelihood that parents' answers reflect social desirability). Also the results of all studies need to be coalesced into a cohesive guide to scoring.

Other Tools in Need of Attention. There are many published measures that we'd like to see better researched and thus standardized on national samples, validated against diagnostic measures, and tested for accuracy. We encourage publishers and test authors of measures such as the Denver-II/PDQ, and the Child Development Inventories to continue to work on their measures in the best interest of detecting children with problems.

ISSUES IN COPYRIGHT

Screening tests are expensive to create and ongoing improvements are required: Translations, periodic restandardization and validation, etc. Unless otherwise stated, published tests may not be reproduced in any manner, placed on websites or included in electronic records without discussion with publishers. Just because you bought copies of a test does not mean you own its intellectual property. We encourage you to treat tests with respect for the hard work that goes into them and to recognize that legal penalties apply when copyright law is violated.

A CASE EXAMPLE OF SCREENING AND SURVEILLANCE

Below is a case example illustrating the effective use of screening and surveillance. This example illustrates how screening and surveillance can often use the same tools and how evidence-based methods are essential for both processes. We refer within this case to various tools described in Table 4-1. This case uses pseudonyms and stock photography and personally identifying information was eliminated.

Nineteen-month old Maria presented for the first time at the continuity clinic in a teaching hospital due to earaches. During the visit, Dr. Samuels, a third year pediatric resident, noted Maria's lack of eye contact, dearth of jargoning and language, and her tendency to play repetitively but also rather passively with toys. He also noticed that her mother, Ms. Roberts, did not redirect her daughter, soothe her when she cried during the physical exam, or otherwise smile or talk to her. Because this was a sick visit, no developmental measures had been given out in the waiting room, so Dr. Samuels asked whether Ms. Roberts had time to fill out some forms that would help him take a closer look at Maria's language and learning. Ms. Roberts agreed and returned to the waiting room to complete PEDS, the PEDS: DM, the M-CHAT, the Family Psychosocial Screen, and the BRIGANCE® Parent-Child Interactions Scale. Dr. Samuels then scored the measures and noted failure on almost all areas of the PEDS:DM, failure on the M-CHAT, Ms. Robert's concerns about her daughter's behavior (and her striking comment sometimes associated with child abuse or neglect), "I don't think she likes me." In viewing her responses on the BPCIS, he discovered endorsements on several of the at-risk parenting items ("My child is not much fun to be with." and "I mostly talk to her when she is crying.") and almost no endorsements on the positive parenting items.

On the Family Psychosocial Screen, Dr. Samuels noticed that Ms. Roberts failed several items on the maternal depression screen, had had two household moves in the previous year, lived with friends but endorsed items about her lack of social support, and was a single mother. Realizing there were multiple psychosocial risk factors, delays, and potentially serious problems with parent-child interactions, Dr. Samuels sought help from the clinic social worker, Mr. Jackson, who fortunately was available, and who invited Ms. Roberts and Maria (now, fortunately asleep) into an exam room for further discussion. He questioned her about living arrangements, child-care, work, family structure and recent moves. Ms. Roberts reported that she also had a 5-month old daughter, and that her boyfriend, the baby's father, had left them without income or explanation. She and her daughters were living in very cramped quarters with friends who were occasionally willing to help with the children while she did sporadic day labor. Ms. Roberts affirmed feeling depressed and overwhelmed and also said she was worried about her children's well-being since the babysitters were into drugs and that sometimes when she got home, she found them

asleep or in a stupor, and the children wet and hungry.

Mr. Jackson and Ms. Roberts then discussed services that could be helpful including subsidized daycare, housing assistance, food stamps, job placement and training, and counseling. While Ms. Roberts waited, he made a number of phone calls and found slots available in a subsidized daycare program. He also established a case manager in the Human Services department who could help with housing, food stamps, employment/job training, and mental health counseling.

Mr. Jackson then stepped out to inform Dr. Samuels of the plan and gave him contact information for Ms. Robert's case manager. Dr. Samuels then returned to the exam room to explain the developmental issues to Ms. Roberts and to help her with a referral to early intervention. He used the referral letter template (in Chapter 6), faxed this to the program, and gave a copy to Ms. Roberts, along with a language stimulation parent education handout. He also asked her to return in 2 weeks to follow up on Maria's earache (while asking the clinic secretary to allow 30 minutes rather than the usual 10 minutes for this visit and also requesting that the social worker be available if possible).

Ms. Roberts missed her next appointment and it was closer to seven weeks before she returned to the clinic. At that time she reported that Maria and her sister had been enrolled for almost a month in the daycare program and that both were doing well, particularly Maria, who now appeared more engaged, less repetitive in her play, less passive, more fun to be with, and less "dopey-acting." Dr. Samuels noticed that Maria was a far more animated child who now vocalized, made eye-contact, played more appropriately with toys, and smiled.

Ms. Roberts reported she was now working part-time and was also involved in job-training focused on improving her literacy, resumé writing, and competence with computers. She was also on a waiting list for public housing and expected this to be in place within 2 – 3 weeks. She had already started receiving food stamps and instruction in nutritional planning for young children. Dr. Samuels commented in his chartnotes that Ms. Roberts seemed more responsive to her daughter, smiling and talking with her during the visit.

In the meantime, the IDEA Early Intervention program had made contact but had not yet assessed Maria's development. Three weeks after the return visit, Dr. Samuels received a faxed report from the EI service who had met with Ms. Roberts and Maria at her daycare center. EI personnel repeated the M-CHAT but found neither signs of autism spectrum disorder nor delays in receptive language, motor, or social-emotional skills. Maria continued to have expressive language delays that the program thought might be secondary to growing up bilingual and being raised by an overwhelmed parent with understandable symptoms of depression. The EI program planned to have a speech-language pathologist work with Maria and her daycare teacher once a week and to meet monthly with her mother to help her work on Maria's language skills at home.

Comment on Case Study. *This family may still have a difficult road ahead but the use of a comprehensive surveillance model helped identify a large pile-up of stressors that were clearly taking a toll on Maria's development and her family's well-being. The clinician's observations suggested the need for screening even within a sick visit. A failed screening test triggered the need to look further at possible causes and scrutinize this family more carefully via a rich set of surveillance measures including thoughtful observation. The combination of surveillance and screening identified a wide range of needs and thus a broader set of helpful interventions. By stabilizing housing, nourishment, income and health care, Maria's mother was able to become a more a responsive and nurturing parent who had supports necessary to promote Maria's development. In turn, these interventions helped ensure a better developmental outcome for Maria (and her sister).*

Chapter Comments. *There are many measurement methods available when screening for developmental-behavioral problems: Parents' concerns, parent report, observational tools, or direct elicitation of children's skills. Problematic screening test results are often the trigger alerting us to define the "big picture," i.e., to use surveillance measures to determine possible causes. The results of surveillance measures, in turn, help*

identify a wider range of needed interventions.

But even though screening tests detect subtle problems, by the time a child has a troubling result, delays are probably present. Ongoing screening/surveillance, in contrast, can identify risk factors predictive of future delays—enabling us to intervene with risk before any delays become manifest. For this reason, we need to conduct screening/surveillance routinely and over time, not just after a problem is found.

So it is helpful that many screens can also be used as surveillance tools. An example is using a parents' concerns screen and discovering comments such as, "I don't know what a 6-month old should be saying" or "I don't talk to my baby much because I know she can't understand what I am saying." Such a child may pass a milestones-focused screen, meaning delays are not present… at least, not yet. But by addressing parents' concerns (and our own), we are conducting surveillance, and surveillance, in turn, leads us to intervene, i.e., educate the parent in developmental promotion and positive parent-child interactions. Bottom line screening and surveillance together, using multiple methods for viewing development and risk are crucial.

While the list of measures described in this chapter is voluminous and may seem formidable given the time constraints of primary care visits, there are efficient ways to implement measures so that we can help prevent problems from developing and swiftly detect and intervene with emerging deficits. Chapter 5 describes how real-life providers implemented screening and surveillance efficiently and effectively (and complied with various AAP policy recommendations). Chapter 5 also delineates hearing and vision screening and the neurodevelopmental exam.

Website note: *New tools arise and research on existing tools is published frequently. Once we receive new information, we will post on the website for this book updates to Table 4-1. Please check the site for any new information on tools, and download an updated table before sharing with colleagues (www.pedstest.com/ TheBook/Chapter4).*

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Chapter 5: A Process Approach to Developmental-Behavioral Screening and Surveillance with Children Birth to Six-Years

Frances Page Glascoe   Kevin P. Marks

INTRODUCTION

In primary care, we have 15 minutes on average for an entire well-visit. Within those 15 minutes we have to address lingering or new health or other concerns, conduct a physical exam, screen vision and hearing, provide developmental promotion and anticipatory guidance, and detect developmental-behavioral problems. Out of the 15 minutes, most providers manage to cordon off about 3 for developmental-behavioral issues. So, in 3 minutes what can we get done in terms of screening and surveillance? Answer: A lot—especially if we ask parents to complete measures on their own and encourage clinic staff to score. If we have results in-hand before a visit, we can walk into the exam room well-informed and prepared (e.g., with informational hand-outs focused on parents' interests, or with referral information if needed).

Although we emphasize well-visits as the best opportunity for primary care detection and intervention, clinicians should be well aware that screening/surveillance can be conducted at sick or return visits. While less optimal (especially if the tools used require an unwell child to perform tasks, and also due to the brevity of sick and return appointments), there is an enormous drop-off in attendance at well-visits, most especially with children on Medicaid. So screening/surveillance should be "opportunistic," meaning that we should be prepared to measure developmental-behavioral or psychosocial issues any time we encounter young children. It is surely wise to schedule a longer sick/return visit with children who have not arrived for recent well-child care.

CHAPTER HIGHLIGHTS

I. Policy, premises and tasks of screening and surveillance;

II. A 10-step process for early detection and intervention incorporating various AAP policies on early detection and intervention in primary care;

III. The content of screening/surveillance (illustrated by case examples), the content for a careful physical exam, details about documentation, referral coordination, communication with non-medical interventionists, and subspecialists, and how to follow up with families and other providers. Within this section we cover:

(a) Well-visit encounter forms showing the different tasks for each visit. We include these in Appendix A and on the website for the book so you can download them for your clinics and customize as needed (e.g., adding prevention of frostbite in Alaska or snake bites in Florida). We've found the forms enormously helpful in getting all our clinicians on the same page (literally) and ensuring that our clinics provide quality care;

(b) An example of a longitudinal form for tracking children's progress, i.e., showing growth or delays in milestones over time. This provides an illustration of what various tests indicate in terms of monitoring development; and

(c) An overall longitudinal problem/process checklist so that you can document what you've accomplished with screening/surveillance, what problems you've identified, what needs doing in terms of follow-up, what referrals you've made, and what was found;

IV. Suggestions for how to stagger the process across well-visits to make it manageable;

V. Referral resources focused on links to national sites (e.g., for IDEA, Head Start, parent-training) from which you can find local services;

VI. Referral letter templates including a two-way consent form.

I. SCREENING AND SURVEILLANCE: POLICY AND PREMISES

The American Academy of Pediatrics (AAP) has four different policy statements on developmental-behavioral screening and surveillance including detection of autism spectrum disorders, mental health, and kindergarten readiness and establishing a medical home.[1-4] In addition, the AAP's Bright Futures Initiative[5,6] adds a needed focus on detecting psychosocial risk and resilience, advocates for developmental-behavioral promotion, and provides a periodicity chart. While all AAP policies are both wise and invaluable, reconciling the many recommendations is needed. For example, the AAP's mental health statement reviewed only narrow-band social-emotional screens and did not consider the voluminous research showing that broad-band developmental-behavioral screens also identify mental health problems (discussed further in Chapter 10). All this means that providers' efforts to comply separately to each statement is distinctly over-whelming and duplicative. Further, some policy statements are misinterpreted and in conflict with the AAP's lobbying efforts to ensure that private payers and Medicaid reimburse for early detection well beyond 24- to 30-months of age.

So, how can we merge the important messages from the various AAP policy statements in a way that is functional and do-able? Here are the premises behind the workable process described in this chapter:

(a) AAP policies and abundant research confirm the need for evidence-based tools. Selected items from measures such as the Denver lack evidence and scoring criteria. Delays and disorders are often so subtle in young children that we can't spot them with "the naked eye" (or if we can, we probably don't need to measure, but simply refer). So, we need to use evidence-based tools with the asymptomatic—those children we think are doing OK but who, in fact, may not be, but we will only know if we actually measure. With that information in hand, clinical reasoning shines brightly and helps us bring to bear on problematic results all that we know about families' psychosocial challenges, family medical history, and children's health. With a combination of quality evidence collected routinely along with our observations and knowledge, primary care providers are thoroughly positioned to determine on the types of help families need;

(b) Kindergarten readiness screening is incorporated into most broad-band screens with an age-range of 3-years to 6+years (e.g., via items tapping letter/numeral/shape/color naming, grapho-motor skills in drawing and writing, group social and attention skills, etc.). A separate measure of kindergarten readiness is rarely, if ever, needed;

(c) If broad-band screens tap social-emotional/mental health/behavioral skills (some do and some don't), a separate measure may not be needed. Nevertheless, when a child fails a broad-band screen, a more careful look is often necessary. When time is limited, measurement of mental health problems should become a recommended focus for subsequent evaluations conducted by IDEA programs;

(d) Developmental-behavioral problems continue to emerge throughout childhood and adolescence. Therefore we promulgate ongoing screening/surveillance beyond 9-, 18-, 24- to 30-months, per the recommendation in the AAP 2006 statement for "a pattern and practice of attention to development that can and should continue well beyond 3-years of age."[2 (p. 406)] Note that the AAP is actively advocating that screening/surveillance should be reimbursable well beyond 30-months of age, and this is already offered and required in many States. The authors of the AAP 2006 statement anticipate a revision by 2014 emphasizing screening/surveillance at all well-visits even after 30-months (Paul Lipkin, personal communication, 2013);

(e) It is critical to keep an eye on risk and resilience factors. Although measuring risk and resilience factors is not needed at every visit, it is wise to assess these issues periodically;

(f) Developmental-behavioral promotion should be an essential component of every visit, even if referrals are also needed;

(g) A narrow-band screen for autism spectrum disorder is recommended at 18- and 24-months or whenever concerns arise. But such screens should never be used alone—they will miss the majority of children with more common disabilities;
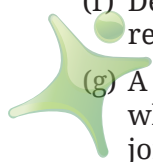
(h) When children fail an ASD specific screen, an IDEA referral is essential (as recommended by the AAP's ASD statement).[2] Only a fraction of children will be found to have ASD after failing the Modified Checklist of Autism in Toddlers (M-CHAT) and the requisite follow-up interview.[7] But failing both the M-CHAT and its interview continues to hold a high probability of other types of disabilities. So it is best to refer to IDEA for further testing, for follow-up interviews, further observation and rule-outs. It is also important to note that ASD specialty clinics inevitably have long waiting lists and children should never languish without intervention in the interim;

(i) Surveillance and screening can depend on the same evidence-based tools—separate measures for surveillance and screening are not needed;

(j) Many States' Medicaid agencies require specific measures. For example, Texas and Tennessee, only reimburse via Medicaid when the ASQ or PEDS Tools are administered. Delaware, Massachusetts, Hawaii and Arizona only reimburse when PEDS Tools are used;

(k) Given a choice among measures, providers tend to select parent-report tools.[8]

THE TASKS OF SCREENING AND SURVEILLANCE

These include:

A. Eliciting and addressing parents'/other caregivers' concerns;

B. Measuring milestones of developmental-behavioral/social-emotional/mental health along with an autism specific screen at 18- and 24-months;

C. Identifying and addressing family psychosocial risk factors (e.g., parental depression or other mental health problems including substance abuse, limited education, single parent, housing or food instability, unemployment, etc.);

D. Determining resilience/protective factors, such as positive parent-child interactions;

E. Identifying child and family medical history and addressing any potential impact of these on children's health;

F. Conducting a thorough physical exam along with periodic vision and hearing screening;

G. Promoting developmental and behavioral skills via parent education;

H. Interpreting results, deciding on any needed referrals, and explaining findings to parents;

I. Documenting findings (e.g., an informative encounter note, a summary report for parents, and referral letters), and making needed referrals;

J. Working with referral sources to share information and determine whether other services are needed (e.g., when children don't qualify for IDEA programs), and follow-up with families on uptake, effectiveness of advice, etc.

II. A STEP-BY-STEP PROCESS FOR DEVELOPMENTAL-BEHAVIORAL SURVEILLANCE AND SCREENING IN CHILDREN FROM BIRTH TO 6-YEARS

Figure 5-1. Developmental-Behavioral Surveillance/Screening at Well-visits with Children from Birth to 6-Years of Age: Step-by-Step

A. Elicit Caregivers' Concerns[*]

B. Measure Children's Skills
1. Screen Milestones in all Domains[*]
2. Add Autism-specific Screening at 18- and 24-Months[*§†]
3. Social-emotional/Mental Health Screening When Screens are Failed[*†]

C. Identify/Update Psychosocial Risk Factors[*§]

D. Observe/Measure Parent-child Interactions and Resilience Factors[*§]

E. Identify/Update Family and Child Medical History and Biological Risk Factors[§]

F. Conduct a Careful Physical Exam

G. Provide Developmental and Behavioral Promotion

H. Interpret Results and Explain Findings
Decide on Any Needed Referrals[§]

I. Document Current Findings
Make Needed Referrals[§]

J. Coordinate Referrals, Update Longitudinal Documentation, and Follow Up[§]

*Use evidence-based measures for each of these components
† Can be accomplished by referral resources
§ Not needed at every visit

III. WHAT WORKS IN DEVELOPMENTAL-BEHAVIORAL SCREENING/SURVEILLANCE: DETAILS FOR EACH OF THE 10 STEPS

The alphabetical assignments in Figure 5 – 1 are described below. Each step begins with a description of the measure(s) used, followed by ongoing case examples offering a real-world narrative. The flexible nature of early detection is highlighted because many steps must vary by the different issues at play for each patient, as well as by practice workflow, office equipment, parents' time and parents'/providers' ability to collaborate with IDEA programs. The focus in this chapter is on children from birth to 6-/8-years (depending on the measures used).

1. **Case example #1** describes the work of more than 200 primary care clinics across 30 US States and is based on their aggregate experiences on more than 100,000 patients. In each of these settings an online screening service was used, whether or not electronic health records were present. Administration methods for tools varied (e.g., having parents go to a web-based parent portal and complete screens prior to the visit, using computers in the waiting or exam room, having parents complete paper-pencil questionnaires while in waiting rooms followed by staff entering parents' answers into the online system, by a hands-on administration or via live interview with clinicians/ nursing staff).

2. **Case example #2** describes a multi-satellite pediatric clinic with 21 providers within a single US State. Within this case we follow a single patient and her provider who used somewhat different measures than in Case Example #1 without use of an online screening service. Measures were administered in various ways depending on parent literacy: live interview and/or parent self-administration via paper-pencil. This case tracks the detection of emerging developmental-behavioral problems and also illustrates issues in referral coordination—both successes and challenges.

STEP A. ELICITING AND ATTENDING TO CAREGIVERS' CONCERNS

At every visit we want to know what concerns parents have and figure out how to address them. Unfortunately some questions don't work well at eliciting parents' concerns, including the ones shown in the AAP 2006 statement.[9] If we don't ask and don't ask well, families may not tell us their worries, most especially families with limited education and elevated psychosocial risk.[10-12] But when we do ask effective questions, parents almost always share concerns—and thus their unique issues. The specific topics parents raise enable us to capitalize on the "teachable moment" wherein parents are thought to be particularly receptive to focused developmental promotion and anticipatory guidance. Asking parents to express their concerns also lets them know clearly that developmental-behavioral issues are a part of health care (something many low-income parents do not know and tend not to discuss spontaneously).[13] Finally, use of carefully constructed questions focused on parents' concerns, lessens the awkward nature of encounters with an "unvoiced agenda," and the problematic consequences of "oh by the way concerns" raised at the tail-end of the encounter when there is little time to address them and when other families (and staff) are waiting.[14]

Description of the Parents' Concerns Measure Used in Case Example #1

An evidence-based approach to eliciting and addressing parents' concerns is seen in *Parents' Evaluation of Developmental Status (PEDS)*, a 10-question measure that prompts parents to describe in their own words how their children are doing in all developmental-behavioral domains. Without the probing questions of *PEDS*, parents tend to announce only worries about children's behavior.[9] With probes, parents are better able to think through competing reasons for misbehavior (e.g., Does my child understand what I say? Does she hear me when I speak? Does he have the motor skills to execute my requests? etc.).

PEDS also elicits the worries of healthcare providers who are advised to enter their own concerns onto

the *PEDS Response Form* before scoring. While a minority of parents fail to share concerns when they should (e.g., due to literacy barriers or anxiety), providers' observations are also an essential part of early detection via *PEDS*. *PEDS* encourages providers to incorporate other surveillance information such as knowledge of psychosocial risk factors and physical exam results to broaden referral recommendations (e.g. mental health or social work services for parents, audiological evaluations for children, etc.). *PEDS* also calls, at times, for implementation of other aspects of surveillance, including administration of a milestones-focused screen for children at moderate but not high risk (usually on about 20% of children).

PEDS is > 70% - 90% sensitive and specific to the presence or absence of probable problems including ASD, cerebral palsy, language impairment, etc. *PEDS* scoring also provides clinicians a basic triage approach to sorting patients and guidance on how best to respond. Its decision-support suggests which:

1. Children need prompt referral to IDEA (and which types of evaluations are needed);

2. Children need further screening. If screening is passed, advise parents on topics of concern and vigilantly monitor development, and/or refer to non-IDEA programs such as Head Start or parent education;

3. Parents are the "worried well," i.e., parents who have concerns needing attention but not concerns associated with measurable developmental-behavioral problems;

4. Families need evaluations for potential mental health problems and/or referrals for parent training;

5. Parents have communication or literacy problems and thus need alternative measures and measurement methods (e.g. interview, direct-elicitation of children's skills), and provider attention to psychosocial risk factors;

6. Children are doing well, and thus have parents who simply need reassurance that their child-rearing skills are appropriate and their children are typically developing;

7. Parents need advice about health issues (e.g., problems with eating, sleeping, vision, hearing, asthma, etc.). In many cases, these difficulties may have been addressed at prior visits but the persistence of complaints affords an opportunity to re-explain and provide more in the way of supportive information (if not also re-evaluate medical issues).

Research on the benefits of *PEDS* shows that when concerns are elicited in advance of the encounter, there is a substantial reduction in "oh by the way" concerns. As a consequence, *PEDS* appears to shave an average of three minutes from the average visit length—leaving more time for actually addressing parents' issues.[15] In turn, when parents have an opportunity to describe their unique concerns, providers can carefully focus the content of developmental promotion.[10] For example, knowing that parents are concerned about toilet training versus temper tantrums enables a selection of specific parenting information appropriate to the issues parents raised. *PEDS* also engenders parent-provider collaboration and increases use of positive parenting techniques (discipline not punishment).[16] Finally, parents are more likely to return for well-visits when *PEDS* is used.[17]

Studies critical of *PEDS* are several and, in general, these studies note that it identifies twice the number of children in need of attention than do other screens and thus that *PEDS* specificity is problematic.[13,18-20] Such findings are quite correct because *PEDS* is designed to identify not just IDEA eligible children (e.g., the bottom 2% on reference standard measures), but also those at moderate levels of risk who likely need something other than an IDEA referral. It is also evident that many providers ignore the recommendations generated by *PEDS* and thus tend to refer far fewer patients than they do when other measures are used. Worrisome is the distinct possibility that the "junk science" of informal milestones may be used to over-ride evidence. Obviously, *PEDS* needs to be deployed with care and its results taken seriously. And so *PEDS* may work best when coupled with another component of screening/surveillance—accurate measurement of children's milestones.[20]

Eliciting/Addressing Parents' Concerns: Clinic Case Example #1

We use PEDS (via PEDS Online) at all visits starting at 4-months of age. At earlier ages we use Bright

Futures Trigger questions. Our rationale is that in the 0 through 3-month age-range, parents are largely concerned about health issues—feeding, diaper rash, sleep—and that existing developmental-behavioral problems are likely to be apparent with clinical observation, knowledge of medical history, and physical exam findings. PEDS Online is used in various ways across our clinics, depending on clinic equipment, provider preferences, and parents' access to the internet from home, by live interview with staff asking parents questions at the medical technician or nursing station, by having parents complete PEDS questions in the waiting or exam room and then having staff or providers enter comments into PEDS Online or by prompting parents to complete measures before the encounter at home or through a public library or school computer.

By using PEDS, we've virtually eliminated "the grenades of the day" that are so disruptive to our work flow, aggravating to staff, and irksome for the parents who must wait even longer. By knowing in advance what parents' concerns are, we walk into the exam room ready to address specific topics, and armed with parent and referral information as needed. PEDS Online also provides a referral letter to mail or email to referral sources, a summary report for parents explaining next steps, and guidance on billing and procedure codes.

Because PEDS calls for a second screen for children at moderate risk, we also use routinely, starting at 4-months, the PEDS:DM, a milestones-focused measure offered by PEDS Online. This helps us better identify the "worried well" and thus address the concerns of such parents via developmental-behavioral promotion and watchful waiting. Because some level of risk remains (e.g., when parents tell us they don't know how to help a 6-month-old talk or what exactly a child that age should be doing), by adding a short but validated milestones-focused screen to PEDS, we can swiftly identify which children and families need hands-on intervention.

STEP B. MEASURE CHILDREN'S SKILLS

Step B focuses on defining what children are able to do and the domains in which they may be having trouble. The information gathered in this step helps confirm or disconfirm parents' concerns, and thus better indicates when parenting advice or referrals are needed. Evidence-based measures are required, so please read or reread Chapter 3 if you remain needlessly confident in ad-hoc milestones— these are thoroughly proven *not* to work well in early detection. Step B has three components, per AAP recommendations, some of which can be staggered across visits and/or become questions posed to referral sources:

STEP B (PART 1): SCREEN MILESTONES IN ALL DOMAINS

Descriptions of broad-band milestones screens used in Case Examples # 1 and # 2

Ages and Stages Questionnaire-3 (ASQ-3) measures developmental skills in five domains: communication (a combination of expressive and receptive language), fine motor, gross motor, problem-solving (cognitive/academic/preacademic), and self-help (referred to as personal-social). Across the 0 to 5½-year age-range, parents answer 30 multiple choice questions—about six per domain. Some questions, especially with children 2 ½-years and older, require parents to elicit skills directly from children. Ideally, parents (and children) complete the *ASQ* at home prior to an encounter (e.g., via an online application or with print-outs taken home or mailed out after prior visits). Otherwise, families can work through the questions given sufficient time (and materials) in the waiting room. Cutoff scores identify children with probable disabilities, i.e., those performing at the 2nd percentile or lower, but also those in "the gray zone" who are at risk, may not qualify for IDEA, but need other types of intervention. The *ASQ's* informal questions to parents may identify other surveillance foci including medical/developmental history, parental worries about vision/hearing, and behavioral issues.

The *ASQ-3* (and its earlier editions) have enjoyed abundant research. When compared with pediatricians' clinical impressions (often based on informal milestones drawn from the Denver), the *ASQ* detected six times more children at 12-months of age, and three times more children
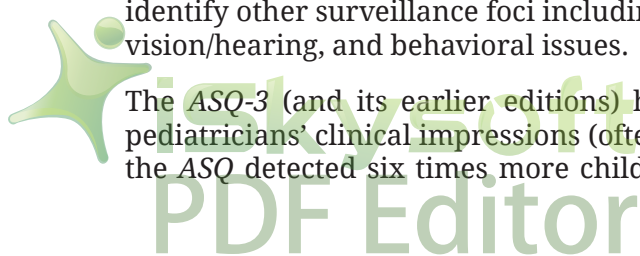
at 24-months of age.[20-29] As with *PEDS*, *ASQ* research has focused on discriminant validity, i.e., what types of conditions are identified via unique performance patterns. In a study conducted in nineteen countries with the *ASQ* (2nd ed.),[22] its sensitivity to neurosensory disabilities (severe cerebral palsy, functional blindness, deafness, etc.) was high, with good specificity to the absence of problems (82.3%).[23] Performance patterns were striking in that the communication domain was most predictive of disabilities, followed closely by deficits in the gross motor and self-help domains.[22] Deficits in fine motor and problem-solving contributed little to the prediction of neurosensory disabilities.[26] Preliminary studies suggest that the *ASQ* is highly sensitive at detecting ASD via unique performance patterns. Retrospectively, children with ASD (N=73) were found frequently to have delays in communication, problem-solving and self-help domains; and parents were likely to have concerns about children's behavior. The *ASQ-3* in Spanish is known to be both sensitive and specific, and studies of its Korean and Norwegian translations also provide evidence of accuracy.[27,28]

PEDS: Developmental Milestones (PEDS:DM) is for children from birth to eight-years of age and has 6 – 8 items per well-visit—one item per domain, i.e., expressive language, receptive language, gross motor, fine motor, self help, social-emotional, and for older children, reading/pre-reading and math/pre-math/writing/spelling. Thus the *PEDS:DM* serves as a developmental-behavioral/mental health, as well as a kindergarten readiness screen. The screen is designed to replace informal milestones checklists (such as those found on age-specific encounter forms) with evidence.

Administration options include parent-report (via *PEDS* Online or paper-pencil in the waiting room), observation (for infants and toddlers) but also direct elicitation (which requires about 3 – 5 minutes of professional time). *PEDS Online* automates scoring instantly, while hand-scoring takes about 1 minute. Results indicate when a child performs at or below the 16th percentile in each domain—meaning that the *PEDS:DM* identifies both at-risk and high-risk children. A cumulative recording form charts progress in each domain over time and indicates how to integrate results with *PEDS*, a measure of parents' concerns. A scored example of the longitudinal tracking form for both *PEDS* and the *PEDS:DM* are shown in Section VI.

In addition, the *PEDS:DM* via *PEDS Online* houses the *Modified Checklist of Autism in Toddlers (M-CHAT). PEDS:DM* in print also includes the *Family Psychosocial Screen, the Brigance Parent Child Interactions Scale*, and several measures for older children, such as the *Safety Word Inventory and Literacy Screener (SWILS)*, the *Pictorial Pediatric Symptoms Checklist (Pictorial PSC)*, and the *Vanderbilt ADHD Scale*.

PEDS:DM items were culled from two diagnostic measures, the *Brigance Inventory of Early Development-II* and the *Brigance Comprehensive Inventory of Basic Skills* via logistic regression to identify skills optimally predictive of performance in each domain. Research illustrates high levels of sensitivity and specificity across ages and per domain in comparison with diagnostic measures of development and school skills.[30] One study showed the combination of *PEDS* and the *PEDS:DM* (a total of 18 items capturing both concerns and milestones) was as sensitive to developmental-behavioral problems as a lengthier screen and more likely than other tools to detect the most common developmental difficulty—language impairment.[31]

Milestones-focused Screening/Surveillance: Clinic Case Example #1

We use the PEDS:DM (also via PEDS Online) at all visits after 3-months, due to its brevity (only 6 – 8 questions, one per domain). Many clinics have parents complete the age-appropriate milestones questions in print in the waiting or exam room although some clinics ask parents to complete the items at home before the visit via the PEDS Online parent portal. The print version for gathering responses (and having staff enter responses into PEDS Online) is the preference of most clinicians, because the PEDS:DM has a built-in developmental promotion component in which parents are encouraged to read aloud to their children (even in early infancy), a story about age-appropriate parent-child interactions (e.g., talking with your baby, imitating his/her sounds, naming things the child is attending to, etc.). We are aware that the

PEDS:DM detects children with mild and often emerging delays; delays often associated with psychosocial risk factors. This means that some children with unmet milestones on the PEDS:DM do not qualify for IDEA but we know such children need other kinds of help.

So here is our decision-making paradigm based on the combination of PEDS and PEDS:DM:

1. *If parents raised concerns on PEDS but the PEDS:DM has not identified any problems, we first attend carefully to the content of parents' concerns. If parents described disordered development such as disinterest in others, repeating the same phrases, loss of words (all issues not well captured by milestones-focused screens), we simply refer to IDEA;*

2. *If parents have concerns on PEDS, but disordered development does not appear present in parents' comments (e.g., "I'm not sure what a 6-month-old should be saying"), and the PEDS:DM does not confirm problems, we advise parents on developmental progress and developmental promotion via information handouts and discussion. We consider parents who don't know much about development to be "pre-risk" and so we monitor development carefully with an eye toward whether our advice was effective or whether parent training and/or IDEA referrals are needed;*

3. *Whether or not parents have raised concerns on PEDS, but the child has unmet milestones on the PEDS:DM, we refer to IDEA for more in-depth screening;*

4. *When screens are failed but IDEA does not find problems, we refer to community programs such as Head Start or quality daycare (and we monitor these children carefully so that mild delays do not become bigger ones).*

Step B (Part 2): Autism Specific Screening At 18- and 24-months

The AAP recommends screening for ASD at 18-months and again at 24-months (and at other ages if concerns are suggestive of ASD). Although many broad-band screens have been the focus of discriminant validity studies showing reasonable sensitivity and specificity to ASD, none are as accurate as adding a separate narrow-band autism specific screen. Nevertheless, ASD-focused screens should never serve as the only screening tool used at well-visits because they fail to detect most children with other types of problems—problems far more common than ASD—such as language impairment, intellectual disabilities, or learning disabilities. Also, not all children who fail an ASD screen will actually be found to have ASD (although they are highly likely to have a substantial disabilities of other types).[32-34] For this reason we recommend referring first to IDEA services for further evaluation and intervention when an ASD screen is failed. Although a simultaneous referral to ASD specialists can be considered, IDEA services can help confirm or disconfirm the need for a specialty evaluation.

Description of the ASD screen Used in Case Example #1 and #2

The Modified Checklist of Autism in Toddlers (M-CHAT) consists of 23 short questions about children's behaviors and social communications to which parents indicate 'yes' or 'no.' The *M-CHAT* is freely downloadable in multiple languages at *www.mchatscreen.com*. A scoring template is also downloadable on the site.

When the *M-CHAT* is failed, the *M-CHAT* Follow-up Interview is required. The exact questions are available at *www.mchatscreen.com* but the interview may be too lengthy to complete during a well-visit. But almost all *M-CHAT* over-referrals are children with other kinds of problems—often language impairment or intellectual disabilities. The best option is to refer to IDEA programs with a specific request to provide the follow-up interview as well as other evaluations—allowing IDEA to decide if an ASD-focused evaluation is warranted. Referring only to ASD services is not advised due to the inevitably long waiting lists.

Research on the *M-CHAT* is voluminous. The *M-CHAT* detects ~ 5 times the number of children with ASD than does clinical judgment alone.[32-34] In a primary care sample of 41 patients diagnosed

with ASD, only 4 had been previously flagged by the pediatrician.[34] Other studies of the *M-CHAT* are housed on its website (*www.mchatscreen.com*). In-progress studies are focused on whether a shorter set of items works as accurately (which would be helpful for fast-paced primary care visits).

Autism-Specific Screening: Clinic Case Example #1

Per AAP recommendations, we use the M-CHAT via PEDS Online at 18-months and again at 24-months (and otherwise flexibly, i.e., when parents' comments describe disordered development consistent with ASD, such as repetitive behavior, lack of interest or responsiveness, etc.). When the M-CHAT is failed, parents usually have substantial concerns, and their children have not performed well on the PEDS:DM and/or PEDS. So in all cases when the M-CHAT is failed, we know we need to refer to IDEA with a specific request to view all aspects of a child's development, and we also ask IDEA to complete the requisite M-CHAT follow-up interview. In the rare cases when parents don't have concerns and other screens are passed, but the M-CHAT is failed, that's when we tend to do the M-CHAT follow-up interview on our own (because parents may have misunderstood items, may have literacy problems we failed to detect, and perhaps parents simply needed more help understanding the questions). PEDS Online shows us which questions on the M-CHAT were failed, and so we can sometimes fit the interview in during a visit, especially if only a few items need more discussion. Our practices downloaded the exact wording for the follow-up interview from the MCHAT website (www.mchatscreen.com) and we keep this in the desk in every exam room.

Step B (Part 3): Social-Emotional Screening When Other Screens are Failed

Developmental problems often co-occur with social-emotional/mental health problems. When broad-band developmental screens do not measure this domain, a social-emotional/mental health screen should be deployed (or referred for) . There are a range of measures for social-emotional screening as described in Chapter 4, (including ones for older children with more extended descriptions of the latter in Chapter 9).

Descriptions of Social-Emotional Screens used in Case Example # 1 and # 2

Parents' Evaluation of Developmental Status (PEDS) and *PEDS:Developmental Milestones (PEDS:DM)* are described above. *PEDS* captures parents concerns about social-emotional and behavioral issues. The *PEDS:DM* includes a brief social-emotional scale.

ASQ:Social-Emotional (ASQ:SE) is for children 3-months through 5½-years. In a specialized medical home which served foster care children, the periodic use of the *ASQ:SE* promptly detected six times more children (ages 6-months to 5½-years) with suspected social-emotional delays (i.e., evolving disorders) than a clinician's unstructured surveillance alone.[22,24,35] Of note, all pediatricians who participated in this study possessed knowledge that each child was high-risk for a developmental and social-emotional delay. Use of the *ASQ:SE* detected 24% of children as having a suspected social-emotional problem, while a clinician's unstructured surveillance detected only 4%.[22,24,35]In these studies caregivers were asked to complete either the *ASQ* or *ASQ:SE* before every well-child visit for children ages 4-months to 5½-years. Administration of the *ASQ* at the first visit was alternated with that of the *ASQ:SE* at the next visit, but for feasibility reasons, both questionnaires were not administered simultaneously. The agreement between the *ASQ:SE* and *ASQ* ranged from 56% to 75% when data were stratified by age group.[24] This research demonstrated the benefit of alternating the *ASQ* with the *ASQ:SE* at every well-child visit (4-months to 5½-years) in a high-risk population.

Despite the *ASQ:SE's* ability to dramatically increase the identification rates of children with social-emotional problems, an organized strategy is needed for preparing a community (e.g., social and educational sectors and a primary care practices).[36] In a general population sample, an Illinois statewide initiative advocated and implemented universal *ASQ:SE* screening in the second year of life, at least by the 18-month well-child visit.[36] In addition, the *ASQ* was completed at least once by the 12-month well-child visit, and again by the 24-month well-child visit. Interestingly,

69% of clinic sites had *ASQ* screening rates > 85%. The feasibility of *ASQ* tools is visible because half of the primary care sites met the objective of screening 85% of children, although in the remaining sites screening rates ranged from 5% to 81%.[36] Developmentalists or mental health specialists co-located in primary care also offer a feasible approach to monitoring progress once children are enrolled in special services.[37] Another common primary-care strategy is to employ the *ASQ:SE* along with the *ASQ* at the 4-year well-child visit because social-emotional skills, as well as developmental skills correlate closely with high school graduation rates.[24] Compared to the *ASQ*, parents typically find the *ASQ:SE* easier to complete because its items do not require children to perform developmental tasks, but instead are based on parental recall.

Social-Emotional/Mental Health Screening: Clinic Case Example #1

When parents repeatedly express social-emotional or behavioral concerns on PEDS, we take this as a sign that our brief advice has not been effective, and that more intensive interventions are needed. When we see this pattern or when social-emotional items on the PEDS:DM are below cutoffs, we refer to IDEA with a specific request to administer the ASQ:SE or, in the case of older children, for administration of mental health measures such as the PSC (as described in Chapter 9). When IDEA finds problems, we often refer to a mental health specialist as well.

C. IDENTIFY/UPDATE PSYCHOSOCIAL RISK FACTORS

Psychosocial risk factors are predictors of future developmental-behavioral problems, even when current status looks fine. Risk factors include: limited parental education, parental depression or substance abuse, housing, food, job instability, difficulty speaking English (for families residing in the US and most Canadian provinces), etc. As with developmental-behavioral problems, psychosocial risk factors are often not amenable to clinical observation. For example, families may have dressed up for an appointment and obvious symptoms of poverty may be masked. Families may be on their best behavior and look happy even in the face of depression simply because a provider is paying attention to them. So, measurement is the best way to capture psychosocial risk factors.[12,38-46]

Description of a Psychosocial Risk screen used in Case Example #1 and #2

> ***The Family Psychosocial Screen (FPS).*** The *FPS* captures many different risk factors including educational attainment and income, health and safety issues (such as gun storage and smoking in the home), parents' medical history, social support, child care arrangements, etc.[40,41] Within the *FPS* are several short (e.g., 4-item) screens for depression, substance abuse, domestic violence, and so forth. Compared with a clinician's medical records, the *FPS* identifies significantly more parents with possible substance abuse, depression, low self-esteem, and/or history of abuse as a child, including worries about current disciplinary methods (p < .01 for each).[40] While clinicians may initially think some *FPS* questions are inflammatory, this is not supported by research. For example, the *FPS* response rate for sensitive questions is > 85%.[40]

> Nevertheless, a cover letter is wise in which you inform parents that in order to provide optimal care for their child, it is necessary to understand and address important issues within the family. We recommend using the *FPS* with parents of all new patients and then repeating subsets of items (e.g., parental depression questions) later in the first year of life and again sometime in the second year, i.e., during the time frame when post-natal depression is common (for both mothers and fathers). In addition, we recommend repeating items focused on any risk factors previously addressed (e.g., did the family actually stop smoking inside the house? Improve the safety of gun storage?).

> Use of the *FPS* requires providers to have thorough knowledge of available services. Without awareness of referral resources, the *FPS* feels like "opening a can of worms" although one worth opening given preparation, i.e., knowledge of referral resources and ability to collaborate with them. At the end of this chapter is a list of referral options including those addressing the many
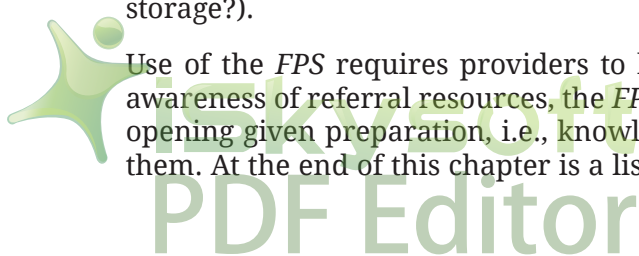
issues of families with psychosocial risk factors.

Psychosocial Risk Factors: Clinic Case Example #1

We use the FPS with all new patients of any age. We address any problems found at intake visits and make any needed referrals (e.g., social work, mental health). Because most new patients are newborns, and because we know that risk factors, including parental depression, change with time, we re-administer by interview the depression items, usually at 6-months and again at 15-months, i.e, close to the middle of the first and again in the second year of life. At such visits (and usually others), we rescreen/follow-up with concerning issues we've previously identified (e.g., housing instability, unemployment) and addressed with referrals to determine whether help was received and effective. For issues not requiring a referral (e.g., smoking in the house, gun safety) we explore in subsequent visits whether our advice helped, and thus whether we need to repeat our messages, provide more information, etc.

Because the most problematic issues (e.g., domestic violence, homelessness) are thorny and time-consuming, we collaborate closely with our local departments of social services who can take over challenging cases. We are also in the midst of hiring care-coordinators who can work with social services, educational programs for children and parents, and keep track of families who are sometimes hard to find for follow-up care.

D. OBSERVE/UPDATE PARENT-CHILD INTERACTIONS/RESILIENCE FACTORS

It is important to take note of parent-child interactions throughout the encounter, including asking staff about their observations. Receptionists are often well aware that a parent is barking orders or spanking a child when in the waiting room. Staff may notice that a child is clingy and wary of other adults (well beyond the typical ages for separation anxiety—a potential indicator of child abuse). During the physical exam providers may notice difficult interchanges between parent and child, as well as positive ones (e.g., when we enter the exam room to find a parent sharing a book with their child). Nevertheless, the full complement of parent/child interactions may not be fully manifest during a visit.

Description of the Resilience Measure Used in Case Example #1

The ***Brigance Parent Child Interactions Scale (PBCIS)****.* The *BPCIS* is designed for children between birth and 30-months of age. Its 18-item parent-report version can be completed by parents in the waiting room or sent home to complete and return by the next visit. The *BPCIS* can also be completed by provider observation (although this may be challenging, because all behaviors may not be visible during an encounter). With either measurement method, *BPCIS* questions identify positive interactions and parents' feelings about parenting (e.g., the parent reads books to their child, enjoys communicating, actively teaches their child new things, feels their child is interested in communicating, feels competent to soothe their child when he or she is distressed). Research on the *BPCIS* showed that 6-, 12-, 18-, and 24-month-olds scored in the average range on developmental measures when their parents had positive interactions and perceptions, even when psychosocial risk factors were present.[42]

The *BPCIS* also identifies non-protective factors, i.e., problematic interactions and perceptions that are highly predictive of future delays (e.g., parents who feel their children aren't interested in communicative play; don't talk with their children during meals; state they don't actually like their children or believe their children don't like them; don't share books with their children; etc.). The development of children whose parents had negative perceptions and a dearth of positive interactions begins to plummet dramatically with differences visible by 6-months of age, and became strikingly low (e.g., ~ the 8th percentile) by 24- to 30-months of age.[42]

So when resilience factors are present, i.e., positive parent perceptions and positive parent-child interactions, but a parent has risk factors such as limited education, resilience factors can trump the potential impact of psychosocial risk factors. Indeed the presence of resilience factors is a stronger predictor of outcome than are psychosocial risk factors alone (e.g, factors captured by the

FPS). But the absence of resilience/protective factors without psychosocial risk factors also calls for swift and early developmental promotion plus careful monitoring of parenting skills. Even more problematic is the absence of resilience/protective factors in the presence of psychosocial risk. This should constitute an alarm call for swift and very early assistance from social work services, mental health programs, along with educational intervention for children and hands-on parent training.

Parent-Child Interactions and Resilience: Clinic Case Example #1

We provided training to providers and staff on observing parents and children during visits so they could keep in mind the content of critical items on the BPCIS:

- *Is the parent playing with their child—talking about and showing him/her things (e.g., toys)?*

- *Is the parent sharing books with their child?*

- *If a child looks at or touches something does the parent talk about the object?*

- *Does the parent face the child (especially infants) when talking to him or her?*

- *Has the parent brought food, toys, diapers, etc. to the visit?*

- *Does the parent seem to enjoy interacting with their child?*

We encourage staff to alert us when they notice parent-child interaction problems in the waiting room, at weigh-in, at the nursing station, etc. [e.g., use of punishment instead of praise and discipline (by which we mean teaching a better way to behave), shouting, excessive use of "No," and the parents' overall affect—angry, glum, passive versus joyful, engaged, etc].

Because we can't always see positive parenting behaviors during our brief visits, we also use the BPCIS by parent report (coupled with clinical observation using the examiner version as a guide) at 6-months and again at 15-months. Because we actively promote development in our clinic, repeating the BPCIS at 15-months confirms whether our advice about talking with children, sharing books, actively teaching new things, etc. is working or not. The BPCIS also helps us see when parents are developing negative perceptions about their children (which is often associated with depression and psychosocial risk factors) and thus that parents need more help than brief developmental promotion can provide, i.e., when we need to refer to more intensive services.

We use the BPCIS flexibly when parents raise concerns on PEDS (even when the PEDS:DM looks OK) that reflect limited knowledge of development or skills in promoting development so that we can explore further whether protective factors are minimal, and thus better focus our developmental-behavioral promotion and progress monitoring.

The *BPCIS* is presented in full in Chapter 10, including the scoring. The six critical *BPCIS* items are shown in Appendix A, including the well-visit envounter forms.

E. IDENTIFY/UPDATE FAMILY AND CHILD MEDICAL HISTORY AND BIOLOGICAL RISK FACTORS

The family and child medical history requires documentation at intake along with periodic updates. Appendix A includes well-visit forms that capture not only the steps in screening and surveillance but also medical history issues. These forms are also downloadable on the website for this book, www.pedstest.com/TheBook/AppendixA.

1. **Child's Medical History:** [a] Note in-utero exposure to teratogenic/ harmful substance, APGAR score less than 5 at 5 minutes, late or moderate preterm (> 32 0/7 to 36 6/7 weeks gestational age), very preterm (< 32 weeks gestational age, low birth weight (< 2500g), very low birth weight (<1500g),

SGA or IUGR, congenital hydrocephalus, meningomyelocele, interventricular hemorrhage (Grades III or IV), respiratory distress syndrome, anoxic brain injury, encephalopathy, genetic, metabolic or neuro-developmental disorder with a high probability of a developmental delay, failure to thrive, iron deficiency anemia, elevated blood lead level, vision or hearing impairment, HIV, congenital heart disease, obstructive sleep apnea, seizure disorder, etc.

2. **Family Medical/Developmental History:**[b] Note the presence of Communication Disorder/ Language Impairment, Learning Disability, Intellectual Disability, Autism Spectrum Disorders, motor disorder, Fragile X Syndrome, Attention Deficit Hyperactivity Disorder, mental illness such as anxiety disorder, major depression, bipolar disorder, and history of deafness, genetic or metabolic disorder, cataract, retinoblastoma, retinal dysplasia, or glaucoma.

[a] *Numerous states in the USA consider children automatically eligible for IDEA Part C (birth to three-years) if they have a diagnosed physical condition (biological/ medical risk factors). Prompt referrals should be made.*

[b] *Some State IDEA Part C programs also serve children whose parents have substantive psychosocial risk factors (e.g., a parent who is mentally ill or intellectually disabled) as well as children in foster care due to a history of abuse or neglect. If IDEA services do not cover psychosocial risk, make sure to refer to (surely a range of) other types of interventions.*

Child and Family Medical History: Clinic Case Example #1

Some family medical history is captured by the FPS (administered at new patient intake), although we have downloaded it for our clinic and added a few questions to it. All noteworthy aspects of medical history are noted separately on our well-visit encounter forms and also on each patient's problem checklist so that we are constantly aware of medical risk as well as current problems, how we've addressed these, and what information we've received from any involved subspecialists. A longitudinal problem checklist reminds us to check at each visit on ongoing issues and their resolution. We are also aware that the conditions (superscripted with a or b above) *are ones that may lead to automatic eligibility for IDEA services. So we carefully document such problems in our referral letters.*

F. CONDUCT A CAREFUL PHYSICAL EXAM

When a child fails a developmental-behavioral screen or when surveillance suggests risk even when development seems typical, the physical exam needs to be particularly attentive to health status, hearing and visual acuity, and the possibility of various conditions that might contribute to delays. Be aware that most children with developmental-behavioral problems do not have a discernable physical cause. But, we still need to look carefully at health, sensory and physical findings, and address these promptly. The foci of a quality physical exam should include the following:

1. Note potentially teratogenic exposures such as radiation or medications, infectious illnesses, fever, addictive substances or trauma. Review results of neonatal screens including phenylketonuria, hypothyroidism, and other metabolic conditions. Your evaluation should also consider perinatal history including birth weight, gestational age, Apgar scores and any medical complications.

2. Identify postnatal medical factors such as chronic respiratory or allergic illness, recurrent otitis, head trauma and sleep problems including symptoms of obstructive sleep apnea.

3. Attend to known symptoms of developmental-behavioral problems including growth parameters, head shape and circumference especially in light of prior visits, such as failure to thrive, microcephaly or markedly decelerating head circumference, macrocephaly or markedly accelerating head circumference, facial and other body dysmorphology symptomatic of genetic conditions, eye findings (e.g., cataracts common to various inborn errors of metabolism), vascular markings, testicular volume, and signs of neurocutaneous disorders (e.g., > 6 café-au-lait spots in neurofibromatosis, hypopigmented macules in tuberous sclerosis), lisch nodules, ash leaf macules,

etc. Neurodevelopmental assessment should include muscle strength, joint laxity, presence of abnormal reflexes, and disturbance of tone and movement. Many of the above findings and associated conditions will automatically qualify children for IDEA Part C programs (birth to 3) and so referral for early intervention should be axiomatic in such cases.

4. Focus carefully on physical findings suggestive of abuse or neglect and ensure prompt referrals to child protective services. When indicated, explain to parents that you are required by law to report such problems and that further assessment of physical findings will be carefully conducted.

5. Undetected hearing loss results in increasingly expensive interventions along with increasingly problematic long-term outcomes for children. Newborn hearing screening is essential but requires follow-up, especially with infants who were asymptomatic at birth. The AAP recommends oto-acoustic emissions (OAE) testing for all children at 6-months of age regardless of risk factors (see Harlor & Bower[43] for AAP practice guidelines, equipment options, etc.). In addition, providers need to consider middle ear (ME) pathology. The following guide is helpful for understanding results of OAE together with tympanometry:

   • Pass OAE + Pass ME: Within Normal Limits

   • Pass OAE + Fail ME: Possible otitis media with effusion

   • Fail OAE + Pass ME: Possible sensorineural hearing loss*

   • Fail OAE + Fail ME: Possible conductive pathology or mixed loss.*

   *The latter two outcomes should result in an axiomatic referral to an audiologist.

Children should be rescreened routinely at 4- to 5-years of age although pure tone audiometry is recommended at these ages because it detects the more subtle losses (e.g., 30 to 40 decibels). In between 6-months and 4- to 5-years, screening should be offered whenever there are risk factors (including deficits in expressive or receptive language).[43] Note that both OAE and ME testing are considered a routine aspect of a well-visit and rarely confer separate reimbursement.

6. Vision assessments should begin at birth because untreated abnormalities in the first few months of life (e.g., cataracts, strabismus) can lead to amblyopia and vision loss. Vision loss can also be a sign of a life-threatening disease. Vision assessment should be included (at every visit):

   • Abnormal red reflex (may indicate cataract, glaucoma, retinoblastoma, retinal abnormality, or strabismus, or unequal or high refractive error);

   • Abnormal ocular alignment (ie, strabismus) or asymmetrical corneal light reflex;

   • Pupillary asymmetry of ≥1 mm (suggestive of neurologic condition);

   • Corneal asymmetry (suggestive of glaucoma);

   • Unilateral ptosis or other lesions obstructing the visual axis (e.g., eyelid hemangioma, which may cause amblyopia; and

   • Nystagmus.

For children 3- to 4-years of age, measures of visual acuity are needed for which the Lea Symbols are helpful because letter naming is not required. At age 5- to 6-years, Snellen charts can be used. Prompt referral to a pediatric opthalmalogist is warranted when acuity is less than 20/40 in children ages 3- to 5-years or 20/30 in children ≥ 6-years. See the American Academy of Ophthalmology for a helpful video on vision screening (*http://one.aao.org*).

7. Lead screening should be provided whenever developmental problems arise, but preferably for all children. Lead screening should be repeated at several points during the 0 to 6-year age-range. Children living in older homes or near busy streets are at particular risk, as are those who play with adult makeup or who have recently immigrated.

Physical Exam: Clinic Case Example #1

Some clinicians feel less than well-versed in neurological and dysmorphology examinations. These are of much importance when investigating developmental-behavioral issues. To help our clinicians refresh and improve their skills, we've done several things:

(a) Encouraged newly hired clinicians to watch an online video on giving a neurological exam (see the Resources section at the end of this chapter)*; and*

(b) Set up collaborative office rounds where we have periodic, rotating discussions with a geneticist, a pediatric neurologist and a child psychiatrist who give us updates on various conditions. In these office rounds we can present cases and talk in-depth about patients we've referred. Our clinicians have learned much from this process (and we've even managed to get Continuing Medical Education Credits for these efforts from our local teaching hospital).

G. PROVIDE DEVELOPMENTAL-BEHAVIORAL PROMOTION

Developmental promotion should be a major part of every encounter—even when you decide to refer (due to delays, health problems, psychosocial risk or absence of resilience). Parents receiving referral recommendations, more urgently than ever, want immediate ideas about how to help at home. We know that some parents don't follow-up with referrals, at least not right away, and some get "lost in the cracks." So at every encounter we need to address parents' concerns and also provide parenting information and guidance.

Clinicians should comment on positive interactions viewed during an encounter *(e.g., "I like the way you are pointing out new things to your baby."; "I like the way you are sharing books with your toddler.")*. Praise works wonders for reinforcing desired behavior and parents very much appreciate hearing they are doing well. Providers should not shy away from gently commenting on and then redirecting problematic interactions *(e.g., "I see that you mostly talk with your baby when she cries but not so much when she is calm. Let me show you the best thing to do to make sure she has the best chance to learn to talk well.")*. Clinicians can then model face-to-face communication, preferably also allowing parents to practice what you've demonstrated (e.g., *"Let me get you to try it."*).

Evidence for the effectiveness of developmental promotion is strong. Findings from the Healthy Steps program reveal a positive, sustained impact on parenting that increases developmental stimulation, anticipatory guidance and well-child care compliance, while also reducing the odds of severe discipline/physical abuse.[44,45] These and other developmental promotion approaches are thoroughly covered in Chapter 7 including the value of providing written information, videos, etc.

But it is critical to note that a few minutes of developmental promotion once or twice a year may not be effective for some parents. Often providers are overly confident that an information handout or a brief effort to model appropriate interactions is sufficient, when in fact, many parents need hands-on, continuous support to promote development or acquire better disciplinary techniques. So, it is essential to monitor the effectiveness of advice to parents. Follow-up is particularly essential when parent-child interactions are problematic, i.e., lack of developmental promotion or use of punishment rather than positive disciplinary techniques. By checking with parents on the effectiveness of our advice and any unresolved issues, we can identify families who need more intensive help (e.g., parent training classes, community intervention programs with a parent training component, social work services, etc.). Options for follow-up include: staff call-back, a text or e-mail message or a request that parents call the clinic in a few weeks to report on progress.

As with other aspects of screening/surveillance, flexibility is needed in the delivery of developmental-behavioral promotion. For example, some providers prefer to offer information at the end of an encounter after conveying screening test results. Others offer developmental promotion at the beginning of an encounter (e.g., Reach and Read). Clinicians with websites often host links to approved parenting sites, and encourage parents to seek information when issues arise between visits.

Summary of Developmental-Behavioral Promotion

- Promote development at each visit;
- Monitor effectiveness of advice;
- Have back-up referral options in hand when advice is not effective;
- Read Chapter 7 for information on parent education methods and resources.

Developmental-Behavioral Promotion: Clinic Case Example #1

Our clinicians feel developmental-behavioral promotion is one of the most important services we provide because we are doing more than just identifying problems. We are preventing problems. We depend heavily on the concerns parents raise on PEDS and address those specifically. We also have a large poster in our waiting room, listing every last developmental-behavioral and health/safety topic we could find (e.g., in books like "Encounters with Children").[46] The poster helps parents know that such topics are an important part of well-child care and it encourages parents to list topics of interest on their PEDS Forms so that we can focus on these during the encounter.

We rely heavily on quality parenting websites for finding information to share with parents (and sometimes to refresh ourselves on issues such as toilet training stages). Our exam room computers enable us to print out hand-outs for parents to pick up when they check out.

In addition, we use Reach Out and Read at every visit. Parents (and children) very much enjoy the positive interchange and having a book to take home. When walking into the exam room, we now find parents sharing books with their children, and that's enormously rewarding to staff and clinicians (and good evidence of resilience, too).

We also have packets of information prepared for every visit and these include not only vaccine information, but also a short guide to what children are doing and learning at each age along with basic anticipatory guidance. We use the downloadable age-by-age guides from the Nemours Foundations (www.kidshealth.org). In addition, when parents raise specific issues (toileting, tantrums), we use the Nemours or the AAP Healthy Children websites to find specific information handouts to give to parents (after we verbally highlight the essentials).

We don't have a website for our clinic yet, but we are keeping a list of parenting information sites we like so we'll be ready to go whenever we find a webmaster and a clinician to spearhead this project!

Finally, we make a chart note on our problem/process checklist (shown in Section J) *about the specific topics parents raised so we can follow-up on the effectiveness of our advice at subsequent visits. If the topic is particularly troubling (e.g., use of physical punishment rather than discipline) we add a "follow-up by date" to schedule a return call or often schedule a return visit in 1- to 2-months to evaluate how well parents were able to use the information we provided. We can decide from there whether hands-on parent training or other services are needed.*

H. INTERPRET RESULTS, DECIDE ON ANY NEEDED REFERRALS AND EXPLAIN FINDINGS

There are three components to this process:

1. **Interpret Results.** At this point, you've gathered lots of information that needs synthesizing. There are many permutations of information from which different conclusions and decisions can be drawn (given combinations of parents' concerns, developmental-behavioral delays, health/physical exam results, psychosocial risk and resilience factors). But with results in hand, the following self-queries aid in decision-making:

   (a) Are subspecialty medical referrals needed and if so what type? Genetics? Endocrine? Audiology? etc;

   (b) Does this child have significant delays, psychosocial risk factors are absent and resilience factors are present? If so refer to IDEA services and audiological and vision evaluations as indicated;

   (c) Does this child have symptoms of autism spectrum disorder? If so, provide or refer for lead/hearing/vision screening, refer to IDEA with a specific request to evaluate possible ASD and discuss whether a simultaneous referral to an ASD specialty clinic is needed;

   (d) Does this child have significant delays together with psychosocial risk factors with or without resilience factors? If so, refer to IDEA services plus consider referrals to social work, adult mental health services, and or parent training. Swift follow-up with families is advised;

   (e) Does this child have mild delays or no delays but psychosocial risk factors are present and resilience factors are absent? If so, refer to Head Start or other non-IDEA services, and consider possible referrals to social work, adult mental health, and most especially parent-training;

   (f) Is the child achieving milestones on time, lacks risk factors, has resilience factors, but the parent describes concerns suggestive of disorder development? If so, refer to IDEA, establish a coordinated flow of information, and follow-up between visits to evaluate progress.

2. **Decide on Any Needed Referrals.** Easily accessible information about referral options is essential (as is knowledge of what various services offer). A visible list (e.g., posted in each exam room) serves as a helpful reminder, for both parents and providers, about what is available and how to contact programs. Keeping brochures about programs is also wise for efficient delivery of the information parents need.

3. **Explain Findings.** Providers are often uncomfortable conveying problematic results. None of us want to be the bearer of bad tidings. We want all families and children to be well and we always hope for the best. But failing to take action when delays, concerns, or psychosocial risk factors are present is just wishful thinking that helps no one. Remembering that developmental-behavioral problems are the most common challenges of childhood, and some of the most subtle problems we confront, should prompt us to learn how to comfortably explain difficult findings, ever mindful that the earliest possible intervention is especially effective. As discussed in Chapter 3, providers are more compelled to take developmental-behavioral issues seriously when there is a possible medical cause. So it is important to remember that for most children with disabilities, a physical cause will never be known. Therefore taking the results of screening/surveillance measures seriously is essential and ensuring referrals (along with developmental promotion) as indicated by problematic findings is a far more helpful and positive response than is dismissing problematic results in favor of "wait and see" or "watchful waiting."

   Explaining results to families requires thoughtful regard for the limitations of any screening/surveillance measure whether physical or developmental-behavioral. But it also requires appreciation for the high probability that evidence-based measures are accurate. All this means
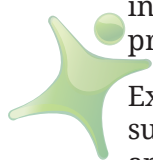
we must strive not to be "sugar-coaters" but rather "straight-talkers."[47] Chapter 8 offers guidance on how to explain findings in a way that is optimistic, clear, and encourages families to seek recommended services.

Interpreting Results, Deciding on Referrals and Explaining Results: Clinic Case Example #1:

Although our clinicians are adept at hypothesizing about possible problems and at figuring out the kinds of referrals needed, some are uncomfortable explaining results to parents and so need training in how to do this well. We built skills by having clinicians read suggestions such as those in Chapter 8. As part of our continuing medical education efforts, we brought in a social worker to role-play with us (taking turns as to who played the provider and who acted as the parent). Our providers, after learning how to explain results in a positive way, became much more comfortable with disclosing interviews. Afterward, we saw an increase in referrals—because clinicians weren't avoiding the delivery of difficult news. Since we also tracked our findings and referrals in a database [used for our ongoing Quality Improvement Initiative (a process explained in Chapter 19)], we could see that families were more willing to seek the services we recommended after we shared our findings in positive ways.

I. DOCUMENT CURRENT FINDINGS AND MAKE REFERRALS

1. **Document Current Findings**. There are three essentials for documenting findings for each well-visit (apart from billing and coding information covered in Chapter 16). These include:

(a) **Well-visit forms** that capture the screening/surveillance measures used, their essential results, details from your physical exam and hearing/vision screens, clinical observations of families, risk and resilience factors, the range of referrals made, expected time frames for evaluations and follow-up.

We provide in Appendix A (and at *www.pedstest.com/TheBook/AppendixA*) sample encounter forms by age. If using electronic records, the well-visit forms in this book illustrate essential modifications to stock digital templates so that you capture critical information about development and behavior. Most electronic software consultants can readily create the necessary fields (although hiring your own information technologist is sometimes speedier). If you haven't yet purchased electronic medical record software, it is best to insist on modifications before you buy (many clinicians find they lack prompt attention after purchasing);

(b) **Referral letters.** When you find problems, you will need to document these in a referral letter to each service you wish to invoke. Online screening services generate referral letters automatically, which is a big time-saver. Whether you use an electronic record or not, electronically generated referral letters can be printed or downloaded (e.g., into a word processing program) and then modified as needed, or simply pasted into the electronic medical record. But if you are not using online screening services, you will need to dictate a referral letter in which you list the results of screens you've administered, any medical diagnoses, medical findings in need of subspecialty attention, hearing/vision status and any specific issues you'd like addressed. If, for example, you could not complete the *M-CHAT* follow-up interview after a failed *M-CHAT* or lacked the time to provide additional social-emotional/mental health screening after a broad-band developmental/beahvioral screen was failed, you should ask IDEA programs to help you with these tasks. If you were not able to screen vision or hearing, you can also ask for help with that (although it is much faster if you take care of this before referring). Indicate in your letter where else you've referred the child and family (e.g., genetics, endocrine, etc.) so that IDEA programs get a good sense of any medical issues that might qualify a child for services.

We include referral letter templates to facilitate dictation at the end of this chapter and they are also downloadable at *www.pedstest.com/TheBook/Chapter5*. Below is a sample referral letter generated by an online screening service.

Figure 5-2. Sample Referral Letter from an Online Screening Service

02-05-2013

Dear Child Development Specialist/ Health Provider,

On **02-05-2013**, we administered three highly accurate developmental-behavioral screening tests to **Peter Piper**, born **04-06-2011**. These include: Parents' Evaluation of Developmental Status (PEDS), the Modified Checklist of Autism in Toddlers (M-CHAT) and/or PEDS: Developmental Milestones (PEDS:DM). All three measures were standardized on thousands of children around the United States and validated against diagnostic measures of intelligence, adaptive behavior, speech-language, etc. All are approved by the American Academy of Pediatrics and shown to be highly accurate in identifying children in need of various types of evaluations and intervention services.

Although the results of the PEDS:DM show milestones met in **Fine Motor, Receptive Language, Expressive Language, Gross Motor, Self Help, Social Emotional**, the results of PEDS place suggest that Peter is at risk. The M-CHAT results suggest difficulties with social-relatedness and understanding of practical language skills.

Given the above results, further testing is needed and should begin with no-cost evaluations through early intervention or through the public schools. Hearing, vision, and overall health status, including lead levels should also be checked. Your clinical judgment is needed to determine whether assessment of intelligence, adaptive behavior, academics/preacademics, mental health, social services or other assessments would be helpful.
After these referrals are made, Peter should also be referred to an autism specialty service, if available.

Assessment is available without charge through your local child-find program (www.nectac.org). or through the public schools-- please contact the school psychologist or speech language pathologist to make a referral. If Peter does not qualify for intervention or special education, please refer for services such as Head Start, after school tutoring, summer school, quality daycare, and parent training.

We encourage you to monitor Peter's progress and encourage you to make sure that families sign a two-way consent form so that you can share these results with other providers and they with you.

Please assist this family in finding timely testing and services and also help them get information on how to help at home.

Sincerely,

Provider

_____
Clinic

_____
Phone

_____

Procedure code: 96110 (X 3)
Possible ICD-9 code: 315.9
PEDS results: at-risk
PEDS:DM results: milestones met
M-CHAT: fail

Scored by PEDS online
The online implementation of the PEDS child development screen
©2013 PEDStest.com, LLC

(c) **Parent summary reports.** Ideally, every family who is referred or who needs developmental-behavioral promotion due to specific concerns, should receive a summary report to take home. We provide a summary letter template in Chapter 8 (where we cover how to explain difficult news to parents). Again, many electronic screening services generate these in real-time so a parent summary can be printed and taken home after the visit. In Chapter 8 we also include a sample summary report generated by an online screening service.

2. **Make referrals.** Along with sending referral letters to relevant services, it is also best to make appointments for families. This keeps parents from avoiding a phone call because they are intimidated by professionals, or too stressed to remember how to describe your findings. This is especially critical for families who don't speak English well and who may not find someone who speaks their language when calling for an appointment. Making appointments for families is known to greatly improve the chance they will follow-up.[48] A list of national services from which you can find local ones is included at the end of this chapter (with live links at *www.pedstest.com/ TheBook/Chapter5*).

Documenting Current Findings and Making Referrals: Clinic Case Example #1

Whether or not our clinics have electronic health records software, the documentation provided by online screening services is still highly efficient and much appreciated. Clinicians find this a major time-saver and are more confident in the results although we had a bit of training to do on how to switch between our EHR and a browser, copy, paste, etc. (Chapter 16 covers how some clinics got this started and other issues in implementation).

We are also working toward use of a parent portal (e.g., a link on each clinic's website) that leads parents into our web-based screening service—so that measures can be completed by parents at home, prior to the visit and with results sent directly to our clinics. We've been impressed at how many parents, affluent or not, have access to computers, and with an email or cell-phone text reminder, are willing and able to complete measures on their own. Parents do not see the results but we get an e-mail when screens are completed and thus results are available for printing or pasting into a patient's charts. This ensures we know, even before entering the exam room, what information we need to bring (e.g., printed information hand-outs on specific topics, brochures about referral sources). This also means we can often arrange appointments in advance and share times and details with parents. The automatically generated parent summary reports and referral letters save time because billing/coding information are supplied for us and we can modify the reports and letters as needed (e.g., adding in details about a physical exam, important medical history, and other details regarding medical diagnoses we've made or are considering). When parents have not completed measures via the parent portal, we show them how when they are in the clinic, and also complete measures by interview.

We still keep a report dictation template handy for clinicians who have not yet trialed electronic services. This also remind us of details, particularly regarding the medical exam and history, that we may need to add to automatically generated reports.

In addition, our careful coordination with IDEA and other services enabled us to establish a two-way consent form (an example is shown at the end of this chapter, downloadable at www.pedstest.com/TheBook/Chapter5) between our clinics and various agencies. This means we can e-mail our reports and receive confirmation that these were received (followed by updates on whether parents arrived and the results of further testing). We are trying to work out a shared appointment system where we can access IDEA's intake calendar and directly schedule patients before they leave our office. That's still in the works so in the meanwhile, we call, get a time, and can usually get an IDEA appointment before the family leaves the clinic.

Above all, our well-visit encounter forms (see Appendix A) have been crucial for reminding us of the tasks at hand. These ensure we remember to use evidence, document our findings, the referrals we've made, dates to follow up, etc. We cannot stress enough the value of constantly seeing these forms, and how these direct us to implement quality screening/surveillance in a timely way.

J. COORDINATE REFERRALS, UPDATE LONGITUDINAL DOCUMENTATION AND CREATE FOLLOW-UP PLAN

This multi-pronged process involves three components:

1. **Coordinating Referrals.** Multiple studies indicate that children with suspected delays, even when identified by quality tools, do not always get to IDEA or other services. The reasons are many and well documented.[9,13,18,20,49-52] All represent problems communicating, collaborating and following up. Below is a list of issues we must address in order to coordinate referrals:

   - Reluctance to explain problematic findings;
   - Skill limitations in delivering difficult news (e.g., if we frighten them with questionable diagnoses or "sugar-coat" to the point they don't take results and recommendations seriously);
   - Resistance from other family members who may disbelieve our results or discourage follow-through with recommendations;
   - Parents sense that they may be capable of intervening on their own and so don't follow through (in which case, careful monitoring and repeated measurement is needed);
   - Our frequent willingness to "temporize," i.e., "wait and see," even when quality measures indicate the need to refer;
   - Lack of knowledge about referral options especially for children with needs who don't qualify for IDEA;
   - Limited familiarity with alternative community programs;
   - Ensuring that our referrals don't become a "black hole" or a "runaway train"—so that we know what happens to our patients and parents and that subspecialty and non-medical services communicate effectively with us or we with them;
   - Our own frustration because some children we refer don't qualify for services and some IDEA programs aren't allowed to refer elsewhere—meaning that we need prompt feedback on children's eligibility so we can decide on alternative services.

   It is understandable that practices struggle to consistently refer and track children with failed screening results (or to monitor the effectiveness of developmental promotion activities). One helpful approach is to participate in State-wide monitoring and service coordination initiatives such as Help Me Grow, ABCD or practice-based programs such as Healthy Steps or PRIDE (described in Chapter 17: North American Models). These projects provide helpful assistance with referrals, referral monitoring, and are known to improve referral rates and uptake.[44,45,53-56] But when national programs aren't present in our communities, we need to reach out to non-medical services and they to us.

   ### Coordinating Referrals: Clinic Case Example #1

   One of the most helpful efforts we've made is to ensure that non-medical services respond to us like the ideal medical subspecialist would, i.e., call us back and let us know that a referral has been received, confirm appointment times, send results, and confer with us after an evaluation so that we discuss results together and devise additional plans, etc. It took a bit of work for IDEA and other programs to discover that when all of us communicated promptly, their referrals increased. Eventually our providers became the main source of all referrals to our regional IDEA (which is as it should be, since we have the children and IDEA has trouble finding children with problems without our help). Our clinicians stopped dreading making referrals to IDEA or making comments like "I never know what happens to my patients when I refer."

   To facilitate coordination, first we needed to know what our IDEA services actually did. So we invited them to meet with us and tell us about their programs. We set up several noon conferences in which we were able to discuss our issues with referring, i.e., that we rarely heard what happened

afterward. Together we established a two-way consent form, and IDEA agreed keep us in the loop on evaluations, eligibility, etc. IDEA personnel brought brochures, shared videos about their programs, and realizing that we were less than fully aware of the range of local services to which we could refer non-eligible children, also made laminated contact lists—one for each of our exam rooms. As it turned out, United Way and Easter Seals had funded a voluminous service directory—a bit too much for us because it included lots of geriatric services, but this helped IDEA cull a list focused on our referral needs.

2. **Update Longitudinal Documentation.** It is also helpful, rewarding, and compliant with AAP policy[2] to have a form that captures children's progress over time. There are two essential components to longitudinal documentation:

   (a) **Growth Charts.** These are forms that track developmental-behavioral growth over time. In general these focus on milestones as measured by evidence-based tools. An example from a print-based screening tool is shown in Figure 5-3 and from an online screening service (*www.ASQOnline.com)* in Figure 5-4. With electronic records (and help from software vendors), the results of online screening tests recorded at a well-visit can simultaneously populate a longitudinal growth chart to illustrate progress over time.

Figure 5-3. Annotated Longitudinal Growth Chart and Documentation for PEDS:Developmental Milestones

Figure 5-4. Example of a Longitudinal Growth Chart and Documentation for the ASQ-3

Status Over Time:
Trended scores scaled to Below Cutoff = scores less than 30; Close to Cutoff = scores from 40 to 30; and scores above 40 are normal, Well Above Cutoff.

Communication

Gross Motor

Fine Motor

Problem Solving

Personal-Social

Legend
1) 2 month 9/2/2010
2) 4 month 11/2/2010
3) 6 month 1/12/2011
4) 8 month 4/12/2011
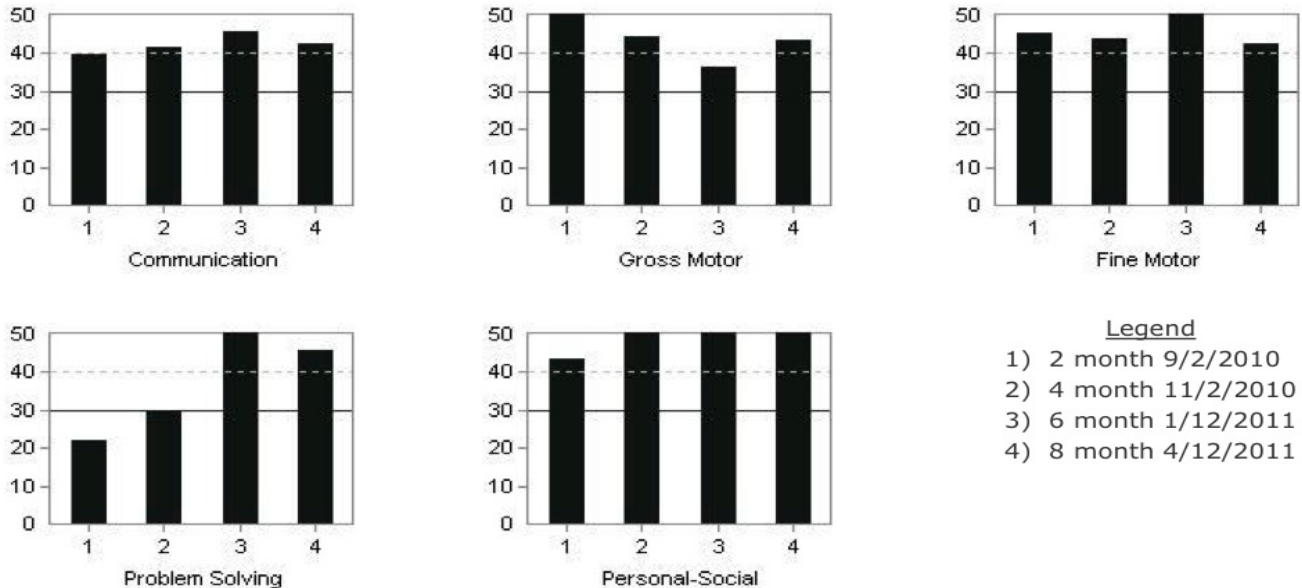
Score Interpretation:
1. If child's score is **Well Above** the cutoff, the child appears to be doing well in this area at this time
2. If child's score is **Close to Cutoff**, provide ASQ activities & monitor (child's score 1 to 2 SD's below mean)
3. If child's score is **Below Cutoff**, referral for an evaluation (child's score > 2 SD below mean)

Referral Considerations:
  - Look at items marked "Not Yet" in domains Below Cutoff
  - Did the caregiver observe skill and/or did the child have an opportunity to try the item?
  - Consider health, cultural and psychosocial factors that may affect performance.

©2001, www.patienttools.com

(b) **Problem/process checklist.** All medical charts whether paper or electronic should include a problem checklist. Ideally these show not only problems but also what's been accomplished with screening/surveillance, what needs additional attention and follow-up, what actions you've taken, etc. Figure 5-5 is an example of such a form, downloadable at *www.pedstest.com/ TheBook/Chapter5*, and modifiable so that you can list the specific measures you use. Note that this chart covers the birth through 21-years of age, not just the birth to six-years' focus of this chapter. So please see Chapter 9 for details about screening/surveillance with older children.

Figure 5-5. Longitudinal Problem/Process Checklist

Longitudinal Screening/Surveillance Process and Problem Checklist

Child's Name _____ Child's Birthdate _____

Directions: place a checkmark to show when task/screenings have been completed. Shaded boxes show optimal timing for the various tasks.

Tasks/Screens	Age in months										Age in Years									List conditions/concerns; Brief statement of action taken, referral source and follow-up date
	0-1	2	4	6	9	12	15	18	24	30	3	4	5	6	7-9	10-12	13-15	16-18	19-21	
Family psychosocial risk & mood disorder[1]																				
Resilience: parent-child interactions[2]																				
Elicit & address caregivers' concerns[3]																				
DB/social-emotional/mental health screen[4]																				
Autism screen[5]																				
Substance abuse Screen[6]																				
Hearing screen																				
Vision screen																				
Physical Exam																				
Family Medical History																				
Developmental-Behavioral Promotion																				

1. (e.g., FPS, PHQ-2, EPDS)
2. (e.g., BPCIS)
3. (e.g., PEDS)/trigger Q's for adolescents)
4. (e.g., PEDS+PEDS:DM (0 – 8 yrs); ASQ with the ASQ:SE as indicated (4 mos – 6 yrs); SWILS + Pictorial PSC (6 ½ –14+ yrs]
5. (e.g., M-CHAT & if time, Follow-up Interview)
6. (e.g., CRAFFT (11-21 yrs)]

3. **Follow-up.** The problem/process checklist shown in Figure 5.5 also serves as an approach to reminding us when to review, i.e., a tickler system that alerts us when to follow up on the effectiveness of developmental promotion advice, to list all referrals made, to check on uptake of referrals and expected time frames in which evaluations will be completed, etc. The example provided in Figure 5.5 can be used in paper charts (and is typically placed in the inside front cover as an overview of issues) but can be included in electronic records and programmed by software consultants so that it is simultaneously updated when the well-visit encounter form is completed. Programming should also include follow-up dates that send alerts to ourselves and staff about the need to check on referrals, developmental-behavioral promotion effectiveness, etc.

Flagging medical charts is essential, whether electronic or paper, to keep track of children with special needs, who are at-risk or chronically ill. It is invaluable to have a care-coordinator who manages follow-up, communicates with services, and locates information (including reports from medical subspecialties).[57] Care-coordinators are also much appreciated by IDEA and other non-medical interventionists who often need information and advice about medical conditions and how to handle them. Chapter 17 (North American Models) provides a case-study of the AAP Medical Home and how helpful it is for providers, both medical and non-medical.

Longitudinal Documentation and Follow-up Planning: Clinic Case Example #1

Our careful collaboration with local IDEA programs has enabled us to get feedback on where our families are in the evaluation process, whether they kept their appointments or whether we need to bring them back for a discussion and rescreening, and whether a child was found eligible or not (meaning that we know we need to refer elsewhere). We wish all our medical subspecialists were as responsive as IDEA, but we do have a note in our tickler system to remind us to call if the subspecialists don't get back to us. We also use our tickler system to remind us to check on developmental promotion advice (especially for worrisome issues with parent-child interactions and discipline).

For those of us still using paper charts, we attach a specific colored tag to indicate that evaluations are in progress and note on the tags an expected completion date—making these visible reminders to follow-up. Our nurses have designated time to make needed calls, although we are striving to implement the Medical Home model and hire a full-time care coordinator to work with special needs children. As for ongoing monitoring, some of our IDEA programs routinely reassess non-eligible children in 6 months, but some don't. So our chart tags indicate which children to bring back for rescreening, alternative referrals and when.

In addition to internal coordination, some of our clinics participate in initiatives such as Help Me Grow or ABCD. Clinicians are routinely appreciative of how these programs bring healthcare and non-medical providers together to establish referral coordination and monitoring. So we highly recommend joining one of these collaboratives (described in Chapter 17, National Models).

Case Example #2

In this next "real-world" case example, we describe one little girl's story, and how her primary care provider implemented the flow chart in Figure 5-1. In this case study, you will see periodic use of various evidence-based screening tools and how these enhanced clinical judgment. Also exemplified is how this provider collaborated with medical sub-specialists and non-medical providers. We start with his correspondence at the point of referral (and show his notes on the family/child's history and the results of screening tests as documented in chart notes). Next we show what the provider observed at subsequent well-child visits and how he followed up with the parents and with the referral resources. You will also see how these services responded in order to engage a reluctant family to move forward, i.e., the inordinate value of communication and collaboration with other service providers. To remain HIPAA compliant, we have changed the names of the provider, patient name and birthdate, and the names of early childhood referral sources.

Figure 5-6. Correspondence between Pediatrician and IDEA

Attachment (continued)

weight/height ratio was still above the 97th %tile. Interestingly, the ASQ-3 results indicated that she was in the "monitoring zone" for the personal-social domain. The ASQ-3 activity sheets and Parent Helpline phone # were given to the mother. At this visit, I considered an IDEA referral but the mother assured me Destiny was "clearly different than her older brother and was doing just fine" so no IDEA referral was made for early intervention (EI).

18-month WCV- Her head circumference had accelerated from the 90th %tile at 12-months to well above the 97% tile at 18-months. The were some possible maternal concerns but the M-CHAT was passed/negative (however, 1 critical item was failed because she was not responding when her name was called and 1 non-critical item was failed because she never used her index finger to point, to ask for something). Interestingly, the PEDS:DM was failed in the expressive language domain because Destiny was not trying to get her mother's attention by pointing to things. Per my clinical observations, Destiny was not responding (turning to face her mother) when her name was called. Hearing screen was normal. A referral was generated to the local IDEA agency by faxing a statewide "IDEA Referral and Referral Feedback Form" so that Destiny's referral could be tracked. Even if the mother failed to initiate contact the IDEA agency, she would automatically receive a follow-up phone call from the IDEA agency. In addition to the IDEA referral, I recommended to mom an early return office visit in 1 month.

SERENITY PEDIATRICS HEALTH GROUP
CLEAR SKIES, USA

IDEA, PART C
Clear Skies County
May, 2011

To Whom It May Concern:

I am referring my 18-month-old patient, Destiny James, to IDEA due to her emerging delays and her family history of an older brother diagnosed with autism spectrum Disorder, ADHD, and a mixed Receptive and Expressive Language Disorder.

I attached my most recent chart notes and her screening test results. Please let me know promptly if Destiny's mother follows through with this referral or if another parent-clinician conversation is needed from my end. Included with this referral letter is Destiny's "IDEA Referral and Referral Feedback Form", which is now being used statewide.

Sincerely,

Kevin Larsen

Kevin Larsen, MD, FAAP

Attachment: Longitudinal Chart Notes

Attachment: Longitudinal chart notes from Destiny's prior visits

4 days- Destiny was a term appropriate for gestational age female, born via an emergency caesarian section. Infant/mother's "drugs of abuse" (DAS 5) urine screen was negative for amphetamines, barbiturates, cocaine, opiates and cannabinoid (THC). A high sensitivity screen for methamphetamines was negative. Newborn metabolic screen was negative.

2-week WCV- Multiple family psychosocial stressors were identified on the Family Psychosocial Screen (FPS). The mother had a history of prior methamphetamine use, the family recently moved and their income is below the federal poverty level. Destiny has Medicaid insurance. There is a positive family history of Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), a mixed receptive & expressive language disorder (RLD and ELD), morbid obesity & obstructive sleep apnea (OSA) in her older brother, plus a positive family history of depression in the mother. The mother is identified as being high-risk for a post-partum mood disorder. To link this family to the appropriate community resources, the mother is referred to a system-wide care coordination phone number. Parenting classes are recommended. In addition, the mother is tactfully instructed to follow-up with her ob-gyn for contraception/family planning and with her family practitioner for her history of mental health problems. The second newborn metabolic screen was negative.

2-month WCV- There were no maternal concerns and the PEDS:Developmental Milestones (PEDS:DM) was passed in all domains; however the fine motor item was skipped. The Edinburgh Postnatal Depression Scale (EPDS) score was below 10 or negative.

4-month WCV- There were no maternal concerns and the PEDS:DM was passed in all domains. Again, the EPDS was negative.

6-month WCV - There were no maternal concerns. Because the mother arrived late for the appointment, no screening test was completed. Instead, the mother was given the age appropriate Ages & Stages Questionnaire-3 to fill out at home and mail back to the clinic. Unfortunately, she never returned the form.

9-month WCV- There were no maternal concerns and the PEDS:DM was passed in all domains. The weight/height ratio had accelerated above the 97th %tile indicating obesity. A complete blood count (CBC) and ferritin level did not indicate an iron deficiency and the C-reactive protein (CRP) was <0.5 (CRP is used to make sure that Ferritin levels are not falsely elevated due to an infection or inflammation). A quantitative blood lead level was unconcerning at <5 ug/dl.

12-month WCV- There were no maternal concerns and the ASQ-3 was administered. Her the

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IDEA, PART C

CLEAR SKIES COUNTY

June, 2011

Dear Dr. Larsen,

Thank you for your IDEA referral for Destiny James, DOB: 11/11/09. As per our routine intake procedures, we first rescreened her with the ASQ-3 and this indicated suspected delays in the communication and personal-social domains. Then, we administered a battery of developmental tests, including PEDS:Developmental Milestones—Assessment Level, and the M-CHAT follow-up interview. Destiny was directly observed by our speech and language pathologist for over 20 minutes. We also screened Destiny's vision and hearing—and both were normal.

Destiny clearly qualifies for early intervention services due to delays in several areas including the communication, social-emotional, cognitive and self-help domains. Ms. James, who is not concerned about Destiny having autism at this point in time, is willing to have her enrolled in EI services. Destiny will begin receiving services at our program through our home-visiting program. We will keep you informed about her progress.

Sincerely,

Evalyn Childs

Evalyn Childs, MS
Assessment Coordinator/Interventionist

Figure continues…

PEDS:DM Recording Form

Child's Name: Destiny James   d.o.b.: —   Provider: Dr. Kevin Larsen

PEDS:DM Developmental Growth Chart

Directions: Shade box ■ if passed, draw a line — if failed

Columns: Using hands and fingers / Listening / Talking / Reading/Prereading / Math/Premath / Using arms and legs / Getting along with others / Self-help

AGE
7-0 - 7-11 yrs.
6-1 - 6-11yrs.
5-6 - 6-0 yrs.
4-11 - 5-5 yrs.
4-6 - 4-10 yrs.
4-1 - 4-5 yrs.
3-8 - 4-0 yrs.
3-3 - 3-7 yrs.
2-10 - 3-2 yrs.
2-5 - 2-9 yrs.
2-2 - 2-4 yrs.
23 - 25 mos.
20 - 22 mos.
17 - 19 mos.
14 - 16 mos.
11 - 13 mos.
8 - 10 mos.
5 - 7 mos.
3 - 4 mos.
0 - 2 mos.

Specific Decisions

0 - 2 mos. Referred to parenting counseling & "Parent Helpline." FPS identified multiple psychosocial risk factors.

3 - 4 mos.

5 - 7 mos.

8 - 10 mos.

11 - 13 mos. ASQ-3 Administered

14 - 16 mos.

17 - 19 mos. Referred to IDEA for EI services. Of note, the M-CHAT was ⊖. FH of ASD.

20 - 22 mos.

23 - 25 mos. ASQ-3 Administered. Referred to multi-specialty DB clinic for ASD-specific evaluation & EI plan

2-2 - 2-4 yrs.

2-5 - 2-9 yrs.

2-10 - 3-2 yrs.

3-3 - 3-7 yrs.

3-8 - 4-0 yrs.

4-1 - 4-5 yrs.

4-6 - 4-10 yrs.

4-11 - 5-5 yrs.

5-6 - 6-0 yrs.

6-1 - 6-11 yrs.

7-0 - 7-11 yrs.

Figure 5-6. Cont'd

SERENITY PEDIATRICS HEALTH GROUP
CLEAR SKIES, USA

December, 2011
To: Ms. Evalyn Childs
IDEA Part C
Clear Skies County

We have corresponded about my patient, Destiny James, who is now registered for your program. I saw her last month for her 24-month well-child visit and am increasingly concerned about the possibility of autism spectrum disorder. To address this, I will refer her to our multi-specialty DB clinic for an autism-specific evaluation, unless such an evaluation is one IDEA can provide. As you know, Destiny has a positive family history of ASD in an older brother, who has moderate to severe impairment.

Ms. James is not convinced that Destiny's milder signs and symptoms are indicative of ASD—perhaps due to the more severe manifestations in her other child. Anyway, I want to make sure Destiny's referral was received and it looks like her mother still hasn't filled out all of the pre-visit paperwork. She is "in your system" but her name was inadvertently spelled incorrectly ("Destiny" not "Destinie").

I'm also attaching my recent chart notes and the longitudinal results of screening tests I administered in case you find this to be helpful. Please keep me informed about her progress and how we can get Destiny an ASD-specific evaluation and a comprehensive early intervention plan as soon as possible.

Sincerely,

Kevin Larsen

Kevin Larsen, MD, FAAP
Cc: Multi-specialty Developmental-Behavioral Clinic at PeaceHealth Group

Attachments: Chart notes and results of screening tests administered

AUGUST AND NOVEMBER, 2011:
SUBSEQUENT WCV ENCOUNTER NOTES FROM DR. LARSEN

19-months - The patient/parent "no-showed" for her early return office visit, which I'd recommended as a 1 month follow-up after Destiny's 18-month WCV.

24-month WCV - Her BMI is found to be over the 97th %tile and she remains slightly macrocephalic. Even though a repeat developmental screening was not indicated (because she was already receiving EI services), the ASQ-3 was completed prior to the WCV. It indicated that Destiny was "below cutoff"/had suspected delays in the communication and personal-social domains. Mom failed to complete the M-CHAT at this same visit. After observing Destiny, my clinical impression is "suspect ASD." In addition to encouraging the mother to keep Destiny involved with EI services, a second referral was generated to multi-specialty developmental-behavioral (DB) clinic in hopes that Destiny would receive an ASD-specific evaluation and more comprehensive EI plan. A courtesy copy was shared with the IDEA agency and the multi-specialty DB clinic.

Figure 5-6. Cont'd

24 Month ASQ-3 Information Summary

23 months 0 days through 25 months 15 days

Child's name: Destiny James   Date ASQ completed: __/__/__

Child's ID #: __   Date of birth: __/__/__

Administering program/provider: Dr. Kevin Laren

1. **SCORE AND TRANSFER TOTALS TO CHART BELOW:** See *ASQ-3 User's Guide* for details, including how to adjust scores if item responses are missing. Score each item (YES = 10, SOMETIMES = 5, NOT YET = 0). Add item scores, and record each area total. In the chart below, transfer the total scores, and fill in the circles corresponding with the total scores.

Area	Cutoff	Total Score	0	5	10	15	20	25	30	35	40	45	50	55	60
Communication	25.17	15													
Gross Motor	38.07	60													
Fine Motor	35.16	50													
Problem Solving	29.78	45													
Personal-Social	31.54	25													

"BELOW CUT-OFF"

2. **TRANSFER OVERALL RESPONSES:** Bolded uppercase responses require follow-up. See *ASQ-3 User's Guide*, Chapter 6.

1. Hears well?   *Mom didn't answer*   Yes   NO   6. Concerns about vision?   YES   (No)
   Comments: *this question & wrote "?"*   Comments:

2. Talks like other toddlers his age?   Yes   (NO)   7. Any medical problems?   YES   (No)
   Comments: Comments:

3. Understand most of what your child says?   Yes   (NO)   8. Concerns about behavior?   (YES)   No
   Comments: Comments:

4. Walks, runs, and climbs like other toddlers?   (Yes)   No   9. Other concerns?   YES   No
   Comments: Comments:

5. Family history of hearing impairment?   YES   (No)
   Comments:

3. **ASQ SCORE INTERPRETATION AND RECOMMENDATION FOR FOLLOW-UP:** You must consider total area scores, overall responses, and other considerations, such as opportunities to practice skills, to determine appropriate follow-up.

If the child's total score is in the ☐ area, it is above the cutoff, and the child's development appears to be on schedule.
If the child's total score is in the ▦ area, it is close to the cutoff. Provide learning activities and monitor.
If the child's total score is in the ■ area, it is below the cutoff. Further assessment with a professional may be needed.

4. **FOLLOW-UP ACTION TAKEN:** Check all that apply.
   ✓ Provide activities and rescreen in __1__ months. *(early return office visit in 1 mo)*
   __ Share results with primary health care provider.
   __ Refer for (circle all that apply) hearing, vision, and/or behavioral screening.
   __ Refer to primary health care provider or other community agency (specify reason): *Done already at 18 mo WCV*
   __ Refer to early intervention/early childhood special education.
   __ No further action taken at this time
   ✓ Other (specify): *Refer to mult-specialty DB clinic for ASD-specific evaluation & EI plan*

5. **OPTIONAL:** Transfer item responses (Y = YES, S = SOMETIMES, N = NOT YET, X = response missing).

	1	2	3	4	5	6
Communication						
Gross Motor						
Fine Motor						
Problem Solving						
Personal-Social						

P101240800

Figure continues...

[Second form, lower portion]

Attachments cont'd....

12 Month ASQ-3 Information Summary

11 months 0 days through 12 months 30 days

Baby's name: Destiny James   Date ASQ completed: __/__/__

Baby's ID #: __   Date of birth: __/__/__

Administering program/provider: Dr. Kevin Larsen

Was age adjusted for prematurity when selecting questionnaire?   ○ Yes   ● No

1. **SCORE AND TRANSFER TOTALS TO CHART BELOW:** See *ASQ-3 User's Guide* for details, including how to adjust scores if item responses are missing. Score each item (YES = 10, SOMETIMES = 5, NOT YET = 0). Add item scores, and record each area total. In the chart below, transfer the total scores, and fill in the circles corresponding with the total scores.

Area	Cutoff	Total Score	0	5	10	15	20	25	30	35	40	45	50	55	60
Communication	15.64	35													
Gross Motor	21.49	60													
Fine Motor	34.50	45													
Problem Solving	27.32	40													
Personal-Social	21.73	30													

"MONITORING ZONE"

2. **TRANSFER OVERALL RESPONSES:** Bolded uppercase responses require follow-up. See *ASQ-3 User's Guide*, Chapter 6.

1. Uses both hands and both legs equally well?   (Yes)   NO   6. Concerns about vision?   YES   (No)
   Comments: Comments:

2. Plays with sounds or seems to make words?   (Yes)   NO   7. Any medical problems?   YES   (No)
   Comments: Comments:

3. Feet are flat on the surface most of the time?   (Yes)   NO   8. Concerns about behavior?   (YES)   No
   Comments: Comments:

4. Concerns about not making sounds?   YES   (No)   9. Other concerns?   YES   (No)
   Comments: Comments:

5. Family history of hearing impairment?   YES   (No)
   Comments:

3. **ASQ SCORE INTERPRETATION AND RECOMMENDATION FOR FOLLOW-UP:** You must consider total area scores, overall responses, and other considerations, such as opportunities to practice skills, to determine appropriate follow-up.

If the baby's total score is in the ☐ area, it is above the cutoff, and the baby's development appears to be on schedule.
If the baby's total score is in the ▦ area, it is close to the cutoff. Provide learning activities and monitor.
If the baby's total score is in the ■ area, it is below the cutoff. Further assessment with a professional may be needed.

4. **FOLLOW-UP ACTION TAKEN:** Check all that apply.
   ✓ Provide activities and rescreen in __6?__ months. *(AT 18-mo WCV)*
   __ Share results with primary health care provider.
   __ Refer for (circle all that apply) hearing, vision, and/or behavioral screening.
   __ Refer to primary health care provider or other community agency (specify reason):
   __ Refer to early intervention/early childhood special education.
   __ No further action taken at this time
   __ Other (specify):

5. **OPTIONAL:** Transfer item responses (Y = YES, S = SOMETIMES, N = NOT YET, X = response missing).

	1	2	3	4	5	6
Communication						
Gross Motor						
Fine Motor						
Problem Solving						
Personal-Social						

P101120700

Figure 5-6. Cont'd

Destiny's Attachments cont'd....

IDEA, PART C
CLEAR SKIES COUNTY

December, 2011

Dear Dr. Larsen,

Thank you for sharing your encounter notes and all screening test results on Destiny. You are the first physician to actually share such information with our agency. These are much appreciated and very helpful to us.

Destiny is in fact enrolled in IDEA services and I am her EI specialist who sees her in her home 2 times a month. I agree she is demonstrating some indicators of ASD and I have been forthright in sharing those observations with mother. We are focusing on improving skills within those areas of concern, namely, joint attention, social referencing, and using more formal gestures or language attempts instead of acting out to communicate.

Destiny is persistent in resisting use of formal gesture/sign or language to get wants and needs met. And she is quick to throw herself back, hit head, cry/scream, grab, etc. On a positive note, counter-indicators are present: Destiny is not demonstrating many sensory issues, preservative play behaviors, unusual physical movement/self-stimulatory behaviors, intolerance to physical touch or affection.

Meanwhile, I've met her older brother once, and am aware of how impaired he is with ASD. I know the mother does not think Destiny has characteristics that meet criteria for ASD, particularly compared to her son. Still, Ms. James is willing to proceed with your referral to the multi-specialty developmental–behavioral clinic but expects that ASD will be ruled out.

In the fall, Destiny can start my Parent-Toddler group where we can observe her in a social setting with other peers. Meanwhile, I'm definitely encouraging Ms. James to proceed with an ASD-specific evaluation at the multi-specialty developmental-behavioral clinic.

My approach with these toddlers and their families is to keep the conversation about possible ASD open and productive, even in the face of diverse opinions, as long as services *are* being delivered. An ASD diagnosis rendered at this very minute won't change the services we give. But we know it is important to determine whether ASD is the qualifying disability for public school IDEA programs and so, we'll definitely work toward establishing that, if appropriate, before Destiny turns 3-years-old. Meanwhile, I'll move with mother's readiness for such an evaluation and gently encourage her to pursue it.

I'll also communicate with professionals at the developmental-behavioral clinic who specialize in ASD. Ms. James told me that she'd completed some initial questionnaires in their referral package but hadn't checked many concerns since Destiny doesn't have the severe symptoms as her brother. She also told me that their evaluation would not occur for approximately 6 months. I let her know that the autism professionals were very interested in evaluating the siblings of children with ASD and are able to schedule appointments for these "rule-out" ASD children within one to two months. So I'll keep encouraging Ms. James to fill out all necessary paperwork while working hard to provide Destiny with appropriate early intervention services.

Sincerely,

Evalyn Childs

Evalyn Childs, MS
Assessment Coordinator/Interventionist

MRN: 02612272   Visit: 29078659   DocType: Cognitive Assessment

oddlers (M-CHAT) Form   7/22/11

Please fill out the following about how your child *usually* is. Please try to answer every question. If the behavior is rare (e.g., you've seen it once or twice), please answer as if the child does not do it.

1. Does your child enjoy being swung, bounced on your knee, etc.?
2. Does your child take an interest in other children?
3. Does your child like climbing on things, such as up stairs?
4. Does your child enjoy playing peek-a-boo/hide-and-seek?
5. Does your child ever pretend, for example, to talk on the phone or take care of dolls, or pretend other things?
6. Does your child ever use his/her index finger to point, to ask for something?
7. Does your child ever use his/her index finger to point, to indicate interest in something?
8. Can your child play properly with small toys (e.g. cars or bricks) without just mouthing, fiddling, or dropping them?
9. Does your child ever bring objects over to you (parent) to show you something?
10. Does your child look you in the eye for more than a second or two?
11. Does your child ever seem oversensitive to noise? (e.g., plugging ears)
12. Does your child smile in response to your face or your smile?
13. Does your child imitate you? (e.g., you make a face–will your child imitate it?)
14. Does your child respond to his/her name when you call?
15. If you point at a toy across the room, does your child look at it?
16. Does your child walk?
17. Does your child look at things you are looking at?
18. Does your child make unusual finger movements near his/her face?
19. Does your child try to attract your attention to his/her own activity?
20. Have you ever wondered if your child is deaf?
21. Does your child understand what people say?
22. Does your child sometimes stare at nothing or wander with no purpose?
23. Does your child look at your face to check your reaction when faced with something unfamiliar?

Comment on Case Example # 2: *This case example shows screening/surveillance in action following the steps in Figure 5-1. The case exemplifies the value of using a variety of tools (e.g., how a brief tool such as the PEDS:DM can be used to "fill in the gaps" between less frequent and more labor-intensive ASQ-3 screening). This case also shows how attention to performance on individual items, combined with the family/child's biological and environmental risk factors, can be used to hone clinical observation and decide on needed referrals. Also of note is the value of communication and collaboration with referral sources. In this example, the parent disagreed with the notion that ASD might be a problem in her 2-year old daughter because the older brother was more impaired at that same age. The mother's "wishful thinking" was much aided by repeated follow-up—not only with her child's pediatrician but also by IDEA services. Effective communication and collaboration was also the key to reducing this child's waiting time at a multi-specialty DB clinic (for an ASD-specific evaluation and comprehensive EI plan) from 6 months down to 1 month.*

IV. SCREENING AND SURVEILLANCE: WELL-VISIT BY WELL-VISIT

At every visit, there are certain routine screening/surveillance tasks, but other efforts can be staggered over time. Below we highlight our recommendations for routine versus staggered measurement. The well-visit encounter forms in Appendix A (and downloadable at *www.pedstest.com/TheBook/Chapter5*) also illustrate what needs to be done and when. We also remind you that screening/surveillance can be performed (and billed for) at sick or return visits. Many families do not adhere to the well-visit schedule and so we need to use the opportunities we have available to identify and intervene with children's and parents' issues. When we notice that families are not coming for well-visits, it is wise to schedule extra time at sick or return visits in order to make sure these (often at-risk) families receive careful attention for developmental-behavioral issues. As always, we recommend use of evidence-based measures regarding all tasks.

TASKS FOR ALL WELL-VISITS IN THE BIRTH TO 6-YEAR AGE-RANGE (OR OPPORTUNISTICALLY IF NEEDED AT SICK OR RETURN VISITS):

Routine Tasks:

- **Elicit and address parents' concerns;**

- **Measure milestones;**

- **Conduct physical exam;**

- **Provide development -behavioral promotion.**

Staggered Tasks:

- **0 to 2-weeks:** Newborn hearing screening, and newborn metabolic screens;

- **0 to 1-month** (or at new patient intake)**:** Screen for a broad array of family psychosocial risk and protective factors, identify family medical history and health risks;

- **2-months or 4- to 6-months:** Re-screen for parental mood disorder;

- **6-months:** Repeat hearing screen; measure parent-child interactions, i.e., presence or absence of resilience factors;

- **9- or 12-months:** Re-measure/address family psychosocial risk factors; screen for iron deficiency and, as indicated, lead screening;

- **15-months:** Rescreen for parental mood disorder; re-measure resilience factors;

- **18- and 24-months:** Screen for autism spectrum disorders;

- **3-years:** Rescreen hearing and vision;

- **4- and 5-years:** Vision screens.

V. REFERRAL RESOURCES: COMMONLY NEEDED SERVICES

American Academy of Pediatrics: Find a Pediatrician (www.aap.org/referral) to locate developmental-behavioral, neurodevelopmental, general and other subspecialty pediatricians.

For after school/tutoring programs, check with the child's school of zone, visit the websites of the Boys and Girls Club (*www.bgca.org*), and the YWCA (*www.ywca.org).*

For locating state, regional and local Early Intervention programs under the Individuals with Disabilities Education Act, and testing services for young children with suspected or known disabilities go to *www.ectacente*r.org.

For help locating Head Start programs see *www.ehsnrc.org.*

For help locating mental health services go to *www.mentalhealth.org.*

For help locating parent training programs see *www.patnc.org* and the YWCA (*www.ywca.org).*

For help locating quality preschool and daycare programs visit *www.childcareaware.org*, and *www.naeyc.org.*

For locating special education services for school age children, call the school psychologist or speech-language pathologist in the child's school of zone.

Social services including domestic violence, child abuse and neglect, adoption, state, and local services, etc. can be found at *www.acf.hhs.gov.*

VI. REFERRAL LETTER TEMPLATES

Below we provide templates for dictating referral letters. The first is a simple form for highlighting results with a request for referral services to return information (with signed parental consent if this is acceptable to parents). The second is a formal two-way consent form plus referral letter template. Negotiating with referral services is needed to ensure they agree to automatically return such information as evaluation reports, progress updates, and, if services provide monitoring for non-eligible children and allow referrals elsewhere, their monitoring updates. These templates are downloadable at *www.pedstest.com/TheBook/Chapter5*.

Figure 5-7. Simple Referral Letter Template

Practice

Address

Phone

Fax

Dear Child Development Specialist/Health Provider,

On _____, we saw _____ , age _____ , d.o.b. _____
parents' names(s) _____ Phone:_____

Address _____

We viewed _____'s development using:

__screening tools including (list measures)_____assessment
tools including (list measures)_____

__diagnostic measures including: _____

          _____

The results suggest significant challenges in these areas:

__fine motor skills

__receptive language

__expressive language and articulation

__gross motor skills

__self-help skills

__social-emotional-behavioral/mental health skills

__preacademic and academic skills

__chronic illness or other conditions associated with developmental-behavioral problems (list): ____
_____

We have responded by:

Figure continues...

Figure 5-7. Cont'd

__giving parents information on things to do at home

__screening hearing, vision, and lead levels: results _____

__scheduling a follow-up visit to address _____

__explaining to parents the need for additional testing of _____'s learning, development and behavior

__recommending that _____ receive additional evaluations (list medical subspecialty, therapy or other specialized evaluation services: _____ _____

We would like your program to:

__contact this family to schedule an appointment

__allow our office to schedule an appointment for this family

__give parents information on things to do at home

__provide parent training in developmental promotion

__address issues in parent and child well-being

__arrange for social services to assist with _____

__administer more detailed measures of learning, development and behavior

__assess these specific area(s) of_____ in addition to your usual assessments.

__screen _____'s __hearing, __vision, __lead levels, __health

Please obtain parents' permission for your program to send us evaluation results and progress updates so that we remain informed about this child's needs.

I prefer to be contacted by:

__e-mail : _____

 __fax: _____

__surface mail: _____

__phone at _____. The best hours to reach our office are _____

Thank you,

_____

__ovider

Figure 5-8. Referral Letter plus Two-way Consent Form (Created in Collaboration with Local IDEA Agencies)

IDEA (EI/ECSE) Agency Referral & Referral Feedback Form – Birth to Age 5

CHILD/PARENT CONTACT INFORMATION

Child's Name: _____ Date of Birth: _____/_____/_____

Parent/Guardian: _____ Relationship to the Child: _____

Home Address: _____ County: _____

Primary Phone: _____ Other Phone: _____

Primary Language: _____ Interpreter Needed: ☐ Yes ☐ No

PARENT CONSENT FOR RELEASE OF INFORMATION

Consent for release of medical information (HIPAA)*

I, _____ (print name of parent or guardian), give permission for my child's

health provider,_____ _____ (print providers name), to share any and all pertinent information regarding my

child, _____ (print child's name), with Early Intervention/Early Childhood Special Education services.

Parent/Guardian Signature: _____ **Date:** _____/_____/_____

Consent for release of educational information (FERPA)*

I, _____ (print name of parent or guardian), give permission for Early Intervention/ Early Childhood

Special Education services to share developmental and educational information regarding my child, _____

(print child's name), with the child health provider who referred my child to ensure they are informed of status of my child.

Parent/Guardian Signature: _____ **Date:** _____/_____/_____

*Consent is effective for a period of one year from the date of your signature on this release.

PROVIDER REASON FOR REFERRAL

Provider completed information. Please check all that apply.

☐ Identified medical or environmental risk factor with a high probability of resulting in developmental delays (automatically IDEA eligible):-
Please describe:_____

☐ Dev-behav. risk factors (medical):_____ (psychosocial):_____

☐ (+) Medical practitioner concerns ☐ (+) Caregiver concerns ☐ Concerning screen(s) *(Please fax scored screen(s) to IDEA agency)*

☐ ASQ ☐ ASQ:SE ☐ PEDS ☐ PEDS:DM ☐ M-CHAT ☐ M-CHAT Follow-up Interview ☐ Other_____

Concerns for possible delays in the following domains *(please check and/or circle all areas of concern)*:

☐ Communication/Expressive Lang. ☐ Communication/Receptive Lang. ☐ Social-Emotional/Behavior ☐ Personal-Social

☐ Gross Motor ☐ Fine Motor ☐ Self-help/Adaptive ☐ Hearing

☐ Problem-Solving/Cognitive ☐ Academic (pre-reading) ☐ Academic (pre-math) ☐ Vision

REFERRING PROVIDER INFORMATION

Name referring provider: _____Signature: _____

Address: _____

City: _____ State: _____ Zip: _____

Office Phone: _____ Office Fax: _____

Please fax (or mail) our office copies of the following documents (to be reviewed by the child's health provider):

☐ Evaluation Report ☐ Eligibility Statement ☐ Individual Family Service Plan (IFSP) ☐ Referral status/ feedback notes

IDEA (EI/ECSE) REFERRAL FEEDBACK

***IDEA agency:** please complete this portion and return to the child's medical home/ referral source above.*

The child was evaluated on _____/_____/_____ (date) and was found to be: ☐ **Eligible for IDEA services** ☐ **Not IDEA eligible**

If not eligible, check those that apply: ☐ Lost to follow-up ☐ Refusal of services ☐ Screened out ☐ Not eligible but to be monitored

Not eligible so referred to this community resource:_____

IDEA County Contact: _____

* This form was developed as part of a collaboration between the Oregon Department of Education (ODE), Oregon Center for Children & Youth with Special Healthcare Needs (OCCYSHN), Oregon Public Health Division and Northwest Early Childhood Institute (NWECI) in partnership with Oregon ABCD Screening Initiative. The original referral form was developed by the American Academy of Pediatrics. Kevin Marks, MD made further modifications to improve communications between medical homes & IDEA agencies.

Figure continues...

Figure 5-8. Cont'd

CONSENT FOR USE OR DISCLOSURE OF HEALTH INFORMATION BETWEEN HEALTHCARE PROVIDERS and EARLY INTERVENTION

This consent for release of information authorizes the disclosure and/or use of your child's health information from your child's doctor to the Individuals with Disabilities Education Act (IDEA) or Early Intervention/Early Childhood Special Education (EI/ECSE) program. This consent form also authorizes the disclosure of developmental and educational information from the Early Intervention/Early Childhood Special Education program to your child's doctor.

Why is this consent form important?

Your child's healthcare provider sees your child at well-child screening visits and for medical treatment. Sometimes your child's healthcare provider may see the need for more information, like evaluation or follow up by other specialists, to identify your child's special healthcare needs. The EI/ECSE program can be a resource to help identify your child's needs. The primary goal of this consent form is to allow communication between your child's healthcare provider and EI/ECSE programs so these providers can work together to help your child.

Why am I asked to sign two separate consents on this form?

The first consent allows your healthcare provider to share information about your child with EI/ECSE. The second consent allows EI/ECSE to share information about your child with your healthcare provider. Your consent for the release of information allows your child's healthcare provider and EI/ECSE communicate with one another to ensure your child gets the care your child needs. However, as your child's parent or legal guardian you may refuse to give consent to this release of information.

What is the purpose of this consent form?

This consent form was developed to ensure compliance with all federal and state laws regarding the protection of patient information. This consent includes the sharing of information as authorized under both Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) guidelines. The purpose of the HIPAA consent is to provide EI/ECSE with information necessary to determine your child's eligibility for EI/ECSE services. The purpose of the FERPA consent is to ensure that your child's doctor receives information regarding the status of your child. By authorizing EI/ECSE to provide the doctor who referred your child with pertinent information the doctor remains an active participant in your child's growth and development.

How will this consent be used?

This consent form will follow your child as he/she is screened and/or evaluated at EI/ECSE. The information generated by this release will become a part of your child's educational record. EI/ECSE will protect this information as prescribed by FERPA. Information will be shared with only individuals working at or with EI/ECSE for the purpose of providing safe, appropriate and least restrictive educational settings and services.

How long is the consent good for?

This consent is effective for a period of one year from the date of your signature on the release.

What are my rights?

You have the following rights with respect to this consent:

- You may revoke this consent at anytime.

- You have the right to receive a copy of the Authorization.

Chapter Comments: *As healthcare providers, we've had to make life and death decisions about patients. And we've had to make these on our own—in a split second—and without any time to ask for advice from colleagues or preceptors. So it understandable that we think we have to know everything and make every decision on our own.*

We must change this mental set when it comes to developmental-behavioral issues, and make use of the supports available to us. These supports come in the form of well-child visit encounter forms and problem/ process checklists that remind us what to do and when. Supports exist within evidence-based screening tools that improve our decision-making. Supports exist in collaborating with parents, eliciting and addressing their concerns, and helping parents promote their child's development.

There is a village of additional supports we need to depend on: School psychologists, social workers, family therapists, teachers, speech-language pathologists, and medical subspecialists. The careful and complex work involved in developmental screening/surveillance is a team effort that depends heavily on how well we make use of quality instruments and how well we collaborate with others. Only by working together, sharing information, using validated tools, and respecting the unique expertise of parents and professionals in various disciplines, can we hope to do an optimal job helping children and families with developmental and behavioral issues.

If you've gotten this far into Chapter 5 you may be feeling totally overwhelmed. But it takes far more time to read through the various steps than it does to execute them. Organizing for well-visits when each may require somewhat different developmental-behavioral agendas is a challenge. We explain how to make this work in greater detail in Chapter 16 (Implementation). And, it is entirely clear that thousands and thousands of primary care providers are thoroughly able to provide quality developmental-behavioral care—all within the 15 minutes allotted for most well-child visits.

We encourage clinicians to send descriptions of their own processes and solutions to the editors (www.pedstest.com/ContactUs). We will post these on the website for this book so that a wide range of approaches, implementation and challenges and ideas are covered (www.pedstest.com/TheBook/Chapter5).

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Chapter 6: Preparing Parents for Early Detection

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INTRODUCTION

This chapter continues with a focus on helping parents understand the importance of surveillance and screening. We describe what parents need to know and how primary care providers should explain their focus on developmental-behavioral (DB) issues. We describe how to help parents understand why repeatedly completing screens is critical and how to address any consternations parents may have about billing or denied claims.

UNDERSTANDING AND EXPLAINING DEVELOPMENTAL-BEHAVIORAL SCREENING AND SURVEILLANCE

What clinicians need to know. Early intervention depends on early detection. And, early detection depends on primary care providers. Standardized screening tools dramatically enhance the quality of care at well-child visits. Quality broad-band, developmental-behavioral screens (see Chapter 4), identify three to six times the number of children detected by informal approaches (milestones, unstructured clinical observation, non-validated questions to parents).[1] Even in foster care populations, already known to be at very high risk, accurate screens double the identification rate of developmental-behavioral delays.[1,2]

Accurate tools make referral and decision-making an evidence-based process that is less prone to subjective human error. And, we know that early intervention is associated with better long-term outcomes such as improvements in math and receptive vocabulary achievement scores. Early intervention lowers a child's risk of subsequent alcohol abuse, smoking, illegal drug use, high-risk sexual activities, teenage pregnancy, antisocial behaviors, suicidal thoughts/attempts and need for special education services. In turn, early intervention leads to enormous cost savings for our schools and society. So clinicians' use of accurate tools followed by prompt referrals is a critical aspect of providing quality care, as is our collaboration with IDEA and other intervention programs. Gathering feedback and/or evaluation reports from these services helps us know far more about the type and nature of any problems than we can possibly garner in a brief well-visit. Meanwhile, providers need to be ever-mindful that we never make a diagnosis on the basis of screening/surveillance tools. The information we gather from referral sources enables us to better define the big picture of problems and progress so that we can collectively decide whether there are better ways to address children's and families' needs.

What parents need to know. Whether or not parents have concerns about their children's development or behavior, parents are intensely interested in how to optimize their children's learning and life success. Parents want to know how well their children are doing, and whether the concerns they hold reflect real problems.

We need to prepare parents for the types of questions we will ask—most especially when probing challenging issues (e.g., parents' own history as a child, domestic violence, substance abuse, etc.). Providing a rationale for asking such questions is essential, i.e., letting them know that we need this information so we can do our best for helping families and their children.

Parents need to be informed in advance that if problems are found, there are many programs available. Families need assurance that your clinic works in a collaborative partnership with community programs, and that all professionals will monitor children's progress and parents' needs for child-rearing guidance. Finally, parents (and adolescents) need assurance of confidentiality that will only be broached due to potentially life-threatening events.

All the above must be conveyed in plain, intelligible language. To assist you in helping parents understand screening and surveillance, we provide a cover letter at the end of this chapter (downloadable at *www.pedstest.com/TheBook/Chapter6*). The letter can be used at new patient intake but if given in the first few weeks of life, it is best to reissue at 4- to 6-months (when formal screening should begin in your practice), along with updated HIPAA forms.

DEVELOPMENTAL-BEHAVIORAL PROMOTION: EXPLAINING ITS VALUE TO PARENTS

What Clinicians Need to Know. Screening/surveillance measures help us know which parents are the "worried well." Parents' verbatim concerns provide a scaffold for enhancing parent-provider communication about specific developmental-behavioral issues along with medical concerns, whether parents have inappropriate expectations or limited health literacy. Quality tools help parents think about development as professionals do; as a range of domains. When families have the opportunity to discuss concerns with providers, this provides some relief from parenting stress, i.e., parents learn they have a collaborator/advisor in the developmental care of their child. Meanwhile, milestones-focused tools such as the *PEDS:DM* and the *ASQ-3* help parents learn a great deal about age-appropriate skills and behaviors important for relieving parents of needless worries (while also helping providers know with precision when parents' concerns in combination with children's skills should be addressed with developmental promotion and follow-up versus referrals).[3]

Whether families need a referral or not, specific parenting information should be provided at each visit, and should be based on clinical observations of children's and families' needs, as well as on the specific issues parents raise. Providing written handouts is always wise so that parents can repeatedly review your suggestions. Be sure to highlight essential points and also hand-deliver written information to families. Your verbal highlights (e.g., circling important points) and your hand-delivery confer credibility and help parents take the messages to heart and home. Even if information is not available in the parents' primary language or if suspecting parents are not literate, providing written information is still wise. Most parents know someone who can interpret or read to them. We also suggest providing parents a list of websites offering quality information. Even if your patient mix is mostly Medicaid families, well over 80% of parents have access to the internet.[4] When our observations or parents' concerns focus on problematic discipline and limited parental skill in promoting development, we need to follow-up on the effectiveness of our advice. We should promptly link families with more intensive community resources when brief advice is found to be ineffective. See Chapter 7 for more information.

What Parents Need to Know: We should inform parents that developmental-behavioral promotion is a critical healthcare service, and that deciding on the best approaches for each family depends, in large part, on information from screening/surveillance measures. We want parents to know that providers are prepared to discuss an enormous range of issues and solutions and that we need parents to tell us about their specific topics of concern.

EXPLAINING BILLING AND DENIED CLAIMS TO PARENTS

What clinicians need to know: In the high-cost world of medicine, standardized screening/surveillance is an absolute bargain for parents and practitioners alike. It may come as a surprise, but having families list their concerns (e.g., on *PEDS*) and complete other screening/surveillance measures before an appointment, saves time at well-visits (e.g., keeps visit length at predictable levels). The time saved can then be devoted to the critical tasks of promoting development and making needed referrals. Ideally, screening/surveillance with quality instruments should be viewed as a potential profit center for practices, and is certainly a profit center for our society as a whole.

Meanwhile, parents may still receive a bill for screening/surveillance and may be understandably upset—especially when their child is typically developing. Some will want to opt out of the process altogether. We don't want that to happen because even if a child's developmental-behavioral status looks fine now, we don't know if that will be the case in the future.

Aside from assuring parents that we will do our best to bill and code accurately so that their insurance is accepted, it is also wise to avoid over-charging for screening. Consider that:

- Parents can do most of the work required to complete measures of development and behavior;
- Staff probably spend just 1 – 2 minutes scoring tools (and even that can be circumvented if online

screening services are used); and

- Clinicians' time is needed to explain results, promote development and make referrals. This time is covered, in large part, by reimbursement for the well-visit, if not from the 96110 screening code.

The above illustrates that parents, and to a lesser extent staff, are usually doing most of the leg-work on screening/surveillance. Under Medicaid, the average reimbursement is about $8.00 per screen—meaning that if you use State-approved measures, for example, *PEDS+ ASQ + M-CHAT*, you would garner $24.00. That seems reasonable.

Clinic supervisors inevitably want to charge the highest possible rate accorded by any payers (e.g., $20 to $70 per measure). While that is understandable, we also don't want families opting out of early detection when claims are denied. This can happen especially with children whose early development is typical. We don't want parents refusing screening because we know that developmental-behavioral status and psychosocial risk/resilience may change with time, i.e., opting out is not in the best interest of the child or the family.

So the many considerations are:

1. Check with each payer on their specific billing/coding requirements (see Chapter 16 for more information);

2. Bill and code accurately for screening/surveillance. Reimbursement is more likely when the results of screens occur on the day of service via face-to-face discussion with parents about the results;

3. Charge amounts in line with Medicaid;

4. Let parents know they will need to appeal denied claims on their own, but that your clinic will work with payers if re-filing is needed;

5. Explain how you will deal with these issues (e.g., in your cover letter to parents);

6. When payers consistently deny coverage for screening/surveillance, clinic business managers need to contact the State AAP Chapter and direct concerns to the AAP Chapter's Council on Practice (which can also advocate with the national AAP);

7. Bottom line, advocacy for payment of developmental behavioral services requires collaboration among parents, providers, and the AAP (both National and State Chapters).

What parents need to know: You'll need to explain to parents that the American Academy of Pediatrics formally recommends screening/surveillance at every well-visit, and that screening/surveillance helps optimize children's developmental-behavioral well-being. Parents need to be informed that most medical insurance plans throughout the country, including State Medicaid plans, usually cover the "quality-driven service" of standardized screening/surveillance. Finally, parents need an alert that there may be costs involved but that your office will do its best to make sure insurance or Medicaid covers these. We explain this in family-friendly terms in our sample cover letter.

Sample Cover Letter To Parents Explaining The Importance Of Developmental-Behavioral Surveillance And Screening.

The following letter is written at the 5th to 6th grade level which is about one to two grade levels higher than the reading level where almost all parents can understand what is said. It is difficult to explain in family-friendly language the complex issues of what screens measure and what reimbursement may or may not cover. So feel free to download it from the website for this book (*www.pedstest.com/TheBook/Chapter6*) and see if you can make it easier. We used *www.readabilityformulas.com* to check on reading levels and you may find the site helpful for working further on our sample letter and for any other communications you write for parents.

Clinic
Address
Phone

Dear Parent,

One of the most important things we do is help with children's learning and behavior. To do this we use screens. Screens are short tests that help us decide how best to help you and your child.

We want you to be the best parent you can be. That means we need to make sure all is well in your own life. Some of our screens check on how you are doing as a parent. We may ask questions about your housing, how your partner treats you, how you deal with guns or smoking in your home, and how you are feeling as a person.

Our screens also check on how your child is coming along and what worries you have. The answers you give let us know how best to help you and your child. Help can be giving you information to take home. Help can also mean referring you and your child to programs that can do more.

As you know, children's learning and behavior changes as children grow. How you and your family are doing can change too. That's why we give screens over time—to make sure all is well, stays well or what other kind of help may be needed.

Just as we charge for shots and other services, we also charge when we give screens. We can't guarantee your insurance will cover this. But we will do our best to bill carefully so that your insurance pays what it should.

If your insurance does not cover screening, we ask you to contact them and figure out why. Please let us know what you find.

Meanwhile, our clinic will work with the American Academy of Pediatrics to make sure that screens for learning and behavior are paid for. When families and clinics work together we can make this happen.

We want you to stick with us as we look carefully during each visit at how you and your child are doing.

Sincerely,

_____

Provider
Clinic Name

Chapter Comments: *Parents aren't always aware of the scope of well-child visits—what we do and why. Some families do not realize we are conducting screening/surveillance when we actually are. Many parents remain unaware that developmental-behavioral issues are something we routinely address. We want families to become partners in care because parents, if asked well, can give us critical information about their child's development—information that is also crucial for clinical decision-making, for encouraging well-visit uptake and positive parenting practices. As importantly, parents are their child's first and hopefully best interventionist (most especially if we help them with developmental promotion and referrals when needed). Informing parents about the care we provide is the first step to soliciting families' willingness to spend time completing measures, and encouraging them to share their worries and challenges so we can address them. Essential to engaging parents is our provision of a compelling rationale for why families should participate in ongoing screening/surveillance. Offering reasons and a description of the process can prevent parents from refusing developmental-behavioral care because our bills are too high or because we've not prevented denied claims effectively.*

Careful billing/coding is critical. In Chapter 16 we describe American Academy of Pediatrics (AAP) recommendations, current reimbursement, dealing with denied claims, and the importance of having a clinic supervisor determine the optimal coding approach for each plan in which you participate. But some private payers make life difficult for parents and providers by electing to not cover the screening procedure code (or only covering it at certain visits and not beyond the 30-month age-range). Wrong and wrong! The AAP is lobbying hard against such restrictions and denials. But in the meantime, denied claims will occur, despite appeals. Appealing denied claims is frequently successful, and informs us how to code and bill appropriately for each of the plans we accept.

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Chapter 7: Developmental and Behavioral Promotion

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INTRODUCTION

In recent decades, pediatric medicine shifted focus from infectious diseases to the effects of behavior, lifestyle and environment on the health and development of children.[1] By the early 1970s, only 12% of patients presented with problems purely physical in nature.[2,3] The most common issues raised during well-visits are behavior management, elimination, sleep, feeding problems, child-rearing, and developmental/school problems.[4-11] Accordingly, the American Academy of Pediatrics (AAP) advocates that well-visits cover far more than health and vaccinations including: Injury prevention and anticipatory guidance (e.g., explaining that parents need to carefully clean under furniture so that a baby who will soon be crawling doesn't find and choke on small objects), developmental-behavioral promotion (e.g., encouraging parents to share books with their children), and addressing parents' concerns (which often embrace developmental-behavioral issues). It is fortunate that in nursing school and pediatric residency, trainees have at least one month of protected time to learn about development and behavior and thus primary care providers are increasingly skilled at addressing parents' developmental and behavioral concerns.

Helpful is the "big-picture" of the developmental-behavioral content we should cover across visits. Our goals are:

- **Promoting Parent-Child Communication.** Parents' ability to engage their child verbally (including sound-play with infants) is highly associated with school success. Providers should routinely counsel parents that early family language experience and children's subsequent intellectual growth and achievement are scientifically substantiated.[12,13] Providers should explain the value of language stimulation and show parents how to talk with their young children: Expanding on what children have said, using new words to describe what children are seeing and doing, and encouraging parents to verbally describe what they themselves are doing during care-giving, mealtimes and play (e.g., "I am washing the plates. Now I am drying the cups.").

- **Preventing Delays and Emergence of Behavior Problems.** Because many children are at-risk for disabilities, behavioral challenges and school dysfunction,[14] in-office counseling is critical for promoting optimal development and one of the most important reasons for health supervision visits.[15] Various committees of the American Academy of Pediatrics including the Bright Futures guidelines encourage providers to use well-child care as an opportunity to: Promote learning, encourage positive parenting practices, help children acquire behavioral self-control, and enhance the well-being of children and their families.[16–19] Via anticipatory guidance we can avert many problems (e.g., by advising parents, by the time their children are 4-months-old, about effective approaches to helping infants go to sleep without enormous disruption. In so doing, we can usually prevent future bedtime hassles and protracted fussiness).

- **Demystifying/Reframing Behavior Challenges.** Parents may think of a child's behavior as aberrant or disobedient when it could be more accurately described as exploratory or exuberant, i.e., an understandable effort on the child's part to get what he or she wants. But such behavior is a clear call to help parents teach their children better ways of self-expression and self-restraint.[20] Parents need to know that children are social creatures and seek attention however it is offered. We want parents' attention focused mostly on positive behaviors, i.e., "time-in" in which children are praised for complying, thus allowing parents to enjoy time with their children in order to encourage them to learn new things, read together, etc. Thus we want parents to use "time-out," i.e., remove the attention children so desire, when they are misbehaving, and to "time-in" far more than "time-out."

- **Capitalizing on "Teachable Moments."** Parental concerns and clinicians' observations offer an ideal teaching opportunity rooted in the real-life context of each visit, i.e., a 'teachable moment,' that helps professionals tailor advice to families' specific needs and thus inspires parents to make use of that advice. Advice comes in many forms including verbal directions and written hands-outs, but particularly powerful are providers' comments and demonstrations: modeling, encouraging parents to practice a new skill, and providing feedback on performance. For example, whether or not parents raise concerns about children's language development, clinical

observation may detect problems with how parents position and talk with their children. So parental concerns and/or providers' perceptions can be used to illustrate how parents should talk with their children and to practice new skills (followed by suggestions for what to do at home).

- **Teaching Appropriate Disciplinary Techniques.** Behavior issues are the most common concern but are also the most challenging to address. Parents often use punishment to deter problematic behavior rather than discipline (which means teaching children better ways to behave). Instructing parents about discipline often requires them to learn multiple steps to better manage their children. Meanwhile, verbal though it is, we also know it is ineffective to manage children's behavior with reasoning, explanations, lectures or yelling. So in teaching effective discipline, we must encourage parents to verbalize less (e.g., using simple commands such as "No" or "Time out") wherein parents deploy differential attention to shape behavior.

These suggestions give rise to many questions. First, what are the best and most effective ways to counsel families during clinic visits so that they adopt needed changes to child-rearing? Second, how can we prioritize visit content given the bewildering array of important topics? Third, how can we promote independent learning (e.g., use multi-media resources to promote health and well being)? Fourth, how can we discern whether parents have learned from our advice, i.e., how can we effectively follow-up with families to make sure they are mastering the skills we've taught? Finally, how can we do all this in the tight time-constraints of pediatric encounters?

Visit length doubled from the mid-eighties to the mid nineties (from 10.3 minutes in a 1983 study to 20.4 + 6.7 minutes in a 1997 study) as did the time devoted to anticipatory guidance (formerly < 1 minute but currently averaging ~ 2 ½ minutes, i.e., 12.4% of visit time).[21-24] Nevertheless, the allotment for anticipatory guidance and counseling remains modest.[5] Primary care providers devote less than 10% of well-visit time to anticipatory guidance—spending 9 - 42 seconds on each topic.[25] Most clinicians report the time available for anticipatory guidance and development-behavioral promotion is inadequate for the range of issues requiring discussion.[26]

CHAPTER HIGHLIGHTS

To address the issues of delivering critical information efficiently and effectively, in this chapter we describe:

- Techniques in building a collaborative relationship;
- How to pin-point topics of interest to families, thereby reducing topics covered and enhancing the teachable moment;
- Efficient approaches to patient education that are minimally time-consuming, use a range of media, and encourage parent self-instruction;
- Methods for following up with families to check on mastery of content;
- How to determine when more than brief methods are needed;
- Resources for parent/patient information.

METHODS AND ISSUES IN PARENT-CLINICIAN COLLABORATION

THE VALUE OF COLLABORATING WITH FAMILIES

Establishing a working alliance between providers and parents/patients is essential for ensuring that families make use of guidance given at visits. The process requires garnering patient trust, improving communication skills, identifying and explaining problems, collaborating on goals, reaching a mutual
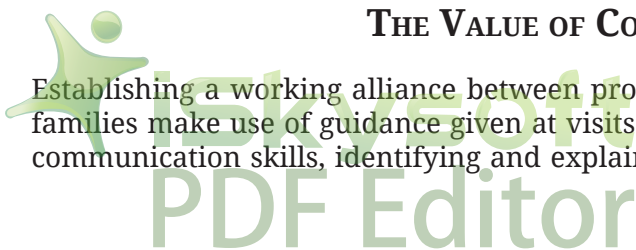
understanding and agreement by engaging the parent/patient in treatment planning, and encouraging adherence.[27,28] Providers report that such efforts contribute substantially to quality of care and satisfaction with visits for both clinicians and parents.[29-30] Parents and patients who perceive their provider to be caring and willing to listen are more likely to be at ease and more comfortable sharing feelings and concerns.[31-34] Satisfaction with healthcare experiences increases the probability that patients will keep future appointments and comply with clinicians' recommendations.[33-36] A collaborative relationship with families contributes more to treatment success than do the specifics of intervention methods or the characteristics of families or providers.[37-39]

STRATEGIES FOR BUILDING A WORKING RELATIONSHIP

So how do providers establish a therapeutic alliance with parents, children and adolescents? Critical to this process are clinicians' expressions of empathy, positive regard, warmth, and genuine interest in families and their experiences.[37-40] The process begins with the recognition that each partner has a sphere of expertise. Clinicians are experts in medical and non-medical diagnosis and treatment. Families are experts in their own experiences, concerns and challenges. It is essential to reframe encounters so that families' perspectives are valued. Below are the three major topics explaining how:

1. **Nonverbal Behavior.** Nonverbal factors are vital for developing and maintaining a collaborative and trusting working relationship. One of the first elements of nonverbal communication is a warm greeting that includes comfortable but consistent eye contact. Another important strategy is for the physician to get on the parents' and patients' physical level during conversation. Clinicians should habitually sit down in the room with the family and the child, even on their most rushed and hectic days in clinic. The act of sitting down models a genuine interest in listening to and helping the family. Children and adolescents are much more comfortable in conversation if the physician is at their level and they are looking eye to eye with them. In addition, getting on the same level as the parents and patient models an equal and collaborative relationship. Other nonverbal factors include maintaining an openness in body position to the family and a forward and attentive but relaxed body posture. In addition, although it is important to take notes and write down pertinent information during the visit, note-taking and looking at the patient chart should be minimized during conversation.

2. **Opening Channels of Communication.** Warm greetings, "small talk," questions about well-being, and a search for shared interests help families feel comfortable raising eventually, troubling issues. For starters parents can be asked, *"How have you and your family been since our last visit?"* Children and adolescents can be asked, *"Tell me some of the fun things you've been doing."* Such questions enable providers to proffer appropriate and well-timed self-disclosure (e.g., "Very exciting. I'm also interested in ...X"). Note that such questions do not fully explore parents' concerns about development and behavior. Evidence-based measures are needed to probe all domains.

   A working relationship is built with active listening skills. These skills include summarizing, restating, questioning and seeking further clarification—all aimed at the goal of ensuring mutual comprehension. Open-ended questions such as "Tell me about concerns or questions you have today," convey that providers want to hear about families' issues and perspectives. When clarification is needed, it is helpful to incorporate the words and phrases used by families. For example, if a parent says, "I think she is hyper," clinicians can restate and request details (e.g., "Please tell me more about why you think she is hyper."). Parents' responses typically include a symptoms list that should be probed further with questions such as "Does she seem more hyper at certain times?"—thus facilitating exploration of whether a high activity level results from specific circumstances or events the child finds overwhelming.

   Active listening also involves accepting and acknowledging the concerns parents raise, even if these seem trivial or misinformed. Providers should allow parents to complete their thoughts thus ensuring that providers are fully informed on each family's need for advice and

information. For example, a parent may be worried that their one-year-old is still wearing diapers. It isn't clear from that comment alone whether the parent can't afford diapers or thinks that a young toddler shouldn't require them. But if allowed to continue, a parent may state, "But I'm really not sure when toddlers are ready to use the potty." The later statement opens the door to parent education about readiness, timing and steps in toilet training.

3. **Setting Up the 'Teachable Moment.'** Because it is impossible to cover the vast range of safety, nutrition and developmental-behavioral topics during a single visit (e.g., those in the Bright Futures Guidelines), we must winnow our list. We can do this by determining which issues are pressing to parents or deemed urgent by clinicians. Focusing on pertinent challenges not only culls topics but also makes sure the issues we discuss are relevant to families. As a consequence, parents are more likely to attend to the advice we give and to follow through with suggestions. Thus we want to create 'teachable moments.' To do this, clinicians should capitalize on either their own observations during the health-care or by eliciting parents' unique concerns—but preferably both. Most parents, if asked well, raise issues about development and behavior. For the small proportion of families who do not raise concerns, clinicians can start a needed conversation by commenting on child or parent behavior during the visit (e.g., "He sure is a busy little boy. Tell me how he is at home." or "She looks very tired today. Please tell me about her sleep habits." or "You seem down. Are you doing OK?").[41,42] Thus sleeping, activity levels, and parents' well-being become a focus for the visit enabling providers to further explore the issues (e.g., "So when he/she does X, what do you?"). After first working through parents' or clinicians' own concerns, additional injury prevention/anticipatory guidance tips can be added at the end of the encounter.

   In initial discussions regarding behavior, it is essential that providers respond calmly and without judgment (even when disagreeing with parents' methods). The initial goal is to fully understand the families' experiences and justification for the techniques used. When these are problematic (e.g., "I just yell at him a lot." or "I usually give her a good whipping."), clinicians should search for examples of any effective disciplinary approaches parents deploy (e.g., "What other things have you tried?" and "How did that work?"). If positive examples are identified, providers can then praise parents for using appropriate methods and thus help families generalize these to other situations.[43]

METHODS IN PARENT/PATIENT EDUCATION

We now shift attention to various approaches to educating parents during primary care visits including: Verbal advice, role-playing and rehearsal, written information, i.e., parent education handouts, group well-visits, use of websites as well as multi-media methods. Covered are the strengths and limitations of each method and the teaching strategies required. We focus heavily on behavioral guidance because it is the most common and most challenging issue clinicians face.

Verbal Instructions

The most common intervention approach is verbal advice. A recent study found that 96% of pediatricians used verbally-delivered suggestions to address: Anxiety or depression (51% of pediatricians), behavioral interventions for ADHD (48%), child-rearing issues (34%), behavior modification techniques for noncompliance and oppositional behavior (29%), and stress management (8%).[27] After establishing a collaborative environment, verbal advice can be a powerful tool for information and behavior change. Delivery of specific rather than general advice appears best for helping families learn and apply new information.[44-46] One study compared three approaches to reducing excessive infant crying: (a) concrete suggestions on behavior management (offered by telephone to mothers of infants between 1- to 5-months of age); (b) general supportive counseling; versus (c) no counseling. Specific suggestions were the most effective method.[45] Other studies found specific verbal advice in combination with general supportive

counseling lead to optimal acquisition of knowledge and skills.[44] An example is seen in a study on helping parents whose children have epilepsy. A combination of informative talks and supportive counseling used together was more effective than information alone in increasing knowledge and decreasing parental anxiety.[46] When it comes to behavioral issues, the AAP urges providers to offer clear verbal advice about what constitutes acceptable discipline and to suggest specific modifications to families' current methods in order to make them more effective and appropriate.[41]

Verbal advice is particularly effective when the content is a single one-step recommendation. Simple messages such as *"Make sure your baby sleeps on her back."* or *"Don't smoke in your home."* are powerful and effective. But requiring parents to remember many different "bullet points" is far more challenging.

Limitations of Verbal Advice

The limitations of human memory impede the effectiveness of verbal advice. Families have known difficulty remembering and understanding information covered during encounters.[47-50] One study showed that 10% of parents had difficulty remembering the diagnosis given at a sick visit, while 23% had difficulty recalling dosing instructions of medications.[50] Human recall is particularly poor when it comes to numerical data—all compounded by challenges understanding the vocabulary used in pediatric encounters.[49] Most clinicians report frequent experiences with parents who failed to understand health information due to problems with literacy, whether verbally or in writing.[51]

Stress, Depression and Impact on Recall. Difficulties remembering and understanding verbal information are often related to stress.[44] For many parents, healthcare encounters elevate stress: Parents may enter a visit already worried about the health of their child, their own parenting abilities, family functioning, and many other everyday chronic hassles. Parents with high levels of anxiety are known to have particular difficulty recalling information immediately following a pediatric visit.[52]

Parental depression also interferes with recall, and depression often co-occurs with anxiety—meaning we should remain alert to the symptoms of both problems. It is helpful to monitor depression (because it can arise postnatally in both mothers and fathers, but not manifest itself for months or years). Measures appropriate for monitoring depression are discussed elsewhere (e.g., selected items from the *Family Psychosocial Screen* which is presented in full in Chapter 10 with follow-up items included in the well-visit forms shown in Appendix A). With possible anxiety, we should be attentive to its symptoms (e.g., agitation, rapid rate of speech, excessive repetition of the same worry, comments about feeling pressured or unduly worried, trouble adjusting to false-positive medical screens, etc.). Providers can point out in a supportive way that a parent seems highly stressed and address this supportively (e.g., *"I worry about how well you are coping and adjusting and I would like to explore this with you so we can think together about what might help."*). Whenever parents are highly anxious or depressed, we should refer when indicated, for example to parents' own healthcare provider or to mental health services).

Parents with anxiety and/or depression tend to focus on negative far more than positive information. Thus anxious/depressed parents need far more repetition than most to ensure recall and understanding. Repeating our messages and having families tell us what they understood is essential. Adding other approaches such as written information (as discussed below) is wise.

Improving Recall of Verbal Advice. The way verbal advice and suggestions are delivered is important for improving recall and understanding. Pediatricians should use consistent and simple language to describe medical and behavioral issues. Many articles on health literacy emphasize the need to simplify language and use plain communication.[53] For complex topics, information should be broken down into the major points and then addressed one step at a time. One simple strategy is to number the major points (e.g., "The first thing I want you to remember is...The second thing is...."). The major points should be colorfully described with specific relevant examples. Recall and memory are improved when guidance relates to families' personal experiences.

Another technique for giving verbal information or advice is to ask parents or older patients to "teach-back" the information given, i.e., summarize it to the clinician. Asking the parent or patient to tell you what they understood in their own words, strengthens understanding and memory. Providers can simply say, *"Please explain that back to me so we make sure I was clear."*

Follow-up after a visit involving complex instructions has established effectiveness. For example a group of parents who received a phone call reminder (e.g., to fill prescriptions, follow discharge instructions) had 90% compliance with directives compared to 55% in the group of parents who did not receive the phone call.[54] Reminder phone calls require staff time but are worth the effort to improve compliance and quality of care.

Standardized Verbal Instructions

To make information easier to understand, scripted verbal directions are another method for circumventing recall problems. Standardized instructions are carefully pre-prepared statements designed to cover all important aspects of diagnosis and treatment and are usually read or paraphrased to families during the visit. Ideally these statements are tested for verbal and written intelligibility (e.g., with reading ease formulas such as those on *www.readabilityformulas.com*). One study of children receiving emergency room care for otitis media found that standardized instructions increased the clarity and scope of information provided, and also improved recall of discharge instructions, medication, dosing, signs of improvement, and worrisome symptoms.[55] Nevertheless, a previous review made the important point that standardized verbal information is useful for simple content and is not as useful for teaching the complex skill sequences required for behavior intervention.[5]

Role-playing, Teach-Back, Modeling and Coaching

These verbally-driven approaches to education involve demonstrations to families, often followed by asking parents or patients to imitate while clinicians offer feedback (and encourage additional practice if needed). For example, with an unruly young patient, providers might say, "OK! We are going to play the 'Obey Game.' I will ask you to do something and then I'll tell you 'Good Obeying.' Now, I want you to stand up. Great! Good obeying. Now your parents will play the 'Obey Game.'" Providers can then turn it over to parents and have them ask their child to sit down, bring something over, and so forth—all while praising both parents and children for their efforts. These simple approaches are helpful for many aspects of developmental-behavioral care such as instruction in book-sharing and promoting parent-infant vocal play. Role-play, modeling, and coaching are helpful in creating the teachable moment, such as when parents fail to comment on a child's interests or simply yell when a child touches even harmless objects (e.g., "Let me show you a good way to talk with him," followed by modeling desired interactions and having parents practice).

A review of role-playing, modeling and coaching research with adolescents showed the value of this approach for reducing aggressive behavior, improving social skills, increasing the use of communication to resolve conflicts, and in preventing substance abuse.[56,57] Modeling and shaping have been shown to improve the ability of children to learn to swallow pills so they can be compliant with their prescribed pharmacological therapy.[58,59] Role-playing, rehearsal and coaching improved children's knowledge about health and safety, parents' ability to identify and report on children's illnesses, and in teaching parenting skills.[60-64] Direct coaching of children is successful in pain management (e.g., use a party blower as a distraction technique) and in helping children learn such procedures as self-catheterization.[65-67]

Modeling is used in multi-media self-instruction, and so the efficacy of videos and interactive CD-ROMs is discussed further in this chapter. Although role-playing, modeling, and coaching may appear time-consuming, several studies illustrate that simple and brief interventions enjoy remarkable success. In an evaluation of brief, preventive behavioral family intervention in a primary care setting (Primary Care Triple P – Positive Parenting Program), families experienced significant reductions in their children's problematic behavior.[68] The simplicity of these interventions, coupled with the power of clinicians' suggestions, indicates the effectiveness of simply pointing out high-risk parenting behaviors, providing

appropriate models and opportunities for practice.[69] Visible demonstrable behaviors should be the focus (e.g., having children pretend to go to time-out with quiet hands, feet and mouth and without crying or talking). And always, when asking children to practice responsiveness to disciplinary techniques, parents should be coached in providing the essential social reinforcement, i.e., praise.

Verbal Advice Summary: Clear one-step directives (e.g., "Put your baby to sleep on her back.") are thoroughly effective in changing simple behaviors. Carefully scripting complex instructions to make them clear and intelligible is helpful. But human recall is hardly infallible and we are especially challenged when asked to remember multiple steps or anything numerical (e.g., dosage, dates, times, etc.). Human recall is enormously disrupted by stress—whether just the hassles of daily living or from ongoing anxiety and depression. Parents are inevitably stressed when they are worried about their children, and one way we can reduce that is by giving parents a chance to share their worries, not appearing rushed, and asking open-ended questions that help parents feel we are interested in their concerns. We should also intervene with parental depression and anxiety because it is not only harmful for parents and parenting skills but also detrimental to recall of instructions. While we can't spend an entire day with a family, we can use tools to capture, before the visit, the central issues parents want to talk about, and gather information about well-being. And by helping parents state their concerns, providers can often prepare the messages to be shared and thus better focus visits.

Verbal messages, given the limitations of human memory, need to be short and concise. We should always check on whether parents understood our recommendations. We can enhance recall with the power of example: With verbal descriptions of both problematic and desirable behavior, and most especially with modeling, role-playing, teach-back and coaching. In the education of medical professionals, we know that case examples are often the most vivid reminders of what we have learned. Parents are no exception. Even so, a combination of teaching methods is always helpful because each of us learn in different ways.

USING WRITTEN HANDOUTS WITH AND WITHOUT VERBAL ADVICE

The use of written information and handouts has enjoyed a great deal of research. We distill the three main conclusions followed by discussion of the literature:

1. Parents and patients appear to take in written information best when the topic is of interest and concern;

2. Written information is a more effective teaching tool if accompanied by a personalized verbal message from a healthcare professional; and

3. Carefully constructed information handouts are helpful for teaching complicated sequences of skills.

Written Handouts Alone

In one study, pediatricians received brief training on sharing written material about discipline.[56] Three weeks after a well-child visit, parents were far more likely to use time-out as compared to the control group which did not receive the written material. Laine and colleagues showed that an informational booklet regarding their child's total parenteral nutrition was more effective in reducing parental anxiety and increasing satisfaction with care than was verbal instruction alone.[70] Sleep problems were effectively eliminated in a group of families receiving written leaflets while on a wait-list for counseling; written information was found to be as effective as individual counseling.[71] A study of oppositional behavior in children with attention deficit-hyperactivity disorder revealed that a ten-page handout on behavior modification reduced problem behaviors and the need for multiple training sessions with parents.[72]

One option for deploying written information is to send newsletter mailings in print or by e-mail. For example, age-paced newsletters addressing common parental concerns were sent periodically to parents following the birth of their child.[73] Seventy percent of the parents surveyed reported improvements in knowledge about development, parent-child relationships, and parental self-confidence. The websites of many parenting magazines use this approach by encouraging parents to register children at birth, create

an online baby book with photographs and milestones updates. At the same time, magazines provide age-appropriate messages about child development and anticipatory guidance (and inevitably highlight the products they sponsor).

Another method of disseminating handouts is exemplified by The Injury Prevention Program (TIPP) from the American Academy of Pediatrics. This involves individualized assignment of instructional content based on information gathered surveying parents. After needs are identified for each individual or family, specific handouts and other materials can be selected for use. The TIPP program improves parents' knowledge and use of safety measures, surely because the program focuses on the specific needs and concerns of the families.[74-76]

Written Information Together with Verbal Advice

With the exception of "just in time" information such as age-paced or individual selected topics, written instructions without verbal discussions do not appear as effective as a combination of verbal and written information.[77,78] Research discouraging smoking in mothers of newborns showed that parents who received written information along with verbal instruction had higher quit rates and lower relapse rates than the parents who received only written information.[79,60] Another study combined 10 minutes of group guidance with an educational booklet encouraging promotion of favorable sleep patterns in infants and compared this to standard education alone.[81] When the groups were questioned three months later, parents who also received written information were more likely to use appropriate sleep techniques.

Written information handouts are an effective intervention tool if offered in the right way and if the information is important to the family. Pamphlets in the waiting room might appear to be a reasonable approach because information is readily accessible to families. Nevertheless, a review of research showed that parents are unlikely to benefit consistently from this method.[5] Families learn best if written information on topics of interest is directly conferred by their provider and the content verbally summarized.

So it is best to incorporate verbal advice along with written information during a visit. The use of handouts as a supplement to verbal counseling allows more complicated or multiple step interventions to be delivered. This approach reduces the demand on human recall as well as the time demands on providers. Combining verbal advice (including role-play, teach-back, modeling, and coaching) along with written handouts is optimal. For example, in our clinical practice we often teach behavior interventions such as differential and positive attention [helping parents praise positive behaviors (time-in), and time-out negative ones]. The main points are reviewed verbally and modeled during the visit. Next, we introduce an information handout and go through techniques step-by-step with parents. The family is then asked to review the handout at home for further understanding. At the follow-up visit, we review and expand on the recommended intervention methods.

We recommend this approach in primary care. For example, once a behavior concern is raised (the most common and complex issues raised by parents at well-visits),[82] clinicians can provide a written information handout and highlight verbally (and also literally with a highlighter pen) the salient points. This approach personalizes and gives credibility to the contents and also enables parents and providers to know precisely what is covered. In turn, this facilitates focused follow-up (e.g., what steps in a toilet training sequence are giving parents trouble).

Literacy Issues in Written Information and Verbal Counseling

When parents' literacy is limited or when families speak languages other than English or Spanish (the most common languages in which information handouts are written, at least in the US) there are many considerations. Although the median reading skills of US adults is roughly at the 8th grade level,[83] written health information often remains too difficult for most adults to comprehend: 1 in 3 adolescents and young adults have limited literacy and read at or below the 4th grade level.[84] Meanwhile most child health information is written above the 10th grade level. Note that adults who do not read well are more

than twice as likely to exhibit negative parenting or child preventive behaviors. Adolescents with low literacy skills are far more likely to exhibit antisocial or aggressive behavior.

Caregiver brochures produced by the American Academy of Pediatrics and the Injury Prevention Program tend to be written at the 10th grade level (range 6th-16th grade).[85,86] As with verbal advice embracing challenging vocabulary, most healthcare providers report experiences with families who could not understand written health information.[51] Nevertheless, it is also clear that literacy and language barriers do not deter parents' interest in receiving information, including written information—meaning that parents can and do find "community helpers" to assist them in understanding/reading content.[5]

Written information needs to deploy the same plain and simple language used for verbal directions. Even highly literate families prefer easy-to-read material.[87] Improving intelligibility/readability is accomplished by reducing: Sentence length and multiple prepositional phrases, use of polysyllabic words, and passive verb tenses. Pairing everyday language with medical terms in crucial. It is wise to check results with readability formulas found in most word-processing programs.[88] Most importantly, when we add verbal advice as a way to highlight written information, we must keep our language simple and perhaps focus on two to three main concepts or points at one time. So bottom line, whether we suspect parents don't read well, don't understand English or Spanish, and when we lack translations in the language parents' speak best (see Chapter 19 for details on translations), we still want to provide written information and highlight verbally (and visually) the central points of our message. "Teach-back" by questioning parents about what they understood is essential for determining whether parents understood our advice and thus whether we need to repeat our messages (in even simpler language).

ALTERNATIVE AND INNOVATIVE METHODS FOR PARENT EDUCATION

There are helpful adjuncts to verbal and written information that are effective for the many parents who need extra help "taking our messages to home and heart." We describe some of these below including intensive hands-on training (e.g., via group well-visits and parent education services) as well as multi-media programs (e.g., videos, DVDs, and internet sites) that promote life-long learning in parenting.

Group Well-Child Visits and Group Education

One alternative to delivering individual behavioral advice and written information in primary care is group well-child visits, usually organized around families with children of the same age. Osborn and colleagues[89,90] found group well-child care just as effective as traditional well-visits. Group well-child care allows significantly more time to be devoted to parent education than traditional visits. Other advantages are that parental participation is active, there is far more time for providers to observe parents and their children, and parents receive more guidance (and peer support).[89] Osborn and Wooley showed that mothers attending group visits were more likely to attend subsequent well-visits and were less likely to seek advice between visits.[90] In their study, the amount of time physicians spent on group versus traditional well care was identical across conditions. However, parents participating in group visits received, collectively, an hour of physician time while those in the traditional care received an average of 16 minutes (most of which is devoted to topics other than developmental-behavioral issues).[90]

Group well-visits are also known to greatly improve parents' use of appropriate safety practices (e.g., improved burn prevention practices in the home).[91] Parents are also more likely to raise topics of concern than they are at individual visits.[92] Parents are more satisfied with group well-visits and 95% prefer this approach over individual visits.[90,93,94] Parents also report greater likelihood of finding social support, peer role models, i.e., other parents to whom they can talk and share ideas.

Organizing Group Well-visits

Establishing group well-visits is a challenge, although one worth addressing. Osborn[89] discusses issues with space and scheduling, noting that a dedicated nurse and receptionist support are essential for group visits to run smoothly. Someone in the pediatric practice needs to be responsible for identifying groups

of families, marketing (e.g., fliers, post-cards, posters), and creating an easy sign-up process.

A compelling alternative to organizing by children's ages is to organize groups based on interest in similar topics or conditions. In this case, providers or clinic staff identify families' issues (e.g., tantrums, sleep problems, toileting, eating, obesity) and organize group meetings around specific topics. Some practices collaborate with various disciplines (e.g., speech-language pathologists or child psychologists) to conduct (and often bill on their own for) group meetings. Such collaboration should include keeping providers apprised of ongoing issues so that reinforcement of information and techniques can be offered at subsequent well-visits. Discussed later in this chapter are published, proven curricula that can be used for topic-focused group meetings, i.e., parenting classes.

Challenges in Organizing Group Visits

Our experience is that one of the most significant barriers to organizing group well-child care visits or topic-focused group visits is simply lack of comfort and experience with the model. In short, it is not a part of residency training and so ability to organize group visits is not a skill set most providers have. How to bill and code for reimbursement is another barrier for providers (and covered in Chapter 16). If such concerns can be addressed by training, this effective delivery model may and should become much more prevalent.

Internet Resources

The world wide web is an ever-expanding source for health information. In 2010, the US Census Bureau reported that 77% of households had at least one member who has access to the internet with 69% of US households having internet access at home.[95] Information provided on the Web has much potential for helping families arrive at visits with (what we hope are) informed choices about diagnoses and treatments. Computer-literate parents (and older patients) inevitably seek information to better manage health and development.[96,97] And there is some evidence that at least certain sites are helpful. For example, randomized-controlled trials of internet-based interventions for anxiety and depression were found to be beneficial.[98-100] Another study showed decreases in depression symptoms in a group of adolescents who used an internet intervention in primary care.[101]

Parents arriving at visits armed with print-outs from websites, change the dynamics and focus of encounters. Healthcare providers have understandable skepticism about the quality of some internet-based information.[102-104] Zuckerman and colleagues commented that media (TV, newspapers, videos, internet) present an array of "expert information" with messages that are mixed if not contradictory. Parents are likely to be confused about which messages to attend. As a consequence, many parents and patients may (and hopefully do) ask their child's healthcare provider to help them make sense of the vast array of available information.[42]

Directing parents to sites with quality information is essential. Ideally, providers need to give parents a list of sites with trusted information (and perhaps a list of sites to avoid). Our recommendation is that clinicians serve as the "gatekeeper" of web based information for their patients and families. One way to accomplish this is to have a written information handout listing websites with quality information (e.g., the list provided in this chapter) along with access locations (e.g., public schools and libraries).

Clinic Websites

Even better is for clinicians to use (or develop) a unique clinic website with live links to sites you've approved. It is easy to register a domain (e.g., with *Yahoo.com*) and use the templates provided to describe your practice and add links to preferred parenting information sites. If you've subscribed to services such as interactive parent self-instruction or to online developmental-behavioral screening, you will need brief help from a webmaster to "pre-load" your links with usernames and passwords. In this way, you also establish a parent portal where families can complete screens prior to a visit or engage in instruction afterward. This approach enables clinicians to be optimally prepared for visits

with specific parenting information, referral resources, etc. Information about online early detection services is included in Chapter 4. Note that many electronic records vendors offer a parent portal but its modifiability requires assistance from the software consultant assigned to your clinic.

Multimedia Approaches to Developmental-Behavioral Promotion and Intervention

Multimedia technology refers to diverse methods for instructing parents. Some technologies offer video and audio, others enable parents to select among topics of interest. Some programs deliver "just in time" information expected to be relevant to the challenges families are probably facing based on the age of their child. Multimedia methods are constantly evolving but to date they include videos, internet and web-based programs, computer-based CD-ROM or touch-screen kiosks, voice response technologies (aka telephony), and interactive electronic medical records including parent portals (where parents can often complete screening/surveillance tools, access information about their children's health and development, and/or be directed to websites approved by providers).

The use of multimedia technology offers exciting and innovative ways to reinforce messages to families. Because patient education, especially for complex procedures is time-consuming, multi-media approaches to developmental-behavioral interventions have enormous potential to both engage families and provide the repetition needed for learning new ways to deal with the inevitable challenges of child-rearing.[29]

Videos

One of the earliest of multimedia methods, videos have much proven effectiveness in advancing parents' knowledge of child-rearing issues.[105,106] For example, parents using abusive punishment methods watched a series of videos about better solutions to common behavior problems or parent-child conflicts. Parents made significant gains in knowledge of normal child development, insight into why children misbehave, and learned alternative behavior management strategies.[107] Video interventions are known to be highly effective in changing knowledge, attitudes and behaviors, particularly with at-risk and culturally diverse populations.[108] It is important to note that videos, including public service announcements on television, work best when the speaker is a peer (e.g., an African-American teen mother speaking to other African-American teen mothers about the virtues of breast-feeding).[5]

Interactive Technology

Although videos continue to be a relatively affordable and easy method of delivering behavioral information, interactive approaches transform instruction from passive viewing to active engagement. Interactive technology includes computer-based tools (e.g., internet and web-based programs, CD-ROM interventions using computers or touch-screen kiosks, voice recognition systems i.e., telephony, personal digital assistants, and interactive electronic medical records). An extended review by Glasgow and colleagues focused on health-related behavioral change. But the authors also describe how technology can address developmental-behavioral interventions and both inform and enhance patient–clinician discussions. Some approaches enable families to complete assessments prior to an encounter and then families and providers receive advice on recommended approaches.[109] Clinicians can then reinforce the information families received. Kelleher and Stevens described the use of touchpad computers or information centers in waiting rooms to overcome practice time constraints. For kiosk style information centers neither clinic staff nor providers need to "man" the system, take time to administer screenings or complete by interview family history.[28] Such approaches enable clinicians to offer more individualized assessment and counseling during face-to-face visits.

Computer-Based Training and Waiting Room Kiosks

A large clinical trial showed that 21 out of 22 computer-based trainings (CBTs) produced positive results including reduction of targeted symptoms or behaviors, improvements in patient knowledge and understanding of information, and high parent satisfaction rates.[110] Among the technologies in greatest

use is interactive waiting-room kiosks to provide patient education.[78,111-116] Sanghavi used a waiting-room kiosk as an interactive, self-guided, computerized delivery for tutorials providing anticipatory guidance and then assessed impact on parents' knowledge. The intervention required no additional physician time and automatically printed a summary report for the medical record. Parents who completed the intervention demonstrated superior knowledge of child development, behavior, and safety issues than a comparison group who received written information only.[111]

Scholer and colleagues asked parents to view from home a 30-minute multimedia program called "Play Nicely" focused on managing children's aggression. One year after intervention, most parents who viewed the program agreed that it helped them better manage aggression.[113] In another study, caregivers of 1- to 5-year-olds who viewed an adjunctive multimedia intervention as part of the well-child visit were 12 times more likely to have learned alternative discipline strategies.[114] The researchers noted that fewer than 50% of parents participated if given a choice, but all parents agreed that viewing the information should be a required aspect of well-visits—95% of the parents who viewed the multimedia program stated that the information about discipline was valuable.[78,117]

In an additional study, families were divided into two groups: One watched "Play Nicely" and then had a discussion with their child's healthcare provider about discipline. The second group had physician counseling if requested. Only 4% of families in the second group reported plans to change how they disciplined their child. But in the first group, 89% of families had plans to change their methods. The authors concluded that multimedia instruction is a powerful and effective tool for instruction especially when delivered along with physician–parent discussions about discipline.[78,114]

Similarly an interactive internet program significantly increased caregivers' knowledge of asthma, decreased children's asthma symptoms as well as emergency department visits.[118-121] The intervention was implemented without disruption of the regular visit flow, and the site, by identifying which parts of the program parents selected, provided feedback to providers who could then provide encouragement and redirection. Overall, use of multimedia educational material along with clinician guidance appears to be a more effective means of affecting parents' skills than are physician–parent discussions alone.

Telephony, E-mail and Cell Phone Messages

Automated phone calls or telephone support services (TSSs), text messages, or e-mails are often used for appointment reminders but are also useful in reinforcing important health and safety messages, behavior intervention issues, and follow-up dates. In addition to answering parents' phone calls, e-mail and text messages can be used to respond to questions from parents—ideally with help from trained support staff with consultation from clinicians. Cell phone messaging (e.g., Text4Baby, Baby Center) is another approach that sends text messages on health, safety, and developmental promotion based on the child's age.

One study found text messages helpful for augmenting face-to-face interactions with healthcare providers by repeating basic messages—essential for mastery of new information.[121] The Text4Baby cell phone text messaging service sponsored by the Maternal Health Bureau is one example. Low-income mothers are enrolled when their child is born and then receive age-paced safety, health and developmental promotion messages. Among participating mothers: 63% reported that Text4Baby helped them remember an appointment or needed immunizations; 75% reported that Text4Baby messages informed them of medical warning signs they did not know; 71% reported talking to their doctor about a topic they had read in a Text4Baby message; and 38% reported they had called a service recommended by Text4Baby.[122] Because of this program's success, it is not surprising that Text4Baby received, in 2013, substantial funding to add developmental-behavioral/mental health screening to its offerings.

Summary of Multimedia Parent Education: *The use of technology in patient education is increasingly common. Multimedia applications reinforce providers' messages, engage parents in selecting specific topics of interest and mastery of content outside pediatric encounters, i.e., help parents become independent life-long learners. Advancing technology often enables medical records to be updated as*

parents work through training programs thus allowing clinicians to track families' acquisition of new information. Portals, often built into electronic records, are useful for such interventions and for eliciting parents' concerns and facilitating screening prior to encounters. Cell phone applications are particularly helpful in reaching families with limited access to other technologies. Providers may need to advocate for assistance from electronic records vendors for installing software on a clinic website or into an electronic record. Collaboration between medical providers and information technology companies is encouraged so that clinicians and families can take full advantage of interactive patient education programs.

PUTTING BEHAVIORAL INTERVENTIONS INTO PRACTICE

General child management strategies

We focus in this section on behavioral interventions because they are particularly challenging for providers to teach. What do clinicians and parents need to know about child development and disciplinary techniques? The most important points are that:

- Children are constantly learning about how their world works;
- Children learn from experience and also by imitation;
- Children are social beings and seek attention and interaction with others.

For these reasons, time-out is a powerful management tool, because it withdraws social attention and stimuli of interest. Time-out involves placing a child in a boring location contingent on the occurrence of an inappropriate behavior and withdrawing all attention including eye, verbal and physical contact. But time-out only works if parents provide "time-in." Families often complain that children don't listen or follow directions. We need to make sure that when children do listen and do follow directions, parents provide lots of attention and praise. In such an environment, children find the contrast between time-in and time-out quite obvious. On the other hand, if parental interaction involves mostly reasoning, lecturing, and reprimands, children learn that the best way to get their parents' attention is by repeating problematic behavior.

The contingent use of praise for pro-social behavior increases the occurrence of desirable conduct. The use of severe or loud reprimands actually increases disruptive behavior.[123] Developmentally, this makes sense because children are pre-abstract thinkers: They cannot process words, easily generalize to new situations and thus change future behavior. Compliant children typically require 6 - 9 seconds to understand the instruction and begin to act upon it.[124] Too many of us pepper children with the same instruction without waiting long enough for children to obey. Too many of us give commands that are actually choices. A question such as "Can you pick up your toys please?" does not convey what we really mean, "It is time to pick up your toys. Now!"

After giving parents behavior strategies, it is critical to find out if recommendations worked. If not, we need to find out what made the behavior worse. Sometimes children engage in "response bursts", i.e., escalating challenging behavior. Response bursts actually mean parents' new disciplinary methods are starting to work and that more time is needed. Parents need assurance from you that if they have tried and failed, it's OK, that you want to hear about it, and will help figure out other ways to help. So ask parents to call back in six or so weeks if problems persist (or plan to contact families).

Table 7-1 highlights the key points of behavior management for parents. On our website we provide downloadable informational handouts in (English and Spanish) addressing parents' most common issues in both developmental and behavioral promotion: discipline and behavior, social development, preschool and school skills, speech and language, death and dying, marital problems and divorce, motor and self-help, and parents and careers (*www.pedstest.com/TheBook/Chapter7).*

Table 7-1. Techniques in Effective Child Management

Preventing Problems:

- Discipline is not mostly punishment. Discipline is teaching new behaviors—in yourself and your children. Children often do the same troubling things over and over because they don't know another way to act, how to ask for what they really want, or how to tell you what is bothering them. So, one of the main goals of discipline is to teach children a better way to behave and communicate. Discipline also involves preventing misbehavior and practicing good behavior. These suggestions should help:

- The single most important part of discipline is to catch your child being good and let him know how proud you are (e.g., *"You put on your shoes this morning—way to go!"*). Use praise often. It motivates your child to want to behave well and to seek your approval. Every 5 to 10 minutes, try to catch your toddler being good, every 15 minutes or so for preschoolers and every 30 minutes or so with older children.

- Spend some time every day doing a few things your child likes to do and that you like to do together. A child who has special attention from parents is less likely to misbehave.

- Childproof your house. Remove dangerous, breakable, and valuable objects from areas where you spend time with your young child so that constant nagging is not necessary. If possible, make your outside yard as safe and child-friendly as possible—get a fence, give away a dangerous dog, move lawn chemicals and equipment. If you cannot make changes in your yard or play area, take turns with other parents supervising children outside.

- Rotate your child's toys. Keep some in a closet out of your child's reach and some where she can play with them. When she needs a new activity and is tired of the toys she has out, switch them with one of the ones in the closet.

- Anticipate children's needs for activities. Have a list of things your child likes to do (you can create this together). When he is restless and needs a new activity, go to the list and let him chose something. When travelling long distances, even on the way to and from the grocery store, have some fun activities prepared like *"I see something…", "20 Questions"*, drawing pads or books that are only for use in the car or bus.

- Help your child keep his or her play area tidy—preferably before playing with different toys and if not, then on a daily basis. This creates an inviting space in which to play and it teaches important thinking skills. Clean-up time and organization are not easy for children because they are easily distracted, i.e., tend to start playing rather than tidying up, and because their understanding of what types of things go together (e.g., putting blocks or Legos in the same place) is still emerging. So make clean-up a game. For example make up a tune to go with *"Pick up your book. Pick up your book. Everybody knows you've gotta pick up your books."* When the books are picked up, offer lots of praise and then start again with blocks, trucks, dolls, or whatever.

- Distract young children from things you don't want them doing by starting another activity—getting out a different toy, reading a book with them, singing a song, etc.

- Offer limited choices. If, for example, a child is reluctant to bathe, say, *"It's bath time. What do you want to wash first—your feet or your legs?"*

- Praise your child even when she does something you expect her to do. Make a short list of things you want your child to do on his own. Put these on a chart (with older children you can also list the days of the week and hours of the day). With younger children every 30 minutes or so, go with him to the chart and draw a star or put a sticker on it if he has done what was required. For older children, two or three times a day may be enough. You can mention a few minutes in advance that it's almost chart time—as a reminder to do what he should.

- Practice in a playful way how you want your child to behave. Try saying *"Now we are going to play 'The Obey Game'. I'm going to ask you to do something and then when you do it, I'm going to give you a big hug. Are you ready? O.K., go get your shoes!"* When your child returns with his shoes say, *"That was very good obeying. I am proud of you. Let me give you a big hug. Now, let's obey Daddy again….."* You can also use this to practice social skills like taking turns, waiting patiently, and so forth.

- With older children have family time for talking about behavior. Let your children talk about why rules are important, what the rules should be and rewards and consequences. Children are more likely to agree and cooperate when they understand why and are also involved in rule-making.

Table 7-1. Cont'd

- Take time for yourself: You will do better with your children when you are refreshed. If you have given your child special time, it is easier to insist on your own special time too.

Dealing with Problem Behaviors: Even if you do the above often and well, children will misbehave. These suggestions should help you manage problem behavior:

- With older children, use natural consequences whenever possible (and safe). For example, if you have to nag your child to get dressed every morning, let her know you will be taking her to school whether she is dressed or not. When the time comes, walk her out to the bus or car in her pajamas and let her get dressed there. End of nagging!

- When your preschool-age child keeps doing something that you have asked him not to do, give one warning and then "time out." Put your child in another room or in a chair facing away from you for a few minutes (only a few minutes is needed) and give her no attention. With older children, use "reverse time out." Say, *"I can't be around you when you act like this. I'll be back when you can ...."* Do not respond to pounding on the door, etc. Come out when he is behaving appropriately. Then practice with your child the behavior you want to see. Another way to do this is to have a time out chair that your child must sit in briefly until he is ready to behave better.

- Sometimes parents don't try good discipline methods for enough time. When you have tried lots of methods and nothing seems to work, think about whether one approach made things worse. This is the one to try again. Children usually try the same misbehaviors a few last times before they learn that it's not working any more.

- Don't hit your child. It only shows them that aggression and anger are a way to solve problems. Physical punishment also drives behavior "underground"—making children more likely to misbehave and also more and more skilled at hiding their misbehavior from you.

- Don't curse or call your children names. Name-calling is emotionally damaging and often causes children to act worse.

- Talk with children during a calm moment about their behavior and help them understand what you want and why. Ask them to tell you what they think should happen. Listen to what they say, rephrasing it carefully. Helping a child state rules helps them put words with desired actions.

Addressing Common Child Behavioral Issues: A Few Examples

Table 7-2 shows examples of techniques to help parents manage specific problematic behavior. All can be enhanced with verbal guidance, modeling, teach-back, adding written information to take home, and/or video instruction.

Table 7-2. Examples of Techniques for Addressing Common Behavioral Issues

Pill Swallowing. Modeling and shaping help children learn to swallow pills and maintain compliance with their prescribed pharmacological therapy.[58,59] Blount and colleagues taught children of different ages to swallow medication in one training session via the following:

- Model the pill-swallowing process;

- Use pieces of cake decorations or small candy, starting with very small sprinkles and gradually progressing in size;

- Move to the next larger sized candy after the child has been successful with two of the smaller sized candies;

- Practice daily while describing and praising cooperation with the steps;

- Model appropriate coping skills for making mistakes (e.g., deep breath, sip of water, try again).

table continues...

Table 7-1. Cont'd

Sleep Problems. Two very brief treatments (ignoring and graduated ignoring) significantly and rapidly improve young children's bedtime and nighttime sleep problems.[125] Parents received information on the interventions during a visit and then received follow-up phone calls so that professionals could answer questions and address concerns. Mindell reviewed studies and reached the conclusion that extinction and parental education are as well-established methods for the treatment of sleep problems: [126]

- Quiet time prior to bedtime (e.g., reading or coloring);

- Low lights and no television, computers, cell phones, etc.;

- Establish a bedtime routine and implement with consistency;

- Provide exercise and physical activity during the day;

- Limit or eliminate naps during the day (depending on age);

- Put child to bed while he/she is awake but tired;

- Have consistent bedtime and wake times (even on the weekends);

- Meet needs prior to bedtime (e.g., drinks and bathroom);

- Ignore all crying; or

- (1) completely ignore any attempt at getting attention; or (2) checking in at increasingly longer intervals once the child is in bed and quiet, and until asleep. Many parents prefer the latter approach.

Biting. Children bite for a reason. Teething babies and toddlers bite because it relieves the pain of tender gums and because mouthing/biting is a way to explore objects. Older toddlers and preschoolers bite to see what happens and because they do not understand yet that biting hurts other people. Young children bite when frustrated because they have not fully experienced the fact that words alone are usually sufficient to get someone to stop doing something bothersome. But, it is especially important to know that children want attention. So if biting gives children lots of attention, they are far more likely to keep biting.

- Never ever bite back! That sets an awful example. Your child does not yet understand that his/her actions hurt others and so will not make the connection between "you hurt me and so I hurt you;"

- Just say a bit loudly *"No biting!"* and *"Biting hurts!"* and remove your child from the action (without additional conversation). Then pay lots of attention to the person bitten;

- Anticipate when biting may occur and prevent it by distracting your child and playmates with other activities;

- A tired and cranky child is more likely to bite so make sure your child has snacks, water and naps before playing with others;

- Make sure your child gets lots of praise for behaving well (e.g., every 10 to 15 minutes) via comments such as *"You are playing very nicely."*;

- If your baby is teething, make sure he or she has something appropriate to bite on (e.g. a teething ring, a cold washcloth, but do not offer ice because it is a choking hazard).

Temper Tantrums. As with biting, children have temper tantrums for a reason: tired, hungry, uncomfortable, can't get or explain what they want, etc. Tantrums increase around two-years of age because children understand lots more than they can say (which is frustrating for them) and because they are increasingly driven to do things for themselves—even if they aren't ready—hence the common refrain, *"Me do it."* The drive for independence is crucial for new learning but independence is also scary for children (and adolescents). Almost every experience is new and children lack the practice and wisdom to confidently control the challenges they try to tackle.

There are two approaches needed for handling temper tantrums.[127] The first is preventing them when possible. Many of the techniques in Table 7-1 help prevent tantrums and other problem behaviors. The second approach is learning effective methods of dealing with tantrums when they occur.

- If at home, remove yourself (if your child is not doing something dangerous) and say, *"I'll come back when you stop."* Do not respond if your child follows you;

Table 7-2. Cont'd

- If your child is doing something dangerous and won't stop after being told, hold him or her for a few minutes (with his/her back toward you);

- Try humor. Raise an eyebrow and say, *"Not that again!"*;

- Ignore the child briefly. For example, simply turn around after saying, "No!";

- Take the child to a quiet place (e.g., the restroom or a car);

- Do not talk or react until the behavior stops;

- Don't give in to demands just because you are in public. If passers-by look critical or you feel embarrassed, just smile and say, *"Terrible twos,"* or *"Minor meltdown."*;

- Children also tantrum when frustrated (e.g., aren't able to put shoes on by themselves after trying). In such cases, they need soothing (e.g., *"It is OK. Putting shoes on is hard to do."*) followed by assistance (e.g., loosening shoelaces and saying, *"Let's try it again."*).

WHEN BRIEF INTERVENTIONS ARE NOT EFFECTIVE

There are times, when despite our best efforts to give parents effective advice and written information, more intensive help is needed—help that is often well beyond what we can accomplish in brief primary care visits. Markers for when more than brief interventions are required include parents with repeated behavioral concerns, those who are depressed or anxious or have other psychosocial risk factors such as limited literacy or major life stressors, and families who have a history of neglect or abuse (whether in the child's or the parents' own history). So, the first step in identifying families who need more than brief advice, is to follow-up to make sure our advice worked. When ineffective, we need to refer families for assistance with parenting. At times, this assistance will need to come from social work services (in the case of child abuse or neglect). From there, families will inevitably be required to attend parenting classes. In the absence of abuse/neglect, clinicians need to know about viable parent-training programs (either ones we can establish within our clinics, or ones we can refer to with confidence that the curricula has proven effectiveness. Described below are several well-researched curricula for parent training.

Positive Parenting Program (Triple P) (*www.triplep.net*)

Triple P was developed at the Parenting and Family Support Centre at the University of Queensland, Australia and refined across the last twenty years. Triple P is particularly unique in that it is a multi-level, parenting and family support strategy that aims to prevent severe behavioral, emotional and developmental problems in children by enhancing the knowledge, skills, and confidence of parents.

Triple P incorporates five levels of intervention of increasing strength for parents of children from birth to 16 years. What distinguishes Triple P from other psychosocial interventions for behavioral difficulties is that Levels 1, 2 & 3 of this program are designed to be carried out in primary care settings within the constraints of a 15 minute visit. It is worth noting that children with behavioral difficulties present with elevated frequency to primary care. Without programs such as Triple P, these visits can be quite lengthy.

Families begin Triple P at the lowest level of service. Movement to more intensive levels is dictated by failure to respond to the prior interventions: (1) Level 1, a universal parent information strategy, provides parents with access to information about parenting through a coordinated media and promotional campaign using print and electronic media. This level of intervention aims to increase community awareness of parenting resources, to encourage parents to participate in programs, and to create a sense of optimism by depicting solutions to common behavioral and developmental concerns. The service includes TV, newspaper, and waiting room materials and presentations; (2) Level 2 are one to two 15-minute sessions in which primary healthcare providers offer anticipatory guidance to parents of children with mild behavior difficulties. Deployed are user-friendly parenting tip sheets and videotapes

that demonstrate specific parenting strategies; (3) Level 3, a four-session primary care intervention (15 minutes per session), targets children with mild to moderate behavior difficulties and includes active skills training for parents; (4) Level 4 involves a referral to a Triple P mental health provider to provide more intensive, longer term training; and (5) Level 5 adds social services. This tiered multi-level strategy recognizes that parents have differing needs and desires regarding the type, intensity and mode of assistance they require. The Triple P system is designed to maximize efficiency, contain costs, and ensure the program has wide reach in the community.

Research on Triple P is extensive and includes randomized controlled trials across various levels of Triple P services. In one study of Level 5 Triple P with a group of ADHD children, teachers and parents reported significant reductions in disruptive child behavior problems and aversive parenting practices, along with maintenance of gains at three months post-training.[128] A study of Triple P Level 4 focused on a group of children reported by their parents as lying and stealing. There were not only significant improvements in child behavior but also in parental depression, anxiety, stress and parents' sense of competence.[129] Other researchers evaluated the success of Triple P's Level 1 cross-promotional media campaign (newspapers, posters, magazine, telephone information lines) in encouraging participation (from families and primary care providers).[130] In a comparison of families participating in Levels 3 and 4 of Triple P versus waiting list controls, 80% of the former had significant reductions in disruptive behavior.[131] Even a televised version of Triple P had remarkable effectiveness in reducing disruptive child-behavior and a high degree of acceptability to families,[132] although in another study, families and children made greater gains when exposed to more intense levels of services.[133] The Triple P website houses ongoing research and information on leadership training and research projects. Also available are books and other resources for parents on specific common issues.

Overall, Triple P is well-researched, embraces a continuum of intervention, has well constructed and tested materials, a high degree of evidence that the program makes positive changes in parenting skills and child behavior, and incurs high levels of family satisfaction. Triple P is also one of the few programs to deploy an approach that focuses on population-based improvement.

Incredible Years (*www.incredibleyears.com*)

The Incredible Years' Parents, Teachers, and Children Training Series was developed by Dr. Carolyn Webster-Stratton at the University of Washington in Seattle after several decades of formidable research on the issue of preventing and intervening with conduct disorders in children and adolescents. The Incredible Years (IY) is actually a series of different programs targeting parent training, teacher training, and child training (with the latter called "Dina the Dinosaur").

IY has two long-range goals. The first is to develop comprehensive treatment programs for young children with early onset conduct problems. The second goal is the development of cost-effective, community-based, universal prevention programs that all families and teachers of young children can use to promote social competence and to prevent children from developing conduct problems in the first place (because these often lead eventually to delinquency, drug abuse, and violence). The short-term goals of the series are to: decrease negative behaviors and noncompliance with parents at home, decrease peer aggression and disruptive behaviors in the classroom, increase children's social skills including better ability to understand feelings (both the child's own and those of others), increased skill in conflict management, decreased negative attributions, and overall to facilitate academic engagement, school readiness and cooperation with teachers.

IY enjoys some of the strongest research of any training program. Participants were significantly more likely than matched controls to show decreased symptoms of conduct disorder, ADHD, and noncompliance.[134] After 13 – 16 weeks of intervention there was a substantive decrease in child anti-social behavior and improvements in the ratio of parental praise to ineffective commands as compared with waiting list controls.[135] In a Head Start population, the combination of parent- and teacher-training decreased negative parenting practices and increased positive ones, improved parent-teacher relationships, reduced child conduct problems, and improved teachers' classroom management skills.

The strongest effects were seen in those children with the most significant conduct problems.[136] Overall, the research supporting this program is voluminous, consistent, and described in detail on the program's website. Recently IY has been successfully exported and adapted for the United Kingdom. The IY website houses materials that parents and teachers can purchase (e.g., books and videos), research studies, video clips of IY in action, etc.

IY should be in the armamentaria of training options for parents and teachers but providers should note that the program is quite specialized. It focuses on older children, those who are referred (or should be) to mental health services, and those with extant or emerging conduct problems including ADHD, oppositional defiant disorder, etc.

Parents as Teachers (PAT) (*www.parentsasteachers.org*)

Originally designed by Burton White, a prominent developmentalist, PAT is a partnership between home, school and community designed to provide parents of children, prenatally through age three, with the information they need to be their children's best first teacher. Used in one of the first large-scale home-visiting programs, PAT offers parents of young children access to monthly home visits from trained parent educators who offer timely information on the child's development and ways to encourage learning. In addition to home-visiting, PAT professionals hold group meetings with parents to encourage community building and support, provide periodic screening of children's development, and connect providers and families with other needed services.

PAT is one of the largest parenting education organizations in the country and has headquarters in each US State. Nationally recognized (due in part to enthusiastic support from members of Congress), PAT is also supported by several longitudinal studies and seems to have the greatest effect with low-income families.[140] Replication studies have not always fared as well: two evaluations revealed small but inconsistent positive effects on parents' knowledge, attitudes and behavior, but no gains on children's health or development. Subgroup analyses in Northern California found PAT particularly beneficial with Spanish-speaking families (whose children made significant gains in cognitive, communication, social, and self-help development) but PAT was less effective with families who spoke English or other languages. Nevertheless, teen parents and their children who received 10 home visits along with case-management services made significant gains. The PAT website houses training information and resources (aimed at professionals). Of note, PAT is one of the only programs to focus on the issues of American Indians and to work with Tribal Councils.[137] Thus PAT appears best invoked with families at psychosocial risk.

Systematic Training for Effective Parenting (STEP) (www.steppublishers.com)

STEP offers training for parent educators in the use of its nine-week program focused on creating support groups and teaching parents the various STEP principles. STEP relies on well-written, easy to read books along with multimedia approaches. There are unique versions focused on teens, early youth, Christian families (Bible STEP), and Spanish-speakers (Next STEP). Each version of the curricula is supported by a leaders' guide, videos, flyers, certificates and audiotapes. Leadership training covers discrete issues such as "Understanding Yourself and Your Child," "Understanding Beliefs and Feelings," "Encouraging Your Child and Yourself," "Listening and Talking to Your Child," "Helping Children Learn to Cooperate, Discipline that Makes Sense," and "Choosing Your Approach."

Research on STEP is reasonably extensive and current. One study showed that role-playing, when added to the STEP curricula, resulted in parents reporting substantial reductions in the frequency and intensity of children's behavioral problems.[138-140] It should be noted that in most studies, parent -subjects were white, middle-class, educated, and married. Attrition appears most likely in parents for whom a sense of entitlement is high,[141] suggesting that screening for adult personality issues may be helpful for deciding when mental health counseling is needed. A monograph summarizing research is downloadable from the site.

Parents Anonymous (PA) (*www.parentsanonymous.org*)

An international self-help organization with over 1,400 chapters in about five countries and all US States, PA is designed to break the cycle of child abuse by providing "safe, supportive weekly meetings where parents under stress can discuss their problems with their peers and with trained volunteer professionals." Founded in 1970, the organization is free and open to all parents who are overwhelmed, isolated or afraid of feeling angry with their children. As of 1981, PA became one of the largest self-help programs in the nation. PA groups are co-facilitated by volunteer human service professionals called sponsors, along with a parent member or chairperson for each group. Sponsors receive training in group facilitation and then work with the chairperson on facilitation skills. When members join, they receive a handbook explaining the goals of PA, its basic guidelines for operation, information about anger management, a needs assessment, and a list of other members' telephone numbers. PA research found that parents, after one month of attending, were able to stop physical abuse, and after two months stop verbal abuse. The site houses information about the many studies conducted.[142,143]

Home Visiting Programs

Home visiting programs have proven effectiveness especially when using an evidence-based curriculum aimed at a targeted group (e.g., low-income, adolescent mothers). Because these initiatives are rare (at least in the United States), we provide links to two additional programs worth exploring for local availability: *www.strengtheningfamilies.org* and *www.parentsasteachers.org*.

Chapter Summary: Few of us are trained in the most important job we do: Raise our children well. So one of the most important tasks in our encounters with families is to help parents with child-rearing challenges and promoting optimal development. Fortunately, there are many viable ways to help. We've emphasized technological innovations because these are engaging, vivid, and, like a riveting movie, stick in our memory for a long while. But even simple approaches such as written handouts provide an opportunity for parents to re-read and thus reinforce learning. We recommend sharing websites and written information even if parents don't read well or lack internet access. Almost all parents will find a way to make sense of the information shared by providers. Parents want to learn how to do their best, but some need more help learning than others. For this reason we've emphasized brief methods as well as more intensive ones.

Whatever methods we make available to parents--written information, website recommendations, videos, interactive DVDs, or referrals to parenting programs, all need to be accompanied by providers' verbal approval and highlighting of contents. Clinicians' advice is powerful and confers enormous credibility on the services and information recommended. Not every problem can be solved with verbal advice because some parenting challenges are complex and need to be backed by other opportunities to learn. But even so, families benefit greatly when providers offer a verbal overview of recommendations. Meanwhile, we encourage all clinics to become learning centers where families come to understand that health care is also about development and behavior, where families are prompted to identify issues of interest (and providers notice any problems parents have yet to recognize), where families receive good advice and information about other trusted resources, and can potentially have access to a lending library or take parenting classes.

But before we embark on behavioral interventions, it is absolutely imperative to make sure children are healthy, hear and see well, and that untreated developmental deficits are not contributors to acting out. Many noncompliant children are those who cannot hear their parents' requests, do not understand what is being said to them, lack the motor, memory or attentional skills to execute commands or who are frustrated by difficulties communicating. Health/sensory plus broad-band developmental-behavioral screening should be a first step in deciding on needed interventions. When health or sensory problems are apparent, we need to either treat these in our clinics or make referrals to subspecialists who can help. When communication or other delays are evident, we need to refer to IDEA or Head Start but also modify our advice to parents in light of children's challenges [e.g., using shorter sentences when giving commands, expanding only slightly on children's utterances and thus carefully modeling the next expected level of communication skills (such as reflecting with three-word sentences when a child is using only two words at a time), breaking down fine

motor and self-help tasks into shorter steps, offering more encouragement for attempts, etc.]. The success of parent education depends on intervention with developmental and health/sensory problems and on helping families understand children's developmental status.

PARENTING RESOURCES

Below are links to many available online resources. Some lead to services while others provide written information on common issues (often in various languages). We have looked carefully at all of these and our descriptions highlight contents and languages available. No single site has everything a parent might need (and parents with concerns surely benefit from looking at information presented in alternative ways). We've divided our voluminous list into two parts: sites that cover a wide-range of issues; and sites with a narrower focus (e.g., specific disabilities). We include a list of live links on the website for this book (*www.pedstest.com/TheBook/Chapter7*) and you are welcome to place any or all of these on your own site or create a handout to share with parents.

SITES/SERVICES ADDRESSING COMMON ISSUES

KidsHealth *http://kidshealth.org*

From the Nemours Foundation, this site has a well-visit guide for each age, anticipatory guidance information, and an easily searchable database for handouts (in English and Spanish) on health and safety, child development and positive parenting for babies through adolescence.

American Academy of Pediatrics *www.healthychildren.org*

The AAP has numerous handouts that can be downloaded for free and are available in multiple languages. Provides information on a variety of topics including health conditions, safety and prevention, mental health issues from birth through adolescence.

American Psychological Association *www.apa.org*

APA has a psychology help center that includes brochures (one copy is free) and articles for a variety of situations including health and emotional wellness, work and school, and family and relationships. The site also has information on how to find a psychologist.

Mayo Clinic *www.mayoclinic.com*

One of the best one-stop-shops for information about various conditions includes diseases and behavioral issues. Although technical, the site is useful for both providers and fairly literate parents.

National Association of School Psychologists *www.nasponline.org*

NASP provides handouts and materials in a variety of languages focused on resilience, school readiness, coping with crises, diversity, child behavior, etc. The site also explains the role of school psychologists and what to expect from a referral to public school special education services.

Phoenix Children's Hospital *www.phoenixchildrens.com*

The website has as a lovely publication called "10 Guidelines for Living with Children" that should be recommended reading for all parents of children 12-months and older. The site also has infomation about vision and hearing screening, information about feeding difficulties, and an enormous set of links to autism-specific sites and other disability-specific information including the Social Security Administration. Many downloadable handouts are also provided in Spanish.

Text4Baby (T4B)   *www.Text4Baby.org*

T4B is a free cellphone text messaging service sending crisp age-paced messages on health, safety, and developmental-behavioral issues. For children birth through 36-months, parents who register can opt for texts in English or Spanish.

American Academy of Child and Adolescent Psychiatry   *www.aacap.org*

AACAP was one of the first professional organizations to develop handouts for families. These are freely downloadable and cover a wide range of topics as divorce, sleep problems, specific mental health diagnoses, help for military families, and how and where to find a psychiatrist. Handouts are written in many different languages including Spanish, Malaysian, Urdu, Arabic, Icelandic, Polish, and Hebrew. Other site offerings include research reviews for professionals, video clips, and links to other resources.

American Academy of Pediatrics, You and Your Family   *www.aap.org*

The AAP offers purchasable child-care books, videos, hand-held health records, waiting room magazines, etc. The site has a "pediatrician finder" by specialty and zip code.

British Columbia Council for Families   *www.bccf.bc.ca*

Provides advocacy and information focused on family issues such as marital issues, divorce, cohesion, extra-martial affairs, as well as child-rearing, especially raising adolescents. The site provides thoughtful articles (for providers and parents with good literacy skills) and a bookstore offering the acclaimed "Nobody's Perfect."

Center for Effective Parenting   *www.parenting-ed.org*

Funded by the US Department of Education, this site offers freely downloadable information in Spanish and English on promoting academic skills, chore completion, selecting a daycare enter, dealing with a death in the family, self-esteem, TV issues, etc.

Children and Youth Health   *www.cyh.sa.gov.au*

This site houses one of the most extensive sources of information and covers an extremely rich range of information on health, development and behavioral issues for young children through adolescence.

Specific Patient Information in Asian Languages (SPIRAL)   *http://spiral.tufts.edu*

Hosts parenting and health information in Cambodian, Laotian, Vietnamese, Chinese, Thai, Hmong, etc.

Raising Healthy Children   *http://raisingchildren.net.au*

Focused on parenting newborns to teenagers including children with special needs, this innovative site includes "Parenting in Pictures", interactive video guides (e.g., for learning how to recognize infants' cues, talking with teens, improving home safety, adjusting to a new country), interactive neighborhood maps (for finding services, although only in Australia), tablet/smart phone apps for finding instant information on behavioral and health challenges, and also for simply having verbal fun with children (e.g., Baby Karaoke, and the value of speaking "Parent-ese" to infants).

Wellness Proposals   *www.wellnessproposals.com*

An information consolidator drawing from multiple federal sites and thus housing a plethora of downloadable posters, information handouts, and a newsletter on health, mental health, etc. The site also addresses healthcare insurance issues, the common questions families have and facilitates insurance quotes (and comparative information about carriers).

Sites Focused on Specific Skill-Building or on Disabilities

Reach Out and Read *www.reachoutandread.org*

Offers parenting handouts on how to share books, literacy milestones, and guidance for professionals. Tabs within the site include: Parents and Educators Home, Importance of Reading Aloud, Literacy Milestones, Reading Tips, Books for Children, and Books for Parents

The U.S. Department of Education *www2.ed.gov/parents*

This site provides guidance for families (in English and Spanish) on how to help their child learn to read, how to help with homework, how to collaborate with teachers, along with helpful information about selecting post-secondary schools and financial aid for college age students.

Play Nicely *http://playnicely.vueinnovations.com*

Focuses on decreasing aggressive behavior. Parents take a pre-test that identifies which among the 20 modules (e.g., ignoring hurtful behavior, speaking angrily, or physical punishment) are most needed. The site has video clips, research, assessment tools for trainers, and ordering information.

Kentucky Center for School Safety *www.kysafeschools.org*

Houses downloadable information on cyber-bullying, sexting, internet safety, social networks, gangs, etc.

Black Dog Institute *www.blackdoginstitute.org.au*

Focused on depression and bipolar disorder, this site offers interactive tests, self-training information, charts for monitoring progress, fact sheets, etc.

Centres for Clinical Interventions *www.cci.health.wa.gov.au*

Covers anxiety, excessive worries, procrastinating, etc. This site uses cognitive-behavioral research as an approach to intervention and includes worksheets, handouts, and manuals for mental health practitioners

Cognitive Behaviour Therapy Self-Help Resources *www.get.gg*

This website is for providers and families. Within are computer-based interactive training, self-help resources, therapy worksheets and written information focused on a range of mental health issues including eating disorders.

Dolls and Associates *www.dollandassociates.com*

A website from a mental health consulting service. Its clinicians offer handouts and links to resources for mental health in children and adolescents, school resources, and family/marriage.

Motivational Interviewing *www.motivationalinterview.org*

This site explains how to interview families in a way that encourages them to avoid substance abuse, comply with medication and treatment recommendations regarding obesity management, diabetes, and other health and mental health issues. Freely downloadable worksheets and purchasable books are housed on the site.

AtHealth   *www.athealth.com*

Provides information for providers (and sophisticated parents) on an enormous range of health issues that often have mental health consequences (e.g., acne, psoriasis) as well as issues such as bullying. The site includes downloadable handouts, newsletters, practitioner directories, treatment center directions, resource centers, and a bookstore.

Autism Speaks   *www.autismspeaks.org*

Includes an enormous repository of current research, policy statements, and other information for families and adults coping with autism spectrum disorder. The site provides e-mail updates on current issues and the organization is a major force for ASD advocacy.

National Dissemination Center for Children with Disabilities   *www.nichcy.org*

This site offers brief fact sheets on specific disabilities and offers tips for parents and teachers with links to related information and organizations with special expertise in that disability. In English and Spanish.

First Signs   *www.firstsigns.org*

Dedicated to educating parents and professionals about autism and other related disorders, the website is a repository of information for both parents and professionals and includes guidance on screening, diagnosis and treatment, and resources.

Here to Help   *http://heretohelp.bc.ca*

Focuses on substance abuse and mental health. Downloadable information is available in multiple languages including Russian, Chinese, Persian, Korean, French, Japanese, Punjabi, etc. The site also has wellness modules and links to other helpful resources.

Adults and Children Together Against Violence   *http://actagainstviolence.apa.org*

The purpose of this site is to mobilize communities and educate families to create safe, nurturing, healthy environments that protect children and youth from violence. It includes a variety of resources: articles, books, handouts. These resources come in English and Spanish.

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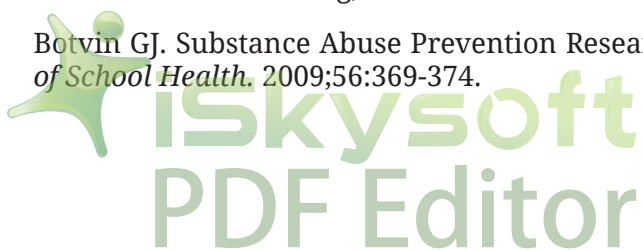
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Chapter 8: How to Give Difficult News, Find Resources and Encourage Follow-Through

CAROLINE DIBATTISTO   FRANCES PAGE GLASCOE

A Parent's Experience

When my son had been in the Neonatal Intensive Care Unit (NICU) for over 3 months, the staff Neonatologist called us in for a meeting to discuss his status. The social worker was present, as were my husband, my father, and myself. My son was still having trouble swallowing, severe reflux, feeding problems, and had copious respiratory secretions. Did the good doctor have any previous experience with these problems in other children? Could he give us an indication of what we might expect?

"Well," said Dr. "J," as he put up his hand towards us, with a serious look on his face. "There are three possibilities." He paused.

"One," sticking up a finger "is that it gets better."

"Two," sticking up a second finger "is that it stays the same."

"Three," sticking up a third finger "is that it gets worse."

Shocked and devastated by his callous attitude, I broke out in tears for the umpteenth time since the NICU ordeal had begun. After being dismissed from the meeting, I tried to find my best friend from the NICU and told her what Dr. "J" had said. "Oh my God," she said. "He did the same thing to us."

I wish that I could say that this was an isolated incident. However, my experience is that many healthcare professionals simply do not understand the devastating impact their words can have on parents in crisis. Often, the delivery is more upsetting than the actual problem at hand. Parents almost always know our children are sick and we sure as hell know this is not the "normal" child-rearing experience.

So, please try not to tell us that our kids aren't "normal"—we get it! We are doing our very best to keep ourselves together, and many of us have other children to care for, problems getting time off work, financial, and other family concerns. For those doctors who deal with sick or "special needs" children, I would say to you:

We are just trying to keep our heads above water and we don't know when the next tidal wave is going to hit. Some of us are drowning in a sea of uncontrollable sadness and worry, and find it hard to get the strength to drag ourselves out of bed, to the hospital, to appointments or deal with the ongoing and exhausting saga of letting therapists into our homes. We know you see sickness, death and disability all the time, but for us the experience of having a critically or chronically ill child is entirely new. So please don't tell us it could be worse—it could be better too!

Our entire worlds are falling apart and our hearts are aching. Please count to ten before you deliver your prognosis, good news or bad news, and think about how you would feel if I said the same thing to you. Do you know what it feels like to be haunted by the sound of your baby screaming in pain? Do you know what it's like to wake up in the middle of the night and replay a delivery gone wrong over and over in your head? Have you ever flashed back, like a movie, to the moments where you almost lost your baby? Do you know what it feels like to leave your baby in the hands of strangers, and be reduced to asking how he is on the phone? You probably don't, so maybe just acknowledge that you really don't have a clue how it feels and treat us with the sensitivity and respect we deserve.

With the exception of bereavement, nothing, and I repeat, nothing is more agonizing and emotionally debilitating than the first weeks, and months, and years of having a sick or disabled child. Please try not to be a "Scare-ologist" and terrify us as you emotionlessly describe all the things that might go wrong—things might get better too.

To all therapists, I ask that you take the word "just" out of your vocabulary, i.e. "Just do ten minutes of physio with him everyday." "If you just do ½ hour a day of flashcards…" "You'll just need to come for check-ups every two weeks to three months," etc. As a parent, I will do my best but I "just" can't do it all, everyday. I need to be a Mom first. I also need to be "just" me.

To the strangers who stare, ask rude questions, and make hurtful comments, I pray for the strength to treat you politely because you obviously have no idea about the pain you cause me and my family.

Memo to myself: take a deep breath. Take it one day at a time. Keep talking about these things. Try to make a difference. Teach providers a better way.

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A PROFESSIONAL'S EXPERIENCES

My abundant experience as a diagnostician made me quite incautious with screening tools. One of the first children I screened was a four-year-old boy referred by his daycare teachers due to concerns that he was behind other children. Because he failed every subtest: language, motor, cognitive, self-help, and preacademic, on a forty-minute screening test, I recognized the probable hallmarks of intellectual disabilities. But, without benefit of his social history, knowledge of his home environment, information about his medical status and history or insight into his mother's awareness and feelings about his difficulties, I advised her that he might have mental retardation (the alarming nomenclature at the time), might need special education, and should have additional evaluations to determine his eligibility for services.

His mother, without another word, put on her coat, wrapped up her son, and walked out the door. I asked her to stop and talk with me but my requests were met only with her retreating figure. She did not return subsequent phone calls and never scheduled a follow-up evaluation.

I feel strongly that I lost this child to apparently much needed early intervention and doomed him to school failure and inevitable secondary emotional problems, by inappropriately using a diagnostic label, particularly an inflammatory one fraught with unpleasant connotation. Clearly, my 'diagnosis' lacked credibility and simply frightened this mother away at a time when she most needed encouragement to seek help.

I've seen the other side of the coin too. I watched a young pediatric resident clap and cheer a little girl all the way through the Denver, a measure not known for its sensitivity to developmental problems in the first place. He bent a lot of rules about standardized administration of tests: reworded items, gave multiple chances, and tons of prompts and cues. Even so, the child performed very poorly. The resident just found it too painful and dissonant to believe. He said things to the family like, "She seemed to have a little trouble with the tasks I gave her, but this test may be wrong. It's just a screen and it may not mean anything. It may be there are no problems...."

This resident, understandably, had much wishful thinking; no one wants to find a significant problem with a child. But he so 'back-pedaled' the results that the parents didn't hear clearly that there was a very large chance their daughter had a developmental problem and needed additional work-ups. And those parents neither came back for further evaluation nor sought recommended intervention programs.

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INTRODUCTION

So now you have a good sense of what not to do. In the rest of this chapter, we'll explain what to do. We focus mostly on disclosing screening test results. First, we list the "what-to-dos" and provide examples of the clear and supportive statements needed. After this, we provide a review of research. At the end of this chapter we present a template for dictating a summary report for parents—it is always a good idea for families to leave with written information in hand whether or not difficult news has been imparted. The stress of the encounter whether or not there are problematic findings, makes recall of recommendations difficult.

Not all schools of medicine, nursing, education, and psychology offer training in delivering problematic results, even though such skills are critical. But interpersonal and communication skills are increasingly

a focus in medical education, i.e., required by the Accreditation Council for Graduate Medical Education (ACGME) (*www.acgme.org*). The ACGME competencies include specific knowledge, skills, behaviors and attitudes and appropriate educational experiences before graduation.

The way "bad news" is delivered can have a lasting impact on those who receive it. An insensitive approach adds to parents' distress, and sometimes provokes a great deal of anger. In turn, poor communication skills on the part of providers is one of the leading causes of malpractice suits.[1,2] Meanwhile, some providers avoid screening altogether because they are unprepared for difficult news.[3]

Explaining the results of screening tests can be confusing for parents if they are not adequately prepared in advance. Professional organizations now pay considerable attention to helping providers prepare parents and explain results well. An example is the Center for Disease Control's "Autism Case Training: A Developmental-Behavioral Pediatric Curriculum." This is available for download free of charge and consists of seven cases with accompanying power-point presentations, handouts and videos. There is an entire module dedicated to communicating screening and diagnostic results that offers step-by-step directions on how to discuss findings and share difficult news. The module emphasizes the challenges providers and parents face and how to help overcome them (*www.cdc.gov/ncbddd/actearly*). The Society for Developmental-Behavioral Pediatrics (*www.sdbp.org*) offers a course on parent-provider communication. Vanderbilt University houses PARS (Patient Advocacy Reporting System) devoted to improving physicians' communicative skills, patient satisfaction, and malpractice reduction (*www.vanderbilt.edu*).

How to Explain Findings

The process of explaining results starts with a shared understanding between parents and providers of each child's challenges. This means we want to find a way to get parents to agree with professionals about the possibility of delays. When professionals and parents are on the same page, parents are far more likely to follow through with recommendations.

Professionals need to remember that tests sort children who *probably* have problems from those who *probably* do not. We are dealing with probabilities—although quite strong probabilities if using quality screens. In contrast, assessment-level measures produce more definitive information about strengths and weaknesses (e.g., age-equivalent scores, percentiles), but do not offer a name for the problem. Only diagnostic instruments identify types of disabilities. (If you need to understand more about the differences among screening, assessment-level, and diagnostic tools, we cover this in detail in Chapter 13). So when we use screening tests and find delays, we must use general terms to describe results. But it is important to note that some of the terms we use, such as "delay" are often interpreted by parents to mean that their child will catch up, even though we don't know for sure that this is the case. Below are steps in explaining results well:

1. Create an Appropriate Environment
Never give worrisome screening results over the telephone. Instead invite parents for a return visit. Sit down when you give difficult news and sit down without a desk between you and the family. Finally, avoid appearing rushed. Parents deserve your attention when you explain results. Make sure you have allocated sufficient time for discussion.

2. Elicit Parents' Concerns
It is always advisable to ask parents in advance whether they have concerns about their child's learning and behavior. When there is a problem, most parents have concerns whether they've shared them with providers or not. So if we can get parents to tell us their worries, explaining screening results is substantially simplified because providers can then affirm parents' concerns and observations. For example, *"I am impressed with how carefully you have observed Maria's development."*

3. Note Strengths

Describe the child's strengths [e.g., *"As I worked with her today, she seems to be doing well in____"* (list domains where performance was age-appropriate in family-friendly terms such as "talking, taking care of herself," etc.)].

4. Note Weaknesses

Next, mention area(s) of probable weakness (e.g., *"...but she seems to be having trouble with_____"*). Use family-friendly terms to describe the broad area of delay (e.g., "using his hands and fingers to do things" for fine motor; "talking and making speech sounds" for expressive language, "listening and understanding" for receptive language, etc.).

5. Arrive at a Mutual Understanding

Strive for a shared perspective with whichever of the following is needed:

    (a) If parents raised concerns prior to your disclosure of problematic results, you can then affirm parents' concerns and your observations, along with a broad recommendation (e.g., *"We've both noticed difficulties and so I recommend that we get some extra help for Maria."*);

    (b) If parents have not raised concerns, try to get parents to affirm what you are seeing (e.g., *"Have you ever noticed him having difficulties with ____?"* again using family friendly terms like "learning school skills" for academics, "getting along with others" for social-emotional/mental health skills, etc.);

    (c) If parents still do not affirm your broad description, try offering slightly more details (e.g., for fine motor: *"Have you noticed him having more trouble than most children using a fork or spoon, holding a crayon, or picking up small toys or food?"*). Be sure to use multiple examples of skills in the same domain so that parents don't over-focus on a single skill that a child might be performing well;

    (d) If possible, avoid discussing specific items/skills children had trouble demonstrating. Parents may have seen children demonstrate a variation of these skills in different settings and circumstances and may disagree about whether the child knows the skill or not. If such discussions cannot be avoided (e.g., if the parent has watched hands-on testing), it is helpful to say things such as, *"When we test children we have to present things in a certain way. Your child might have been able to answer if we had reworded it, but the hundreds of children on whom this test was developed all had to answer the questions in exactly the same way so we could compare their performance. When children cannot answer a question if it is worded a little differently, it means they are still learning the skill but need more practice to master it;"*

    (e) If the above statements haven't worked, try asking *"Have you watched him alongside other children? Do you think he does as well as they do with _____?"* (list domains of difficulty in family friendly terms);

    (f) If such questions don't yield agreement, it is helpful to ask parents to   watch a classroom of children and to have teachers guide observations and encourage comparisons.

6. If Needed, Confirm your Observations

If you still can't get parents aligned with your observations (this is rare but may occur), reiterate your findings and gently evoke comparisons (e.g., *"Compared with other children I see, Toby is doing well in ____ but seems to be having trouble in ____."*):

    Use euphemisms rather than diagnostic labels when interpreting screening tests. Use phrases such as, *"seems behind other kids in ____;"* or *"He appears to be having difficulty with ____."*

This means completely avoiding terms for disabilities so that parents do not conjure images of a child in a wheelchair or one with multiple genetic anomalies (which is what most people think of when the word "disabilities" is used). The phrases above are effective terms but not devastating ones. They encourage families to seek additional evaluations without causing paralytic fear and distress;

(b) Avoid using terms such as "positive" or "negative" results to describe screening tests. These terms are confusing to parents (and to many non-medical professionals as well);

(c) Avoid expressing results of screening tests as percentages, odds or in other numerical ways based on the positive predictive value of the screens you've used. Such approaches, while helpful with diagnostic testing, are not as useful for explaining screening tests given their "fuzzier" probabilities. And, it is important to note that false-positive screens (meaning children you've referred but who did not qualify for IDEA services) are highly associated with psychosocial risk factors and emerging delays in domains critical for future school success. Thus false-positive results are often an indicator of need for other types of services (e.g., Head Start, quality daycare, parent-training, and thoughtful developmental promotion coupled with careful monitoring of developmental status);

(d) Acknowledge emotions. When parents appear to be anxious, depressed or disbelieving, it is helpful to state, *"This is surely hard to hear"* or *"You look bummed by what I've just said."* Then pause for a minute to allow parents to express their fears or reluctance. This can help them move forward and follow through with recommendations;

(e) Avoid false assurances. It is natural to want to comfort parents and assure them that nothing is the matter. However, since problematic screening results reflect a high probability of a problem, false assurances may deter follow-through and make parents' adjustment more difficult in the long run. Simply repeat, *"We need to look further to decide if _____ needs more help learning."*

7. State your Recommendations In a Positive way and Provide a Parent Summary

Explain the need for further evaluation in an upbeat manner (e.g., *"There are lots of programs that can help _____ do his best. So let's talk about ways to help him."*):

(a) Put recommendations for parents in writing. Make sure parents have a summary of results and referrals to take home with them. At the end of this chapter is a simple template for dictating a parent summary report (downloadable on the website *www.pedstest.com/TheBook/Chapter8*). Note that many online screening services automatically generate a take-home summary for parents. An example is shown in Figure 8-1;

(b) Assist parents with referrals, and better still, make appointments for families. This increases the likelihood parents will follow through. Follow-through is especially challenging when families have psychosocial risk factors (e.g., limited literacy, language barriers, etc.). Nevertheless, some referral services require that families themselves make appointments. In these cases, try to establish a two-way consent/referral form (see examples in Chapter 5, downloadable at *www.pedstest.com/TheBook/Chapter5*) between your clinic and programs. If parents must call on their own, provide telephone numbers and also brochures about the program (programs can provide these for you to hand out);

(c) Verbally describe the services to which you are referring. This helps parents visualize their child participating and increases their willingness to make this happen. This means that providers need to learn about programs, are prepared to field questions from parents and provide adequate answers;

Professionals and all trainees should, ideally, visit referral sources to best understand the services offered and thus how to describe them effectively to families. Ask for brochures when visiting so you can share these with families.

8. Finalize Referrals in Writing

In documenting your results and recommendations:

(a) Be aware that in some States, referrals for further testing through IDEA programs, i.e., Early Intervention or public schools, often require information on the status of a child's vision, hearing and health (including lead levels) before testing can proceed. So be sure to screen and document these findings in your referral letter or note that you have made referrals for sensory/health screening (e.g., to an audiologist). Sometimes programs can provide vision and hearing screening—another good reason to know lots about the programs to which you refer;

(b) If the results of the measures you've administered suggest the need for certain kinds of evaluations (e.g., speech-language, physical therapy), be sure to mention in your referral letter the types of testing needed. If autism-specific referrals are needed, send your referral letter to autism specialty clinics, but also to IDEA services because autism-specific evaluations/treatments usually have long, long, long waiting lists;

(c) Most early intervention/public school services comply with the mandates of IDEA to provide evaluations and placement within 30 - 45 school days. But some States are woefully non-compliant. For this reason it is wise to mention your awareness of the IDEA mandate (e.g., "I understand that your program is required to provide testing within 30 - 45 school days.");

(d) Try to establish two-way consent (meaning that when you ask parents for permission to send your results, you also get parents' consent to allow referral sources to send you their results and updates). This is important because professionals, especially healthcare providers may be asked in the future to prescribe additional services (e.g., occupational therapy). It will feel like a "runaway train" if you don't know the results of further testing. Establishing two-way consent requires working with each referral service (since they have to agree to this too). This is yet another good reason to get to know the programs to which you refer.

9. Offer Ongoing Support to Families

Some families will not follow through with recommendations for further evaluations or services. Here are some reasons and what to do next:

(a) Parents may return home with your news, have difficulty explaining it (more so if parents aren't given a summary report), and may be dissuaded by family members who weren't present when you explained your results and recommendations. To address this ask parents something like, *"Do you think other members of your family will try to talk you out of this recommendation?"* If the answer is yes, acknowledge parents' fears and then talk about strategies—including your willingness to meet with the entire family to discuss the results;

(b) Let parents know that if they get "cold feet" and don't follow through with your recommendations, that you want them to call you back. Let families know that you'll be happy to rescreen their child's development, check on his/her progress, and talk again about what to do next;

(c) Parents (and especially family members who are not present when you explain results), even if they observe a problem, may rationalize its meaning (e.g., *"His dad was just like that as a boy and he's doing fine now," "It's just a phase, she'll grow out of it."*). It may take the family time to realize that a problem may well exist. So be sure to follow up with referral uptake and when that has not occurred in a reasonable time frame, encourage families to return in a few months for rescreening and a re-explanation of results;

(d) Some parents hear your message but think they can address the problems on their own and want to try that first (a very good reason to give information about what parents can do to help). See Chapter 7 for suggestions on developmental-behavioral promotion. Again make sure you have a follow-up plan to check with families in a few months to confirm referral needs. If results are consistent, repeat your messages and recommendations;

(e) A few parents worry about what others will think and wonder whether participation in special services will stigmatize their child or isolate him/her from typically developing peers. Encouraging families to visit programs is wise, as is offering options such as special services through Head Start/Early Head Start (or via private therapies in conjunction with a good daycare or preschool program) along with IDEA;

(f) Always give parents a summary report to take home so that your results and recommendations are in "black and white."

10. Collaborate with Existing Programs and Referral Sources

Inevitably you will find a few parents who, despite your use of optimal communicative skills, are unwilling to recognize problems with their child. So in addition to following up with families and referral sources, one final strategy is to confer with existing programs [assuming a child is enrolled (e.g., with daycare personnel or classroom teachers)]. If parents have given permission for you to share information, you can ask that existing program staff offer guided observation where they sit with a parent and discuss differences between their child's development and behavior and that of similar age peers. This approach can be enormously effective for ensuring parents understand your message and follow through with recommendations.

WORKING WITH CHILDREN WHO HAVE ESTABLISHED DISABILITIES: A COMMENT FOR INTERNS AND ADVANCED NURSING/MEDICAL STUDENTS

You will see families of children with disabilities in your continuity clinics, general pediatrics or community rotations. Many of these families have long received care in these clinics and from various providers. When families have a child with major disabilities and are already receiving services, screening is not exactly needed. Still, you may be required to practice your skills at early detection. View parents as your best guide for tips on how to work well with a child who has known disabilities. Here are some tips:

(a) Review medical records before you enter the room to make sure you are as familiar as possible with the child and family. If possible, ask preceptors for information;

(b) When you enter, greet the parent and the child. Then say something like *"Tell me about your child and how he is doing?"*, *"What does he do best?"*, *"What skills is she working on at home and school?"* and *"How is he coming along in the services he is receiving?"*;

(c) When asking about concerns, anticipate that for children with major disabilities, parents will be enthusiastic about the smallest of gains (e.g., an 8-year-old with cerebral palsy who has finally managed to lift his head independently). While you may be perturbed at such a minor accomplishment, for families this is a big deal and does not mean they are "in denial." Families learn to focus incrementally on their children's skill acquisition and that's an important part of their adjustment to a special needs children. Be sure to share their enthusiasm;

(d) When asking parents of children with established disabilities about their concerns, do not expect they will raise worries about current developmental status. Instead, anticipate a discussion about the services their child receives and their satisfaction level. If parents are satisfied, they will probably tell you they don't have concerns but that doesn't mean they don't know their child has problems. If parents are disgruntled with special services, this issue is more than can be handled in primary care. Referrals to advocacy programs are needed (See Chapter 20 for options);

(e) If you are using a screening test focused on skills, ask parents first about what their child can do. This will give you a good feel for where to start testing. But be sure to start at an even younger level to ensure success and build compliance. Chapter 14 provides helpful tips on working with children during hands-on testing. Always be prepared to use interview-only versions of screens with an upset or noncompliant child;

(f) If the measures you use reveal a specific age range for the tasks presented, consider masking that information. Parents of children with disabilities don't need to be constantly confronted by their child's deficits. They know what these are already;

(g) If you are conducting a physical exam, ask the parents for suggestions on positioning the child and which components are likely to be upsetting. For example, if a parent tells you their child gets completely distressed when having his ears examined, save that for the end of the physical.

REVIEW OF LITERATURE ON DELIVERING DIFFICULT NEWS

More than 1 in 10 parents raise multiple concerns known to be significant predictors of disabilities. More than half their children have significant developmental or behavioral disabilities and the rest tend to score far below average on measures of language, intelligence, motor, self-help, and school skills. An additional 2 in 10 children have parents who raise a single significant concern for which the best response is to offer a second screening test. Of these children, 30% will fail screening and need to be referred. Another 2 out of 10 parents raise only nonpredictive concerns about behavior. Of their children, 20% fail screens of behavior and emotional well-being and thus need referrals. Finally, providers may notice via clinical observations, additional children who appear to have developmental or behavioral/emotional problems but whose parents have not raised concerns. When added together, about 15% to 20% of all pediatric patients need referrals due to developmental and/or behavioral/emotional difficulties—a figure that is quite close to the prevalence of disabilities in childhood.[4,5] Practices working with greater numbers of high-risk patients (e.g., those whose families are poor and have limited education) will identify a higher percentage of children who need further assessment and intervention.

A literature review in 1996 about giving bad news identified five major themes: the physical location during the discussion (comfort, privacy, quiet); participants (support, seniority of physician, other health professionals); conduct of the discussion (timing, pacing, body language); content, and how the information is exchanged.[6] A review conducted in 2010 includes general recommendations for giving bad news and different methods for teaching these skills.[7] Most of the literature on this topic is based on opinion and clinical experience. Investigational studies are usually interviews or surveys with family members and/or patients who received bad news.[3] In addition to qualitative research, there are also a few quantitative studies comparing approaches to delivering difficult results, including Harrison and Walling who researched specific approaches to giving news about childhood cancer, critically ill children, long-term neurological/ developmental diagnoses.[7]

The discussion below is broken out by the critical dimensions of delivering difficult news along with supporting research. In the absence of research devoted to developmental-behavioral screening or diagnosis, studies on other types of screens are described.

Research on Preparing Parents for Screening

Parents need information about the value of screening. Throughout the world, as children reach two or more years of age, parents become less and less likely to seek well-child care. This is disturbing for many health-related reasons, but with regard to developmental and behavioral issues, we know that children's risk for disabilities increases greatly after 24 months of age, and that parents' concerns rise dramatically.[8] Clearly parents need more encouragement and information about the value of health supervision visits where surveillance and screening occur (and probably an increased sense that such visits can address their concerns). A few studies view how best to do this. Clayton et al developed written and videotaped information about screening for cystic fibrosis and then assessed how effective these were in educating parents about disease risks and the meaning of test results.[9] Both methods produced equally high levels of comprehension although less educated parents learned somewhat less (70% comprehension and recall, compared with 95% for those who had graduated from college). Nevertheless, interest in pursuing screening did not vary by educational level. Seventy-six percent (76%) of subjects followed through by submitting blood samples. Of those with negative results, 89% understood their low but continuing

risk of having a child with CF. Those with positive results were referred to genetic counseling and not followed in this study.

Kendall and Hailey viewed three methods for encouraging women to attend breast cancer screening clinics by comparing letters in which the tone was either reassuring, anxiety-provoking, or a standard clinic prompt.[10] Significantly more women who received the reassuring letter actually kept their appointments compared with those who received standard or anxiety-provoking letters. Appointment keepers were also more likely to have a positive family history of cancer and to have age-related risks (e.g., to be older than 50). Another study found that phone calls were effective in helping low income families seek well-child visits. The frequency of reminders and their timing (e.g., day before, day of) seems to improve uptake.[11]

Such findings, however limited, provide guidance in how to prepare families for additional screening, and also in facilitating their attendance at well-visits. In general, reminder letters or closing statements at the end of well-visit should have an encouraging tone. These messages should also alert parents about the purpose and content of well-visits (e.g., *"We need to schedule your child's annual check-up. This is a time to check his health, vision, hearing and immunizations. It is also a time for us to talk about how he/she is learning and behaving and decide together whether he is developing well or how best to help."*).

Parental Perceptions of Screening and Reactions to Test Results

Once parents are aware of the value and existence of screening, they typically adopt quite favorable attitudes, citing such reasons as a desire for reassurance and improved medical surveillance for themselves and their children. For example, after an intensive public education program on the virtues of beta-thalassemia screening, most prospective parents who were carriers opted for prenatal diagnosis, with a resulting 50% to 97% reduction in the numbers of children born with the condition.[12] One study found positive attitudes toward screening (for cystic fibrosis genes) and little anticipatory maladjustment.[13] Similarly, parents are known to be quite responsive to screening test results (e.g., of slightly elevated blood lead levels in their children or positive screens for tobacco use and environmental smoke exposure) and use these to make appropriate modifications (e.g., smoke outside, reduce children's exposure to leaded paint, etc.).[14,15]

Nevertheless, parental perspectives on screening are not always placid. A survey of parents whose children had spina bifida reported anguish, confusion, and ambivalence about the need to seek screening especially if they decided to have another child. Even so, most parents stated that they would obtain testing if becoming pregnant again.[16]

Lag Times Between Screening and Diagnosis

The most stressful aspects of screening are apparent when families must wait for long periods of time for either screening test results or for diagnostic confirmation after a positive screen. A study by Carr of parents whose children were born with Down syndrome showed that the long lag time between suspicion and confirmation was difficult for parents, particularly when they themselves suspected a problem.[17] In the interim, few parents received any confirmation of their suspicions and many were either met with false assurances or simply told to wait for test results (which in 1970, took considerably longer to produce than at present). Parents of boys found to have Duchenne muscular dystrophy had similar complaints. Most families had waited an average of 2½ years between their observations of symptoms and the final diagnosis.[18] As a consequence, 75% advocated for neonatal screening in order to improve financial planning, decisions about contraception and housing, and to better prepare for their own and their children's emotional needs. Even a delay of two to four weeks was not tolerated well by parents with positive screens who were waiting for possible confirmation of genetic or metabolic disorders in their children.[19,20]

Lag times seem particularly challenging to individuals who have high levels of anxiety to start with. A study of women at risk for breast cancer showed that those who were very anxious or psychologically distressed were less likely than better adjusted women to adhere to preventive regimens (e.g., self-

examinations and clinical exams). Anxious adults were also those with few social supports and diminished social capital, which suggests that referrals for support groups may be helpful—even during the phase between screening and diagnosis.[21]

Adjustment to Positive Screening Test Results

Most studies suggest that parents/patients who receive positive screens experience understandable distress, but relief replaces distress when treatment begins. In one study, substance abusers about to be screened for HIV, received psychological evaluations at three points in time (before screening, one - two weeks after, two - three months after). This group was compared to non-tested abusers in terms of psychological and behavioral impact. Those found to have HIV had higher levels of anxiety immediately after testing, as might be expected. Several months later anxiety was substantially diminished, and HIV-positive patients had developed healthier lifestyles between screening and follow-up.[22] Parents who learned they had positive markers for a genetic condition reported a sense of relief due to improved ability to plan for the future (e.g., arrange appropriate medical surveillance and take other preventive steps).[23]

Nevertheless, adjustment to positive screens is not a simple matter of temporary anxiety followed by adaptive improvements and subsequent relief. In a study of screening for colon cancer genes, parents unaffected by colon cancer but whose children had the gene, had greater levels of depression and anxiety three months after screening.[24] Children themselves were found to have higher levels of depression and anxiety, but only if their mothers but not fathers were affected by colon cancer. The authors suggest that much of this is explained by the known relationship among chronic illness, parental mental health and children's mental health. Certainly, these findings corroborate studies showing that parents and children with vulnerabilities to anxiety or depression are more likely to be adversely affected by difficult news and events. Even so, many parents do not share their distress about adverse test results.[24] This clearly makes it harder for providers to identify when patients are troubled. In any case, one seemingly appropriate response is to routinely refer families to supportive services (e.g., parent groups, family resource centers, etc.) after positive screening results are found.

Preparing parents for screening, well in advance, facilitates acceptance of screening test results. In one study, 208 (mostly low birth-weight) children received developmental, vision, hearing and growth screening at 8-months of age from a health visitor. About one-third of children failed some aspect of screening but 30% of parents appeared to disregard or disbelieve screening test results. Many reported that screening procedures were not explained to them or that their child had been rushed and so had not performed up to potential. More than 10% did not realize that their child had been screened at all. Almost 60% found the assessments reassuring even though their child had not performed well.[25] The authors recommended that providers give parents adequate information about the tests performed, suggesting this might improve parents' ability to value screening test results and follow through with recommendations.

Adjustment to False-Positive Screens

Some researchers speculate that parents who receive false-positive test results (meaning that the child failed screening but was found on diagnostic testing not to have a problem) have, as a consequence, long-term, lingering worries about their children. For example, parents whose children had false-positive screens for cystic fibrosis had substantial levels of ongoing anxiety.[26] Some parents who received false-positive information about congenital hypothyroidism in their newborns were found to have high levels of anxiety as many as four years after screening.[27]

In neither of the above studies was there an attempt to ascertain base rates of anxiety in parents, whether or not they received positive test results. Thus we cannot be confident that the presence of anxiety is any different from what might be ordinarily found among new parents (or in parents with anxiety disorders). Tluczek et al based their conclusion (of high levels of lingering anxiety) on the fact that 5% of parents (6 of the 126) receiving false-positive screens, had continuing concerns about cystic

fibrosis.[26] Of this group, all had received results over the telephone (a method of presentation shown to be problematic) and all six parents had children whose Apgar scores were well below average at 1 and 5 minutes. In contrast, the majority of parents were grateful that a potential problem was found early, and experienced a sense of relief that their baby was not ill. Although this group was not immune to anxiety, distress was restricted to elevated concerns about children's health during the three-day wait to have screening results negated. Another study compared anxiety related to false-positive screens to base rates of anxiety in a control group. Psychiatric morbidity was found to be transient and minor (in women screened for cervical cancer).[28] Similarly, false-positive results (about ovarian cancer) increased short-term distress, but this was neither severe nor persistent.[29]

Parents' willingness to use health care in the future was compared between infants with false-positive newborn screening results and those with normal results.[30] The authors analyzed the administrative claims of 49,959 Medicaid-enrolled infants in Michigan in 2006. Of all infants, 818 were found to have had a false-positive newborn screening result when retested between 3- and 12-months of age. There were no differences between the families with false-poisitive versus negative newborn screening results, in terms of their attendance at subsequent healthcare visits. Nevertheless, preterm infants with false-positive results required more acute outpatient visits than those with normal results—findings that may be explained by either underlying illness and/or parental anxiety.[30]

Lingering anxiety over false-positive screens appears not only related to how the news was delivered but also to the quality of information parents received. In one study, 55% of families who received false-positive screening results (of metabolic problems in their newborns) had incorrect or incomplete information.[20] Most believed that retesting was routine or that mistakes had been made in the first set of tests. Many parents in this group appeared untroubled by recommendations to pursue further testing. In contrast, parents who understood that the first test was abnormal were not shown to be more anxious or depressed than ill-informed parents, although more than one-third had increased health concerns for their child. Nevertheless, such concerns were mostly associated with parents' perceptions that they had not received sufficient information about the screening process and implications for their children's health. Indeed, most had sought opportunities to talk about the issue with friends or family members and 30% had sought information from other healthcare professionals. As with most research on parents' reactions to screening, misinformation about the testing and its implications are common, particularly among parents with limited education.

There is some evidence that poor quality information and increased anxiety co-occur whether or not positive screens are confirmed by diagnostic testing. This makes sense because anxiety is repeatedly shown to be a deterrent to information recall. A study of men receiving prostate cancer screening identified substantial increases in serum cortisol (an indicator of emotional stress) between initial screening and biopsy two weeks later. Serum cortisol dropped following biopsy regardless of the results. The findings suggest that unanswered questions evoked by screening provoke stress and that once definitive answers are provided, coping skills improve.[31] Still, some parents attribute lasting concerns to false-positive results. Because this is probably a marker for generalized anxiety, it is advisable to provide parents repeated opportunities to understand the results and to offer parent-to-parent support groups or counseling when indicated.[32] Again, written take-home information is invaluable.

Adjustment to False-Negative Screens

Because screening tests have inherent error, results need to be interpreted cautiously. This is particularly the case with developmental and behavioral issues because difficulties may not be fully apparent until later in childhood (e.g., learning disabilities are difficult to detect before 6-years of age or older). One study focused on a subset of parents who had held concerns (about their child's health), who were told initially that nothing was wrong, but whose children were later diagnosed with cancer.[33] Although the diagnosis marked the end of frustration for many parents, those with false-negative results were often angry with healthcare professionals. These parents felt providers had neither listened to them nor taken their concerns seriously. Many felt denigrated when told they were simply over-anxious. Not surprisingly, such parents were far less tolerant of the time-lag between symptoms and diagnosis and

construed this as further evidence of their providers' thoughtlessness. In contrast, parents who felt health professionals had been responsive to their concerns, were less critical of negative screening test results even when disabilities were found. The results suggest the need to convey to parents that development develops, developmental problems do too, and that your clinic will measure children vigilantly for any signs of developing problems.

Screening Refusals

As with immunizations, some patients and parents refuse to participate in developmental-behavioral screening. This phenomena has implications for preparing families if screening and for conveying screening test results. In one study, researchers interviewed patients who elected not to receive screening for Huntington's disease. Most "refusers" felt they would be unable to cope emotionally with the results.[23] Unfortunately, refusing to be screened may not reduce stress. In a long-term study of substance abusers at risk for HIV, those opting to receive screening had lessened anxiety and healthier lifestyles two - three months after screening, regardless of test results. In contrast, subjects who elected not to be tested had increased anxiety at follow-up about contracting HIV.[22] So screening refusals may be an indicator of pre-existing anxiety requiring unique attention from clinicians.

Another dimension of screening refusal is visible when parents are less than careful or (less commonly) untruthful when answering screening test items. For some parents, literacy factors may be at play. For others, there may be a "fatigue" or "response set" factor where parents answer the first few questions accurately but then start circling all "yes" or all "no" answers. And some parents don't want to tip the provider's hand by stating their concerns. For example, in unpublished studies of *Parents' Evaluation of Developmental Status (PEDS),* parents were debriefed after participating in research about the relationship between parents' concerns and children's performance on developmental and behavioral tests. Some parents who had not raised concerns but whose children performed poorly were particularly distressed when informed of the results. Many such parents stated they had deliberately refused to disclose their worries to researchers. Some had declined similar opportunities during prior encounters with their child's healthcare provider (e.g., *"I thought I was just being overly worried and that if there really were a problem, her pediatrician would notice and tell me."*). While it is not clear that some parents are less than truthful on screens because of limited ability to cope emotionally with adverse responses, it does appear that parents who are worried or anxious about their children need encouragement over time to discuss their worries.

Some parents may couch their psychosocial concerns in somatic terms—a finding noted in some cross-cultural studies. For example, Asian patients with psychiatric problems were more likely to present with physical complaints than were non-Asians with psychiatric problems (the latter were more likely to clearly complain about emotional and behavioral difficulties).[34] Ideally, by repeatedly encouraging parents to discuss their behavioral and developmental concerns, families receive a clear message that these topics are the province of health care and that parents' concerns are of legitimate interest to providers. This, in turn, may deconstruct barriers to effective provider-parent communication.

Some parents refuse developmental-behavioral screening because of its costs—especially when claims are denied. Chapter 6 discusses fees, parent preparation, and other ways to encourage parents to continue to participate in screening.

Conveying Screening and Assessment Results and Ensuring Follow-Through

Only a few studies evaluated the way in which parents were informed of screening results. One showed that parents informed of screening test results over the telephone were far more likely to misunderstand the findings than were parents given results in person.[26] Another study revealed that parents given results over the phone were more likely to have lingering distress, anxiety, worry, and misinformation. Parents themselves appeared aware of these problems and most felt that they had received unclear or inadequate information.[35]

Communication skills are essential in delivering bad news and medical education research increasingly focuses on the effects of building such skills. For example, nine junior residents at the University of

Melbourne were given two scenarios to role-play with a simulated parent/actor. Residents gave difficult news to the parent and then received feedback on their delivery. The interaction was recorded so that interactions could be reviewed by another simulated parent and a pediatrician. The video ratings helped clarify "parent-centered" communication skills: asking about support, encouraging the parent to ask questions, and repeating key messages that parents may forget when hearing bad news.[36]

An analysis of ten feedback sessions with parents of children with developmental disabilities illustrated better outcomes when parents received forthright information.[37] Some researchers report that take-home audiotapes help families process information and aid their ability to share results with others.[38] A study on mothers' preferences about breaking bad news found that a one-size-fits all approach does not work well for all. A study of 402 mothers participated in a study of preferences for delivery of difficult information (via a hypothetical diagnosis of Trisomy 21). The mothers showed moderate agreement (via Kruskal–Wallis non-parametric one-way analysis of variance) that bad news should be given as early as possible (K=0.48), in detail (K=0.52), in person (K=0.58), and in a quiet setting (K=0.53). Having both parents present was preferred but with weak levels of agreement (K=0.29). Having a known person present for support, to have close bodily contact with their babies, and to have no other patients present had extremely weak agreement in this study. Parents agreed on the value of defining in advance their preferences about receiving difficult news (K=0.36). Because preferences for delivery of a problematic diagnosis lack consensus across parents, identifying preferences in advance and keeping these in the medical record may be useful.[39]

Other studies viewed positive and negative factors in delivery of a Down Syndrome diagnosis and rendered a number of helpful recommendations leading to the PACE strategy [Planning, Assessing, Choosing (the optimal strategies), Evaluating and Understanding].[40-42] These are summarized in Table 8-1.

Table 8-1. Summary of Recommendations for Conveying Bad Medical News to Parents

1. Private, appropriate location;
2. News given by clinician most responsible for the management decisions;
3. Both parents informed together and directly;
4. Parents informed as soon as possible after diagnosis/change in condition;
5. Consider having infant/child present;
6. Adequate uninterrupted time for questions and discussion;
7. Private location provided for family reflection and discussion after the encounter;
8. Follow-up call and interview arranged (within days);
9. Written information on the condition and resources provided;
10. Contact information provided for questions and support.

Even with adequate information, parents may still have difficulty following through with recommendations and results. One study showed that single parents, with limited incomes and multiple adversities (indeed those most likely to have children with substantial behavioral problems) were the least likely to seek and receive services.[43] Many such parents had trouble "negotiating the system," especially if non-English speaking. These families clearly benefit from assistance with referrals.[44] Other parents felt problems would get better on their own or that parents should be able to handle problems independently. Providers should educate parents and positively influence their attitudes about help-seeking.

IX. Encouraging Follow-Through

Schonwald and colleagues found that only half of parents with children who had been referred due to problematic screening test results followed through with recommendations. These researchers discovered that if appointments were made for parents, families were more likely to complete the recommended evaluation.[44] Additional reasons for limited follow-up rates may be that parents need some time to process the information given to them (and discuss with other family members). Parents may wish to try harder at home before seeking services. Some parents view special services as only for children with substantial and obvious difficulties and may not realize there is a continuum of problem severity

and interventions (e.g., therapists coming to the home, daycare, Head Start or regular classroom). It is essential for providers to: inform families about what is available (see Chapter 1 for more information); assist parents with referrals to specialists and early intervention services; and check on progress and uptake as part of the longitudinal screening/surveillance documentation clinics should provide.

Parent Take-Home Summary Reports

Figure 8-1 shows a sample summary report automatically generated by an online screening service. It describes the screens administered, the results, recommendations, a request to share the referral with recommended services, as well as receive information back from these programs. Table 8-2 provides a dictation template (or a fill-in-the-blank letter) that can be customized for each clinic. The template is downloadable at *www.pedstest.com/TheBook/Chapter8* (in a modifiable version in both English and Spanish). Whether using an online service or a template, the specific local programs recommended (e.g., brochures) need to be attached to the summary by each office. See Chapter 5 for live links to service options (or *www.pedstest.com/TheBook/Chapter5*).

Figure 8-1. Sample Parent Summary Report Generated from an Online Screening Service

About the Results of your Child's Screen

Dear Parent,

On **02-05-2013** we administered to **Peter Piper**, born **04-06-2011**, several highly accurate brief tests of learning, development and behavior. These include: Parents' Evaluation of Developmental Status" (PEDS), the Modified Checklist of Autism In Toddlers (M-CHAT) which is a measure of social skills and understanding everyday language) and PEDS: Developmental Milestones (PEDS:DM).

Peter performed well on the PEDS:DM which suggests progress in **Fine Motor, Receptive Language, Expressive Language, Gross Motor, Self Help, Social Emotional**. But your concerns along with Peter's difficulty on the M-CHAT suggest that further testing is needed. This office will make several referrals starting with a program that will not cost you and will lead to recommendations for any no-cost programs for which Peter may be eligible.

In addition, this office would like to have Peter seen by a service that specializes in autism spectrum disorder to decide if Peter needs special help learning to understand others.

We would also like to make sure that Peter gets vision, hearing and lead screening to make sure there are no problems in these areas, and address any health questions you may have.

We would like your permission to send the results of today's testing to the services we are recommending. We would also like your permission to receive information from them on the additional testing they do and the recommendations they have for helping Peter.

We would also like to give you information on things you can do at home to help your child learn. If you have access to the internet, you will find helpful links at www.pedstest.com.

Sincerely,

Provider

_____

Clinic

Table 8-2. Sample Parent Summary Report/Dictation Template for Screening Tests

---

(PRACTICE LETTERHEAD)

_____ _____ _____

date   date of birth   child's name

Dear Parent(s),

During today's visit, we looked carefully at how your child is learning, developing and behaving. _____ seems to be doing well in:

        (child's name)

__Using hands and fingers to do things
__Listening and understanding
__Talking and speech
__Using arms and legs
__Learning to take care of himself/herself
__Getting along with others and behaving
__Learning preschool and school skills

We had concerns about how he/she is doing in these areas:

__Using hands and fingers to do things
__Listening and understanding
__Talking and speech
__Using arms and legs
__Learning to take care of himself/herself
__Getting along with others and behaving
__Learning preschool and school skills

We would like to:

__Give you information on things you can do at home.
__Look at his/her learning, development and behavior more carefully.
__Screen his/her hearing, vision, and lead levels.
__Have your child seen by _____, _____ for tests of _____, _____.

If there are difficulties, good help is available. Getting help early is wise.

   __We have made an appointment for your child at (time) _____ on (date) _____
   at (service)_____ located at _____phone: _____
   __With additional appointments at (time) _____ on (date) _____
   at (service)_____ located at _____phone: _____

   __We ask you to make appointments for your child at (time) _____ on (date) _____
   at (service)_____ located at _____phone: _____
   __And also at (time) _____ on (date) _____ at (service)_____
   located at _____ phone: _____

   __This office would like to see you and your child in ___ month(s). We will look again at health, learning, and progress.

If questions come up before then, please contact me at _____

Thank you,

_____
___der

Chapter Summary: Explaining the results of screening tests differs substantially from explanations of diagnostic findings. With the latter, we have definitive information. With screens, we are only dealing with a high probability of a problem—but what kind of problem or even if there is a problem are not known. For example, even though the M-CHAT is a narrow-band screen focused on autism spectrum disorders, only 17% of children with failing M-CHATs and a failed follow-up interview, will actually end up with a diagnosis of ASD.[45] Most of these children will, nevertheless, receive a different diagnosis instead (e.g., speech-language impairment, intellectual disabilities) while others may have psychosocial risk, symptoms of neglect or abuse, etc. So even while screening test failures need to be taken seriously, a diagnosis is absolutely not advised.

But whether we are using diagnostic or screening measures, the settings in which we deliver bad news (e.g., face-to-face, sitting down) and the words we use are crucial in propelling parents to go forward with referrals. It is also critical we make sure parents leave our clinics with a written summary (as well as written patient information hand-outs), because some parents will try to work on the issue on their own rather than follow-through with referrals). We must remember that parents may need to explain findings to other family members and friends (who, just like professionals, really don't want anything to be wrong and thus may be quite dissuasive). Parents may be burdened by arranging their own referrals (although we know that clinic-arranged appointments have far better uptake rates), meaning that we should help parents with this task whenever possible and most especially if families are not English-speaking.[44] So, summary reports should carry a clear message, offer opportunities for review, and thus the repetition of information essential for new learning.

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Chapter 9: Screening and Surveillance with Older Children

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INTRODUCTION

This chapter covers brief methods for screening/surveillance with children and adolescents, 6- through 18-years of age. Many students are not yet identified because their deficits are either subtle or still emerging. In school-agers, difficulties can arise in a range of academic skills. Mental health problems may emerge for the first time and manifest in various ways (e.g., depression/anxiety, conduct problems, substance abuse, suicidal thinking, eating disorders, etc.). Described are methods for capitalizing on information collected routinely by schools. Such data has greater depth and richness than afforded by brief primary care screens. But when healthcare providers bring their clinical acumen to bear on school data (including longitudinal experiences with patients and families), causes and treatment plans can be carefully honed. When information from schools is unavailable, we provide quick tools for triaging academic and mental health difficulties and refining referral options. Finally, on the well-visit templates shown in Appendix A, we provide essential health-risk screens for adolescents: Risky behaviors are often a correlate of developmental and/or mental health problems.

WHY HEALTHCARE PROVIDERS SHOULD ENGAGE IN DETECTING PROBLEMS IN SCHOOL-AGE CHILDREN

Well-visits with school-age children are important opportunities to identify developmental-behavioral problems. Even though the chance for intervention in infancy and early childhood are long past, in school-agers new problems can arise and intervention is still invaluable. Prompt detection in the earlier grades may ameliorate or prevent long-term academic deficiencies. Ongoing screening of both academic and mental health issues is needed throughout the well-visit schedule: The American Academy of Pediatrics (AAP) recommends screening/surveillance continue beyond 30-months of age. The AAP periodicity schedule does not specify an age at which screening/surveillance should stop.

Timely identification of developmental/behavioral problems pays enormous dividends. Children whose learning, behavioral and/or emotional needs are identified and addressed become much more likely to remain in school and graduate from high school. Not only does academic success reduce much misery in the lives of children and their families, but academic success also generates terrific societal returns, primarily in the form of decreased rates of teen pregnancies, decreased criminality, and higher rates of employment. No single non-medical intervention does more good than efforts to facilitate school success.[1,2]

WHY HEALTHCARE PROVIDERS SHOULD COLLABORATE WITH NON-MEDICAL PROVIDERS

While many of the problems older children and adolescents face are educational in nature (e.g. learning disabilities, dyslexia, ADHD), it is unwise to rely entirely on the school system to identify these difficulties. Although teachers spend many hours with students, a classroom rarely avails the opportunity for working one-on-one with a child and family (imagine having 25 patients in your exam room!). Teachers work with each child only for a single year and rarely have healthcare providers' long-term knowledge of developmental-behavioral, medical and family histories that are helpful in identifying causes and needed interventions. Physicians have often known the child for many years and have a rich sense of the family's environment. Nevertheless, a partnership between physician and teacher represents an optimal alliance for helping a struggling child: Schools have long-term information on children's skills, but benefit from collaboration with clinicians on interpreting school test results.

Collaboration with teachers and other non-medical providers is critical because healthcare providers identify only about 50% of children with emotional problems.[3] Even when using quality screens, clinicians tend to refer only about 20% of those with positive results, often due to limited awareness of referral resources.[4] For example, it is not well known that school systems are one of the largest purveyors of otherwise hard-to-find mental health services. Collaborating with schools and other non-medical professionals cultivates clinicians' knowledge of community resources.

What Types of Difficulties Might School-Age Children Have?

In broad terms, the problems of school-agers often begin early in life as developmental deficits (e.g., language or cognitive delays, etc.) or behavioral-emotional/attentional difficulties. Left unattended, such problems tend to become co-existing conditions. It is hard to feel good about yourself if you are failing in school. It is hard to learn efficiently if distracted by depression, anxiety, anger issues, etc. It is hard to attend if you don't know prerequisite academic skills and thus don't understand what is being taught.

Developmental-behavioral difficulties (including social-emotional/mental health problems) are common and occur in 16% - 20% of school age children, as described in Chapter 1 and 2. In the early grades, such difficulties are hard to recognize without measurement. A child may appear to be attending in class but is, in reality, ruminating on difficult issues or day dreaming because instruction is too advanced, etc. Problems that begin as language or cognitive deficits quickly acquire secondary morbidities such as behavior problems or diminished emotional well-being.[5-7] And problems that begin as behavioral or social-emotional can quickly morph into language, intellectual or academic deficits. Our first goal is to prevent problems from occurring in the first place whenever we can (See Chapter 7). Our second goal is to prevent problems from acquiring co-morbidities and thus school dysfunction with its life-long adverse consequences.

HOW CAN PRIMARY CARE PROVIDERS IDENTIFY SCHOOL-AGED CHILDREN WITH EMOTIONAL OR DEVELOPMENTAL DIFFICULTIES?

School-age children are best identified and served by:

    I. Questioning Students and/or Parents.

    II. Gathering Existing Test Data.

        A. Reviewing standardized test results from schools ; and

        B. Deploying a decision-making algorithm to aid clinical reasoning;

    III. Annual administration of mental health screens (and use of in-office screens if data from schools is not available).

    IV. Referring to Appropriate Services.

    V. Working Collaboratively with Schools

I. Questioning Parents and Students

Parents and students may not realize that health care embraces developmental and emotional issues. Because encounters tend to begin with questions to students and families, exploring school performance and well-being is an essential first step. Open-ended questions work best and multiple questions are needed to elicit concerns (most particularly because school performance can vary across subject areas). Schools provide abundant feedback to parents and so almost all parents are able to describe their own as well as teachers' concerns. But asking is essential—parents with low socio-economic status are less likely than more educated parents to raise concerns spontaneously.[8,9]

Table 9-1 is a list of suggested questions to parents and students. Either or both sets of questions help elicit valuable descriptions about emotional well-being and school skills. Not all questions need to be asked if the student is doing well. But when school performance is problematic, additional questioning is needed. Note that closed-ended questions are ineffective with students (e.g., *"How is school going?"* will most likely be answered with *"Fine"* whether that's the case or not). Better lines of questioning are needed. For students who may be in trouble, asking multiple open-ended questions is necessary because children are often reluctant to reveal their weaknesses and woes unless you reveal your abiding interest in how they are doing.

Table 9-1. Suggested Questions to Students and/or Parents

QUESTIONS TO PARENTS	QUESTIONS TO STUDENTS
Please tell me about how he/she is doing in school?	Please tell me what's up with you at school.
Do you think he/she is doing as well as most students?	How do you think you're doing compared to other kids?
Are any subjects giving him/her trouble? If so, which ones and why?	What kind of grades are you getting in (*probe each subject*)?
What kinds of grades is he/she getting in each subject?	What's your favorite subject?
Does your child do better with homework or with tests?	Why is (*favorite subject listed above*) your favorite?
How long does it take him/her to get homework finished?	Are there any subjects you don't like?
Can he/she get homework done on his/her own or do you have to help him/her a lot?	What are you studying right now in (*probe a few subjects*)?
Where does he/she study? Is there a TV or music playing?	Do you do better with homework or with tests?
Is he/she organized? Bring home the right books? Use an assignment sheet? Put his/her homework in the right place or have trouble finding it?	Do you ever study for a test but then find you can't remember things the next day?
How does he/she study for tests?	How often do you get your homework finished?
What does he/she do after school (*may need to probe for each day of the week*)?	How long does it take you to do your homework?
How much time do you spend each day helping with homework or test preparation?	How often do you need help with your homework?
Do you have enough time for your other children (*if any*)? Is helping with homework or preparing for tests interfering with family life?	When you are doing homework is the TV on?
After studying for tests, does your child remember and perform well on the test?	Do you ever forget to do your homework? Do you do your homework but sometimes can't find it? Forget to take home the right books?
Does he/she try to avoid going school? How many absences on average each month?	What are your favorite subjects? What are your least favorite subjects?
Does he/she like to read?	How do you study for tests? *(If an older student and more info needed, ask),* How do you study for math, spelling, or foreign languages? How do study for history, science or English?
What are his/her favorite things to do?	What do you do after school (*may need to probe for each day of the week*)?
Does he/she have a very close friend with whom he/she plays or does things with a lot?	How often do you try to get out of going to school?

table continues...

Table 9-1. Cont'd

Does he or she get teased a lot?	Do you like to read? Do you ever read just for fun?
Did he/she start kindergarten on time? Has he or she ever been held back in a grade(s)? If so which grade(s)? Ever tested to see if more help is needed?	What are your favorite things to do? Have you thought about what you'd like to be when you grow up?
Has he/she ever gotten in trouble in school? If so, what for?	Do you have a good friend? What kinds of things do you together?
Which subjects is your child doing best in? Worst in?	Do you get teased a lot at school? If so, what for? Do you tease others? *If yes*, What about?
Does your child have a TV or computer in his or her room?	Have you ever gotten in trouble at school? If so, what for? How often?
How long does your child sleep from bedtime to wake up time? Is there time for breakfast?	Have you ever had to stay back (repeat) a grade?

Table 9-2 is a sample of parents' and students' comments associated with school difficulties.

Table 9-2. Red-Flag Comments from Parents or Students

- Inconsistent performance/does better one-to-one
- Poor retention of information
- Has been held back a grade (or entered kindergarten late)
- Excessive parental involvement in homework or tests/Takes too long to complete homework
- Loss of self-esteem
- Dropping grades
- Does less well on tests than homework
- Does not always finish homework
- Loses homework
- Short attention span/hyperactivity
- History of speech-language problems, therapy, otitis media with fluctuating hearing loss
- Frequent school absences
- Previously tested but not eligible for special education
- Hates school/school phobic/psychosomatic symptoms
- Hides school work/lies about assignments/loses homework repeatedly
- Trouble with letter sounds or letter naming
- Hates to read/reads very slowly
- Reads well but doesn't take in information
- Trouble with spelling or handwriting
- Makes lots of mistakes when reading or completing math problems (e.g., doesn't pay attention to signs in mixed computational tasks, consonant or vowel sounds when reading)
- Insufficient sleep, lack of breakfast before school, TV on while doing homework, TV or computer in bedroom
- More than 15 hours per week of extracurricular activities including after school jobs (and job-related travel)

Are Red-Flags Enough?

No! Supporting evidence is needed to triage problems, i.e., for acquiring an educated guess at the root causes and problem types so as to determine what kinds of evaluations, referrals or treatments are needed. Note that parents (and providers) have a particularly difficult time identifying mental health problems: Children may be smiling and attentive during an encounter but this may mask inherent difficulties. So the best approach is to measure mental health in your office and also gather information from schools on academic performance including data from group achievement tests. If school data is unavailable, other measurement options are described later in this chapter.

II. Gathering Evidence

A. Making Use of Existing Information From Group Achievement Tests

Developmental and mental health difficulties manifest across varied skill areas within school subjects: Reading (reading vocabulary, word attack skills, reading comprehension); Math (math calculations, math concepts/applications); Written language (handwriting, spelling, punctuation, capitalization and grammar); Knowledge (science, social studies, humanities); and Study/organizational skills. Measuring all areas is not feasible in primary care—it takes schools 3 – 9 hours annually or biannually to assess performance via standardized group achievement tests—while healthcare providers have 15 minutes or less, annually. Thus it makes sense for clinicians to gather evidence from schools whenever possible, and learn how to interpret results and triage potential problems.

Common Group Achievement Tests

The more common group achievement tests include the *Terra Nova* (formerly California Achievement Test), *Iowa Test of Basic Skills*, *Metropolitan Achievement Tests*, and the *Stanford Achievement Test*. Many states produce their own versions, increasingly so since the passage of *No Child Left Behind*.

All such tests reflect national curricular trends: Younger children are measured on prereading skills such as letter naming, while high school students are measured in multiple subjects including reference and study skills. Despite their length and scope, group achievement tests are considered screens, not diagnostic measures—meaning that they do not confirm disabilities, but instead suggest probabilities of problems and the various types of probable problems.

Which Scores on Group Achievement Tests Are Most Helpful?

Results from group achievement tests produce a wide range of scores, such as percentiles and stanines per subject area. Stanines are the most helpful statistic for screening because they divide the typical distribution (the bell curve) into nine equal parts. Stanines, unlike percentiles, enable a clear view of significant strengths and weaknesses:

- A **stanine of 1** is equivalent to percentiles ≤ 2, and includes all scores that are two or more standard deviations below the mean, i.e., substantially below average;
- A **stanine of 9**, corresponds to percentiles ≥ 98, and includes all scores two or more standard deviations above the mean;
- **Stanines 4 through 6** constitute the average range (although stanines of 4 are sometimes problematic);
- **Stanines 7 through 9** are in the above average range;
- **Stanines 1 through 3** are in the below average range;

Also note that **stanines 2 through 8** each account for one-half of a standard deviation. Any child whose stanines on individual subtests (e.g., reading, language, math) differ by more than two stanines has statistically significant test score scatter, which is often associated with learning

disabilities;
- A **stanine of 3** is equivalent to the 16th percentile. This is acceptable for head circumference, height and weight, but it is extremely problematic in a classroom where only a few children in a class of 25 - 30 will score in this low range. Instruction will not be geared toward their skill levels, and accretion of academic deficits is typical and problematic.

Figure 9-1. Performance Variations by Percent, Stanines, Percentiles and Ratings

		34%	34%		
	14%			14%	
2%					2%

Stanines	1	2	3	4	5	6	7	8	9

Percentiles   1   16   50   84   99

- - - - - - *Below average* - - - - - + - - - - - *average* - - - - - - - - + - - - -*above average*
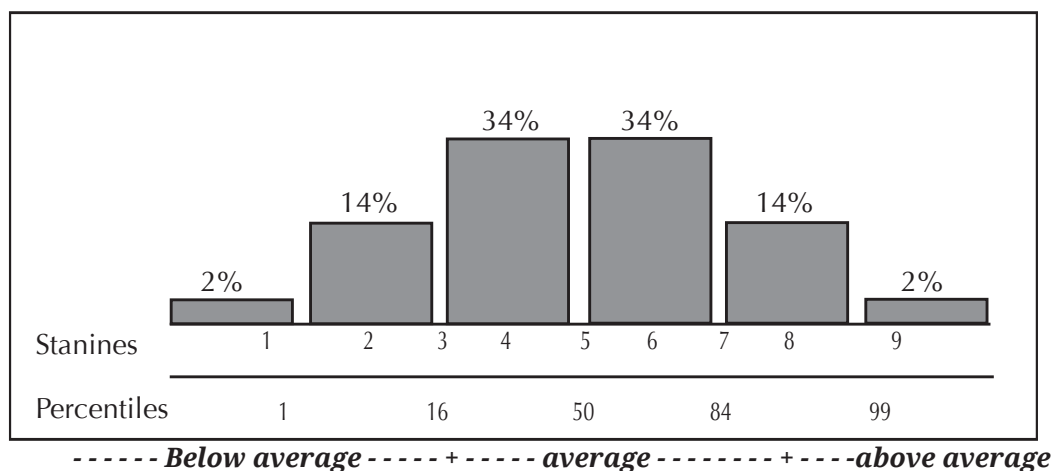
A Case Example

Emily Bliss, age 12, was seen in my clinic for a well-visit. Her parents expressed concerns about her poor performance in the rigorous private school she attends. The curriculum was understandably challenging and her parents wondered whether she had the necessary academic skills to keep pace with her peers.

Mrs. Bliss reported that Emily took an excessively long time to complete homework, that she had failing grades in her foreign language class and that she was increasingly despondent about her ability to do well in school. Emily herself commented, "When we have silent reading assignments in class, I am always the last to finish."

As with all my patients, I ask parents to bring copies of group achievement test results administered by the schools. Emily's 6th grade Stanford Achievement Test scores are shown in Figure 9 - 2.

From Emily's scores, I could discern that her overall performance was in the average to above average range—meaning she should be able to keep up in a challenging private school. Her highest stanine (of 9) suggested she was probably quite bright. But her stanines across subtests were significantly scattered and spanned more than 2 standard deviations. Her glaring weakness was in word-study skills, also known as phonics or decoding—i.e., knowledge of letter sounds and blends, syllabication, and recognition of common prefixes, suffixes, and word roots. (With older students, word attack subtests are not always included in the group achievement test battery, but low scores in spelling often indicate weaknesses in phonics.)

My thoughts were that Emily's struggles with French probably reflected a weakness in word analysis: Romance languages require associating new sounds with letter combinations such as "au" "ou", etc. Because group achievement tests are timed, Emily's relatively low score in reading comprehension but high scores in vocabulary, social studies and science were likely due to a slow reading rate as Emily herself reported. So my working hypothesis was that Emily probably had a learning disability in basic reading skills, i.e., dyslexia.

Figure 9 - 2. Emily's Group Achievement Test Scores (Grade 6)

SUBTEST	STANINE	PERCENTILE
Word Study Skills	4	23
Reading Comprehension	6	64
Vocabulary	8	94
Listening Comprehension	6	70
Spelling	6	69
Language	6	73
Concepts of Number	8	95
Math Computation	7	77
Math Application	6	76
Social Science	9	96
Science	5	48
Using Information	7	85
TOTAL READING	5	41
TOTAL LISTENING	7	85
TOTAL LANGUAGE	6	74
TOTAL MATH	7	86

I referred Emily for a psychoeducational evaluation (meaning measures of intelligence, academic skills). The school psychologist proved my suppositions correct. Emily's intelligence score was high (IQ of 128), but she performed more than 1 standard deviation below average in decoding skills, i.e., she had mild dyslexia. Unlike many less capable students, she had learned to compensate for her decoding difficulties by guessing at unfamiliar words based solely on visual appearance (e.g., substituting "curtains" for "cutaneous"). When her guess failed to make sense in context, she had to reread the sentence and guess again. As a consequence, she took 2 - 3 times as long as most students her age to read through a paragraph. The psychologist recommended tutoring once or twice per week in word attack skills.

After 4 months of tutoring, Emily's decoding ability and reading rate improved substantially. Subsequent achievement test scores showed marked improvement in all academic areas (group achievement tests are timed and faster readers are able to complete all items). Emily's grades rose and she eventually matriculated to a prestigious university and then to graduate school (although French never became a strong suit)!

So, group achievement scores together with carefully questioning Emily and her mother, gave me great insight into the nature of her difficulties and reflected what was discovered on further testing. As a clinician, I find great value in gathering existing information (including seeking teachers' opinions). Such data gives me greater insight into the types of challenges facing school-age children than I could measure on my own, and helps me better determine evaluation and service needs.

B. An Algorithm For Triaging Problems In School-Age Children

Emily's case provides an example of one predictable profile, that of a child with a learning disability in reading, i.e., dyslexia. In the algorithm shown in Figure 9-3 are six profiles visible within group achievement test results, representing different but common problems. Following the profiles are seven issues to explore when performance on group achievement tests is adequate but grades are poor.

Six Problem Profiles on Group Achievement Tests

1. Below average performance in most areas suggests slow learning (stanines ranging from 1 – 3 to 4). A referral for psychoeducational and language assessments is warranted. This can be obtained privately or through the schools, and facilitated if pediatricians screen vision and hearing. These results should be included in a letter requesting evaluations and then sent to the school's department of psychology and/or special education. Nevertheless, many slow learners (e.g., IQ between 74 and 85) do not qualify for special education assistance through the schools
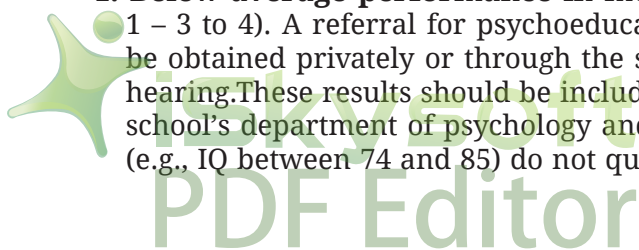
due to omissions in Federal and State laws. For such students alternative services are: Chapter I Reading and Math (Federally funded remedial programs available in schools where the average family income is low); after-school tutoring (often freely available from community centers and volunteer literacy programs, Boys and Girls' Clubs, etc.); summer school; and vocational training during high school. See Chapter 10 for preventing academic delays.

2. **Above average performance in most areas** (with at least some stanines of 8 and 9) suggests academic talent or giftedness. Schools usually have a range of services for such students although psychoeducational testing is needed to determine eligibility. Services include magnet schools, programs for academic acceleration, enrichment programs, parenting groups, and community mentors. Skipping grades is unwise. Although bright children have advanced intellectual and academic skills, their social and motor skills remain inevitably closer to chronological age— meaning that such children will be noticeably awkward compared to classmates who are chronologically older.

   Parents often feel their bright children are "bored in school." It is important to know that bright children, by nature and by virtue of above-average test scores, are clearly learning on their own. Nurturing giftedness is important via special activities, mentoring, and public school services. Bright children and their parents should be redirected into finding independent learning activities (e.g., taking books of interest to school to supplement topics of instruction, helping less able children, etc.). Children need to know that "bored" is something of a 4-letter word!

3. **Deficits in word analysis or spelling** (2 or more stanines below performance in other areas) suggest a learning disability in basic reading skills, (e.g., dyslexia as described in the case study above). A referral is needed for psychoeducational testing (meaning intelligence and diagnostic evaluation of academic skills focused heavily on basic reading skills including decoding, sight word vocabulary, reading comprehension and reading rate). Interventions may include special education services in the public schools, usually in the form of resource services. For children who do not qualify for IDEA (see glossary of terms at the end of this chapter) private, individualized tutoring is needed.

   Note that dyslexia is not a problem with ocular motility or saccadic eye movements.[10] Although some optometrists recommend visual-perceptual training to reduce reversal errors (which are rare after seven-years of age), the real reason most children read "backwards," such as "saw" for "was" are:

   (a) Deficits in phonics (meaning sound-symbol association) including difficulty swiftly recognizing common phonograms within words (e.g., –ing, -ed, -ame, etc.);

   (b) Problems mastering the organizational skills required for reading, i.e., left-to-right and top-to-bottom sequencing (the common direction in which Western languages are read);

   (c) Difficulty attending to details.

   Intervening in dyslexia needs to focus on systematicity in phonetic analysis (including decoding from left to right). Dyslexia and other types of learning disabilities (shown below) are associated with co-morbidities, particularly ADHD and mental health. "Failure is not happy-making" and no one, whether adult or child, can attend to content for which they lack prerequisite understanding. Careful follow-up after appropriate interventions into learning disabilities are initiated, should focus on attentional and affective issues.

4. **Deficits in reading comprehension and general information** (2 or more stanines below performance in other subtests) suggest language impairment. Refer these children for both psychoeducational and language evaluations. At risk are patients with otitis media with fluctuating or stable monaural or bilateral hearing loss or a history of speech-language difficulties. Those who have been dismissed from speech-language services are also at risk because language skills

Figure 9-3. Decision-making Algorithm for Interpretation of Group Achievement Test Scores, Report Cards, and Red-Flags from Parents' and Students' Comments

Screening Children for School Difficulties

Elicit Parents' Concerns

Yes? → Screen or Refer for screening

No? → Monitor progress

Obtain Test Scores

Yes? → Screen or Refer for screening

No? →

No? →

Analyze Stanine Patterns

Average? →

1. Low Word Attack/ Spelling, or Math? → Suspect Learning Disabilities → Refer for Psychoeducational Testing, Tutoring, Classroom Modifications

2. All low → Suspect Slow Learning → Above, plus speech-language and private/community services if not eligible for special education

3. All High → Suspect Giftedness → Refer for Psychoeducational Testing, Extra-Curricular, Parent Support Classroom Modifications

4. Low Reading Comprehension and/or General Information → Suspect Language Impairment → Refer for Language and Psychoeducational Testing

5. Low Applied Math and/or Reading Comprehension → Suspect Emotional Problems → Refer for Family/Individual Counseling and Tutoring

6. Wide Scatter Over Time or Deficits in Written Language → Suspect ADHD with Learning Disabilities → Refer for Psychoeducational Testing, Tutoring, Consider stimulant Medication, parent training/support

Explore Other Factors and consider tutoring, alternative placements, retention, counseling, medications, etc.

Setting too difficult?

Recent Life Events?

Frequent Absences?

Young For Grade? No? →

Previously Retained? No? →

Poor Study Skills/Lack of Motivation? No? →

ADHD without learning disabilities? No? →

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sometimes plateau when therapy is discontinued.[11]

These youngsters may not have visible problems until third grade or so, which is when children begin "reading to learn" and not just "learning to read." In 3rd grade, children are, for the first time, required to read written language commensurate with spoken language. Consequently, deficits appear in most or all subtests that have high language demands (e.g., science, social studies, math concepts and reading comprehension). Recommended interventions include language therapy and resource services with consultation between the language therapist, home, and regular class. Private language therapy, if affordable, may further speed progress.

5. **Deficits in math concepts and/or reading comprehension** but not general information (2 or more stanines below performance in other subtests) suggests emotional/family difficulties. High general information scores suggest that understanding of language is not the problem. Lowered math reasoning and reading comprehension scores reflect difficulties with tasks requiring concentration. A child who is preoccupied with worries, or has the ruminant thinking characteristic of depression or anxiety disorders cannot sustain focus on lengthy tasks requiring manipulation of ideas. Such children often daydream in class and their school history usually includes declining school performance over a period of years—often after divorce, bereavement, bullying, family history of mental health or other psychosocial problems, frequent moves or exposure to traumatic events. Nevertheless, mental health problems remain hard to detect, and so it is wise to routinely use a mental health screen with all school-age children.

Referrals should include evaluations (which the schools can provide without charge) of intelligence, language, emotional well-being, and language skills. A language evaluation is wise because the overlap between emotional well-being and language impairment is striking, with some research showing that 50% of children presenting to psychiatric clinics have both language impairments and mental health issues.[12] After confirmatory testing, services should include mental health, academic intervention, and language intervention as needed. Note that public schools can provide some, although often minimal mental health services (e.g., via the school guidance counselor). Alternatives are family and/or individual counseling.

6. **Deficits in language mechanics, math computation, and/or wide, inconsistent scatter in scores across several school years,** suggests ADHD. These children do not do well on tasks requiring attention to detail (e.g., spelling, capitalization, punctuation, noun-verb agreement in written language, signs in mixed math computations). Random gains or losses in scores over time can also reflect inconsistent attention. It is not uncommon to see performance in the same subtest over time jump from a stanine of 2 to 8 and then to 4, all in the absence of intervention. This suggests students paid attention some years to some tasks but not to others.

Other characteristics of ADHD (and also many learning disabilities) are obtainable by parent/student questioning. Answers include: Loses homework, doesn't always write down assignments, partial completion of assignments, makes numerous careless errors and fails to double-check his or her work, doesn't bring home needed textbooks, can't find materials in school locker because it is a complete mess, etc. In sports or other recreational activities, comments include: Fails to keep "eyes on the ball," doesn't finish projects, etc.

Refer these children for psychoeducational testing through the schools due to the high concordance between ADHD and learning disabilities. If learning disabilities are diagnosed, students require special education (usually resource class services) and/or private tutoring. If learning disabilities plus ADHD are present, a combination of special services or tutoring plus medications for ADHD are needed.

If ADHD is the only diagnosis, tutoring/special services through the schools are still needed to build skills. Note that attention to detail and ability to organize are learned skills. Medication facilitates such learning, but skill training is still needed. Schools can provide some in-classroom services through Section 504 (see Chapter 1 for definitions of services) such as help creating assignment

sheets, making sure the right books are brought home, and devising behavior modification strategies. Healthcare providers should discuss medication management with families but should also stress the value of "learning to attend." Proper use of ADHD measures in confirming the diagnosis and for monitoring medication effectiveness (are discussed at the end of this chapter, along with mental health and academic screens useful when school data is not available.)

When Achievement Scores Appear Adequate but Grades are Poor:
7 Common Problems

There are times when, despite parents' and teachers' concerns, test results show at least average achievement across all subtests. In these cases, the chief complaint is usually poor grades. While this may seem paradoxical, grades, unlike achievement tests, reflect a student's effort (e.g., turning in homework, making good grades on classroom tests). But grades do not always indicate whether children are still learning. For example, a bright student who "goofs off" and fails to complete assignments or study for tests, may have an abysmal report card but superior test scores. He or she is learning but is not "performing up to potential."

Although poor grades may seem superficial, they are not benign. Poor grades can limit participation in extra-curricular activities, restrict post-high school options, and above all, contribute heavily to poor self-esteem, parent-child conflict, and family distress. To address reasons for poor grades in light of adequate achievement scores, consider each of the following explanations and obtain a thorough description of the nature of the student's difficulties. Teachers' observations are invaluable.

1. Has the child had frequent school absences? Children who miss more than 20 school days are at risk for school failure and those who miss more than 30 are generally nominated for in-grade retention. Children with chronic illness or trauma (or who have parents with similar problems) may miss a substantial amount of school but it will take a year or more for their problems to surface as lowered achievement scores. Primary care providers may be the only generalist among multiple specialists on a child's medical team, and thus have unique perspective on the ecology of children's lives. To prevent school problems, one or more of the following may be helpful:

- Prompt initiation of homebound services after hospitalization or serious injury;
- Frequent review of the continued need for homebound services (because intensity and frequency are minimal and students with academic challenges may become school-avoidant);
- Referrals for tutoring to make up for missed work along with summer school;
- When parents' health or well-being is a factor in school absences refer for social and mental health services (and ask permission to share information with parents' physicians);
- Children who miss school due to chaotic family lives or truancy benefit from the services of a social worker who may be able to help families provide sufficient structure and consequences. Family counseling is advisable, as is contacting the public schools' attendance officers. These professionals are skilled in a range of interventions to promote school attendance;
- Seek information from the American Academy of Pediatrics on managing children and families with chronic health problems (*www.medicalhomeinfo.org* and *www.dbpeds.org*);
- If a child requires medications at school (e.*g.*, an inhaler, stimulants, or psychotropic drugs), the school needs documentation from your office. See Table 9-6 for an example that is also downloadable at *www.pedstest.com/TheBook/Chapter9*.

2. Have recent life events adversely affected grades? Sharp declines in grades may be the only consistent indicator that a child is not coping well with recent life events such as divorce, a death in the family, psychological trauma, etc. Left unattended, poor grades may result in a diminished rate of learning and lowered achievement in subsequent school years. Prompt referrals for mental health services (including school guidance counseling) following a difficult life event can prevent a downward spiral. Services may

include specialized support groups (e.g., on bereavement or divorce). Short-term individualized tutoring is also beneficial in supporting a student during a time of understandable emotional distractions. Public schools often provide a range of mental health services, although quality and intensity vary.

3. Is the child an average learner in a school that demands above-average performance? In most private schools and some suburban public schools, the average achievement of enrollees is at the 6th to 7th stanine (65th to 80th percentile). Students in the most rigorous private schools often need to score even higher to be considered average. In such schools, students whose achievement scores hover around a stanine of 5, will be performing near the bottom of the class. Such children can sometimes be successfully maintained in an overly-challenging school with some of the following modifications: A reduced course load (which may require summer school or an extra first grade or senior year), private tutoring, use of a tape-recorder or word-processor in class, and parental tolerance of B's and C's. Even with such modifications, children may spend an inordinate amount of time on homework, tend to be excluded from worthwhile extracurricular activities due to poor grades, and develop secondary emotional problems such as excessive anxiety, depression or loss of self-esteem. In these cases, a change in placement is an appropriate solution.

4. Are test scores misleading because of retention in grade? Norms for achievement tests are established by grade, not age. Older children who have been held back may have an automatic improvement in test scores (e.g., a rise from the 2nd to the 4th stanine). What appears to be adequate achievement may be a temporary artifact masking learning or language disabilities, slow learning, etc. Misinterpretation of current test scores can be avoided by obtaining scores from prior years along with a good educational history from parents. Table 9-3 covers issues in holding children back a grade also known as "redshirting," when it comes to delaying kindergarten entrance.

5. Is the child younger than others in his or her grade? This issue usually pertains to children 4- to 7-years of age whose birthdays occur in summer and early fall and who have not been retained, i.e., are younger than their peers. The difference in development between a 5-year, 0-month-old and a 5-year, 11-month-old is substantive; younger children tend to perform less well than older classmates. Young-for-grade children are often less mature and experienced. When such children have grade-appropriate skills but teachers and parents describe them as "young" or "immature," there is no justification for having children repeat a grade: In time, they will catch-up in lagging social and motor skills. Nevertheless exceptions may need to be made for highly competitive private schools where children may be routinely held back (or held out), usually in kindergarten. See Table 9-3 on issues in "in-grade retention."

6. Are poor study skills and/or lack of motivation a problem? These issues may arise with middle and high school students. Rarely are children taught how to organize their notebooks, manage their time, avoid distractions while studying (e.g., turning off the TV when doing homework), etc. Ask the student directly how he or she studies for tests, where and when homework is completed, the frequency and timing of extracurricular activities (a daily after-school event and most weekends is too much), whether assignments are always completed or often lost, whether the correct books are always brought home, whether they use assignment sheets, know how to create study guides for tests, how far in advance of a test they study (or start on essays and other long projects), what their locker looks like, and how they prepare themselves for tests. Equivocal answers should be construed as problematic (e.g., *"sometimes I forget"* usually means *"often"*). *"I ask my mom to quiz me"* is not an acceptable approach to test preparation. Older students should be able to describe different study techniques for different subjects: Daily practice and memorization is needed for math and languages; Study guides, outlines, and practice essays are needed for science, social studies, and English.

Sometimes the study skills issues of older students can look like ADHD (and ADHD may well be parents' and students' chief complaint). But, providers, after eliciting a thorough patient history, will see an absence of prior complaints about inattention and distractibility. In such cases, brief tutoring in study skills can often rectify performance problems.

Table 9-3. Issues in In-Grade Retention and "Redshirting"

- Holding children out of kindergarten for a year due to lack of readiness or "immaturity," is a phenomena sometimes called "redshirting." Redshirting is quite problematic because it is unlikely that "more of the same" will ensure mastery of needed skills. The AAP's Committees on School Health, Early Childhood, Adoption and Dependent Care suggests that children who perform poorly on readiness screening (imbedded in most broad-band tests), should not be excluded from kindergarten but rather enrolled as well as referred for more thorough evaluations from which appropriate placement decisions can be made;[13]

- If parents or teachers insist on "redshirting" make sure children are enrolled in pre-kindergarten programs with an emphasis on academic skills;

- Rigorous private schools sometimes recommend "redshirting" before entrance to kindergarten or first grade. Most children in such schools will be older than expected for grade. "Going with the flow" is acceptable but only if the child is enrolled in a preschool program (particularly one catering to children preparing to enter a challenging private school);

- Recommendations that "immature" children repeat public school kindergarten is unwise, assuming students have the requisite skills for success in 1st grade. Such children are usually young for grade but will catch up behaviorally with their older classmates;

- Schools, despite their enormous efforts to individualize instruction and carefully monitor progress, may still suggest in-grade retention for some children. Nevertheless, many of these children have undiagnosed disabilities. Healthcare providers should advocate for axiomatic referrals for psychoeducational and language evaluations. See the website for the National Association of School Psychologists (*www.nasponline.org*) for policy statements and supporting research;

- Even with psychoeducational testing in hand, some children (most often slower learners) will not qualify for IDEA services, and so teachers' recommendations for in-grade retention may persist. It is important to note that retention is strongly associated with high school drop-out and should be avoided where possible. Nevertheless, there is arguable evidence that retention in 1st grade can be helpful because it affords practice leading to, we hope, mastery of critical reading and other skills. Similarly, retention in 12th grade may offer a chance for maturation and increased competence with study skills, career orientation, etc. Even so, for any child who has been retained, it is critical to vigilantly monitor progress, continue to search for emerging disorders, and encourage extra help such as summer school, after school tutoring, etc;[14]

- Retention in grades other than 1st or 12th grades is not known to be effective because nominees usually have substantive gaps in learning (e.g., lack of mastery of first grade skills will not be aided by retention in 3rd grade because 1st grade skills will not be covered);[15]

- Even when psychoeducational evaluations rule out learning disabilities and support curricular repetition as helpful for mastery of basic reading skills, being held back in grade is often disturbing for children and parents. This can be dealt with by having the child participate in the decision and by brief counseling for families, i.e., present the pros and cons and facilitate a discussion;

- Retention should be avoided and can often be avoided if class sizes are small (approximately 15 – 20 students), when teachers have access to curricular materials appropriate for students working below (or above grade level), and are trained in methods for individualized instruction.[15] (See the Center for Development and Learning website, *www.cdl.org.*) Advocating for small class sizes by parents and providers is much needed.

Under-motivation is more challenging and may reflect habitual "power struggles" in the parent-child relationship: children's desire for autonomy versus parents' desire for accomplishment and perfection. Parents may provide excessive external structure and thus inadvertently reinforce dawdling and incomplete work rather than initiative and promptness. This struggle can diminish children's intrinsic interest in learning and create an unpleasant cycle of family conflict. Study skills tutoring, family counseling and parent training can teach parents (and students) how to encourage independent and responsible learning. Additional information on this complex and challenging problem can be found in Mandel HP, et al. *'Could Do Better': Why Children Underachieve and What to Do About It.*[16]

7. Is ADHD the cause? By holding out the issue of Attention Deficit Hyperactivity Disorder as the last consideration when children have good achievement test scores but poor grades, providers can avoid over-diagnosing ADHD. Short attention span may be a symptom of other conditions such as learning disabilities, slow learning, and mental health problems. Differentiating attentional problems as a symptom versus attentional symptoms as a cause, is critical for identifying optimal interventions. Physicians should keep in mind the compelling findings that ADHD most often co-occurs with other conditions such as learning disabilities or affective disorders, than it does without them.[17]

When nothing but ADHD explains school performance problems, the next step is to ask parents and teachers to complete instruments that can confirm this diagnosis. (See the section below on appropriate tools.) When clinicians, parents, teachers (and possibly students) all report symptoms matching criteria for an ADHD diagnosis, medication management and effectiveness monitoring are in order. Nevertheless, medications for ADHD only create a readiness to learn to attend. Medication should be combined with brief tutoring on organizational skills, optimizing study environments, and training in behavioral management as needed.[17]

Table 9-4. *How to Obtain Group Achievement Test Scores (and Other Information about School Performance)*

Below are different ways to obtain information from schools. At the end of this chapter (and downloadable at *www.pedstest.com/TheBook/Chapter9*) is a template for dictating a letter to schools requesting existing records:

- In advance of the visit, send parents a release form to sign and deliver to the schools in which they grant permission to share group achievement test results, special education testing, attendance records, and/or report cards. Be specific in your request so that schools know what you need. See the release and consent form (at the end of this chapter) as an example you can emulate;

- Consider establishing a two-way consent form between your office and the schools wherein you both agree to share needed information on health or other issues and the schools agree to share group achievement test results and copies of report cards. This will need to be negotiated in advance;

- Have office staff request records annually so that you have the information you need prior to any visit and as an indicator to encourage visit attendance;

- Ask parents to bring their copy to annual well-child visits during the school year (parents are rarely able to verbally describe scores in enough detail). But note that the version of scores sent to parents often lacks detail and so it is best to obtain the school's copy;

- Ask parents (if work and transportation permit) to go by the school and pick up a copy of school records;

- Have parents call the school while in your office and give verbal permission to report verbally test scores and other information. When calling, parents will need to speak to the school secretary, as records are usually stored in the front office and not with the child's teacher;

- If scores cannot be obtained (e.g., the student has recently changed schools), elicit parents' and students' concerns and contact one or more of the student's teachers. In addition, use one or more of the screening tools at the end of this chapter.

III. WHEN SCHOOL DATA IS NOT AVAILABLE

Every healthcare provider working with school-age children should have in their armamentarium of screening tools, measures such as the ones described below. Schools do not administer mental health screens routinely and so healthcare providers must take on this task. When group achievement tests cannot be procured (e.g., the student has recently transferred or schools are slow to deliver information), clinicians need available the following:

- A brief screen for academic skills;

- A psychosocial risk screen to determine family issues including parental depression that may well effect students' well-being and school performance;

- A mental health triage measure for sorting those with depression/anxiety, conduct disorders and other externalizing problems from those who probably have ADHD—these three conditions need very different treatment approaches;

- A diagnostic measure of ADHD for confirming whether ADHD exists and whether any medication prescribed is effective. Suggested tools are described below along with evidence for their use; and

- Health risk screens for adolescents.

Office-Based Screens

The psychometric properties of the screens described below are presented in Chapter 4. All are freely available in the public domain meaning that you may photocopy these tools as long as authors and attributions are shown. Most of these measures are shown in full at the end of this chapter along with scoring directions, downloadable at *www.pedstest.com/TheBook/Chapter9* (in English and Spanish) and are also included in *PEDS:Developmental Milestones* (laminated for reuse).

Academic Skills Screening

A helpful and brief measure for identifying academic deficiencies for children 6-years through 14-years (and helpful if parental literacy needs assessing) is the *Safety Word Inventory and Literacy Screener (SWILS)*.[18] This 29-item instrument is administered hands-on by clinicians or parents. The measure also introduces an opportunity for injury prevention counseling.

Psychosocial Screening

One of the root causes of academic deficits and mental health problems in infancy, preschool, elementary school and beyond, is psychosocial risk status. The *Family Psychosocial Screen (FPS)* assesses families for psychosocial risk factors (e.g., limited education, unemployment, housing instability, parental depression, substance abuse, domestic violence, presence or absence of social support, and parents' history of abuse as a children.[19] The *FPS* is often used at new patient intake to give clinicians a sense of a family's challenges and assets. The *FPS's* set of depression screening items (if not the entire measure) should be repeated periodically. The *FPS* and detailed information about psychosocial risk are presented in Chapter 10 (and downloadable in English and Spanish at *www.pedstest.com/TheBook/Chapter10*).

Mental Health Screening

Suitable for routine mental health screening, especially for children 6-years and older) is the *Pediatric Symptom Checklist (PSC)*. Thoroughly researched and carefully adapted, the 17-item version *(PSC-17)* and especially its pictorial version, the *Pictorial PSC-17,* are particularly helpful. Available in English and Spanish, the *Pictorial PSC-17* helps parents with limited literacy complete the measure successfully and its three-factor scoring system gives a richer picture of the potential causes of a child's distress. The *Pictorial PSC-17* factors include:

1. Internalizing—meaning a likelihood of problems with depression, anxiety, obsessive-compulsive disorder etc.;

2. Externalizing—meaning probable problems with conduct, oppositional-defiance, impulse control, rage disorders; and

3.   Attention problems, including likely ADHD with and without hyperactivity.

Although many clinicians jump into an ADHD diagnostic measure such as the *Vanderbilt Scale,* it is essential to use a tool such as the *Pictorial PSC-17* first to make sure that other potential mental health problems masquerading as ADHD, are ruled out and addressed. The *Pictorial PSC-17* is shown below in its parent-report version in English and downloadable (also in Spanish) on the website for this chapter. The full *PSC,* the *PSC Youth Self-Report* version, and its numerous translations can be downloaded at *www.massgeneral.org/psychiatry/services/psc_home.aspx.* If the attention factor is the only elevated score, then proceeding to the *Vanderbilt Scale* is recommended (and described below).

Health Risk Assessment for Adolescents

Whether or not psychosocial risk factors are present (e.g., poverty, domestic violence), most adolescent morbidity and mortality are related to mental health problems, academic failure and/or health problems. Risky behaviors and unhealthy decision-making are preventable and treatable. On the well-child visit templates in Appendix A (and downloadable at *www.pedstest.com/TheBook/AppendixA*), we include a guide to history-taking with adolescents including substance abuse and eating disorders screeners.

Diagnostic ADHD Scales

The *Vanderbilt ADHD Diagnostic Rating Scale (VADRS)* is a validated two-page questionnaire which is completed by a parent and a teacher.[20] The questionnaire asks about parent and teacher report for features of inattention and hyperactivity as defined by the *Diagnostic and Statistical Manual*. The *VADRS* also determines presence or absence of features of oppositional-defiant disorder and conduct disorder. The measure requires gathering information from both parent and teacher regarding classroom performance and behavior. When the diagnosis of ADHD is made and the child placed on stimulant medication, it is critical to recognize that stimulant medication creates only "a readiness to attend." If children with ADHD are also behind in school, tutoring or special services will still be needed. The *Vanderbilt Diagnostic ADHD Scale*, its parent-report version (in English and Spanish), the teacher-report version, and scoring for all three are downloadable at *www.pedstest.com/TheBook/Chapter9*.

A follow-up measure, *Pittsburgh Side-Effects Scale (www.nichq.org)*, is essential for monitoring medication side-effects and effectiveness. For some children, medications must be administered during school hours. For this to occur, a letter from your office is needed. Although schools may require use of their own forms, Table 9 – 6 is an example of requisite documentation (also downloadable on the website for this chapter).

IV. REFERRING TO APPROPRIATE SERVICES

Because school problems have varied causes, varied referral and treatment services are needed. Although we always want to refer to the public schools to see what help they can provide, some of our patients won't qualify. For these students, we need to consider other options. With many students, multiple interventions are needed (e.g., stimulant medication and tutoring). Below (with live links on *www.pedstest.com/TheBook/Chapter9*) is information about national services from which you can find local programs:

- When recommending evaluations for school-age children, call the school psychologist or speech-language pathologist in the child's school of zone or school district;

- For help locating mental health services go to *www.samhsa.gov;*

- Social services including domestic violence, child abuse and neglect, adoption, state, and local services, etc. can be found at *www.acf.hhs.gov;*

- For after-school programs and homework help, check with the child's school of zone, and visit the websites of the Boys and Girls Club (*www.bgca.org*), and the YWCA (*www.ywca.org*);

- For guiding parents in how to help children who struggle in school, visit the "Nobody's Perfect" site (*www.bccf.bc.ca*) or Kids Health *www.kidshealth.org;*

- Finding private tutoring is usually via "word of mouth." Teachers can often identify local tutors who can help with the curriculum used by each particular school. Although there are national tutoring services, these do not always address specific curricula, tend to have large class sizes, and are generally more expensive and less effective than individual tutoring;

- Avoid visual therapies or other optometric (or chiropractic) interventions. Reading problems are not caused by visual difficulties or jumpy saccadic eye movements (given appropriate acuity). If parents are invested heavily in such therapies, simply suggest adding a referral for testing by the schools and/or tutoring in reading.

V. Working Collaboratively with Schools

When working with children who have school difficulties, you will need to collaborate with schools for records requests, gather permission to share and receive information with teachers and diagnosticians, ensure your office has provided needed directives when medications are required during school hours, etc. Other communications with schools require creating effective referral letters and generating a summary report for parents to take home. A variety of templates are needed!

Requesting Records and Obtaining Parental Permission to Confer with Schools

When requesting records, it is wise to establish parental permission to confer with school personnel (and they with you). This may require working with schools on establishing a protocol for a two-way consent form. Schools must comply with Family Educational Rights and Privacy Act (FERPA) which is a much more rigorous mandate than is the Health Insurance Portability and Accountability Act (HIPAA). Table 9-5 provides a template for negotiating records requests and parent/school permission to discuss patients (downloadable at *www.pedstest.com/TheBook/Chapter9*).

Writing and Customizing Referral Letters and Parent Summary Report

Because healthcare providers often have more insight into family functioning and complications from a patient's or family's health history, providing the schools background information (e.g., in your referral letter) is invaluable (given parents' permission). Chapter 5 provides examples of referral letters and a template for dictation. Chapter 8 provides examples of parent summary reports and a dictation template. The templates can also be downloaded at *www.pedstest.com/TheBook/Chapter5* and *www.pedstest.com/TheBook/Chapter8.*

In general, schools tend to respond to requests for testing with a basic psychoeducational evaluation consisting of an intelligence test and a measure of school skills. So if mental health, self-help or language problems are a concern, these apparent difficulties should be mentioned specifically as a direction for further testing. Customizing your referral letter is often needed.

Documentation if Medications Must Be Administered at School

If a child needs medications during school hours, information from your office is needed. Many school systems have their own required forms. Although we provide a template in Table 9-6, it is wise to scour school system websites for their permissions templates and otherwise ask school personnel if they can send you a form.

Table 9-5. Records Release and Parental Consent Template

Provider:
Practice:
Address:
Telephone:
Fax:
E-mail:
Date:

To: Parents of (*name of child*)_____, (*birthdate*)_____
(*address*):_____, (*phone*)_____(*e-mail*)_____

To: School_____

As part of routine health care, we would like to review school records including:
      ___ Standardized academic achievement test scores
      ___ Any special education or Chapter I test scores
      ___ Attendance Records
      ___ Discipline records (if applicable)
      ___ Contact information for this patient's teacher(s)

We ask that (*check one of the following*):

   ___Parents request these records from the school and deliver to our office on or before your child's
   next appointment on (*date*): _____
   ___Schools release the above information to this office before (date): _____
   ___You provide teacher name and contact information:

Teacher name:_____ and preferred contact method:
   ___telephone
     telephone number _____
     best time to call: _____
   ___fax, fax number: _____
   ___e-mail, e-mail address: _____

If school records are not available, please contact our office.

We also request permission to communicate with school personnel about this child's difficulties and progress and to share our findings. You can contact us by (*check all that apply and complete contact information*):

   ___telephone
     telephone number _____
     best time to call: _____
   ___fax, fax number: _____
   ___e-mail, e-mail address: _____

Parent consent and signature:_____Date: _____

Please return this form to me, when completed, at the above address.
Sincerely,

_____

Provider

Cc: Parents

Table 9-6. Exampe of School Permission Form for Administering Medications

PERMISSION TO GIVE MEDICATION AT SCHOOL
School, School District, Address, Phone, Fax

_____

Student: Last Name_____ **First**_____ **Middle** ___ **Age**____ **Date of Birth**_____

**TO BE COMPLETED BY THE PHYSICIAN

Name of Medication	Dosage	Method	Approximate Time of Day	Reason

Side Effects:
_____
_____

Precautions / Special Directions: _____

If PRN medication, list symptoms: _____

Does the above medication(s) need to be evacuated with the child in the event of an emergency?

☐ Yes   ☐ No

Signature of MD or NP/PA & Supr. MD   Lic.#/Furnishing #
Address   Phone

**TO BE COMPLETED BY THE PARENT/GUARDIAN

My child is under the care of Dr. _____. I understand it is my responsibility as the parent/guardian to keep the school supplied with and informed of any changes in my child's medication(s). I, or a designated adult, will bring the medication to the school in its original container or prescription bottle. I also understand it is my responsibility to monitor expiration dates of all prescription or over-the-counter medications I bring to school. I authorize the school nurse to communicate with the healthcare provider when necessary.

I give permission to _____ School to administer medication

_____ (Name of school)

to my child, _____.

_____ (Print name of child)

Parent/Guardian (Print):   Signature of Parent/Guardian:

Address: Home Phone: Work Phone:

Date:

A new form is required every school year and if there are changes in the medication(s) or dosage(s).

* *Please pick up all medications from school site at the end of each school year. Medications not picked up will be discarded.*

UNDERSTANDING SCHOOL TERMINOLOGY

Schools, just like health care, have their own set of terms and an abundant variety of assessment methods. When you receive reports and recommendations, you will want to be familiar with the language used by school systems. To help you, we provide in Table 9-7, a glossary with definitions.

Table 9-7. Glossary of Common Terms in Measures Used by Public Schools

Criterion-Referenced Tests/Curriculum-Based Assessment (CBM)	Measures that define a child's progress toward mastery of specific skills (e.g., how many letters of the alphabet among the 26 can a child name?). CBM ties instruction to measurement of progress on specific skills.
Norm-referenced Tests (NRTs)	Measures that compare children to same age/grade peers (e.g., among 5-year-olds, what is the average number of letters named?). NRTs provide standard scores, age equivalent scores, percentiles, stanines or other numerical comparisons.
Response to Intervention (RTI)	RTI involves both criterion-referenced and norm-referenced comparisons to inform any needed changes to instruction, planning and monitoring of progress.
Psychoeducational Evaluation	A diagnostic battery consisting of norm-referenced intelligence and academic tests used to diagnose disabilities. Because tests of language, adaptive behavior (meaning self-help skills) and mental health are not routinely offered, clinicians need to suggest these when they seem needed.
Group Achievement Tests	Often administered over several days and requiring students to independently answer questions tapping various skills in reading, math, spelling, written expression. These measures produce a range of norm-referenced scores in which same-grade students are compared to the performance of their peers. Many group achievement tests are nationally normed but many States have developed their own—making it challenging to compare results when working with relocated students.
Individual Achievement Tests	These measures are administered by school psychologists or educational diagnosticians and enable norm-referenced comparisons to both same-grade and same-age peers, and produce a wide range of scores (e.g., quotients, age-equivalents, grade-equivalents, percentiles, etc.). Because such measures are individually administered, diagnosticians are optimally positioned to observe attentional, language, organizational, and often mental health problems that characterize various disabilities.
Authentic Assessment	As with criterion-referenced tests, authentic assessment (also known as direct, alternative or performance assessment) focuses on skill mastery but in the case of authentic assessment, the skills are "real-world" tasks. For example, a student's ability to correctly answer multiple-choice questions about how to cross a street is obviously less meaningful than demonstrating ability to actually cross a street safely!
Portfolio Assessment	Portfolios are a collection of a student's work samples that represent progress toward goals. Goals are collaboratively defined by students and teachers and also define the meaning of progress toward those goals. An example is a student who wishes to develop a resume that includes skills with Microsoft Word including typing rate and facility with various features of word processing. Portfolios and portfolio assessment are often used with older students, incarcerated youth and adults, etc.

Table 9-7. Cont'd

No Child Left Behind (NCLB)	Passed in 2002, NCLB required all schools to administer reading and math tests every year, and to increase the proportion of students reaching 100% mastery. Schools failing to keep pace are labeled as failing, and eventually their principals may be fired and staffs dismantled. The unintended effect of NCLB has been to encourage States to: lower standards, teachers to focus on test preparation and instruction in math and reading, and crowd out history, art and foreign languages. The mathematical impossibility of making all children average and the absence of provisions for preschool intervention programs contributed to the challenges within NCLB. Thus, in the Fall of 2011, States were allowed to apply for waivers to NCLB provided they established high and honest performance and accountability standards. The nature and generalizability of State-defined standards remains an ongoing debate, but current efforts by the Federal government now focus on pre-school intervention.
Common Core Standards	This national initiative works to define what students should be learning in each grade, with an eye toward real-world relevance, reflecting skills needed for careers and/or college. Not all States have adopted core standards but many have. More information can be found at *www.corestandards.org*.
Family Educational Rights and Privacy Act (FERPA)	Student/treatment records held by schools may not be shared without parental consent except in the case of healthcare emergencies.

Appropriate Billing and Coding for Reimbursement

Chapter 16 describes how to bill and code for visits involving developmental-behavioral screening. Also included are diagnosis codes appropriate for describing screening results with school-age children, and how clinic coordinators or other staff can determine preferred coding methods across various payers.

Chapter Comments: *The academic and mental health problems of children, especially for those who fail in school, loom larger and larger with time. The consequences are devastating and compounding. And so we must do our best to prevent problems by detecting and addressing these in the preschool years. But some children will still struggle and for them we need to quickly marshal services to improve their performance and well-being. The public schools and their panoply of services are the first best approach. But because many children with special needs don't qualify, primary care providers must be prepared to enlist other services (such as after-school tutoring, mentoring, summer school, Head Start, etc.).*

But first up, we need to know exactly which children are struggling. We can do this most easily if we establish two-way information sharing with schools or get parents to help retrieve information. When information from the schools is unavailable, we need a back-up plan, i.e., an arsenal of brief measures workable in primary care—together with the decision-support provided in this chapter, to help us reason through likely causes and into wise referral decisions.

Below are helpful tools also downloadable on the website: *www.pedstest.com/TheBook/Chapter9*.

```
┌─────────────────────────────────────────────────────────┐
│  Patient's Name_____                  │
│  d.o.b_____                                        │
└─────────────────────────────────────────────────────────┘
```

The Safety Word Inventory And Literacy Screener Scoring Instructions

Description: A 29-item measure of children's academic skills for children 6- to 14-years of age that can also be used as quick assessment of school performance while also acting as a springboard to injury prevention counseling. Normed on 934 children around the country, the *SWILS* is 78% sensitive and 84% specific to academic status in the areas of reading, math and written language. Items were donated by Curriculum Associates (*www.cainc.com*) publishers of the *BRIGANCE Screens*. We have not provided a Spanish translation of this measure because Spanish-speaking children in predominately English-speaking countries are exposed to English safety words and need to learn to read them.

Directions: Compute child's age in years and months. Present the *SWILS* items to the child and ask him or her to read each one. Stop after 5 words read incorrectly or not attempted.

Scoring Criteria: Do not give credit if emphasis is not on the correct syllable or if sounds or syllables are segmented without immediate self-correction (e.g., "warnING" is not credited because the child emphasized the wrong syllable while "WARN—ing" is also not credited due to segmentation—unless he/she reread spontaneously, rapidly and correctly).
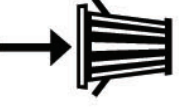
Give credit if the child reads or rereads the word correctly.

To decide if referrals are needed, use the following chart. Children scoring below cutoffs have a high probability of significant academic deficits. When making referrals to the public schools, document findings in writing and send to the school psychologist/director of special education as well as to the principal and include information on vision and hearing status.

SCORING AND DECISION CHART

Age Range Years - months	Date	Cutoff	Results	Decision Notes (e.g.,: no action needed, injury prevention counseling, referral, etc.)
6-0 thru 6-6		< 1	Pass Fail	_____
6-7 thru 6-10		< 2	Pass Fail	_____
6-11 thru 7-2		< 3	Pass Fail	_____
7-3 thru 7-6		< 5	Pass Fail	_____
7-7 thru 7-10		< 5	Pass Fail	_____
7-11 thru 8-2		< 12	Pass Fail	_____
8-3 thru 8-6		< 12	Pass Fail	_____
8-7 thru 8-10		< 12	Pass Fail	_____
8-11 thru 9-2		< 19	Pass Fail	_____
9-3 thru 9-6		< 24	Pass Fail	_____
9-7 thru 9-10		< 24	Pass Fail	_____
9-11 thru 10-2		< 25	Pass Fail	_____
10-3 thru 10-6		< 25	Pass Fail	_____
10-7 thru 10-10		< 28	Pass Fail	_____
10-11 thru 11-2		< 28	Pass Fail	_____
11-3 thru 11-6		< 28	Pass Fail	_____
11-7 thru 11-10		< 28	Pass Fail	_____
11-11 thru 14-0		< 28	Pass Fail	_____

Safety Word Inventory and Literacy Screener (SWILS)

GO	**KEEP OUT**	EXIT	**BEWARE OF DOG**	
NO SMOKING	Fire Alarm	*DANGER*	**Shake Well**	Don't Walk
Police	**Do Not Disturb**	*No Trespassing*	EMERGENCY FIRE ESCAPE	Warning
Emergency Exit	Please Use Handrail	Keep out of reach of children	High Voltage	Quiet Zone
Employees Only	Fragile	*POISON*	*Caution*	POISON
Flammable Explosives	DISCARD UNUSED PORTION — After expiration date of 6/10/00	RESTRICTED AREA		CAUTION: If swallowed, call MD or poison control center. Induce vomiting only if recommended by MD. Acids and lye solutions should be neutralized and **not** vomited.

Pictorial Pediatric Symptom Checklist- 17 Scoring Instructions

The Pictorial PSC-17 is for children 4- to 18-years of age and serves as an accurate quick screen for attentional, behavioral, and emotional/mental health problems. To score the Pictorial PSC-17, a value of 0 is assigned to "never [*nunca]*", 1 to "sometimes [*algunas veces]*" and 2 to "often [*con frequencia.*]" Groups of items (described below) are then summed to create factor scores. Totals can be placed on the parent-completed form or in the child's chart. If you need this measure in languages other than English or Spanish or wish to use the Youth Self-Report version go to *www.psc.partners.org* for downloads.

Assign a value of 0 to "never/nunca," 1 to "sometimes/algunas veces" and 2 to "often/con frecuencia." Then add the values for each set of items that produce the three Pictorial PSC-17 factors:

Factor 1: Attention Subscale consists of these five items:
1. Fidgety, unable to sit still [*Nervioso, incapaz de estarse quieto*]
2. Acts as if driven by motor [*Es incansable*]
3. Daydreams too much [*Sueña despierto con mucha frecuencia*]
4. Distracted easily [*Se distrae con facilidad*]
7. Has trouble concentrating [*Tiene problemas para concentrarse*]

Children who receive 7 or more points on these five items need a work-up for attention deficit hyperactivity disorder. With children 8-years or older administer the Safety Word Inventory and Literacy Screener since inattention can be a symptom of learning disabilities. The Vanderbilt ADHD Scale is a good choice for confirming possible ADHD.

Factor 2: Internalizing Subscale (meaning features consistent with depression and/or anxiety) consists of these five items:
5. Feels sad [*Se siente triste, infeliz*]
6. Feels hopeless [*Se siente sin esperanzas*]
9. Is down on self [*Se critica duramente a sí mismo*]
10. Worries a lot [*Se preocupa mucho*]
11. Seem to have less fun [*Parece divertirse menos que antes*]

Children who receive 5 or more points on these five items need to be referred for counseling and may also need to be considered for anti-depressants, anxiolytics, etc.

PSC Externalizing Factor (meaning features of conduct, oppositional-defiant or, rage disorders, etc.) consists of these 7 items:
8. Fights with other children [*Pelea con los demás*]
12. Does not listen to rules [*Desobedece las reglas*]
13. Does not understand others feelings [*No entiende los sentimientos de los demás*]
14. Teases others [*Molesta o se burla de otros*]
15. Blames others for his troubles [*Culpa a otros por sus problemas*]
16. Takes things that do not belong to him or her [T*oma cosas que no le pertenecen*]
17. Refuse to share [*Se rehusa a compartir*]

Children who receive 7 or more points on these seven items need behavioral/ mental health intervention and counseling with medication management if relevant.

Pictorial Pediatric Symptom Checklist - 17

_____   _____ _____
Child's Name   Date of Birth   Today's Date

Please mark under the heading that best fits your child:

1   Fidgety, unable to sit still

NEVER   SOMETIMES   OFTEN

2   Acts as if driven by a motor

NEVER   SOMETIMES   OFTEN

3   Daydreams too much

NEVER   SOMETIMES   OFTEN

4   Distracted easily

NEVER   SOMETIMES   OFTEN

5   Feels sad, unhappy

NEVER   SOMETIMES   OFTEN

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6 Feels hopeless

NEVER   SOMETIMES   OFTEN

7 Has trouble concentrating

NEVER   SOMETIMES   OFTEN

8 Fights with other children

NEVER   SOMETIMES   OFTEN

9 Is down on him or herself

NEVER   SOMETIMES   OFTEN

10 Worries a lot
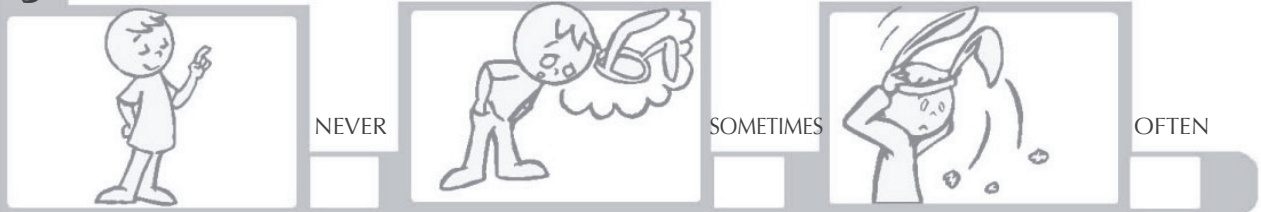
NEVER   SOMETIMES   OFTEN

11 Seems to be having less fun

NEVER   SOMETIMES   OFTEN

Keep Going! ➤

12 Does not listen to rules

NEVER   SOMETIMES   OFTEN

13 Does not understand other people's feelings ;
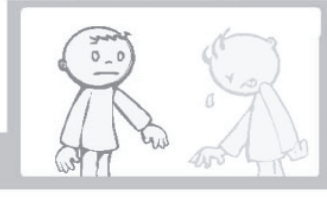
NEVER   SOMETIMES   OFTEN

14 Teases others

NEVER   SOMETIMES   OFTEN

15 Blames others for his or her troubles

NEVER   SOMETIMES   OFTEN

16 Takes things that do not belong to him or her

NEVER   SOMETIMES   OFTEN

17 Refuses to share
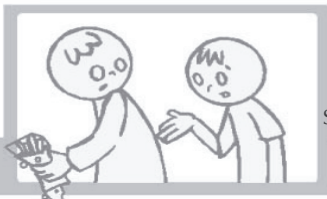
NEVER   SOMETIMES   OFTEN

For office use only

- -

Factor 1_____

Factor 2_____

Factor 3 _____

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Chapter 10: Psychosocial Risk, Language Development, and Bilingual/Dual Language Learners

Patricia A. Prelock   Maricela Dominguez Gulbronson
Tiffany Hutchins   Evelynne J. Green   Frances Page Glascoe

INTRODUCTION

In this chapter, we cover psychosocial risk and its adverse impact on developmental outcomes. Psychosocial risk takes a unique toll on emerging language skills. In turn, communication difficulties are the single best early predictor of problematic long-term outcomes such as school failure, high school dropout, and unemployment.

While psychosocial risk may be a cause of language delays, language difficulties are also inherent to almost all developmental disabilities including autism spectrum disorder, intellectual disabilities, orthopedic impairment (including cerebral palsy, traumatic brain injury), and learning disabilities (a communication problem focused on oral and written language difficulties). Language deficits can be a stand-alone condition or occur in the absence of other diagnoses.

Finally, there are predictable and typical delays in some aspects of language development when children are learning a second language or learning two languages at once. But often, children have a combination of the above three factors: psychosocial risk, bilingual/dual-language learning and developmental disabilities. Teasing apart the causes is important because interventions need to vary accordingly.

Language is a unifying thread across a host of developmental challenges, and thus language skills deserve the most vigilant and careful scrutiny in efforts at early detection. Sadly, language is the domain least attended to in primary care. This may be because we have an understandably intense focus on physical health and thus motor development or because the informal tools we often use are not up to the task of detecting language problems or because we don't prioritize language delays when we spot them. In any case, language problems are not only the most common of childhood difficulties, but are virtually impossible to detect without quality screening tools.

Some of the issues in this chapter touch on cultural differences among Americans of various backgrounds and languages. We also recommend reading Chapter 12 for information on working with diverse families. For specifics on quality screening tools, please read Chapter 4, and for a workable detection process, read Chapter 5.

CHAPTER HIGHLIGHTS

I.   Glossary of Terms

II.   Impact of Psychosocial Risk and Resilience

III.   Typical Language Development

IV.   Language Issues Across Developmental Vulnerabilities and Disabilities

V.   Red-Flags in Language Development

VI.   Acquiring English as a Second Language

VII.   Dual/Simultaneous Language Learning

VIII. Bilingualism With or Without Psychosocial Risk

IX.   Case Examples

X.   Recommendations for Early Detection of Language Problems in Primary Care

XI.   Developmental Promotion with Families at Risk or Multi-/Bilingual and Dual Language Learners

XII.   Referring for a Speech-language Evaluation

XIII. Resources for Parents and Professionals

I. GLOSSARY OF TERMS

Table 10-1. Glossary of Terms in Psychosocial Risk and Bilingual/Dual Language Learning

DEFINITIONS
Psychosocial Risk Factors Limited parental education, single parent status, parental mental health problems, problematic parenting style, large family size, frequent household moves, poverty, and ethnic minority/non-English speaking. Multiple psychosocial risks often lead to developmental delays.
Resilience Refers to protective factors, that even in the face of psychosocial risk help ensure typical development.
Simultaneous Language Acquisition Two languages are spoken to a child in early infancy; child develops both languages simultaneously in naturalistic settings with competence in both languages similar to monolinguals.
Sequential Language Acquisition (also Known as Bilingualism) Consecutive language learners encompassing different groups of children; typically used to describe children who speak their native language in the home and are later exposed to English in school or elsewhere in the community.
Language Delay The emergence of language that is relatively late, albeit typical in its pattern of development. Nevertheless, "catching up" is not guaranteed. Aggressive developmental promotion and intervention is essential.
Speech and Language Impairments Occur when a child has substantial language delays or disordered language development that may be acquired (e.g., result from illness, injury or environmental factors) or congenital and usually involve difficulty putting words together to form sentences.
Interference or Transfer Occurs when a child makes an English error due to the direct influence of their (non-English) first language.
Silent Period When children are first exposed to a second language they frequently focus on listening and comprehension, often remain quiet and speak very little while they focus on understanding a new language.
Code-Switching Involves changing languages within phrases or sentences, a common occurrence in bilingual speakers.
Language Loss or Subtractive Bilingualism Occurs when early language learners (ELLs) lose skills and fluency in their first language when it is not reinforced and maintained.
Additive Bilingualism A recommendation for instruction, i.e., that if ELLs are learning English, their first language and culture should be maintained and reinforced.

II. The Meaning And Impact Of Psychosocial Risk

Psychosocial risk refers to the many challenges facing children whose families have limited socioeconomic status (SES). Risk factors include parents with less than a high school education, who are single, have more than three children to care for, abuse substances, are victims of domestic violence, lack extended families to provide social support and advice, have mental health problems including depression and anxiety, are unemployed, homeless, have frequent household moves, are ethnic minorities or do not speak English.[1] Four or more such factors in families tend to generate a downward developmental spiral in children. In infancy, development is typical. By preschool there are substantial delays. By kindergarten entrance, children at risk are far behind their more advantaged classmates. This troubling progression leads to subsequent problems including grade-retention during elementary school, high school drop-out, teen pregnancy, unemployment and criminality. By the time children are 4-years-old, those with multiple risk factors tend to score at or below the 16th percentile in academics, and also on measures of other skills essential for school success (e.g., language, intelligence).[2]

Should providers worry about academic performance at or below the 16th percentile, given that the 16th percentile is normal for height, weight, and head circumference? Yes! In a classroom of 25 children, those performing at the 16th percentile and even up to the 25th percentile, are in the bottom fourth of their class. Teaching is aimed at the middle third of learners—usually the 33rd to 66th percentile and instruction will not resonate with children who are delayed and thus lack prerequisite skills. Children who arrive behind, tend to stay behind and to become further and further behind with time.

We know that smaller class sizes enable teachers to individualize instruction thus preventing in-grade retention and high school dropout.[3] But short of a Federal funding miracle, dramatic increases to the teacher workforce are unlikely. And because children's difficulties often emerge by 6- to 12-months of age, early prevention and intervention are the first and best lines of defense. So how do we spot children with developmental vulnerabilities due to psychosocial risk? How do we prevent problems from developing in the first place?

Parenting, Psychosocial Risk and Resilience

There are a number of distinct parenting behaviors associated with positive developmental outcomes. These include: communicative play and conversation (e.g., repeating a baby's sounds and modeling new ones; naming objects and people in which a young child is showing interest, i.e., actively teaching new words; and frequent book-sharing).[4] Indeed, the sheer volume of words spoken to children is a powerful predictor of cognitive and language skills.[5] But we also want parents to enjoy communicative play (and to sense their child is interested and responsive)—meaning we need to model and encourage happy interactions. Important for encouraging positive perceptions is helping parents learn to soothe their child when he or she is upset.[6] Even in the face of psychosocial risk factors positive parent-child interactions build resilience that protects against declines in developmental status.

Figure 10-1 shows the powerful nature of parent-child interactions in promoting development. Also visible are the consequences of problematic interactions and perceptions. When parents reported they rarely read aloud or commented on children's interests, felt their child did not enjoy communication, or was difficult to soothe, etc., children's developmental status dropped precipitously starting at 6-months of age (see lighter line with diamonds). In contrast those parents who talked with their children at meals, read aloud, and perceived their child as enjoying communication had strong, consistent and positive developmental outcomes (see darker line with squares).

The impact of psychosocial risk also speaks well to the various American Academy of Pediatrics' policies (described in Chapter 5) on early detection. Primary care providers, indeed all professionals who encounter young children, need to carefully counsel and monitor families in the face of parenting practices associated with less than optimal language development. If we focus on supporting and improving parenting skills, we can help prevent language delays that lead in turn to cognitive delays that result in ongoing academic problems, that lead to school failure, disenfranchisement, high school

dropout, unemployment, and most other adverse adult outcomes. We also need to intervene with parents' psychosocial risk factors (e.g., referrals to social services for assistance stabilizing housing, food, job training, mental health interventions, etc.).

Figure 10 – 1. Impact of Parent-Child Interactions on Developmental Status*†
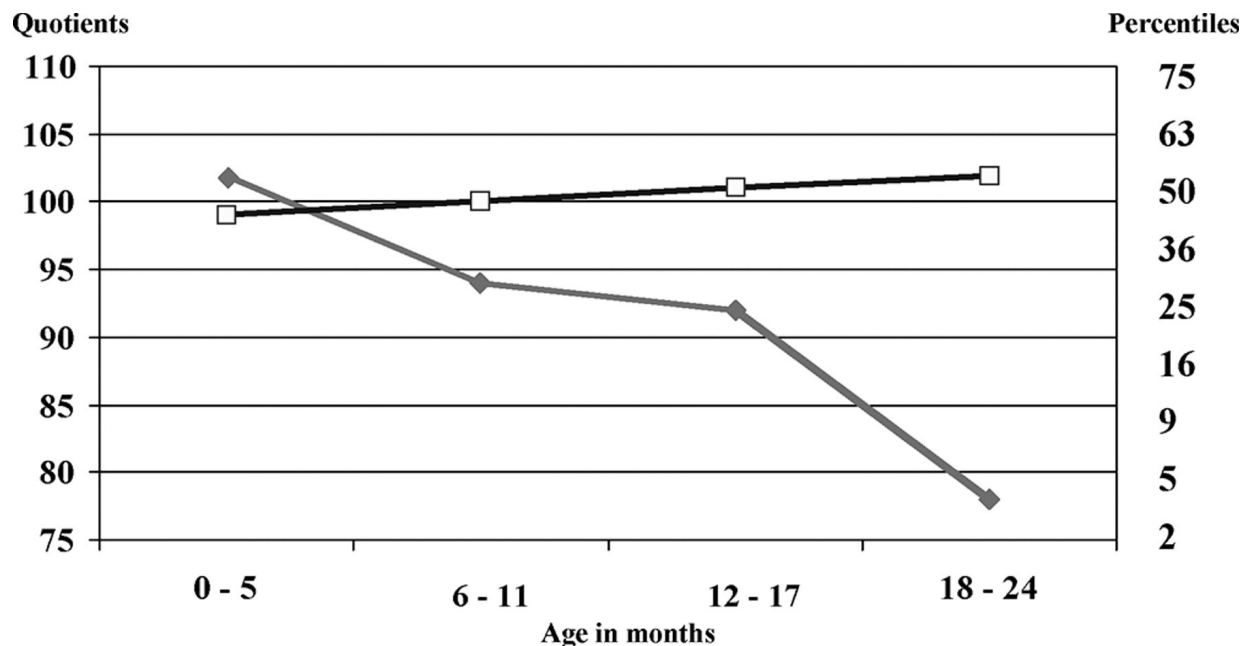
Parent's perceptions and parent-child interactions significantly associated with positive outcomes included 3 or more of the following: talking during meals, helping children learn new things, reading aloud, confidence in soothing, enjoying the child, and sensing the child as interested in conversing. Parents who reported fewer than 3 such perceptions or interactions had children who performed substantially lower on developmental measures.

† *from Glascoe FP, Leew S. Parenting Behaviors, Perceptions, and Psychosocial Risk: Impact on Child Development. Pediatrics. 2010; 125:313-319. Used with permission.*

Working with Parents Who Have Psychosocial Risk Factors, Including Those Who are Non-English Speaking or Have Literacy Challenges

Early detection and intervention with families with psychosocial risk factors is not always easy: Parents may have difficulty communicating in English and may have literacy problems in any language. These factors can lead to potentially difficult encounters involving:

Parents' Issues:

(a) Parents may not realize that primary care embraces non-medical issues and thus may not consider PCPs as helpful sources for child-rearing information;[7]

(b) Low SES families are not likely to raise concerns spontaneously—meaning that if providers don't ask about developmental-behavioral concerns, parents may not share their worries;[8]

(c) Parents with limited literacy may engage in "face-saving" (e.g., when presented with written questionnaires. They may just circle "no" to multiple choice questions and thus inadvertently threaten the validity of screening test results);

Providers' Issues:

(d) Clinicians sometimes assume that families with psychosocial risk are too consumed with day-to-day challenges to even notice when their children are behind;

(e) If unsure how to check on literacy, clinicians may give parents written forms to complete that families cannot read;

(f) Limited skills in dealing with language barriers (including how to determine whether translation services are effective in relaying the critical information);

(g) Finding parenting information or children's books in languages other than English or Spanish is an ongoing challenge for health professionals (although publications in other languages are increasing rapidly);

(h) Clinicians may be unprepared for the large increase in screening test failures if working with an at-risk population. In one study, 80% of children newly enrolled in Head Start performed poorly on screens;[9]

(i) Providers are often frustrated with referrals to IDEA because many children at psychosocial risk will not qualify. Clinicians may be unaware of alternative referral options.

Barriers to quality developmental-behavioral care are surmountable. At the end of this chapter are suggestions for handling the challenges presented by families with low SES and thus psychosocial risk. It is crucial to implement solutions for families whose children have developmental vulnerabilities because we can often prevent the downhill trajectory that leads to school failure, disenfranchisement, and poor overall life outcomes.

III. Typical Language Development

Because psychosocial risk takes a subtle yet burgeoning toll on language development and because deficits in language are harbingers of substantial problems in the future, it is helpful to become familiar with the increasing diversity and progression of language skills in typically developing children. In Table 10-2 we provide definitions for the many terms used by speech-language professionals. In Table 10-3 we list (approximately) 50th percentile milestones for receptive and expressive language skills by age.

Also included are social-emotional skills because effective communication depends on response to and expressions of affect (e.g., a smile, a raised voice, a head nod, a scowl). The emphasis and inflections we use in a sentence such as "*I did it.*" can convey very different meanings (e.g., an admission of guilt versus an exclamation about success and pride). Healthy language development is dependent on warm, responsive transactions with parents and these interchanges ensure that children learn to communicate meaningfully—express their own needs and feelings while also learning to understand and respond to the needs and feelings of others.

Note carefully that determining the adequacy of language skills requires measurement. Even the most seasoned of speech-language pathologists do not rely solely on clinical acumen, but instead carefully evaluate language ability. Discerning complex skills such as breadth of vocabulary, average sentence length, quality of grammatical constructions, or articulation prowess is not possible without measurement. In a brief well-visit that also includes an enormous health agenda, children's skills may be variably demonstrated if at all. A young patient may be ill, intimidated, crying, or even asleep. Screening tests, particularly those relying on information from parents, enable quick determination of the presence or absence of probable difficulties, even when children do not demonstrate the full compliment of their skills. Screens are, by nature, brief, so not all skills described in Table 10-3 are sampled by screening measures. But understanding age-related features of typically-developing language and concomitant social-emotional skills, helps providers understand the diverse and evolving nature of language, and thus the content of screening as well as diagnostic tools.

Table 10 –2. Terminology in Speech-Language Development

Receptive Language	Understanding of words, sentences, and gestures
Expressive Language	Use of words, sentences, sounds, and gestures to communicate
Articulation	Pronunciation of sounds and words
Proto-Declarative Pointing	Use of index finger to indicate to another person something of interest meaning, "*Look at that.*"
Proto-Imperative Pointing	Use of index finger to indicate to another person something desired, meaning "*Get that for me.*"
Babbling:	
Reduplicative Babbling	Repetition of nearly identical consonant+vowel sounds (e.g., "*mamamamama*")
Non-Reduplicative Babbling	(Also called variegated babbling, is the use of repeated but varied consonant+vowel sounds (e.g., "*pamadobeda*")
Holophrases	Also called "megawords" are the use of single or compound words to express a complex idea (e.g., "*Up*" meaning "Pick me up," "*Allgone*" meaning "There's nothing left")
Intonation	Variations in pitch used to convey meaning (e.g., a rising pitch when asking a question)
Jargon	Use of sounds along with intonation (and the occasional megaword) in a way that sounds like the language a child hears most often but lacking much discernable meaning [e.g., "*pamadobeda*?" (with a rising pitch) versus "*pamadobeda!*" (with emphasis on the last sound)]. Offering a toy telephone to a young toddler usually elicits jargonning with all the intonations typical of the language(s) spoken by parents.
Telegraphic Speech	Use of varied, non-memorized two-word noun+verb utterances to convey complex ideas (e.g., "*cookie want*" or "*want banana*"). Words such as "*I*" or "*the*" are non-essential and rarely used at this level of language development.
Echolalia	Repetition of words or sentences usually those just spoken by others. Echolalia can be typical (e.g., if a child is asked "*do you want milk?*" they may repeat the question before answering "*want milk*"). Echolalia is a way to internalize and practice the meaning of what a child has heard and peaks around 30-months of age. In children with autism spectrum disorder, echolalia continues at older ages and often without an actual answer to questions. Nevertheless, echolalia is an important indicator of future ability to communicate independently.
Stuttering	Typical stuttering is the repetition of whole words or initial syllables (e.g., "*be-be-be-because*") and is common in preschoolers. Atypical stuttering is repetition of only the initial sound (e.g., "*n-n-n-n- no*") with emerging frustration, vocal spasms, etc.
Intelligibility	How well a child articulates sounds of words and is understood by parents and most especially by unfamiliar others.

Table 10 – 3. Language and Social-Emotional Development in the 0 - 8-Year Age-Range

Chronological Age	Social/Emotional	Receptive Language	Expressive Language
~ 1 month	Discriminates mother voice Cries out of distress	Startles to loud noise	Makes sounds other than crying
~ 2 months	Reciprocal smiling - responds to adult voice and smile	Alerts to voice / sound	Coos (e.g., "oooh" and "aah") Social smile (6 wks) Gurgles when vocalizing
~ 3 months	Expression of disgust (sour taste, loud sound) Visually follows person who is moving across a room	Regards speaker	Chuckles Vocalizes when talked to
~ 4 months	Smiles spontaneously at pleasurable sight/sound Stops crying at parent voice To and fro alternating vocalizations with others	Orients head in direction of a voice Stops crying to soothing voice	Laughs out loud Vocalizes when alone
~ 5 months	Recognizes caregiver visually Forms attachment-relationship to caregiver	Begins to respond to name	Says "Ah-goo" (or other vowel +consonant combinations) Razz, squeal Expresses anger with sounds other than crying
~ 6 months	Stranger anxiety: recognizes familiar vs. unfamiliar people	Stops momentarily to "no" Gestures for "up"	Reduplicate babble with conso-nants Listens then vocalizes when adult stops Smiles/Vocalizes to mirror
~ 7 months	Looks from object to parent and back when wanting help (e.g., with a wind-up toy)	Looks toward familiar object when named Attends to music	Increasing variety of syllables Repeats same syllables (e.g., "mamamama")
~ 8 months	Lets parents know when happy vs. upset Engages in gaze monitoring: adult looks away and child follows adult glance with own eyes	Responds to "come here" Looks for family members when asked, "Where's Mama?...etc.	Says "Mama" (non-specific) Non-reduplicate babble (e.g., "wapa") Imitates sounds
~ 9 months	Uses sounds to get attention Separation anxiety Follows a point "Oh look at... " Recognizes familiar people visually	Enjoys gesture games Orients to name well Turns head upward and diagonally to view source of sound	"Mama" (non-specific) Increased non-reduplicate babble (e.g, "wapa" +"mada") Imitates sounds Gestures (e.g., reaching, pointing)
~ 10 months	Experiences fear Looks preferentially when name is called	Enjoys Peek-A-Boo Waves "bye-bye" back	Says "Dada" (specific) Waves bye-bye Adds new consonant sounds to babbling
~ 11 months	Gives objects to adult for action after demonstration (lets adult know he needs help)	Stops activity when told "no" Bounces to music	Says first word Vocalizes to songs
~ 12 months	Shows objects to parent to share interest Points in order to get desired object (Proto-imperative pointing)	Follows 1-step command with gesture Recognizes names of two objects–looks at each correctly when named	Points in order to get desired object (Proto-imperative pointing) Uses several gestures with vocaliz-ing (waving, reaching, etc.)
~ 13 months	Shows desire to please caregiver Solitary play Functional play	Looks appropriately when asked "Where's the ball?", etc.	Uses three words Immature jargoning (Inflections without real words)

Table 10 – 3. Cont'd

Chronological Age	Social/Emotional	Receptive Language	Expressive Language
~ 14 months	Points at object to express interest (e.g., to get parent to name it) (Proto-declarative pointing) Purposeful exploration of toys through trial and error	Follows one-step command without gesture (e.g., "give it")	Names one object Points at object to express interest (e.g., to get parent to name it) (Proto-declarative pointing)
~15 months	Shows empathy (if someone else cries, child looks sad) Hugs adult in reciprocation Recognizes without a demo that a toy requires activation and hands it to an adult if can't operate	Points to 1 body part Points to 1 object of 3 Gets object from another room upon demand	Uses 3 - 5 words Mature jargoning with real words
~ 16 months	Kisses by touching lips to skin Periodically visually relocates care-giver Self-conscious: embarrassed when aware of people observing	Understands simple commands "Bring to mommy" Points to one picture when named	Uses 5-10 words
~ 18 months	Passes M-CHAT Engages in pretend play with other people (e.g., tea party, birthday party Begins to show shame (when does wrong) & possessiveness	Points to 2 of 3 objects when named Points to 3 body parts Points to self Understands "mine" Points to familiar people when named	Uses 10-25 words Uses giant words (all gone, stop that) Imitates environmental sounds (e.g., animals) Names one picture on demand
~ 20 months	Begins to have thoughts about feelings Engages in tea party with stuffed animals or dolls Kisses with pucker	Points to three pictures Begins to understand her / him / me	Holophrases ("Mommy?"and points at keys, meaning "These are Mommy's keys") Two-word combinations Answers requests wtih "no"
~ 22 months	Watches other children intensely Begins to show defiant behavior	Points to 4 – 5 pictures whennamed Points to 5 – 6 body parts Points to 4 pieces of clothing when named	Uses 25-50 words Asks for more Adds 1-2 words per week
~ 24 months	Parallel play Begins to mask emotions for social etiquette	Follows two-step command Understands me / you Points to 5-10 pictures 2 word sentences (noun+verb) Telegraphic speech 50% intelligibility Refers to self by name Names 3 pictures	Uses two-word sentences (noun+verb) Telegraphic speech 50 + words in vocabulary 50% intelligibility Refers to self by name Names 3 pictures Add new consonant sounds (e.g., "g", "h")
~ 2 years, 4 months	Reduction in separation anxiety	Understands "just one"	Repeats 2 digits Begins to use pronouns (I, me, you) Names 10-15 pictures
~ 2 years, 6 months	Imitates adult activities (e.g., sweeping, talking on phone, pretending to hunt animals)	Follows 2 prepositions: "Put block in . . .on box" Points to objects by use: "ride in" ... "put on feet" . . ."write with"	Echolalia and jargoning gone Names objects by use Refers to self with correct pronoun Recites parts of well-known story/fills in words
2 years, 9 months	Begins to take turns Tries to help with household tasks	Understands three prepositions Understands dirty, wet	Gives first and last name Counts to 3 Begins to use past tense Enjoys being read to (short books)

table continues...

Table 10 – 3. Cont'd

Chronological Age	Social/Emotional	Receptive Language	Expressive Language
~ 3 years, 0 months ~ 3 years, 6 months	Starts to share with/without prompt Fears imaginary things Imaginative play Uses words to describe what someone else is thinking ("Mom thought I was asleep")	Points to parts of pictures (nose of cow, door of car) Understands action words: "playing... washing...blowing" Names body parts when functions described Understands negatives Groups objects (foods, toys) Understands long/short	Uses 200+ words 3 word sentences Uses pronouns correctly 75% intelligibility Acquires new consonant sounds (e.g., "f", "t", "j", "s") Uses plurals Names body parts by use Asks to be read to
~ 4 years, 0 months ~ 4 years, 6 months	Deception – interested in "tricking" others, and concerned about being tricked by others Has a preferred friend Labels happiness, sadness, fear and anger in self Group play	Follows three step commands Points to things that are the same versus different Names things when actions are described (e.g., it swims in water, you cut with it, it's something you read, it tells time.)	Repeats 4 – 6 syllable sentence Uses 300-1000 words Tells stories May repeat words in sentences (e.g., ("Mom, Mom, … I, I want….")) 100% intelligibility with few articulation errors Uses "feeling" words Uses words that tell about time
~ 5 years, 0 months ~ 5 years, 6 months	Has a group of friends Apologizes for mistakes Responds verbally to good fortune of others	Knows right and left on self Points to different one in a series Understands "er" endings, (e.g., batter, skater). Understands adjectives:bushy, long, thin, pointed Enjoys rhyming words and alliterations Produces words that rhyme Points correctly to "side", "middle", "corner"	Repeats 6 – 8 syllable sentence Defines simple words 2000 words Knows telephone number Responds to why questions Retells stories with clear beginning, middle, end Word repetitions in sentences wane (single sound repetitions e.g., s-s-s-s-, absent)

~ 6 years, 0 months
 	
~ 6 years, 6 months
	Has best friend of same sex
	
	Plays board games
	
	Distinguishes fantasy from reality
	
	Wants to be like friends and please them
	Enjoys school
		Asks what unfamiliar words mean
		Can tell which words do not belong in a group
			Repeats 8 – 10 word
			    Sentences
			Describes events in an
			    orderly way
			Masters sounds of "r" and "l"
			
			Knows days of the week
			10,000 word vocabulary
			Masters pronunciation of consonant digraphs (e.g., "st-", "dr")

~ 7 - 8 years	Avoids hurting others in play Learns from mistakes Helps younger children Strong notions about what is fair Takes turns in conversations Delays gratification and waits to take turn Interested in the opinions of peers	Understands "opposites" and word analogies Answers "who", "why", "when',"where" and "how" questions Knows right from left on others Understands days and months	Masters "r" sound in speech Tells time Uses complex and compound sentences Talks about a range of topics

IV. LANGUAGE ISSUES ACROSS VARIOUS TYPES OF DISABILITIES

Of all human capabilities, facility with language is the most sophisticated and complex. Language skills reflect our cognitions, i.e., understanding of and relatedness to our world. So it isn't surprising that language deficits are also a distinguishing feature of almost all developmental-behavioral/mental health problems. For each type of disabiity there are unique language problems. Included in Table 10-4 are descriptions of language difficulties associated with various conditions. Table 10-4 is also designed to aid clinicians in attending carefully to language development.

Table 10 – 4. Common Conditions and Their Language Manifestations

CONDITION AND CAUSE	RECEPTIVE COMMUNICATION PROBLEMS	EXPRESSIVE COMMUNICATION PROBLEMS
DEVELOPMENTAL DELAY		
Psychosocial Risk (including abuse, neglect, and slow learning)	Trouble understanding abstract terms and following multi-step instructions—relies on behavior of others as a guide to comprehension or may act out when failing to understand	Less talkative with fewer conversational skills than expected; seldom volunteers ideas or discusses feelings; utterances shorter than peers; may engage in aggressive behavior instead of using language to solve problems
Bilingual with Psychosocial Risk	May misinterpret directions or have difficulty transitioning from native language to English when there is not a native language word to represent a concept in English	Speech fluency and usage may be affected when complex language is developing—and with emotional stress. This may be seen when expressing feelings via increased stuttering
Dual Language Learner with Psychosocial Risk	May have difficulty acquiring language if concepts in either language are newly emerging	Ability to explain difficult situations or emotional challenges may impact formulation of coherent sentences, especially in the absence of encouragement and models. Fluency difficulties or stuttering is likely
DEVELOPMENTAL DISABILITY		
Autism Spectrum Disorder	Difficulty analyzing, integrating and processing information; misinterpretation of social cues	Variability in speech production from functionally nonverbal to echolalic speech to nearly typical speech; use of language in social situations is more challenging than is producing language (e.g., may have adequate articulation skills and sentence structure), but difficulty selecting the right words to represent intended meaning; often mechanical voice quality
Brain Injury	Difficulty making connections, inferences and using information to solve problems; challenges in attention and memory affect understanding; challenges in understanding figurative language and words with multiple meaning	Difficulties with pragmatics—using language in context, especially narratives and conversations; challeges in executive functioning, including planning, social judgment and organization that impacts ability to formulate thoughts, attend to relevant information and engage in socially appropriate ways

Table 10 – 4. Cont'd

CONDITION AND CAUSE	RECEPTIVE COMMUNICATION PROBLEMS	EXPRESSIVE COMMUNICATION PROBLEMS
Cerebral Palsy and Motor Coordination Disorders	Speech sound discrimination, information processing and attention can be areas of challenge; language comprehension is affected by intellectual status	Dysarthric speech—slower rate, with shorter phrases or prolonged pauses; articulation is often imprecise with distorted vowel productions; voice quality can be breathy or harsh, hypernasal with a low or monotone pitch; apraxic speech—sound substitutions that are inconsistent, groping for sound production; nonfluent volitional speech is more fluent than automatic speech; language production affected by breath support and cognitive status
Fetal Drug Or Alcohol Exposure	Difficulty comprehending verbal information especially understanding abstract concepts, multiple word meanings and words indicating time and space	Fewer vocalizations in infancy; poor use of gestures and delays in oral language; poor word retrieval, shorter sentences and less well developed conversational skills than peers
Fluency Disorders including Articulation Impairment	None—assuming hearing and cognitive status are within normal limits; can discern differences in sounds despite oral production problems	Difficulty with the rate and rhythm of speech; false starts; repetitions of sounds, syllables and words. Word and phonogram repetitions are typical in children 4-years of age and younger, but of concern are those who repeat isolated sounds (which may be accompanied by atypical physical behaviors such as grimacing, head-bobbing)
Hearing Impairment	Difficulty with sound perception and discrimination, voice recognition, and understanding of language especially under adverse hearing conditions	Sound productions made until about 6-months; limited oral output depending on degree of hearing loss; for oral communicators, vocal resonance, speech sound accuracy and syntactic structure often affected
Intellectual Delays/ Disabilities	Comprehension of language is often below cognitive ability; difficulty organizing and categorizing information heard for later retrieval; difficulty with abstract concepts and interpretation of information presented auditorily; challenges in recalling steps in multiple-step directions	Production is often below cognitive ability; similar but slower developmental path than typical peers; uses more immature language forms; produces shorter and less elaborated utterances
Specific Language Impairment/Learning Disability in Reading Comprehension	Slow and inefficient information processing; limited understanding of language; difficulty comprehending passages in reading[10,11]	Shorter, less elaborated sentences than typical peers; difficulty in rule formulation for speech sounds, word and sentence productions; ineffective use of language forms in social contexts sometimes leading to inappropriate utterances; poorly developed vocabulary; trouble finding the right word when speaking; words and sentences may be out of order
Mental Health Problems (including internalizing and externalizing disorders, ADHD, etc.)	Preoccupations/distractions interfere with listening comprehension including direction-following and completing tasks	Tangential response to conversational topics; pressured speech; fails to express thought before jumping to another topic; returns excessively to the same topic; blurts answers; interrupts

V. Red-Flags In Language Development

Red-flags, like typical milestones, provide background information for clinicians. Red-flags ensure that providers understand what screening tests measure and also enhance clinical acumen (e.g., help clinicians notice problems at a sick-visit where screening tests are not usually administered). Clinicians should also note family history of language problems, autism spectrum disorder, and physical findings associated with developmental problems (See Chapter 5 for more information on medical history and physical exams). Again, red-flags are not a substitute for quality screening, and should not be used to decide when a screen is needed. A validated, accurate screen should be used at each well-visit.[12] Table 10-5 lists red-flags across the birth to 8-year age-range.

Table 10 – 5. Red-Flags in Language Development Across the Birth to 8-Year Age-Range

AGE RANGE	RED-FLAG INDICATORS	AGE RANGE	RED-FLAG INDICATORS
0-3 months	Excessive "tuning out" of surroundings Lack of awareness of sound Lack of awareness of environment Cry undifferentiated, problems sucking/swallowing	18-24 months	Same concerns as at 12- to 18-months Reliance on gestures without vocalization Labeling of objects in place of commenting or gesturing Less than 50 words or does not put two words together by 24-months No pretend play
3-6 months	Cannot focus, easily over stimulated Lack of awareness of sound, no turning to sound Lack of awareness of environment	24-36 months	Frequent tantrums when not understood Echoing words the child hears Few or no multi-word utterances Does not demand a response from the listener Does not ask questions like "what?" or "why?"
6-9 months	Infant does not appear to understand or enjoy the social rewards of interaction No babbling or babbling words with few or no consonant sounds	36-48 months	Unable to re-tell the beginning and end of a short story Does not use presupposition or indirect requests Inappropriate pronoun use Does not understand or use spatial relationships like "behind" or "in front of," temporal relationships like "before" and "after" or quantitative relationships like "more" or "less" Does not produce sounds like 'v' in 'vase', 'ch' in 'church' or 'z' in zebra
9-12 months	Same concerns as at 9- to 12-months Does not attempt to spontaneously use words or imitate words Child is more interested in objects and less interested in people Child does not persist in communication, and gives up if the adult does not respond immediately Lack of joint attention	60-72 months	Makes inappropriate judgments in social situations Difficulty describing the events of the day Difficulty telling stories with identified problems and solutions Difficulty re-telling a story by describing the beginning, middle, and end Difficulty with rhyming
		72-96 months	Fails to understand strategies to hide and detect deceit Fails to segment compound words (e.g., sea...shell) Unable to judge whether or not an utterance is grammatically correct Does not detect errors in speech and language production

VI. Acquiring English as a Second Language

Now that you are familiar with typical and atypical language development, we take up the topic of second language acquisition also known as sequential language acquisition (meaning learning a second language after a first language is already established). Sequential language learning usually occurs when a child who speaks a language other than English goes to school for the first time. In this section, we describe the process of second/sequential language learning—its typical features and when to be concerned.

Typical progression of second language acquisition

Interference

Children who are English Language Learners (ELLs) may manifest interference or transfer from their first language to English. This means a child may make an English error due to the influence of their first language. For example, in Spanish, *"esta casa es más grande"* means *"this house is bigger."* However, a literal translation would be *"this house is more bigger."* A Spanish-speaking child who said, *"this house is more bigger"* is transferring the structure of Spanish into English. Such errors are a normal phenomenon—a sign of a language difference, not a language disorder. Similar miscues are often evident in reading. A child who is truly 'reading to learn' relies on inference and existing oral language skills, i.e., does not read literally. Thus, an African-American child may read *"I ain't"* when the printed words are *"I'm not."* This should not be construed as a reading problem—instead such errors convey that a child is reading for meaning.

Silent Period

A common second-language acquisition phenomenon is called the "silent period." When first exposed to a second language, children focus frequently on listening and comprehension. Thus children are often very quiet, speaking little as they learn to understand a new language—much, in fact, as adults do when traveling in foreign countries. The younger the child, the longer the silent period tends to last. Older children may remain in the silent period for a few weeks or a few months, whereas preschoolers may be relatively silent for a year or more.

Code-Switching

Many children who are ELLs also engage in a behavior known as "code-switching," which involves changing languages within phrases or sentences. For example, a Spanish speaker might say, *"Quiero apples"* instead of *"Quiero manzanas"* or a Filipino speaker might say, *"With my teacher, I have utang ng loob [debt of gratitude]."* Code-switching is a normal phenomenon engaged in worldwide by many fluent bilingual speakers including adults.

Problematic Phenomena: Language Loss

Some children who are ELLs experience language loss while learning English. Children may lose skills and fluency in their first language, especially if it is not reinforced. This worrisome process is called subtractive bilingualism, and can be cognitively and linguistically detrimental to children's learning and to family life (especially if the parents do not speak English). Ideally, children should experience *additive bilingualism*, wherein they learn English at the same time their first language and culture are promoted.

VII. Dual (Simultaneous) Language Learners

The Office of Head Start defines Dual Language Learners as children who are acquiring two or more languages simultaneously. Head Start policy notes that when it comes to young children, dual language learning as well as second language learning later in life, often overlap. Young children are inherently

learning language but may be differentially exposed to a second language (e.g., one at home and another in daycare).

Research shows the unequivocal importance of thoroughly supporting young children's acquisition of English along with their home language. Knowledge of the home language facilitates learning a second language. Children who know two languages often have higher levels of cognitive achievement than monolingual children and will have, almost certainly, a broader array of social and economic opportunities available to them as they become adults. Via their home language and culture, families share a sense of identity and belonging—which is how children learn how to relate to and communicate with others. Loss of home language can interfere with these important aspects of a child's life, disrupt family communication, inhibit relationship development, lead to the loss of intergenerational wisdom, negatively affect a child's self-concept, and potentially interrupt thinking and reasoning skills.

Supporting language variants across English-speakers is also critical during early reading instruction. For example, we should not correct a child speaking British-English who reads, "*I shall not go,*" when the literal text reads, "*I will not go.*" Similarly with children who speak Black English, we should not correct reading miscues such as "*ain't*" for "*aren't*" early in life. When children substitute words that essentially mean the same thing (even if Standard American English is not used), that tells us children are reading for meaning and thus inferring content. Correcting dialectic and language variants is denigrating and likely to interfere with reading acquisition. There is a time later in life (e.g., high school) to teach Standard American English (e.g., via a focus on success with job interviews) but that time is not until reading skills are fully mastered.

VIII. BILINGUAL AND DUAL LANGUAGE DEVELOPMENT: WITH AND WITHOUT PSYCHOSOCIAL RISK

More than 20% of the US population (over 5-years of age) speaks a language other than English at home.[13] More than half of this group, i.e., 12% of the total US population, report they do not speak English well (*www.census.go*v). Those who are foreign-born or who are not US citizens tend to speak English less well than those native-born; especially if from Spanish-speaking or Asian/Pacific Island nations.

There are distinct disadvantages to limited English facility when residing in the US: 80% of native English-speakers graduate from high school in contrast with 41% of Spanish-speakers. This means that psychosocial risk is often elevated when English is not mastered. The public schools provide many services to help students with limited English but early detection and intervention with delays in the preschool years is invaluable.

Deciding on causes and types of intervention for children with limited English proficiency (LEP) is complex. We know that most will not do well on the language items on screening tests: Some are bilingual children with LEP who will become typically developing language learners and eventually attain proficiency with an adequate bilingual education. Too often though, the presence of second- or dual-language learning obscures evidence of other disabilities—meaning that we should not chalk off language delays simply to second language learning. Language disorders and/or psychosocial risk may be the fundamental contributors; each of these causes require very different types of attention.

IX. Case Examples

Below are several case examples illustrating a range of difficulties children face, and professional challenges in early detection.

Case Example #1

A family from Japan who had lived in the US for several years made an appointment at a developmental-behavioral specialty clinic due to worries about their 11-year-old's school performance. He and his older brother were enrolled in a particularly challenging private school. The older boy was doing fine and so parents and teachers wondered whether the school was too hard for the younger son, and how well he'd learned English (because the family spoke Japanese at home). The family came to their appointment with a bilingual friend who served as a translator. After interviewing the parents and administering screening tests in both Japanese and English (all looked average although not high enough for his challenging private school), the translator commented, "Even when he speaks Japanese, his words are not in the right order." That statement alerted me to the probability that this child had a language disorder and not just a delay due to second language learning. No wonder he was struggling in school! Speech-language therapy was recommended along with English as a Second Language classes, and a public school placement where such services are readily accessible.

Case Example #2

In a pediatric clinic serving as a community rotation for 4th year medical students, students were required to visit a public school and also practice screening tools with elementary age students. One medical student, Emile, was Haitian and spoke multiple languages including English, Haitian Creole, French, and some Spanish. During Emile's visit to the schools, a kindergarten teacher asked Emile to screen Cassandra who was struggling with the curriculum. The teacher noted that Cassandra's mother was Haitian and spoke mostly Creole at home, the dad spoke English and, when both parents were at work, the babysitter spoke Spanish to the children. Cassandra had three older siblings who spoke English reasonably well although all were having trouble with grade-appropriate school skills. The teacher wondered whether this mixture of languages was contributing to Cassandra's difficulties. Emile then screened Cassandra in all three languages. Cassandra was unable to demonstrate age-appropriate skills in any language although she was markedly better with English. She also had substantial delays in most non-language areas including fine motor and self-help, and overall performed close to the 3-year-old age-range. Emile recommended further testing by the school's psychologist and speech-language pathologist (and also that her siblings be tested). Cassandra and her siblings were subsequently diagnosed with intellectual disabilities including deficits in adaptive behavioral skills as well as receptive and expressive language—all commensurate with IQ. All were enrolled in a range of special education services, including speech-language therapy. Clearly a multilingual environment was not the sole or primary cause of her difficulties.

Case Example #3

A bilingual family, recently emigrated from the Middle East, enrolled their 6-year old daughter, Aabirah, in first grade and established pediatric care in the local community clinic. The public schools promptly put her in English as a Second Language (ESL) classes because her English was quite limited. When she was seen in the clinic, she rarely spoke and when she did (in Arabic or English) her utterances were only 1 - 2 words long and repetitive. Eye contact was minimal (with either the clinician or her parents). She was hard to engage during screening (would not name pictures or even look at them much). Her play was marked by stereotypies and aimlessness. Despite her age, the Modified Checklist of Autism in Toddlers was administered via interview. Aabirah failed most of the critical items. Clearly language exposure did not explain Aabirah's difficulties. She was referred to a developmental-behavioral pediatric clinic and seen by a range of professionals including a developmental psychologist, a pediatrician, a social worker, and a speech-language pathologist. Aabirah was diagnosed with autism spectrum disorder, receptive and expressive language impairment and intellectual disabilities. The public school personnel were contacted the next day but were resistant to the recommendation for special education placement and felt that Aabirah simply

needed more English language exposure. But by the time the diagnostic evaluation reports arrived, the schools had observed Aabirah more carefully, noted her unusual behaviors, lack of progress, and were making arrangements for special education services.

Case Example #4

Miguel, a new patient, came in for a 4-year-old well-child check. Miguel's dad spoke English and Spanish well, although neither he nor his wife had graduated from high school. The father had a full-time job, Miguel's mother worked part-time, and Miguel stayed with his Spanish-speaking grandmother while the parents worked. Miguel's mother spoke mostly Spanish but seemed to understand what her husband and the clinician said, although her answers were brief and in broken English. Miguel's mother raised concerns about Miguel's talking, but his father said, "I'm not worried. Boys are like this. It is just a phase. He'll grow out of it." Miguel was very quiet throughout the visit and did not ask questions or make comments. On screening (in English), Miguel was able to point to pictures, numbers, and a few letters when named. His self-help, social-emotional, fine and gross motor skills were also average for age. But he did not do well on expressive language tasks (e.g., repeat sentences, name pictures, etc.). Given his parents' limited education, the pediatrician worried they might not be talking or reading with him much, i.e., that psychosocial risk was present.

To discern whether problematic parenting skills were a possible cause (and to help determine types of needed referrals), the Brigance Parent-Child Interaction Scale (BPCIS) was administered (presented at the end of this chapter and downloadable at www.pedstest.com/TheBook/Chapter10). By observation and report, Miguel's parents read to him often, engaged him in conversation, described things he looked at and what he was experiencing. Both parents did a good job modeling language (in both Spanish and English). Still, it was unknown if Miguel's delays were substantive enough to warrant intervention. With the mother's help, the Spanish version of the expressive language screening items was administered.

Miguel passed expressive language items on a screen administered in Spanish. This suggested he was mastering Spanish a bit better than English. The English-language screening items designed for slightly younger children were then administered and Miguel did well on these. The physician concluded, appropriately, that Miguel's delays in English were probably minor, and that his parents were doing a good job promoting language (although more so in Spanish than English). The family was given information on promoting dual language skills. His dad was encouraged to speak English more at home, while the mother and grandmother continued speaking Spanish. All were encouraged to expose Miguel to English-speaking children (e.g., play groups, Sunday school, etc.)—to better prepare him for kindergarten the following year.

Comment on Case Examples: *In the first three examples, the presence of second or dual language learning made it difficult for professionals to see the substantive underlying problems needing referral for services. In the fourth example, attention to psychosocial risk combined with screening in both languages, enabled a rule-out of significant language deficits: The child demonstrated age-appropriate skills in one language, and resilience factors were present. This indicated the need for increased exposure to English prior to kindergarten, rather than formal intervention. So what should primary care providers do with all these nuanced issues, including any literacy problems with parents—and all within a brief well-visit?*

X. RECOMMENDATIONS FOR EARLY DETECTION OF LANGUAGE PROBLEMS IN PRIMARY CARE

Children and families from diverse cultures and language backgrounds contribute richly to life in America. Nevertheless, assessing bilingual children and those who are just starting to learn English presents challenges. Table 10-6 includes suggestions for making screening tools work with families who have psychosocial risk (especially in the presence of language and literacy barriers) and with bilingual children or those newly exposed to English.

Table 10 – 6. Screening Children (and Families) from Diverse Backgrounds and Languages

- Probe literacy before dispensing written questionnaires and screens (e.g., "*Would you like to go through this on your own or have someone go through this with you?*");

- Establish a medical home. Start by eliciting parents' actual concerns because this increases the likelihood parents will perceive primary care providers as a source of parenting support, and return for visits—a critical issue for ensuring quality of care.[14] When parents perceive professionals as a helpful resource, they are more likely to use appropriate disciplinary techniques (e.g., more time-out, less spanking);[15]

- Screen hearing (and vision) even if newborn hearing screening was negative. Avoid informal approaches to hearing screening as such uncalibrated noise-makers, distraction tests, or reliance solely on language delay or parental concerns (parents will identify many children with hearing loss, but not all, and not early enough). See Chapter 5 for guidance on in-office audiometry. When hearing screening produces problematic results, refer for a full audiological evaluation;

- Use tools such as the *Family Psychosocial Screen (FPS)* periodically as they are helpful for discerning the types of referrals needed when a child is behind. Although referral to IDEA programs should be axiomatic in the presence of delays, intervention in families' issues may also be needed. The *FPS* captures most risk factors and is often used at new patient intake, with sections repeated at some follow-up visits (e.g., readministering the parental depression questions in the second year of life);

- Use a measure of parenting behaviors such as the *Brigance Parent-Child Interaction Scale (BPCIS)* periodically to help identify parenting strengths and weaknesses. The value of this tool is its power to inform primary care providers about when to reassure parents who are promoting development well, and when to intervene when skills are lacking. The *BPCIS* is presented at the end of this chapter;

- Use accurate screening tools at all well-visits (see Chapter 4 for options);

- Screen children in both English and in their native language. Note where mastery of skills has occurred in each language (using the longitudinal charts provided by most measures);

- Make sure to use translations created by screening test publishers. Usually these have been vetted by multiple bilingual speakers and are known to work well. If relying on a translation service (including telephone translators), make sure personnel have copies of validated translations;

- If translations are not available, contact test publishers for guidelines and other assistance;

- If administering screens directly to children, provide guidance to interpreters (including parents who accompany their children). To ensure that screens are administered in a valid manner, items cannot be reworded, and no prompts may be offered. Feedback on performance must focus on a child's effort, not his or her success (e.g., "*Good trying!*" or "*I like the way you are paying attention!*"). See Chapter 14 for additional guidance on building rapport, administering hands-on tests in a valid manner, etc;

- Ask the translator or parents about the quality of the child's primary language. If children, when speaking their native language, produce sentences with words out of order, use incorrect verb endings, have articulation delays and so forth, a language disorder may be present and children should be referred for a speech-language evaluation;

- Anticipate grammatical errors when children are learning a new language, but be concerned about grammatical errors if occurring in all languages spoken. Bilingual children and children new to the English language make more grammatical errors when speaking English than do native English-speakers. But if grammatical errors are present in all languages, this may be an indicator of language impairment for which a referral to a speech-language pathologist is needed;

- Establish performance on an English-language screen as a baseline against which future growth can be compared. Since future instruction is likely to be in English, baseline information on English language skills is needed for tracking progress;

- Monitor vigilantly, i.e., rescreen in a few months, and compare progress. If progress is slower than normal, then the presence of disabilities is more likely, but if progress is on track, then referrals are not indicated (although we should encourage one parent to speak English at home where possible, and children to participate in daycare or playgroups);

- If the above suggestions are not feasible in primary care (e.g., too complicated, time-consuming, or translators are not available), refer to IDEA programs for further evaluation every time screens are failed.

Table 10-7 provides support for nuanced clinical reasoning about language development.

Table 10 – 7. Guidance for Clinical Decision-Making with Language Delays

SELF-PROBES FOR FORMING CLINICAL IMPRESSIONS	RECOMMENDATIONS
Does a child appear to have a language disorder (e.g., scrambled syntax in any language)?	Refer to IDEA Obtain evaluation results and refer elsewhere if ineligible Monitor progress between visits
Is this child in an environment that provides adequate support for language learning in all languages, i.e., lots of resilience factors?	Provide developmental promotion focused on dual-language learning Monitor progress between visits
Is this child in a language-rich environment but has differential levels of exposure, i.e., hears one language far more than another?	Encourage participation in play groups or daycare to build English skills prior to kindergarten, and where possible for one parent to speak English at home Monitor progress between visits
Is this child in an environment with psychosocial risk and limited resilience—meaning limited parent-child interactions that promote development?	Refer to IDEA but anticipate lack of eligibility and the need to refer to Head Start or quality daycare. Enroll all bilingual and dual language preschoolers in programs that will prepare them for success with English before kindergarten Advise parents on developmental promotion or refer to parent training Monitor progress between visits

XI. DEVELOPMENTAL PROMOTION WITH FAMILIES AT RISK OR MULTI-/BILINGUAL AND DUAL LANGUAGE LEARNERS

Table 10 – 8. Key Messages in Language Promotion

- Advise parents on optimal methods for promoting language development. See Chapter 7 for suggested methods and content (with downloadable handouts and live links at *www.pedstest.com/TheBook/Chapter7*) including sites providing parenting information in multiple languages, DVDs (helpful for families lacking literacy), etc;

- The ability of children to speak well in a second language depends in large part on his or her family's ability to speak more than one language well, and on the care-givers' ability to promote communication (e.g., share books and converse with their child);

- There are different ways to introduce a second language:
  - by setting (e.g., English is spoken only in the school, and Urdu is spoken only in the home);
  - by event (e.g., French is spoken only during meal time, and Spanish is spoken during school/work activities);
  - by speaker (e.g., Mom will speak only in German, and Dad speaks Russian only);

- Neither parents nor teachers should focus more on grammar than on meaning. Acknowledging and expanding on a child's utterances is a better approach. For example, if a child asks "*Me go store?*" an appropriate acknowledgement and model is, "*You want to go to the store?*";

- Demonstrate to parents how to affirm and expand on children's utterances (whether babbling, jargon, or sentences);

- Continue to suggest book sharing even when parental literacy is minimal (many can read very basic books). When needed, suggest "*wordless readers*" (meaning books with few words and lots of pictures) that parents can share with their children;

- Whether parents are thought to read well or not, provide information handouts (preferably in their native language). Highlight (e.g., with a marker) the main points. Many parents can find 'community helpers' or relatives to translate;

- Check on the effectiveness of the parenting advice you've provided (e.g., in six weeks) in order to determine when more intensive services (such as hands-on parent training) are needed;

- Provide parents a summary report of your recommendations and contact information. See Chapter 8 for templates that are also downloadable at *www.pedstest.com/TheBook/Chapter8* and generated automatically via online screening services.

XII. Referring for a Speech-Language Evaluation and What to Expect

IDEA evaluations are free, of good quality, and should be your first referral option for any child who has difficulty on a screen and particularly on its language items. Table 10-9 provides information on how to request an evaluation and make sure that speech-language skills are thoroughly assessed.

Table 10 – 9. How to Request an Evaluation

- Describe in your referral letter: screening results, parents' concerns, issues with psychosocial risk factors, presence of multiple-language exposure, relevant health issues, and your own observations about the child and family. See Chapter 5 for a referral letter template (downloadable at *www.pedstest.com/TheBook/Chapter5*), or use web-based screening services that will generate these for you;

- Document in your referral letter the status of vision/hearing screening or if you are not able to screen sensory skills, include a request that IDEA provide this. Sensory status must be established before testing can proceed;

- Specifically request a speech-language assessment;

- Refer families to social services when they are unemployed, homeless, when domestic violence is a factor, etc;

- Refer consistently to IDEA as the first best start due to free evaluations. In some States IDEA provides monitoring for non-qualifying children together with referral assistance to non-IDEA services;

- Make appointments for families, especially those with limited English, if at all possible. Parents are more likely to keep follow-up appointments if made by clinics.[16] Many families with risk factors are intimidated when encountering professionals, most particularly those whose English is not fluent. Encourage families to take a 'community helper' to their appointment;

- Collaborate with your local IDEA programs on a two-way consent form in which parents agree that your clinic and IDEA can share information (see Chapter 5 for templates, downloadable at *www.pedstest.com/TheBook/Chapter5*);

- Create a list of local services to which you can refer when children are deemed at risk but not eligible for IDEA programs (e.g., Head Start/Early Head Start, parent training, quality daycare, social services, mental health programs, after-school tutoring, etc.). See Chapter 5 and *www.pedstest.com/TheBook/Chapter5* for links to national services from which you can find local programs.

What to Expect After Referring for a Speech Language Evaluation

Anticipate that IDEA intake may involve in-depth screenings as a first step in deciding whether a complete speech-language assessment (or other diagnostic assessment measures) is needed. Note that the in-depth screens used by IDEA are often domain specific and far more detailed than what can be accomplished in primary care. IDEA examiners are likely to be professionals with much skill in the domains assessed, i.e., they will bring to screening much clinical acumen needed for determining what is typical progress and what is not.

From the information provided in your referral letter (and with the results of additional in-depth screens used in IDEA intake), when a speech-language diagnostic evaluation is conducted, the precise focus and measures administered will differ depending on the areas of concern raised. For example:

- If articulation skills are the central issue, speech-language pathologists view oral-motor skills (e.g., tongue lateralization and elevation, phonation, coordination of breathing with speech production, pitch, nasality, resonance, swallowing, chewing, etc.);

- If understanding language is an apparent problem, receptive skills are assessed via a focus on syntax, grammar, processing speed (how quickly a child understands what is heard), and semantics, i.e., a child's ability to meaningfully interpret communication whether gestural or verbal;

- If abilities with expressive language skills seem problematic, assessment focuses on production of sentences, use of morphemes (meaningful word parts such as "*–ing or –ed*"), word order, i.e., syntax, vocabulary, and again on pragmatic language, such as how well a child engages the interests of

another speaker;

- If fluency is a problem, articulation skills are assessed along with rate of speaking and prosody, i.e., inflections, loudness, pitch and rhythms of speech, and how they reflect the emotional state of the speaker, and how well a child responds to the emotional state of the listener;

- If hearing loss is confirmed, speech-language pathologists will need to collaborate with healthcare professionals on needed treatment. Speech-language evaluations will cover all the above areas.

XIII. RESOURCES FOR PARENTS AND PROFESSIONALS

Below are sites providing information focused on language development for both professionals and parents. Live links are provided on the website for this chapter and also for Chapter 7. In the reference section is a list of journal articles and textbooks for further reading.

www.asha.org is the website for the American Speech and Hearing Association. The site houses articles and policy statements on a wide range of issues including bilingual and dual language learning.

www.nabe.org is the site for the National Association for Bilingual Education where research and training guidance for English as a Second Language can be found.

www.ncela.gwu.edu is the National Clearinghouse for English language acquisition. The site includes standards for assessment, state networking, and webcasts.

www.literacytrust.org.uk focuses on coaching parents to talk with their babies. Included are tip sheets in 13 languages including Arabic, Chinese, Portuguese, Turkish, Somali and Urdu.

www.colorincolorado.org includes Spanish language resources to help parents promote language development through play.

www.infanthearing.org is the National Center for Hearing Assessment and Management at Utah State University. The site includes professional training videos, practice recommendations for primary care, newborn hearing screening and early childhood programs, research findings, and webcasts.

www.aap.org houses a collection of helpful policy statements from the Committee on Psychosocial Aspects of Child and Family Health. These cover issues in bereavement, postpartum depression, divorce and separation, disaster-related challenges, the role of fathers, and other psychosocial challenges.

After the chapter comments is a sample information handout for parents about language development. Following are measures of psychosocial risk and resilience. These are also downloadable in Spanish and English at *www.pedstest.com/TheBook/Chapter10*.

Chapter Comments: *Language is the domain of development to which healthcare providers should pay closest attention. Language disturbances and delays are the hallmarks of many disabilities. Children who are culturally and linguistically diverse may have depressed vocabulary skills[17] because vocabulary is dependent on experience and shaped by culture.[18] Delays and disorders in language development have an adverse impact on success in school and indeed in life. Preschool children from low income families have greater difficulty identifying and manipulating sound structure, recognizing letter names and sounds and developing vocabulary than preschoolers from middle and high income homes: The average child on Medicaid has less than half the experience listening to and speaking with their parents (616 words per hour) than a child from a working-class family (1251 words per hour)—and the latter frequency is less than half that of a child from a professional family (2,153 words per hour). By the time children are 5-years of ___ those from affluent families have been exposed to millions more words than have children in lower SES families.[19] Thus providers must attend carefully to risk and resilience factors when screening language skills, especially in low-income young children who are dual or sequential language learners.*

Parents are crucial informants in early detection, and are often called upon to assist healthcare providers in completing screening measures; often in more than one language. The screening procedures discussed throughout this text highlight the value of family insights on the day-to-day functioning of their children.[20-24] It is helpful to engage families in a dialogue about their worries and concerns about their children's language skills. When problems are apparent it is essential to promptly refer to speech-language pathologists or IDEA intake teams for ensuring that language is comprehensively assessed. In the face of psychosocial risk and limited resilience, referrals for social work services and parent training should be axiomatic.

Meanwhile, parents are their child's first and ideally best interventionist. To optimally assist families, even when a referral is needed, clinicians should always promote language development by actively teaching parents to listen, talk, and share books.

Building Speech And Language Skills

Skills in speech (sound pronunciation) and language (listening, understanding and using words) develop in an orderly way, although the pace may differ for different children. Below are general guidelines. Most children will show the listed skills within six months of the times listed:

Expressive Language Milestones
1 year: 1 word sentences
2 years: 2 word sentences
3 years: 3 to 5 word sentences
4 years: 4 to 7 word sentences.
         Uses different parts of
           speech almost all the time.

Expressive Vocabulary
1 year: 1-10 words
1 1/2 years: 10 - 100 words
2 years: 100 - 250 words
2 1/2 years: 250 - 400 words
3 years: 450 - 900 words
4 years: > 1500 words

Speech Milestones:
3 year: sounds of the letters: m, b, p, h, w and all vowels
4 years: k, g, t, d, n, ng, f
5 years: s, z, l, v, y, th, sh, wh, ch
6 years: r, j

Speech Intelligibility (how well your child can be understood by others)
2 years: 25%
2 1/2 years: 60% - 65%
3 years: 75% - 90%
4 years: 90% - 100%

Fluency
Stuttering in the preschool years is normal (as long as whole words or word parts, not single sounds, are repeated). Be sure to give your child time to say what he is trying to say.

ACTIVITIES
Here are some things you can do to help build your child's speech and language skills:

1. **TALK, TALK, TALK**. Talk about what your child is doing as he does it ("*You're smiling.*"). Talk about how she might be feeling ("*You're happy because you have your favorite toy*"). Name people ("*Look! There's your sister.*") and everyday objects ("*bottles, juice, bed, diaper*"). Talk about what things look like ("*That ball is red and it's big. It is a big red ball.*") Talk about sounds around you and imitate them (cat's meowing, dogs barking, bacon sizzling). Sing songs and say nursery rhymes.

2. **LISTEN, LISTEN, LISTEN**. Conversations have two sides. Follow your child's lead and talk about things he or she brings up. Give him a chance to label things ("*Oh, you're thirsty. You want a drink. What do you want?*"). A young child will need an example ("*There's the orange juice. Mmm... orange juice tastes good.*"). An older toddler may need a choice ("*Do you want juice or milk?*") A young child may say only part of a sentence such as "*want truck*". You can expand on this and answer ("*OK, you want the big truck.*" or "*Here is the big yellow truck. It carries dirt! Varoom.*").

3. **READ, READ, READ**. Start reading early even though your child may be too young to understand what you are saying. This helps children learn that reading is fun. Early on let your children explore the books as they want to (using cloth books or action books like "Pat the Bunny"). Encourage your child to name the pictures ("*What's that?*", "*What do you think will happen next?*", "*Look! The bunny ate the carrots.*")

4. **EXPLORE, EXPLORE, EXPLORE**. Go places—the grocery store, the gas station, the park, the library. Talk about it all. Ask your child what he sees and what were his favorite things and why.

5. **DO, DO, DO**. Let your child help do things for himself ("*We have to get dressed. Go get your (new) (black) (tennis) shoes*"). Let your child help you do things and talk about it while you work together

("*Let's wash the dishes. I'm getting the sponge. I'm putting soap on it. Now there's soap on the sponge. Can you turn on the water?*"). Meal and bath times are great times for talking about activities.

TIPS:

1. Look at your child while he or she is talking.
2. Take your time and think more about the message rather than the way your child says it.
3. Set a good example. Speak slowly and don't rush.
4. Spend time every day with your child, talking in an unhurried, relaxed way.

REMEMBER:

1. Talking is special and fun.
2. At the end of a conversation, praise your child's efforts to talk.
3. Don't correct grammar. Just restate her words in the way adults talk.
4. Use other natural cues when talking and listening. Facial expressions, gestures, and body language communicate a lot (e.g., *"You look happy....upset...angry, etc.. Tell me about it*."").
5. Repeat main ideas frequently and in different ways.
6. Remember talking and communicating is a natural thing—"just do it."
7. If you have concerns about your child's speech and language skills, discuss it with your child's doctor, early intervention program or the speech-language pathologist at the public school where your child will, or already does, attend.

NATIONAL RESOURCES

American Speech-Language Hearing Association (*www.asha.org*). Consumer Helpline 1-800-638-8255

Stuttering Foundation of America (*www.stutteringhelp.org*)

The Audiological Foundation of America (*www.audfound.org/*) for information on locating an audiologist, dealing with hearing loss, etc.

Every Day Matters: Activities for You and Your Child. Circle Pines Minnesota: American Guidance. 1-800-328-2560. (*www.agsnet.com*)

Childhood Speech, Language and Listening Problems: What Every Parent Should Know, by Patricia Hamoguchi. John Wiley & Sons, 1995 (*www.amazon.com*)

The Language of Toys: Teaching Communication Skills to Special Needs Children, by Sue Schwartz & Joan Miller. Woodbine House, 1988. (*www.amazon.com*)

SUGGESTIONS FROM PROVIDERS AND FOLLOW-UP DATE:

Scoring Directions for the BRIGANCE PARENT-CHILD INTERACTIONS SCALE (BPCIS): A MEASURE OF RESILIENCE AND RISK

Rationale: Children often appear to be typically developing early in life. But given a dearth of resilience factors, i.e., problematic parent-child interactions, delays will inevitably emerge over time. We need to have answers to such questions as: Are parents talking a lot with their children? Are parents responding to children's attempts at communication in an encouraging way? Are parents teaching new words? Are parents sharing books? Do parents feel their child is interested in communication? Are parents confident in their ability to soothe their child (an effort that usually involves calm physical and verbal communications, such as "sweet-nothings", "there-there-ing")?

Positive parent-child interactions and positive perceptions of parenting are strongly associated with ongoing typical development. Negative perceptions and lack of positive interactions are strongly associated with emerging delays and disabilities. Differences in development between these two groups are striking—as early as 12-months of age.

The importance of developmental-behavioral promotion is clear: To help assure typical development, we need to make sure parents know how to encourage development via interactions with their children that emphasize talking, listening, reading, teaching and verbal soothing.

Research Support: The BPCIS is a surveillance tool designed to identify positive versus problematic parent-child interactions—well before delays emerge. Research on the BPCIS can be found in this publication: Glascoe FP, Leew S. Parenting Behaviors, Perceptions and Psychosocial Risk: Impact on Child Development. *Pediatrics*. 2010; 125: 313-319.

Timing: We recommend use of the BPCIS at 6-months and again at 15-months (or whenever parents' concerns indicate lack of age-appropriate knowledge of child development). If problematic interactions are found, developmental-behavioral promotion with careful follow-up to assess effectiveness is needed. If follow-up suggests ongoing problems, hands-on parent training is essential, i.e., referrals to parent-training programs.

Administration: If you wish parents to complete the BPCIS questions on their own, be sure to ask whether they would prefer to answer the questions on their own or have someone go through it with them (most parents will ask for assistance if literacy is a problem). In Spanish ask, "¿Les gustaría completar el formulario solos o prefieren que alguien lo responda con ustedes?" If using the examiner version, it is best to wait toward the end of the encounter to score so that multiple parenting behaviors can be observed and rated.

Measurement Methods: There are two versions of the BPCIS. The first is parent-report (preferred because it taps parents' perceptions and feelings) and the second is examiner observation. Some parent-report items, i.e., parents' perceptions, are not included in the examiner version because these cannot be observed. Both the English and Spanish versions of both scales are included below.

Scoring Directions: The BPCIS uses a three-point scale (e.g., not likely, sometimes, often). "Sometimes" ("a veces") is not a desirable response and is associated with problematic parent-child interactions. Spanish responses are shown in parentheses. Note that not all items are required for scoring but collectively answers add insight into parenting behaviors.

Other Observations Of Psychosocial Risk (four or more are predictive of delays in development)

_____ Parent(s) have less than a high school education.

_____ Parent(s) have limited literacy (e.g., They had difficulty completing questionnaire, poor spelling, unpracticed handwriting, etc.)

_____ There is less than twenty years' age difference between parent and oldest child.

_____ Child is member of a racial/ethnic minority.

_____ Family does not speak English at home.

_____ Child lives in a single-parent household.

_____ Four or more children live in the home.

_____ Child has changed schools frequently. (It may be helpful to view school records of older siblings.) or family has twice or more in the past 12 months.

_____ Child has no prior participation in structured preschool/daycare programs.

_____ Child has a history of being abused or exposed to domestic or neighborhood violence.

_____ Child or siblings participate in free lunch program or Medicaid

_____ Parent(s) are unemployed.

BRIGANCE® Parent-Child Interaction Scale
Parent-Report Version

_____   _____
Child's name   *Today's date*

_____
Date of birth

1. I play with my child and show him or her things about toys.
   Not very often   **Sometimes**   **Often**

2. I hug and kiss my child.
   Not very often   **Sometimes**   **Often**

3. I mostly talk to my child when he is crying.
   Not very true   **Sometimes true**   **Mostly true**

4. I help my child learn by talking and showing him or her new things.
   Not very true   **Sometimes true**   **Mostly true**

5. I look at or read children's books to my child.
   Not very often   **Sometimes**   **Often**

6. My child does not calm down or seem very interested when I talk to him.
   Mostly true   **Sometimes true**   **Not very true**

7. I make up games or songs for my child.
   Not very often   **Sometimes**   **Often**

8. When my child looks at or touches a toy, I talk to him about the toy.
   Not very often   **Some of the time**   **Most of the time**

9. When my child is looking at me, I talk or make sounds with him.
   Not very often   **Sometimes**   **Often**

10. My child doesn't seem to like me.
    Mostly true   **Sometimes true**   **Not very true**

11. I enjoy feeding my child or eating with him.
    Not very often   **Some of the time**   **Often**

12. I talk to my child in a special way.
    Not very often   **Sometimes**   **Often**

13. My child is <u>not</u> very much fun to be with.
    Mostly true   **Sometimes true**   **Not very true**

14. I can make my child feel better when he or she is upset.
    Not very often   **Sometimes**   **Often**

15. When my child looks at or touches something, the first thing I say is "*no*".
    Mostly true   **Sometimes true**   **Not very true**

16. Most of the time I like my child.
    Not very true   **Sometimes true**   **Mostly true**

17. My child does not need my help learning new things.
    Mostly true   **Sometimes true**   **Not very true**

18. I talk with my child when feeding or eating with him or her.
    Not very often   **Sometimes**   **Most of the time**

_____
Today's date

Brigance Parent-Child Interaction Scale
BPCIS Examiner Observation Form

Child's name_____ Date of birth_____

Please circle the answers that correspond to your observations. You will need to use your clinical judgment about some items.

1. Parent plays with child and shows him or her things about toys.
   Not likely/Not often   **Sometimes**   **Often/ Likely**

2. Parent hugs and kisses child.
   Not likely/Not Often   **Sometimes**   **Often/ Likely**

3. Parent talks to child only when child is crying.
   Often/ Likely   **Sometimes**   **Not likely/Not Often**

4. Parent helps child learn new things.
   Not likely/Not Often   **Sometimes**   **Often/ Likely**

5. Parent reads children's books to child.
   Not likely/Not Often   **Sometimes**   **Often/ Likely**

7. Parent makes up games or songs for child.
   Not likely/Not Often   **Sometimes**   **Often/ Likely**

8. When child looks at or touches a toy or object, parent talks to him/her about the toy.
   Not likely/Not Often   **Sometimes**   **Often/ Likely**

9. When child is looking at parent, parent talks or make sounds with him/her.
   Not Likely/Not Often   **Sometimes**   **Often/ Likely**

10. Child seems to avoid parent or to prefer the company of other people.
    Often/ Likely   **Sometimes**   **Not likely/Not Often**

11. Parent seems to enjoy child.
    Not Likely/Not Often   **Sometimes**   **Often/ Likely**

14. Parent soothes child when he or she is upset.
    Not Likely/Not Often   **Sometimes**   **Often/ Likely**

15. When child looks at or touches something, parents' first response is "No" .
    Often/ Likely   **Sometimes**   **Not likely/Not Often**

19. Parent faces child when talking with him or her.
    Not Likely/Not Often   **Sometimes**   **Often/ Likely**

20. Parent brings food, toys, diapers or other helpful child-support materials to the encounter.
    Insufficient for child's needs   **Sufficient**

For the Parent-Report version of the BPCIS:

Indicators of Resilience are two or more of the following:
(a) Items 1, 4, 5, 8, 12,16, 18 answered with "often/likely" ("a menudo"), "mostly true" ("es bastante cierto") "most of the time" ("la mayor parte del tiempo")
(b) Item 17 answered as "not very true" ("no es muy cierto")

Indicators of Risk:
(a) Fewer than 2 positive answers from the above set of items/responses and/or two or more of these answers:
(b) Items 3, 13, and 15 answered with "mostly true" "(es bastante cierto")

For the Examiner observation version of the BPCIS:

Indicators of Resilience are two or more of the following:
(a) Items 1, 4, 5, 8, answered with "often/likely" ("a menudo"), "mostly true" ("es bastante cierto") "most of the time" ("casi todo el tiempo")

Indicators of Risk:
Fewer than 2 positive answers from the above set of items/responses and/or two or more of these answers:
(a) Items 3 and 15 answered as "mostly true" ("es bastante cierto")
(b) Item 19 answered as "not likely/not often" ("No muy seguido")
(c) Item 20 answered as "insufficient" ("insuficiente")

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Scoring Instructions for the Family Psychosocial Screen

Scoring Criteria and Interpretation:

Under "Family Activities [*Actividades Familiares*]" are 3 items that screen for parental depression. Two or more positive answers are considered a positive screen. Depression is not only debilitating for parents but is also associated with developmental delays and mental health problems in children. When parental depression appears present, it may be helpful to explore other symptoms such as changes in appetite, weight, sleep, activities, energy level, ability to concentrate, feelings of hopelessness, and thoughts and plans about suicide. Reassurance about the frequency of depression is helpful as is noting the availability of various treatment options such as psychologists, psychiatrists, family doctors, internists, and support groups.

Under "Drinking and Drugs [*Consumo de Alcohol y Drogas*]" are 7 questions that screen for parental substance abuse. A positive response to any of the first six is considered a positive screen. This should be met with further questions about frequency of use, impact on the family, and impression of the effects of parental drinking on children. Physicians' advice to quit smoking is often highly effective but it is unlikely that abuse of other substances could be eliminated as easily. Referrals for further assessment and treatment should be made. Working with a social worker can facilitate compliance and help with arrangements for treatment.

Under "Family Health Habits [*Hábitos de Salud Familiares*]" there are 4 questions assessing domestic violence. Parents who respond positively to any of these should receive further counseling including exploration of the extent and patterns of violence, and safety issues for children (including gun storage). Parents may need assistance making escape plans and should be referred to hot-lines or shelters. Clinicians should affirm that domestic violence is wrong but not uncommon. Victims need follow-up visits and ongoing support even if they return to the batterer. Forming a therapeutic relationship around the child's safety and well-being is recommended since children are at risk for physical abuse in homes where there is domestic violence. Again, referrals for social work services may be the best first step.

Under "When You Were a Child [*Cuando Usted era Niño*]" are 8 questions assessing parents' history when they themselves were children of physical or verbal abuse. Such backgrounds predispose parents to disciplinary practices that may be abusive but more often are too permissive. Positive responses to any of the first 4 questions are considered a positive screen. The last 4 questions help gather additional information about disciplinary techniques and parents' need for counseling and parent training.

Under "Help and Support [*Ayuda y Apoyo*]" are questions assessing social support, a strong factor in reducing life and parenting stresses. Adequate social support helps ensure appropriate models for parenting practices and social control on disciplinary techniques. A problematic result is evident in responses to the first 3 questions, i.e., fewer than two supportive persons or when the parent is less than very satisfied with their support. Referrals to parenting groups, social work services, home visitor programs, or community family support services are warranted.

The Family Psychosocial Screen also assesses other risk factors for developmental and behavior problems. These include frequent household moves, single parenting, three or more children in the home, less than a high school education, and unemployment. Four or more such risk factors including mental health problems and an authoritarian parenting style (observed when parents use commands excessively or are negative and less than responsive to child-initiated interests) is associated with a substantial drop in children's intelligence and subsequent school achievement. In such cases, children should also be referred for early stimulation programs such as Head Start or a quality daycare or preschool.

Family Psychosocial Screen

This office is dedicated to providing the best possible care for your child. In order for us to serve you better, please take a few minutes to answer the following questions. Your answers will be kept strictly confidential as part of your child's record. Ongoing evaluations of our care may involve chart reviews by qualified persons, but neither your name, nor your child's name will ever appear in any reports.

Child's Name_____ Doctor_____   Today's Date_____

Circle either the word or the letter for your answer where appropriate. Fill in answers where space is provided:

Are you the child's	A. Mother	C. Grandparent	E. Other relative	G. Self (Are you the patient?)
	B. Father	D. Foster Parent	F. Other	

What is the highest grade you have completed?   1 2 3 4 5 6 7 8 9 10 11 12 (High School GED)
13 14 15 16 17 18 19   Some college or vocational school
College Graduate Postgraduate

How many times have you moved in the last year?   _____ times

Where is your child living now? A. House or apartment with family B. House or apartment with relative or friends
C. Shelter   D. Other_____

What is your current monthly income, including public assistance? $ _____

Besides you, does anyone else take care of the child. If yes, who?   Yes   No

Does your child have any allergies to any medications? Yes   No If yes, what? _____

Has the child received any immunizations?   Yes   No
Which ones? _____ Where? _____

Family Medical History

Does the child's mother, father, or grandparents have any of the following? If yes, who?

High blood pressure Yes No _____	Diabetes Yes No _____
Lung problems/asthma Yes No _____	Heart problems Yes No _____
Miscarriages Yes No _____	Learning problems Yes No _____
Nerve problems Yes No _____	Depression/Mental Illness Yes No _____
Drinking problems Yes No _____	Drug problems Yes No _____

Other _____

Family Health Habits

How often does your child use a seatbelt (carseat)?   A. Never B. Rarely C. Sometimes D. Often E. Always

Does your child ride a bicycle?   Yes   No
If yes, how often does he/she use a helmet?   A. Never B. Rarely C. Sometimes D. Often E. Always

Do you feel that you live in a safe place?   Yes   No

In the past year, have you ever felt threatened in your home?   Yes   No

In the past year, has your partner or other family member pushed you, punched you, kicked you, hit you or threatened to hurt you?
Yes   No

What kind of gun(s) are in your home?   A. Handgun B. Shotgun C. Rifle D. Other _____ E. None

Has the child ever been hospitalized? Yes   No When? _____ Where? _____
Why? _____

How would you rate this child's health in general?   A. Excellent B. Good C. Fair D. Poor

What are your main concerns about your child? _____
_____
_____

How old are you? _____ years old   Are you? A. Single B. Married C. Separated D. Divorced E. Other

Does anyone in your household smoke? Yes   No
Do you currently smoke cigarettes?   Yes   No   If yes, how many cigarettes do you smoke per day? ____

When you were a child

Did either parent have a drug problem?   yes   no

Were you raised part or all of the time by foster parents or relatives (other than your parents)?   yes   no

How often did your parents ground you or put you in time out? A. Frequently B. Often C. Occasionally D. Rarely E. Never

How often were you hit with an object such as a belt, board, hairbrush, stick, or cord?
                                                                            A. Frequently B. Often C. Occasionally D. Rarely E. Never

Do you feel you were physically abused?   yes   no

Do you feel you were neglected?   yes   no

Do you feel you were hurt in a sexual way?   yes   no

Did your parents ever hurt you when they were out of control?   yes   no

Are you ever afraid you might lose control and hurt your child?   yes   no

Would you like more information about free parenting programs, parent hot lines, or respite care?   yes   no

Would you like information about birth control or familt planning?   yes   no

Family Activities

How strong are your family's religious beliefs or practices?   A. very strong B. moderately strong C. not strong D. n/a

What religion/church/temple? _____

How often do you read bedtime stories to your child?   A. frequently B. often C. occasionally D. rarely E. never

How often does your family eat meals together?   A. frequently B. often C. occasionally D. rarely E. never

What does your family do together for fun?   _____

How often in the last week have you felt depressed?   0   1-2   3-4   5-7 days

In the past year, have you had two weeks or more during which you felt sad, blue, or depressed, or lost pleasure in things
that you usually cared about or enjoyed?   yes   no

Have you had two or more years in your life when you felt depressed or sad most days, even if you felt okay sometimes?   yes   no

Drinking and Drugs

In the past year have you ever had a drinking problem?   yes   no

Have you tried to cut down on alcohol in the past year?   yes   no

How many drinks does it take for you to get high or get a buzz?   1   2   3   4   5   6   7 or more

Have you ever had a drug problem?   yes   no
If yes, which ones? cocaine   heroin   methadone   speed   marijuana   other

Are you in a drug or alcohol recovery program now? yes no
If yes, which one(s)? _____

Would you like to talk with other parents who are dealing with alcohol or drug problems?   yes   no

Help and Support

Whom can you count on to be dependable when you need help? (just write their initials and their relationship to you)
A. No one   B. _____   C. _____
D. _____   E. _____   F. _____
G. _____   H. _____   I. _____

How satisfied are you with their support?   A. very satisfied   B. fairly satisfied   C. a little satisfied
                                                   D. a little dissatisfied   E. fairly dissatisfied   F. very dissatified

Who accepts you totally, including both your best and worst points?
A. No one   B. _____   C. _____
D. _____   E. _____   F. _____
G. _____   H. _____   I. _____

How satisfied are you with their support?   A. very satisfied   B. fairly satisfied   C. a little satisfied
                                                   D. a little dissatisfied   E. fairly dissatisfied   F. very dissatified

Whom do you feel loves you deeply?
A. No one   B. _____   C. _____
D. _____   E. _____   F. _____
G. _____   H. _____   I. _____

How satisfied are you with their support?   A. very satisfied   B. fairly satisfied   C. a little satisfied
                                                   D. a little dissatisfied   E. fairly dissatisfied   F. very dissatified

Thank you for helping us help your child and family!

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Chapter 11: Children Adopted or in Foster Care: Early Detection and Intervention

ROBIN K. BLITZ   WALN K. BROWN   JOHN R. SEITA

INTRODUCTION

Children in foster care and those who have been adopted (especially later in life) have inordinate risks for developmental as well as mental health problems. Within this chapter we provide two narratives. In the first, Dr. Robin Krause Blitz explains her work with foster and adopted children from the perspective of a pediatrician. She reviews American Academy of Pediatrics' policy, describes what she's learned from her long history of engagement with children in-care or adopted, and explains how specialized clinics can help. The second narrative is from Drs. Waln Brown and John R. Seita both of whom experienced foster care first hand. As adults, Drs. Brown and Seita became professional advocates for children in-care and provide intervention recommendations for professionals.

A Developmental-Behavioral Pediatrician's Experiences

About the Author

Robin K Blitz, MD is a board-certified developmental-behavioral pediatrician and Clinical Associate Professor in Pediatrics at Phoenix Children's Hospital, University of Arizona. She is a fellow of the American Academy of Pediatrics, the Society for Developmental and Behavioral Pediatrics, and Zero-To-Three, a national resource on child development in the first three years of life. Dr. Blitz established the Developmental Center for Foster and Adopted Children at St. Joseph's Hospital, piloted a health passport program for children entering foster care, and created the Developmental Clinic at the Phoenix Indian Medical Center. She received a First Things First grant to improve and expand resident and community physician education focused on young children's development and behavior. Dr. Blitz specializes in the unique needs of foster and adopted children, in utero alcohol and drug exposure, Attention Deficit Hyperactivity Disorder and its co-morbidities, autistic spectrum disorders, Fragile X syndrome, learning disabilities, the care of premature infants, and children with multiple developmental disabilities.

Dr. Blitz's Narrative

In 1997 I worked in our state Children's Rehabilitative Services (CRS) Clinic once a week, as a General Pediatric "Screener." My role was to see new and follow-up patients with complex medical conditions, review past records, assess history and physical examination, and triage to other medical subspecialty and therapy services. I also worked one day per week at the Phoenix Indian Medical Center (PIMC) running the Developmental Clinic.

One Monday in CRS Clinic, I had a patient scheduled who had a congenital heart malformation. This patient did not show up for his appointment. That same Thursday, I had an opening due to a cancellation at PIMC. Our administrative assistant had received a panicked call from a foster mother the day before, requesting an urgent appointment in my Developmental Clinic at PIMC. This mother and I had a long history because I had taken care of many of her foster children in the past.

At 8:00 AM, the foster mother and her new foster child came into my clinic at PIMC. This infant had been dropped off at her door, early Wednesday morning, transferred from a local emergency shelter, where the baby had been placed by Child Protective Services on Sunday night. The foster mother not only had significant concerns regarding the child's development, but was also concerned about how fussy this baby was, that he was not eating, and simply did not look "right."

Taking one look at this child, I noticed perioral cyanosis that increased with crying, tachypnea, and with overall irritability. Fortunately, my Developmental Clinic is located in the General Pediatric Clinic at PIMC. I asked my nurse to get a pulse oxygen reading and gather other vital signs while I listened to the baby's heart. I called my General Pediatric colleague to come help while we placed the baby on oxygen and notified the emergency department that the baby was headed over.

Once the baby was transported to the Emergency Department, I called the CRS nurse because I recognized

the baby's name from somewhere. Indeed, this was the same child with the congenital heart malformation who'd "no-showed" the previous Monday. He was supposed to be on Digoxin and Lasix. Fortunately, the CRS nurse still had the baby's records and was able to fax the information to our Pediatric Department at PIMC for transfer over to the Emergency Department.

Here's the other troubling part about this tale: Only because I worked in both clinics and because the foster mother knew me and trusted me to help, did this child receive much needed care. The baby had been dropped off on the foster mother's doorstep, with no medical history and no heart medication. The foster mother was left out of the loop, but nevertheless was expected to provide 24-hour care for this medically fragile child. This child had not yet been seen by a primary care provider, and the CPS caseworker had not shared any information regarding the child with the Primary Care Provider or the foster mother. This one event, on this one day, not only changed the life of this child, but also changed my professional career path towards more involvement and advocacy for children in-care.

EXPERIENCES FROM FOSTER CARE ALUMNI TURNED PROFESSIONAL: STRAIGHT FROM THE HORSES' MOUTHS

About the Authors

Dr. Waln K. Brown, is the Founder and CEO of the William Gladden Foundation. Dr. Brown spent his adolescence in a series of out-of-home placements, including an orphanage, juvenile detention facility, state psychiatric hospital and reform school. A former special education student who failed the 9th grade and graduated 187th in a class of 192 students, Waln earned a Ph.D. at the University of Pennsylvania. He has authored over 240 publications, including five books. Prior to founding the William Gladden Foundation in 1983, Waln held positions with the Pennsylvania Department of Education, the National Center for Juvenile Justice and the Sonia Shenkman Orthogenic School at the University of Chicago.

Dr. John R. Seita is a former youth at risk. The court removed John from his mother's home when he was eight-years-old. He spent the rest of his youth in multiple foster homes, detention facilities, group care settings and on the streets. Abused and neglected as a child, he describes his journey though children's institutions and countless foster homes as a litany of degradation and humiliation. Because of Dr. Seita's advocacy on behalf of foster children, his alma mater, Western Michigan University, developed the John Seita Scholarship to help undergraduate students who have aged out of foster care in pursuing their educational goals. In 2007, John received the Ruth Massing Foster Care Alumni of the year award from the Casey Family Programs. Dr. Seita is the author of four books, dozens of chapters and numerous scholarly articles about foster care. Dr. Seita is Assistant Professor of Social Work at Michigan State University.

Drs. Brown's and Seita's Narratives

The various professions serving foster youth tend to forgo alumni feedback in favor of theory. Although the former does not preclude the latter, the latter is of questionable value if it doesn't match the experiences of the former. Put plainly, professionals who rely on theory in lieu of client feedback put the lives of foster youth at risk. Conversely, alumni feedback facilitates both a positive in-placement experience and a healthy adult outcome. Failure to embrace this commonsense approach when formulating policies, programs and "best practices" is the main reason why many foster youth suffer while in-placement, and why far too many emancipated foster youth struggle to transition successfully to independent living.

A Wayne State University study of youth aging out of foster care in Southeast Michigan found that among 268 recently emancipated alumni: 49% experienced homelessness; only 41% graduated high school; 48% received public assistance; and 70% lived below the poverty level.[1] On average, these youth were: unemployed 48% of the time since leaving care; 33% had significant mental health problems; 27% were imprisoned for 8 months on average; 33% were substance abusers; and 48% became pregnant as teens. Costs accumulated by this group during the first 3 ½ years after leaving foster care amounted to: $1.0 million in public assistance;

$1.6 million spent on prisons and jails; and $3.7 million in lost wages compared to working full time at minimum wage.

Precisely why so many among the Wayne State University sample of foster care alumni struggled to transition successfully to independent status is open to discussion. Family and personal factors predating foster care experiences—such as abuse and neglect, behavioral or emotional disorders—certainly played a role. Nevertheless, in-placement experiences resulting from policies, programs and "best practices" that failed to include alumni feedback, surely affected each child's outcome.

A prime example of a failed policy that pursues theory despite alumni feedback to the contrary, is the "best practice" of favoring the placement of youth in foster homes over orphanages and children's homes. Youth placed in foster homes comprised the sample in the Wayne State University study, and produced extremely high rates of post-emancipation adjustment problems.

In sharp contrast, a 1994 column written by Richard McKenzie for the Wall Street Journal argued that privately run orphanages are a "pretty good idea for some children."[2] Dr. McKenzie later detailed the positive influence of growing up in a North Carolina orphanage in his memoir "The Home: A Memoir of Growing Up in an Orphanage."[3] His book recounts surveys of more than 1,000 living alumni of "The Home" who now average 66-years of age. When asked if they would rather have grown up in foster care, over 90% said "no," less than 1% said "yes," and the rest were uncommitted. The orphans in residential facilities described themselves as "very happy" at twice the rate of the general population, and surpassed national norms in education, employment and income. Compared to the general population, those from orphanages reported relatively low rates of emotional difficulty, incarceration or need for public assistance.

Drs. Craft and Friedland, authors of "An Orphan has Many Parents," grew up in orphanage care and reinforce Dr. McKenzie's positive sentiment regarding orphanage over foster care. In an informal survey of more than 200 boys and girls who aged out of The Pride of Judea, a Jewish orphanage located in Brooklyn, New York, the authors found that none of the residents were ever involved with the law, all graduated high school, most graduated college, and many went on to graduate and professional schools.[4] One of the authors asked me in a recent email to add a comment to this chapter: "Many of those surveyed also had foster care experience in their childhood and, to a person, all felt that their orphanage residency was far superior in every respect."

Dr. Rosalind Folman, who experienced both orphanage and kinship care, makes this perceptive and vitally important point: "Finally, one major theme came to the fore, both in my life and in the lives of the hundreds of children whom I have interviewed: It is how children live that matters, not where children live." The best example of this is an overlooked and underestimated group of foster children who thrive because of their placement experience: children who grew up in institutions, such as children's homes and orphanages. Because of the misguided emphasis on 'where' children live, as opposed to 'how' they live, policymakers and politicians dismantled many of these institutions in favor of foster care. They mistakenly believed that foster care would provide children the next best thing to the nuclear family ... this approach failed decades ago."[5(p156-157)]

Because of the continued blind reliance on this failed policy, too many foster children suffer much emotional turmoil resulting from multiple placements; exacerbating pre-existing mental health issues. Stability and mental health are simpatico, yet most boys and girls who spend a few years in the foster care system will be moved at least once if not several times, including juvenile justice and mental health placements. Some youth even experience all three, often to their further detriment.[6]

In the epilogue of our own book, "Growing up in the Care of Strangers," we summarize personal reflections of the eleven authors who shared their foster care experiences as follows: "... the negative effects of multiple placements rings as clearly as a church bell in many of the personal histories, but as powerful and logical as this truth would seem, children continue to suffer unnecessarily from the instability of having to adjust to multiple unfamiliar settings. Sometimes they remain only in the foster care system, while other times they move into the juvenile justice and mental health systems too, perhaps experiencing double-digit placements."[7(p159)]

Our book describes the negative effects of enduring multiple placements felt by all the books' contributors, "Talk about causing developmental issues! Consider the emotional trauma you might have suffered had you been abruptly separated from your family in childhood and then moved about in the care of one stranger after another until eventually, you came to believe that the reason you do not 'belong' is because you are worthless and unlovable. Now imagine what it is like to carry that psychological burden into adulthood and perhaps to the grave." If you read the authors' chapters carefully, you see that even though they have transitioned to adulthood 'successfully,' the childhood trauma of feeling unattached, unwanted and unimportant remains. Belonging is essential for healthy human development just as surely as instability promotes dysfunction.[7]

Another example of failed policy pursuing theory despite alumni feedback to the contrary, is making kinship care a preferred placement option. Kinship care is not a panacea; in fact, it can be quite the opposite. In "The Home: A Memoir of Growing Up in an Orphanage," Dr. McKenzie asked his fellow orphans if they would have preferred to grow up with the available members of their own families.[3] Over 80% said "no," 10% said "yes," and the rest were not able to say.

Dr. Folman describes her kinship experience this way: "While I lived primarily in my maternal grandmother's home, it was a shared guardianship with her six children. This kinship constellation was supposedly my new family. My grandmother hoped her children would take me in and raise me as their own, but no one wanted me. In fact, they did everything they could to communicate that I was worthless, unloved, unwanted and definitely not part of their family. I still remember these hurtful words, 'Even your own parents don't want you, so you should be thankful that you have a roof over your head and aren't sleeping on the street.' In today's foster care system, the rush to place children in kinship care leads to pressuring relatives to take the children without any consideration of the relationship between the children's parents and the relatives, often causing children to pay the price for earlier family conflicts or animosities."[5(p150-151)]

Indeed, of the eleven contributors to our book, all of whom spent time in kinship care, none had a kind word to say about their experience.[7] This is not to imply that all kinship care placements are as deleterious as Dr. Folman's or as uniformly inappropriate. Many families welcome dependent relatives into their homes and lovingly raise them as their own children. But blood does not automatically equate to an appropriate match. As foster care alumna, Dr. Angelique Day, advises, "Kinship care homes must receive the same careful monitoring and the same resources as non-kinship homes, if we are to ensure the safety and success of children and youth placed in relative care." [8(p162)]

Logic dictates that to improve a product, one should solicit feedback from consumers and then adjust the product accordingly. This does not happen in child welfare, constituting a serious "blind spot" that jeopardizes the in-placement experiences and adult outcomes of foster children. Rather, as Dr. John Seita learned by surveying 104 private Michigan child welfare agencies, only six of the responding agencies had board members who were child welfare alumni, and no agencies had either a chief executive officer or any executive staff who had first hand experiences in foster care. We suspect this is true nationally, not only for foster care, but also for juvenile justice and children's mental health placement services.[9]

Several contributors to our book condemned this obvious omission of client experience in the decision-making process at both the policy-making and program administration levels.[7] The authors ruminated about how people who have not walked in their shoes can possibly know what is in their best interest. This is akin to a man describing menstrual cramps to a woman or a trust fund millionaire telling homeless people how to pull themselves up by the bootstraps. There is no substitute for the perspective gained by actually experiencing real-life events.

Kids need role models too, especially children and adolescents burdened with the misfortune of having incompetent or troubled parents or no father or mother at all. They need to know they are not alone in experiencing fractured families and foster care placements, and that others somehow managed to become productive members of society. Who better to address the challenges than someone who has had similar experiences and can thus inspire trust? Foster care alumna, Meloney Barney, describes meeting with her new therapist this way: "When I met Dr. Folman...who was a former foster child, not a therapist; I opened up like a flower at dawn. She was so like me. She so understood me. She knew my pain and confusion."[10(p164)]

Current foster children need opportunities to learn how alumni survived foster care and made a better life for themselves after emancipation. Former clients should be included on advisory and directorial boards and engaged in policy and programmatic decisions. Such board members are also well-positioned to serve as role models to help children overcome the emotional challenges arising from out-of-home placements, and view success as realizable.

The problem is that the obvious—but largely ignored—resource of alumni feedback remains mostly untapped. The consequence of this "blind spot" is that the almost one million American girls and boys placed in foster homes, juvenile justice and mental health facilities each year are deprived of the experiential wisdom, guidance and dedication to excellence that only alumni can provide. Until this systemic myopia is remedied, hundreds of thousands of vulnerable children will suffer for want of understanding.

In horse racing the best way to pick a winner is to ask those in closest touch, such as the trainer or a stable boy. An even better way is adhering to the idiom "straight from the horse's mouth"—meaning that the highest authority comes from those who actually experienced various types of out-of-home placements, i.e., "the horse itself."

ADDITIONAL RESEARCH ON CHILDREN IN-CARE OR ADOPTED LATER IN LIFE

On any given day, approximately half a million children are in foster care in the US.[11-12] Most of these children are young and entering the system during the most active time of brain growth and development.[11] Neuronal synapses are being formed, pruned and dependent on environmental stimulation. Neglect, abuse and other types of trauma have an adverse impact on the structure and function of the developing brain. Children's ability to form healthy attachments are created in these early years. It is crucial that young children in foster care are provided with the stability, nurturing, medical care and safe environment necessary to repair damage from prior experiences within problematic biological homes and from the stress of separations.

All children require ongoing medical care via monitoring of health, developmental, behavioral, and mental health status, optimally in a medical home. Children in foster care require more scrutiny than most due to their history of neglect and trauma, the separations and insecurities associated with foster care, the significant emotional distress often arising from visits with birth parents, transitions and changes of placement.[13]

The Child Welfare League of America (CWLA) and the American Academy of Pediatrics (AAP), in 1988 produced the *Standards for Health Care Services for Children in Out-of-Home Care*.[13-14] Healthcare providers, foster care workers and agencies alike, should adhere to these standards in order to care for our society's most vulnerable children.

According to the AAP policy statement on foster care, all children removed from their biological homes and placed in foster care should receive an initial health screening soon after placement, in order to identify acute or chronic conditions (medical, dental, and mental health) that may require immediate attention and treatment.[11,13] The AAP policy statement also states that children in foster care need more frequent well-child visits with "reassessments monthly for the first 6-months of age, every 2 months for ages 6- to 12-months, every 3 months for ages 1- to 2-years, every 6 months for ages 2-years through adolescence, and at times of significant changes in placement (foster home transfer, approaching reunification)."[13]

Primary care physicians (PCPs) are in an ideal position to guide the care necessary for these children by providing a medical home. In order to do this, PCPs need to recognize the high prevalence of chronic health conditions, developmental disabilities, and psychosocial problems found in children in the foster care system i.e., provide continuity of care, comprehensive care, and coordinated treatment. PCPs need to be aware of the special healthcare needs of children in out-of-home placement. Often, the PCPs must investigate children's risk factors and play a major role in care-coordination including referrals; all in partnership with the child welfare agency. The case worker is often the legal guardian of the child and

likely has more longitudinal information than any other person involved.

But for children in foster care, continuity of care is often significantly less than that of the general population.[15] Because multiple foster care placements are common, PCPs often change. Advocates and researchers recommend paper or electronic health passports, and these have been used in some States. Nevertheless, a national system of care continuity has yet to be established. Thus communication between PCPs, foster parents, foster caseworkers, and biological parents is critical in order for children in foster care to receive coordinated care.

The American Academy of Child and Adolescent Psychiatry published a policy statement supporting family participation in all aspects of planning, service delivery and evaluation.[16] Using the Federation of Families' definition, "family" is defined as "biological, foster, and adoptive parents, grandparents and their partners, as well as kinship caregivers and others who have primary responsibility for providing love, guidance, food, shelter, clothing, supervision, and protection for children and adolescents."[17] Caseworkers are encouraged to gather as much information from the biological parents as possible, along with all past medical, school, intervention history, and current medications.

Communication is crucial between PCPs and foster parents because these professionals are on the front-line caring for children. Foster parents should be apprised of any and all medical, developmental, and behavioral issues regarding children in their care. This means allowing foster parents to understand the history of a child's removal and placements (often multiple), and educating foster parents on the impact of past trauma, neglect, and multiple placements on the developing brain.

Table 11-1. Summary of Research in Foster Care and Adoption Later in Life

- Compared to other children living in poverty, children in foster care have increased rates of mental health problems, chronic medical conditions, developmental delays, educational disabilities, and other behavioral problems.

- Studies estimate that 35% - 85% of children in-care have mental health, emotional or behavioral problems such as Oppositional Defiant Disorder, Attention Deficit Hyperactivity Disorder, Conduct Disorders and Anxiety Disorders. The percent of young children entering foster care with developmental problems ranges from 20% to 60% and deficits include language disorders, delayed fine motor skills, learning disabilities, poor social-adaptive skills, cognitive impairment, and mental health problems.

- More than 40% of children in care qualify for special education services. Unfortunately, only 15% of those eligible receive intervention.[18]

- 40% to 80% have chronic health problems (infectious diseases, skin conditions, asthma, anemia, vision and hearing impairment, GI problems, enuresis, neurological disorders, dental problems); 43% have growth abnormalities; and 33% have untreated health problems (in addition to immunization deficiency).[19-21] These percentages are much higher than the general population.

- A study by McCue-Horwitz, Owens, and Simms found that community providers identify medical and educational needs of children in foster care, but to do not regularly identify their developmental and mental health needs.[21] In this study, the cohort seen in a multidisciplinary intervention program specializing in the care of children in foster care, were more likely to be identified with developmental and mental health problems, had higher referral rate for health services at baseline, and had more frequent follow-up care at 6- and 12-months of age.

- Identification of the developmental and mental health needs of children in foster care is crucial, because problems in these areas can affect the amount of time spent in foster care and children's ability to experience stable living conditions. By identifying early risks and problems and referring for intervention services, PCPs can promote healthy development during vulnerable periods of change.

- Children are often placed in care with only minimal records leaving foster parents with little to no information about health and educational issues or reasons for removal, i.e., the kinds of trauma children have endured.

Table 11-2. What Should Primary Care Providers Do Before, During and After a Visit?

Preparation

- Read up on the issues of children in-care and those recently adopted. PCPs who understand the multiple special needs of children in foster care and who can provide the much-needed comprehensive medical home are in the best position to coordinate children's care and facilitate better outcomes. PCPs should serve as an educator and resource for foster and adoptive families, encouraging communication and offering support. See the Resources Section below and *www.pedstest.com/TheBook/Chapter11* for live links.

- Recognize that developmental-behavioral screenings are vital to the comprehensive understanding of children's needs and to the success of a foster care placement. The Committee on Early Childhood, Adoption and Dependent Care recommends that the pediatric assessment should "at a minimum...[assess] the following areas:... gross motor skills, fine motor skills, cognition, speech and language function, self-help abilities, emotional well-being, coping skills, relationship to persons, adequacy of caregiver's parenting skills, [and] behaviors."[11]

- Have available quality screening measures (particularly ones with various administration methods): Hands-on (if a child is cooperative and foster parents are not sufficiently familiar with the child to complete measures independently), versus clinician observation or care-taker self-report. New foster parents may have a "gist" of children's issues and so may be able to describe concerns but have initial difficulty answering questions about specific skills—hence why hands-on/professional observation measurement methods should be available. A veritable arsenal of quality measures is requisite (see Chapter 4 for options) and should include:

   (a) One or more types of developmental-behavioral/mental health measures focused on children (and preferably use of assessment-level measures that better define strengths and weakness. See Chapter 4 for more information);

   (b) A measure of psychosocial risk such as the *Family Psychosocial Screen*;

   (c) A measure of parent-child interactions (focused on the current care-taker such as the *Brigance Parent-Child Interactions Scale*);

   (d) A narrow-band measure of ASD such as the *M-CHAT*;

   (e) A substance abuse screen such as the *CRAFFT* (for use with adolescents and biological parents);

- Establish in advance a collaborative relationship with IDEA personnel and encourage them to join you during initial visits to provide assistance with comprehensive screening/assessment.

Before and During Visits

- Make sure office staff instruct the caseworker and foster parents to bring the child's medicines and medical records, Medicaid card, etc;

- If possible, have staff search the national or state immunization registries to determine the child's vaccination history;

- If your clinic has a social worker or experienced nurse on staff, ask that they be assigned to the visit to assist with interviewing, records gathering, completion of measures, etc;

- Office staff should also request that both the foster parent and the caseworker be present at the first visit and that the case worker fax or bring case notes and other details about the reasons for a new placement, frequency of prior placements, and the biological family's history;

- Schedule a new patient/complex type preventive service visit with a time frame of one if not two hours for children newly in-care;

- Directly address the child (and the caretakers/caseworkers). If the child has brought photos or a favorite toy, talk with him about these. With preschoolers and older children, acknowledge that changes are scary but that things will get better. Explain the purpose of the visit;

Table 11-2. Cont'd

- Per AAP recommendations[11,13] for what should occur in the first 24 hours of placement, ask the case-worker to complete, on behalf of the biological family, substance abuse screens (e.g., *FPS* and the *CRAFFT*) in order to gather information on parental history of substance abuse). Older children can also complete the *CRAFFT* on their own or by interview. Mental health screens should be administered [e.*g*., *Pictorial PSC* (via youth self-report if the child is old enough), or broad-band developmental screens that also measure social-emotional/behavioral domains];

- Because school records are unlikely to be available, the *SWILS* should be administered to view academic status (see Chapter 9). For younger children administer broad-band developmental-behavioral screens (*ASQ + ASQ:SE, PEDS + PEDS:DM)* to get a sense of developmental status. If possible, also administer the *M-CHAT* to identify features of ASD (although it is important to recognize that neglected children often have ASD symptoms but not the actual condition—see case example in Chapter 4);

- It is wise to ask the foster parent to complete the *FPS* and the *Brigance Parent-Child Interactions Scale (BPCIS)* (or PCPs can complete, about themselves, the *BPCIS* by observation). See Chapter 10 for copies of these measures or download at *www.pedstest.com/TheBook/Chapter10*;

- While the foster parent and case worker are busy completing screens, PCPs can conduct the acute medical assessment required within 48 hours of placement to identify infectious diseases, skin conditions, asthma, anemia, vision and hearing impairment, GI problems, enuresis, neurological disorders, dental problems, immunization deficiency, growth problems, etc.).[19-21] See Chapter 5 and Appendix A for details on the physical exam. Make use of the national or state immunization registries to determine vaccination status or have office staff investigate prior to the visit;

- Observe the child for attachment issues—moodiness, excessive clinginess and fears, disinhibition, inattention, hyperactivity, etc. Attachment problems and disorders are quite prevalent in this population, and comprehensive assessment must always address attachment issues in the child and must be done with every change in placement. A recent study cited in *A Call to Action on Behalf of Maltreated Infants and Toddlers* sponsored by the American Humane Association reported that over 80% of infants who have been maltreated have problems with attachment to caregivers;[18]

- Once you have the completed screens, take time out of the exam room to score and identify the major issues at hand;

- Interview the foster parent and caseworker (and older children) separately if needed:

  (a) Interview the new foster parent about the terms of placement (temporary or potentially permanent), willingness to take on a new child, numbers of foster and biological children in the home, history of voluntary relinquishment and why (e.g., trouble handling teenagers, children with challenging behavior, or chronic illness). Recognize that foster parents, often those providing kinship care, may do so under duress, i.e., alternative placements have not been found. Look for signs of stress, disinterest or unwillingness. These observations will assist you in creating recommendations for services or alternative placements.

  (b) Next ask the caseworker the same questions. If there are known or likely problems with this placement, discuss options such as residential services. Recognize that many foster care workers find it anathematic to recommend residential placement. Family reunification is often the policy of child welfare services even if reunification and a series of troubled foster care placements are clearly not in the best interests of the child. Healthcare providers can recommend alternatives if these seem a wiser and more stabilizing approach.

Drawing Conclusions and Generating Documentation

- Ensure that part of the visit provides time for the cognitive work of assimilating the plethora of data accumulated (and for dictating a detailed report);

- Recognize that the measures used, the results of the physical exam, reporting and interpretation of results, and recommendations for services will become a part of legal documentation for each child in-care. Detailed, careful reporting is essential and copies should be sent to all involved with the child;

table continues...

Table 11-2. Cont'd

- PCPs comprehensive assessment should direct schools, foster parents, and caseworkers to develop an individualized, court-approved, treatment plan and ongoing monitoring. Ensuring a medical home is essential given the multiple needs of children in foster care;

- Always recommend developmental/academic, mental health interventions along with any needed health treatment for children in-care. Early interventions for delays/disorders are crucial for ameliorating the long-term effects of neglect and trauma on the developing brain. Recommendations may include mental health referrals, special education services, neuropsychological and speech-language assessments and treatment, physical and/or occupational therapy evaluations and interventions, opthamological, dental, audiological, lab tests, and other medical subspecialty work-ups, child and family counseling, etc. PCPs should include opinions about the adequacy of placement decisions: appraising the care, attention and stability of foster parents is crucial;

- Discuss recommendations with foster caseworkers and foster parents, so that all involved are aware of the child's needs. Communication and coordination is mandatory in the care of this very vulnerable population;

- Include recommendations for follow-up visits and provide foster parents a list of resources to support their efforts.

INFORMATION RESOURCES

The below are included as live links at *www.pedstest.com/TheBook/Chapter11*.

Child Welfare League of America   *www.cwla.org*

A coalition of hundreds of private and public agencies serving vulnerable children and families since 1920, the site provides standards of care, leadership training, covers research on child welfare, a national data analysis system, publishes the Child Welfare Journal, e-newsletters, etc.

Healthy Foster Care America   *www2.aap.org/fostercare*

From the American Academy of Pediatrics, this site offers AAP policy statements, helpful videos including "10 Things Pediatricians Should Know About Children in Foster Care", guidance on care coordination, transitions, research, policy statement for parents, judges, advocates, etc.

Zero to Three   *www.zerotothree.org*

Includes information about court teams, child maltreatment, impact of trauma, etc. The site has numerous webcasts, and broad information about the foundations of health development and mental health.

American Academy of Child and Adolescent Psychiatry   *www.aacap.org*

Houses practice and training guidelines for medical/nursing students, residents, and primary care providers. Includes downloadable Facts for Families (in multiple languages) and a child and adolescent psychiatrist finder.

Adoption.com   *www.adoption.com*

Has information about adoption, both domestic and international, helping children understand adoption according to age, adoption discussion forums, etc.

William Gladden Foundation   *www.williamgladdenfoundation.org*

Has helpful articles and books on helping foster and adopted children and their families with placement options, adjustment, mental health issues, delinquency, anger, grief, self-esteem, bullying, etc.

Chapter Comments: *We must do better by foster children, and before foster and adoptive parents. For starters, better communication across health, social services and care-takers is needed to ensure that critical information about health issues follow the child. We also need to do better by biological parents in crisis—screening and addressing difficulties, and wherever possible, preventing mental health problems, housing and food insufficiency, etc. Adoptive and foster parents need ongoing help managing children who may be understandably difficult with the goal of stabilizing living situations. We need to recognize and address the highly prevalent developmental and mental health problems of children in-care. All such children and their (many) families need utmost scrutiny.*

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CHAPTER 12: DIVERSITY AND CULTURAL ISSUES IN EARLY DETECTION AND INTERVENTION

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INTRODUCTION

The United States of America is home to the third largest population in the world (after China and India). The US is a representative democracy in which the rule of the majority is tempered by the rights of minorities. Even so, disparities of income are enormous and health care is not universal. We are a diverse nation, with 50 States, 51 capital cities, and many far-flung territories from the Caribbean to Pacific Islands. Because the US encompasses an enormous land-mass, literacy is valued, i.e., ability to read newspapers, and so 99% of the population read reasonably well. School attendance is compulsory from age 5 (or so) through age 16, although 85% continue through age 18 and receive a high school diploma, and 30% complete college and beyond (*www.census.gov*).

English is spoken, to some extent, by 94% of the population, but the US Federal government has not declared English the official language. Several States legislated official languages in addition to English (e.g., Spanish in New Mexico and California; French in Louisiana; Hawaiian in Hawaii). About 12% of the population i.e., ~36 million people, do not speak English well, and 6% do not speak English at all. After English, Spanish is the most frequently spoken language, followed distantly by French, Chinese, Filipino, Vietnamese, German, Korean, and Arabic (*www.census.gov*).

In this chapter, we've tried to pair terms for ethnic minorities in current use by the US Census Bureau (e.g., African-American and Black, Latino and Hispanic, etc.). We describe four ethnicities whose cultures hold distinct values and methods of child-rearing: Latinos, Asians, Middle Easterners, and Native Americans. We've not provided much coverage of unique groups such as Christians and Anabaptists who home-school, gay and lesbian youth and the unique support they need, but have included many references and links to sites for professionals and family development. In all cases, professional understanding of culture and diversity is essential for accurate early detection and effective parent-provider communication.

LATINO-AMERICANS

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Demographic Characteristics of Latinos

Latinos are the largest racial/ethnic minority group in the United States, and among the fastest-growing. The Latino population accounted for more than half of US population growth from 2000-2010.[1,2] The Latino population is projected to be 102.6 million by 2050, comprising 24.4% of the projected US census.[1] In 2010, there were 50.5 million Latinos in the US, accounting for 16% of the total US population, and 17 million Latinos were less than 18-years-old. The majority of Latinos are of Mexican origin (64%), followed by Puerto Rican (9%), Central American (7.6%), South American (5.5%), Cuban (3.4%), Dominican (2.8%), and other Latino groups (7.7%).[2] About 16 million Latinos are limited-English-proficient (LEP), defined as self-rated English-speaking ability of less than "very well," and 37% are foreign-born.[2] Almost one in four Latino children lived in poverty in 2009 and 2.6 million lacked health insurance coverage, resulting in challenges for access to care for this population.[2] Latina mothers, on average, have lower educational attainment and higher unemployment compared with white and African-American mothers.[3]

Health and Developmental Problems in Latino Children

Latino youth have the highest school dropout rates in the US (17.4%),[4] and the lowest rates of enrollment in early childhood education programs (20%),[5] and a greater proportion of Latino children are held back in school compared with white children.[6] There is a scarcity of high-quality preschools in low-income Latino communities, and Latino children are underrepresented in early childhood education programs compared with children of other races/ethnicities.[7,8] Latino children also have higher rates of learning problems and emotional problems, such as depression, anxiety, and phobias.[6,9] Although Latino children

appear to have similar rates of ADHD as white and African-American children, they are less likely to be diagnosed with ADHD and treated with medications.[10] Parental reports of ADHD symptoms are lower among Latinos compared with whites and African-Americans, and Latino children receive medications for ADHD at half the rate of white children, despite evidence that Latino children benefit from these medications when they are used.[10] The types and rates of developmental concerns also may vary by Latino subgroup. Puerto Rican children, for example, have high rates of developmental problems (20%), including 11% with chronic developmental conditions.[11]

Latino Normative Cultural Values

Normative cultural values noted among various Latino subgroups include *simpatía,* a value for politeness and avoidance of hostile confrontation; *personalismo,* which entails the creation of warm, personal relationships; *respeto,* which encompasses the maintenance of harmonious relationships through respect for the self and others, respectful behavior towards others, and respect for each family member's role in the family; and *familismo,* which stresses the importance of the family in providing support, maintaining family ties, loyalty to the family, and valuing the family over the individual.[12,13] The normative Latino approach to the education of children can encompass both academic and moral education, and may include training in responsibility, morality, and interpersonal relationships, with "well-educated" children perceived normatively as needing good manners, politeness, respect, and responsibility.[8,12] These values can influence parenting practices, perceptions about development, and parental interactions with providers.

Cultural Influences on Developmental Expectations and Developmental Activities

Latino normative cultural values tend to emphasize relationships and social-emotional development in younger children, and place less importance, on average, on the independent completion of motor tasks.[12] Children of Latino immigrants enter kindergarten with similar social-emotional skills as white children.[8] The normative child-rearing goals and priorities of Latino families are important to consider when evaluating the development of Latino children. *Familismo* and *respeto* emphasize compliance with the authority of parents rather than asserting independence. Ethnographic research of Mexican mothers indicates a common belief that children do not have the reasoning ability to meet expectations for behavior until 6-years of age.[12] After this age, however, parents expect children to adhere to strict rules and behavioral expectations, with harsh consequences for violation of rules. Studies also show that Latina mothers spend more time conducting tasks alongside their children under 6-years-old, compared with European-American mothers who encourage greater independence.[12]

Developmental expectations and the influence of cultural values on parenting may vary by the level of acculturation, socioeconomic status (SES), and Latino subgroup. Parents who are less acculturated and are lower SES may value proper respect more than do higher acculturated, higher SES parents, who may place a greater value on autonomous behavior.[12] The emphasis on the value of familial support is similar across several Latino groups and does not decrease with acculturation.[12] Puerto Rican mothers have been shown to expect their children to name colors later than do white mothers, and to smile and put on shoes later than mothers from other racial/ethnic groups.[9] Latino and Spanish-speaking parents with limited-English proficiency are less likely to read to their children daily and spend less time reading with their toddlers and preschoolers; those who participate in literacy programs read to their children more often.[8,14] When formulating care plans with Latino families, clinicians should therefore address parental expectations about children's development and emphasize activities that promote motor and language development, in addition to social-emotional skills.

Parent-Provider Communication

Normative cultural values also may affect parent-provider interactions. *Respeto* may extend to a respect for the authority of healthcare providers, leading to parental hesitation to ask questions.[7,13] Latinos may prefer a physician-directed style, with greater preference for delegating decision-making to providers

than do whites.[15] The physician may be viewed as the expert rather than a partner in care, and parents may view their role as following through on instructions provided by the expert, rather than questioning or clarifying physician advice.[7] This may vary by parental acculturation level. Latino parents may perceive encounters with clinicians to be less participatory than parents of white children.[16] Less-acculturated Latino parents, however, may perceive visits as more participatory than more-acculturated Latino parents.[16]

Personalismo is an important normative cultural value, and includes a social component within the parent-provider interaction and in establishing rapport with the child and family.[7] A failure by the physician to establish such a relationship with patients and their families may result in parental hesitation in bringing up concerns about their child, and a failure to comply with physician recommendations. In one study, Latino parents, significantly more often than white parents, reported their provider rarely understood parents' child-rearing preferences or took the time to understand their child's special needs.[3] Latino parents identify lack of understanding of Latino culture by physicians and nurses as a significant barrier to seeking care.[13,17]

Language Barriers

Language barriers affect access to care, communication, screening, and treatment.[18] Latino parents identify language barriers as the challenge in quality to care for their children.[13,17] LEP families also report higher support needs for children with special healthcare problems compared with non-LEP families.[7] Communication difficulties can lead to confusion about diagnostic and therapeutic options, and lower satisfaction with, and confidence in, providers.[7] Poor communication may be due to a lack of Spanish-speaking providers who can speak with LEP families or a lack of available, adequately trained medical interpreters.[11] Studies show that fewer than half of parents needing interpreters receive translation services.[13,19,20] The lack of interpreters or inadequately trained interpreters can lead to increased medical errors.[11,18,21] Compared with non-LEP patients, LEP patients are less satisfied with care and give lower ratings of provider communication.[20,22] Providers who work with LEP families should provide bilingual services or access to appropriately trained medical translators for all families.[23]

Lack of Culturally-Sensitive Services

Language barriers also impact the evaluation and treatment of developmental-behavioral problems in Latino children. For example, studies show variable results on the validity of commonly used behavior scales, such as the *Child Behavior Checklist* and *Conners' Parent Rating Scale*, among Spanish-speaking children and Latinos from different countries of origin.[11] There is also a lack of culturally-sensitive programs to assist Latino children with emotional/behavioral problems and academic deficits, and inadequate provision of educational services for Spanish-speaking families. Parents of Latino children with special healthcare needs report larger unmet needs for information compared with parents of other racial/ethnic groups.[7] Parents who experience language barriers in communicating with school personnel in addressing their child's behavioral or developmental problems may also be reluctant to seek help from professionals. A parental lack of perceived need for mental health care may be a barrier to obtaining services among racial/ethnic minority parents.[10] Providers should use instruments validated in LEP families and among Latino subgroups, address parental perceptions about mental and behavioral health services, and provide referrals to bilingual developmental intervention and therapeutic services.

Identification of Developmental-Behavioral Concerns

There are differences in provider elicitation of, and screening for, developmental-behavioral concerns in Latino children compared with children of other racial/ethnic groups. One study showed that provider elicitation of developmental and behavioral concerns was significantly lower for Latino children compared with non-Latinos, even among children at moderate/high risk of developmental or behavioral disorders.[24] Less than one-third of parents in Spanish-primary-language households reported provider elicitation of developmental and behavioral concerns.[24] Another study showed that

Latino parents in Non-English-Primary-Language (NEPL) households, particularly those without a usual source of care, are less likely to experience provider elicitation of developmental-behavioral concerns, even after adjusting for SES.[25] Children of Latino parents who received needed referrals also are less likely to experience provider elicitation of developmental-behavioral concerns.[25] These recent findings update those of earlier studies which suggested that less-acculturated Latino parents were more likely to report receipt of a developmental assessment than other racial/ethnic groups[26] and that parents who completed surveys in Spanish were more likely to report that their child's provider informed them that a developmental assessment was performed.[3,26]

Latino parents may have a different perception of normal development compared with parents of other racial/ethnic groups, and this may affect the identification of developmental concerns by parental report. A study of immigrant South American mothers found that they had difficulty answering questions about normal child development, including developmental milestones such as babbling, and about the role of parents in their child's development.[27] Latino parents may have more concerns about medical and sensory issues than social or language development. Latino parental reports of an emotional, developmental or behavioral problem in their child are lower for children in Spanish-primary-language households than non-Latinos, although quality of translations is a contributor to lower rates of concerns.[24] It is also critical to ask parents about their knowledge and expectations of normal child development, in conjunction with provider assessment of developmental milestones.

Language and culture play a significant role in Latino parents' perceptions of their children's development, access to care, accurate identification of disabilities in Latino children, and provision of appropriate services. Providers should be aware of cultural influences on Latino parents' communication with providers and developmental priorities for their children, and modify their behaviors accordingly to more accurately elicit concerns and identify children in need of services. Providers should also minimize language barriers to accessing care, use appropriately trained interpreters and validated instruments. Providers can thereby appropriately identify children in need of early intervention for developmental disabilities and provide referrals for linguistically and culturally-appropriate intervention and therapeutic services for Latino children and families.

ASIANS AND ASIAN-AMERICANS

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Growth and Diversity

Asian-Americans are one of the fastest growing ethnic groups in the United States. They are also one of the most diverse populations due to highly varied educational and socioeconomic backgrounds, cultural/linguistic characteristics and the unique conditions of their respective countries of origin. More than 65% of the Asian-American population are foreign-born; the major countries of origin include China, India, Korea, the Philippines, and Vietnam (*www.census.gov*).

Cultural/Linguistic Characteristics

Despite such diversity as well as rapid growth and increasing visibility, Asian-American immigrants and refugees have been persistently confronted with stereotypic perceptions. These perceptions serve to disguise the reality of distinct lifestyles, customs, traditions, social norms, values, and folk beliefs with ancient religious and philosophical origins. In particular, the Chinese, Korean, and Vietnamese cultures are rooted in some of the world's oldest civilizations. A deeper understanding of these roots enhances healthcare professionals' ability to more effectively serve Asian-American immigrant families (particularly those with children who may have special needs). Among selected Asian ethnic groups, Chinese, Koreans, and Southeast Asians (specifically Cambodians, Laotians, and Vietnamese) collectively represent approximately half of the total Asian-American population. A few examples of key cultural

and linguistic characteristics follow.

Religious Origins

Chinese, Korean, and Southeast Asian cultures have been principally influenced by the doctrines and philosophies of Confucianism, Taoism, and Buddhism—the "three teachings." Together with ancestor worship, shamanism (including animism and spirit worship) and Christianity, the "three teachings" evolved into a complementary system of blended beliefs. These beliefs further shaped the traditional collectivist values that are common to the various Asian cultures.

Values

The predominant Asian values pertain to family, harmony, education and selected virtues, and offer fundamental guidelines for living. The family, for example, is the basic unit of society and the central focus of the individual's life. Harmony is the keynote of existence. Successful academic achievement is the greatest tribute a child can bestow on parents and family. Virtues such as patience, perseverance, self-sacrifice, maintenance of inner strength, self-restraint, modesty, and humility are each considered necessary expressions of dignity that promote group welfare.

Child-Rearing Beliefs and Practices

Although traditional values have been transformed with time, the extent to which these have historically influenced child-rearing beliefs and practices among Asian cultures is readily apparent. The family is characterized by well-defined, highly interdependent roles within a cohesive patriarchal vertical structure. Parental roles and/or responsibilities typically entail significant personal sacrifice and accountability in return for the right to assume strict authority over children, including unquestioning obedience and loyalty. Children, in turn, are viewed as extensions of their parents. They are treasured, protected, and readily indulged within a very nurturing, secure, and predictable social environment (involving both immediate and extended family members) throughout infancy and the toddler period.

But among Southeast Asian cultures, Vietnamese parents traditionally avoid praising the infant and may become anxious if complimentary comments regarding the infant's health or appearance are made by others, for fear that a lurking evil spirit may overhear and attempt to steal the baby away. If an infant becomes ill, Cambodian parents may temporarily change the infant's name to confuse the spirits. Such more traditional child-rearing beliefs and practices promote family interdependence and deference to the needs of the group.

Health Beliefs and Practices

Among Chinese and Korean immigrants and Southeast Asian refugees, the more common traditional health orientations include a blending of traditional Chinese medicine and folk medicine practices. Related fundamental concepts include maintaining balance between the cosmic forces of yin and yang, the "five elements," and internal body organs. The contrasts between traditional Asian healthcare practices and those of Western medicine include: Significantly fewer invasive diagnostic and treatment procedures; use of herbal medications versus prescription medications; and use of therapeutic massage, acupressure, acupuncture, moxibustion (various applications of burned dried mugwort), and dermabrasion. The importance of understanding these traditional healthcare practices is underscored by the fact that many Asian families utilize a "pluralistic" system of care that blends folk medicine with Western medicine. Dermabrasion, for example, derives from "hot–cold" therapy and is a traditional practice that is self-care in nature and one of the most common treatments among Southeast Asians. It is generally used to treat "wind illnesses" such as fever, chills, muscle ache, headache, and symptoms of a cold or a respiratory infection. The most popular form of dermabrasion is *coining* or *cao gio* ("scratch wind"). The practice involves first covering the affected area with a medicated ointment such as Tiger

Balm, then gently rubbing the area with the edge of a coin (or spoon), downward and away from the head, until dark marks that look like bruises can be seen. This procedure allows the "toxic wind" to be brought to the body surface and released; supposedly, the more ill the affected person, the darker the marks will be.

Beliefs about Causes of Disability

Many traditional beliefs and attributions regarding the etiology of various disabilities directly reflect traditional health beliefs about the varying causes of illness. Mothers may believe that they directly contributed to their children's disabilities by violating certain taboos during pregnancy. For example, an ethnic Chinese-Vietnamese mother worked throughout her pregnancy as a seamstress and thus frequently used scissors. She felt that this caused her daughter's unique congenital hand anomaly, which was characterized by fused fingers and a split thumb. This attribution is consistent with the traditional belief that women should avoid using scissors, knives, and other sharp objects during pregnancy for fear of causing a miscarriage or birth defects. Among other types of causal explanations for disability in a child is the more popular belief that it represents a divine punishment for sins or moral transgressions committed by the parents or their ancestors. For example, a Cambodian father attributed his daughter's "club" foot to an incident when he and his pregnant wife were escaping as refugees through the jungles of Thailand. In an attempt to hunt and kill a bird with a rock, he instead only wounded its claw and leg.

Language and Communication Styles

There is considerable diversity both within and among respective Asian languages. For example, in contrast to regional American-English dialects, up to ten Chinese dialects have evolved into distinctly different spoken languages that are mutually unintelligible (although written Chinese is readable across all dialects). By comparison, although 50% of the Korean vocabulary is derived from Chinese, the various Korean dialects are mutually understandable. Also, unlike all Chinese language dialects (which are tonal), Korean is a phonetic language.

The communication patterns of Asian languages serve to reinforce traditional cultural values and beliefs. Asian cultures are among the "highest context" cultures in the world. They are often dependent on the receiver's ability to correctly interpret the speaker's intent without specific reference to what he or she means. Consistent with the primary value of preserving harmony and face in human relationships, Asian languages employ communication patterns that promote harmonious social interactions. These include indirect communication styles such as reluctance to criticize or contradict overtly, and ability to "read" others' genuine attitudes, opinions or feelings through nonverbal cues. A significant amount of information is thus conveyed through nonverbal forms of communication, including silence (and the timing of verbal exchanges), facial expressions (e.g., smiling), eye contact, body movements and gestures, posture and positioning, and interpersonal space. An indirect style of responding, demonstrated by head-nodding and polite use of the word "yes," can actually mean "no." Consistent with the importance of nonverbal communications and their traditional meanings, certain customs may need to be observed. For example, touching the head (including a child's) is often considered threatening or offensive by Cambodians, Lao, and some Buddhists because of the spiritual belief that the head is the most sacred part of the body.

Promoting Insights Versus Stereotypes

The complex cultures of individuals and families within given Asian groups vary considerably and change over time. While stereotypic perceptions of Asian-Americans persist, their diversity and complexity obviously defies generalizations applicable to entire ethnic subgroups. This article was intended to enhance culture-specific knowledge. Readers are also encouraged to examine their own cultural values, assumptions, and biases. Throughout this process, those who serve Asian-American

families are called on to demonstrate flexibility, versatility, and sensitivity in responding to their diverse nationalities, immigrant histories, cultural orientations, language characteristics, life experiences, and unique personal circumstances.

Impact on Early Detection

As described in further detail in Chapter 19 covering research methods, T*he California Health Interview Survey (CHIS)* found that Asians reported an exceptionally high risk of developmental delay. *CHIS* asks parents about their concerns and the word "concerns" in most Asian languages can also mean "care," as in *"Do you care about how your child is talking?"* A stronger term such as "worries" is more helpful in teasing out delays. Within the clinical application of *Parents' Evaluation of Developmental Status,* in which the English version involves frequent use of the word "concerns," Asian language translations use "worries" instead, and this greatly reduces over-referrals. An alternative is to use only milestones-focused measures (although this degrades parent-provider communication and the quality of surveillance).

Many Southeast Asians who immigrated to the United States have a long history of exposure to violence. Many arrived without literacy skills or technological expertise. In these cases psychosocial risk factors may be frequent, especially poverty, limited education, language barriers, and mental health problems in parents or extended family. Although their close-knit families and communities offer some buffers to substantial life stressors, psychosocial risk requires careful screening and intervention as needed. Because use of complimentary integrative medicines is common, providers will need to become familiar with these substances and oversee their safety.

ARABIC-SPEAKING MIDDLE EASTERN FAMILIES

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The Middle East covers a large region of Western Asia and North Africa. The majority of Middle Eastern countries form what is called the Arab World. These countries are divided into two major regions: (1) The Sham Land or Greater Syria (e.g., Palestine, Jordan, Lebanon, Syria, Iraq, and Israel); and, (2) The Gulf Region (e.g., Saudi Arabia, Kuwait, Oman, Qatar, United Arab Emirates, and Yemen).[28] Middle Easterners define themselves as people who speak Arabic, have a link with the nomadic tribes of Arabia, and are primarily Muslims, although about half those who immigrate to North America are Christian.[28,29] Whatever the religion, Middle Easterners share unique cultural values, health and religious beliefs, family structure, parenting styles, and understanding of child development. Even so, across the many nations, child-rearing practices are not monolithic.

Culture and the Family

Families in the Middle East have many shared values and beliefs that emerge from being part of the Arab World. Commonalities can be seen in language in which Arabic is the dominant spoken language; Islam is the dominant religion; and the extended family is the basic structure.[30,31] Regional differences can be seen in types of food, dress, life styles, and the degree of exposure to Western culture. Perhaps these differences depend on the types of political systems (e.g., the application of democracy), patterns of living (such as rural, urban or Bedouin); by social class differences (such as upper, middle or lower class); and by religious affiliations (such as Sunni, Shi'ite, Druze, Alawi, Isma'ili, Copt, Orthodox, Maronite, Catholic, Protestant or Jewish).[28,29]

Core cultural values include commitment to family: honoring its traditions, fulfilling its obligations, practicing loyalty, and respecting its authority.[32,33] Family is the basic unit in Middle Eastern communities. Middle Eastern families are extended, hierarchical, and male-dominated.[30,31] The extended family remains the main feature that shapes the family structure.[34,35] The term "extended family" traditionally refers to living arrangements where more than one generation of the family live in the same household.[31(p78)] This

close proximity is considered influential within all family decision-making processes.

Family roles are clearly prescribed along the lines of gender and age. Fathers are required to fulfill specific duties. They are responsible for securing the family income, making decisions, and protecting the family. Mothers participate mainly by raising children, fulfilling spousal needs and guiding children through their development.[36]

Many families have encountered recent changes in structure and roles due to industrialization, urbanization, war and conflict, migration, and Westernization.[28] These factors promulgate increasingly nuclear and independent families (e.g., in household, income, socialization). For example, both men and women now participate in securing the family income: A role previously restricted only to men. Another change is use of servants from other countries. Moving toward nuclearity does not isolate the family from the extended one. It is expected in time of crises or stressors that parents reach out to their own parents (or any members of their extended family) for help and support.

Parenting styles are clustered into three patterns: (1) Inconsistent (combining permissive and authoritarian styles); (2) Controlling (combining authoritarian and authoritative styles); and (3) Flexible (combining authoritative and permissive styles).[37] Dwairy et al notes that parenting styles are affected by urbanization, parents' education, family economic level, and more importantly the social-political system in the country.[37] The authors also mentioned that more democratic and liberal systems (such as those found in Lebanon, Algeria, and Jordan) are associated with a flexible pattern, while non-democratic systems (such as those of Saudi Arabia and Palestinian occupied territories) are associated with a controlling pattern of parenting. Mixed and contradictory social-political systems (such as in Yemen and among Palestinians in Israel) are associated with inconsistent parenting. Such parenting patterns affect children's psychological development, parents' child-rearing practices, and understanding of children's behavior.

Children are considered gifts from God and are highly valued because they represent a continuation of the family name, traditions, and values. Children are frequently held, kissed, and cared for all the time. Raising children in the Middle East is shaped by Islamic principles and family traditions in promoting maturation and independency. When a baby is born, Islamic principles require the father to make "*Athan*" (the calling for prayer in Islam) in his/her right ear; and "*Eqama*" (announcing the preparation to pray) in his/her left ear.

The social values among Middle Eastern families dictate that mothers and their female helpers (e.g., unmarried daughters or grandmothers) are responsible for the care of infants and young children. In contrast, fathers, with some exceptions, are not fully involved in daily supervision or care of their children. Children are responsible for honoring and respecting their parents, acquiring family traditions, respecting and caring for their elders, and obeying parents.[29,30] In some cultures, children are allowed to "act like children" and rates of parental concerns about behavior are usually far less than in Western parents. It is not until adolescence that strict demands are placed on compliance. But as Middle Easterners interact increasingly with other cultures, there are greater demands for children to be obedient, polite, and disciplined. Children's misbehavior can be a source of shame and embarrassment; parents are often blamed for not being able to discipline their children.[32] The concept of individuality is neither practiced nor valued. Children, especially adolescents, are taught that family needs are a priority, over and above their own.

Health Beliefs

Health practices are affected by cultural beliefs and values. According to Middle Eastern beliefs, being healthy means being able to function without suffering from any physical complaints. Sickness is interpreted as the will of God and often thought to be a punishment from God.[33] Accordingly, families strive to accept God's will and to be close to him through prayers. A second health belief includes the concept of "hot and cold" as a source of illness.[32] This concept means that exposure to cold will cause gastrointestinal ailments, muscle pains, and respiratory diseases; treatment will be based on throwing

up, drinking hot drinks, and keeping the person warm.[33] A third health belief includes the concept of Evil Eye or being occupied by an evil spirit (especially with children).[38] Treatment in such cases consists of reading verses from the Qur'an (the Holy book for Muslims). These beliefs affect relationships with health providers, confidence in Western medicine, and willingness to seek health care.[33]

Understanding Child Development and Implications for Early Detection

Culture has a great impact on children's development. Taylor, Willies-Jacobo, and Dixon stated that "culture influences parenting practices, developmental expectations, and perceptions of child's behavior as well as the behavior itself." [32(p45)] Middle Eastern families care for their children with a great amount of love. In infancy, children are frequently held, kissed, spoken to, wrapped with blankets, attended to quickly when crying, breastfed until 2- or 3-years-old, and kept between parents in the same bed.[33]

Ability to walk and talk is considered a core feature for healthy development, but delays in spoken language may alert parents to seek professional help. A healthy child in Middle Eastern families should not be skinny or pale; instead being a chubby child is considered healthy.[33]

Delays in linguistic and motor domains are concerning to parents, but deficits in other devlopmental domains may not be noticed. Knowledge of typical development is increasing among families due to internet access, innovations in telecommunications, and TV broadcasting.

Detecting developmental abnormalities or disabilities in children is often correlated with stigma (especially if the child is female), feelings of guilt or shame among parents (they may interpret it as a punishment from God), community attitudes, and level of support.[31] Culturally, families might deal with these situations privately (relying on themselves) or by seeking help from other family members. In a study of help-seeking behaviors among Middle Eastern immigrants, May[39] noted that depending on the situation, families tended to rely on themselves or seek help from other family members.

Many barriers can affect parents' help-seeking behaviors. Nasir and Al-Qutob mentioned several barriers to obtaining healthcare services among Arab families are: (a) poor education; (b) cultural norms; (c) geography; (d) socioeconomics; and (e) logistical challenges.[40] Other factors include lack of: appropriate assessment tools, knowledgeable experts, financial resources, and governmental awareness and support.

Despite these barriers, it is advisable that professionals rely on parents for early detection.[41] In this process, specialists need to be aware of the following cultural issues in their interactions:

1. **Religion.** Islam is the religion of the majority of Middle Eastern families. Believing that everything is controlled by God is the way families deal with everyday events. Bad or good events are considered a part of ones' destiny. It is important to understand that families will rely on God (by praying) for support and help. It is crucial for specialists to understand the impact of spirituality on families. A related issue is "Islamic restrictions." These restrictions affect how families communicate with others. For example, gender sameness (males interacting with males and females with females) is recommended. Greetings are important, especially using the Islamic way of greeting (by saying *Aslam Alekum*, meaning "peace upon you"). Hugs and kisses between same genders is also acceptable. Women and men might refuse to shake hands because it is mandated by Islam not to do so. Minimizing eye contact between genders is important. Mothers may prefer to interacting with a female specialist and this may facilitate more open discussions about matters usually considered private.

2. **Privacy.** Families might be reluctant to disclose detailed information about their lives and their family members. They tend to give few details and as little information as possible. Inculcating trust is essential for encouraging families to open up and start talking. In the case of child illness or disability, a sense of stigma or feelings of guilt and shame might impede families' disclosure; repeating questions about child development is wise.

3. **Family Structure.** It is important to understand that the extended family has a powerful impact on parents' behaviors, parenting style, and child-rearing practices. The concept of "it takes a village to raise a child" is completely correct among Middle Easterners. The help-seeking and social networking of Middle Eastern parents depends on their immediate and extended family members. It is common that other family members (e.g., grandparents and aunts) are present at healthcare visits along with parents. The presence of extended family is meaningful and they might be of great help in providing insights or information about the child's development. Servants, including nannies, are common among families (especially from the Gulf region). Nannies interact with children sometimes more than parents and so it is valuable to include the nanny's observations when gathering information.

4. **Language.** Arabic is the most commonly spoken language among Middle Eastern families. All questions need to be in Arabic so parents can comprehend and give appropriate answers. Using interpreters or translators is important. Formal or classical Arabic is unified among all Middle Eastern countries. Although some dialects differ, all literate families have the ability to read and understand formal Arabic. All questions must be written using the formal language (called *Fusha* in Arabic). In some cases it might be suitable if the specialist reads the question and then uses the common dialect to explain its purpose. This is helpful especially with parents of limited education. Nevertheless, specialists need to be fluent in Arabic to understand the meaning of the question and how to incorporate an appropriate dialect in order to maintain the meaning and the purpose. In some countries (e.g., Jordan, Lebanon, United Arab Emirates) English is widely used. Therefore, it might be advisable to pair questions by using both languages.

5. **Geography.** If working with recently relocated families, it is important to consider the geography of the Middle East and its difference from most Western countries. Desert environments are more common than forests; children are more familiar with farm animals (e.g., camels, sheep, chickens, dogs, and cats) than other animals; pools, seas and oceans are more familiar than lakes; and cars and trucks (rather than buses or trains) are the most common forms of transportation. Knowing these important details is crucial especially when parents are in need of examples to explain a question (e.g., the majority of Middle Eastern families do not keep pets, although often raise chickens or sheep).

6. **Understanding Normal Development.** Culture affects understanding of normal development or behavior. Some behaviors might appear appropriate in some cultures but in others they are not. For example, giving hugs and kisses as a sign of warm welcome is important among Arabs. This behavior might not have the same value in other cultures. Culture effects perceptions of what is typical. For example, having an active boy is preferable among families in Jordan. Nevertheless, the opposite is true for a girl. Grandparents are likely to be more tolerant of problematic behavior and development than are parents, and may be a factor in parental delays in help-seeking. Helping all family members to arrive at a mutual conclusion about delays may be needed.

It is important for parents to feel that professionals understand and respect their cultural values and beliefs. Cultural sensitivity is essential for facilitating parent-professional communication, and professionals must strive to understand parents' fears, worries and anxieties when engaged in early detection.

AMERICAN INDIANS

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There are almost three million Native Americans living in Alaska, Hawaii and across the lower 48 of the United States. Representing approximately 1% of the US population, American Indians belong to many different nations or tribes, from Aaene to Zuni. The different nations are grouped according to broadly accepted tribal regions, such as the Plains, the Great Basin, Woodlands, Alaskan, the Southwest, and

Northwestern. Hundreds of languages are spoken (usually in addition to English or Spanish) although Navajo enjoys the greatest number, with about 200,000 speakers.

About one-third of American Indians live on reservation land within which there are almost 600 federally recognized tribal governments with the right to enforce laws (criminal and civil), generate tax revenues, regulate business activities, and establish criteria for membership. The Indian Child Welfare Act allocates to tribes exclusive jurisdiction over adoption and foster care decisions to help ensure that Native American children grow up within their culture (*www.nicwa.org*). As with all US States and territories, tribes do not have the power to make war, engage in foreign relationships or coin money. Tribal governments are overseen by the US Department of the Interior's Bureau of Indian Affairs, which after much activism by the American Indian Movement has slowly moved from a supervisory to an advisory role.

Education and Economics

For many American Indian school children, education is provided by tribal nations in which cultural preservation and language revival are a part of the curriculum. There are also more than thirty different Native American universities and colleges offering post-secondary education. Political activism has lead to the establishment of departments of American Indian Studies in many universities, along with American Indian newspapers and television stations.

Economically, American Indians, despite the success of some tribes at garnering income from casinos and other business, have numerous psychosocial risk factors: the lowest per capita income of any ethnicity in the US, enormous unemployment rates, the highest rate of high school drop-out (> 50%), and greatly elevated rates of teen suicide (*www.census.gov*). Healthcare issues are many. Disproportionate numbers of American Indians die prematurely of diabetes, alcoholism, tuberculosis, and other health conditions (*www.usccr.gov*). All federally-recognized Native American and Alaska Natives are entitled to healthcare through the Indian Health Service (IHS) (*www.ihs.gov*) and about half of all American Indians receive care through the IHS.

Trends in Child-Rearing Practices and Implications for Early Detection

Although tribes and nations differ substantially, one commonality seems to be that children are respected and treated gently. At the same time, children are taught obedience and careful respect for their elders. Chief Si'ahl (anglicized as Seattle and for whom the city is named) said, *"We do not inherit the earth from our ancestors; we borrow it from our children."*

As with other indigenous peoples (e.g., Australian and Canadian Aboriginals), grandparents, especially grandmothers are often the main disciplinarians. This is not surprising, given that many tribes are matrilineal, meaning that property and hereditary leadership are passed from mother to daughter. Aunts and uncles often play a large role in child-rearing.

Punishment rarely involves spanking. Instead, children who are verbally or physically aggressive or who talk back to elders, are disciplined by verbal redirection, explanation and loss of privileges. Families are rarely troubled when children are dependent, clingy, silly or attention-getting, i.e., *act like children,* but families place high value on children's ability to get along with others.[42] In one study, Native Americans had more than twice the rate of concerns about children's social-emotional development as whites and African-Americans, but fewer concerns about language development or other predictors associated with developmental-behavioral problems.[43]

Implications for providers engaged in early detection include:

1. The need to acquire knowledge and respect for tribal customs while recognizing these often differ across American Indian groups;

2. Careful exploration of parents' concerns about social-emotional issues (within which may be clues to developmental-behavioral delays);

3. Inclusion of extended family members in exploration of developmental-behavioral concerns;

4. Implementation of all aspects of AAP screening and surveillance policy including eliciting parents' concerns and use of milestones-focused screening tools;

5. A thorough assessment of health and nutrition issues, both in family members and in children, followed by thoughtful intervention and monitoring, preferably making use of peer role-models;

6. Vigilant attention and intervention with psychosocial risk factors including mental health status.

Chapter Comments: *We have hardly done justice to the diversity of issues and cultures within the United States—Christian communities with homeschooled children, African-Americans or Anabaptists (e.g., Mennonites and Amish who often speak "Pennsylvania Dutch" and who greatly value agrarian skills but not necessarily sophisticated literacy skills or acquisition of knowledge about other nations). Note that across many societies, Asian, Arabic and others, males dominate. This is an important issue particularly when parents have limited education. We point this out because it may be necessary to interview mothers and fathers, grandparents, and adolescents separately when eliciting concerns, psychosocial risk factors or completing milestones measures. But, encouraging fathers' active involvement in child-rearing is also invaluable.*

We have not addressed the fact that many minorities are the target of racism or classism. This has a profound impact on children's and families' well-being, not only psychologically but also on health status. Minority families with the means to do so, may withdraw their children from public encounters, seek private schools, and otherwise try to prevent racist encounters, thus leaving less in the way of role models for disadvantaged minorities. Addressing issues in bullying and discrimination are much needed for improving social relations. Measures such as Perceptions of Racism in Children and Youth[44] are a helpful adjunct to routine measures of psychosocial risk and resilience (described in Chapter 10). Other helpful information is listed in the Resources and Further Reading section below.

Another unique group requiring thoughtful care is children and families who are bisexual, gay, lesbian or transgendered. Assurances of confidentiality and use of gender-neutral language (e.g., "partner" not "girlfriend" or "husband") are needed, as is guidance regarding health risks. Both the American Academy of Pediatrics and the American Psychological Association provide information for providers, parents and youth.

Although we discussed in Chapter 8 how to give difficult news to parents, we have given short-shrift to the culture that evolves when families have children with known disabilities. The Council for Exceptional Children (www.cec.sped.org) offers guidance on talking with families, especially during initial encounters (e.g., asking positive questions about what a child likes to do, not expecting families to raise concerns if they are satisfied with special education services, etc.). The American Academy of Pediatrics' Medical Home Initiative includes abundant information on arranging primary care to aid children with disabilities and their families (e.g., hiring a care-coordinator to collaborate with teachers and parents). Information and links are within Chapter 17 (North American Models).

But whatever background—ethnic, religious, gender orientation or exceptionality—sensitivity on the part of providers is important for establishing a viable relationship with children and youth, their parents, extended families, and with non-medical service providers. Early detection and intervention depend on effective communication and effective communication depends on an understanding of the many unique groups within our society.

RESOURCES AND FURTHER READING

The American Academy of Pediatrics has a section devoted to complimentary and integrative medicine (with a discussion list, policy statements, a newsletter, a list of publications, coverage of what is known about various food additives, etc.) *www.aap.org.*

The American Academy of Pediatrics within its Bright Futures initiative offers guidance on helping families cope with disasters and terrorism. *www.aap.org.*

The American Psychological Association houses white papers and research from its Committee on Gay, Lesbian, and Bisexual Concerns. *www.apa.org.*

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Chapter 13: Measurement for Subspecialty Follow-Up and Early Intervention Intake

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INTRODUCTION

In settings where children are at very high risk for developmental-behavioral problems, it is essential to use in-depth measures providing much more detail than screening tests can offer. For children born prematurely, for IDEA intake, in triage on developmental-behavioral rotations, for research studies on specific conditions or for intervention outcomes, the binary cutoff scores provided by screens (e.g., refer/don't refer) are sufficient. Screens also have limited ability to view strengths and weaknesses in development and behavior or to illustrate progress over time. Yet leaping from screening to diagnostic measures is expensive and time-consuming—and this leap often creates bottlenecks to services—greatly delaying enrollment in early intervention. Not good. There are alternative approaches that offer an economy of measurement along with a rich set of scores responsive to outcomes, i.e., assessment-level tools. Such tools are useful for:

- Children who are graduates of neonatal intensive care units (NICU);

- Previously screened children who are referred to IDEA programs for intake;

- Developmental-behavioral triage clinics;

- Research, intervention and outcomes studies;

- Progress monitoring and initial instructional planning (e.g., in early intervention programs).

We do not cover in this chapter criterion-referenced or curriculum-based measures that tie test performance to intervention goals and thus to detailed instructional planning (e.g., Bricker, 2006).[1] We focus only minimally on diagnostic test batteries needed to determine eligibility for IDEA Part C (3-years and older). Most states have extensive manuals listing which diagnostic measures can be used and the types of professionals needed to administer them. Nevertheless, when it comes to follow-up for NICU graduates, teaching hospitals often have research-driven protocols using diagnostic batteries, and so we describe some of these along with some of the unique challenges these children face.

Toward the end of the chapter we provide a dictation template that outlines how to capture findings from non-medical and medical test results. We hope this is useful for those on rotations offering follow-up services for NICU or other subspecialty developmental-behavioral evaluations. Finally, we provide a list of resources including links to further information, such as how to conduct a neurodevelopmental exam.

WHAT ARE ASSESSMENT-LEVEL MEASURES?

Assessment tests are tools that:

- Present more items at once than do screens;

- Ensure that strengths and weaknesses in skills are probed;

- Offer scores in a range of domains;

- Typically include a basic way to monitor progress;

- Provide a continuous metric, typically a range of raw or age-equivalent scores (as opposed to binary cutoff scores used in screens or the static metric of quotients, which tend not to change over time);

- Help determine percentage of delay (often needed for IDEA Part C eligibility);

- Can, at least for some measures, be self-administered by parents;

- Enable use of a wide and richer range of statistics for research studies;

- Take less time and thus cost less than diagnostic measures;

- Do not require sophisticated, multi-disciplinary teams to administer (e.g., a psychologist, speech-language pathologist, physical therapist, etc.);

- Can be administered in much less time than diagnostic tools, although they do require a bit more time than screening measures, i.e., 30 - 45 minutes is common for assessment-level measures, while screens are typically 5 - 10 minutes, and diagnostic measures usually require one to two full days (or more) of time from multiple professionals.

EXAMPLES OF ASSESSMENT-LEVEL MEASURES BY METHODS OF ADMINISTRATION

Below, we describe instruments with current standardization, validation and reliability. The issue of test accuracy, i.e., sensitivity and specificity, is not germane to assessment-level tools because cutoff scores are not often produced (although some researchers and authors do report accuracy indicators). All assessment level tools are also described in Chapter 4 with live links at *www.pedstest.com/TheBook/Chapter4*. We divide the discussion into tools relying mostly on parent report versus direct elicitation, although many measures have flexible administration options.

Parent-Report/Interview Measures

Parent-report assessment-level tools are the least expensive and most flexible measurement approach because they can be completed via self-report, interview or via mail-out. Parent-report is known to be as accurate as hands-on professional administration if test items are clearly written at a reading level of 4th – 5th grade or less. Because parents observe their children in familiar surroundings where newly emerging skills are especially apparent, over-reporting is minimized when items have at least three multiple-choice response options (e.g., "Rarely," "Just Beginning To," "Most of the Time").

Nevertheless, when asking parents to read and answer questions, a literacy/language probe is essential. Options include: asking parents whether they would like to complete a measure on their own or have someone go through it with them; asking which language they prefer to use; or in the case of mail-out initiatives, adding a note as to whether they can find someone to help them complete the form if needed.

The *Developmental Profile-III (DP-III)* (*www.wpspublish.com*). This 180-item multiple-choice measure spans birth through 12-years, 11-months. Administered exclusively by parent interview, the *DP-III* produces standard scores, percentile ranks, stanines, and age-equivalents. Each of the five subscales has its own norms so that selected scales can be administered as needed. The subscales cover: adaptive behavior (ability to cope independently with the environment; to eat, dress, work, use modern technology, and take care of self and others); social-emotional (interpersonal abilities, social and emotional understanding, functional performance in social situations, and the manner in which the child relates to friends, relatives, and adults); cognitive (intellectual abilities and skills prerequisite to academic achievement); communication (expressive and receptive communication skills, including written, spoken, and gestural language); and physical development (large- and small-muscle coordination, strength, stamina, flexibility, and sequential motor skills). The *DP-III* takes 30 or more minutes to complete. The measure is available in English and Spanish, along with a CD-ROM for scoring and report-writing.

***PEDS: Developmental Milestones (Assessment Level) (PEDS:DM-AL)* (*www.pedstest.com*).** This 118-item multiple-choice measure covers birth through 7-years, 11-months. As with the *DP-III*, basal-ceiling rules are used to restrict the number of items required to produce scores, but at least six items per domain are required for scoring. The *PEDS:DM-AL* can be completed by parents, by interview or hands-on (and its manual includes directions on how to manage children during testing, build rapport,

etc.). Age-equivalent and cutoff scores are produced and the *PEDS:DM Assessment Level* booklet can be reused over time with the same child for progress monitoring. The booklet houses a photocopiable family-friendly scoring grid so that progress can be readily visualized. The *PEDS:DM-AL* provides scores in fine motor/written language, gross motor, receptive language, expressive language, self-help, social-emotional, and for children 3-years and older, math and reading. It takes parents about 15 minutes to complete by self-report or interview. Hands-on administration takes 20 - 30 minutes depending on the age of the child. The *PEDS:DM Assessment Level* is available in English, Spanish, Portuguese, Arabic and Chinese, and will soon be available online with automated scoring, referral letters, and parent summary reports (*www.pedstest.com*).

Promising Parent-Report Measures in Need of Further Development

The *Child Development Inventory (CDI)* (*www.childdevrev.com*) is a 330-item multiple choice measure for children birth to 6-years using (an often problematic) yes-no format. The *CDI* produces a profile of strengths and weaknesses across multiple domains. Unfortunately, it was normed on a small sample of mostly white families in Minnesota, and its standardization has not been updated in more than 30 years. The latest study reported on the *CDI* website is from 1999 on a sample of 63 NICU graduates and shows high correlations with the *Bayley-II* and other measures, but no association with psychosocial risk, which is troubling and probably reflects the limitations of its norming research. So, we'd like to see further work on this measure so that its apparent usefulness can be better demonstrated in families outside of Minnesota.

HANDS-ON ASSESSMENT LEVEL TOOLS

Some assessment-level tools require direct-elicitation of children's skills. Such an approach is useful:

- If the primary caretaker is not present;

- If the primary caretaker does not read well;

- If the parent does not read or speak the language in which translations are available, and thus hands-on administration (with translators present) is needed;

- When the caretaker is unfamiliar with the child (e.g., new foster parent);

- When research (or funders) require a hands-on approach to measurement;

- If caretaker report is suspect (e.g., due to florid mental health problems);

- When training young professionals (to give them an opportunity to build rapport, manage child and parent behavior during testing, build knowledge of child development and behavior, build clinical acumen, etc.);

- When professionals prefer to gather information on children's actual performance, and acquire a greater sense of how to work with and plan instruction for a child.

EXAMPLES OF ASSESSMENT-LEVEL TOOLS RELYING ON DIRECT-ELICITATION OF CHILDREN'S SKILLS

Hands-on measures take much more time to administer than measures relying on parent-report whether via self-administration or professional interview. Nevertheless, hands-on measurement is needed if parents are not familiar with the child or if funders/research studies require direct elicitation of children's skills. Note that few screens (especially lengthier tools such as the *BDIST* or *Brigance*) produce more than just cut-off scores, but also a continuous set of metrics (e.g., age-equivalents, raw scores). All this means that the distinctions between some screens and assessment-level measures blur

a bit, depending on which scores are used. Several of the assessment-level measures we describe offer a related screening test (often with a broad range of scores)—meaning ultimately that there are shorter versus longer assessment instruments wherein the "screening test version" can be used to determine whether a more in-depth instrument is needed. Such graduated measurement is economical because we don't want to spend large amounts of time testing children who are typically developing. Even so, for researchers developing study protocols, the fact that a measure includes "screen" as part of its title, may not be acceptable to funders, whether or not a range of scores is produced.

Battelle Developmental Inventory-2 (BDI-2) and the Battelle Developmental Inventory Screening Test (BDIST-2) (*www.riversidepublishing.com*)

For children birth through 7-years, 11-months, the screening version of the *Battelle*, the *BDIST-2*, functions as both a screen and a preliminary assessment-level measure. The *BDIST-2* takes at least 15 - 30 minutes to administer and renders age-equivalent scores plus cutoffs for each of five domains: adaptive, social-emotional, communication, motor, and cognitive skills. Problematic performance suggests administration of the more extensive assessment-level measure that is the full *BDI-2* (requiring about 60 minutes of time). The *BDI-2* produces more extensive scores such as quotients, percentiles, z-scores, etc. Examiner skill is required for managing the many materials needed to administer the *BDIST-2* or the *BDI-2*. Adaptive-behavior items, as with most other measures, are administered by interviewing parents (e.g., about toileting, grooming, bathing, etc.).

Mullen Scales of Early Learning (*www.pearsonassessments.com*)

The *Mullen Scales* are for children from birth to 68-months. Its five scales measure gross motor, visual reception, fine motor, expressive language, and receptive language. Each scale generates age-equivalents, percentiles and T-Scores. The scales combine to create an Early Learning Composite for which standard scores and percentile ranks are produced. The *Mullen Scales* are administered hands-on, and as with the *Battelle* measures, require examiner skill in managing children and the many test stimuli. About 15 minutes is needed to test children ages 0 to 12-months; 25 – 35 minutes for 12- to 36-months; and 40 – 60 minutes for children 3-years and older.

Brigance Inventory of Early Development-III (IED-III), Comprehensive Inventory of Basic Skills (CIBS-II), Brigance Screens-II (*www.cainc.com*)

The *IED-III* is designed for children from birth to 7-years. The *IED-III* is a norm-referenced battery drawn from its lengthy criterion-referenced scope and sequence measures (often used for developing Individual Family Service Plans and IEPs). In both its norm- and criterion-referenced versions, the *IED-III* measures expressive and receptive language, adaptive behavior, social-emotional skills, fine and gross motor, and cognitive/academic skills for older children. The norm-referenced version takes 20 - 60 minutes (depending on age) and produces age-equivalents, quotients, and percentiles. Portions can be administered by parent-report and for younger children via play-based observation. Physical test stimuli are few, meaning that the *IED-III* is easy to administer. For children 5-years and older, the *Brigance Comprehensive Inventory of Basic Skills-II (CIBS-II)* measures motor, language, and academic skills, and produces a wide range of scores. The *IED-III* and the *CIBS-II* are the sources for items used on the *PEDS:DM* and the *Brigance Screens-II* which have the same age-range as the *IED-III*. The *Brigance Screens-II* produce three composite results (verbal, motor, adaptive) for which quotients, percentiles and age-equivalents are available. The *Brigance Screens-II* take 15 – 20 minutes to administer and are translated into English and Spanish. Online scoring is available for all three *Brigance* tools. The *Brigance Screens-III* are currently undergoing restandardization and validation, and revised editions are expected to be published in late 2013.

Promising Hands-On Measures in Need of Further Research

The *Capute Scales: Cognitive Adaptive Test (CAT)* and *Clinical Linguistic and Auditory Milestone Scale (CLAMS)* are best known as the *CAT/CLAMS* (*www.brookespublishing.com*). The CAT/CLAMS is designed

for children 1-month to 36-months and measures only a limited range of domains. Normed on referral populations only, its results cannot be generalized beyond high-risk groups. But to the extent that tests are administered only to a high-risk population (e.g., extremely low birth-weight NICU graduates), the *CAT/CLAMS* is an economical measurement option because it requires only about 15 minutes to administer, and enjoys high correlations with the *Bayley Scales-II*. Its relationship to the *Bayley Scales-III* is not known An extensive set of test stimuli are required.

SETTINGS APPROPRIATE FOR ASSESSMENT-LEVEL TOOLS

Triage Clinics/Early Intervention Intake and Monitoring

Because of the expense, time, and often lengthy waiting periods that accrue when a multi-disciplinary team administers diagnostic tools, triage clinics are ideal for reducing service bottle-necks. Triage clinics using assessment-level tools provide a viable, swift and low-cost substitute for deciding whether services are needed, and for monitoring progress. Many children can be seen in a single day, short reports are easily generated for referring providers and families, and for most US States, assessment-level tools provide essential eligibility criteria for early intervention services and monitoring. Triage services are popular with community healthcare providers and are more likely to "break-even" in terms of clinic expense versus revenues, than are diagnostic evaluation services.

Foster Care Intake/Adoption Services

Foster care intake is a challenge because long-term caretakers (e.g., biological parents) are rarely present and new foster parents and social workers lack a history of children's skills and needs. Children in-care are at high risk for developmental-behavioral/mental health problems, and so require careful monitoring over time. Assessment-level tools are surely too long for a home visit where swift decisions need to be made about possible placement. In these situations, screening tools are more useful.

But after a new placement, all children in-care need careful follow-up for which longitudinal assessment-level tools are optimal. In services that provide an opportunity for testing within a few days of placement, some clinicians find that newly-placed children are quite cooperative. A hands-on administration of measures is useful (because knowledgeable informants are not likely to be present and new foster parents may not be able to report on the range of children's skills). After foster parents have time to know children better, progress monitoring via parent-report or interview administrations of assessment-level tools may be productive (and easier).

Daycare, Preschool, Head Start, Early Head Start

In early education settings, teachers need to know a great deal about children's actual skills for determining children's need for referrals. Screening tests are helpful and many provide a longitudinal record of progress. But, screening tools offer such a limited sample of skills that assessment-level tools may be more helpful. Neither screening nor assessment-level tools are a substitute for tracking progress within a curriculum, but either type of measure offers a reasonably quick indicator of developmental status, and provides a comparison to typical development. Nevertheless, assessment-level tools provide more definitive insight into strengths and weaknesses, and assistance with decisions about goals and objectives.

The ability to compare a child to how others are doing across the nation is particularly critical for Head Start and Early Head Start. Teachers develop "internal norms" and sometimes come to think that a child performing averagely in their classrooms, is average by national standards. But for many children "average" for Head Start may be far behind national norms.

For example, in one study teachers of 4- to 5-year-olds participating in Head Start or in public school pre-kindergarten and kindergarten classes, were asked to rate their students as "below average," "average"

or "above average." Examiners then administered a hands-on screen to children. Head Start teachers' ratings of "average" corresponded to performance rated "below average" ratings by public school teachers. All this means that test norms provide critical information about performance standards that teachers need to make use of—so as to optimally prepare children for public school curricula.[2]

Although teachers need to focus on children's skills and progress, it is also important to get a sense of parents' concerns. Eliciting parents' concerns makes for a more productive parent-teacher conference (and encourages parents to attend these). The well-behaved child in a classroom may be a holy terror at home. And so if programs seek to help parents with child-rearing, preparation for school and so forth, we need to know what their unique challenges are, and offer parents advice. We can do that best if we elicit parents' concerns carefully.

Kindergarten/Pre-Kindergarten Screening/Public Schools

Many public schools provide pre-kindergarten screening (often as a mail-out to the families of incoming students). This is a helpful approach for swiftly identifying children who may be far behind and in need of further evaluation and intervention. Screening tools are probably best for this application (and assessment tools can be used for immediate follow-up).

One of the challenges in mail-out screening initiatives is limited knowledge of the language(s) parents speak at home. To cope with this, some initiatives request permission from publishers to print measures front and back in two languages (having taken a guess based on the child's last name as to the probable languages spoken at home (e.g., English + Vietnamese). This approach appears effective, although follow-up on non-responders is needed. In many cases families, even if lacking literacy in any language, will find "community helpers" to aid them in completing forms. In the case of refugees, resettlement programs often have workers who can assist (e.g., Catholic Social Services, World Vision, etc.).

Once a screening test produces suspect scores, school psychologists or educators need to conduct further evaluation (including classroom observation for students already enrolled). Using an assessment-level measure for clinical observation and brief hands-on testing can facilitate decision-making about whether diagnostic testing is needed.

Developmental-Behavioral/Neurodevelopmental Rotations and Triage Clinics

When medical students and residents are assigned to developmental-behavioral/neurodevelopmental rotations, we want them to learn, among other things, developmental milestones (e.g., month-by-month in the first year of life, and at broader age-ranges throughout the 0 - 7+ year age-range). While it is critical to master a screening test that trainees can deploy in their continuity clinics, community and general pediatric rotations, we also want them to assist in the tasks of a developmental-behavioral clinic. Having students and residents watch endless diagnostic testing is less than helpful and is not a skill of benefit to the majority, who tend to become generalist providers. See Chapter 14 for training issues in hands-on measurement.

Assessment-level tools offer an alternative approach that can help both preceptors in subspecialty clinics and trainees:

- Trainees can learn to administer assessment-level tools as part of the clinic intake process;

- Many subspecialty clinics have triage clinics wherein four or so children are seen in a single day to determine whether diagnostic testing is needed. Assessment-level tools are optimal in such services;

- NICU Follow-Up clinics and Early Intervention intake services are other settings where assessment tools can be used as an economical alternative to diagnostic, multidisciplinary team evaluations.

Research Protocols and Subspecialty Medical Services

In clinics serving children with significant medical histories, developmental strengths and weaknesses are often acute (e.g., children born prematurely, who have cardiac or other biological problems at birth, trauma-related challenges, who are referred because of suspected difficulties such as ADHD or who have environmental or psychosocial risk). For such groups, assessment-level measures are ideal because they offer more items, probe strengths and weaknesses across domains, and better determine children's needs for specialized services by focusing on the developmental areas that are problematic. A carefully conducted physical exam is also needed.

Most subspecialty and referral clinics need to provide longitudinal monitoring. In many clinics, outcome studies are conducted for which the metrics of assessment-level tools are particularly advantageous (e.g., raw or age-equivalent scores enable a wider range of analytic techniques). Assessment-level measures ensure less expensive evaluations than that of a multi-disciplinary diagnostic team. Assessment-level tools can also be used by trainees such as residents and psychology interns, provided they are given appropriate training or self-training. See Chapter 14 for guidance. Nevertheless, research protocols (e.g., focused on rare diseases or treatment outcomes) often demand in-depth testing of specific skills and deficits, especially when a great deal is known about the condition under study, as described in the NICU Follow-Up section below. Chapter 19 covers additional issues in establishing research protocols and how to conduct research on tools themselves.

Neonatal Intensive Care Unit Follow-Up

The expansion of NICU Follow-Up clinics reflects the increasing number of infants with complex needs. Neurodevelopmental outcomes are often used to measure efficacy of medical treatment methods in preterm and other high-risk infants. Such studies are inevitably complicated given the high cost of following children over time, and frequent subject attrition in the duration. Developmental-behavioral status in NICU graduates (just as with children born at term and who appear typically developing early on) is compounded by the presence of psychosocial risk factors. In children born prematurely, both psychosocial risk and biological risk (including types of perinatal interventions) have a slow impact on development and may not be evident until after the first few years of life.[3]

Neonates are divided into four groups for follow-up:[4]

- Extremely preterm (ELBW), meaning those born at < 28 weeks gestation;

- Very preterm (VLVW), i.e., those born at 28 - 32 weeks gestation;

- Moderately preterm (32 - 33 weeks gestation);

- Late preterm (34 - 36 weeks gestation).

Of these groups, children who were extremely preterm/extremely low birthweight (ELBW) and very preterm/very low birthweight (VLBW) are the most worrisome. About 25% of ELBW infants and 14% - 17% of VLBW infants have high-severity disorders such as intellectual disabilities, cerebral palsy, and sensory impairments (as compared to 6% - 8% in low birthweight children and a 5% rate in full term infants). If escaping high-severity conditions, 50% - 70% of VLBW and ELBW children exhibit high-prevalence, low-severity dysfunction, including learning disabilities, borderline to low-average cognitive abilities, ADHD, specific neuropsychological deficits, and behavior problems.[5] More than half of VLBW/ELBW children require special education services and 16% - 20% repeat a grade in school.[6]

Long- lacking has been a consensus regarding standardized guidelines about follow-up care and assessment of high-risk neonates. A National Institute of Child and Human Development (NICHD) workshop was convened to address this gap. Surveillance and research were the two areas of prime importance identified for established neonatal follow-up programs, with surveillance defined as serial evaluation of health and neurodevelopmental outcomes after discharge.[7] Specific areas for measurement include social issues, neurologic, cognitive, behavioral, physical issues, quality of life and functional

outcomes. NICU Follow-Up protocols are often shared across teaching hospitals and in many cases, diagnostic measures, rather than assessment tools are required for measuring the unique issues of NICU graduates, particularly with the NICHD test battery.

Follow-Up: Intensity of Measurement (NICHD Protocol)

The National Institute of Child and Human Development workshop identified four levels of follow-up intensity as follows:

Level 1: Telephone interview administration of a screen by NICU or NICU Follow-Up staff member or mail-out of a parent-completed screening measure. Subsequent referrals (e.g., to IDEA and for Level 2 evaluations by the NICU Follow-Up team) are warranted when results are problematic;

Level 2: Clinic visit with use of a directly administered screen such as the *Bayley Infant Neurodevelopmental Screener (BINS)*. Other health professionals such as nutritionists, physical, occupational or speech-language therapists may be needed. Problematic results indicate the need for more detailed evaluations, i.e., Level 3;

Level 3: Entails administration of at least one comprehensive assessment measure (described below) and is administered at a single visit. Problematic results indicate the need for Level 4 follow-up;

Level 4: Involves serial diagnostic measures conducted by a multidisiciplinary team.

Timing and Frequency of Follow-Up

Frequency of re-evaluation is determined by optimal ages for assessment and level of follow-up. Time, cost, personnel constraints are all considerations. Below is a suggested follow-up schedule:

6-months corrected age: Provides contact with the family, and indicators of severe disabilities can be identified. Tone, gross and fine motor function, sensory function (hearing and vision), prelinguistic skills can be evaluated. Medical/biologic factors still may affect test results;

12-months corrected age: Cognitive and language processes can be assessed, although these are highly interrelated. The neuromotor examination should include assessment of tone and strength, and fine and gross motor function. Behavior and social interactions should be reviewed;

18- to 24-months corrected age: Cognitive, language, and motor functions can be assessed more discretely. Social-emotional development should be screened, including screening for autism spectrum disorders. Psychosocial risk factors increasingly influence performance;

3- to 4-years chronological age: Intelligence can be assessed, including concept development, pre-academic readiness, early executive function and attention, and visual-motor integration. Psychosocial risk factors strongly influence test results, particularly language and cognitive function;

6- to 8-years chronological age: Beginning at 6-years, and more definitively at 8-years, additional tests can be used to assess attention problems, academic skills, neuropsychological function, behavior and socialization.

ADDITIONAL PROTOCOLS FOR FOLLOW-UP WITH NICU GRADUATES

Below are other ways to measure outcomes in NICU graduates. The first two follow-up protocols were established by NICHD. The second two follow the Vermont-Oxford protocol and use less expensive measures. All four examples include variations in the targeted group (e.g., ELBW versus ELBW and VLBW), timing of measurement, the intensity of measurement, and thus the cost of measurement. Each example lists the specific measures used (by name and acronym/abbreviation). We have not provided

detailed descriptions for each diagnostic measure, but researchers can find more information from publishers' websites by "googling" the name of each test. For all protocols, age is usually corrected for prematurity up to 24-months (although some services continue to correct even at older ages). But for most clinics/tests, chronological age is used starting at 24-months.

Case Example #1 (Targeting ELBW and VLBW)

6- to 24-months: *Bayley Scales of Infant Development, 3rd edition (BSID-III)*;

3- to 4-years: *Differential Ability Scales-II (DAS II), BSID-III* (at 3-years), *Stanford-Binet Intelligence Scales, 5th edition, Wechsler Preschool and Primary Scale of Intelligence-III (WPPSI-III), McCarthy Scales, Bracken Basic Concept Scale-3, Kaufman Assessment Battery for Children-II* (KABC-II);

6-years: *Wechsler Abbreviated Scale of Intelligence (WASI), Stanford-Binet Intelligence Scales, 5th ed., Wechsler Intelligence Scale for Children-IV (WISC-IV), Developmental Test of Visual-Motor Integration (VMI), Developmental NEuroPSYchological Assessment (NEPSY-II), Behavior Rating Inventory of Executive Function (BRIEF), Continuous Performance Test (CPT)*, the Rating Scale portion of the *KABC-II*;

8-years: WISC-IV, *WASI, Stanford-Binet Intelligence Scales, 5th ed., NEPSY-II, BRIEF, CPT.*

Case Example #2 (Targeting ELBW and VLBW)

6- to 24-months: *BINS, ASQ3, Capute Scales, Bayley Scales of Infant and Toddler Development Screener-III*;

3- to 4-years: *Kaufman Brief Intelligence Test-2 (KBIT-2), Stanford-Binet Intelligence Scales, 5th ed.* (abbreviated battery), *VMI*;

6-years: *WASI, Stanford-Binet Intelligence Scales, 5th ed.* (abbreviated battery), *KBIT-2, WISC-IV* (selected subtests), *CPT, VMI*. Achievement testing is usually initiated at school entry or later. Tool options include the *Wechsler Individual Achievement Test-III*, the *Kaufman Test of Educational Achievement-II, Woodcock-Johnson-III* or the *Wide Range Achievement Test-4*;

8-years: *WASI, Stanford-Binet Intelligence Scales, 5th ed.* (Abbreviated Battery), *KBIT-2, CPT, VMI, NEPSY-II* (selected subtests).

Case Example #3 (Targeting ELBW Only)

In contrast with the NICHD network protocols described above, the following approach is based on the Vermont-Oxford Network (*www.vtoxford.org*) for NICU Follow-Up. This case example comes from a rural and relatively impoverished southern US State in which funding for NICU Follow-Up services is not available except for children with birthweights < 1000 grams or a gestational age of < 28 weeks. Chronological age adjusted for prematurity is used in the 0 - 24-month age-range. Age ranges reflect the time-frames for assessment:

2- to 4-months: *PEDS:Developmental Milestones* is administered by a developmental-behavioral pediatrician via a combination of parent report, observation or hands-on, with the child and family present;

6- to 12-months: *Bayley-III Screener* administered by a developmental-behavioral pediatrician;

12-months: *Peabody Developmental Motor Scales-2,* administered by a physical therapist;

13- to 24-months: *Bayley Scales-III*, administered by a child psychologist;

- to 36-months: *Preschool Language Scale-4* or other language-focused measures administered by a speech-language pathologist;

36-months: *Bayley Scales-III*, administered by a child psychologist.

Problematic results are reported to IDEA Part C or Part B (depending on the child's age). Note that in this State, IDEA programs do not monitor progress, refer non-qualifying children elsewhere or make use of existing test results. These limitations create hardships for healthcare providers and families who greatly benefit from referral coordination. Duplication of evaluations is an unnecessary expense for IDEA. Collaboration and shared resources is a wiser plan (e.g., invoking IDEA personnel to assist with evaluations).

Case Example #4

An AAP State Chapter together with Medicaid and IDEA, developed the following collaborative protocol for NICU graduates within their large, rural and relatively poor State in the southwest US.

All well-visits in the 0 - 8-year age-range: *Parents' Evaluation of Developmental Status (PEDS)* is used by primary care providers working with any NICU graduate of any birth weight or gestational age;

If problems on *PEDS*: Children are referred to (depending on provider preferences)**:** (a) either IDEA for further testing where the *Ages and Stages Questionnaire (ASQ)* is used for initial intake with children from birth to 5½-years of age; or (b) Private services including teaching hospital developmental-behavioral clinics;

Referral Coordination remains a work in progress, but the State's AAP Chapter is working closely with IDEA to establish two-way consent forms. The AAP Chapter is also advocating for IDEA to monitor children referred but whose families did not seek services, and for monitoring/referring elsewhere children not found to be eligible for IDEA.

DOCUMENTATION

In many follow-up services, a single provider is required to dictate a report encompassing the medical, family and developmental-behavioral history, current measurement results, findings from prior and current physical exams, and recommendations for future care. Table 13-1 provides an outline for the many issues to be captured when working with extremely high-risk children and is focused on use of assessment-level tools. This template is also downloadable as a modifiable Word document at *www.pedstest.com/TheBook/Chapter13.*

Annotations for some of the headers used in the dictation template are presented first.

Table 13-1. Dictation Template for NICU Follow-up and Developmental-Behavioral Triage Clinics

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Annotations

Chronological Age: Usually adjusted for prematurity if < 2-years-old and > 3-weeks premature;

Social/Developmental/Behavioral History/Current Services: Brief description of impressions from previous testing and current medical and non-medical services;

Family History: Significant medical problems, family psychosocial risk factors (e.g., level of education, housing and food stability, employment, language spoken at home/facility with English, marital status, etc.) See Chapter 10 for psychosocial risk and resilience measures;

Observations: List parents' chief complaints, children's behavior during testing/medical exam, parent behavior, parent-child interactions during the exam, parents' well-being, engagement, visit preparedness (e.g., food, diapers, toys), etc. See Chapter 10 for guidance on observing parent-child interactions;

Measures Administered: List all given, including those administered to parents (e.g., *Family Psychosocial Screen*) and those given to children;

Developmental-Behavioral Test Results: List the raw score (meaning number of passed items), age-equivalent score and the age-equivalent range (as provided by test manuals). If quotients and quotient ranges are provided by a test list these separately. In the far right column compute percentage of skills mastered (this data becomes a positive way to convey results to parents). The formula for percentage of skills mastered is: [age-equivalent divided by chronological age (with adjustments for prematurity if appropriate) times 100]. For example, if a 36-month-old receives an age-equivalent score of 31-months, 31 divided by 36 = .86. Multiplying .86 by 100% = 86% of skills mastered]. To compute percentage of delay, the formula is 100% minus percent of skills mastered, and so in this example 100% - 86% = 14% delay. Percentage of developmental-behavioral history, current status and progress, preferably coalesce into a big picture of the child's and family's strengths and weakness, health issues, etc.;

Recommendations/Plan: These may need to be grouped by "Family," Medical" and "Developmental-Behavioral" and should include any needed referrals to subspecialty and non-medical services. Also identify when the child and family should return for follow up. Be sure to send copies to the child's primary care provider, the parents' healthcare provider if needed, to all services currently engaged with the child and family, including educational services—both current or recommended;

Clinic/Address
Patient:
Date of birth:
Date of visit:
Chronological age
Parent(s) Name(s):
Address:
City, State, zip:
Telephone:
Email address:

Chief Complaint:

History of Present Illness:

BIRTH HISTORY/MEDICAL HISTORY:

BIRTH WEIGHT:
DISCHARGE WEIGHT:
GESTATIONAL AGE AT BIRTH:
APGAR SCORES:
BIRTH STAY #DAYS:
VENTILATION DAYS:
IMAGING:
Other:

---

table continues...

Table 13-1. Cont'd

Interim Medical History:

Ophthalmology:
Audiology:
Pulmonary:
GI/Nutrition:
Other:

SOCIAL/DEVELOPMENTAL/BEHAVIORAL HISTORY AND CURRENT SPECIAL EDUCATION AND SUBSPECIALTY CARE:

FAMILY HISTORY:

CURRENT REVIEW OF SYSTEMS:

General:
Eyes:
ENT:
CV: RESP:
GI:
GU:
MUSCULO:
SKIN:
NEURO:
ENDO:
ALLERGY/IMMUN:
HEME/LYMPH: SLEEP:

DIET:

IMMUNIZATION STATUS:

CURRENT MEDICATIONS:

NEURODEVELOPMENTAL/PHYSICAL EXAM:

Weight: kg, Weight %, Length:, Height % OFC%:

General:
HEENT:
Lungs:
CV:
Abdomen:
GU:
Musculoskeletal:
Spine:
Extremities:
Skin:
Neurologic:

 TONE:
 MUSCLE MASS:
 STRENGTH:
 DTR'S:
 CLONUS PRESENT:
 PRIMITIVE REFLEXES:
  ATNR:

Table 13-1. Cont'd

<div style="border:1px solid">

        Tonic labyrinthine:
Moro:
    PROTECTIVE REFLEXES:
          SITTING:
        Anterior:
        Lateral:
        Posterior:
        Parachute:

CLINICAL OBSERVATIONS:

MEASURES ADMINISTERED:

DEVELOPMENTAL-BEHAVIORAL TEST RESULTS:

	Raw Score	Age-Equivalent	Range	Quotient	Range	Percent Skills Mastered	Percent Delay
Gross Motor:							
Fine Motor:							
Expressive Language:							
Receptive Language:							
Cognitive							
Academic							
Self-Help:							
Social-Emotional:							

IMPRESSION:

RECOMMENDATIONS/PLAN:

_____

Provider

Cc:

</div>

Chapter Comments: *Assessment-level tools offer an economical measurement option while still yielding an informative data set for researchers, educators, and medical subspecialists. Sharing information across services offers greater economy. Testing children, whether via screens, assessment-level measures or diagnostic tests, is only a "means to an end." The "end" is to get children into needed services that can ameliorate difficulties and enhance school success. Getting to that "end" requires generating the types of test scores needed for making eligibility decisions, probing strengths and weaknesses, and for following development over time. Related to such measurement is the clear need to make sure that psychosocial risk and resilience factors are also captured and addressed, because these may become with time, more powerful predictors of outcomes than is biological risk.*

The "means to the end" should be as inexpensive as possible, and there are clearly many ways of exploring problems in-depth without substantive expense. But too often the enormous amount of quality information from NICU Follow-Up is used only for research purposes and not for actually helping children with substantial deficits. This is wasteful and wrong. Collaboration and communication across services is important for reducing unnecessary testing, and making sure the data we collect becomes useful in providing assistance to families with needs. We should reach out to IDEA and other intervention programs and encourage them to share the information they collect with healthcare providers.

At the same time, planning affordable research protocols, studying measures, and monitoring progress over time requires much deliberation. Chapter 19 provides information for researchers on test construction, translations, methods, and the challenge of the "Flynn effect" (meaning a rise in intelligence and other quotients over time).

RESOURCES AND FURTHER READING

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Stephens BE, Vohr BR. Neurodevelopmental outcome of the premature infant. *Pediatric Clinics of North America.* 2009;56 (3):631-646.

NICHD protocol and workshop on follow-up of the NICU Patient: *http://thehealthscience.com/showthread.php?170753-Follow-up-of-the-Pediatric-NICU-Patient.*

Ambulatory Pediatrics Association. Better Outcomes through Research for Newborns (BORN). BORN is a network focused on collaborative research protocols. More information can be found on this site: *www. ambpeds.org.*

For an overview of essential topics for a neurodevelopmental exam, via slide shows, see: *http://library.med.utah.edu/pedineurologicexam/html/introduction.html.*

Videos on neurodevelopmental exams are available at: *http://library.med.utah.edu/pedineurologicexam/html/home_exam.html.*

For information and links on vision and hearing screening from the American Academy of Pediatrics, see: *http://www.aap.org/healthtopics/visionhearing.cfm.*

For videos on hearing screening go to: *http://www.infanthearing.org/videos.*

For videos on vision screening, see: *http://one.aao.org/Flash/VisionScreening/PediatricVisionScreening.html.*

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Chapter 14: Teaching Residents, Fellows, Medical and Nursing Students and Other Trainees

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INTRODUCTION

Trainees, such as medical and nursing students, residents, and fellows, must acquire many skills and much background knowledge in order to work effectively with children and families. These basics are fundamental to skilled care and need to be included not only in medical/nursing school coursework, but also developmental-behavioral pediatric rotations or other subspecialty pediatric services, medical clerkships, rotations in primary care, and continuity clinics. In this chapter we explain how to work with trainees whose background knowledge and skills differ substantially. We focus on how preceptors can build on trainees' existing skill-sets and make sure these are maintained over time. We present tools useful for ensuring that teaching opportunities become active, memorable learning experiences (tools are also downloadable at *www.pedstest.com/TheBook/Chapter14* and */AppendixA)*.

At all levels of training there are many common goals:

- Ability to effectively glean information from parents (or children) via interview;

- Skill in delivering difficult news in a productive way;

- Making use of existing data and test reports, and integrating these with information gained from a clinical interview;

- Willingness to find and deliver supportive information for educating parents and locating helpful services when needed;

- Mastering a careful physical exam including neurodevelopmental assessment;

- Skill in managing children and parents during an evaluation;

- A working knowledge of child development and why children behave as they do at various ages;

- An understanding of childhood disabilities and their many causes;

- Ability to work well with families whose cultural experiences with child-rearing differ (including families who may not speak the same language, may not read well or may not cope well due to numerous life events and psychosocial risk factors);

- A workable way to detect children with preventable or existing problems (e.g., that aids both subspecialty services and translates to briefer early detection methods needed in primary care settings);

- Frequent questioning of assumptions behind clinical reasoning, i.e., to use meta-cognition to debate the possibility that conclusions are correct, whether more evidence is needed (or needs to be looked at in alternative ways), thus rendering thoughtful decisions about possible problems and referral needs;

- To become life-long learners who seek information for continual acquisition of knowledge and skills.

In order to build a generalizable set of skills that works on all pediatric services and in coursework, preceptors must recognize that trainees enter with substantial differences in background knowledge. So in this chapter we discuss:

- How to deal effectively with the differences in knowledge of child development that learners bring to the study of child development;

- How preceptors and medical educators can ensure skills and knowledge are truly "taken home" and thus fully deployable in other settings;

- A developmental model of instruction appropriate for various levels of nursing and medical school versus levels of residency and fellowship training;

- Strategies for teaching requisite knowledge of developmental milestones;

- How to teach screening or other developmental measures in a way that is vivid, memorable and focused on ensuring the much needed skills of managing children and families during an encounter;

- The numerous resources needed for instruction (e.g., a detailed table of milestones from birth to 8-years, an observation form to help trainees gather background information on patients in developmental-behavioral clinics, etc.). We also discuss textbooks and websites useful for teaching and learning, along with pre- and post-testing to assess mastery.

In this chapter we add personal experiences and tips from two training programs—sharing some of our best and most successful approaches to teaching developmental-behavioral pediatrics along the continuum of medical education. We suggest that all trainees read this entire book to gain the essential background knowledge for learning clinical skills. But if constraining preparatory reading is necessary we recommend: The nature of child development including definitions/types of disabilities, and the impact of parenting styles and psychosocial risk (Chapters 2 and 10); challenges in clinical judgment (Chapter 3); disclosing interviews and parent-provider communication (Chapter 8); the focus of a well-visit including a basic physical/neurodevelopmental exam (Chapter 5); methods and content for developmental-behavioral promotion (Chapter 7); and guidelines for administering measures and resources for life-long learning (Chapter 14).

CHALLENGES IN MEDICAL EDUCATION: VARIATIONS IN BACKGROUND KNOWLEDGE, EXPERIENCES AND INTEREST

Most trainees (and practicing providers) feel their training in developmental and behavioral pediatrics was insufficient, and so are often interested in improving their skills.[1-6] Studies of trainees (and parents) illustrate that myths and misunderstandings about child development abound, and that general knowledge about developmental milestones is weak, especially in the developmental domains most predictive of long-term outcome: Cognition/academics, language comprehension and expression, and social-emotional skills. Lack of skill in addressing parents' most common complaint, children's behavior, is frequently mentioned by trainees and providers in practice, followed by gross motor, fine motor, oral motor/speech, and self-help skills.[7-10] Surveys of practicing providers reveal limited knowledge of referral resources and swift methods for early detection.[11] Often there is little opportunity for ongoing learning beyond developmental-behavioral rotations, and so real-life longitudinal experiences are not always available or sufficiently emphasized.

Normal child development is a topic that is at once both intuitive and complex. Our trainees enter our courses and rotations with a background derived from public knowledge: Everyone knows that human infants are born far more dependent than other mammals, and that skills emerge gradually. Often unknown is that skills build on each other, i.e., there are prerequisite skills to master before new skills emerge. What babies know and when they know it are also not commonly understood.

Several studies of public understanding of typical child development show that people have a weaker understanding of skills that are less visible, such as cognitive and interpersonal skills, but demonstrate more solid knowledge of those that are more easily observed, such as walking or grasping an object.[7,10] Such studies also indicate that many people don't understand the process of development, that developmental skills arise from the interaction of the infant and young child (and his/her genetic make-up) with their environment, and that development and behavior are brain-based. Older ideas remain popular. For example, development is conceived as a process whereby children are a "tabula rasa"—a blank slate to be filled with externally supplied knowledge—when in reality children are born with a surprising number of skills, awareness, and unique temperament that ideally effects how their parents respond. Trainees in medicine, nursing and the allied health professions are not exempt from the misconceptions found in the general public.[8]

Trainees enter medical or nursing school with varying exposure to young children and families: Some are parents themselves, have cared for younger siblings or have backgrounds in speech-language pathology, education or psychology. Others enter with backgrounds only in the physical sciences and have had little exposure to the real-life issues of children's development and behavior. Some learners enter with a life-long interest in how children grow and learn. Other trainees are already focused on subspecialty training or research, and may be less than enthused about having to learn skills that seem irrelevant to their goals—and so need to be disabused of these erroneous notions. Clearly developmental educators have their work cut out for them.

CHALLENGES FOR MEDICAL EDUCATORS: MAINTAINING PERSPECTIVE AND ENSURING LEARNERS ACQUIRE ENDURING, USEFUL SKILL SETS

Given that medical learners enter training with varying degrees of experience, interest, and knowledge (including misinformation), it is worrisome that they may be told (often early in their training) that development is "easy to learn," "intuitive" and "can just be picked up as you go"—without needing to be specifically taught. Some instructors lack appreciation for the complexity of child development, while developmental experts may not appreciate just how difficult concepts such as "domains," "milestones," "cognition," "normative skills," "screening versus diagnosis," and "transactional models" can be for novice learners. And so, learning may devolve into memorizing milestone charts with little comprehension of underlying developmental principles, processes or an understanding of how to think clearly about and address families' needs and issues. An additional challenge stems from the fact that textbooks and lectures present developmental disabilities as discrete, precisely defined, often severe disorders, while in real-life clinical care, disabilities are usually subtle, complex, have co-morbid conditions along with considerable ambiguity and variability of expression.

Most medical educators function at the expert level; this creates a problem when they attempt to teach complex material to beginners, i.e, "the curse of knowledge."[12] Experts may:

- Overestimate the ease at which material can be understood by novice learners. Experts can't always remember what it was like "not to know what they know;"

- Lack a realization that their life-long interest in developmental-behavioral pediatrics and innate enthusiasm for the topic may not be "infectious;"

- Not recognize that the informal approaches used by experts, due to their advanced training and well-honed clinical acumen, cannot be fully conveyed in a short rotation;

- Fail to ensure that learners leave a rotation with a skill-set that is evidence-based and effective for the much briefer encounters of primary care or other subspecialty rotations wherein developmental-behavioral issues need to be addressed swiftly (e.g., instruction in use of screens and not just exposure to diagnostic measures that are not workable in other rotations and often leave learners using bits and pieces of lengthier measures without clear decision-making criteria);

- Neglect to address the inevitable and enormous forgetting of knowledge and skills that occurs after a rotation (e.g., provide a subsequent review or collaborate with other preceptors on reinforcing and using skills while learners are on other rotations).

Challenges in the "How-To's" of Training

Excellent training curricula have long existed for nurses, medical students, general pediatrics residents and subspecialty trainees [e.g., Academic Pediatric Association (*www.ambpeds.org)*, Royal College of Physicians and Surgeons (*www.royalcollege.ca*)]. There is much professional agreement on the content of training in terms of knowledge and skills. The problem is with the "how" of training, i.e., equalizing the background or prerequisite skills upon which new learning is based. This involves: Presenting

information in a systematic way that builds on prior learning; ensuring that information is retained; establishing over time a trajectory of skill acquisition that is increasingly sophisticated; facilitating independent deployment of skills so that once in practice, providers can provide quality care for families. A "developmental model" for training in child development is needed.

A DEVELOPMENTAL TEACHING MODEL FOR DEVELOPMENT AND BEHAVIOR

With poor baseline knowledge in many trainees, combined with medical education's growing emphasis on increasingly autonomous demonstration of skills over time, medical educators are finding particularly helpful "developmental models" of training. Often used is the Dreyfus Model of Skill Development, where learners move through stages of decision-making from novice through advanced beginner, competent, proficient, expert to master. The novice and advanced beginner do not have much knowledge or experience, and so rely on rule application and analytical reasoning. Experts are adept, not only at recognizing patterns, i.e., judgment heuristics, but also at seeing when a pattern does not fit or when a new and unexpected situation arises. Master practitioners are able to see the big picture, understand the effects of context, and engage in deliberate practice—using reflection to integrate new experiences and guide self-study.[13,14] Elevating learners to the highest level of judgment is our instructional goal.

Another helpful model (that we've adapted a bit) is the work of Pangaro who developed an instructional approach to medical education (and evaluation of progress) focused on teaching at the medical/nursing student clerkship and residency levels.[15] This schema is explained in Table 14-1.

Table 14-1. Pangaro's (Modified) Instructional Model: (B)RIME [15]

<u>B</u>ackground Learner: The student acquires an understanding of how and why children progress (or don't), a knowledge of developmental domains and typical progressions with age, knowledge of how to elicit information from families and disclose difficult news, components of a neurodevelopmental physical exam, and an understanding of the strengths and weaknesses of clinical reasoning. Even though such learning sounds rote in nature, as with all instruction, teaching should be interactive and challenge background learners to engage the material at hand.

<u>R</u>eporter: The student can accurately gather and clearly communicate the clinical facts on his/her own patients. Mastery in this step requires the basic skill of history and physical examination and the knowledge of what to look for. It emphasizes day-to-day reliability, for instance, being on time, or following up with patients' test results. Implicit in the step is the ability to recognize normal from abnormal and the confidence to identify new problems. This step requires a sense of responsibility and achieving consistency in "bedside" skills in dealing directly with patients. These skills are often introduced to students in their preclinical years, but now they must be mastered in clinical care.

<u>I</u>nterpreter: Making a transition from "reporter" to "interpreter" is an essential step in skill acquisition, and often the most difficult. At a basic level, the student must prioritize among problems identified during patient encounters. The next step is to offer a differential diagnosis. Because a public forum can be intimidating to beginners, and learners cannot be expected to have the "right answer" all the time, we define success as offering at least three reasonable diagnostic possibilities for new problems. Follow-up of post-tests and mid-course evaluations provides another opportunity to "interpret" the data (especially in the clinic setting). This step requires a higher level of knowledge, more skill in selecting the clinical findings that support possible diagnoses, and in applying clinical test results to specific patients. The learner has to make the transition, emotionally, from "bystander" to seeing himself/herself as an active participant in patient care.

<u>M</u>anager: This step takes even more knowledge, more confidence and more judgment in deciding when action needs to be taken, and thus select among treatment options. Once again we can't require students to be "right" with each suggestion, but we should ask them to include at least three options in their diagnostic and therapeutic plan. A key element is to tailor the plan to the particular patient's circumstances and preferences.

<u>E</u>ducator: Success in each prior step depends on self-directed learning and a mastery of basics. To be an "educator" means to go beyond the required basics, to read deeply, and to share new learning with others. Defining important questions to study in more depth takes insight. Having the drive to look for hard evidence on which clinical practice can be based, and having the skill to know whether the evidence will stand up to scrutiny are qualities of an advanced trainee; to share leadership in educating the team (and even the faculty) takes maturity and confidence.

It is important to note that stages of learning overlap and that re-exposure to background learning is an essential part of each step. We cannot expect that one-time instruction in foundations of child development will be remembered. Learners may have long stretches in which they will be exposed to decidedly different aspects of medical curricula. Graduate-level nurses and residents often come from different schools and we don't always know their background knowledge. So at each opportunity to teach developmental-behavioral pediatrics we must step backwards a bit and review prior content before proceeding to increasingly complex instruction in clinical decision-making.

We also need to know how to move learners from one stage to the next. Effective learning is a collaborative process by which the learner helps the instructor understand what students are ready to learn, and the instructor ensures that this is learned accurately and well. To do this, application of child development theory is helpful. All learners are best taught when instructors recognize "the zone of proximal development" wherein we establish prerequisite knowledge and then teach slightly above that level—with coaching, interactive learning and problem-solving.[16,17]

Another functional way to view both stages of learning, instruction, and measurement of progress is seen in the work of James Popham.[18] Students' skills, whether they are children or adults, progress from:

- **Matching** and **Discriminating** (e.g., is this a variant of the same condition or developmental domain or not?);

- **Recognizing** (e.g., when an instructor shows an example of a condition, a domain or developmental theory and also provides a list of competing terms, students are able to select the correct answer from an array of options);

- **Identifying**, i.e., a learner can, given a case description, independently define and identify a condition or term without prompts or reminders;

- **Generating**, i.e., a learner can create new hypotheses and explore symptoms independently to determine increasingly complex conditions.

Presenting content in such a systematic way is helpful for thinking about instruction and creating measures of proficiency. Popham's work suggests that evaluation items should be designed to alert us to the level of remedial training needed (e.g., if learners fail at identification tasks, do they have the prerequisite skills of recognition? If so, instruction should begin with recognition level approaches). Overall, developmental models of training can and should be adopted for instruction in child development and developmental disabilities. In developmental-behavioral pediatrics we can begin to address this by recognizing that what we are teaching is complicated, involves the most complex skills human beings possess, and that we as teachers must provide graded presentation of complex material over time, with appropriate focus and learning activities for each level of learning.[19-23]

CONTENT AND METHODS OF INSTRUCTION ACROSS STAGES OF TRAINING

In this section, we describe training goals and instructional strategies for pre-clinical and clinical coursework and rotations.

Pre-Clinical Medical and Nursing Students

Didactic instruction is common at this level of training and should:

- Focus on knowledge of developmental domains and their expression over time (see Chapter 2 in this book for a description of domains and the milestones table in Appendix C);

- Provide a framework for understanding how and why development progresses. We do not recommend, at this stage of learning, covering all developmental theories because this is not only dull but confusing. Instead it is best to expose students to the best theory, that of Lev Vygotsky.[16,17] Even though sequestered in Soviet Russia without access to the work of other developmentalists,
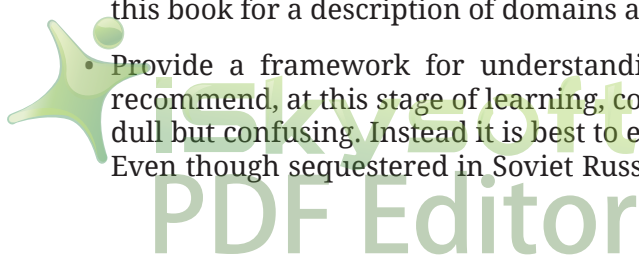
Vygotsky created a theory that improved on both Skinner's and Jean Piaget's work by focusing on the transactional nature of child development;

- After establishing prerequisites (knowledge of domains, theory of development) students are ready for additional case-based learning, preferably as problems to solve. This book is percolated with real-life examples of typical and atypical development that can serve as fodder for case-based instruction. The examples in this book focus on high prevalence but difficult to detect problems—representative of real-life children. These are, in reality, "the classic case;"

- Students also need an introduction to clinical interviewing and disclosure (covered in Chapter 8) as well as reasoning errors that deter effective use of judgment heuristics (see Chapter 3).

Instructional Strategies for Pre-Clinical Training

Below are some general suggestions for instructional methods with nursing and medical students:

- Goals for coursework should be explicit. Post-tests should be made available as pre-tests so that learners know how they will be evaluated and have a clear sense of what knowledge and skill base they need to work toward;

- Background reading by students is essential for establishing prerequisite knowledge of child development because this is the foundation for the many problem-solving skills required to detect and intervene with problems;

- To ensure a common ground for discussion, learners need to understand domains of development and have a way to remember what they are;

- Instruction should be vivid. For example, there are many fun videos on *www.youtube.com* that explain Vygotsky's theory (and contrast it with Jean Piaget's and other theories) showing parent-child interactions, developmental progression in various domains, etc;

- It is best to present a range of cases for both typical and atypical development. For example, with intellectual disabilities, present children with and without obvious dysmorphology; those who are "high functioning" and those who are less so. Helpful are the web-based, case-based sites that enable students to problem-solve and learn to think carefully, know when to ask for additional information, provide opportunities for life-long learning, and enable preceptors to evaluate progress. (See the Resources section at the end of this chapter.);

- Clinical interviewing and disclosing difficult news are also aided by live demonstrations or videos. *www.youtube.com* has many examples, although instructors will need to sift through these to decide on quality and applicability to young children and their families. We also cover issues in communicating with families in Chapters 7 and 8.

Instructional Strategies for Advanced Medical and Nursing Students Beginning Clinical Care

These trainees need a review of prior learning together with opportunities to see skilled generalists and developmental clinicians in real-life clinical settings (e.g., job shadowing). Ideally the preceptors' skills and enthusiasm are such that trainees develop a life-long interest in providing healthcare for children that embraces careful attention to the most common of childhood problems—development and behavior. Nevertheless, ongoing instruction is needed and content can be taught by various means, all of which have been studied for effectiveness:[1,4,24-26]

- Instructors should carefully collaborate with developmentalists and preceptors in general pediatrics, so that clerks and advanced nursing students can see exemplary care that embraces developmental-behavioral issues;

- Instructors should clearly state the goals for learning, both knowledge and skill-based. Consider providing post-testing as a pre-test, so that learners can appraise their own strengths and weaknesses and determine which areas need particular focus;

- Combine didactic lectures, readings (and re-readings) with: computer-based teaching modules or tutorials; problem-based cases; real-life examples; and video clips depicting children at various developmental stages;

- To ensure that learners get a strong sense of typical development (something that is very difficult to acquire when seeing only one family at a time), arrange for learners to observe in a daycare, preschool or early education site where there are children of various ages. Provide a structured observation tool on which the student makes notes (e.g., the milestones chart included in Appendix C). Such activities should be followed by small-group discussion with a preceptor;

- It is also wise for learners to observe programs designed for children with disabilities but important to make sure they observe children with a range of problems—not just severe cases;

- Clinical skills sessions using parent-child dyads and a clinician facilitator are also effective methods for teaching interviewing and disclosing skills;

- Clerks, residents and advanced nursing students benefit from a personal or small-group discussion of their post-test performance so they can identify areas of knowledge and skills on which they need additional improvement.

RESIDENCY AND GRADUATE NURSE TRAINING

In this section we list challenges and considerations in teaching: Rotation placement and timing, coordination across services, call schedules, etc. We also include two case examples of instructional approaches showing the issues involved.

Challenges and Considerations for Preceptors

Those who have chosen advanced medical training in Family Medicine or in pediatric specialties (general pediatrics, child psychiatry) have clearly decided their careers will involve providing healthcare for children. They don't need to be convinced that children are important. Unfortunately, residents in particular, may be overwhelmed by the acute care needs of the very sick and tertiary hospitalized patients who are often an excessively large part of their training. The main challenges for both developmental-behavioral and general pediatrics are how to help learners remember, amidst the riveting nature of acute and chronic illness, that children's development and their disabilities are the most common of all conditions, i.e., to help them find time and focus for developmental-behavioral issues within a very crowded curriculum.

Advanced nursing students and residents often come from various medical schools, meaning that preceptors cannot be sure what background knowledge they've acquired. Meanwhile, residency and nurse training programs are mandated to cover specific curricular content that is described by the accrediting body. These same accreditors lay out minimum requirements for educational experiences that all learners should have completed by the end of the program, also assigning content to specific post-graduate years (e.g., PGYs in Canada, PLs 1 - 3 in the US).

In pediatric residencies, programs require one to two 4-week blocks of developmental pediatrics [often there is just one rotation with the (often vague) expectation that knowledge and skills will be built in-vivo (e.g., within continuity clinics)]. For family medicine residents, some content will be covered in pediatric or general ambulatory blocks, but such coverage is often sparse when it comes to developmental-behavioral issues. Post-graduate nursing students focused on outpatient pediatric care usually have focused didactics and lengthier clinical experiences. Residents sometimes have the option, usually later

in training, for an elective rotation in developmental-behavioral or neurodevelopmental rotation, but most do not.

Issues in Rotation Timing and Placement

Pediatric programs may have latitude in terms of where the mandatory child development rotation is placed. Since developmental and behavioral problems are so common, placing the mandatory block in the first year of residency provides a strong basis for further developmental learning that should be taking place across the training program. Nevertheless, the first year of residency is often the year where the number of nights on-call limit the number of available clinical teaching days. Again, developmental-behavioral rotations are taught by the developmental pediatrics subspecialists, in tertiary referral clinics, and first year residents often lack the prerequisite understanding of development to handle the complexity of patients or the diagnostic measures administered to them.

On the other hand, even with excellent developmental teaching by general pediatrics/ambulatory preceptors, waiting until residents are more senior (and may have gentler call-schedules), delays trainees' ability to integrate knowledge and skills in normal and abnormal development into their ambulatory care routines—unless there is ongoing developmental-behavioral instruction in primary care rotations. Whatever block placement is chosen (e.g., within continuity clinics), the teaching staff will need to recognize that junior versus senior residents have different baseline skill-sets, and content requires adaptation according to background training and past experiences. It is expected that as residents progress in their training they will be able to take on more and more responsibility and work more independently. The various "milestones" models for residency training are an attempt to standardize expectations for residents' performance across different years of training.[19-23]

Issues with Call Schedules

The nature and types of call schedules has an impact on learning opportunities. For example, residents in a developmental rotation who are on call in an emergency room where there is a social worker triaging families at psychosocial risk, will have lots of personal case examples (and active questions) to explore with preceptors. Intensivist calls, such as PICU or NICU, should be avoided on developmental rotations since there are few opportunities to view developmental issues (and post-call residents are too stressed to take in much information).

On short rotations (e.g., when there is holiday coverage) residents may only end up with 7 – 10 days of time to learn about child and family issues. In these cases, preceptors should definitely require a second rotation, because there is absolutely no way, when a rotation amounts to less than one to two weeks of time, to master the complexity of child development, disabilities, early detection, developmental promotion, interviewing/disclosing or knowledge of referral resources.

Content and Focus of Rotations

Going back to the (B)RIME model described in Table 14-1, first year residents need to solidify basic information-gathering skills and begin moving into the "Manager" role (in which they take ownership for formulating and implementing a management plan and communicating recommendations to parents/patients). In developmental pediatrics, core junior-level skills include: Attentive observation; mastery of screening tests; comprehensive history-taking; neurological and musculoskeletal examinations; and vision and hearing screening. As residents advance they begin to play a larger role as "Educators" not only becoming involved in patient education and counseling, but also actively working to help junior colleagues learn (in both formal didactic sessions, such as rounds, seminars, and during clinical services).

Educator-level skills require a strong knowledge-base along with much clinical experience. Some residents feel pressure to do it all themselves before they are properly trained, and so plunge right into advice-giving that often relies on "common sense," pop psychology or personal experience. Parents can frequently tell if a resident really understands the recommendations presented and is engaging fully

in the complexity of problems or is simply repeating what was said by a preceptor in a similar clinic situation—or worse yet—making it up on the fly.

The pressure to assume a senior role as soon as possible, combined with a weak knowledge base and lack of appropriate role-modeling can result in residents passing along outdated, inappropriate and just-plain-wrong advice. It is imperative that residents know there is a body of developmental pediatric literature and learn to use it in providing advice and care. Residents need formal training in anticipatory guidance (see Chapter 7). They need to feel comfortable using medical technology efficiently (e.g., asking a family to wait a second while the resident retrieves online informational handouts to share with the family). Younger residents also need encouragement to discuss cases involving developmental-behavioral issues with senior residents and preceptors.

ORGANIZING ROTATIONS: ESTABLISHING BASELINE SKILLS, LEARNING OBJECTIVES AND ACTIVITIES FOR REACHING GOALS

A well-organized curricula is essential and must include clear goals, activities to ensure goals are met, assigned readings, mini-didactic sessions, opportunities for discussion, a pre-/post-test focused on skills and knowledge, and careful collaboration with continuity clinic preceptors. A tall order, but here is an example of how's and why's:

Case Example #1. Here are my personal experiences directing a developmental-behavioral pediatrics rotation, including some lessons learned the hard way. My residents (all first years) were bleary-eyed, often post-call from the NICU, and clearly bored into a stupor watching endless multidisciplinary exams. They weren't doing all that well on their practice boards. There had to be a better way. Sensing that general and developmental-behavioral pediatrics had alot in common (e.g., that most parents have developmental-behavioral concerns needing attention although in various ways), and not being an MD but rather a special educator, I decided to spend time in continuity clinics watching residents and faculty work with families. I could see how residents were struggling to ask and answer questions (e.g., about toilet training), let alone deal with more challenging issues, such as identifying delays, sharing results with parents, and deciding what types of referrals were needed. So here's what I did:

(a) Met with general pediatrics' and continuity preceptors (and surveyed former residents who were now community providers). I asked them to comment on the strengths and weaknesses of my rotation. A painful earful was lobbed including this compelling comment, "You don't really help us."—meaning that my division wasn't prompt in taking referrals, available for "sidewalk" consults or helpful in reinforcing basic knowledge of child development, community resources or training on disclosing interviews. Ouch!

(b) Together we established a list of shared (as well as separate) goals for our rotations and a pre-/post-test.

(c) We asked the continuity clinic director to assign to residents' clinics, a range of children with known problems, so that each resident would, ostensibly, have a chance to see children with a variety of conditions.

(d) In collaboration with continuity and general pediatrics' preceptors, we agreed to include in their libraries some critical texts on the issues of child development in primary care along with video training that residents could work through during clinic down-time.

(e) We then selected screening tools to use in both continuity and developmental-behavioral clinics and ensured, depending on the timing of the rotation, that one or the other rotations would provide training and review progress towards mastery. We selected measures that could be used in primary care by parent report, but also via a hands-on administration in the developmental-behavioral clinic to make sure residents acquired skills in managing patients and parents while also learning a tool they could use efficiently within the time-constraints of primary care.

(f) *Continuity and general pediatrics' preceptors agreed to make sure residents used screens at all well-visits, and we established a time to confer, initially once a month, to see how things were going and amend our plans as needed.*

(g) *The developmental-behavioral rotation faculty established a triage clinic wherein we scheduled four patients per day, twice a week, to be seen by a social worker and a developmental-behavioral pediatrician/resident (for a social work interview plus in-depth, hands-on screening and a physical exam). Residents were coached on explaining results and were given a template for dictating a two- to three-page summary report of findings and recommendations (that we then sent to referring providers within one week). The triage clinics were popular with community and teaching-hospital providers (because we could see families within 3 weeks) and also helped the developmental-behavioral clinic run in "the black" (for a change)—meaning that residents were able to learn needed skills while also actually helping with patient care on the developmental-behavioral rotation.*

(h) *We contacted professionals working in non-medical services, particularly those to which our developmental-behavioral service commonly referred. We arranged for once-a-month meetings wherein our residents could visit community services, could observe with guidance, hear an explanation of program offerings, and ask questions about the children and families they met. These included visits to: A daycare center where parent training was offered (during which residents conducted structured observations of different age groups); a family home visit with an IDEA intake worker; two separate special education classes serving a range of children with disabilities (where residents had an opportunity to observe with guidance from parents and teachers); a speech-hearing clinic; Head Start, etc.*

(i) *We also asked residents to identify, from their continuity clinics, a school-age child whose parents had concerns about their progress, and then get permission from parents and teachers to visit the school, observe, and gather teachers' observations.*

(j) *We cut back to two days the time residents spent observing in the developmental-behavioral clinic's multidisciplinary team, and also asked the various professionals to meet with residents to explain their professions, tests given, etc.*

(k) *We instituted video-taped training focused on interviewing and disclosing difficult news. In this training, residents, with preceptor supervision, could practice skills and receive feedback [much aided by a clinic secretary with great acting skills holding a (decidedly dysmorphic-looking) "Cabbage Patch" doll].*

(l) *We asked the developmentalist faculty to take turns attending the chief resident's conference.*

(m) *We collated a notebook for each resident to take home. These included goals, pre-/post tests, critical articles, online resource lists, and suggestions for books we thought each trainee should own (with all texts housed in the residents' workroom and also available in the medical library and bookstore).*

(n) *We created a monthly schedule of activities tied to goals and used a spreadsheet so we could change start dates along with continuity and post-call schedules. Into this we inserted appointments for community visits (mostly mornings), participation in the afternoon physical exams, reading time, didactics on various conditions, typical development, developmental promotion, and follow-up discussions about cases from continuity clinics, community visits, and cases from the ER, etc.*

(o) *We asked residents to create (and/or update) a list of referral resources and contacts, and to make sure this was posted in each continuity and general pediatrics' exam room.*

(p) *Residents championed an effort to organize information handouts in the primary care clinics. They created bins (on the outside walls of the exam rooms) where packets of parenting information per well-child visit were housed (including vaccine disclosure) along with print-outs about development at each age. Residents established separate bins for handouts on common issues such as toilet training, temper tantrums, etc., and not only made copies but put one in a plastic binder to alert others to*

photocopy (and not give away the original copy). This enabled residents to retrieve copies, reread before giving to parents and then highlight contents with parents before the family left the clinic.

(q) *We included in the schedule a 30-minute orientation to the rotation and a 2-hour end-of-rotation evaluation during which residents had the first hour to complete their post-test and the second hour for discussion (e.g., what residents wished they'd learned, suggestions for the rotation, etc.). We asked preceptors to gather in advance brief feedback from other faculty who worked with residents. The preceptor was asked to provide residents feedback about which skills and knowledge needed further attention, to complete the requisite resident evaluation forms, and also share residents' feedback with other faculty.*

(r) *At the end of the post-rotation evaluation session, residents were alerted to the likelihood they would forget about 90% of what they'd learned within 30 days. To prevent that, we asked them to leave us messages about well- or other visits where developmental-behavioral issues were raised and how they solved them, to call us when they needed advice with challenging cases, and to review the content of their notebook in preparation for a phone call in 1 month in which we would briefly review new cases and any outstanding issues.*

There were a few things we tried that didn't work. For example, we established a screening clinic for cardiology patients, one half-day per week. But there weren't always enough patients and so rather than having residents stand around for long periods of time, we discontinued that effort. Our residents set up a parent-training class after general pediatric clinic hours, but we lacked secretarial support to keep up this effort. Our residents also explored group well-visits but again scheduling this was a challenge. One project we are still working on is a crash course (maybe just a single day) for graduating 3rd year residents on practice issues (to make sure they know how to bill and code for screening, know where to purchase tools, how to find referral resources in their future communities, etc.). This may end up being a national project supported by the AAP or SDBP, but currently, we give residents a "going away" packet that covers most of the above.

But of all the things we did, collaborating with general pediatrics' and continuity faculty was the single most important. It improved the quality of developmental-behavioral care in primary care, and made the content of our rotation relevant to all other rotations. We were fortunate to have a physician-champion in general pediatrics who reinforced skills and knowledge (and who would not sign off on residents' charts until they had screened and addressed parents' non-medical issues)! That collaboration also meant that by the time residents rotated with us, they were willing and enthusiastic learners who really wanted more information and skills. Even though our teaching hospital does not have a required second rotation in the developmental clinic, collaboration with the continuity clinic coordinator ensured that our instructional goals filtered into other rotations, and most importantly into primary care.

So it is probably not a surprise, given all the above efforts, that our residents' scores on the developmental-behavioral portion of the boards continued to improve (and actually ended up being the highest scores of any subspecialty training). We were impressed with ourselves and our residents!

Case Example #2. *The University of Alberta, Canada has a two-month developmental rotation split into junior (PGY-1) and senior (PGY-3) blocks. Residents receive, on the first day of the junior rotation, a full-day orientation by the block coordinator/primary preceptor. Each first-year resident has an entrance interview where past formal and informal training in developmental pediatrics is reviewed and personal learning objectives are developed. The orientation day includes: A tour of the facility with introductions to important staff, a review of chart organisation and the report dictation process, distribution of core readings, study guides and other resources. These are followed by formal learning sessions on typical development, developmental assessment, and what to do in the clinic when developmental delays are suspected.*

Normal development and behavior are reviewed through guided interactive observations of DVDs depicting normal development, discussion of toys typical for play at each developmental stage, and guided daycare observations. The DVDs were created for the purpose of medical student education and feature staff developmental pediatricians administering selected items from standardized screening tests to children

aged 12-months, 18- to 24-months, 3-years, and 4-years. The orientation day is rounded out with a visit to an on-site daycare centre, where the residents are given an exercise in naturalistic observation of normal child development. The concentrated didactic content is much appreciated by learners and helps them fall quickly into their new routines.

Typical child development has changed little over time and is best described in excellent developmental pediatric textbooks (see the Resources section at the end of the chapter). Unfortunately general pediatric trainees generally do not have time to read through entire texts and may need to be directed to more manageable resources (e.g., a few relevant chapters), particularly with junior residents. A reasonable number of core readings should be assigned, with supplemental articles supplied for learners who have more background knowledge or who are especially keen. In our program, core reading sets have been developed to match learning objectives and curricula for the junior and senior blocks. Reading sets are updated annually. In addition, we have developed a short reference document for both learners (and their supervisors), summarizing developmental trajectories, i.e., the typical themes experienced by a child at each developmental stage as it affects children's behavior and parents' responses. Understanding trajectories provides a basis for anticipatory guidance and interpreting parents' developmental-behavioral concerns.[27]

Beyond the Mandatory Block Rotation: Championing Child Development Throughout Training

Much of developmental pediatrics is learned, we hope, outside the dedicated developmental-behavioral rotation. Collaboration with general pediatricians or family doctors in office-based practice or ambulatory clinics is necessary. The developmental pediatric block is simply too short to provide the cumulative experience needed for mastery of learning such as developmental-behavioral screening/surveillance. Practice must occur during ambulatory experiences to ensure consolidation of skills. Longitudinal resident continuity clinics are an especially good venue for practicing developmental surveillance since residents will see for themselves how developmental milestones unfold over time.

In pediatric residency programs, most continuity clinic preceptors will be general pediatricians. In family medicine, residents are supervised by generalists. Developmental pediatric faculty play an important role in training and mentoring community preceptors, and providing well-chosen, evidence-based training materials and other resources to ensure that developmental-behavioral surveillance and management of conditions meet current best practice (because physicians working in the community settings may not have had much training in developmental pediatrics in medical school or residency). A certain amount of gentle developmental myth-busting may be necessary (e.g., that clinical judgment drawn from informal milestones checklists is sufficient for early detection). It is important to share teaching tools across settings to ensure consistency of key messages. Faculty development via continuing medical education (CME) activities can increase capacity for high-quality, evidence-based developmental-behavioral teaching across generalist preceptors.

Case Example: *At the University of Alberta, a common learning framework and curriculum are used across all levels of learners and reinforced with any new faculty teachers. We use a number of teaching protocols including observations forms and a milestones chart. We also provide CME opportunities open to all comers. These include: monthly inter-disciplinary rounds; pediatric rehabilitation grand rounds (also available by tele-health to distant and rural sites as well as other hospitals in the city); child psychiatry grand rounds; a general pediatrics journal club in evidence-based developmental practice; and specialty journal clubs and rounds in autism spectrum disorders, ADHD, and infant mental health.*

Fellowship and Sub-Specialty Residency: Creating a New Generation of Experts

Developmental-behavioral and neurodevelopmental fellows (in the US) and sub-specialty residents (in Canada) arrive with solid general pediatric training and a strong interest in child development. Nevertheless, preceptors, early in the fellowship/sub-specialty residency, need to identify and rectify any training gaps. Self-evaluation via a pre-/post-test offers a good start along with modifications to include types of childhood conditions with which trainees have already had experience. Self-evaluation becomes the basis for collaboration with preceptors to form personal learning goals. Preceptors will need to add training goals of their own (e.g., practice and time management, research training, grant-writing, effective consulting with community providers, administrative skills) because fellows and subspecialty residents are likely to seek academic/tertiary positions at the completion of their programs. A portfolio approach, with semi-annual reviews, is a good way to document progress.

One of the most important skills for learners at this very senior level is ability to integrate information of multiple types from multiple observers, obtained at multiple times and from multiple perspectives, and somehow achieve a coherent developmental-behaviorial picture of a whole child surrounded by a family, community and cultural context. It is a daunting but rewarding task and often one that attracts advanced trainees to this field.

One step in the process of synthesizing information is to create a review paper (after learning to critique individual studies carefully). Next steps toward independent research involve: learning to frame questions; search literature (across medical, psychology and education databases) and work with reference librarians; write well; speak well; present findings; create slide shows; and prepare a manuscript for submission to a journal. After demonstrating ability to integrate existing literature, trainees can proceed to hypothesis formation (learning to prove both the null and the alternative), ethics considerations, data collection, analysis, reporting of results, discussion of study limitations and strengths. See Chapter 19 for considerations in research using new or existing measures. Trainees also need to complete coursework in statistics, study design, and training in use of statistical software packages, as well as learn to collaborate with other researchers.

Case Example: *At the University of Alberta, fellows/subspecialty residents assist in precepting continuity clinics. This allows them teaching opportunities, a chance to emulate a small-group consulting practice (addressing triage, time-management and quality improvement while also learning how to provide follow-up care plans including medication management, collaboration, and counseling skills). Advanced trainees are also expected to contribute to patient education activities, community outreach and advocacy by doing a small project during the second year of training.[28] A one-month "(Assistant) Manager" rotation helps them experience physicians' roles in leadership, clinic administrative duties, and the value of collaborative encounters including meetings, shared documents and policies.[29,30] Generalist preceptors and staff developmental pediatricians supervise trainees and evaluate not only medical management skills but also communication and collaboration. Feedback from non-medical support staff and allied health professionals is also part of the trainees' end-of-rotation evaluation.*

Teaching Specific Skills

Assessment of development requires many specific skills that may not have been taught or emphasized in other rotations. Trainees who are extremely proficient and comfortable performing complicated and even invasive medical procedures may not have received any specific training on detecting and addressing developmental problems. They may have no framework with which to learn milestones and may forget to apply careful systematic history-taking in their approach to behavior because behavior doesn't seem "medical" to them. Confusion between subjective and objective evaluations abound. Advanced trainees may become overwhelmed with the complexity and sheer volume of information provided by a comprehensive developmental assessment. Below we detail content and specific approaches for teaching the many components of developmental-behavioral pediatrics and provide helpful templates

and resource lists.

Teaching Milestones

Memorizing developmental-behavioral milestones is the bane of every trainee—an unfortunate truth that nevertheless must be accomplished. Training programs have specific requirements about normal child development content that must be met, but if we consider the concept of "the curse of knowledge," we recognize that these requirements will not and cannot be met all at once. So, the challenge is where to start.

If we want the learning to persist long after evaluations or exams, we must guide our trainees in constructing a framework for ongoing learning. Novice learners, here meaning medical/nursing students or junior residents, should start with general principles of development and how skills cluster into domains. The concept of developmental domains is not always intuitive, and students often mix up terminology. Milestone charts should not simply be handed out with the expectation that learners know how to use them. Orientation to the content is required (e.g., as in Chapter 2) along with case examples of both typically and atypically developing children. See the Resources section of this chapter for video options useful for instruction and Appendix C for a well-constructed milestones chart.

Learners also need to know that there are many different milestones charts (e.g., in the Harriet Lane Handbook) and that some (like the one in Appendix C) are more comprehensive than others. Learners also need emphatic instruction that milestones charts are not screening tools—they do not provide cutoffs, are not truly normed (but rather reflect expert opinion), and are designed to indicate performance at the 50th percentile—meaning that 50% of children will not be able to do the tasks; leaving providers with insufficient guidance for determining referral needs.[31]

When medical/nursing students or junior residents begin to learn milestones, they should not be expected to learn the whole chart at once. Medical students are especially used to memorizing large amounts of factual material for exams and are very likely to attempt to do this. Instead, they need to learn the underlying concepts on which milestones charts are constructed in order to understand development in a clinically useful way. After reviewing definitions and meaning of domains, you can trace skill acquisition on the y-axis (e.g., evolution of grasp, expressive vocabulary) and then by specific ages on the y-axis (illustrating at the same time how domains work together). Finally, students can be invited to observe children and discuss their milestones with others (for practice describing milestones and for creating mental images of skills).

Case Example: *We provide medical and nursing students a laminated copy of a milestones chart as a pocket reference. The chart defines the domains of development and helps establish a framework for observing and thinking about antecedents of various skills (including how these may be delayed or disordered in children with various disabilities). We present this carefully with many case examples and discussion to ensure that learners can identify the domains tapped when a child demonstrates various skills, i.e., we play "Name that Domain!" We use videos of encounters with children including interactions with parents to help students see the complex interplay of domains. We have students read Chapter 2 of this book. To encourage uptake of this framework, you can have students create a mnemonic for remembering domains [e.g.,* **Go** *(Gross Motor),* **Find** *(Fine Motor),* **Some** *(Self-help),* **Children** *(Cognitive),* **Stat** *(Social-Emotional)—* **Real** *(Receptive Language),* **Emergency** *(Expressive Language)* (adapted with permission; Kathleen Hegan, personal communication, April 23, 2013)]. *But as always we emphasize that milestones are a framework for thinking about children's progress and skills, and not a substitute for a real screening test. Rather, using milestones charts for decision-making is akin to putting a hand to a forehead to detect temperature—a good start, but not definitive for decision-making.*

Teaching Naturalistic Observational Skills

Experienced clinicians take advantage of all activities occurring in a clinic encounter to make observations about the children they are assessing, and use the standardized test results provided during team assessments to confirm (or disconfirm) their clinical impressions. This valuable activity is often invisible to learners, especially more junior ones, and needs to be made explicit if trainees are to master it. Training in naturalistic observation skills is important, and can help learners combine didactic information with hands-on learning experiences (e.g., observing in a daycare for typically developing toddlers and preschoolers, using the milestones list provided in Appendix C).

Case Example: At the University of Alberta, all second-year medical and dental students have a half-day experience in normal child development during their ten-week preclinical neurosciences block (including a week of dedicated developmental-behavioral pediatric content). During clinical skills training, groups of 8 - 10 students rotate through three stations containing parent-child dyads and trained faculty facilitators. Each station lasts approximately 25 minutes. During each session students may ask questions using the Ages and Stages Questionnaire (ASQ) as a prompt or make developmental observations based on the milestones chart. Parents are encouraged to interact with their child to make parent-child interactions and childrens' skill-sets observable to students. Each facilitators' job is to guide students in observation of spontaneous interactions and behavior. Facilitators can "catch" and label subtle developmental attainments often missed by novice observers (e.g., joint attention, object permanence, attachment behaviours).

The value of observation is re-presented to first-year residents during a seminar session on developmental-beahvioral screening/surveillance. In this seminar trainees are taught to observe parent-child behaviors during a health encounter (e.g., dressing/undressing, eating a snack, the social referencing occurring in response to a stranger entering the room, confirming parents' concerns by using items on a formal screening test such as PEDS:Developmental Milestones).

Junior residents visit a daycare during their mandatory developmental pediatrics rotation. The daycare is located on campus and attended by typically developing children whose parents work in our rehabilitation centre or in the acute care hospital across the street. The daycare is divided into two rooms—one for 1- to 2-year-olds, and one for 3- to 4-year-olds. Residents thus observe typical development in a natural setting and are able to compare and contrast skills between younger and older children. Accompanied by the primary preceptor, residents focus on 1 - 2 children from each age group, noting temperament traits and milestone attainments. Preceptors participate by modeling skills needed in naturalistic observation, and also supervise, answer questions, and reassure daycare staff and parents. This activity is followed by interactive discussions with preceptors. If several learners are observing during the same session, they can be invited to compare the children they saw and guess the relative ages (e.g., arranging the children from youngest to oldest).

Teaching Clinical Assessment Skills

For any field of medicine, it is essential to take history prior to conducting a physical exam or screening developmental status. Trainees need to make skilled observations, synthesize results, and decide on needed treatment. In developmental-behavioral pediatrics there is also a need to report past testing, compare that with current results, and review recent services. Templates for recording complex history information encourage a basic standard approach for novices (an example is included in Chapter 13 and downloadable at *www.pedstest.com/TheBook/Chapter13*).

Case Example: We provide learners a report-writing template showing the topics to cover, even if they are simply observing testing. After trainees observe and take notes on the template, they will continue to use this form when sufficiently skilled and ready to examine patients themselves. The template also serves as a guide to dictating results (another skill they must learn).

We also provide in their take-home notebooks, a reference list of the various measures they are likely to encounter, including their acronyms, the subtests within each measure, and a description of the skills

tested. Finally, we require trainees to read through several multidisciplinary team reports. In didactic sessions we make sure learners understand test scores and their interpretation.

In the procedure-based world of acute care, residents spend a lot of time learning how to deal with volume. They are used to seeing quickly many children with short, straightforward complaints. Trainees may avoid exploration of "bag-of-worms" topics that would slow them down and perhaps cost valuable sleep when on call. In developmental pediatrics learners are asked to switch gears and delve into complex issues: This requires a change in mindset. Residents are asked to do fewer procedures and more observations. Some may express concerns that they are not learning (e.g., if they are not physically doing something such as taking histories, using equipment to examine children, performing tests), and so complain about "just observing." Often residents are not as adept at "just observing" as they think they are, and so this skill needs to be explicitly re-taught. Active learning tools are helpful, such as using a template for note-taking. Post-observation precepting helps highlight interesting details trainees may have failed to spot.

In developmental pediatrics, we often have two-way mirrors, which can be an excellent teaching tool when trainees' observations are guided by faculty. Nevertheless, preceptors cannot always afford such time. In addition, parents may be observing at the same time, which can constrain professional discussion. Observation rooms are by necessity dark and thus potentially soporific. So here are some options:

- Include trainees in the actual examination room (in note-taking mode) followed by discussion from the examiner;

- When this is not possible and when parents are observing, trainees can watch along with parents but should remain strictly in question-asking mode (e.g., "What are you noticing? How do you think your child is doing?"), and should be instructed not to provide advice;

- If an attending or other skilled examiner is present for supported observation and real-time discussion, the preceptor can describe observations of the child, the examiner's behavior and parent-child interactions if parents are in the exam room. If parents are in the observation room, preceptors, if comfortable and skilled, can make discrete comments (e.g., pointing out subtle developmental behaviors such as joint attention and social referencing, verbal and nonverbal communication skills). Turning off the sound and focusing on body language can be especially telling;

- Whether trainees are present in the exam or observation room, opportunities for post-observation discussion is essential for ensuring meaningful learning. Such discussions should engage learners and begin with questions about what they noticed;

Such learning experiences can be very engaging and help junior learners focus on the non-Medical Knowledge/Medical Expert (refer to Table 14-1) learning objectives to be mastered on the rotation. Extended teaching around observation and communication skills can fill out the learning experience and decrease complaints such as "I only saw one patient."

With a lower volume of extended assessments, patient cancellations can seem disastrous for those trainees for whom "learning = seeing patients." Having back-up plans is wise. These can include having trainees watch relevant videos, spending time reading, practicing screening or assessment in other clinics, arranging for community visits (most particularly to see one of their own patients in schools or other services), and also by reducing the number of extended assessments trainees must observe in favor of higher volume triage clinics and community visits.

Case Example: During initial orientation we help learners understand the cultural difference between the acute care world and that of chronic developmental conditions. Trainees are prepared in advance for the possibility that schedules may change. A set of independent learning activities, originally developed for residents who must take leave during the already too-short rotation, is available for their use during "down time." The menu of self-intruction options is designed to be engaging, and all activities include a short

reflective component. Having an adept and dedicated scheduling administrative assistant for the training program, who is available and familiar with all the learning options, is invaluable for successful rotations and electives.

As we engage in detection of spectrum disorders and we are asked increasingly to decide what side of the diagnostic line to place "grey-zone" patients, our learners complain they feel less sure of what constitutes a "real" diagnosis. Although an effort should be made to identify and teach "classical" symptom clusters, we also have to help our learners to understand that in the real-world there may <u>not</u> be clarity or precision in the case material seen; both the learner and preceptor need to have a tolerance for ambiguity. There may not always be a "yes" or "no" answer. Sometimes we can't know—it often takes time for developmental-behavioral disabilities to fully manifest.

Building Collaboration Skills: Working with Other Disciplines, Parents and Patients

Developmentalists are trained in team skills and thus ideally positioned to teach these. Collaboration, as a learning objective, should be an integral part of any developmental pediatric rotation and can be taught at any level of learner. Medical/nursing students and junior residents can learn the specific roles of the various team members, with senior residents and fellows participating in the complex interactions of a team (and read some of the literature on effective team functioning).

Collaboration across professionals of diverse disciplines can be challenging for trainees who are used to a more hierarchical 'medical model' on inpatient wards. Effective team functioning requires all to respect each team members' contributions, including abundant respect for nurses. Professionals must integrate information and cope with imprecision or ambiguity in findings. The presentation of team diagnostic formulation to a family (particularly when it incorporates the findings of other team members) is another important part of communication training.

Fundamental to collaboration (whether working with other professionals, parents or patients) is skill in asking good questions. Ideally, this engages the interests of both trainees and their interlocutors. With good questioning we can find out what others think, learn from them, and, in the case of working with families, do a far better job at clinical decision-making if we "actively listen." Studies of healthcare providers' interviewing behaviors indicate that most allot only about 20 seconds for open-ended questions (before jumping mentally to a few diagnostic options and using only confirmatory close-ended questions thereafter). Meanwhile it takes patients much longer to reveal their symptoms, and they tend to reveal these in no particular order of relevance. Many difficult encounters relate to failure to elicit families' agendas—resulting in disruptive "oh by the way" concerns or insufficient description of important symptoms.[32-33]

Some strategies for building collaboration skills, all of which involve effective interviewing, include:

- Teaching students the difference between open- and closed-ended questions;

- Having trainees observe interviewing (social work interviews are particularly helpful because questions are usually worded in a way that is easy to understand and elicits thoughtful comments);

- Helping trainees take note of effective questions they've observed, and work at creating effective questions on their own (e.g., "How's school going?" sounds like an open-ended question but when the inevitable answer is "Fine," that doesn't give us much information). Some helpful questions to children and parents are found in Chapter 9. Many measures, such as *PEDS* also provide an introductory model for open-ended interviewing to which trainees can add other questions, most especially the prompts, *"Tell me more."* or *"Anything else you've noticed?"*;

- Helping trainees recognize the scope of other professionals' work and create questions to elicit the constructs others have assessed along with their unique observations (e.g., "What broad issues *were you looking at in your testing?"; "What did you notice about....?"; "Can you highlight for me the main issues that led to your conclusions?"*);

- Role-modeling is essential, and preceptors including non-medical diagnosticians should always ask trainees for their observations and hypotheses. Sample questions include: *"What did you notice about..."* (e.g., aspects of testing, parents' or children's behavior, etc.); *"What is your best guess at what is going on with this patient and family?"*;

- Encouraging trainees to call subspecialists, educators and other professionals who are or have been working with a patient to ask them for their opinions and recommendations;

- Having trainees participate in intake for developmental-behavioral clinics (e.g., returning calls to families or providers, preferably with a structured intake form for systematic information gathering);

- Providing learners a chance to politely disagree with the clinical opinion of others and discuss their points of contention (and take in new information);

- Reviewing texts on interviewing skills including disclosing interviews (covered in Chapters 7 and 8 of this book).

Case Example #1: One very bright first-year resident who was well-informed about typical development but just beginning a developmental-behavioral pediatrics rotation, observed testing of a 4-year-old, found to have an IQ of 83 with commensurate performance, i.e., the 13th percentile in language, academic, and self-help skills. The multi-disciplinary team recommended a range of interventions. Our resident disagreed and felt strongly that she was a typically developing child with age-appropriate skills. We described what a truly typical 4-year-old should be doing but this discussion was admittedly dull and not sinking in. The next day, this resident, armed with a milestones observations checklist and instructions to observe children across various ages, was scheduled for a community visit to a daycare center (one that had a sliding scale and thus included families of children from various socioeconomic strata, as well as many children whose parents were refugees from other countries). That afternoon, I met with him to hear about his observations. He said, "Now I get why our patient from yesterday was concerning. I could see today that other 4-year-olds were doing much more than she." So this resident's opportunity to relate his disagreements with other professionals and explore developmental status on his own was a helpful process for making child development (and developmental delays) real and compelling.

Case Example #2: At the University of Alberta, all elective medical/nursing students and residents on their junior rotation go through an exercise in interdisciplinary practice called "Follow the Child," in which they are assigned to observe a child and his/her family throughout a complete two-day interdisciplinary assessment (see Table 14-2). During the medical portion of the schedule, learners perform the history and physical examination. There is a written assignment to help ensure active observation.

When the family arrives, the trainees introduces him/herself to the parents and child, and explains the purpose of the exercise, obtaining consent to be present during the evaluation. Parents generally find this acceptable and frequently enjoy discussing their reactions to and observations of the child's testing as they sit with the learner, observing the assessment together through a two-way mirror. Due to prior training the learners are well-prepared for the history and physical exams, are comfortable with families, and families are equally comfortable with young medical/nursing sudents and residents.

Afterwards, learners must describe the specific roles of each team member, list at least one test that person performed, understand its domains and purpose, and identify at least one thing they have learned from each professional that is in their own practice (e.g., history questions about social skills, terms to identify a specific type of abnormal pincer grasp or age-appropriate milestones). Trainees must also describe in writing what they have learned from observing assessment. Our methodical and careful training opportunities have been well-received by our learners.

Table 14.2. Follow the Child: A Guide to Learning from Other Professionals

During your rotation you will observe multi-disciplinary assessments. "Follow the Child" is a guide to appreciating the expertise of other professionals, and collaborating effectively.

Before meeting with families, be sure you have reviewed the child's chart, intake comments, past history, and taken notes throughout the evaluation on a dictation template (see Chapter 13). As you follow the various team members, first introduce yourself to the family and ask their consent to observe and be involved with the assessment.

In addition to taking notes on your dictation template, the form below is helpful for note-taking during your observations of professionals. You can download this chart at *www.pedstest.com/TheBook/Chapter14* and expand the space for optimal note-taking. Trainees should note:

• The questions various professionals ask the parent or child;

• The types of skills each discipline assesses;

• What tests were used (and in subsequent discussions with professionals), why they used those tests and what specifically they were measuring;

• What strategies they use to encourage attention, effort, and compliance;

• Consider whether you could use any of these strategies in your own history-taking or physical exam;

• How the information from parents was incorporated into the evaluation.

Name of Clinic or Service: **Date:**

Name of Child:

Presenting issues:

Professional discipline	Areas assessed	Tests used	Take-home Ideas
Audiology			
Speech-Language Pathology			

form continues…

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Table 14-2. Cont'd								
Occupational Therapy	Physical Therapy	Psychology	Education	Social Work	Nursing	Medicine	Other	Parent Observations

USING DEVELOPMENTAL-BEHAVIORIAL SCREENING TESTS IN TEACHING AND LEARNING

Teaching trainees to use developmental measures is a compelling approach to independent learning, assistance with clinical care, and one that facilitates mastery of skills and knowledge. Trainees should always start by observing a skilled clinician administering the test. Remember to prepare learners for observing and make this as active as possible. An example is to orient learners to test materials beforehand and have them co-score. A follow-up discussion is needed and should cover children's behavior, how it was managed during testing, and shared observations not captured by test items.

We recommend "over-training" during developmental-behavioral rotations, in order to "bring home," i.e., make vivid and real, the constructs of child development. For medical and graduate nursing students, and fellows, training on a directly elicited assessment level tool (see Chapter 13 for test options) means that learners can actually help with the patient load in the developmental-behavioral rotation (while also learning a great deal about development, child management, building rapport, eliciting background information from parents, explaining results, etc.). For rising medical and nursing students and first-year residents, training in screening tools is usually sufficient, but we should:

- Teach trainees to administer tools hands-on to make sure they have skills in managing children (and parents) and can work effectively with children whether typically developing or not—a skill-set that translates well to working with families during well visits;

- Train learners in use of a tool that can also be administered by parent-report (since the latter application is more useful in busy primary care settings), and ideally teach a single tool that can be administered both by interview and hands-on;

- Help trainees understand the enormous concordance between hands-on administration and parent-report, i.e., appreciate the vast experiences and valuable observations parents have;

- Explain when to use screens, i.e., at all well-visits or opportunistically if well-visits are missed;

- Ensure trainees know how to use tools precisely, understand the value and meaning of standardized administration, and thus make use of test directions at all times;

- Make sure trainees avoid copyright infringement and recognize that most measures cannot be photocopied;

- Provide instruction on interpreting and explaining results.

Case Example #1: *After our residents and fellows observe multi-disciplinary team evaluations and in daycare centers/home visits, we train them in hands-on administration of PEDS: Developmental Milestones-Assessment Level (and the Safety Word Inventory and Literacy Screener (SWILS). To do this, we first ask that trainees read about management of children and parents during testing* (see the following section, "How to Administer Tests"). *Second, we ask trainees to conduct several practice administrations (e.g., with our patients, their own or a colleague's child). Third, we ask them to administer measures while we observe (followed by discussion and feedback), and then write a report (followed by more discussion). Fourth, we ask trainees to administer the screening version of the PEDS:DM in their continuity clinics (to get them comfortable with parent-report and use of screens in primary care). We discuss their cases after continuity clinics. With third-year residents and fellows, we provide the same level of supervision, but then ask them to participate in our triage clinics (where children are seen by a developmental-behavioral pediatrician and a social worker), and to administer the PEDS:DM-Assessment Level followed by preceptor and social worker observation and approval of reports generated. Finally, we ask advanced residents and fellows to visit continuity clinics and provide feedback on administration and interpretation of the PEDS:DM-Screening Version.*

Case Example #2: *With advanced learners (graduate nurses, third-year residents and fellows) we teach the mini-ADOS derived from the Autism Diagnostic Observation Schedule, which is a short mix of structured and unstructured play tasks used to elicit signs of autism although the Screening Tool for Autism in Two-Year Olds (STAT) is another viable option with abundant training materials.[34,35] Our rationale is that trainees should learn a great deal about management of children during testing, how to observe carefully, and adhere to standardized administration—skills that are readily generalizable to other measures and other types of patients. For residents, observing a Mini-ADOS and watching videos (e.g., Autism Speaks Video Glossary) during their developmental pediatric rotation helps teach signs of autism and the kinds of props and prompts useful in early detection. Trainees' test results, observations, and reporting of the Mini-ADOS are discussed with preceptors after the clinical encounter.*

How to Administer Tests: A Guide for Trainees

Overall Considerations

1. Although some measures come with a box of test stimuli (e.g., the Battelle or Brigance), measures focused on parent-report as the primary administration method do not. In such cases, trainees learning to use hands-on measures or preceptors will need to create a tool-kit of test stimuli that correspond with test items (e.g., variously colored blocks, paper, writing implements, a spoon, cup, doll, and small edibles such as children's cereal or oyster crackers). Materials lists are included in test manuals when tests are normed for a hands-on administration.

2. Trainees should be required to read through the test manual, understand how to use test protocols, how to score measures, and especially the meaning and value of a standardized administration, so that each patient's performance can be confidently compared to tests' norms, i.e., the performance of children around the country who were administered a measure in exactly the same way.

3. Watching a skilled examiner at work is helpful, and having trainees videotape the testing session is even better, especially if followed by guided discussion wherein professionals spend time pointing out testing issues (e.g., dropping down to easier items or changing subtests if a child appeared frustrated and lost compliance, the speed with which skilled examiners retrieved needed materials and make efficient notes so as to focus their attention on the child, how they kept the test stimuli out of the child's reach, offered praise, set limits, explained results, etc.).

4. After guided observation, trainees need to practice on their own or with other trainees. Abundant familiarity with tools is requisite for being able to carefully observe a child while testing.

5. Publishers' websites often have videos on how to administer measures, and trainees should spend time on these sites as they practice administration of tests.

6. Ensure that trainees understand copyright law. Do not allow them to make photocopies of test materials or sections of test manuals unless permission is given in the copyright notice appearing on the page(s) of interest. Photocopying (and all other methods of reproduction) violates copyright law, is likely to result in non-standard administrations (since directions may get separated from test protocols), and does nothing to support on-going quality improvements to measures that are enormously expensive to develop and keep current. Set a good example and seek permission from the publisher if interested in reproducing materials.

7. When trainees are ready to demonstrate their skills, they should be observed and/or videotaped when they first attempt to test a child and explain test results to parents (use of volunteers or surrogates is wise, and clinic staff and their children may be willing to "stand-in"). Afterward, professional examiners can go through the videotape with trainees pointing out what they did well and what they could have done better.

Establishing Background Information, Sensory Status, and Overall Reminders About the Purpose of Testing

1. It is helpful before testing a child to have a conversation with parents about the strengths and weaknesses they perceive, and especially the kinds of skills with which a child is struggling. This information provides a very helpful guide on where to start testing and which domains to administer first. Avoid starting with domains in which a child is known to have weaknesses. You want to get many initial successes in order to establish behavioral compliance during testing.

2. Make sure to gather information about a child's hearing and vision. If that has not been measured beforehand, request (or conduct) vision and hearing screening. Children with undiagnosed hearing impairment, for example, will perform poorly on most measures and often will appear delayed in language and cognitive skills. We certainly don't want to penalize them because we didn't establish that sensory skills were adequate.

3. The goal of testing is to measure mastered skills (meaning skills children regularly use in a variety of settings). It is not the goal to ensure that a child is successful on every item presented (by coaching, prompting, giving partial credit when none is due, violating standardized administration, etc.).

4. Knowing which skills are not yet mastered (e.g., demonstrated only some of the time or only in certain settings) is valuable because it means these skills are emerging. Such information gives teachers helpful entry points for instruction. So if you are writing a report, add information about emerging skills.

5. Adhere to the purpose of each item and stick to the actual wording (in the case of items with verbal directions to children). Avoid the temptation to reword directions since this may end up eliciting a different skill. For example, if the item involves naming letters, do not change the wording to something such as "Point to the ...." Pointing is a much easier task (by almost one to two years) and will lead to invalid results. Nevertheless, it is usually acceptable (but check tests' manuals acceptable options) to reword items to ensure comprehension (e.g., "Show me..." can usually be substituted for "Point to..." or "Where's the....," while naming tasks can usually be reworded as "What's this?"... What do we call this?").

6. Be aware of your gaze and body language. For example, when children are presented with multiple images and asked to "Name the....." try not to look at the correct response. Children with disabilities have often learned to follow a gaze and thus select the correct option from your inadvertent cues even while they may not know the skill. Be sure to position directions when answers are also visible so that older children cannot see them (some can read upside down)!

7. All the above details may seem picky, but it is only by administering a measure correctly and observing carefully that test results yield useful information. A standardized administration means that you give tests exactly as directed. This enables you to confidently compare a child you've tested to others around the country, i.e., make use of tests' norms, which in turn, identify what level of performance is behind and what is not.

8. Make notes about your observations during testing if you can do this without making the child wait, and if not, immediately afterward. For example, when asking a child to describe a picture, note intelligibility (how much of what a child says can a stranger understand), specifics of articulation (e.g., which sounds are missing in speech production), vocal quality (hoarseness, excessive volume, vocal tremors, stuttering, lisps, nasality), and also count the length of spontaneous sentences. Observe handedness, quality of pincer grasp, and whether, when writing letters, strokes are down-going, generally counter-clockwise, and consistent. Note whether the child tends to work from top-to-bottom and left-to-right, attends to details, rate of work, and how well he or she concentrates on a story read aloud. Consider how much prompting was needed to gain attention and maintain appropriate behavior, what techniques worked best, and whether cooperativeness changed according to the type of task (e.g., a child with fine motor deficits may

cooperate well on language items but misbehave when asked to write or draw). Such observations are helpful for advising parents and teachers about ways to work effectively with their children, and serve as foci for interventions.

Preparing and Guiding Parents During Testing

1. When testing children who are unfamiliar to you or the setting, it may be helpful to have a parent or guardian remain with the child, although the inclusion of any additional adults should be avoided because it may make children shy and reluctant to respond. When a parent or guardian accompanies a child, guidance will be required regarding how to maintain standardized testing conditions.

2. Parents should be told not to reword items or provide any cues (e.g., "You know, we talked about this yesterday.") and preferably and gently, not to talk, nod or shake their heads during testing.

3. If parents feel compelled to be encouraging during testing, suggest they use such phrases as "Good trying" and "Nice job" whether or not the child is successful with a task. Parents must be discouraged from displaying disappointment in children's performance on any or all tasks.

4. Explain to parents that tests must be administered in the same way to every child so that performance can be compared with that of others who have taken the test. Parents can be encouraged to take notes about whether the child would have responded correctly if the item had been worded differently.

5. Let parents know that their own observations about what children can do at home but did not do on the testing are valuable for teaching and will be discussed after the session is completed.

6. Parents need to know that children in a strange environment are not expected to demonstrate all the skills parents have observed at home, and that when recently learned skills are elicited, children are typically inconsistent in their performance. It may be helpful to remind parents that such inconsistencies are helpful evidence of emerging skills that need more practice to achieve mastery.

7. Let parents know that you will readminister items by interview and that testing can be repeated at a later date if their children failed to demonstrate the full complement of their skills. Examiners should remember that agreement between direct-elicitation and parent-report is quite high. Nevertheless, if parents qualify their responses (e.g., "She could, but we won't let her.") credit should not be given unless measures have a "just beginning to" or "sometimes" response-option.

Building Rapport with Young Children

1. If possible, testing can be speeded and rapport better established by first observing children in waiting rooms, classrooms or visiting their homes. Most gross motor and many fine motor items can be scored simply by observing (e.g., what type of pincer-grasp is used to hold materials, locomotion methods, etc.). Some language, social, and self-help skills can also be scored by observation (e.g., whether a child watches other children, looks back at his or her parent when engaged with a less than familiar person, holds up objects to show the parent, etc.). Simply being present or near the child for a short interval and in a setting in which the child is comfortable, can build rapport and make the administration of the remaining items easier.

2. If a parent is present, ask how their child will be most comfortable during the screening. Infants and toddlers can be placed on a parent's lap or in a car seat facing you.

3. Make sure the room is well lighted and ventilated and that the room temperature is comfortable.

4. Take cues on your demeanor from the child. If he or she is quiet and shy, approach him/her

quietly and gently. Too much enthusiasm can be overwhelming or frightening to young children. Generally, a relaxed and playful manner works well.

5.   It is usually wise to begin with fine motor tasks and to start with items well below expected performance for the child's age (unless you already know that a child has fine-motor problems in which case start with other subtests). An alternative, depending on the age of the child, is to use play-based assessment. This involves setting a stage for typical circumstances in children's lives (especially meal or snack times). To do this, have toys, cookies or crackers (slightly crumbled), a cup of water, a spoon and doll, all placed slightly out of reach. This often elicits spontaneous communication and a visible array of social skills since young children usually express interest in playing with toys, having food or drink, etc. In turn, this often allows the examiner to score a number of items by observation (e.g., combining objects such as feeding a doll with a spoon, putting objects in the truck).

6.   If a child doesn't respond well to a task, know that the required skills have prerequisite steps that eventually lead to mastery. There is a hierarchy within learning: Naming is harder than pointing, pointing is harder than discriminating (e.g., "find the one that's different"), discriminating is harder than matching (e.g., "find one that's the same"). One way to build rapport when confronted with limited success and refusals to attempt tasks is to present the item again in a less demanding way. For example, if a child can't name a picture, try asking, "Where's the ......?" If that doesn't work try, "Show me one like this" while pointing to an example (e.g., a paper with a letter written on it, an image of something with a specific color, etc.). Don't give credit for prerequisite skills but do recognize that the skill is emerging and a good focus for future instruction because the child has demonstrated at least some of the background needed for eventual mastery. As importantly, your effort to enable success at some level also builds rapport and engenders cooperation.

7.   If you cannot obtain a response from a child, even when presenting below age-level items (e.g., the child is asleep, hungry, fussy, frightened, sick), be prepared to interview the parent about children's skills. In these cases adhere strictly to the standardized questions listed in the manual. Parents often report on emerging but not yet mastered skills (via answers such as "sometimes," "if I let him" or "a little"), so it is important to note these for instructional planning, but do not give credit if beyond the correct responses listed in the test manual.

Building Rapport with Preschool and School-Age Children

Preschoolers are often slow to warm up and cooperate with unfamiliar people. They may refuse to answer questions, attempt to leave the testing area, become tearful or alternately grab for test materials or play with toys they've brought with them. The following suggestions should be helpful.

1.   Schedule testing for early in the day—for all young children—since they need to be especially refreshed and free from hunger and fatigue.

2.   If a child needs to be accompanied by a parent, give the child an interesting toy to play with, and engage the parent first (although be careful about discussing problematic issues that the child may overhear and understand). Engaging parents first usually makes both parent and child comfortable. This is also an opportune time to offer guidance in appropriate parental behavior during screening (see the comments above on testing with the parent or guardian present).

3.   Do not ask children whether they would like to participate since any subsequent refusals are challenging. Instead use clear but pleasant requests such as, "Come with me. We are going to look at a book and play with some blocks. It will be fun."

4.   Guide the child into desirable behavior. It is often helpful to cheerfully remind a child that this is like school and that he/she gets to "act like a big school boy/girl. This means sitting in your chair and listening to your teacher." Nevertheless, it is unlikely that young children can remain seated throughout testing, so "wiggle breaks" (or switching periodically to gross motor items) can be

interspersed among subtests. It is also acceptable to move to the floor, back to the chairs or even to sit under the table.

5. Introduce tasks as "games" rather than tests and present items rapidly enough to maintain interest, but not at a rate that rushes the child.

6. Use verbal reinforcement and show interest and enthusiasm in the child's effort. Phrases such as "good job" and "way to go" are appropriate since they do not indicate to the child that he/she was incorrect or correct, and such comments also provide encouragement to continue. It is critical that personal feelings of disappointment in a child's performance are carefully concealed.

7. Usually it is most effective to begin with fine-motor items such as stacking blocks or drawing (unless parents have already reported concerns about progress in this area). Otherwise, fine motor tasks usually allow children some success and can decrease self-consciousness which is a typical initial response to language tasks. After that, you can switch to receptive language and then to expressive language. It is wise to save gross motor items toward the end since these are disruptive and often result in a loss of control over the testing situation. Last of all, administer self-help and social-emotional items which are best addressed by parent report.

8. If children have not warmed up by the time language items are attempted, consider having puppets available. Introduce the puppets and have your puppet "talk" to the child's puppet. This often reduces apprehension and facilitates conversational behavior in reluctant children.

9. With older children (e.g., 3-years and up) who are non-compliant, try using stickers or something similar to reward effort (not success). If you anticipate following a child over time, you will need to retain their drawings and so, be sure to write the child's name and birthdate on these and store in his or her chart. Children are often interested in having something to take home; in this case have them draw another picture, etc.

10. With children 5-years and older, a timer may also be helpful and children can be allowed to turn the dial to a predetermined point. They can be told that when the timer goes off they will have a chance to play briefly, but they must work until then.

11. With older preschoolers or children who seem very distractible, it may be helpful to use a strip of paper to block out stimuli other than those the child needs to view in order to respond (e.g., on visual-discrimination tasks). This may reduce distractions and facilitate demonstration of skills.

12. Assessment should be stopped if children become very upset, persistently cry, and are unable to be soothed. Parents are likely to be embarrassed by this and should be told that this is often very normal and nothing to worry about. It is wise to then switch to a parent-interview administration. But be aware that children who fail to cooperate with screening have an elevated risk for developmental and behavioral disabilities (e.g., a child who receives a result of "Untestable" on the Denver, is most likely a child with problems. Just refer if you are not able to elicit skills).

13. If a child refuses to participate, offer choices (e.g., "Would you like to play with blocks first or crayons?"). A second option is to switch to a task in a different domain and then later, once cooperation is re-established, return to the item the child refused. A third option is to present a lower level task—one that the child can obviously demonstrate. If there are excessive refusals, the child's performance should be considered suspect for possible developmental or behavioral problems because children generally demonstrate readily the skills they have mastered.

14. Remain objective. Be aware that any subtle clues or extra assistance given to a child during the screening may influence the child's performance and invalidate the results. Avoid gazing at the correct response (when options are available) since children with developmental weaknesses are often aware of their difficulties and may have learned to look for extra cues.

15. Write all child identifiers on test protocols before testing so as to avoid "down-time" and thus

potential loss of control over children's interest and willingness to cooperate. Similarly, calculate scores only after testing. The same goes for recording observations if this cannot be accomplished during the examination without taking attention away from the child.

16. Eliminate distractions. Every attempt should be made to conduct testing in an environment free of background noises or disturbances. Remove from view any materials (such as preferred toys) that may be distracting to the child during testing. Avoid having the child bring his or her own toys into the testing room.

Working with Special Populations

It is helpful, especially during a developmental-behavioral rotation, to have trainees test children with known disabilities. While such children have had or are in the midst of more thorough testing, having trainees administer screening or assessment tools builds skills and confidence in working with children who have a range of problems, and can actually be helpful in determining children's needs and abilities not yet assessed. An example is when the parents of a child with visual impairment ask healthcare providers about their child's speech-language skills.

Note: We do not recommend teaching diagnostic instruments to medical/nursing students or residents, and have some reservations about even teaching them to fellows—these are tools on which non-medical professionals are trained under close supervision and are ultimately certified by their various licensing boards to use. Teaching diagnostic tools to medical/nursing students and residents (but not screening tools) leaves learners, most of whom end up working in primary care settings, using bits and pieces of measures (and thus they will have problems obtaining psychometrically sound and accurate results). Fellows, however, should be taught assessment level tools (see Chapter 13 for details), which are a close approximation of diagnostic instruments but do not require the rigorous supervision of measures such as the *Bayley-III, WISC-IV*, etc.

The following modifications are designed to help children with unique needs demonstrate skills they possess under the conditions and methods they are most likely to use in real-life. These adaptations are also designed to avoid giving credit for skills that are insufficiently mastered. Although we recognize that such modifications may result in non-standardized administration of measures, the goal is to adjust for known impairments so that children can best demonstrate skills in other areas.

Children with Motor Impairment

1. Ensure that seating is appropriate. This may include allowing a parent to position a child on his/her lap in order to provide adequate trunk and head support. Use of corner sitters or other adaptive equipment may be needed. Alternatively, some children perform best when lying on their sides. Parents are usually the best source of information on the most effective seating. However, if the parent cannot advise the examiner or is unavailable, a physical therapist should be consulted.

2. Some children with motor impairments have significant difficulty with articulation, rendering their responses hard to understand. The accompanying parent may be especially helpful in interpreting oral answers. Learn to use the child's augmentative communication system if the child has one.

3. For children with severe motor and oral-motor disabilities who can neither point nor express themselves orally, the direction of eye gaze can be used to assess skills. To do this, examiners can make photocopies of the stimuli showing response options, cut them apart, and place copies on separate cards. The cards can then be placed at least six inches apart on the table in front of the child. Instead of asking the child to point, ask them to look at . . . (a specific picture, letter, etc.). Examiners must be careful not to look at the correct choice but rather at the child and at the direction of his/her gaze (children with physical disabilities are often alert to eye-gaze as a clue to

the correct answer).

4. Children with motor impairments usually need extra time to respond and examiners must be patient. Asking the parent about processing time is helpful.

5. It is often helpful to interview the parent first (and privately, especially with older children) about the skills he/she thinks the child has. Such information gives examiners more confidence in deciding when and when not to probe responses.

Children with Hearing Impairment or Deafness

1. Find out from parents how their children communicate. If sign language or total communication is used, the examiner should either have sufficient sign-language skills or use the services of a reliable interpreter, providing the latter with appropriate guidance regarding his/her behavior such as that given to the parents.

2. Sign language may also be used by children with autism spectrum disorders or intellectual disabilities.

3. Children should be wearing prescribed amplification devices with fresh batteries.

4. The room should be very quiet and free from visual distractions.

5. Children's attention must be obtained before directions are given.

6. For a basic introduction to signing, the following web sites may be helpful: *www.handspeak.com* and *www.sign2me.com.*

Children with Vision Impairment or Blindness

1. When testing students with limited vision, it is advisable to obtain as much information as possible from the parent or gather existing reports from the child's vision teacher. Referred to as a functional vision assessment, such reports provide helpful advice on appropriate lighting, magnification, positioning, size and color of objects or pictures, enabling the child to see to the best of his/her ability.

2. When vision is too low to enable pictures to be viewed, substitute real objects (not toys) for pictures where possible.

Children with Severe Speech Impairments and Poor Intelligibility

1. Have the parent with you during testing and ask him or her to interpret verbal responses.

2. Give credit for gestures that clearly convey a correct response.

3. If a child is using a communication system, test him or her with the system in use (after having the parent explain to you how it works).

Children with Severe Behavioral Problems and Non-Compliance

1. Start with a series of imitation tasks (such as clapping, eye blinking) so that a child has some immediate success. Ask the parent about the child's preferred activities and begin with subtests that are similar to help win compliance.

2. Note changes in the child's behavior across tasks. Children with emotional problems often react especially poorly to tasks that are challenging for them. Such observations can help identify areas of particular weakness.
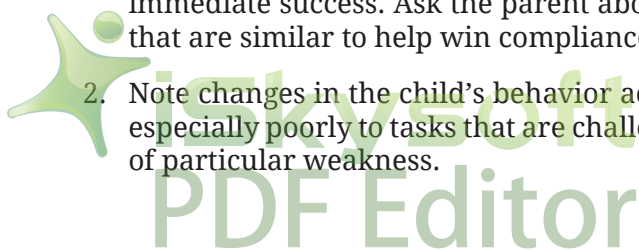
3. Allow the child some control in the testing situation, such as by taking turns (e.g., the child gets to engage in a preferred activity after completing a subtest). Allowing the child to set a timer for a predetermined interval may also be effective.

4. Have a variety of tangible reinforcers (e.g., crackers, cereal, stickers, etc.) to use along with praise when the child attempts tasks.

5. Let the child know promptly when he/she demonstrates unacceptable behavior (e.g., throwing materials at the examiner) by saying "No." Temporarily switching tasks may be helpful.

6. When returning to a subtest on which a child misbehaved, start with easier items and give clear guidance for appropriate behavior (e.g., "This is like school so you need to be a big girl and listen to your teacher!"). If behavior becomes more challenging as tasks become more difficult, this may be a sign of frustration at insufficient skills for success. Try presenting prerequisites (e.g., matching blocks of the same color, then having the child point to the color when named, and then back to naming the color). The relationship between cooperation and success is often a helpful indicator of skill levels.

7. Parents can often give examiners helpful advice on behavior management. Ask questions such as "Other than spanking, what do you do to get your child to cooperate?"

8. Present items quickly and as appealingly as possible since this may distract a child from engaging in challenging behavior.

9. Avoid making threats or promises that cannot be delivered.

10. Try using puppets, allowing the examiner's puppet and child's puppet to communicate. This method can relieve stress and anxiety, and facilitate willingness to respond.

Children with Significant Physical Health Problems

1. Schedule testing for a time when the child is as refreshed as possible.

2. If fatigue is evident during testing, reschedule or take frequent breaks.

3. Omit gross motor items if these are too challenging physically, and administer these by parent-report.

4. Children with chronic illness may have uneven development (e.g., large gaps in knowledge due to limited schooling or other learning experiences, deficits in gross motor skills due to restrictions in movement, etc.) It is important to note these carefully so that missing skills become a focus for intervention, if health and physical exertion permit.

5. If testing hospitalized children of school age, ensure they are receiving instruction while on the wards. An inordinate number of children with major health issues also have developmental difficulties, and evaluations of developmental status must often occur while children are hospitalized.[36] Nevertheless, assessment should be done near the end of hospitalization or as an outpatient when the medical condition is sufficiently stable for results to reflect the child's actual capabilities. Medical stability is an important concept to review with residents requesting "stat" developmental assessments on the wards.

6. Residents and preceptors should make sure that discharge instructions include educational interventions or other therapies if children are home-bound. Children and their parents may be fearful of re-engaging prior activities, and so providers need to review discharge instructions (and reauthorize or not) every few weeks to facilitate a return to school, daycare or other activities.

Children with Autism Spectrum Disorders

1. It is advisable to interview the parent first to obtain a detailed description of what the child has been observed to do at home. Parents can usually give very helpful information about how to work with their child, what kinds of reinforcers to use, and how to elicit optimal responses.

2. Remove extraneous materials from the area, particularly those that prompt stereotypical responses from children (e.g., if the child likes to spin wheels on cars, it is advisable to keep these out of sight).

3. Begin with items that provide immediate success (e.g., items meant for much younger children) and establish rapport through the use of toys or activities rather than with items that are verbal only.

4. It is often helpful to tap on the stimulus materials to direct the child's gaze to the appropriate stimuli.

5. Since children on the spectrum often respond adversely to loud noises, use a soft voice to praise and to redirect misbehavior (unless the child is destructive to test materials, at which point say, "No" a bit louder, and then move the materials out of reach).

6. Do not require the child to make eye contact with you during testing because this is not necessary for assessing most skills and can be provoking.

7. Simplify your language as much as possible while maintaining standardized procedures and instructions. Supplement verbal directions with visual cues and gestures.

8. Use tangible or edible reinforcers rather than social ones.

9. Because it is difficult for children with suspected autism spectrum disorders to make transitions, trade one toy for another when changing to a new domain/subtest.

10. Arrange seating that will inhibit children from leaving the test area (e.g., place the child's chair against the wall with a table in front or sit at the same level as the child with your knees on either side of his or her chair).

11. Avoid making assumptions about one skill area based on others. Children with developmental disorders often have unexpected areas of strength and weakness. For example, expressive language may be at a higher level than receptive language.

12. Start testing with items the parent is fairly sure the child can do easily and well (see also the previous section on testing children with severe behavioral problems and non-compliance).

Children with Traumatic Brain Injury

1. Attention span, distractibility, and difficulties with memory often pose challenges. It may be necessary to repeat directions several times. Use of visual cues can often aid recall.

2. Children with traumatic brain injury often process information slowly. They may need additional time to respond. Patience on the part of the examiner is usually required.

3. Expect wide variations in skills and a departure from typical development (e.g., the possibility that expressive language, for example, may be higher than receptive).

4. Interview parents thoroughly about self-help and social-emotional skills (and if working with adolescents, also interview the patient). Most such children have challenges with executive thinking such as poor judgment, problematic organization, planning, and memory. In social-emotional areas there are often difficulties with empathy, cooperation (or excessive compliance with troubling peer suggestions), and lack of inhibition.

Children with Giftedness and Academic Talent

1. Be alert to the possibility that bright children often have well-developed reading skills. It is advisable to cover the examiner's directions (even if upside down) to prevent the possibility of their reading answers to items.

2. The high degree of creativity often exhibited by gifted children may lead them to produce a range of alternative answers to items. Additional probing may be required (e.g., "What else do we call this?" or "What do most people call this?").

3. Humor and side-bar discussions are common (and often fun) but when time is limited, redirection may be necessary (e.g., "Great, but let's talk about this later.").

4. Uneven development is common in gifted children. Motor and social skills are usually age-appropriate, while language and academic skills may be substantially higher. Bright children are often aware of their strengths and weakness and readily frustrated especially with fine motor tasks. It may be wise to begin testing with language items and save fine motor tasks until later in the testing session (starting with age-appropriate items—not the age of performance of language/cognitive tasks).

Bilingual and Non-English Speaking Children

1. Children who are non-English-speaking should be tested in their primary language, the language spoken most in the home. Even children who speak some English perform best when tested in their native tongue, although testing in both languages is often wise, especially if they are enrolled in an English-speaking daycare, preschool or school program. If the examiner is not fluent in the child's language, an interpreter will be needed during assessment (be sure to use established translations for measures if these are available). Interpreters must be available to elicit parental information and explain results. If an interpreter is not available parents should be asked to bring a friend to help interpret to both the parent and child.

2. Lay interpreters will need the same guidance given to parents who accompany children into testing (see the section on testing with parents present). Professional (and lay) interpreters should be asked to comment on the children's articulation and syntax skills in their native language. These areas of language development are difficult to assess by examiners who do not speak the child's native tongue. Casual comments by interpreters such as, "When he speaks Japanese, his words are not in the usual order," offer invaluable clues to the possible presence of a language disorder.

3. Overall, it is critical to recognize that many professionals miss developmental-behavioral problems in bilingual/dual-language children and are far too willing to dismiss poor performance on measures. To avoid this error, be alert to behavioral problems that may manifest during language-related tasks because these are important clues to the presence of difficulties. Also listen carefully to parents' observations about how a child performs compared to his or her peers, take careful note of psychosocial risk factors because these predict ongoing difficulties whether a child is a dual-language learner or not. Ultimately err on the side of caution—refer rather than defer.

4. When interpreting screening results, recognize that bilingualism often contributes positively to cognitive development and typically produces only temporary and mild expressive language delays. Below-cutoff performance in areas other than expressive language is not due to bilingualism alone. Bilingualism rarely contributes to native language difficulties in the areas of receptive language or articulation, and is not a contributor to disordered patterns of expressive syntax, i.e., putting words in the wrong order in the native language. Such difficulties suggest the presence of a language disorder or other developmental disability.

5. Additional information on how bilingualism and cultural issues in development is found in Chapters 10 and 12.

Final Considerations For Trainees: Explaining and Reporting Test Results

1. Be sure to use a dictation template to guide you in how to report results, observations, etc.

2. Make sure your report concludes with recommendations for any needed non-medical services and for follow-up in your clinic (if needed).

3. For explaining results to parents, remain positive and encouraging about the value of recommended services. Also read about the best ways to give difficult news (see Chapter 8 for guidelines and rationale).

4. Make sure you give parents telephone numbers and descriptions of recommended services, brochures if possible, and preferably also make appointments for parents.

5. Establish two-way communication with referral services so both you and they can remain updated on progress.

6. For children with chronic illness who may need temporary home-bound instruction, make sure to create a time-frame for reviewing discharge instructions and updating recommendations for returning to school.

7. All parents, even when their children are referred to special services, benefit from developmental promotion. When children have a vast range of needs, provide parents a list of websites and parent support programs. When issues are fewer in number, provide one or two written information handouts.

FACILITATING LIFE-LONG LEARNING

The complex nature of developmental-behavioral pediatrics (e.g., the many variations of presenting symptoms and causes for each diagnosis) requires on-going self-instruction and advice-seeking/collaboration with a range of professionals:

- Preceptors should model a commitment to ongoing learning (e.g., via journal clubs, sharing articles, actively questioning and learning from other professionals) and do so with enthusiasm and curiosity;

- Learners need to be actively guided toward information resources, and need to be able to critique information that is less than optimal;

- It is wise to have a small library in residents' work areas. Good texts should be pointed out and reading time encouraged. Requesting the medical bookstore to stock these (as well as the medical library) is wise. Trainees should also be given a take-home notebook or a loaded memory stick with resource lists, information about disabilities, national services for families, etc. (see the Resources section below);

- Setting rotation goals that include self-instruction opportunities is needed and should include opportunities for trainees to learn via a variety of media (e.g., webinars, DVDs, online videos, parenting information sites, etc.);

- Trainees should be encouraged to add to a master list of learning opportunities, books, websites, etc., to share with subsequent residents;

- Preceptors themselves, whether in general or developmental pediatrics, need to conduct quality improvement initiatives and maintain certification. More information about these is provided in Chapter 15.

EVALUATING TRAINING

Assessing Trainees' Knowledge and Application

During rotations and fellowships there is ample opportunity to observe and provide feedback on the host of skills required of trainees: Comprehensive history-taking; physical examination skills in neurologic, musculo-skeletal and dysmorphology exams; interpersonal communication (with parents and other professionals); and ability to administer, interpret and report on standardized test results. But self-evaluation by trainees, and objective evaluations by preceptors are also a critical aspect of determining knowledge and the skills for applying that knowledge. We have included a pre-/post-test in Appendix B, downloadable at *www.pedstest.com/TheBook/AppendixB*. The measure focuses almost exclusively on developmental-behavioral measurement, milestones, psychosocial risk, disabilities, and referral options. If downloaded the tool can be customized to add questions about physical exams, disclosing/interviewing skills and other important objectives. As a pre-test, the tool can be used for self-evaluation and goal-setting for rotations. As a post-test, the tool can be used to assess mastery of knowledge and skills.

Ideas for improvement and feedback on precepting are critical for improving rotations. Many residency programs have their own required forms, usually completed privately and after the rotation ends. Even so, it is helpful to have an end-of-rotation discussion, an opportunity for trainees to comment on what they liked best, least, suggestions for changes, and how they plan to use the information and skills they've acquired. The pre-/post-test in Appendix B provides a few helpful starter questions. Making use of trainees' suggestions requires regular staff and faculty meetings focused on rotation improvement.

Case Example: *In addition to pre-/post-testing, daily evaluation cards with the "MiniCEX" format are useful for focusing on specific skills.[37-39] These short checklists, which are organised according to various competencies required by accrediting bodies, can be quickly completed by each day's supervising attending physician and then passed along to the primary preceptor.*

We assess trainees' skills in collaboration via a "360 degree" evaluation, also known as multi-source feedback. In this process, trainees are evaluated individually by all team members with whom they work.

Entrance, mid-rotation, and exit interviews are done by the block coordinator/primary preceptor to guide the residents' goal-setting for their personal learning objectives and ensure the rotation schedule meets residents' learning needs. The primary preceptor discusses daily evaluations completed by other supervising staff in order to provide residents with formative feedback on their performance, and what they may need to do in order to achieve satisfactory progress. These discussions also embrace whether and how trainees were able to achieve their personal learning objectives. At the end of the rotation, there is a final compilation of preceptor evaluations, progress, and provision of summative feedback including future training needs.

Chapter Comments: *We have taken a decidedly developmental approach to learning about development! This has enormous value because prerequisite skills are the foundation for subsequent learning including ability to generalize appropriately to new encounters with different patients. As with all learning, knowledge and skills are best acquired when experiences are vivid, active, fun, participatory and thoroughly supported by engaged and enthusiastic instructors.*

Preceptors in developmental-behavioral and general pediatrics are particularly challenged because trainees' exposure to developmental-behavioral issues can be sporadic and is often eclipsed by the graphic procedures of medical care. We need to impress upon trainees, whether they become subspecialists or not, that all of us share the same goals—ensuring that patients are not only healthy but also as competent with life skills as possible. Thus all trainees need to understand that what they learn on their developmental rotations is enormously relevant to their effectiveness as healthcare providers: Managing challenging children, addressing the implications of chronic conditions on well-being, eliciting parents' observations,

detecting problems, explaining difficult news, providing advice on health and behavioral management, and accessing non-medical referral resources. In other words, skills in developmental-behavioral pediatrics should be viewed by instructors and learners as a unifying theme relevant to all other aspects of medical training.

We have not focused specifically on training emerging professionals in other disciplines (e.g., speech-language pathologists, occupational and physical therapy students, social workers, psychologists or educators). But the same stages of learning apply (as does much of the same content and process). Cross-training is wise so that those in one discipline learn to appreciate other professionals, know where to turn when patient issues are complex, and know how to collaborate effectively.

RESOURCES FOR TEACHING AND LEARNING

In addition to this textbook, there are many other indispensible references for instruction and self-instruction. Below we describe books (and highlight the content and the level of training for which they are most appropriate) and other media helpful for teaching and learning (with live links on *www.pedstest.com/TheBook/Chapter14*).

Texts on Typical Development and Behavior

Brazelton TB. *Touchpoints: Your Child's Emotional and Behavioral Development.* Reading, MA: Addison-Wesley, 1994. *This text is helpful for advanced residents, fellows and community providers and is focused on parent-child interactions, temperament, and attachment. More information and helpful videos can be found on www.brazeltontouchpoints.org.*

Coleman WL. *Family-Focused Behavioral Pediatrics.* Philadelphia: Lippincott, Williams & Wilkins, 2001. *Useful for all levels of training and offers information on interviewing and family counseling.*

Dixon SD, Stein MT. *Encounters with Children: Pediatric Behavior and Development,* 4th ed. St Louis, MO: Mosby Inc., 2005. *This text should be in every resident's personal library and is helpful at all stages of medical education and for providers in practice. It includes brief descriptions of theories of child development including temperament, covers pre-birth as well as well-visit interviews, and provides a well-visit by well-visit guide to children's skills and parents issues, along with great case examples, images of children's motor and fine motor skills, etc.*

Landy S. *Pathways to Competence: Encouraging Healthy Social and Emotional Development in Children.* Baltimore: Brookes Publishing, 2002. *Useful for all levels of training and provides guidance on developmental promotion, effective advice to families, etc.*

Texts on Problems/Disorders of Development, Behavior, and Learning

Diagnostic and Statistical Manual of Mental Disorders, 4th ed. Washington, DC: American Psychiatric Association, 2000. *The Classification of Child and Adolescent Mental Diagnoses in Primary Care – Diagnostic and Statistical Manual for Primary Care (DSM-PC) Child and Adolescent Version.* Elk Grove Village, IL: American Academy of Pediatrics, 1996. *These books are helpful additions to the libraries/work rooms in general, developmental, and psychiatry rotations; defines diagnostic codes for billing; expect updates when the DSM-V is published.*

Andrews D, Mahoney WJ, eds. *Children with School Problems: A Physician's Manual.* 2nd ed. Ottawa: Canadian Pediatric Society, 2012. *For fellows and developmentalists, this book covers diagnoses of learning disabilities, medications, advising families, etc.*

Augustyn M, Zuckerman B, Caronna EB. *The Zuckerman Parker Handbook of Developmental and Behavioral*

Dosman CF, Andrews D, Goulden KJ. Evidence-Based Milestone Ages as a Framework for Developmental Surveillance. Paediatrics and Child Health. 2012;17(10):561-568. Pediatrics for Primary Care. 3rd ed. Philadelphia: Wolters Kluwer, Lippincott Williams & Wilkins, 2011. *Best used with advanced residents and fellows, fourth-year clerks, upper/graduate level nursing students, and community providers; provides brief coverage of a huge range of conditions but also issues such as bereavement, divorce, child care, obesity, witnessing violence, masturbation, night terrors, raising twins, gay and lesbian parents/youth—in short most of the issues that come up in primary care.*

Dosman CF, Andrews D, Goulden KJ. Evidence-Based Milestone Ages as a Framework for Developmental Surveillance. *Paediatrics and Child Health.* 2012;17(10):561-568.

Jones K. *Smith's Recognizable Patterns of Human Malformation.* 6th ed. Toronto: Elsevier Health Sciences, 2005. *This is a standard reference book on metabolic and genetic problems that should be available on all rotations and owned by fellows and preceptors in developmental pediatrics.*

Wolraich ML, Drotar DD, Dworkin PH, Perrin EC. *Developmental-Behavioral Pediatrics.* Philadelphia: Elsevier, 2008. *This is best used by fellows, preceptors; provides in-depth coverage of various conditions including health related issues.*

Web-Based and Other Resources for Teaching and Learning

Academy of Medical Educators *(www.medicaleducators.org):* provides training, links, certification, discussion forums, an annual meeting and other resources for medical educators.

American Academy of Cerebral Palsy and Developmental Medicine *(www.aacpdm.org):* focuses in large part on children with several conditions. Its website has multi-media learning opportunities (for parents and professionals), including a series of grand rounds lectures, an annual meeting and evidence-based reports on various conditions.

AAP Section on Developmental and Behavioral Pediatrics (*www.dbpeds.org):* with articles on developmental screening/surveillance, conditions, learning tutorials, etc.

Autism Case Training *(www.cdc.gov/ncbddd/actearly/ACT/class.html):* A Developmental-Behavioral Pediatrics Curriculum.

Autism Speaks Learn the Signs *(www.autismspeaks.org/what-autism/learn-signs).*

Autism Speaks Video Glossary *(http://depts.washington.edu/uwautism/resources/autism-online-tools.html)* and other resources at the University of Washington: Provides helpful examples of typical and atypical child development.

Bright Futures (*http://brightfutures.aap.org/web):* American Academy of Pediatrics' health supervision guidelines and resource kit on promoting child development with case examples for learning and teaching.

British Medical Journal *(www.bmj.com)* Freely searchable without needing library access, the classic journal has an excellent education series called "ABC of Teaching and Learning in Medicine"

Canadian Paediatric Society (CPS) *(www.cps.ca)* has resources professionals (e.g., a mental health tool kit with listings of assessment tools and web links related to mental health in its broadest description, evidence-base statements and practice points relating to child development).

Centers for Disease Control and Prevention *(www.cdc.gov/ncbddd/childdevelopment/screening.html):* Provides information on prevalence and the CDC's Act Early campaign on identification of autism spectrum disorders.

Center on the Developing Child at Harvard University *(http://developingchild.harvard.edu/):* Helpful

for exploring research on the importance of early childhood development.

First Signs *(www.firstsigns.org/screening/dev.htm):* Houses research on autism spectrum disorders, parenting information, referral guidance for parents, and links to the Autism Video Glossary.

Encyclopedia on Early Childhood Development *(www.child-encyclopedia.com):* Houses articles on various aspects of psychosocial development such as social violence, immigration and adjustment, prenatal and antenatal stress, etc.

Institute for Innovative Technology In Medical Education *(www.med-u.org):* Offers The Computer-assisted Learning In Pediatrics Program, aka CLIPP. This is a subscription service available in most medical schools (or can be purchased by individuals) developed by faculty at Stanford, Duke, Case Western and other universities in collaboration with societies such as the Council on Medical Student Education in Pediatrics and the Society of Teachers in Family Medicine. CLIPP is a curriculum-based product that translates national general pediatrics curriculum into 31 interactive cases. CLIPP enables independent learning experiences or its content can be used for didactic case-based instruction. Learners are prompted to answer questions along the way and also have access to expert advice when needed. CLIPP also enables faculty to evaluate each learner's progress and growing expertise.

Journal of the American Medical Association *(www.JAMA.org):* Has a collection of articles (more than 600 at last count) on training and evaluation of medical/nursing students and residents.

Pediatric Neurological Exam *(library.med.utah.edu/pedineurologicexam/html/home_exam.html):* From the University of Utah. Has a detailed video on how to conduct a pediatric neurodevelopmental exam with young children.

PEDICases *(www.pedicases.org):* An initiative from Harvard Medical School and Children's Hospital in Boston. On the site is a guide to case-based instruction and various downloadable cases on such topics as child abuse and neglect, chronic pain, anorexia, etc.

Society for Developmental and Behavioral Pediatrics *(www.sdbp.org):* Has an annual meeting with training on how to teach strategies and skills. The Society publishes the Journal of Developmental-Behavioral Pediatrics where collections of articles can be searched.

Medscape *(www.medscape.com/pediatrics):* Medscape houses a journal scan, webcasts, e-mail alerts, highly readable articles on various conditions, news, and resource centers on topics such as addiction, autism, development, depression, ADHD, etc.

The United States Medical Licensing Examination *(www.usmle.org):* includes a series of videos linked to *www.youtube.com* on the clinical interview (although they are oriented toward parents and adult medicine).

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CHAPTER 15: TRAINING PROFESSIONALS IN PRACTICE

FRANCES PAGE GLASCOE

INTRODUCTION

Even though most primary care providers make an effort to detect children with developmental and behavioral problems, only about 30% of children are identified and referred to intervention programs.[1,2] Why? Most clinicians use informal approaches that lack criteria for accurate decision-making (e.g., "trigger questions" to parents, clinical judgment, and informal milestones checklists such as those built into age-specific well-child encounter forms, etc.,). See Chapter 3 for more details on the hazards of informal detection methods. Because primary care is "where the kids are," it is essential to train providers in optimal early detection approaches including referral collaboration.

In this chapter we discuss self-training, group training for practicing healthcare providers and staff, cross-training with both healthcare and non-medical professionals, training-the-trainer, and training researchers and policy-makers. Presented are goals, training strategies and resources such as downloadable slide shows, short movies, handouts and pre-/post-tests for evaluating training effectiveness.

BACKGROUND

Healthcare providers who are already in practice (e.g., nurses, physicians) often need convincing that informal approaches to early detection do not work:

- Many providers believe that milestones drawn from well-known measures, usually the Denver, are accurate. But these lists are completely vague—both the items themselves and the criteria applied for decision-making. For example, a common item is "Knows Colors." What does that mean? Which colors? How many at which age? Should a child just match colors? Point? Name? There are huge differences in what skills are age-appropriate depending on items and scoring criteria—and this is only one example of the vagaries of informal checklists.

- Many clinicians consider clinical judgment sufficient due to their expertise in identifying dysmorphology (physical features associated with various syndromes). However only about 15% of children with disabilities have visible conditions.

- Other challenges in early detection are that few providers get systematic feedback about the numbers of children with problems they've detected or failed to detect. Families may quietly exit practices and rarely confront providers about failure to refer when needed. Even when providers refer, few get feedback about what happened with their patients. As one pediatrician commented, *"When I refer [to IDEA programs], it feels like a 'runaway train.' I never know what the results were but then families come back wanting me to authorize physical therapy or whatever… and I don't have credible information on why that's needed."*

- To compound the headaches of accurate early detection, healthcare providers are also strapped with time-constraints, i.e., well-visits lasting only 14 – 18 minutes in which there is a huge agenda—a physical exam, health and safety counseling, anticipatory guidance, developmental promotion, let alone screening for developmental-behavioral problems. Many providers are unaware that quality screening tools administered prior to the visit actually save time.

- Many providers comment, when shown easy-to-use screening tools, *"I can do that but there's nothing out there to refer to."* Providers are often unaware of referral options.

- Clinicians often note, *"I want to use a good screen, but can't get my staff to help or my colleagues to cooperate."* Providers need guidance in how to get cooperation within their own clinics.

- Few providers know how to get reimbursed for screening or when unavailable value practice expenses/cost-savings and need guidance on this topic.

- In the meantime, non-medical professionals don't always recognize the importance of collaborating with health care providers—what information to share, optimal times to communicate, the value

of keeping providers apprised throughout the referral process, etc. This is hardly a win-win situation for the goal of early detection and prompt referral! And, such challenges mean that those responsible for training (and those charged with selecting tools for State or national initiatives) need to have empathy for the challenges facing primary healthcare providers and ensure that tool selection and training is responsive to the many demands doctors and nurses face (including the mandate to embrace electronic health records).

GOALS AND TOPICS FOR TRAINING

Whether self-training, presenting to a group of clinicians and staff or addressing non-medical providers, the same abiding concern is this: If we want to do an optimal job at early detection, we must facilitate the efforts of those working in healthcare settings. Health care is where almost all young children and parents encounter a professional—often the only professional—and ideally a professional able to swiftly identify and address difficulties. Whether working with healthcare or non-medical providers, we all share the same goals of early detection and very similar training foci that must cover these topics:

- Assuring medical professionals that deploying recommendations from the American Academy of Pediatrics is not only feasible but may make well-visits shorter (e.g., by reducing "oh-by-the-way concerns," having parents complete screens in waiting rooms, etc.).

- Early detection is a collaboration among medical providers and clinic staff working closely with non-medical providers, i.e, clinicians are not alone in the process of early detection but instead are supported by quality tools and by the helpful 'village' of colleagues, staff, non-medical providers, and parents.

- Tenets of various American Academy of Pediatrics policies and recommendations. Note carefully that the AAP 2006 statement on early detection promulgates "establishing a pattern of practice that continues beyond the 24- to 30-month age-range and into all subsequent well-visits," i.e., screening cannot stop at such young ages when the most common problems, language impairment and learning disabilities are not fully detectable—see Chapter 5 for details.[3]

- Federal and State mandates with which providers need to comply.

- How screening and surveillance can be accomplished for optimal efficiency and accuracy with many of the same tools.

- Screening with accurate tools in combination with appropriate billing/coding (or careful valuation of the cost-savings quality early detection provides) may increase clinic revenues.

- Why informal methods don't work well and often lack compliance with Federal and State mandates.

- What are the domains of development, causes of problems, risk for problems, risk for problems in the future and factors associated with resilience.

- Available services (many providers are quite unaware of the many programs in their communities and may lack enthusiasm about early detection due the common, but erroneous sense, "there's nothing out there").

- Methods of collaborating with non-medical services (e.g., two-way consent forms, set telephone times, types of information to share, etc.).

- Knowledge of referral options for children especially those who don't qualify for IDEA Early Intervention (EI) or public school special education (providers are often frustrated when their patients don't qualify and need to be aware of alternative programs, i.e., understand that intervention includes a wide range of service options).

- How to explain results (some providers have trouble with this task and so are reluctant to screen

because they don't know how to convey difficult information to families).

- Options among quality tools that suit the measurement preferences of different providers (clinicians do best with choices).

- Experiences trying out different tools in order to master administration, scoring, interpretation, etc.

- Implementation planning—figuring out the optimal work flow given various staffing patterns and available computer equipment (the latter is essential if electronic applications are of interest).

- Sources for ongoing support with the challenges of screening and referral (e.g., a local physician champion).

TRAINING CLINICIANS, TRAINING-THE-TRAINER, TRAINING ACROSS DISCIPLINES, SELF-TRAINING, AND TRAINING RESEARCHERS/POLICY-MAKERS

In the following section, we cover techniques for training various types of providers including researchers and advocates. Each section begins with time frames followed by how to individualize the content of training according to trainees' needs. All sections refer to the goals listed above.

TRAINING PRACTICING HEALTHCARE PROVIDERS

Time Frames

Covering the goals above will take about 3 - 5 hours, and can be spread across more than one day. Providers need time to consider the tools on which they wish to be trained along with potential implementation strategies. If large time-blocks are not available, an alternative is to divide topics across multiple presentations (e.g., nine to ten 20-minute presentations over lunch/staff meetings).

Individualizing Content and Preparing for Training

- Be sure to invite nurses and other office staff to your presentations because much of the burden of administering, scoring and implementing tools falls to clinic staff.

- Identify a "champion" at each clinic who can offer encouragement to others and facilitate progress toward implementation.

- Consider inviting non-medical providers to offer short presentations and informational handouts about their services (most especially from EI, public school special education, Head Start, and parenting training programs).

- If at all possible, create a list of local referral resources and sources for parenting information as a printed handout for your audience. See Chapter 5 and 7 (and *www.pedstest.com/TheBook*) for national resources that will help you find local ones.

- If possible, visit a few clinics before you train so that you are aware of staffing patterns and workflow.

- A pre-presentation clinic visit should also involve careful observation of computer equipment, whether or not an electronic record is in use. The availability of computers in waiting rooms, the weigh-in station, nursing station, and/or exam rooms helps determine optimal ways to implement

screens.

- If a pre-presentation visit is not possible, consider sending a pre-presentation questionnaire such as the one shown at the end of this chapter.

- In preparation for question-answer time, consider various possible scenarios for implementation given various staffing patterns, equipment and work-flow options. See Chapter 16.

- View your presentation(s) as a workshop wherein providers and staff have time to collaborate on how best to deploy measures in their settings. You can use (and modify) our implementation worksheet to guide the process. See Chapter 16 or *www.pedstest.com/TheBook/Chapter16*.

- Rehearse your presentation so that it fits within the time frame(s) allotted and leaves lots of time for discussion.

Presentation Strategies

- One of the best ways to begin a presentation is to start with a series of interactive exercises encouraging providers to consider whether their current approaches are working well. Helpful is the slide show, "WhyScreen.ppt" downloadable at *www.pedstest.com/TheBook/Chapter15*. This show is designed to create discomfort with ad-hoc milestones checklists and with informal questions to parents. It helps providers recognize the time-consuming nature of "door-knob" concerns, while also acknowledging their understandable worries about time, costs, etc. The slide show offers a good overview of issues, encourages providers to adopt better approaches, and sets the stage for additional discussions on tool selection, implementation, service coordination, etc. If you turn on "Notes pages" in Powerpoint, you will see comments to help you deliver this short presentation.

- Make it real and moving. Show providers what their colleagues have worried about and how their attitudes changed after they started using good tools. Most helpful is a video housed on *www.developmentalscreening.org,* a site created by researchers at Harvard University and devoted to implementation of screens in primary care. In the video you see and hear providers discuss their initial confidence with informal detection methods, their worries that adoption of formal measures would increase well-visit length, a hospital administrator's worries about expense, etc. But then, after encouragement to try better methods, voila, there was widespread appreciation of the value and time-savers when deploying good tools. To use this video in training, you will need to have internet access and a microphone for your computer.

- Make it fun and show lots of examples, particularly when covering the potentially "dry" topics of developmental domains, types of disabilities, psychosocial risk, resilience factors, etc. Case examples (with photos) are riveting and are an expected approach when teaching healthcare providers. See Chapter 2 of this book for interesting case examples.

- Ensure that clinic staff are provided a thorough rationale for early detection and intervention, and that they have a voice in work-flow issues. Staff are critical to adoption of improved early detection methods because most of the implementation work falls on their shoulders.

- Encourage the clinic coordinator/supervisor to explore billing/coding for optimal reimbursement across the various third party payers with whom each clinic works (and make sure each clinic has current information on billing/coding). See Chapter 16 for how to bill/code effectively and Chapter 6 for explaining billing/coding to parents.

- Help participants understand that implementation requires time and many trials. It can take a few weeks or longer to figure out a workable process, given all the hands needed to push test protocols around a clinic; from receptionist to med tech, to nursing station/physician-extenders to physicians—let alone managing the delivery of parenting information, the referral process, coding on the billing sheet, and supervision of the check-out process (e.g., making sure that informational

handouts are given to parents and follow-up appointments are made).

- Create a list of local services and highlight the most common programs to which providers should refer. Find local services from the national list in Chapter 5 (*www.pedstest.com/TheBook/Chapter5*). Provide a copy to trainees and encourage clinic staff to duplicate (and preferably laminate) the list, and then place one in each exam room.

- Allow time during your presentation for clinic staff and providers to work on a plan for implementation so that they are ready to trial a process. You can use the implementation form in Chapter16 (*www.pedstest.com/TheBook/Chapter16*).

- Anticipate that some staff and colleagues will be reluctant to adopt accurate screens and incredulous about their value in early detection. Advocate for a short-term trial (e.g., 3 months, followed by discussion of pros and cons). If necessary, offer to have other clinicians/staff screen children after the exam and compare results of informal detection methods to accurate ones. One pediatrician who reluctantly trialed an accurate screen stated sheepishly, "We're findin' stuff." (Marian Earls, personal communication, 2005). Encourage reluctant providers to watch the video at *www.developmentalscreening.org*.

- Advocate that clinics make referral appointments for families. This increases the likelihood that families will follow-up with recommendations.[4,5] Establishing effective two-way communication with referral resources will be needed (see Chapter 8 for consent form templates and downloadable on the website for this book).

- After describing options among tools, let participants try them out. Quite effective is asking someone to serve as an ersatz parent informant and have participants score measures while this person speaks. However, ask that the informant not disclose their relationship to the child they describe so that discussion can flow freely when it comes to practice with explaining results and potential referral needs.

- Either purchase a test kit for clinics to trial (e.g., charging for this as part of your training fee) or use case examples (downloadable from publishers' websites) for scoring practice. An alternative is to assign a number to each trainee also to the blank protocols used in training and require these to be returned at the end of training.

- Make sure participants understand copyright law. Screening tests must be purchased and in most cases test protocols may not be reproduced in any manner including electronically. Bottom line, set a good example when training and make sure you and your trainees avoid copyright infringement.

CROSS-TRAINING

By cross-training we mean working simultaneously with both medical and non-medical professionals in order to promote effective collaboration. Cross-training is an ideal approach, provided that the presenter, especially if a non-medical professional, acquires much insight into: the enormous challenges of early detection within brief well-child visits; provider preferences among tools and measurement methods; implementation issues; and the need for collaboration across services. We preface recommendations with two case examples illustrating the value of communication and information-sharing across services.

Case Study #1: *When I directed the developmental-behavioral rotation at Vanderbilt University, I trained residents and medical students to use screening tests in their continuity clinics. Problems arose as detection rates improved: Both trainees and faculty preceptors commented that although the screens were helpful, referring to early intervention was much like a "run-away train" (e.g., "We never know what happens. Parents return a year later asking us to authorize services like PT, OT or speech therapy. Meanwhile, we've never seen reports on why that's needed.").*

So, when the Tennessee Early Intervention System (TEIS) became a part of Vanderbilt's Child Development

Clinic, I asked the new director of TEIS to establish a protocol wherein intake workers would call clinicians when a referral was received, predict due dates for further evaluation, provide copies of test reports and recommendations, and then call clinicians again to discuss next steps. This process was met with much enthusiasm from providers and referral rates from primary care to TEIS rose dramatically—and eventually exceeded those from non-medical providers including parents, as well they should.

But later, the director of TEIS left and I failed to alert her replacement about the referral protocol. Back to baseline. Grousing ensued from clinicians who no longer knew what was happening with their patients. Referral rates plummeted. At that point it was clear that we needed to resurrect our far more effective communication protocol.

Case Study #2: *As a young special education teacher, I had a student with Turners Syndrome. I'd read enough to know that coarctation of the aorta was common. One day this child's hands and legs turned blue—really, really blue. I freaked and called her pediatrician and parents to report the symptoms. The pediatrician called me back swiftly, explained that she'd had a full cardiac work-up and was OK. He then wondered (correctly and amazingly) whether she had on new jeans (wherein blue dye had rubbed off on her skin)!*

Special ed teachers do get some background training in the healthcare problems of children with various conditions associated with developmental delays, but that's only enough to make things scary and not enough to solve problems. I should have been informed in advance that my student didn't have heart problems. I need not have totally alarmed her mother. But, I also needed to know in advance from her pediatrician whether to look for such problems and what to do if "blueness" had truly indicated a heart problem.

These cautionary tales highlight the importance of collaboration between medical and non-medical professionals. Establishing timely communication across disciplines is essential for supporting early detection and for the quality of services provided by all professionals involved with a child and family. For this reason, creating an effective process for sharing information and resources is a major focus in the cross-training recommendations below.

Time Frames

Covering the goals above will take about 3 - 5 hours, and can be spread across more than one day. Providers need time to consider the tools on which they wish to be trained as well as possible implementation strategies. If large time-blocks are not available, an alternative is to divide topics across multiple presentations (e.g., nine to ten 20-minute presentations over lunch/staff meetings). Follow-up contact to establish approaches to collaboration is essential.

Individualizing Content and Preparing for Training

- When early detection training is conducted by non-medical providers (who naturally are interested in lengthy skill-based measures more appropriate for early intervention intake and monitoring), it is critical to recognize that healthcare providers need very brief tools. They also need options among tools since there are indeed, "different strokes for different folks." Some prefer milestones-focused screens while others are comfortable working with screens focused on parents' concerns. Less resistance arises if there are choices. Responsibility without choices is sheer drudgery. Responsibility with choices engenders a sense of ownership, control and greater willingness to go forward.

- Both medical and non-medical providers need to be familiar with policy recommendations from the American Academy of Pediatrics[3] (and Federal and State mandates for screening). See Chapter 5 for a discussion of AAP policy and Chapter 1 for information about early intervention services.

- AAP policy is a tall order and at first seems difficult for healthcare providers to implement within the well-visit schedule. Collaborative "gated-screening" across services is enormously helpful (e.g., healthcare professionals use brief broad-band tools and then refer questionable results to nonmedical services for more extensive screening, such as administering the *M-CHAT Follow-up Interview* for suspected autism spectrum disorders). This approach requires careful and prompt communication between medical and non-medical services.

- Care-coordination across services must address appointment-making. The requirement that families initiate services independently is often problematic because parents may be intimidated by professionals (e.g., families with psychosocial risk factors, who don't speak English or who are simply unsure) and so may not follow up. If possible, work toward allowing healthcare providers to make appointments for children because this is known to improve uptake.[4] Even so, non-medical services should follow up with families and providers when appointments are not kept.

- Help non-medical services understand that healthcare professionals tend to refer primarily to services with which they are familiar. Services garner familiarity when they call back after a referral is made, provide prompt updates on whether appointments are kept or not, and collaborate in decision-making about evaluation results. Without such feedback, clinics may well implement tools successfully but may not refer when results are positive (meaning problematic).[6,7] Preventing under-referrals requires collaboration between clinics and non-medical services.

- Work toward establishing two-way consent forms wherein parents agree that various providers can share information. Ensure that non-medical services keep healthcare providers in a frequent feedback loop including when referrals are received, whether families followed through, plus results of subsequent testing and recommendations. See Chapters 5 and the website for this book for a template.

- Determine optimal times and ways to communicate across services. Some professionals are comfortable with e-mail, others prefer faxes or phone calls (for which a time to call needs to be established).

- Discuss preferences for content to be shared across services. Some healthcare providers don't find a long list of goals and objectives (e.g., IEPs and IFSPs) particularly informative, but some do. Some healthcare providers are comfortable reading through lengthy evaluation reports but some are not and thus prefer a brief summary of findings and recommendations.

- Healthcare providers should advise non-medical interventionists on health issues (e.g., complex health problems and syndrome-related healthcare issues such as ventilators, GE tubes, infections, allergies, nutrition, etc.). Similarly non-medical providers should be encouraged to offer clinicians advice about the many behavioral challenges parents face, particularly about troubling issues such as preventing expulsion from daycare. Again, best contact times and contact methods should be established across services.

- Address what happens when children don't qualify for programs. This can be frustrating for providers and may well deter use of quality screens in primary care. Meanwhile, some State IDEA programs do not offer monitoring services and are not allowed to refer to outside services. Healthcare providers do not have such proscriptions and so collaboration can be essential for making sure children with delays or risk factors (but who do not meet IDEA eligibility) are still referred to needed services such as Head Start. To ensure collaboration, healthcare providers require information on current test results and an opportunity to candidly discuss other referral options.

- Address whether IDEA provides monitoring services for non-qualifying children. If possible, create shared plans between healthcare and non-medical providers on the how's, when's and what's of monitoring. Healthcare providers need to know whether IDEA can: monitor ineligible children; provide parenting information; make referrals to non-IDEA services, etc. Clinicians

need this information so they can follow up if necessary and find other resources.

- If training subspecialty medical providers (e.g., neonatologists, geneticists, cardiologists, etc.), expose them to more than screens. Subspecialists usually need in-depth, assessment-level measures that track progress and produce raw age-equivalent scores (since these are better for outcomes and research studies). Refer to Chapter 13 for discussion of assessment-level measures.

- Debate possible solutions to service "bottle-necks"—meaning the lengthy and frustrating slow-downs between referrals based on screens' eligibility determination. Most excessive lag-times are born by leaping from a failed screen straight into multi-disciplinary diagnostic evaluations. Such testing is expensive, may be unnecessary, and often violates the 30 – 45 school-day time frame for conducting evaluations and making placement decisions. It is less expensive and more expedient to follow a failed screen with assessment-level tools—deciding from there which children need further diagnostic testing.

- Ensure that all professionals leave your presentation with a list of local services including parent-training programs, websites for parenting information and professional development, a list of healthcare professionals willing to consult with non-medical providers about unique health issues, guidelines for explaining results, a table of high quality tools and how to find their publishers, reimbursement information, etc.

- Consider issuing certificates of attendance/participation to each member of your audience. Attendees often value a visible acknowledgement of their participation in training and their employers may also wish to have confirmation of course completion. A downloadable and modifiable pre-/post-test and a training certificate can be found at *www.pedstest.com/TheBook/AppendixB*.

- In preparing materials for training note that photocopying of test forms or sections of books is illegal except when copyright notices specifically state that reproduction is permissible. It is preferable to use case examples (often downloadable from publishers' websites) and have trainees rescore these when new cases are presented. An alternative is to assign a number to each trainee and to the blank protocols used in training and require these to be returned at the end of your presentation. Bottom line, set a good example when training and make sure your trainees avoid copyright infringement.

Presentation Strategies

- Seat together medical and non-medical providers who work in the same service area. Round tables, rather than auditorium-style seating are more conducive to collaboration and developing shared implementation forms.

- Provide time for working on referral and monitoring issues between services, two-way consent forms, etc.

- Include success stories about effective collaboration.

- Describe local resources or have non-medical providers present briefly about their programs.

- Allow time for informal interaction (so that various providers can get to know each other, talk about cases in common, solutions, etc.).

- Set a time for a follow-up meeting so that teams of medical and non-medical providers can share their challenges, successes, and plans for a better future.

- Encourage medical and non-medical providers to visit each other's programs.

Training-the-Trainer

Training those who will in turn train others, means you and your trainees have to know well... just about everything.

Time Frames

You will need a full day to ensure that your train-the-trainer participants fully master the tools on which you train them, presentation skills, how to organize future workshops, evaluate effectiveness of training, etc.

Additional Objectives for Training-the-Trainer

Besides covering the basic training goals (listed at the beginning of this chapter), you and your future trainers must be able to:

- Answer frequently asked questions (FAQs) about administration, scoring and interpretation of tools. Publishers' websites usually house these. Make sure trainees have a handout with links so that they can master answers to all FAQs for the measures on which they will train.

- Present well and plan for an effective workshop that adheres to allotted time frames.

- Identify, preferably in advance via a pre-presentation survey, trainees prior professional experiences and exposure to tools, understanding of development, knowledge of service options, etc.

- Grasp the unique implementation challenges for any groups your trainees will then train, i.e., work flow across various settings (e.g., primary care clinics, foster care, early childhood services, etc.).

- Understand and teach copyright law so that you and your trainees avoid infringement.

- Plan a budget for training-the-trainer sessions including a complete set of the tools for each trainee.

- Obtain continuing medical education or continuing education credits for your training session and teach future trainers how to obtain such credits for their own presentations.

- Share training materials such as slide shows, videos, resource lists, informational handouts and worksheets (e.g., by making DVDs or pre-loaded memory sticks for all participants).

Preparing For and Delivering Train-the-Trainer Workshops

1. Some publishers can provide a trainer for you (usually for a fee). Other publishers have websites with sufficient materials to enable trainers (and those who are comfortable training themselves) to work through content, view videos, how to score tools, etc. So, be sure to check the publishers' sites for the tools you plan to cover.

2. It is best if your audience is assigned homework before they come to training (e.g., domains of development, causes of delays, types of disabilities, available resources, etc.). The advantage of background preparation is that you can then focus your presentation on mastering tools, and teach trainees how to deliver an effective presentation honed toward the various types of trainees your participants will train.

3. Along with required background reading, consider sending a pre-test that trainers can complete after they've self-trained on background information. You can ask them to return their pre-test before your presentation if you plan to offer individualized feedback. If not, a pre-test is still helpful for focusing learners on the range of topics they need to master. See Appendix B or *www.pedstest.com/TheBook/AppendixB* for a downloadable and modifiable pre-/post-test.

4. Add to any course fees, the cost of complete copies of tools on which you will train, one set per trainee. Consider adding the cost of this book because it includes essential background information, implementation strategies, etc. Assign specific chapters in advance. An alternative approach is to provide, prior to training, a list of websites providing fundamentals of child development (See Chapter 2 for details). Publishers are often able to discount multiple copies of measures for train-the-trainer events, provide informative brochures and other materials. Be sure to request materials at least 1 – 2 weeks in advance of your training event.

5. In preparing materials for training (and for informing future trainers) note that photocopying of test forms or sections of books is illegal except when copyright notices specifically state that reproduction is permissible. Reproducible pages in this book are clearly marked or shown as website links so as to be helpful for audience handouts (e.g., tables of tools, milestone charts, lists of resources). Make sure trainees fully understand that most test protocols may not be reproduced in any manner including electronic applications (e.g., entered into an electronic record). If it isn't feasible to have attendees pay for a complete set of tools, use case examples (often downloadable from publishers' websites) and have trainees rescore these when new cases are presented. Bottom line, set a good example and make sure you and your trainees avoid copyright infringement.

6. Select a discrete set of tools for training and expose trainees to their features. Be sure to select several different, but high quality tools, so that future trainers can share options with those they train (in consideration of different measurement preferences and time constraints in various settings).

7. Ensure time during your workshop in which trainees create and share case examples with the group (e.g., a volunteer pretending to be either a parent or examiner working with a child). This dynamic and interesting approach offers practice with scoring and referral planning. Nevertheless, see comments in the prior section about how to advise informants willing to offer spontaneous case examples.

8. Prepare case examples in various stages of completion. Consider showing examples that have errors in administration, scoring, and interpretation. With these, you can ask trainees to find mistakes and correct them.

9. Make sure trainees are familiar with electronic applications of measures and have a chance to practice with these. A live demo is helpful and best provided after trainees have worked through print applications of measures. This will help them see the joys of automated scoring, generated referral letters, etc. Options are to:

   • Ask trainees to bring their laptops to training (but to put them away when you or others are presenting);

   • If internet access is available, consider having a portion of your talk devoted to demonstrating sites focused on parenting information, publishers's FAQs, etc.;

   • Given internet access, have trainees trial online screening services via a live case example or two. Make sure you have obtained site access before your presentation and have enough trials for all trainees;

   • Check with publishers on availability of training DVDs or downloadable training materials. Publishers may be able to send copies of slide shows and other information so that each participant leaves with his/her own copies.

10. Trainees need to thoroughly understand implementation issues and have a good sense of differences in workflow across different types of services (e.g., health care, foster care, Head Start, etc.). Share a copy of the implementation worksheet (included in Chapter 16) and include in your slide show a sample workflow chart (workflow scenarios and the implementation work sheet are downloadable at *www.pedstest.com/TheBook/Chapter16*).
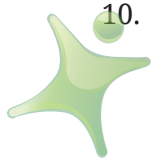
11. Provide for each trainee the materials they'll need for their own presentations. Create DVDs (or pre-loaded thumb-drives) that include slide shows, videos, resource lists, audience informational handouts and worksheets. Local print/copy services can inexpensively duplicate these for you (and affix a custom label).

12. Prepare print materials you'll need available for your conference (e.g., post-tests, case examples, numbered test protocols, etc.).

13. Consider optimal date/times and locations for your training (avoiding the run-up to holidays, voting days, etc.).

14. Announce the dates and times of your training workshops two to three months in advance. Ask agencies and societies most likely to be interested for help sending out fliers. Require an RSVP in which participants must provide both e-mail and snail mail addresses. Anticipate sending the flier several times, starting at least three months before your training date.

15. Follow up with all those who have RSVP'd with both reminders and preparation requirements (e.g., completing a pre-test, advance readings, etc.).

16. Test publishers often reserve space on their websites for announcements of training events so you and your trainees should submit training dates and times—a few weeks' notice is wise.

17. Discuss with any sponsoring agencies how to feed and refresh attendees (e.g., box lunches, coffee breaks, etc.).

18. Plan the timing of your workshop with a mixture of lectures and interactive activities (e.g., practice with scoring/interpretation, question-answer time), and allow time for completion of post-tests.

19. Use a post-test after your presentation so that you can determine who is "ready to go" and who needs more guidance and additional training. The measure shown in Appendix B and downloadable at *www.pedstest.com/TheBook/AppendixB* can be used for pre-testing as well as post-testing. Post-testing is required if offering continuing education credits.

20. Consider issuing certificates to all who successfully complete your course. Attendees often value a visible acknowledgement of their participation in training and their employers may also wish to have confirmation of course completion.

21. Some train-the-trainer programs provide certificates of mastery only after vetting (e.g., learners are required to complete and return several correctly scored tests along with a short interpretive report and recommendations). This is a wise approach especially if your trainees have a limited background in test administration or child development and disabilities.

22. Keep notes on all your preparation activities because you will need to share a distilled list of these with your future trainers.

23. When you present, remember that you are also teaching "how to present." So side-bar periodically during your presentation to comment on your use of images, animations, humor, empathy for the challenges of screening in healthcare and other settings, your use of periodic pauses for questions, etc. You need to be a role model for your trainees and they will benefit from your example and insight on how to make presentations interesting and compelling. Be sure to point out the value of case examples in maintaining audience interest and engagement.

24. Help future trainers figure out how to divide presentations into 15 – 20 minute chunks (if they will be working with healthcare providers within their weekly clinic staff meetings).

25. If training a small group and if time permits, consider asking trainees to prepare a 1- to 2-minute portion of a slide show to share, and then allow time for comments on presentation effectiveness. Brave volunteers will be needed (and lots of advance notice).

26. Provide a list of presenters' tips such as those in Table 15-1.

Table 15-1. Train-the-Trainer Presentation Tips

- Begin with humor because it relaxes presenters and trainees.

- After the title slide (with your name and name of your program), your second slide should state the goals/topics to be covered. Number these and refer to numbering throughout your presentation. This helps orient participants and maintains their attention.

- Know the unique issues for each type of professional to be trained and craft a set of slides appropriate for their issues.

- Acknowledge likely points of resistance, preferably with a bit of levity (e.g., a slide of an overwhelmed professional surrounded by piles of paper).

- Provide a handout of slides (three to a page usually works best) with space for attendees to take notes. The Notes pages in PowerPoint (which presenters need to know how to turn on) need not be printed. Rather these are to help presenters organize their thoughts.

- Slide appearance is important. Use a dark background and much lighter font. Avoid a red background and minimize verbiage, i.e., keeping the font size in Powerpoint no less than 30 point). Animations help maintain attention (e.g., consider having bullet points fly in and then dim when it is time for the next bullet point to be discussed) but don't overdo animations—too dizzying.

- When making slides, keep at least a 1" distance from the edges of the frame. Some projectors are not centered well and so may cut off some your text.

- Speak clearly and at a reasonable pace. Read bullet points, but also elaborate slightly on each before moving to the next bulleted statement.

- Practice, practice, practice any pending presentations to make sure you know the sequence of slides, preferably have content essentially memorized, and can stay within the time frame while also allowing 10 – 15 minutes for questions. Anticipate that introductions may take about 5 – 10 minutes and your presentation may need to be shaved accordingly. If you are a speaker on a multi-panel presentation, recognize that others may take more than their allotted time and perhaps cover some of the same information. So, know your slides and content and which ones can be skipped over if needed. Bottom line, it is always irritating to busy professionals when talks take too long since they generally have to leave at the designated ending time.

- Truly master the content of presentations and avoid just reading from notes or looking excessively at slides (always boring).

- Plan for periodic bathroom, stretching, and food breaks.

- Leave lots of time for questions and answers. It is wise to set points for Q & A after discrete sections of your presentation (e.g., how to probe for literacy, scoring, interpretation, finding resources).

- Be comfortable with the "pregnant pause" that sometimes occurs when posing the first few questions to participants.

- If trainees interrupt with questions at unplanned times, feel comfortable saying things like, "Good question, we'll get to that in a few minutes" or "Let's continue this discussion after the presentation."

- If your version of Powerpoint enables you to turn on "Presenters Tools," make use of it to time your practice presentations and view upcoming slides. This facilitates a smoother verbal transition across topics.

- Use "Notes" pages in Powerpoint to write out what you plan to say so that you stay on point.

- Recognize the power of example in teaching—break up text-laden slides with photos and descriptions of individual cases.

- Send AV needs in advance [e.g., a mike for the computer if showing videos, speaker preferences for a lavalier mike (that allows mobility) versus a stationary mike].

table continues...

Table 15-1. Cont'd

- Understand your natural voice levels—if your voice is small, it may not carry to the back of a room of 30 people. Be sure to ask for a microphone.

- Learn how to play videos on a computer (and to download these in advance of their presentation and then make sure they run).

- If a computer microphone for videos is not available, be prepared to provide voice-over, meaning you need to know thoroughly the videos you show.

- Make sure you have your presentation on a thumb drive. If you are one of several speakers, AV will want to insert all slide shows onto a single computer. If instead you want to use your own computer, make sure you bring your own cabling to connect to the projector (most especially if projecting from a Mac), power cords, and be sure you know how to connect cables.

- Be physically prepared for talks (e.g., have a bottle of water at hand. All those exhalations, if not anxiety, make speakers thirsty). Be sure to use the restroom beforehand.

- Arrive early to set up and address AV issues. Double-check your slides, especially if placing a slide show made on a Mac onto a PC—there are sometimes resizing problems with fonts. Make sure any videos still run well.

- Turn off your wireless mic before heading to the bathroom (icky stories abound about the failure to do that)!

SELF-TRAINING

Life-long learning is a requirement for all professionals and is absolutely essential when it comes to the most complex aspects of human beings—development and behavior. Self-training is do-able on the topics of early detection and intervention, appropriate use of screens, how to locate referral resources, establish collaboration with referral services, etc. Continuing (medical) education and Maintenance of Certification credits are often available for self or group training.

Time Frames

Expect to spend at least two or more hours re-familiarizing yourself with essential background information on child development, disabilities, referral and parenting resources. Selecting and trialing various tools with colleagues and staff will take an additional one to two hours. Implementing tools in your clinic and establishing an effective workflow takes additional time and collaboration, usually via multiple staff meetings.

Self-Training Strategies

1. After reviewing the training goals listed at the beginning of this chapter, read Chapters 1 - 3, and then 6 - 12 so that you acquire fundamental concepts of child development: Its domains, definitions of disabilities versus delay, psychosocial risk and resilience, and the hazards of informal methods—enormous under-detection rates are the sad result.

2. Next read Chapter 5 to become familiar with American Academy of Pediatrics' policies on early detection. Although AAP policy can sound overwhelming, it can be implemented efficiently. So, wait until you've explored which measures you want to use before reading about how to make early detection efficient. In the meantime, note that:

   - Screening and surveillance must continue beyond the 24 – 30-month age-range because the more common disabilities (e.g., language impairment and learning disabilities) are not completely manifest;

   - The AAP is actively working with private payers to ensure reimbursement at well-visits beyond the 24 – 30-month age-range;

- Both screening and surveillance can best be accomplished with the same, accurate measures.

3. Identify a few tools from Chapter 4 you want to explore further. The chapter has links to publishers' websites which house detailed information on what each tool measures, how they work (e.g., videos, case examples, electronic options, etc.). For accurate early identification (and compliance with AAP policy) you will need to identify:

- A screen that elicits and addresses parents' concerns as well as a screen measuring milestones across development, social-emotional and behavioral/mental health domains;

- A screen for autism spectrum disorder for use at 18- and 24-months;

- Tools measuring psychosocial risk and resilience;

- Screens for school-age children.

4. Practice tools before using them with patients. Many screens are also available online and provide automated scoring, report writing, billing/procedure codes, etc. Even if you do not plan to use online administration, try scoring a few practice administrations and compare your scoring to the free trials provided for online approaches. Note that an electronic record is not necessary for use with online measures. See Chapter 4 for links to electronic options for screening.

5. When it comes to mastering administration of screens in print, it is essential to read the test directions and refer to them often. Although this sounds axiomatic, it isn't. Human beings have "cognitive drift" and stray from systematic standardized methods over time. This is a big problem when it comes to standardized tests that have to be administered and scored in the exact same way every time they are given. So referring to directions periodically, whether seemingly needed or not, is essential.

6. Consider conducting a Quality Improvement Initiative (QI) and work towards Maintenance of Certification (MOC) by implementing screens and viewing your progress at improving early identification and promoting development. Documentation of effort and improvement is generally easier with online screening because a database is generated that enables you to view decisions and use of screens over time. See Chapter 19 for more information.

7. If you don't believe accurate tools do better at early detection than informal ones, test your current methods, and then compare your decisions to that of accurate screens. See *www.developmentalscreening.org* for an interesting video of Harvard clinicians who completed their own comparison study, finding that quality screens served them best.

8. Recognize that when using accurate screens measuring milestones and parents' concerns, you can save time during well-visits by eliminating any informal milestones checklists and ad hoc questions from age-specific encounter forms. Well-child templates with suggestions for indicating screening test results are included in Appendix A and downloadable at *www.pedstest.com/TheBook/AppendixA*.

9. Once you've decided on which screens to use, read next about implementation strategies, training office staff, and planning a trial workflow as described in Chapter 16.

10. Emulate the workflow of any other questionnaires that float from reception to med tech to nurses and doctors. A similar process may have been established that will also work well for screening.

11. Engage clinic staff. This is critical for getting "buy in" for implementation and for devising a workflow plan effective for all involved.

Anticipate that trials will be needed, as well as careful thinking about organization of materials.

13. When implementing accurate screening tools, there will be an increased demand from parents for advice on developmental-behavioral topics. See Chapter 7 for links to reputable parenting information sites and parent training services. Consider how to organize your clinic for efficient delivery of parenting information. See Chapter 16 on implementation strategies.

14. Use of accurate screens will increase your referrals for services—meaning you'll need a thorough knowledge of local referral options. Consider inviting your local IDEA programs to present at a staff meeting and ask if they can provide a list of local services including their own, Head Start, parent training programs, etc. Alternatively, you can use the list of services in Chapter 5 and on the website for this book. The list in Chapter 5 is focused on national links. Clinics will need to "drill down" within these websites to create a list of State, regional and local services. If you have residents or medical students rotating in your clinic (or otherwise interested staff) ask them to find local service numbers, referral forms and so forth. Consider laminating your local list and putting a copy in each exam room.

15. If you, your colleagues and staff want to test their knowledge and skill at early detection, use of tools, knowledge of resources, etc., consider self-administering the post-test housed in Appendix B (and also on the website for this book *www.pedstest.com/TheBook/AppendixB*).

TRAINING DEVELOPMENTAL SPECIALISTS, RESEARCHERS AND POLICY/DECISION-MAKERS

Professionals who are advocates, researchers designing protocols or developmental specialists requiring in-depth tools each have a range of needs for information about early detection:

- Policy-makers, including panelists making decisions about use of screens, need familiarity, not only with tools, but also with various State and Federal policy mandates. If initiatives focus on improvements to healthcare services, it is critical to understand AAP policy and the challenges of brief well-child visits. Exposure to effective advocacy methods is needed;

- Developmental specialists should already have a substantial background in child development. In addition to learning about test options, developmentalists often need exposure to parenting issues and to psychosocial risk and resilience factors and to the exigencies of primary care;

- Researchers need to define carefully what they want to measure (e.g., developmental status, outcomes, unique developmental aspects of various conditions, metrics rendered by different tests, the impact of psychosocial risk, and statistical techniques appropriate for answering the empirical questions posed).

Time Frames

Presentation times will vary across the types of groups you train. At least 3 hours are needed to dissect and refine research protocols (with ongoing work on wording of new questions). Exposing developmental specialists to tool options takes about 3 hours (with follow-up meetings for debate among measures). Policy panelists will probably need multiple 1 - 2 hour conferences with clear goals for each meeting. This estimate does not address the voluminous background preparation participants need (as described below):

Individualizing Content and Preparing for Training

1. Get to know the needs of your group in advance so that you can make your presentation relevant. Consider sending a pre-presentation survey to help participants define their issues and to help you refine your leadership role, meeting goals, and presentations.
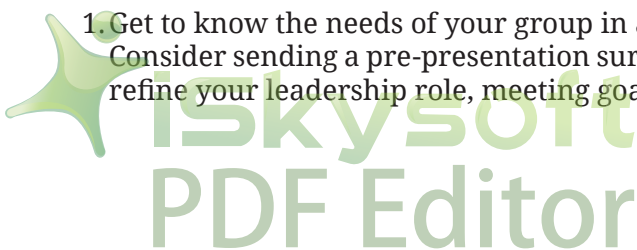
2. Participants should be assigned background reading to ensure an enlightened discussion during meetings, workshops or conferences:

   • Researchers should carefully peruse Chapter 19 where we discuss research methods, item writing and test psychometry. Chapter 13 provides information about the more confirmatory assessment tools that are often better for research than are screens. But see also Chapter 10 where we discuss psychosocial risk factors which often eclipse the syndrome or medical condition under study (and thus should be included in research protocols);

   • Policy-makers and panelists making decisions about early detection initiatives (particularly initiatives involving primary care) should read this entire book (!) to garner insight into the nature of child development, the need for cross-disciplinary collaboration among medical and non-medical services, methods for efficient early detection methods in healthcare settings, and learn about other initiatives;

   • If policy-makers wish to become effective advocates (e.g., legislative, grass-roots), they should read carefully Chapters 17 - 18 that cover national and international models, as well as Chapters 20 - 22 on advocacy and suggestions for a better future;

   • Developmental specialists, depending on their work settings, should read Chapter 13 because it focuses on the detailed measures usually needed for NICU follow-up, children in-care, early intervention intake, etc. If developmental specialists are also precepting in primary healthcare settings, they should read about workable approaches to early detection (Chapter 5), training emerging professionals (Chapter 14), and implementation challenges (Chapter 16);

   • If training emerging professionals, Chapter 14 provides a guide for how they may be able to help on developmental-behavioral/neurodevelopmental rotations. Trainees will surely need to read other chapters in this book including how to advise on parenting issues, give difficult news, and collaborate with non-medical professionals.

3. Become thoroughly familiar with the kinds of tools you and your colleagues are likely to discuss. See Chapter 4 for information about accurate screens and Chapter 13 for assessment measures.

4. If working with small committees to make decisions about measures, you may want to purchase specimen kits so that panelists can view measures in full. If working with larger groups, download and photocopy case examples from publishers' websites. If panelists are not primary care providers, the exigencies of short visits and the need for workable tools require careful attention.

5. If electronic options are a topic for discussion (which is wise given Federal mandates for adopting electronic records), ensure internet access at presentations and meetings so that you can demonstrate online applications (described in Chapter 4). Consider asking participants to bring their laptops so they can experience and trial electronic tools. Alternatively, you can send participants a list of links to online/electronic tools and ask them to trial these before your meetings.

6. If working with researchers who are creating study protocols:

   • Be prepared to provide information on why psychometric support for tests implodes if pulling bits and pieces of various measures, i.e., it is optimal to use an entire measure to ensure research is sound and enables a comparison to existing studies on the measures selected;

   • Ensure that you can raise and discuss the value of open- versus close-ended questions. Survey researchers usually want to adhere to multiple-choice questions, but data is much richer and more compelling when at least some open-ended questions are included (and subjects/parents are more likely to answer carefully given an opportunity to express their thoughts). Arm yourself in advance with a basic understanding of the value of qualitative

research techniques for generating original hypotheses and preliminary testing of these (a good summary is available at *www.socialresearchmethods.net* and in Chapter 19);

- If studies focus on unique populations (e.g., Americans who are not English-speaking, families who live in developing nations) researchers will need guidance on cultural competence and possibly on translations, although with the latter it is best to check with publishers on existing translations. See Chapter 12;

- Anticipate that researchers devising study protocols may need to write new items focusing on developmental-behavioral variables and outcomes of interest. Thus you will need to guide your group on issues of readability (for written protocols) and intelligibility (for interview protocols). It is wise to avoid multi-syllable words, professional jargon, long sentences, etc. Be sure to check draft items and multiple-choice response options to make sure that they are written at (or preferably below) that of a 9-year-old's reading level, i.e., in the US, at the 4th grade or lower. Encourage follow-up discussion, preferably by e-mail, of alternative wordings [(it is supremely tedious to conduct live group editing) but consider a live demonstration of readability (e.g., *www.online-utility.o*rg)];

- Consider having a statistician consult with you and your colleagues so that all understand the differing statistical techniques needed according to various types of measurement results (cutoff scores provided by screens versus the continuous metrics typical of assessment-level tools). See also Chapters 13 and 19.

JUDGING THE EFFECTIVENESS OF TRAINING

When training-the-trainer, you will need indicators of how well content has been mastered. You'll also need to know which trainees need remediation, i.e., additional opportunities to acquire needed skills. For training those learning to use a tool but who will not necessarily turn around and train others, you'll want to ensure your trainees are able to accurately administer, score, interpret and explain tests results.

As a trainer, you'll want feedback so you can improve future presentations, identify what else your audience needed to know, what they liked best and least about a workshop, and most especially how they will use the information you gave them. So below are suggestions for measuring learning, presentation effectiveness, and what to do when remediation is needed.

MEASURING SUCCESS

1. Use a post-test at the end of your presentation so that you can assess trainees' competence. We include one in Appendix B, downloadable at *www.pedstest.com/TheBook/AppendixB* so you can select questions on topics you've covered, add your own questions, etc.

2. Provide 20 or so minutes at the end of your workshop for attendees to complete the post-test.

3. There may not be time to score post-tests immediately. Anticipate that you will need to score later, and so make sure you have e-mail and surface mail addresses for all trainees so you can send feedback, certificates of completion, continuing education credits, etc.

4. We have not indicated criteria for mastery on the post-test in this book, but a general rule is at least 90% correct answers for train-the-trainers, and at least 80% for trainees. Nevertheless, some questions are more critical than others (e.g., questions on test administration and scoring). You may want to double the number of points assigned for correct answers to essential questions. After that, you will want to determine the total number of points available and define success.

5. Trainees, even if successful on post-tests, need opportunities for life-long learning. Child development (including behavior and mental health) are the most complex of human skills and there is always something new and valuable to learn. Resources change, tests change, test

applications change, and so we really want those engaged in early detection to remain always interested and engaged in this fascinating evolving field. Encourage trainees to avail themselves of our list of resources for life-long learning and to consider a Quality Improvement Initiative/ Maintenance of Certification activity as described in Chapter 19.

WHEN REMEDIATION IS NEEDED

When trainees have not mastered critical skills there are several possibilities for helping them further. Several suggestions include:

1. Consider mailing or e-mailing a few unscored but completed case examples of tools (publishers' sites often have these), so that trainees can practice scoring, write up short reports/referral letters with local referral resources, and then send all back to you.

2. Check with publishers with online applications of tools as to whether you can establish a trial. Next give trainees a case description to score by hand and ask them to write a case summary/referral letter. After trainees turn in their work, you (and they) can compare their scoring and report-writing to the results rendered by online screening services.

3. Ask trainees to retake your course after reading additional background material and practicing on their own or with others.

RESOURCES FOR TRAINING

PRE-PRESENTATION QUESTIONNAIRE

Below are broad questions focused largely on primary care. These can be refined according to your presentation focus and participants' likely needs for content. If using these or other questions, make sure to provide lots of "white space" for answers.

1. What do you hope training will cover?

2. What obstacles and successes have you encountered if you've attempted to implement screens?

3. Please list your preferences for measurement within screening tests: Parents' concerns? Milestones reported by parents? Measuring children directly? Some or all of these methods?

4. Which areas of development, including behavior/social-emotional/mental health, do you feel it most important to measure?

5. If you already use questionnaires (either electronically or in-print), how do they "flow" through the office (e.g., from receptionist, to med-tech, to nursing station, to exam room)?

6. Do you have a clinic website? If so, do you know (or can your webmaster tell you) which families make use of it (e.g., by demographics/socio-economic status)?

7. Do you use an electronic record? If so, does it have a parent portal? Are most parents able to use the parent portal pre-visit?

8. How does your office organize and disseminate written information to parents?

9. How do you anticipate using the information from your training sessions?

10. What kind of guidance do you think you need for implementing screens?

PRE-/POST-TESTING

Appendix B contains a pre-/post-test that can also be downloaded (and thus modified to focus on training specifics) at *www.pedstest.com/TheBook/AppendixB*.

PRESENTATION SUPPORT

- Chapter 4 includes a list of tools with links to publishers' websites. These are invaluable resources for slide shows, videos, case examples, trials of online services, etc. In addition, publishers can often help with announcements about training opportunities, and may be able to provide training materials.

- Background reading is often needed, especially for train-the-trainer sessions. Please see prior chapters in this book for suggestions.

- For help creating resource lists see Chapters 5 and 7. The website for this book houses live links and updates. See (*www.pedstest.com/TheBook*).

- Implementation is the greatest challenge and worksheets are helpful for getting providers and staff to consider optimal workflow options. A worksheet is available in Chapter 16 and on the website for this book.

- For obtaining continuing education credits for medical and non-medical providers, speak to State or national chapters of societies (e.g., NAPNAP, AAP) or to local universities or teaching hospitals. For information on Maintenance of Certification and Quality Improvement Initiatives see Chapter 19.

- Many journals and websites (such as *Contemporary Pediatrics, Pediatrics in Review, Medscape Pediatrics*) offer continuing medical education credits for reading a collection of articles on early detection, and answering questions. These might be used for background reading followed by time for participants to answer questions after your training sessions.

- Along with a post-test, you can also download a customizable certificate of attendance or mastery. See *www.pedstest.com/TheBook/AppendixB*.

Chapter Summary. *Trainees come to us with varying levels of interest, attitudes, background skills, and leadership commitment. We will work with "provider champions" as well as those who are incredulous that informal methods don't work and thus see no need to change. Because we as trainers must also serve as role models for creating change, our presentations must be interactive, compelling, i.e., aimed at social, legal, ethical, and economic issues in early detection. We want "the reluctant" to walk away with better convictions. We also want those who will train others or champion the cause of early detection to know how to engage other disciplines.*

As trainers, we need to recognize there are "different strokes for different folks." While we may have personal preferences for one measure over another, we must consider the various policies of State and Federal agencies and the policies of societies to which trainees belong. Related to this is an empathic understanding of time constraints and measurement needs, i.e., presenting options among tools is essential.

We also know that many medical providers are unaware of community services—in large part because non-medical services may not provide feedback. Collaborative training that emphasizes a shared plan and resource lists is invaluable. Training clinicians and clinic staff simultaneously is needed.

Implementation of screening/surveillance tools in primary care is a huge obstacle. Ideally, clinicians, with help from non-medical providers, leave training sessions with at least a general plan for how to make quality early detection methods work in busy clinics. We discuss in Chapter 16 the many issues and decisions required to ensure that tools are implemented. Following up on training (e.g., meeting again in one month) is often needed so that providers are impelled to work toward a fully viable implementation plan. There's nothing like a deadline!

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Chapter 16: How to Plan and Initiate Developmental-Behavioral Services in Primary Care

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INTRODUCTION

Probably the most challenging aspect of adopting quality approaches to screening/surveillance is figuring out how to make it work in our practices. There are many considerations but there are also many effective models. So in this chapter, we provide numerous strategies and examples from other clinics that have been able to implement screening and surveillance—whether in clinics using electronic records versus paper charts or those using online versus paper-pencil measures. We use abbreviations when referring to various tools so if a refresher is needed, please see Chapter 4. Within this chapter and downloadable at *www.pedstest.com/TheBook/Chapter16* are worksheets and other resources to assist in planning.

CHAPTER HIGHLIGHTS

To aid in implementation, this chapter covers:

  I.   Case models including details about how various clinics made quality screening/surveillance work;

  II.   Billing and coding information, considerations for practice time and expense, and how to get paid for the good work needed;

  III.   Workflow issues including a modifiable blueprint for mapping;

  IV.   Implementation planning—including a worksheet for getting started, divvying up the many issues to consider and address, as well as how to collaborate with referral sources;

  V.   Resources for implementation.

I. IMPLEMENTATION: CASE MODELS

Case Model #1: Detailed Example of Planning Considerations, Trialing, Adjusting Approaches and Tracking Progress Using *PEDS Online* Across Low- to High- Risk Populations

Goals and Challenges

Several clinicians (working within our large multi-clinic system spanning several counties and serving thousands of children annually) were interested in improving our developmental-behavioral services. After surveying many providers and staff about their concerns, we were able to define our goals and challenges as these:

1. *We wanted to make sure our referral rates to IDEA programs were commensurate with prevalence. We could see we weren't referring at expected rates despite a collaborative relationship with local IDEA services, including two-way consent forms between our clinic and Early Intervention.*

2. *We suspected our low referral rates were probably due to informal methods of early detection (e.g., selected items from the Denver-II placed on age-specific encounter forms) and that we needed to use accurate screens. But we weren't sure which tools would work for us, be acceptable to all clinicians or how long measures would take as compared to our current methods.*

3. *We knew that when we made referrals, we were spending lots of staff and clinician time dictating and proofing reports, and rarely did we have time to create a take-home summary for parents.*

4. *We figured that online screening tools would help us save time, even though not all our clinics were using an electronic health record. But we weren't sure how online screening would work across all*

settings, i.e., those clinics with and without electronic records—and whether all providers would want to use this approach.

5. *We wanted to make sure that all providers knew how to refer when confronted with children who didn't qualify for IDEA programs (e.g., Head Start or quality daycare). But we didn't know all the resources available across our various clinic locations or how to make sure our referrals resulted in our patients receiving services.*

6. *We had links on our clinic websites and in our electronic health record (EHR) to parenting information sites and professional resources, but few providers used them and even when they did, parents weren't always given printouts when they checked out (each clinic's printer is in the busy receptionist areas and information handouts were often overlooked amid check-in and check-out). We wondered if there were better ways to ensure families received the information we wanted them to have.*

7. *We also wanted to make sure that parents could capitalize on the parenting suggestions we gave them or whether they needed other kinds of help. We lacked a follow-up plan and needed to devise one.*

8. *We wanted our clinics to be efficient and to keep appointment length at predictable times (we recognized that frequent "oh by the way" concerns disrupted clinic flow, aggravated parents who had to wait too long, and made our clinic staff anxious, if not irritable).*

First Step: Dividing (and Ideally Conquering Issues) and Planning!

Obviously we couldn't work on all 8 goals at once so we created four small teams to address different aspects of our issues. The teams consisted of enthusiastic doctors and nurses along with at least one other clinic personnel. Each team met for lunch discussions 1 – 2 times a week to further define the challenges, talk with other providers, and come up with preliminary solutions. The teams started the first sessions with a "pep-talk" from an especially exuberant provider or staff about why early detection and intervention (including parent education) was worthwhile. Several teams had a member with a personal story to share and that gave impetus and compelling focus to our initiative. We agreed to have all teams meet together in 4 – 6 weeks to share observations and recommendations.

Below are the teams we established, what each team worked on, and their findings and recommendations:

The Parent Education Team *was charged with making sure providers used our EHR's website links to parenting information, ensuring that families received written handouts, and what parents themselves liked and disliked about our parenting education efforts. Here's what they found:*

1. *That providers were reluctant to click on EHR links (e.g., to www.kidshealth.org) because they didn't always know how to get back to the EHR once a new browser window was spawned.*

2. *That receptionists needed a reminder when parents had printouts waiting for them.*

3. *That the EHR needed a tickler system to remind clinic staff to check on whether parenting information had been effective or whether more intensive parent-training was needed.*

4. *Parents routinely reported they loved Reach Out and Read and they and their children looked forward to their next book. But parents had two main points of dissatisfaction with other parent education efforts:*

   • *They'd heard too many times the same advice about issues previously addressed. One parent, whose four children all received care in our clinic commented, "If I hear that trampoline safety lecture again, I am going to scream. Now I just say we don't have a trampoline so I can avoid hearing that talk for the gazillionth time.";*

   • *One parent suggested a waiting room checklist so that parents could identify topics of interest;*

- *Another parent suggested having posters in the waiting room listing topics—to trigger interest and help parents know what providers were prepared to discuss.*

5. *Some parents were using the parent portal through our EHR/clinic website mostly to confirm appointments or get shot records for school. Few were making use of the parenting information links.*

The Parent Education Team came up with these recommendations:

1. *Adding to our usual age-specific information packages for families (wherein we had information on vaccines, a book for Reach Out and Read, etc.), a pre-printed handout on child development per age at each well-visit.*

2. *Creating waiting room posters listing topics on which clinicians had information, as well as a checklist of Bright Futures topics that parents could fill out prior to the visit to indicate what information they wanted (and which topics had been covered sufficiently in prior visits).*

3. *Offering providers brief training in keyboarding skills and creating sticky notes for each clinicians' computer (some walk into the exam room with laptops, some have computers in each exam room) explaining how to click on links and then how to get back to the EHR [i.e., (since all clinics use the Windows operating system) Alt+Tab to see all open windows, click mouse to select program].*

4. *Making pre-printed sticky notes to put on the billing form (that parents take to the front office), stating "Print-outs Waiting" as a reminder to receptionists to take them out of the printer and give to parents.*

5. *Creating fields in the EHR or paper chart listing the informational handout topics, another for checking with the family in 6 weeks as to effectiveness (with an alarm system reminder for a call back). If ineffective, to create a third field indicating that a parent-training referral had been made.*

6. *Periodically providing parents a flier about the parent portal and all the information it contains.*

The Referral Resources Team *was charged with identifying non-IDEA services (since our IDEA programs, while quite responsive to our clinics—swiftly sharing referral status, test reports and recommendations were not allowed to refer to non-IDEA programs or to monitor the progress of non-qualifying children). The Referral Resources Team was also asked how best to indicate in the charts that a referral to non-IDEA services had been made (e.g., Head Start, daycare, social services, parent-training programs, etc.), whether appointments had been kept, whether children/families had enrolled, and whether follow-up from clinicians' was needed. These were the recommendations:*

1. *Because our clinics span several counties, the Referral Team quickly realized they needed to include office staff and providers from other clinics. One team member pointed out that the United Way in our State had created a service directory county by county. So they obtained copies and culled a list of likely local referral sources (e.g., contact numbers of Head Start, Early Head Start, mental health, social services and its daycare referral team, parent-training, etc.).*

2. *Each local Referral Resources Team created a laminated list of community resources to post in each exam room in each clinic.*

3. *A member of each local Referral Resources Team then contacted Head Start/Early Head Start (having identified that two-way communication, unlike IDEA programs, had not been established).*

Working with various Head Start/Early Head Start directors, as well as with the State-wide director, consent forms were established in which parents agreed that our clinics could share relevant information and that the various programs could share information with us.

5. *The various local teams realized that programs still needed reminders to keep our clinics informed. They also found that the many programs often had medical questions about patients. So the Team suggested sending a list of medical topics on which clinicians could advise (e.g., asthma management, obesity, working with parents, etc.). The thinking overall was that if we wanted programs to share information with clinics we should be helpful to non-medical services.*

6. *The Referral Resources Team also recommended adding fields to the charts regarding type of referral made, whether appointments were kept, other referrals needed, along with a tickler system wherein clinics would be reminded to check on enrollment if, within 6 weeks or so, information had not been sent from programs.*

The Observation Team *was charged with conducting a small time/motion study—viewing how long providers were spending on early detection and exactly what they were doing. The rationale was to figure out whether online screening could fit into the time-frames for encounters without compromising the other tasks of well-visits. The Observation Team was also asked to interview at least some parents to find out their recommendations for improving services. These were the Observation Team's suggestions:*

1. *Providers were eliciting milestones directly from children/parents and spending about 2 minutes on this activity (including marking the check-boxes for each milestone in the patient records).*

2. *There was enormous variability across providers in criteria applied to milestones items. For example, the "knows colors" item used at ages 4, 5, and 6 was administered in various ways and with varying content. Some providers asked children to point to colors, others asked children to name them. Some asked for all six primary/secondary colors. Others added "pink," "brown," "black" and "white." All this variability meant there was a lack of standardized administration and scoring.*

3. *Meanwhile, referral criteria varied as well. Of the six or so milestones at each age, some referred when a child was unsuccessful with 2 of the 6, some referred if 3 of 6 were missed, others if 4 out of 6 were missed, etc. All this meant that providers were "all over the place" and surely failing to identify many children with problems.*

4. *Parents, meanwhile, felt that most developmental tasks were too easy for their children and didn't address pressing issues such as learning to read.*

5. *Next up, "door knob" concerns were common and occurred at about 20% of visits or more. These events extended visit-time substantially and were frustrating to parents, providers, and clinic staff.*

6. *The Observation Team then asked one of our family practice residents to review research on parent-provider communication (covered in Chapter 8). Her review suggested that "unvoiced concerns" made for an awkward and aggravating encounter wherein providers alone determined the content of visits and did not elicit parents' issues well or early enough in encounters.*

7. *The Observation Team concluded that we needed to elicit parents' concerns before the encounter, and also have parents complete milestones and other screens on their own, if possible.*

The Screening/Surveillance Team *was charged with testing various online/electronic screening services, trialing them in several clinics in order to consider workflow and time required, and discussing with providers how they preferred to screen (e.g., interview, hands-on with children, parent self-report). The Screening Team was also asked to speak with our software consultant about the costs of integrating results into our EHR (all providers wanted results to "automagically" appear without having to leave the EHR, go to a website, and then return to the EHR). After several trials across clinics, the Team's findings and recommendations were these:*

1. *Online screening was feasible and that all online services (PEDS Online, ASQ Online and CHADIS) took 2 – 10 minutes to self-administer measures (at least after a bit of practice).*

2. *Because those minutes had to come from somewhere, the Team suggested removing informal*

milestones from our EHR and paper charts (so that clinicians wouldn't feel compelled to do both screening and informal assessment).

3. That all online screening services had a parent portal option available, meaning that parents could complete screens at home but would not see results. Rather these could be sent directly to the clinic thus virtually eliminating the 2 - 5 minutes of administration time.

4. Many clinicians (although not all) preferred to interview families or measure children directly—most especially in clinics where parent literacy was not high or when parents spoke Spanish or other languages.

5. That a viable workflow model existed in how our routine health and fitness questionnaire was deployed, i.e., completed by parents in the waiting room or administered by interview at the medical technician station, scored and interpreted at the nursing station, and then followed by a note in the record and thus visible to clinicians before they entered the exam room.

6. Integration between online screening and our software would be expensive and time-consuming—not because the online services charged for this but because our software consultant would bill us (in the neighborhood of $70,000 or more), i.e. we needed to save up!

7. The recommended alternative was to establish fields in the EHR for capturing online screening results and teaching clinicians how to "copy and paste." For those practices still in the midst of adopting our EHR we recommended printing out results for a paper record as do-able and time-saving.

8. The Screening/Surveillance Team also advised us to flesh out our encounter forms so they captured the essential tasks for each visit. The Team recommended we create a problem checklist form that captured results and recommendations, along with follow-up times.

The Billing/Coding Team was charged with figuring out how we would get paid for screening. This group consisted of several clinic coordinators (all are responsible for entering information from the billing sheet into our administrative software) who checked with Medicaid and various private payers on billing and coding procedures that would assist with reimbursement. Here's what they found and recommended:

1. All private payers and Medicaid were willing to reimburse for developmental-behavioral screening although rates varied (between $8.00 and $20.00).

2. Different payers required different modifiers to the preventive services procedure code to indicate a separately billable service, i.e., 96110 (the developmental-behavioral screening code).

3. None required a diagnosis code, meaning that whether screening was positive or negative, we would still get reimbursed.

4. None would reimburse separately for parent counseling/advice or screening test interpretation, but instead expected such services to be a routine aspect of the preventive service visit.

5. One private payer would not reimburse for informal milestones and instead only when accurate tools were used.

6. Providers would benefit from a "cheat sheet" created by clinic coordinators, covering billing/coding procedures for Medicaid and private payers. (See issues for Federally Qualified Health Center, below).

Second Step: Reuniting and Sharing

Next we had the Teams meet together to discuss their findings and recommendations. Each Team took 15 – 20 minutes to present. We set aside an additional 1 ½ hours for guided discussion starting with comments about abiding themes across all Teams. There were many recommendations in common, including:

1. *A need for all staff and clinicians to receive training in keyboarding skills so they could access parenting information and online screening sites.*

2. *We needed to do a better job eliciting parents' actual concerns so as to focus the visit, identify specific parenting information needs, and reduce "oh by the way" concerns.*

3. *Using accurate screens focused on parents' concerns and milestones would help with both parent/patient education, early detection, and in complying with AAP policy.*

4. *We needed to make better use of our waiting and exam rooms in terms of triggering parents' interest in discussing their concerns, and to help providers offer focused developmental-behavioral promotion.*

5. *We needed to encourage parents to use our parent portal for ensuring screens were completed prior to the encounter, and for parent self-education.*

6. *Flexible workflow approaches were needed, given providers' preferences for interviewing versus direct administration versus parent self-report, and given differences in literacy and languages spoken within our clinics.*

7. *Providers, even though pleased at the thought of screening with parents' concerns and with defining those concerns in advance, still wanted to know about milestones, i.e., that a milestones-focused screen was an important confirmation of parents' concerns.*

8. *Our charts needed new fields to indicate screening results and parent education topics, as well as the status of referrals and follow-up.*

9. *We needed to collaborate better with non-IDEA services (and urge them to keep us apprised of what happened with our patients). We needed to have a tickler system in our records regarding the status of these referrals.*

Third Step: Preparing for Trials

1. *Before we adjourned, we selected one online screening service to trial further: PEDS Online (www.pedstest.com/online), which includes Parents' Evaluation of Developmental Status (PEDS) for eliciting/addressing and screening with parents' concerns; PEDS:Developmental Milestones (PEDS:DM) for viewing children's skills; and the Modified Checklist of Autism in Toddlers (M-CHAT), needed at 18 and 24-month visits. PEDS Online seemed to meet multiple needs: (a) brevity; (b) identifying parents' concerns early, if not prior to the encounter, and thus their unique needs for advice; (c) screening with parents' concerns but also with milestones; (d) providing autism specific screening at ages targeted by the AAP; (e) a parent portal into electronic screening; and (f) a database we could use for our quality improvement efforts.*

2. *We realized that at least several different implementation processes would be needed given variations in patient mix across clinics. So, we asked all Teams to sort themselves according to clinic types (high, medium, versus low SES, with an additional group focused on clinics with a preponderance of non-English speakers). The four clinic-focused teams then drafted a trial process for implementation and workflow. The teams used the workflow template and implementation form as a starting point. (See Table 16-1 and Figure 16-1, and downloadable at www.pedstest.com/TheBook/Chapter16.)*

3. *After creating implementation drafts, we asked the staff at four clinics to trial the process on 20 families, document needed adjustments, and reconvene in three weeks.*

4. *Meanwhile, members of Teams most involved with our EHR issues met together and worked on improvements to our EHR's well-visit forms. We refined recommendations for our software consultant in terms of fields we wanted her to add, and also found that simply adding new fields to our EHR came at no cost—and that our consultant could teach us how to add fields ourselves. (See Table 16-1.)*

5. *Separately, we decided to work on improving computer skills among providers in preparation for increasing access to parenting information sites as well as for use of online screening.*

6. *The Referral Resources Team created a laminated list of local referral options and sent copies to each clinic to post in exam rooms.*

7. *The Referral Resources Team decided to work face-to-face with Head Start and other programs on referral coordination, in the hopes of establishing a prompt feedback mechanism about the status of our referrals.*

Fourth Step: Trials in Several Clinics

1. *The newly created Trial Clinic Teams (4 in all) first met with staff and providers in four different clinics to generate enthusiasm, describe the draft plan, and seek suggestions for improvement. In two clinics, staff suggested minor alternations to workflow patterns. The other two clinics thought the plans were workable and agreed to try them as is. After a week of trials, all clinics tweaked their plans slightly and also identified several needed contingencies (e.g., what to do if parents had not accessed the parent portal before the visit or had literacy or language barriers, and thus what alternative workflow processes seemed needed). For example, one clinic had a recent influx of Laotian immigrants who could not speak English well, and only some could read even in Lao—meaning that clinics needed translations of screens to share with the telephone translation service (since none of the clinic providers could speak Lao). So, a slightly different workflow was needed in this clinic for the translation services used, and for making sure translators used validated translations of the tools we'd selected.*

2. *In another clinic, staff preferred to use a paper-pencil version of the screens and questionnaires in the waiting room, after which parents' responses were entered into the EHR for scoring and interpretation. But because many parents had not graduated from high school, literacy levels were limited. This clinic inserted into the workflow a gentle question asking whether parents preferred someone to go through the screens with them. They taped the question to the receptionists' clipboards to remind them to ask. If help was needed, the nurse was alerted that screens and other questionnaires needed to be delivered by interview.*

3. *We discovered that flexibility and individualization was needed: After additional trials, it was clear the receptionists in some clinics were too busy to probe literacy, dispense questionnaires, and/or alert the nursing staff. Fortunately, clinicians preferred to conduct screens by interview anyway, and so nursing staff together with the medical technicians took over administering the other questionnaires.*

Fifth Step: Tweaking the Workflow, Trials in Several Other Clinics, and Ongoing Support

1. *At our follow-up meeting, the Trial Clinic Teams presented their revised plans. Together we created roll-out plans with six other clinics.*

2. *We assigned to each clinic, one Trial Cinic Team member to detail staff and providers on the process. Team members held a series of staff lunch meetings.*

3. *The Teams began with a "pep talk" about the value of early detection and parent education, and then outlined what would be covered in the subsequent four meetings: (1) The screens we chose and why; (2) what results meant and what services were available; (3) the workflow that seemed best in similar clinics; and (4) the changes made to charts, i.e., where to put results, topics of parent education (along with a mini-refresher on keyboarding).*

4. *The Trial Clinic Teams offered assistance throughout the implementation process. We established a small telephone support group to help clinics with questions, problems, suggestions, and provided clinics with phone numbers and e-mail addresses for the support group.*

5. *The Referral Resources Team, meanwhile, had made headway with non-IDEA programs on establishing a two-way consent form so that information could be shared freely, given parents' approval.*

6. *The Trial Clinic Teams also explained that we wanted to conduct a Quality Improvement Initiative (QI) with the goals of offering parent education at every visit focused in large part on parents' issues, screening at all well-visits, referrals when indicated, follow-up to ensure IDEA enrollment or alternative services, etc.*

7. *As part of our QI, the Trial Clinic Teams described our feedback mechanism—that we would look at progress toward goals at a follow-up meeting in 3 months at which time we would share with each clinic how they were coming along compared to their original benchmarks. Over time the QI data would enable a comparison of similar clinics (given similar patient mix), and along the way, gather suggestions for improving our outcomes.*

8. *As the next six clinics completed implementation, we expanded our initiative to include the remaining clinics.*

9. *It wasn't always easy! We had some clinicians who felt strongly that they were identifying kids just fine without quality measures. We asked them just to try it for a few months. Almost all were willing and said later, they were surprised at how many more children they were identifying. One provider just refused altogether, so we screened for him and then compared findings on a weekly basis. He came around eventually when he could see that he was missing the majority of children with problems.*

Case Model #1 Summary: Surely not every setting would need an implementation process as elaborate as the above, given the many satellite clinics, enormous variations in patient populations including language and literacy barriers, differences in services across counties, multiplicity of private payers, etc. But the many different challenges identified and addressed, illustrate a wide range of solutions for other clinics—solutions that offer improvements in early detection, referral, parent education, follow-up, needed modifications to paper encounter forms or electronic health records, computer skills and staff/clinician training. Below are additional case models of how different clinics working with different tools and varying populations implemented developmental-behavioral services.

Case Model #2: Screening and Surveillance with Print Versions of *ASQ* Tools and Other Measures Across a Low to Moderate Risk Population[1,2]

Setting and Findings

Practitioners (N=20) at a pediatric practice (PeaceHealth Medical Group) in Eugene, Oregon serve a population that is 38% Medicaid with more than 9% of parents speaking Spanish only. We universally implemented the Ages and Stages Questionnaire (ASQ) at the 12- and 24-month well-child visits to better detect developmental delays and improve referral and enrollment rates to IDEA services. Our detection rates soared, and at 12- and 24-months we detected 3 to 6 times as many children with suspected delays than we had with informal methods. Referral rates climbed too: The ASQ led to a 6-fold increase in IDEA referrals at 12-months and a 3-fold increase at 24-months,compared to informal milestones checklists (ours were pass/fail items extrapolated from the Denver II). Approximately half of the children screened with the ASQ qualified for IDEA.

After this success, we expanded the periodicity of ASQ screenings to include the 36-month visit. We then looked at enrollment rates in IDEA for our 3- to 5-year-old patients and found that ~13% had been identified as IDEA eligible—in keeping with prevalance estimates from the Centers for Disease Control.

In addition to using the ASQ at targeted visits, we also used: The AAP Pediatric Intake Form (which includes the Family Psychosocial Screen) to identify risk and protective factors; the Edinburgh Postnatal Depression Scale at 2- and 4-months to identify maternal mood disorders; the Modified Checklist for Autism in Toddlers (M-CHAT) at 18- and 24-months to identify possible autism; the ASQ:SE at 18-months and 4-years to identify

social-emotional/behavioral problems; and the Pediatric Symptom Checklist to identify mental health problems in children and teenagers, 5- to 18-years.

Finally, we crafted well-visit encounter forms that noted the measures to use at specific ages. Providers found these helpful reminders of what to do and when to do it. That we staggered measures across visits helped providers find the evidence-based process for screening/surveillance doable. We also use Reach and Read at every visit. Providers (and families) were enormously satisfied with the positive and productive nature of this effort to promote development. Below is a description of how we implemented measures in our practice.

Implementation Procedures

1. **Scheduler.** *The scheduler (aided by an automated phone appointment reminder system) instructs caregivers to come in 15 minutes early for the well-child visit so they can thoughtfully complete a paper-pencil screening test in a quiet corner of the reception area. The scheduler's message is: "Your doctor and the AAP strongly recommend parents complete these questions prior to the well-visit."*

2. **Receptionist.** *For universal screening visits, the receptionist gives the caregivers the designated screening tools. With the ASQ and ASQ:SE, the correct age-interval questionnaire is offered as soon as caregivers enter the waiting room. The receptionist has five specific tasks including asking parents these questions: (a) "How many months old is your child?"; (b) "Was your child a preemie?" If yes, "How many weeks premature was he/she?" (These questions are necessary so the age-adjusted ASQ can be provided); (c) then the receptionist says, "This questionnaire is an important part of your child's well-child visit. Please fill it out thoughtfully."; (d) the caregiver is given a pen, clipboard and the screening tool. With the ASQ, if the caregiver checks "not yet" for an item but is unclear as to whether their child can complete that developmental task, an ASQ toy kit is available so that caregivers can directly assess their children's skills; and (e) whenever possible, a receptionist, nurse or other designated clinic staff scores the screening tool before clinicians walk into the exam room.*

3. **Nurse.** *Double-checks to make certain caregivers have received the correct version of the screen for their child's age, and that all questions have been answered. If needed, the nurse scores the screening tool prior to clinicians entering the exam room. Nurses are typically overloaded with tasks prior to any well-child visit. This is why the receptionist or another designated staff member is typically responsible for scoring screens.*

4. **Clinician.** *Clinicians elicit parents' concerns. If the ASQ has not been completed, caregivers indicate concerns or clinicians' surveillance suggests developmental or behavioral problems, providers administer the ASQ or ASQ:SE. Clinicians check to see that no questions were missed. For items marked "not yet," clinicians ask the caregiver if the child has ever tried that paticular developmental task. Then, after thoughtfully interpreting the scored ASQ, clinicians provide developmental-behavioral promotion (e.g., Reach Out and Read, positive parenting advice, etc.) and then indicate one of the following patient management options:*

   - *Caregiver to schedule next routine well-child visit (observation only);*

   - *Add problematic screening tool result to patient's problem list;*

   - *Administer age-appropriate ASQ or ASQ:SE activity sheets (or mail them to home);*

   - *Refer to IDEA or other early childhood programs;*

   - *Refer to mental health provider;*

   - *Refer to other community resource (e.g. parent education/ support group, domestic violence program, high-quality daycare, evidence-based preschool like Head Start);*

   - *Early return (< 1 month) office visit for a repeat assessment, which might include supplemental social-emotional (ASQ:SE), autism-specific (M-CHAT with or without the Follow-up Interview) and other, medical screening tests;*

- *Refer to developmental-behavioral, non-medical or medical sub-specialty services, in addition to IDEA, Head Start or other early childhood programs.*

5. **Resource Staff.** *After clinicians acted on screening tool results and discussed next steps with caregivers, designated staff generate the necessary referrals to the medical, educational or social sectors. Staff then fax a referral form that the parents signed to give consent to share information between our clinics and IDEA or other referral sources.*

6. **Response from Referral Sources.** *Once a referral is received, these programs contact caregivers to encourage follow-up. Programs also let us know periodically (usually by e-mail or fax) that they've received our referral and where families are in the process. Services also fax (or e-mail) evaluation reports and recommendations so that we can include them in our charts along with updates.*

Case Model #3: Screening and Surveillance using *PEDS* in Print with a Moderate- to High-Risk Population[3,4]

Setting and Findings

Harvard University's pediatric practice (Children's Hospital Primary Care Center) implemented Parents' Evaluation of Developmental Status (PEDS) at two clinical sites. Physicians (and the hospital administrator) were initially reluctant but agreed to give it a try. All were surprised at how many more children they were able to identify, and that PEDS saved substantial time if administered in advance of the visit. A video describing before/after impressions is housed on www.developmentalscreening.org along with a guide to implementation. Eventually, PEDS was employed at every well-child visit from 6-months to 8-years in a largely urban, high-risk population (e.g., 65% Medicaid, 40% black, 35% Latino). As a pre-visit screen, PEDS saved an average of 3 minutes per visit and increased identification rates of developmental concerns in 3-year-olds and behavioral concerns in 2-year-olds. There was no difference in referral rates to IDEA programs before and after implementation of PEDS in 2-year-olds, but referral rates for 3-year-olds increased. Enrollment rates for those referred were not described, but the findings suggest a "wait and see" effect for 2-year-olds, and perhaps that providers were prompted to refer after parents repeated their concerns over time.[3,4]

Implementation Procedures

1. *Administrative staff provide parents at check-in with the PEDS Response Form on a clipboard and ask if they prefer help answering the PEDS questions. If not, a statement on the clipboard reads, "Please complete this survey. Your provider would like to know how your child is doing."*

2. *Caregivers complete PEDS in the reception area (or in the exam room while their child is getting vitals prior to the pediatrician entering).*

3. *If PEDS was not completed prior to the encounter, providers can administer it by interview. (Providers are also instructed to identify what broke-down in the workflow.)*

4. *Clinicians are instructed to add their own concerns to the PEDS Response Form (but not remove any parental concerns, per PEDS' scoring instructions. Afterward, providers score PEDS on the Longitudinal Score/Interpretation Form using the PEDS Brief Guide to Scoring to remind them of essential directions and how to interpret results:*

   - *For children scoring on Path A (two predictive concerns and thus high-risk), a referral is generated to the local early intervention or early childhood special education agency;*
   - *For Path B (one predictive concern and thus moderate-risk), providers refer to IDEA or other community programs for the requisite second-stage screening;*

- *For Path C, parents' concerns are addressed with in-office counseling. Nevertheless, clinical judgment is incorporated so that additional evaluations are arranged if clinicians are concerned, regardless of a reassuring PEDS' result;*
- *Children scoring on Path A, B or C who have medical issues suggestive of conditions associated with developmental-behavioral problems are also referred to our division of child development for further assessment.*

Summary of Case Models #2 and #3: Implementation research is rare and difficult to conduct, but both case models have enjoyed peer-reviewed studies.[1-4] Findings include: (a) eliciting parents' concerns in advance of encounters shaves ~ 3 minutes from well-visits, due to a reduction in "door-knob" concerns, thus allowing providers to focus on issues pressing to families; (b) families are more likely to follow through with referrals when appointments are made for them; (c) and collaboration via two-way consent forms facilitates service uptake and/or monitoring. In addition, when families are asked carefully about their concerns, they are more likely to return for well-visits.[5] Thus use of accurate screens along with information-sharing across services saves time and improves quality of care for children with a range of developmental-behavioral needs.

Case Model #4: Screening/Surveillance with the Child Health and Development Interactive System in a Low- to Moderate-Risk Population.[6]

Settings and Findings

Two practice sites at a health maintenance organization (Kaiser-Permanente Colorado) in Denver, serving a low-risk metropolitan population implemented a pilot project using the Child Health and Development Interactive System (CHADIS). Periodic online screening was employed using pre-visit questionnaires two weeks prior to the patient's well-child visit appointment. For children 0- to 3-years, parents universally completed the ASQ to identify developmental delays, and the M-CHAT to identify autism. For children > 4-years, all parents completed the PSC-17 to identify mental health problems. When a comprehensive mental health assessment was deemed necessary by the parents or providers, the CHADIS-DSM was completed. To engage parents in family psychosocial screening, the Edinburgh Postnatal Depression Scale and Partner Violence Screen were completed. Using this online, multi-tool, previsit screening and surveillance system (that allowed parents to select the appropriate visit type such as an e-visit, e-visit with brief provider visit, or extended encounter), 75% of parents thought quality of care was "improved" or "very much improved;" nevertheless, 12% of parents found CHADIS somewhat or very difficult to use.

Implementation Procedures

The CHADIS website has abundant instructions for implementation and guidance on interpretating tools. See www.chadis.com for information.

Case Model #5: Screening and Surveillance with Print Versions of ASQ Tools in a High-Risk (Foster Care) Population[7,8]

Settings and Findings

In a specialized county-based pediatric practice (Starlight Pediatrics) serving all children in family-based foster care in Monroe County, New York, systematic ASQ screening doubled the detection rates of developmental delays for children new to foster care, compared to a clinician's unstructured surveillance (1?% vs. 37% in infants; 42% vs. 89% in toddlers; 44% vs. 82% in preschoolers; 29% to 58% overall; p < .001 fo? ?ge groups).[8] Starlight Pediatrics consists of three part-time pediatricians, three part-time pediatric nurse practitioners and one social worker.

The ASQ:SE was implemented periodically between ages 6-months to 5½-years. The ASQ:SE promptly detected 6 times more children with suspected social-emotional delays and evolving disorders than clinicians' informal judgment alone, even though all were apprised that each child was at high risk for developmental-behavioral/social-emotional/mental health problems.[7] Use of the ASQ:SE detected 24% of children as having a suspected social-emotional problems, while clinicians' surveillance alone detected only 4%.[7] The ASQ:SE detected significantly more children with social-emotional problems than the ASQ-2. in this high-risk sample. The agreement between the ASQ:SE and ASQ-2 ranged from 56% to 75% when data were stratified by age group.[7] This study demonstrated the benefits of alternating the ASQ with the ASQ:SE at every well-child visit between 4-months to 5½-years.

Implementation Procedures

1. *All pediatric providers were first given verbal instructions, a demonstration about using and scoring the ASQ, guidelines for referring process, and a list of local referral resources. To facilitate implementation, the clinic held monthly meetings to discuss the process during the first six months.*

2. *Caregivers were mailed and asked to complete either the ASQ or ASQ:SE one week before each well-child visit for children ages 4-months to 5½-years. The preferred English or Spanish language versions and age-adjusted (for prematurity) questionnaires were used in the mailing.*

3. *Mailings or delivery of the ASQ at the first well-child visit were alternated with the ASQ:SE at the next well-child visit. For feasibility reasons, both standardized questionnaires were not administered simultaneously.*

4. *An office secretary called caregivers the day before the scheduled well-child visit to confirm appointments and remind parents to complete and bring in the ASQ or ASQ:SE.*

5. *When caregivers failed to bring questionnaires to the appointment, the correct language version and age-adjusted ASQ or ASQ:SE was again offered at the well-child visit. If there was limited time to complete the screen at the well-child visit, the office staff requested that caregivers complete and return the questionnaires by mail.*

6. *Pediatric providers scored and reviewed the ASQ or ASQ:SE during the well-child visit. Reviewing ASQ tools with families also provided an opportunity for clinicians to give appropriate anticipatory guidance and demonstrate age-appropriate developmental tasks.*

7. *The clinic assembled a toy box of materials necessary to complete all tasks on the ASQ, which was used during clinical visits and enabled providers to test developmental skills if parents were not sure if children could complete certain tasks. In addition, the toy box was used to emphasize during the visit the value of child-directed play with foster parents.*

8. *When the results of the ASQ or ASQ:SE were problematic, a team of nurses was responsible for generating IDEA referrals. To expedite referrals, the results of the ASQ or ASQ:SE were shared with IDEA programs, which was helpful to them because they also used the ASQ at intake.*

9. *When clinicians' surveillance (in combination with ASQ or ASQ:SE results) detected the need for a developmental-behavioral subspecialty referral (e.g., audiologist, developmental-behavioral pediatrician, etc.), providers wrote a short summary or referral letter to the subspecialist, and then nurses helped caregivers and foster parents with arranging subspecialty appointments.*

II. Billing and Coding for Optimal Reimbursement

Needless to say, guidance on how to bill and code is volatile and can change at any minute. Billing and coding procedures vary widely by State Medicaid plans and by private payers—meaning that clinic supervisors/business managers need to check on preferred coding approaches. Much of this may change under the Affordable Health Care Act. So even while we provide current information from the American Academy of Pediatrics, please check the website for this chapter (*www.pedstest.com/TheBook/Chapter16*) and the AAP's website for updates.

Note that in some States and for some types of practices (e.g., Federally Qualified Health Centers), there is enhanced reimbursement for an EPSDT visit when screening is used, but separate billing for screening is not allowed. We explain below how to reduce practice time and expense by using quality screening/surveillance tools.

For those practices able to bill separately for screening, we urge you to avoid excessive fees. With parents doing most of the work (assuming you are wisely using parent-report tools), you only spend time scoring and dictating reports (and even that time-consuming, practice expense can be avoided if using online screening applications). So, the Medicaid reimbursement rates of $8.00 - $10.00 are quite reasonable. We've seen cases where providers charge the highest possible reimbursement rate (e.g., $70 per screen) whether or not patients' insurance covers this. The consequences are that some parents opt out of screening/surveillance and this is unwise for children and families. Thus it is best to keep your fees at reasonable rates, help ensure that all families find early detection affordable, are willing to participate in screening, and that your clinic isn't excessively hassled by families complaining about your fees and denied claims.

1. Select an Appropriate Code for the Preventive Service (e.g.,):

99402   Preventive medicine counseling and/or risk factor reduction intervention(s) provided to an individual (separate procedure); approximately 30 minutes (Problem Counseling)

99429   Unlisted preventive medicine service (Initial Patient Education/Counseling)

99205   New patient of high complexity

99204   New patient with moderate complexity or use the appropriate sick or return visit codes if screening during such visits

2. Add a Modifier to Your Visit Code Denoting a Stand-Alone Service Deserving Separate Reimbursement:

For Medicaid (in most States) the modifier is -25 but in some States it is -59 (which is often the case for third-party insurance), but it is best to check with all to find out which is preferred by each of your payers.

3. List Separately the Screening Procedure Code:

The 96110 code seems to work best whether screening focuses on psychosocial or developmental-behavioral issues. Nevertheless, the AAP has endorsed 99420 as a reimbursable code for children in at-risk environments (e.g., when parents are depressed, there are other psychosocial risk factors, absence of resilience factors). We don't know how well this one actually works. So for the sake of your patients' financial health, if 99420 doesn't work, resubmit with 96110. In general, 96110 garners an average of $8.00 per screen, although some States (e.g., North Carolina, and increasingly California) have opted for an overall higher reimbursement for the preventive visit codes instead (see #10 below). Bottom line, know your payers and their preferred billing procedures.

4. List the Number of Screens Administered:

For example, if you've used two screens (e.g., *PEDS* and *ASQ*), write 96110 X 2 to indicate the number of screens administered or X 3 if you've also given the *M-CHAT*.

5. A Diagnosis Code is Rarely Needed:

If required by a payer, use codes sufficiently vague so as not to interfere with future, more specific diagnoses made by those to whom you refer for additional evaluations. Examples are:

783.4   Developmental Delay

309.23   Academic Inhibition (school problems)

315.4   Developmental Coordination Disorder

314.9.1.1 Hyperkinetic syndrome, NOS (NOS = Not Otherwise Specified)

784.5   Other Speech Disturbance

309.3   Disturbance of Conduct

799.9   Unknown unspecified cause

799.89   Other ill-defined conditions

309   Adjustment Reaction

315.10   Unspecified adjustment reaction

300.00   Anxiety state, unspecified

312.9   Disruptive behavior, NOS

315.9   Unspecified delays in development

If rule-out codes are needed to identify a patient as normal, the following may help (although payers vary on their tendency to financially recognize V codes):

V20.2   Encounter for routine child health examination without abnormal findings

6. For Coding Parent Education and Follow-up:

Routine parent/patient education is considered part of any well-visit and so unlikely to be reimbursable. Nevertheless, if your clinic has a care-coordinator (e.g., via deployment of the Medical Home model), case-management may well be reimbursed. If so, these procedure codes may help:

99339   Care Plan Oversight (15 - 29 minutes per month)

99340   Care Plan Oversight (30 or more minutes per month)

99401   Preventive medicine counseling and/or risk factor reduction intervention(s) provided to an individual (separate procedure); approximately 15 minutes (Method Specific Education)

T1017   Targeted Case Management

7. Review Denied Claims:

Although parents must participate in appealing these, it is wise to follow up with payers on any systematic errors in billing/coding that your clinic can and should correct.

8. Report Systematic Denials of Valid Claims:

If payers refuse to pay for screening (and you are not in a State with higher coverage for preventive service visits), let your State AAP Chapter know, regardless of whether you are a FAAP or not, and seek their advice about what to do. Your State AAP Chapter works with the national AAP and you can check for updates on *http://practice.aap.org*. In addition to reading the AAP website and contacting your State AAP Chapter, you can also e-mail: *aapcodinghotline@aap.org*. Note that the AAP is actively fighting payers who refuse to reimburse for screening after 24 - 30-months.

9. Be Prepared to Advise Parents on How to Appeal:

It may be wise to create a fact sheet to send or read to parents over the phone. They will need to know exactly what to say to insurers and exactly what number to call. See Chapter 6 for additional information for preparing parents and *www.pedstest.com/TheBook/Chapter6* for a downloadable copy.

10. When Reimbursement for Screening is Not Available:

In some States and for some types of practices (e.g., Federally Qualified Health Centers), clinics are paid a rate "per medical encounter." When developmental screening is provided, a specified "visit code" (typically a pre-defined preventive service code) is used to trigger enhanced reimbursement. The 96110 screening code is not reimbursed separately even when States have a specified list of tools required for Early Periodic Screening, Diagnosis and Treatment (EPSDT) visits.

In such clinics, adoption of quality screens is best evaluated in terms of time saved plus reductions in practice expenses. Consider these self-evaluation questions, especially in light of the advantages afforded by online screening services:

- How much time do clinicians spend eliciting informal milestones such as those on age-specific encounter forms? (Published research on this topic does not yet exist but informal time/motion studies suggest that providers spend ~ 1 – 2 minutes on these activities—time that could be saved if parents complete quality skills-focused tools on their own. Accurate parent-report tools are also known to vastly improve detection rates).

- How much time is spent eliciting parents' concerns with informal questions? What percent of visits incur "oh by the way" concerns and how much time is required to address these? (Research shows that informal questions do not work well and result in "door knob" concerns in about 20% of visits.) In contrast, accurate measures eliciting parents' concerns, preferably by self-report in advance of the visit, shave about 3 minutes from average visit length and make encounters far more relevant.[3,4] Also families are more likely to return for subsequent visits when their specific concerns are elicited and addressed.[5]

- If using quality tools in print, how much time is spent handscoring or administering screens by interview? Clearly brief screens using online scoring save a great deal of time. (Chapter 4 shows the scoring time per tool, cost of various administration methods and associated practice expense.)

- How much time is spent dictating/proofing referral letters and parent summary reports? (Published research on this issue does not yet exist but we can anticipate that for about 20% of patients, referrals and thus report dictation/proofing will be needed. These activities require at least 5 – 10 minutes of professional time. To this expense must be added requisite staff time for transcribing

dictations.) Much of this time/expense is eliminated if using an online screening service that automatically generates reports.

Informal measures, whether focused on parents' concerns or children's milestones, incur costs to practices; but these approaches are, unfortunately, without much benefit to patients. Quality screening tools are not without costs, but these expenses are minimal and the benefits to children, parents and society are enormous. Practice time/expense is reduced if parents self-administer measures. Practice time/expense is reduced even further when using online screening services wherein scoring is automated and referral letters and parent summary reports are automatically generated.

III. PRACTICE WORKFLOW

It is often helpful to map the workflow in your clinic when figuring out who should do what. So below, in Figure 16-1, is an example you can customize for your setting and implementation plans. To do this, you can download this blueprint at *www.pedstest.com/TheBook/Chapter16* and rearrange it in Word or Powerpoint, typing in the specific type of staff or clinician who will be responsible for the various steps. You can also draw arrows to help visualize the work flow. Another option is to photocopy the figure and use scissors and tape to reorder the sequence as needed—primitive but it works!

Figure 16-1. Workflow Example

Screening & Referral, Parent Education Practice Flow

_____ distributes measures in clinic → Parent completes screens in waiting room with paper-pencil

Or

_____conducts screens by interview, assesses need for parenting information ← Parent completes screens online at home or via waiting room computer

Or

_____ types results into online scoring or scores print measures

_____ retrieves online results and adds to chart

_____explains results to parents

_____ makes referrals if needed

_____updates patient chart

_____ distributes parent information sheets

_____implements follow-up plan

_____ adds coding to the billing sheet

Parent checks out

IV. Implementation Planning

Table 16-1 is a worksheet to assist you in considering the many details for implementing screening/surveillance in your clinic. Some steps won't be relevant, so feel free to eliminate these items; easiest if downloading the modifiable Word document from *www.pedstest.com/TheBook/Chapter16*. Use the far left columns to sequence your objectives and workflow and the far right columns to list successes, challenges, new issues that arise, etc.

Table 16-1. Screening/Surveillance Implementation Worksheet (for EHRs and Print Charts)

	ACTION ITEM	TIME FRAME	PERSON(S) RESPONSIBLE	DATE TO BE COMPLETED	COMMENTS
	PREPARATION AND PLANNING				
	Who will enthusiastically champion the cause of early detection in your office?				
	Who will explain to all clinic staff the compelling rationale for higher quality screening and surveillance and then elicit their ideas, concerns and suggestions?				
	Who will investigate any State mandates regarding appropriate tools?				
	Who will select among the available screening tools (those that are well-standardized, reliable and accurate)? *Selected tools should target conditions needing early identification (i.e., developmental delays, social-emotional problems, autism, etc.), and be well matched to the needs of the practice, the population being served, and the availability of community resources.*				
	Which clinician (or clinic site) will trial the screening tool(s) while collaborating with all staff members involved in the process? *Try incrementally working towards a screening tool periodicity schedule that embraces all well-visits.*				
	Who will collaborate with office staff to design a workflow process that is effective for everybody? *Such a workflow process should allow for screening results to be discussed with caregivers in real time (preferably, face-to-face) during well-child visit.*				
	Is there an existing process for delivering questionnaires that could serve as a model?				

table continues...

Table 16-1. Cont'd

	ACTION ITEM	TIME FRAME	PERSON(S) RESPONSIBLE	DATE TO BE COMPLETED	COMMENTS
	After the workflow is mapped, who will train the appropriate office staff and providers in how to administer, score and interpret the screening tools?				
	Who will deal with staff and provider complaints (patiently) and consider modifications to the workflow? And how will this person handle things if staff/clinicians are unwilling?				
	DELIVERING SCREENS ONLINE OR IN PRINT				
	Exactly how will you administer the screens, i.e., how will you notify caregivers that they need to complete screens, and succinctly explain the process? Will this be done via: (a) a pre-visit e-mail with an online link? (b) by mailing a print version of the tool to the home? or (c) by giving caregivers a reminder phone call to come 15 to 20 minutes early to the appointment in order to complete the screens in print or online? *Experts recommend that screens should be administered and scored prior to (not after) the well-child visit.*				
	Who will identify the literacy deficits and the languages spoken by parents and ensure that needed translations of instruments are obtained?				
	Who will score (if using print) and interpret the screens? *Office staff and/or online applications are typically responsible for scoring with online applications often generating referral letters and parent summary reports, but clinicians are usually responsible for explaining results to caregivers.*				
	Who will make sure visit encounter forms (whether paper or electronic) have space for capturing the screens used and their results?				
	PREPARATION FOR REFERRALS AND PARENT EDUCATION				
	Who will provide caregivers with referral information? And how exactly will referral information be provided to parents (e.g., faux prescription pads with phone numbers)?				

Table 16-1. Cont'd

	ACTION ITEM	TIME FRAME	PERSON(S) RESPONSIBLE	DATE TO BE COMPLETED	COMMENTS
	How will referral resources be notified that a referral has been generated by your clinic (e.g., faxing statewide IDEA referral forms)?				
	Because the referral process is more efficient and effective when clinics have two-way consent with referral agencies sharing information, who will negotiate the process? Is there an initiative like Help Me Grow or ABCD that has already helped with such arrangements?				
	Screening usually leads to greater need for parenting education. Who will locate educational materials for caregivers (including developmental-behavioral handouts)? How will this person judge the effectiveness of brief advice? *Continuing complaints should serve as an indicator that a referral for more intensive services is likely needed.*				
	Who will make certain that children with suspected problems get connected to a system-wide care coordination program or linked to appropriate community services?				
	Who will bill/code for completion of screens and document positive/negative screening results for the medical record?				
	Who will check with various payers for differences in procedure/diagnosis codes?				
	Who will explain to utilization review personnel (i.e., coders) your decisions about CPT and diagnosis codes?				
	If planning on a quality improvement initiative, who will track progress? *An easily retrievable data base should be created so this person can monitor the percentage of children screened, the percentage of children referred, and make certain that office procedures encourage caregivers to follow through with referrals. Note: this is much easier to accomplish with online pre-visit screening programs like CHADIS or PEDS Online.*				
	Who will oversee longitudinal problem/ process checklists in patients' charts (e.g., milestones progress, completion of surveillance activities, referrals made, etc.)?				

table continues...

Table 16-1. Cont'd

	ACTION ITEM	TIME FRAME	PERSON(S) RESPONSIBLE	DATE TO BE COMPLETED	COMMENTS
CONSIDERATIONS FOR USING SCREENS IN PRINT					
	Who will ensure that printed forms for measures are available each day for caregivers or providers to complete?				
	Who will ask whether caregivers can complete forms on their own and whether they need assistance? *This person will also need to determine the correct language version and, with milestone-based screens, the correct age-interval.*				
	Who will help caregivers when they need assistance due to language and/or literacy barriers?				
	Who will collect the screens from families?				
	Who will score the screens?				
	Who will generate an easily retrievable note about the screening results in the child's chart so progress can be tracked longitudinally over time?				
	Who will attach screens to the chart or otherwise make sure responses and scored results are available to clinicians?				
	Who will generate or dictate a clinic note and/or referral letters when indicated?				
	Who will make certain that the scored and interpreted screening test results are shared with the system-wide care coordination program or referral services (e.g., EI/ECSE agency, developmental-behavioral subspecialist, etc.)?				
	What will you do with the screening materials once they've been discussed with families (e.g., if abstractors are involved in billing/coding)?				
CONSIDERATIONS FOR USING SCREENS ONLINE (WITH SUPPORT FROM PRINT MATERIALS AS NEEDED)					
	Who will trial various online options and decide on an optimal service?				
	Who will explain how to use online applications to office staff and providers?				

Table 16-1. Cont'd

	ACTION ITEM	TIME FRAME	PERSON(S) RESPONSIBLE	DATE TO BE COMPLETED	COMMENTS
	Who will map out the most efficient and effective implementation procedures using online services? *For example, (a) E-mailing caregivers a link to the online screening service in combination with a reminder phone call, so that tools can thoughtfully be completed at home prior to the well-child visit; (b) Sending parents home with a link to online screens, preferably via your clinic website; (c) Arranging for caregivers to come 15 to 20 minutes early to their child's appointment and then, have them complete the screen online while waiting in the clinic reception area (or exam room) using computers or via paper-pencil prior to the well-child visit; or (d) Having a para-professional, nurse or translator read aloud questions for caregivers while completing online measures.*				
	If multiple approaches to screening are needed (e.g., for home visits, due to clinician preferences, staffing patterns, waiting/exam room wait times, parental literacy issues, etc.), how will staff and clinicians accommodate this?				
	If screens are to be completed in writing before using the site, who will make sure print materials are available and enter the results into the online service?				
	Who will teach staff and providers how to use the site? *Computer skills are often needed including: (a) How to keep a browser open along with the electronic record software and switch back and forth between them as needed; and (b) How to select, copy and paste online results into the electronic record.* Who will teach providers how to use computers and make reminders if needed, (e.g., sticky notes placed on the computer)?				
	Where will the results/recommendations and billing/procedure codes be pasted into the electronic record or noted in a paper chart?				
	Who will make sure parents receive any summary reports generated from online screening services as well as informational handouts that promote developmental-behavioral wellness?				

Table 16-1. Cont'd

	ACTION ITEM	TIME FRAME	PERSON(S) RESPONSIBLE	DATE TO BE COMPLETED	COMMENTS
	Who will make sure that referral letters generated by an online screening service are e-mailed, faxed or mailed?				
	Who will ensure that clinic coordinators or abstractors have access to the unique database created by an online screening service so they can review procedure and diagnosis codes, and ensure information is included in electronic or paper charts?				
	If progress tracking or quality improvement initiatives are needed, who will be responsible for monitoring the database created by online services/ export data?				
	If in a multi-clinic setting, is a master account needed so that all clinic records can be viewed? If so, who needs access to the overall database?				
	Most providers want integration between online screening services and their electronic record. This requires support from the EHR vendor or other Information Technology specialists. Who will vet the expenses, contact software consultants and keep them on track?				
ANY OTHER IMPLEMENTATION CONSIDERATIONS?					

V. Resources for Implementation

Below are several sites with guidance for initiating thoughtful developmental-behavioral care. Adding early detection and intervention services often leads to training demands and so we encourage you to also read Chapters 14 and 15 wherein there are extensive lists of training/self-training resources. Improved early detection also leads to an increased need for developmental-behavioral promotion. Be sure to capture links and information from Chapter 7 when establishing your own model of service delivery. Live links are hosted on *www.pedstest.com/TheBook/Chapter7*.

www.developmentalscreening.org

Created by Dr. Alison Schonwald at Harvard University, this site focuses on the challenges of implementing early detection in primary care. There's a compelling video about the processes, challenges and solutions, strategies for encouraging colleagues and clinic staff, selecting tools, etc. The site also has helpful information on how to help reluctant clinic staff and providers.

www.pedstest.com

This site houses rousing slide shows and videos for encouraging interest in early detection and intervention. Also included is information about *PEDS Tools* including case examples and links for trialling *PEDS Online*.

www.agesandstages.com

This site houses case examples, tutorials and a webcast for print and online applications of *ASQ Tools*.

http://practice.aap.org

This AAP site includes information on practice management, billing/coding, webinars, suggestions for efficient and effective care, and also dates for live workshops.

www.medicalhomeinfo.org

The American Academy of Pediatrics' Medical Home Initiative is designed to help establish care for children with special healthcare needs, that is "accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally-competent." The site has training materials, practice rating scales, an e-mail announcement list for providers, how-to's, etc. Medical Home also sponsors several conferences each year.

Chapter Comments: *Implementing early detection, parent education, referral and follow-up—in short, all aspects of the processes for providing a medical home—are challenging but workable. Different methods are needed for different clinics. Approaches depend on the types of families served, staffing patterns, equipment available, staff/provider preferences for delivery of services, and how well clinics and non-medical services collaborate to share information and follow-up plans. The examples in this chapter offer starting points for planning and trials. We hope these cases and the implementation and workflow guidance provided enable you to establish effective developmental-behavioral care in your own clinics.*

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Chapter 17: North American Models for Prevention, Early Detection, Intervention and Professional Training

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INTRODUCTION

In this chapter, we provide examples of the many different, innovative initiatives in the US and Canada that focus on early detection, collaboration across medical and non-medical services and measurement of outcomes. The many contributors are listed along with the projects they have described. The resources section of this chapter provides website addresses for the various initiatives with live links on *www.pedstest.com/TheBook/Chapter17.*

MEDICAL HOME PROJECT: AMERICAN ACADEMY OF PEDIATRICS

Greg Prazar, MD, Exeter Pediatrics Associates, Exeter, New Hampshire

A Case Example

Children with special healthcare needs who live in rural areas face many challenges. Local expertise may be lacking. Care is usually fragmented. Getting there takes longer. Finding support and information is harder. Schools may have had little experience with unique and rare conditions. Ultimately, children with complex conditions and their families typically lack a medical home—leaving them with little continuity—if not a confusing welter of recommendations and treatment plans (or lack thereof).

We are doing something about this! Since 1997, our practice of seven physicians and three pediatric nurse practitioners has been involved with the Rural Medical Home Improvement Project. The project is funded by the US Maternal Child Health Bureau (MCHB) and by the Center for Medical Improvement at Dartmouth Medical School. Led by Carl Cooley and Jeanne McAllister, the intent of the project is to make systematic improvements in care given to children with special healthcare needs and their families. Our practice was one of four rural practices initially enrolled (the other practices are in Plymouth, New Hampshire; Randolph, Vermont; and Bradford, Vermont). We have now expanded to include nine more practices in New Hampshire, Maine, and Vermont.

How does the project work? First we were helped by project facilitators to identify areas in need of improvement (using the Chronic Conditions Management Practice Self-Assessment Tool, developed at the Hood Center for Children and Families at Dartmouth Hitchcock Medical Center). The tool identifies areas for manageable steps for improvement followed by outcome measures to make sure the results were effective. This helped us realize that our first task was to figure out which patients actually had special healthcare needs.

Of our 14,000 active patients, we have identified 1480 with complex needs (and we are still counting). The two most common complex conditions in our practice are asthma and ADHD—conditions with strong co-morbidities.

To address the needs of these children and their families, we began using a simple pre- and post-visit questionnaire. The pre-visit questionnaire asks parents to identify the two biggest concerns. This gives clinicians a sense of the parents' needs and issues so that providers can help solve or at least address them. The post-visit questionnaire focuses on parent satisfaction with the encounter.

We also identified a care-coordinator. In our practice, this is a social worker, but the Project often uses nurses or administrative office person. The care coordinator helps with insurance eligibility, crisis intervention, locating mental health and other services, parent counseling, and also advocates for and with parents at Individual Educational Program planning meetings at the schools.

Integral to the success of this project is the involvement of parent-partners. In our practice, one is a parent whose child has had a liver transplant (s/p biliary atresia); the other parent has a child with Aicardi Syndrome (a congenital condition that includes partial or complete absence of the corpus callosum, retinal lesions, infantile spasms, and significant developmental delays). The parent-partners meet twice monthly at team meetings (90 minutes each). These also include the care-coordinator, the pediatrician and a facilitator (provided by the Center for Medical Improvement), and an office person (in our case, a medical assistant).

The meetings are very structured and focus on planning, implementing, and evaluating incremental improvements in care given to patients with complex conditions. One of the improvements is the use of a parent journal—essentially a hand-held health record with a clear action plan of treatment steps, which has space to record who is responsible for calling subspecialists. Another improvement is a practice bulletin board with information about services and other patient information. The efforts of the parent-partners facilitates family-centered care and enables true parent-professional partnerships.

At least twice a year, we also meet with other care-coordination teams to share our successes and brainstorm about better methods. We recently described our efforts at the National Summit on Children With Special Health Care Needs. It addressed national progress in establishing medical homes for children with complex conditions.

I hope you can feel my passion and excitement for our participation in this great program! As a result of involvement in this project, my attitude toward practice has changed. I enjoy going to work and believe that through the project we are making unique contributions to care of children with special healthcare needs.

Comments on the Medical Home Project: Dr. Prazar highlighted the many delightful aspects of participating in the AAP's Medical Home project. His non-medical colleagues in Exeter, New Hampshire's IDEA programs cannot say enough good stuff about his office having a care-coordinator with whom they can share information about children's developmental-behavioral evaluations and receive information about children's medical needs. Clearly Medical Home has been a win-win situation for all involved. The AAP's Medical Home project has a rich website (*www.medicalhomeinfo.org*) with links to webinars, training, and continuing medical education opportunities, tool kits, activities in each US State, etc. Also included is very helpful advice for families entering IDEA services (e.g., how to create a notebook for filing important documents).

THE AMERICAN ACADEMY OF PEDIATRICS' BRIGHT FUTURES INITIATIVE

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In the United States, almost one century ago, pediatrics was founded as a unique medical discipline. From inception, the specialized pediatric care of infants, children, adolescents and young adults focused on preventive care. Ever since, pediatricians have been champions for improved public health, better nutrition, public hygiene, and reductions in childhood morbidity and mortality. Our predecessors recognized the importance of nutrition to healthy growth and development, and appreciated the magnitude of infectious disease in children. As a consequence we have specialized not just in the treatment of common child infections, but also in disease prevention.

The founders of pediatrics speculated wisely that the population of healthier children would in turn face "the new morbidities"—harms caused by problems in mental and behavioral health, including social stressors to families and communities that deter growth and development.[1] Ability to address persistent threats to the health and well-being of children have also become core competencies in pediatrics.

Pediatricians and other clinicians who care for children—family medicine physicians, nurses in pediatrics sand family medicine, and physician assistants—rely on guidelines and other identified standards for preventive care. If preventive care is to be successful, it must be studied and make use of available evidence of effectiveness. Guidelines demonstrate standards of care for assuring that every child and adolescent and their families are provided quality guidance regarding nutrition, growth and development, oral health, behavioral health, injury prevention and other topics. *The Bright Futures Guidelines for Health Supervision of Infants, Children, Adolescents and Young Adults* is the contemporary standard for preventive care and defines the standard of care for youth in the United States under the

Affordable Care Act of 2010.

Now in its third edition, *The Bright Futures Guidelines*[2] describe preventive care visits from the prenatal visit to 21-years of age. Each well-child visit attends to disease detection, disease prevention, health promotion and anticipatory guidance. To achieve these outcomes, health care professionals employ techniques to screen for disease, screen for risk of disease, and provide advice about healthy behaviors. These activities lead to the formulation of appropriate anticipatory guidance and health advice.

Clinical detection of disease in the well-child encounter is accomplished by a complete physical examination which is augmented by surveillance and screening. In well-child care, surveillance occurs in every health encounter and is enhanced by the opportunity for repeated visits and observations with advancing developmental stages. It relies on the experience of a skilled clinician over time. Screening is a more formal process utilizing some form of tool, which has been validated and has known sensitivity and specificity. Even so, validated screening tools can serve in the capacity of both screening and surveillance, i.e., evidence-based longitudinal measurement with clinical decision-support, engaging parents' concerns and observations, under the watchful eyes of pediatric providers who are experienced in child development.

The Bright Futures Guidelines includes screening for various conditions in every visit. Some screening is universal, for all children at that visit (e.g., anemia screening by hematocrit or hemoglobin testing is a universal screen at the one-year-old visit). Screening can also be selective, based on risk assessment (e.g., anemia screening is selective at other visits based on risk assessment questions found in the Bright Futures Visit or in the Pre-visit questionnaire). Developmental-behavioral screening and surveillance should be both routine and selective (e.g., at sick or return visits if a family has missed a prior well-visit).

The Bright Futures Toolkit

The second essential action of the well-child encounter, disease prevention, may include both primary prevention activities applied to a whole population and secondary prevention activities aimed at patients with specific factors of risk. For example, counseling about reducing fat intake is appropriate for all children and families. Counseling is intensified for overweight and obese youth or in the presence of a family history of hyperlipidemia and its sequellae. Disease prevention strategies are individualized to specific families, patients and their communities.

Health promotion and anticipatory guidance activities distinguish the well-child health supervision visit from all other encounters within the healthcare system. Disease detection and disease prevention activities are germane to all interactions of children with physicians and other healthcare providers, but health promotion and anticipatory guidance shift the focus to wellness and to the strengths of the family, for example, what is being done well and how this might be improved.

Although not all well-child care activities have been evaluated for efficacy, lack of study does not imply lack of benefit. *The Bright Futures Guidelines* utilized available evidence. When evidence was absent, the rationale for well-child care activities was based on a balance of evidence from research, expert opinion, clinical practice guidelines, professional recommendations, experience, habit, intuition, and preferences or values. Effective preventive services require sound clinical and counseling decisions that are responsive to family needs and desires, and support "patient-centered decision-making." It would be proper to describe *The Bright Futures Guidelines* as "evidence-informed." Work on the Fourth Edition has begun with a careful analysis of the rationale and evidence that will support any new guideline components.

Strategies to improve the preventive services delivered to children and youth follow AAP Recommendations for Preventive Pediatric Health Care (*http://brightfutures.aap.org*). Practice strategies to complete this will include screening schedules and flow sheets, registries, and the use of parent and youth pre-visit questionnaires and handouts for parents and older youth. Such tools are available in *The Bright Futures Guidelines Toolkit*.[3] A coordinated team approach via use of continuous measurement to improve

techniques has been an effective method for helping clinics adopt new preventive care practices. Stay tuned at *www.brightfutures.org*.

NATIONAL ACADEMY FOR STATE HEALTH POLICY (NASHP) AND ASSURING BETTER CHILD HEALTH AND DEVELOPMENT (ABCD)

Jill Rosenthal, MPH, Program Director, National Academy for State Health Policy

The Assuring Better Child Health and Development (ABCD) Program is a grant from The Commonwealth Fund and administered by the National Academy for State Health Policy (NASHP). Several multi-year projects under the ABCD umbrella have supported State efforts to develop or expand service delivery and financing strategies aimed at enhancing healthy child development for low-income children and their families. Early detection of developmental delays has been a central theme of these efforts.

Since 2000, four States (North Carolina, Utah, Vermont, and Washington) have participated in the ABCD-I Learning Collaborative focused on general development. Five States (California, Illinois, Iowa, Minnesota, and Utah) have participated in the ABCD-II Learning Collaborative focused on social and emotional development; and 20 States and Territories* participated in the ABCD Screening Academy to implement policies and practices that move the use of standardized screening tools as part of well-child care from a 'best practice' to a 'standard of practice.'

More than half of all States have participated in an ABCD initiative. The ABCD experience demonstrated that Medicaid and other State agencies, in collaboration with primary care partners, can play an important role in promoting policy- and practice-level change. ABCD participation improves routine identification of young children with developmental delays (or at risk of delays) by promulgating use of validated screening by pediatric primary healthcare providers.

The ABCD approach features three common elements: (1) public/private partnerships to enable state teams to use their resources most effectively; (2) demonstrations to develop, test, and refine plans for statewide with improvements; and (3) measurement to plan, incentivize and monitor system-wide policy improvements. Fostering change at the office-based primary care level, community level, and State policy level has been found to be critical to success. Private sector involvement and pilot testing allowed the ABCD projects to ground proposed policy and systemic changes in real-world experience. This approach has been critical to identifying and making the case for specific changes, as well as gaining provider acceptance of (and adherence to) the changes.

ABCD leaders across various US States reported significant progress in helping primary care practices better identify children by incorporating validated screening tools into regular well-child care. In all States that reported baseline and follow-up data for their demonstration sites, the proportion of children screened using a standardized tool increased during the course of the initiative.

ABCD State teams used various combinations of methods to support changes in the demonstration sites and statewide spread of their practice improvements. A variety of training formats support providers' efforts to incorporate screening into standard office practices, along with leadership by physician champions in the State. Formats included in-office trainings, learning collaboratives, workshops, and presentations at grand rounds and/or conferences focusing on child health and development. Training also included development of web-based curricula for providers and staff designed to integrate screening tools into primary care.

In terms of State policy, ABCD States clarified existing policies and established new policies, changed claims processing systems, provider handbooks and contracts with managed care organizations, and conducted workshops and other activities to inform providers of the new policies. Policy improvements can be categorized into three groups:

1. **Program coverage:** An example is improving Medicaid's coverage of services by adding developmental screening with a validated screening tool to the benefit package or clarifying that the service was already covered. Some States added the 30-month visit to their EPSDT periodicity schedules as recommended by the AAP.

2. **Reimbursement:** An example is establishing, modifying, expanding or clarifying the conditions under which Medicaid pays for CPT code 96110 (developmental testing: limited) or increasing the reimbursement rate for this code.

3. **Program performance:** An example is conducting Medicaid managed care quality improvement activities or facilitating exchange of information between primary care providers and IDEA Part C providers through standardized referral and feedback forms.

NASHP and The Commonwealth Fund are currently implementing the ABCD-III learning collaborative, through which five States (Arkansas, Illinois, Minnesota, Oklahoma, and Oregon) are tackling the next set of challenges that arise after appropriate early detection of developmental delays. These States are identifying, implementing, testing and then spreading the policy and system changes that create and support efficient linkages between primary care clinicians and providers of child and family services; the collaboration needed to optimize child health and development (e.g., mental health, Early Intervention, early care and education programs such as Head Start, family support such as WIC, and specialty health services). Participating States are targeting policy improvements through these approaches: (a) maximizing the use of personnel to assure effective linkages; (b) undertaking quality initiatives that engage clinical practice settings and networks of providers, along with other mechanisms for assuring and monitoring quality related to referrals; (c) improving data, information and technology (e.g., common referral forms and data linkages); and (d) supporting individualized care plans and cross systems planning.

The ABCD Electronic Resource Center (ERC) (*www.nashp.org/abcd-welcome*) provides State policymakers, primary care providers and other child and family service providers with easy access to research and resources they can use to promote early childhood health and development. The resources in the ERC include tools and materials developed by each of the States participating in the ABCD initiative. The ERC also features clinician toolboxes containing information for primary care providers interested in promoting the use of structured developmental screening in their office practices. Each toolbox contains information about key activities related to developmental screening, such as a discussion of screening tools, coding and reimbursement, and practice guidelines. NASHP has synthesized lessons and recommendations from each ABCD project to maximize adoption in other States. These are included in a variety of reports also available on the ERC website.

Providers and State provider association chapter representatives who participated in ABCD State activities cite a number of reasons for involvement, including opportunities to shape State policy, improved office efficiency and patient/family satisfaction, better care coordination and awareness of partners in the community, potential financial incentives (through enhanced reimbursement), and public acknowledgment of efforts to strengthen the quality of care for young children. Providers also cited increased involvement of parents in their children's care, time saved by using standardized screening tools, and satisfaction in knowing that children are referred to appropriate services.

For primary care providers and other community service providers interested in becoming involved in State ABCD initiatives, contacts include the State Medicaid office, the State AAP Chapter (*www.aap.org*) or the National Academy for State Health Policy to identify local contacts (*www.nashp.org*).

[*] (AK, AL, AR, CA, CO, CT, DC, DE, KS, MD, MI, MN, MT, NJ, NM, OH, OR, PR, VA, WI)

HELP ME GROW (HMG) AND THE HMG NATIONAL CENTER

Joanna Bogin, MS, Project Coordinator, The Commonwealth Fund, Help Me Grow Replication Project;
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The Help Me Grow initiative began in 1998 in Hartford, Connecticut, based on the following assumptions: (a) that children at risk for developmental and behavioral problems were escaping early detection; (b) that despite capacity issues and gaps in services, a variety of community-based programs existed to address children's developmental needs; and (c) that children and their families would benefit from a comprehensive, systems approach to the early detection of at-risk children and the linkage of children and their families to community-based programs and services. Research demonstrates that health care, early care/education, and human service providers often have difficulty recognizing the early signs of developmental or behavioral challenges. Meanwhile, we also know that early detection and connection to services lead to the best outcomes for children with developmental delays or behavioral issues. Research also suggests the unique benefits of identifying and linking at-risk children (meaning those likely to have delays in the future) to appropriate community-based supports whenever possible, thus reducing or even preventing the subsequent need for more intensive services. While the importance of early screening and detection is frequently cited in the literature, screening without a referral mechanism is unacceptable. Perrin emphasizes that detection without referral and intervention is certainly ineffective, and may even be judged unethical (although it may still be helpful for needs assessment, service development, etc.).[4]

The Help Me Grow system creates a statewide infrastructure that efficiently and effectively links children at risk for developmental and behavioral problems to existing, community-based programs and resources. Core components of Help Me Grow include: (a) the training of health care and early education providers along with families, in the early detection of at-risk children through the process of developmental screening and surveillance; (b) the compilation of an accurate and informative inventory of community-based programs and services; (c) a centralized information and referral center serving as a point of access to such programs and services; and (d) data collection to ensure the effectiveness of the system and to document gaps and capacity issues to inform advocacy. Engagement of healthcare clinicians is a critical component of the Help Me Grow system. Outreach to medical providers promotes developmental screening and surveillance according to AAP policy, and encourages the use of a centralized call center. A key message is that healthcare professionals are ideally suited to promote cross-sector collaboration with early care and education and family support providers, which is so important in promoting children's healthy development.

The Help Me Grow National Center, established in 2010 and based at Connecticut Children's Medical Center in Hartford, supports the building of Help Me Grow statewide systems throughout the country. Orange County, California replicated HMG with guidance from the Connecticut team in 2007. In 2008, a two-year grant from The Commonwealth Fund enabled a team of Connecticut HMG leaders to provide technical assistance to five States in their efforts to develop Help Me Grow systems. In 2010, a three-year grant from the W.K. Kellogg Foundation supported the establishment of HMG National that enabled continued support to the five initial HMG States and the recruitment of ten additional States as HMG affiliates for system development. The goals of HMG National are to ultimately support HMG system development in all States; to ensure that all families have knowledge of and easy access to statewide systems that support them in addressing their children's developmental needs and finding appropriate services. States affiliated with HMG National use the Help Me Grow system to implement effective, universal, early screening and surveillance for all children and then link them to existing programs and services. By 2013, sixteen States and organizations will be Help Me Grow affiliates, actively engaged in the planning and implementation of Help Me Grow systems throughout the country. The National Center is poised to support additional States and create even greater nationwide impact.

Help Me Grow affiliates collect and analyze data on client calls and outreach to healthcare providers, communities, and families. Centralized call centers assist families with identifying their children's needs

and connecting them to relevant services. Call centers collect a wide range of data including: How callers learn about the call center; caller demographics; facts about the child and/or family in need; the specific assistance being requested; referrals provided and other actions taken to assist callers; and the outcomes of the contacts with the call center. Call centers are in a unique position to collect data that reflect system-level issues and regularly identify gaps and barriers to services.

An annual analysis and summary report of available data assess how well the HMG system is working and what is needed to improve or enhance the service. In addition, the data is shared with funders and policy makers to inform their views on service delivery and to demonstrate how to best use resources to promote optimal child development. For example:

- Connecticut Help Me Grow was established in 2002 as a statewide entity. Data (2006-2007) shows that 86% of families calling the centralized center (Child Development Infoline) are successfully connected to services.

- In 2009, the Orange County, CA annual evaluation report states that the two top concerns of families focused on their child's behavior and communication skills.

Further information about Help Me Grow and the HMG National Center, including annual evaluation reports for Connecticut and Orange County, California can be accessed on the Help Me Grow National website at *www.HelpMeGrowNational.org.*

Promoting Resources in Developmental Education (PRIDE)

Desmond Kelly, MD, Medical Director of the Division of Developmental-Behavioral Pediatrics at the Children's Hospital of the Greenville (South Carolina) Hospital System; Jane Witowski, PRIDE Program Coordinator.

Promoting Resources in Developmental Education (PRIDE) began in 2004 in Greenville, SC as a pilot program to involve the medical, education, and early intervention communities in ensuring that children birth to 3-years of age with developmental delays are identified as early as possible, and that they are connected to appropriate services. The program targets the key players in a young child's life: Parents, primary care physicians, and early childhood providers and educators. Over six years, the program has expanded its reach from a single county to eight counties, and expanded its focus on the developmental-behavioral concerns of children birth to 5-years of age.

The program builds a greater awareness of developmental milestones among parents and child care providers through training and education activities. Physician outreach focuses on creation and maintenance of a system for routine standardized developmental screening.

The PRIDE program was developed as a community collaboration, and this is the key to the program's success. The Gardner Center for Developing Minds at Children's Hospital-Greenville Hospital System University Medical Center serves as the program's fiscal agent, and Dr. Desmond Kelly, Developmental-Behavioral Pediatrics Division Director, serves as the program's medical director. The program is funded by grants along with significant in-kind support from Greenville Hospital System.

Medical Outreach

Physician outreach began in a single county with 19 pediatric practices. In 2011, more than 65 practices in eight counties benefited from initial training with ongoing technical support and academic detailing on best methods of incorporating standardized developmental screening into their practices. While physician practice has been slow to change due to perceived and real barriers such as electronic medical records, coding and reimbursement, and lack of time, 52% of area pediatricians responding to a recent survey indicated an interest in making changes to their current screening practices.

It is evident that the successful implementation of a sustainable model of developmental screening in a primary care office is dependent on education and involvement of all staff members, starting

with the physicians. Our findings confirm previously published recommendations. Because changing circumstances within offices, including changes in staff or the financial structure of the office can contribute to attrition, there is a clear need for "booster" visits by a representative of the program to uncover and to help address emerging problems. Another implementation challenge is the reluctance of physicians to identify problems for which there are no easy solutions, but providing information about community resources has been very well received.

Parent Outreach

PRIDE's parent outreach builds a greater awareness of developmental milestones through an educational series called "Mind Your Milestones." Informative cards are mailed periodically to parents from their baby's birth through 5-years of age. Parents learn about typical development, activities to promote achievement of milestones, and warning signs of possible delays. Families are enrolled in a variety of ways; through their child's health provider, through community agencies serving at-risk families, and through the hospital's women's education program (labor and delivery). More than 15,000 families benefit from this free service. Not only do parents report an increased knowledge of child development, but say this knowledge has improved communication with their child's health provider by opening up dialogues on specific developmental topics or concerns. One example shared on a recent survey describes a parent with limited formal education who took a milestone card to her child's doctor to use as a conversation starter about concerns she had about her child. The integration of information provided to parents with the education and support of physicians is a unique aspect of the PRIDE program. Parents facilitate the process of developmental screening by being educated consumers and raising their own concerns with physicians regarding their child's development.

Early Care and Education Outreach

PRIDE's outreach to child care providers includes a five-hour training that focuses on early childhood development, identification and assessment of developmental delays, parent-teacher conference strategies, and positive disciplinary techniques to use in the classroom. Participants receive a customized toolkit with developmental guides, curriculum support, and community resource information. More than 900 child care providers have completed our training, and referral rates from developmental screening increased an average of 25% annually. Early care providers report that the program's training and materials provide legitimacy to their observations and support their conferences with parents. Changes in teacher behaviors and classroom activities are also reported as a result of PRIDE's training.

Lessons Learned

- PRIDE demonstrates that an integrated approach to early detection and intervention for developmental problems is more likely to be an effective model than reliance on a single group of professionals.

- The chance that children with problems will be missed is greatly reduced by involving parents, early care/education and healthcare providers in developmental screening and surveillance.

- A truly family-centered healthcare model provides parents with tools for taking a more active role in evaluating their child's development and collaborating with professionals. Through education, parents are more informed consumers and better advocates for their child's optimal development.

- Educators have largely been neglected as key observers of children. Our experience indicates that child and early care providers are eager to embrace a role in the effort to improve early identification of children at risk for developmental or behavioral delays.

Planned Outcomes Study

A 5-year program evaluation study is underway by the University of South Carolina Health Sciences Research Core located within the School of Public Health.

Head Start/Early Head Start

Jennifer K. Poon, MD, Assistant Professor of Pediatrics, Division of Developmental-Behavioral Pediatrics, Medical University of South Carolina

Head Start (*www.nhsa.org*) is a Federally funded program under the United States Department of Health and Human Services. Created in 1965 and focused on low income children ages 3- to 5-years-old, Head Start promotes education, nutrition, health, and social-emotional well-being. Head Start emphasizes parents as primary interventionists in helping children.

Early Head Start was created by a Congressional Act passed in 1994. Early Head Start provides services for expectant mothers and children birth to 3-years of age. Each of the 50 States is responsible for determining eligibility criteria, including services for children of American Indians and Alaska Natives as well as migrant and seasonal workers. Family income is one of the eligibility factors, but each program determines who their target population is, depending on the needs of their community. Early Head Start also includes children with disabilities, eligible for Part C services under IDEA. Because Head Start and Early Head Start Programs are tailored to each community, program settings are diverse, and may include schools, child-care programs, or home-based services.

Research on Head Start and Early Head Start is voluminous. Head Start research spans almost 50 years and is summarized at *www.acf.hhs.gov*. Highlights of findings are that a structured curriculum with an emphasis on language development (e.g., High Scope) is particularly effective. Although many Head Start graduates remain behind their more advantaged age-mates and may still struggle in school, they are nevertheless far more likely than equally low SES but unenrolled peers to graduate from high school, become employed, avoid teen pregnancy and criminal behavior. In short, Head Start confers a huge benefit to tax payers. More information about parent-training, progress monitoring and other efforts by Head Start/Early Head Start can be found on the website. Of note: IDEA services collaborate well with Head Start/Early Head Start, meaning that enrolled children can also receive physical, speech or other therapies through IDEA.

Healthy Steps for Young Children: Supporting Young Children and Their Families Using Primary Care as a Vehicle for Service Delivery

Margot Kaplan-Sanoff, EdD, Associate Professor of Pediatrics, Director, Healthy Steps National Office, Boston University School of Medicine

Parents often come to well-visits with one passionate question: *"How is my child doing?"* Parents are often unsure how their child's learning and behavior measure up. In answering this question, well-child care becomes a critical impetus for determining a child's developmental status and families' need for assistance. But this same question also reflects this underlying issue: *"How am I doing as a parent raising this child?"* As practices attempt to answer this second question, they expand the scope of developmental well-child care to include both the social-emotional development and behavioral health of young children and the well-being of the family: Do they have enough food?; How do parents handle conflict within the family?; Do families feel safe in their home/community? Parents often feel more comfortable having these issues addressed in the context of well-child care (as opposed to a neighborhood early childhood program) because healthcare offers protection, individual attention, and confidentiality so that families can more easily explore their worries about their children or themselves.

Rationale: Healthy Steps for Young Children

Healthy Steps for Young Children (*www.healthysteps.org*) is a national initiative emphasizing a close relationship between pediatric clinicians and parents that focuses on physical, emotional, and intellectual growth and development of children from birth to 3-years of age.[5-7] In a traditional pediatric practice, there may be only one clinician who tries to address all of the child's health and developmental needs, often without much success. Healthy Steps expands the model of a solo pediatric clinician to add

a new member to the healthcare team—the Healthy Steps Specialist who enhances the information and services available to parents. The Healthy Steps Specialist can be a new team member or a nurse, child development specialist or social worker already working in the practice. Healthy Steps Specialists have training in child development, early intervention, child care, social work, counseling or nursing and can address major behavioral and developmental issues, focusing on the child within the context of the family.[8] Healthy Steps Specialists co-manage families with pediatric clinicians, ensuring that the practice has the time and expertise to address each family's need for information and support.

Healthy Steps provides relationship-based practice by using a team approach, allowing both the pediatric clinician and the Healthy Steps Specialist to interact together in the same exam room with the family when they come in for well-child visits.[7] As a team, they build on each other's knowledge and resources, responding to parents' questions and concerns with both a medical focus and a developmental perspective. For example, when a family expresses concerns about their toddler's limited language, the pediatrician will check for recurring ear infections, hearing problems and parents' use of language to the child—ending the visit with a discussion of how to use books to support language and then giving a developmentally and culturally appropriate book from Reach Out and Read. Then the Healthy Steps Specialist might ask about the family's routines for talking and sharing books with their toddler, their expectations about the child's use of language at this age, and whether this concern is based on feedback from other family members, child care providers or friends.

Components of Healthy Steps

A team approach to primary care offers families enhanced well-child visits that emphasize the promotion of children's development, including strategies to improve "the goodness of fit" between parent and child, closer attention to parental questions and concerns, and the use of "Teachable Moments" to support better parental understanding of their child's behavior. An enhanced Healthy Steps visit may be conducted jointly or sequentially by the pediatric clinician and Healthy Steps Specialist (HSS). Other critical components of Healthy Steps include:

- Home visits by the HSS, timed to specific developmental needs in young children.
- A dedicated child development telephone information line.
- Child development and "family health checkups," including developmental screening of the child and a review of adult strengths and risk factors which impact the child's development.
- Written materials for parents that emphasize prevention and health promotion within the context of their relationships with family, pediatric and community resources.
- Facilitated linkages and referrals to community resources.

Well over 500 pediatric clinicians, family physicians and pediatric and family medicine residents participate in Healthy Steps. The Johns Hopkins University's Bloomberg School of Public Health rigorously evaluated Healthy Steps using medical record review, parent and provider satisfaction and knowledge questionnaires, telephone interviews and contact logs. Three year follow-up data reported in the J*ournal of the American Medical Association* indicates that for all children, not just those at high-risk, the quality of pediatric care in the first three years of life dramatically improved because of Healthy Steps. By changing the structure and process of pediatric care, Healthy Steps significantly improved the delivery of pediatric developmental services.[9] The evaluation found that families involved in the Healthy Steps program were more likely than non-participating families to:

- Discuss concerns with someone in the practice about the importance of routines, discipline, language development, child's temperament, and sleeping patterns, etc.
- Be highly satisfied with care because someone in the practice went out of their way for them.
- Discuss feelings of sadness following screening for maternal depression.
- Are 27% less likely to report using severe physical discipline (slapped a child in the face or spanked him with a belt or other object) at 3-years of age.

- Are less likely to rely on other harsh strategies such as yelling, threatening, slapping a child's hand or spanking with their hand at 3-years of age.
- Ensure that infants slept on their back to help reduce the risk of Sudden Infant Death Syndrome.
- Receive timely well-child visits and vaccinations.
- Remain with the practice until the child was at least 20-months-old

Healthy Steps helped parents better understand children's behavior and development, thereby producing more favorable disciplinary practices. Pediatric clinicians were highly satisfied with the program and viewed Healthy Steps as a valuable service that helped to keep families in their practices. The research team at Johns Hopkins analyzed data from a five year follow-up study of Healthy Steps children and families focused on school readiness: Researchers followed Healthy Steps children from birth to 5½-years and found that families continued to use more appropriate disciplinary methods and remain more sensitive to the child's behavioral cues. Parents tended to remain with the Healthy Steps practice, ensuring continuity of care.

Based on the strength of these program evaluations, Healthy Steps was selected as an approved evidence-based practice for both the Substance Abuse and Mental Health Services Administration and the Maternal Infant and Early Childhood Home Visiting Programs funded under the Affordable Care Act Federal initiatives.

Healthy Steps Strategies that Support the Development of Both Young Children and Their Families: Teachable Moments

To help pediatric clinicians provide effective information and support for parents within the time constraints of a typical office visit, the use of "Teachable Moments" represents a highly effective strategy. By using the basic assessments of the pediatric visit—history taking, physical examinations, and developmental screening/surveillance—as potent Teachable Moments, providers can exploit the educational opportunities they present for intervention. The strategy of Teachable Moments is to use the behavior of the child during the visit and the clinician–parent interactions in the office as compelling, shared experiences that further parents' insights into their child and enhance their sense of competence as parents. Using everyday questions and experiences in the office as a shared context for discussion while the visit progresses are efficient ways to address issues without appreciably lengthening the visit. The goals of Teachable Moments are to:

- Enhance parents' understanding of the child's needs.
- Promote "goodness of fit" between parent and child.
- Conduct developmental screening/surveillance using both observed behavior and evidence-based tools.

Using Behavior in the Office as a Teachable Moment. Discussions of the infant's or child's behavior in the office provide a fruitful context for Teachable Moments. Newly emerging and developed skills and behaviors can challenge the equilibrium between parent and child. Frequently a specific behavior that parents find disturbing (e.g., mouthing toys at 6-months of age, throwing blocks or food at 8-months, refusing to lie down to be diapered at 10-months, irrepressible exploration at 18-months) is developmentally normal and predictable yet can activate a parent's anger, confusion or anxiety.

Parents' concerns about these issues create a special opportunity to promote parental understanding of typical health and development. Concerns that new parents bring to pediatric visits in the first months of a child's life provide a wealth of Teachable Moments. The infant's behavior creates a special opportunity to promote parental understanding and support. For example, if the infant cries inconsolably during the visit or her cues are difficult to read, the clinician can explore how parents feel and empathize with their frustration at not being able to calm or read their baby. The goal of this Teachable Moment is to blend information about development with knowledge about possible "red flags," which the pediatrician will note for future observation, further assessment or for making a referral to early intervention.

When a child's behavior in the office provides a Teachable Moment, it is up to the pediatric clinician or HSS to capitalize on it. During these Teachable Moments, one might infer or "read" the child's behavior or temperament together with the parents, and offer constructive interpretations of its significance. The clinician should then ask parents how they feel about the behavior or use their own reactions to explore parental concerns.

Creating Teachable Moments. If a child's behaviors do not produce Teachable Moments spontaneously, the clinician may employ specific strategies to engage the child and discuss the implications for behavior and development. Parents tend to watch carefully as a pediatric clinician engages the child in activities (e.g., handing the child a toy or a book, rolling a ball back and forth, listening to the heart or looking into the ears) that demonstrate a particular behavioral or temperamental quality or developmental skill. In some cases a pediatric clinician can remark on a child's unsteady gait or inability to follow a point as an introduction to the screening process using an evidence-based tool. By observing and commenting on the child's behavior, the pediatric clinician encourages the parents to step back and speculate about its meaning. Unrealistic expectations, which can contribute to parental frustration and lead to child abuse or neglect, can be gently corrected. The clinician can create a Teachable Moment by narrating the child's actions, reframing them as acts of exploration rather than as deliberate attempts to make life difficult for the parent. The clinician can explain how seemingly unimportant tasks, like using a pincer grasp to pick up a Cheerio, are important windows into a baby's development and learning.

Asking Questions and Shared Dialogue

Questions about children's behavior and development give parents a chance to discuss concerns in these areas. Especially useful in the early years are questions about children's temperamental characteristics, developmental milestones, behavioral and family issues, and how parents feel about these issues. Evidence-based methods are superior to informal lines of questioning for determining which concerns are predictive of developmental-behavioral problems (and thus need further screening or referral). Clinical judgment should be used to decide when it is appropriate to expand, and when to narrow, the content of the discussion, but should not be used to over-ride the evidence behind screening measures. In any case, the well-child visit can also serve as a natural springboard to elicit more information or concerns from the observing parent. Neutral, nonjudgmental comments about children's behavior (e.g., "He certainly is a busy guy, isn't he?") may trigger a host of parental concerns, elicited all the more easily by the stimulus provided when providers share their own observations.

Recommendations and Conclusions from Healthy Steps

The challenge for all pediatric practices is the mandate to "do more in limited time." In recent years, as parent expectations and expert recommendations for pediatric primary care have increased, so have the demands on pediatric clinicians. Currently, during brief 10- to 15-minute encounters, clinicians are expected to provide a complex set of health, developmental and behavioral assessments, therapies, and counseling services. Yet it has been reported that in 60% of all routine well-child visits, providers ignored parental concerns or provided no developmental or behavioral information or guidance.[10]

By adding a new professional to the healthcare team, Healthy Steps provides a vehicle for enhancing well-child visits and moves practices toward becoming patient-centered Medical Homes. Healthy Steps Specialists have the opportunity to observe parents and children during physical exams and to comment on the affect of babies and/or parents. By describing how children and families might be feeling or thinking during visits, Healthy Steps Specialists become a very tangible symbol for the potentially charged issues of development and parenting that can surface within the context of pediatric care.

Reach Out and Read: Ensuring Children Enter School Prepared to Succeed

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The Need for Reach Out and Read

Studies demonstrate that young brains are highly malleable and are shaped by an infant's day-to-day interactions with the important people in their lives. Given that 96% of all children younger than 5-years of age see a pediatric healthcare provider, Reach Out and Read clinicians are in a strategic position to coach parents about the impact that reading aloud can have on the development of the young brain. Reading aloud, even to the tiniest of babies, helps build crucial central nervous system connections for language and literacy learning. Infants are soothed by the rhythm and tone of the spoken language around them and may even try to 'mimic' the melodic contour of the mother's voice to attract her attention.[11]

At the same time, too many children begin school ill-prepared to learn. Children raised in poverty, children whose second language is English, children whose parents struggled with learning to read, and toddlers who experience language delays are highly represented in groups of children who experience early difficulties in learning to read.[12,13]

The learning gap begins in infancy, especially for low-income children. A nationally representative sample of 1100 infants born in 2001 were studied using data from the Early Childhood Longitudinal Study-Birth Cohort, gathered by the National Center for Educational Statistics along with the US Department of Education. Children from low-income families scored lower on cognitive assessments, were in poorer health and had more behavior problems at 9- and 24-months than their counterparts from higher-income families.[14] Mendelsohn and colleagues studied babies after coaching low-income parents (with video and modeling) to read to and otherwise stimulate their newborns once they brought them home. Differences were already present at 6-months between babies whose parents were coached and those who were not.[15]

Vocabulary development at 3-years of age predicted future reading achievement. By age 3-years, children from more educated families have typically heard 30 million more words than children from low-income and undereducated families.[16] Furthermore, while a record number of young children are being cared for outside their homes, studies also show many children are in daycare settings of poor quality.[17,18] Half of all kindergarten teachers across the US report that at least half their students have problems such as difficulty following directions, working independently, and beginning knowledge of books, letters and numbers. When children begin kindergarten with fewer language and cognitive skills they often fall further behind, while the children with higher skills make gains in reading and math with increasing velocity.[19,20] As they reach first grade, the consequences of reading failure are so profound that without intervention children are not on course to make the necessary transition from "learning-to-read, to reading-to-learn." The 2010 Annie E. Casey Kids Count data show that 83% of low-income 4th graders score "Below Proficient" reading levels vs. 55% of middle income cohorts.[21]

The Evidence for Reach Out and Read

Since 1991, this model has been researched by academic investigators in a variety of settings, culminating in several independent, peer-reviewed studies showing positive effects on children and families whose primary care practices provided books and literacy anticipatory guidance. As a result of Reach Out and Read, preschool children make gains in vocabulary and comprehension. They also have parents more likely to read aloud to them on a regular basis. As a result of increased parental investment in nurturing early literacy, children gain a 6-month developmental edge over children who do not participate in Reach Out and Read before they start school.

Among Reach Out and Read programs across the US, a number of peer-reviewed studies point to the effectiveness of the program. The Reach Out and Read model has been shown to be effective in:

- Increasing the number of days per week parents read aloud to their children.
- Enriching the home literacy environment by increasing the number of books in the home.
- Improving the language skills of older toddlers at risk for reading difficulties.[22-26]

Going Beyond the Reach Out and Read Model: Using Books as Tools for Developmental Surveillance

Giving a book to a child during a routine health maintenance visit allows healthcare providers a unique opportunity to relate to children and families. When a child picks up a book, opens it, and begins to interact with its content, the healthcare provider can view the child through a different lens. Though not considered a screening tool because of its inherent lack of standardization, books can serve as a unique way to observe children's developmental skills and interactions with caretakers.

During a well-child visit, depending on each child's age and developmental level, a provider who offers a book may be able to:

- Assess eye contact: normal, brief, sustained.
- Assess attention to tasks as well as joint attention and focus.
- Observe a child bringing items for shared enjoyment.
- Consider language development.

Note skills in various domains such as:

- Verbal (babbling, words, phrases, rhyming, spontaneous conversation).
- Nonverbal communication (gestures, pointing).
- Observe receptive language skills (understanding directions, pointing to pictures, etc.).
- Discern pragmatic skills, i.e., the social context of language such as responding to speaker's facial expressions, affect, and gestures (e.g., "head shaking").
- Identify atypical language such as excessive repetition, dysfunctional language or echolalia (immediate and delayed).
- Observe fine motor skills such as holding the book, turning pages, pointing, and tactile abilities.
- Note the presence of positive parent-child interactions such as turn-taking between the adult and child.[27]

Giving a book to a child during the healthcare visit elicits spontaneous language from many children. Gross and fine motor skills can be observed: a 6-month-old sitting alone, reaching for the book, grasping it in his/her whole hand, and transferring it to his/her mouth; a 12-month-old pointing to pictures; an 18-month-old holding the book, turning it right-side up, and walking around holding it; and a 3-year-old turning paper pages without difficulty. The provider and parent enjoy listening to a 2-year-old who is beginning to name animals. Practitioners hear pronoun use or complex sentences as an older child comments on illustrations.

The Reach Out and Read model relies on the trusting relationship formed between the pediatric primary care providers, children, and families. This relationship is facilitated by the gift of a developmentally and culturally appropriate book and literacy anticipatory guidance provided at each well-child checkup. The observations in the examination room of how a child relates to a book and the parent-child interactions are extremely helpful in encouraging families to incorporate books and reading into their everyday lives.

Kids Count and the Annie E. Casey Foundation

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Effective child advocacy requires strong and reliable data, both to inform direction and to effectively make a compelling case for policy makers and for the community at large. One organization that has dedicated itself to collecting high quality data on the status of American children on a national, State and local basis is the Annie E. Casey Foundation. This private charitable trust was created in 1948 by Jim Casey, who built the United Postal Service. He named the Foundation after his mother and it continues to be directed by the Casey family and UPS executives. The primary mission of the Foundation is to foster public policies, human service reforms, and community supports that meet the needs of today's vulnerable children and families. The foundation also makes grants that fund initiative with potential to demonstrate innovative policy, service delivery, and community supports for disadvantaged children and families within the United States.

One major initiative of the Casey Foundation is Kids Count. The Foundation provides funding and technical assistance for a national network of Kids Count projects. There is one in every State, the District of Columbia, the US Virgin Islands, and the Commonwealth of Puerto Rico. Each site is charged with measuring and reporting on the status of children at both the State and local level, so that this data can inform public debate and encourage public action that improves the lives of children. Each State Kids Count site publishes a State data book, special reports, and issues briefs and fact sheets. More information about the Kids Count grantee network, as well as local level data can be found at *www.kidscount.org*.

Each year, often in early autumn, Kids Count publishes the Data Book containing updated State profiles of child well-being. Ten key indicators have been tracked in the Data Book over the past two decades. These indicators demonstrate a decline over time in infant mortality, death rates for children and teens, some decreases in high school dropout rates and teen births, but they also point to increases in proportions of children born with low birth-weights, living in single-parent families, and living in low-income families. Compelling analysis in the 2011 Data Book on effects of the recent recession shows a significant jump in numbers of children living in families with at least one unemployed parent and reveals that millions of children have been affected by housing foreclosures.

Online resources sponsored by Kids Count are even more extensive and accessible. The Kids Count Data Center provides access to hundreds of child well-being indicators in areas of education, employment and income, health, poverty and youth risk factors. Data are not only available for the US as well as for States, but also on a city, county, congressional district and school district level. The Data Center also offers many tools to customize and share indicators, including national and local rankings as well as mapping and graphing tools. The center can be found at *datacenter.kidscount.org*. Mobile browsers can access Kids Count via *Mobile.kidscount.org*.

An example of a successful advocacy effort informed by the Casey Network is Rhode Island Kids Count's involvement with lead poisoning. Thirty-three of 100 children entering kindergarten in the core cities in Rhode Island had a history of elevated blood lead levels in 1998, compared with 4 out of 100 core city children entering kindergarten in 2012. This 88% decrease in the percentage of children entering kindergarten with a history of elevated lead levels in 14 years was monitored closely by Kids Count, and the frequent use of Kids Count data provided momentum to maintain continued change over time. Currently Rhode Island Kids Count is using the goal of reading at grade level by the end of third grade to advance the birth- to third-grade policy agenda in the State. A high level leadership group of public and private sector partners are regularly tracing third-grade reading proficiency as a "proxy indicator" of success. A Kids Count Issue Brief has specific recommendations for birth to 5-years, and for kindergarten through third grade; policy changes that are evidence-based and achievable.

THE HANEN CENTRE

Frances Page Glascoe, PhD, Professor of Pediatrics, Vanderbilt University

Started in Canada in 1975, The Hanen Centre (*www.hanen.org*) focuses on early language intervention, parental guidance, and aiding speech-language pathologists and educators to develop language and literacy skills in preschool children. Based on abundant research, Hanen's guiding principles are that parents' involvement in their child's early intervention is critical and that the earlier parents are involved, the better the outcome for the child. Investigators found that children learn best in their natural environments, where they are motivated to communicate with the important people in their lives. Professionals at the Hanen Centre have now focused on changing the way speech-language therapy is offered to young children.

The Hanen Centre provides research-based parent programs and resources as well as professional development within four areas of expertise: general language and literacy development; language delays; autism spectrum disorder (ASD) including Asperger syndrome.

The Hanen Centre is not only a North American initiative but also an international one. It offers training workshops (in English) to parents and professionals in Canada, the United States, the United Kingdom and Ireland, Australia, New Zealand, Singapore, and The Netherlands.

Research support is both abundant, current and peer-reviewed for the various target groups: children with delays and ASD. The Hanen website (*www.hanen.org*) offers e-seminars to professionals, DVDs, as well as classes for parents.

211 LOS ANGELES (211LA)

Patricia Herrera, MA, Project Director Developmental Screening, 211 LA County

In July of 2000, the Federal Communications Commissions assigned an expedited telephone number enabling citizens of the United States and Canada to access community information and referral services. Thus was born the 211 "warm-line." Developed by the Alliance of Information and Referral Systems in partnership with the United Way Worldwide, 211 addresses a wide range of non-emergent crises including loss of housing, inability to pay utility bills, food insufficiency, and domestic violence. As of January 2011, 211 had served more than 246 million Americans (more than 82% of the entire population) and covered all or part of 47 States plus Washington, DC and Puerto Rico. In Canada, more than 56% of the population has access to 211.

Los Angeles County is home to 10 million people, with 16% living below the Federal poverty level and more than 50% who do not speak English at home. Ten years ago in California, IDEA early intervention enrollment rates were far lower than the national average. These dismal statistics led to the 2003 creation of the Early Identification and Intervention Collaborative for Los Angeles County (EII Collaborative), whose members quickly began to advocate for accurate developmental screening through the 211 helpline. The EII Collaborative is discussed further in Chapter 21, along with the personal narrative of its director who engaged in grass-roots as well as State and Federal legislative advocacy.

As the 211LA Developmental Screening Project began in 2009, bilingual parenting support specialists were hired to receive call transfers from families willing to participate in screening, enter the parents' responses into *PEDS Online* and help parents, especially those whose children scored at-risk, get additional services. In the first two years more than 2800 children received early developmental screening via 211LA and were then connected with needed services.

Families calling 211LA are disproportionately low-income and have limited education. More than 80% are enrolled in California's Medicaid program (MediCal) but use of healthcare services is extremely low. This means that many 211LA children do not otherwise come under professional scrutiny for health and

developmental-behavioral issues.

Not surprisingly, 211LA children are four times more likely to score at high-risk on *PEDS Tools* as compared to national norms: 28% (N = 803) were identified as high-risk and in need of further developmental evaluation; an additional 28% were at moderate-risk (for which additional screening is recommended); while 16% (N = 463) were at risk for mental health problems. Only 28% had limited risk (as compared to 60% in *PEDS* standardization studies). Not all of the 2800 families had time for the additional measures offered by *PEDS Online* (or were within the targeted age-range) but 1605 (57%) agreed to complete the *Modified Checklist for Autism in Toddlers (M-CHAT)*. Of those completing the *M-CHAT*, 21% (N = 341) failed—more than twice the expected rate compared to national norms.

To deal with the extensive follow-up needed to ensure families receive services, a thorough case management component was developed including referral/consent partnership agreements between 211LA, the families served, and referral resources. Capitalizing on the database created by *PEDS Online* screening, every family is tracked to determine whether recommended services were received or other services were needed. Referrals were made to a range of health care, parenting, Head Start and other early childhood programs for the 67% of children failing screens, and 16% were referred to IDEA services. To ensure families connected with services, case-coordinators often had numerous follow-up contacts: 37% of families required three or more contacts. In the first two years of the 211LA Developmental Screening Project, 53% of children were enrolled in services or had services in progress, with 38% scheduled for additional screening, and only 8% lost to follow-up.

The 211LA Developmental Screening Project serves as a national model for 211 services in other States in terms of early detection, care-coordination, and database support. 211LA is also evidence that:

- "It takes a village," i.e., coordination among agencies is crucial.
- Some of our nation's most vulnerable families do not access services such as primary care.
- Novel approaches to early detection are needed.
- Vulnerable families require extensive support to ensure access to and enrollment in needed services.

OTHER INITIATIVES BRIEFLY NOTED OR IN PROGRESS

Text4Baby (T4B)

In recognition that more than 85% of Americans own a cell phone and 72% of cell users send or receive text messages, T4B is an initiative launched by the National Healthy Mothers, Healthy Babies Coalition (*www.text4baby.org*) in partnership with the technology business, Voxiva. T4B is the first free text messaging service in the US in which parents are provided age-paced information about health, safety and developmental promotion. T4B works in collaboration with many professional societies such as the AAP, government agencies (including the White House Office of Science and Technology Policy, the US Departments of Defense, Agriculture, Health and Human Services, and the US Consumer Product Safety Commission), and with charitable foundations established by cell phone carriers. Expansion plans, via advocacy and grant-writing, include adding to T4B a quality age-paced developmental-behavioral screening tool (described in Chapter 21).

Safe Environment For Every Kid (SEEK)

Safe Environment for Every Kid (SEEK) created by Dr. Howard Dubowitz and colleagues at the University of Maryland, provides training and in-clinic, hands-on support for detecting and addressing risk factors for child maltreatment. Training consists of a one-time, small-group session lasting four or eight hours, followed by periodic "booster" sessions. In-office support includes use of the *Parent Screening Questionnaire (PSQ)* to identify risk factors (completed while families are waiting to be seen), customized educational handouts for parents, and "cheat sheets" for health professionals, including a social worker to support health professionals and parents. The project's website provides references on SEEK's effectiveness (*www.umm.edu/pediatrics/seek_project.htm*).

The State Of Delaware

With advocacy and support from Delaware's Lt. Governor Matt Denn, almost every State agency involved with children [e.g., private payers such as United Health Care, Nemours Foundation (the state's largest child health system), the Delaware Chapter of the AAP, the public library system, school nurses, Autism Delaware, the Delaware Speech-Language Association, etc.] banded together, asked for, and received a funded mandate to provide free developmental screening and referral services for all children in the State. Directed by the Delaware Division of Public Health, providers in Delaware have access to *PEDS Online* without cost to clinics. Help Me Grow (HMG) is directing the State's 211 call center to assist professionals in referring children to needed services. The initial goal is to engage healthcare professionals in using *PEDS Online* and 211HMG, to detect problems and facilitate needed referrals. The next step is to make *PEDS Online* available directly to families so they can elect to complete screening on their own (with results sent to their healthcare provider).

American Academy of Pediatrics' State and District Chapters

Many of the AAP chapters have effective and unique hands-on initiatives to assist providers in detecting and addressing developmental-behavioral problems (e.g., Illinois, Delaware, Oklahoma, Arizona, Georgia, Pennsylvania, etc.). The national AAP website has links to all chapter and district websites (*www.aap.org*) .

RESOURCES AND LINKS FOR NORTH AMERICAN MODELS

Below are descriptions of programs discussed in this chapter along with their websites. Links are live at *www.pedstest.com/TheBook/Chapter17*.

Medical Home   *www.medicalhomeinfo.org*
From the American Academy of Pediatrics, the Medical Home website provides webinars, training, continuing medical education opportunities, practice improvement tool kits, etc.

Bright Futures   *http://brightfutures.aap.org*
From the American Academy of Pediatrics, the Bright Futures Initiative website provides practice recommendations and strategies along with pre-visit questionnaires, workflow sheets, registries, and parenting information.

National Association for State Health Policy (NASHP)   *www.nashp.org*
NASHP houses information on the Assuring Better Child Development (ABCD) project. The site includes "how-to's" for practitioners and guidance for State policy advocates.

Help Me Grow (HMG)   *www.HelpMeGrowNational.org*
HMG's national center provides information on establishing programs, use of call centers to coordinate services, etc.

Promoting Resources in Developmental Education (PRIDE)   *www.unitedwaygc.org*
Offers details about PRIDE; additional information can be found on the HMG website.

Head Start/Early Head Start   *www.nhsa.org*
Describes both Head Start programs and provides guidance on finding local services. Outcomes research on both programs can be found at *www.acf.hhs.gov*.

Healthy Steps   *www.healthysteps.org*
Provides technical assistance on training, staffing needs, and administration.

Reach Out and Read (ROR)   *www.reachoutandread.org*
Offers guidance on establishing ROR in pediatric clinics, guidance for parents, and research on program effectiveness.

Kids Count   *www.aecf.org*
From the Annie E. Casey Foundation, Kids Count provides advocacy for families' issues by providing national and State-by-State data on the well-being of children in the United States.

Hanen Centre   *www.hanen.org*
The Hanen Centre provides research and advice for speech-language pathologists, educators and parents on building literacy and language skills.

211LA   *www.211LA.org*
Describes the value of crisis call centers to provide online developmental-behavioral screening and care-coordination for families at high psychosocial risk.

Text4Baby   *www.text4baby.org*
Covers use of a cellphone text-messaging service funded by the Maternal Child Health Bureau to promote development, prevent injuries, and provide screening for developmental-behavioral problems.

Safe Environment for Every Kid (SEEK)   *www.umm.edu/pediatrics/seek_project.htm*
Devoted to reducing child maltreatment, SEEK provides hands-on training, measures focused on parents' well-being, educational handouts for parents, and research updates.

Delaware Division of Public Health (DDPH)   *http://dhss.delaware.gov*
The first State initiative to receive mandated legislative funding, DDPH serves as a model of advocacy supported by diverse professional groups. Delaware provides high quality online screening tools—without cost to providers.

State and District Chapters of the American Academy of Pediatrics   *www.aap.org*
AAP Chapters have a variety of initiatives and proven successes. The site provides links for finding information about each State.

Chapter Comments: *The above is hardly an exhaustive list of initiatives including those of many professional societies [e.g., the Ambulatory Pediatric Association's efforts to establish curricula for medical students and residents; the National Association of Pediatric Nurse Practitioners (NAPNAP)'s focus on childhood literacy and developmental-behavioral pediatric care.] We've neither covered foundations nor government agencies that fund proposals in early detection and intervention (e.g., Robert Wood Johnson, Lucille and David Packard Foundation, Commonwealth Fund, etc.). So just know there is lots out there to help.*

We should also view the screening and surveillance measures we use, as initiatives in their own right. Accurate tools shape our decision-making, clinical acumen, and willingness to find resources. Often the use of quality tests are and should be at the heart of each initiative designed to detect and address children's and families' difficulties.

The diverse projects described in this chapter provide evidence-based examples of how to care for the developmental-behavioral needs of families and children. Professionals designing new initiatives are encouraged to capitalize on existing ones by viewing them carefully, and by contacting those involved to gather details on what worked.

National, State and local initiatives are inextricably engaged, not only in creating and testing models for early detection and intervention, but also with training and implementation. As a consequence, such initiatives also serve as fundamental sources for advocacy on various ways to do the best for children and families.

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Chapter 18: International Models for Prevention, Early Detection, Intervention and Professional Training

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iSkysoft
PDF Editor

INTRODUCTION

Needless to say, the United States of America is not the only nation with an interest in promoting early detection and intervention. In this chapter we describe work conducted in other countries along with several cross-nation initiatives. There is much to be learned from the various ways other countries offer services, the types of programs provided, the training methods deployed, and how outcomes are assessed. The descriptions below are hardly exhaustive but provide a sample of diverse efforts and inventive solutions.

Healthcare service arrangements in other nations differ substantially from those in the US and suggest alternative approaches to helping children and families. For example, in England and Australia physicians care for families and children who are unwell, while nurses (e.g., health visitors or maternal child health workers) see families in their homes, screen children, advise parents about developmental-behavioral issues, and make recommendations to physicians about needed resources. Home-visiting approaches afford nurses an opportunity to view developmental-behavioral issues without the distractions of a concomitant healthcare agenda (such as primary care well-visits in the US). Such an approach is known to improve the accuracy of clinical decision-making. But in many ways, service delivery systems in England and Australia are similar to those US initiatives involving home visiting, although home-visiting programs in the US are not wide-spread because they usually involve targeted populations (e.g., single, low-income parents).[1]

Most international initiatives begin with a thorough review of research, rather than starting with clinical opinion. Empirical evidence is then used to devise policy and implementation approaches. Almost all international initiatives involve an ongoing research agenda including outcomes monitoring. Data is then used to adjust policy. Researchers outside the US seem to have less consternation about industry-academic partnerships, and so avail themselves of test authors' expertise in psychometry (and the often needed changes to test standardization). Nevertheless, in all nations, members of professional societies and researchers increasingly consider the effectiveness of policy recommendations as applied in real life settings.[2] The many US initiatives have much of value to share with international researchers and policy makers and the US has much to learn from the efforts of other countries. Figure 18-1 is a map showing the locations of the international initiatives described.

Figure 18-1. Locations of International Initiatives

1. Bhutan
2. Phillipines
3. Galicia, Spain
4. Iceland
5. Norway
6. South Africa
7. Haiti
8. Thailand
9. Pakistan
10. India
11. Australia
12. World Health Organization (WHO)
13. Fiji

The Republic of the Philippines

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The Philippines is an archipelago of more than 7,000 islands housing the twelfth most populous nation in the world (with approximately 91 million citizens, plus another 10 million living abroad). Claimed by Spain in 1521 by Ferdinand Magellan (who introduced to Europe such Filipino crops as corn, tomatoes, chili peppers, potatoes and pineapples), the Philippines was subsequently occupied by Japan and the United States. As a consequence, numerous languages are spoken including Visayan, Spanish, Arabic and many more, although the official languages are Filipino (also known as Tagalog) and English. Literacy rates are high: Approximately 92% of the population reads well, and life expectancy averages 71 years (*www.indexmundi.com*, accessed October, 2012).

The Philippines achieved independence in 1946 and created a constitution similar to that of the United States: A bicameral congress, an executive branch, and a supreme court. Although subverted by the Marcos regime in the 1980s, The Republic of the Philippines now enjoys many laws supporting the rights of individuals with disabilities and establishing early intervention services including quality child care, parent training, developmental promotion and outcomes monitoring. Below are highlights of important legislation.

Magna Carta for Disabled Persons

In 1992, Republic Act Number 7277 or Magna Carta for Disabled Persons was approved.[3] It granted the rights and privileges of persons with disabilities that included access to employment, education, health and auxiliary services, among others. The law has in its policy the provision of special education in the public schools for the vision- and hearing-impaired, those with intellectual and other disabilities. The law also provided financial assistance to economically marginalized persons with disabilities, vocational, technical or other training programs and non-formal education. The Magna Carta for Disabled Persons was subsequently amended in 2007 and expanded the privileges of persons with disabilities including discounts on various services such as medical, dental, entertainment, transportation and food.[4]

The Early Childhood Development Project

The Early Childhood Development Project was approved in 1998 through funding from the National Government, the World Bank, the Asian Development Bank and the Asian Development Fund. The lead agency was the Department of Social Welfare and Development working in close coordination with the Department of Health, Department of Education and the Council for the Welfare of Children. The main purpose of the Project was to give support to the government's efforts to "improve child survival and increase readiness for productive life."[5] The project eventually paved the way for The Early Childhood Care and Development Act.[6]

The project was designed to implement the government's ten-year National Early Childhood Development Program to strengthen child health, nutrition and early education programs.[6] Improving child survival, nutrition and health service packages involved the integrated management of childhood illnesses, expanded immunization programs, supplemental feeding, micronutrient supplementation, and deworming. To prepare children for entrance to first grade, the Project also provided an improved eight-week early childhood education curriculum.

A Parent Effectiveness Service was then established to improve the skills of daycare and child development workers. Two monitoring tools were developed: (1) the Mother and Child Book used to monitor the services received during pregnancy, postpartum and from birth to 6-years-old; and (2) the Early Childhood Care and Development Checklist which was used to monitor children's progress in terms of health, nutrition and psychosocial development from birth to 6-years-old.

The Asian Development Bank progress report from June 2005 reported an increase in daycare

attendance from 17% in 2001 to 34% in 2003, although attendance remained below the 75% benchmark. Improvements in some aspects of psychosocial skills were found, particularly in gross motor development in the 0 to 4-year age-range.

The Early Childhood Care and Development Act

The Early Childhood Care and Development (ECCD) Act was signed into law in 2000.[6] The ECCD Act requires the State to promote: (a) the rights of the children to survival, development and special protection; (b) parents in their roles as primary caregivers and as the children's first teachers; and (c) a National System for Early Childhood Care and Development. The National System involved the collaboration of sectors and agencies at the national and local government levels, service providers, families, communities, public and private sector, non-governmental organizations, professional associations and academic institutions. It includes children birth to six-years-old and children with special needs.

Among the objectives of the ECCD Act that are pertinent to child development, include enhancement of the physical, social, emotional, cognitive, psychological, spiritual and language development of young children, enhancement of the roles of parents and caregivers as the primary caregivers and educators of their children from birth onward, facilitation of a smooth transition from home care and education to community or school-based setting and to primary school.

The ECCD System framework includes center- and home-based programs. The center-based programs include daycare and preschool services among others. The home-based programs include parent education, playgroups and home visitation.

The gains and challenges of the ECCD Act were described by the ECCD Council.[7] The policy framework and implementation mechanisms as iterated in the law, enable inter-agency coordination. Enforcement remains a challenge due in part to lack of political commitment and financing challenges.

The Newborn Screening Act of 2004

The Newborn Screening Act of 2004 institutionalized the National Newborn Screening System to ensure that every baby born in the Philippines is offered newborn screening. The Act provided for the integration of newborn screening into the public health delivery system and promoted awaremenss among health practitioners and parents of the benefits.[8] Newborn screening in the Philippines is focused on five diseases: congenital hypothyroidism, congenital adrenal hyperplasia, galactosemia, phenylketonuria and glucose-6-phosphate dehydrogenase deficiency.

The Newborn Screening System is composed of six program components: (1) education; (2) screening; (3) early follow up; (4) diagnosis; (5) management; and (6) evaluation. The management component includes counseling, treatment monitoring and long-term follow up. The evaluation component is under construction with plans to periodically assess developmental outcomes for all children who test positive for any of the five diseases.

Philippine Professional Societies

The many professional societies in the Philippines have convergent policy statements. The Philippine Pediatric Society (PPS) recommends developmental surveillance at each well-child visit: Monthly in the first six months of life, at 9-, 12-, 15-, 18-, 24-months, and annually thereafter.[9,10] Developmental surveillance activities are similar to those in the American Academy of Pediatrics policy statement but with additional emphasis on red flags in each developmental domain. The PPS policy statement is also supported by the Philippine Ambulatory Pediatric Association.[11,12]

The Philippine Society for Developmental and Behavioral Pediatrics (PSDBP)

In response to laws, mandates and statements from other professional societies, the PSDBP (*www.devpedphil.org*) embarked on an initiative to increase use of screening tools among primary care providers. In preparation, the PSDBP conducted numerous studies beginning with translations into Filipino and Visayan of *Parents' Evaluation of Developmental Status* and the *Modified Checklist of Autism in Toddlers*, followed by careful vetting with clinicians, clinic staff and families. Next up, the PSDBP studied parent and provider satisfaction, feasibility, compared US incidence to that of the Philippines, and viewed validity by having children assessed by subspecialists whether or not screening results were problematic (see *www.pedstest.com* for abstracts of the various studies). Given favorable findings, the PSDBP negotiated a co-publishing contract to ensure the local availability of screening tools in the languages needed.

Next, the PSDBP initiated a training program for general pediatricians focused on developmental screening and surveillance. Inaugurated at the PSDBP's 4th Biennial Convention in 2007 and entitled, "Developmental Surveillance: Empowering the Frontlines of Child Care," training began in 2008 with general pediatricians from the southern part of the Philippines. In 2009, the program was made available to other general pediatricians in the Metropolitan Manila area.

PSDBP Training Initiative. The training program on developmental screening and surveillance consists of a workshop that includes:

1. A lecture discussing the value of developmental screening and surveillance;

2. Case examples along with practice administering, scoring and interpreting two screening tools;

3. Group discussion on two sample cases;

4. A post-test in which pediatricians independently score and interpret screens. If competency is not demonstrated, additional practice with guidance is provided;

5. A group feedback session (within which participants have stated routinely that developmental surveillance and use of screening tools were practical and useful in their general pediatric practice).

The Medical City, a tertiary hospital in Metropolitan Manila was the first to institutionalize developmental screening and surveillance through its Center for Developmental Pediatrics.[13] The Center offers a full range of services beginning with developmental screening using standardized tools. All families referred for screening are counseled about developmental promotion and subsequently referred for language promotion or basic behavior management classes. Children who pass developmental screening tools are scheduled for follow-up screening in accordance with the well-visit schedule. Children with problematic screening results are referred for further evaluation with developmental pediatricians. A follow-up study on how well pediatricians are using screening tools is in progress.

GALICIA, SPAIN

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Galicia is one of several autonomous self-governing regions within Spain's Iberian Peninsula. Galicia is bordered to the north and west by the Atlantic Ocean and Bay of Biscay, to the south by Portugal, and to the east by other autonomous communities such as Castile and León. Home to about three million people, two languages are commonly spoken, Castilian Spanish and Galician (which shares roots with Portuguese and other Romance Languages). Galicia embraces numerous archipelagos and islands, mountains, rivers, mineral resources, hydroelectric dams and deep-water ports that are an essential part of the economy. But Galicia's terrain also creates challenges in the delivery of health care and education services. Nevertheless, 76% of Galician's have at least a high school education: School is compulsory at ages 6- through 16-years, and optional, but also publicly funded, from birth to 6-years of age. Priority

enrollment in the 0 to 6-year age-range is given to children who are socially disadvantaged or whose parents are employed and in need of daycare. In Galicia, and throughout Spain, there is a constitutionally-guaranteed single-payer health system (ranked in the top 10 by the World Health Organization) in which there are no out-of-pocket expenses except for medications. Only 10% of the population use and pay for private care.

To design and explore an effective universal screening and surveillance procedure for early identification and attention of developmental disorders in young children, the A_Tempo project was created. A_Tempo project directors reviewed voluminous studies on models of care (most particularly projects in Norway and the US). Their working premise was that early detection would improve greatly by gathering and objectifying the concerns of parents, educators and early intervention specialists (usually referred to as tutors). To initiate the project, researchers developed translations of various standardized tools. Next, an early intervention specialist was assigned to every school to explain and implement the screening program with school staff and parents and to observe children's development and behaviour in classrooms across three months (completing 12 hours of observation in every classroom).

A_Tempo includes a three-stage approach in which parents' concerns were gathered with *Parents' Evaluation of Developmental Status* and teachers, blinded to parents' concerns, self-administer a rating form through which they are required to select those children whom they consider developmentally at risk. Follow-up was conducted with the *Ages & Stages Questionnaire* and the sample included children deemed at risk by either parents or teachers, as well as those without risk.[14,15] Next, early intervention specialists (guided by previous data and classroom observations) rated each child in the sample as "high risk," "at-risk" and "no concern." Throughout the four-month process involving 1,089 children ages 6- to 42-months, the opinions of teachers and parents were culled. Finally, overall results were compared to US and Norwegian studies that used a similar early identification paradigm (see Table 18-1).

Table 18-1. A_Tempo Screening Model

A_TEMPO MODEL		
Stage 1	**Stage 2**	**Stage 3**
Families-PEDS → ASQ at school → El tutors ← Teachers-EDS		
Universal screening All children	**Risk Group + Control Groups**	**High Risk -Risk -No concern Groups**
4 months →		
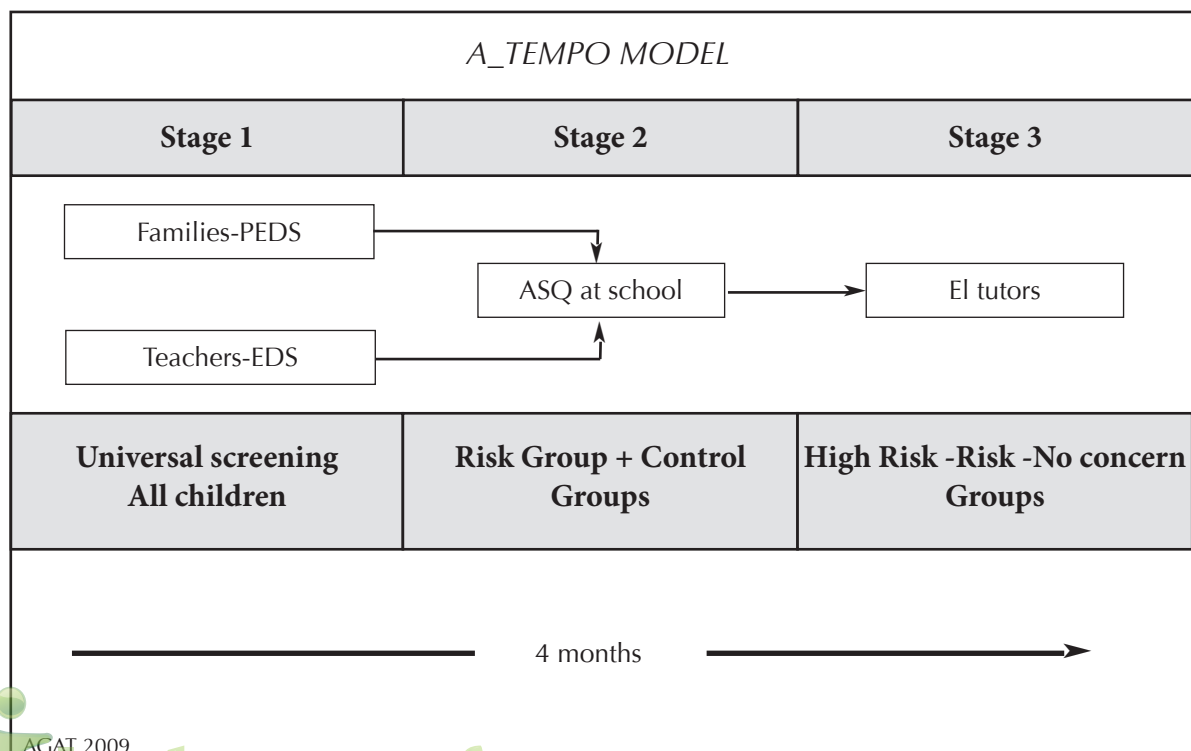
Preliminary and final results of the initial implementation of a three-stage universal screening system in Galician pre-primary schools apparently have been successful.[16,17] Parents, educators, and early intervention specialists welcomed the opportunity to provide their observations and points of view on children's development and to access specialized services or follow-up for children as indicated. Gathering parents' and educators' input easily ruled out children with developmental delays. Children selected as "at risk" by parents and teachers, when formally screened in the second stage using the Spanish translation of the *ASQ*, had significantly lower *ASQ* scores in all developmental domains than the random sample of children categorized as "no concerns." Mean *ASQ* scores in this latter group were similar and followed a very close profile to those of US and Norwegian samples. The *ASQ* results and early interventionists' ratings significantly corrects for over-referrals from parents' and teachers' ratings, refines types of risk, and the course of action needed.

In comparing the performance of Galician children to those in Norway and the United States, Galician children performed less well (lower means and larger standard deviations) on the *ASQ*. Differences are likely attributable to the predominance of socially disadvantaged children in the Galician sample. In addition, there were differences in fine motor and problem-solving skills that may reflect cultural differences in the Galician preschool curricula. As a consequence, additional research is underway to establish unique cut-off scores for Galicia (a process also required in Norway, Taiwan, and Korea).

A_Tempo research provided interesting information about how parents, teachers, and early intervention specialists attend to children's development: Parents focused on communication and fine motor skills; teachers attended more to gross motor and problem-solving tasks; while early intervention specialists focused on communication, personal-social and problem-solving areas. Diachronic analysis (meaning research over time) of correlations across all three raters/tools, points to moderate but meaningful changes in the predictive accuracy of families, educators and tutors. In other words, despite using different measures, results tended to converge over time. This suggests that use of screening tools improved observation skills, and facilitated communication and cooperation among the three groups—supporting the working premise of A_Tempo's paradigm. In addition, the project increased early identification rates via a process that was simple and satisfactory to all stakeholders.

PREVENTIVE CHILD HEALTH SERVICES IN ICELAND

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The Republic of Iceland is an island in the North-Atlantic Ocean with a population of about 315,000 who are primarily of Norse and Gaelic descent. Only 8% of its population is foreign-born. Iceland is one of the most geologically active places on earth (the term "geyser" is Icelandic) and has regular volcanic eruptions, earthquakes, and geothermal hot springs due to its placement on the rift between the rapidly separating Eurasian and North American tectonic plates. Despite its latitude just below the Arctic Circle, the Gulf Stream tempers Iceland's climate creating mild winters and cool summers. About two-thirds of the population live in the Reykjavík capital area in the southwestern part of the country. Education is compulsory for children 6- to 16-years and all have the right to upper secondary education in Icelandic universities. Icelandic is the official language but children are required to learn English and Danish in school. The government is the world's oldest parliamentary democracy, established in the 10th century. The Icelandic naming tradition wherein each child's last name is a combination of the father's first name plus "-dottir" or "-sson" means that last names are rarely used. Births to unwed mothers are not stigmatized and same-sex marriage is legal.

Iceland has a mixed market economy and a Nordic welfare system that provides universal health care and education to its citizens. The Nordic countries rank globally as those with the lowest infant mortality rates (IMR) that partly illustrate their good socio-economic development; the IMR in Iceland is now just less than 3 per 1000 live births. In recent years, Iceland has been one of the wealthiest and most developed nations in the world. In the Human Development Index (HDI) for 2007/08, it ranked highest out of 177 countries. The economic downturn of 2009 - 2011 dropped Iceland's ranking, although it still

remains in the top 93% of nations in terms of life-span, health and wealth.[18]

The Icelandic Healthcare System

The Health Care Service Act of 2007 states that all Icelanders should have the most perfect healthcare service available to them at all times, with the goal of protecting the mental, physical, social health, and general well-being of all Icelandic people. The Act also states that primary healthcare centres, mainly staffed by medical practitioners, nurses and midwives, should provide curative and preventive health services, accessible to all.[19] One of the cornerstones of the preventive work in the health centres is directed to mothers and young children with the aim of early detection and intervention as found appropriate.[20]

Preventive Health Services for Young Children

Preventive child health services in Iceland have, since the 1920s, been an integral part of normal care and up-bringing of preschool children. The first general guidelines for preventive child health services were published by the Directorate of Health in 1984, revised in 1996, and again in 2009.[20] The services are run by the state, free of charge, and clearly appreciated as evidenced by the high participation rate: Services are attended by about 90% - 95% of all children for each planned visit. The main objective of visits is to monitor the growth and general development and well-being of children and to give targeted age-adapted health education.

In line with national guidelines, families of newborns are offered home visitation by a nurse as needed, most often two to four times postpartum.[20] Additional services by nurses and medical practitioners are delivered within a framework of organized visits to the health centre at the ages of 6-weeks and 3-, 5-, 6-, 8-, 10-, 12-, and 18-months and at 2½- and 4-years of age, with further visits in case of need. During visits, health professionals discuss with parents their children's overall appearance and well-being, and offer consultation and advice as necessary. Information about nutrition, sleep, crying, fussiness, comforting, teething, hearing, family bonding, stimulation, accident prevention, other environmental factors like smoking are provided via leaflets or other means of communication and education. Parents are also informed about safe practices concerning swimming, cycling, the use of strollers and car seats. All through the program, information regarding best parenting practices is given to parents.

One of the most important innovations introduced in the 2009 edition of the guidelines aimed to improve and standardize surveillance of child development in all health centres in the country. This includes the introduction of two new screening tools in the services, i.e., the *Parents' Evaluation of Developmental Status (PEDS)* and the *Brigance Screens* for all 2-, 4- and 5- year-old children with *PEDS* used alone at 18-month visits. This change of practice is the result of extensive consultation among health professionals as well as a positive outcome of a pilot-test among 5-year-old children.[21] The tools were translated and slightly adapted to the Icelandic setting (e.g., on the *Brigance Screens*, images of people, stoves, refrigerators and milk cartons all needed to be adapted to ensure familiarity to Icelandic children). And, because there are no snakes in Iceland, we included "worms" as an acceptable response for the vocabulary questions for which a picture of a snake is the stimuli. Measures were pilot-tested in five health centres, before a nationwide introduction in late 2009. The screening tools were also incorporated in the electronic child health record called Saga which is the Icelandic patient journal system used by all governmental health services. The data are electronically retrieved and analysed in collaboration with the Educational Testing Institute in Iceland.

One of the options under scrutiny is the effectiveness of gated screening, i.e., using *PEDS* for all well-visits followed by the *Brigance Screens* in case of parental worries. Implementation in daycare services is under consideration due to high participation rates in Icelandic preschools. In all cases, if screens indicate probable problems, children are referred for further assessment, either to specialists or interdisciplinary teams within the primary healthcare services. The most important of such teams is within the Centre for Child Development and Behavior (CCDB) in Reykjavík capital area.[22] The CCDB provides services to children who deviate from the norm or have significant problems in development

or behavior. An interdisciplinary team provides an individual approach with analysis, consultation, treatment and education for parents until the child reaches the age of 12 years. The CCDB is in an organized and professional collaboration with the educational, social and health services in Iceland. The services are free of charge except for a small fee for courses or workshops for parents. Out of the capital area, there are other smaller inter-disciplinary teams, supported by CCDB or other specialists from Reykjavík.

It is estimated that the prevalence of mental health disorders among children and adolescents who need help is about 12% - 15% and 2% - 5% have severe mental health problems.[23] The prevalence figures are in line with those found in neighbouring countries, (e.g. Finland).[24] Those with severe mental disorders are referred to the Child Psychiatric Clinic (BUGL) within the National Hospital of Iceland. In addition to in-patient services, ambulatory services are available, including a home visiting team. BUGL also supports services within health centres for children with mental disorders.[25] In case of suspected autism spectrum disorder, motor disorders and/or mental retardation, children are referred to the State Diagnostic and Counseling Centre in Iceland. It serves children and adolescents with a disability wherever they live in the country, according to national law (Act nr. 83/2003).[26]

If assessment of children raises concern about speech development or hearing problems children are referred to The National Hearing and Speech Institute of Iceland for further assessment and treatment.[27] Children diagnosed with disabilities have the right to special assistance throughout their youth, pursuant to laws about the affairs of the disabled. They enjoy the services of the Regional Offices for the Needs of Disability or support for the disabled under the auspices of the municipality. Regional Offices also provide counseling and assistance for parents (e.g., in applying to the State Social Security Institute for caregivers' support due to increased expenditure related to children's disabilities).[26]

Conclusions: Icelandic Services for Young Children

Preventive child health services in some high income countries, (e.g. Sweden and the UK) have in recent years been criticized for lack of evidence for the services offered. Rather than disentangle current services, in Iceland we have sought ways to improve our child-focused preventive services with universalism that enjoys high parental compliance and appreciation. The regular visits are an excellent entry point with age-adapted health promotion and support to parents and children. The visits are also one of the means the state has to support children to be successful learners, both in the preschool and compulsory school settings, and later, to become healthy and productive individuals.

FIJI: PRELIMINARY EXPERIENCES IN DEVELOPMENTAL SURVEILLANCE OF NICU GRADUATES

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Based on the prevalence of stunting and extreme poverty, the 2007 *Lancet Child Development Series* indicated that 33.6 million children under the age of 5-years in East Asia and the Pacific are failing to reach their developmental potential.[28] In Pacific Island countries, the challenges faced by children with developmental disabilities and their families are increasingly recognized.[29]

Fiji is a middle-income country and the largest in the South Pacific, with an estimated population of 854,000 people.[30] Fiji consists of 332 islands spread out over 1.3 million square kilometres in the South Pacific, although the population is concentrated on the two largest islands: Viti Levu and Vanua Levu.[30] Approximately 51% of the population live in urban areas, especially in and around Suva, the national capital.[30,31] The population consists of ethnic Fijians (57%) and Indo-Fijians (38%), with a minority of other ethnic groups.[30] The three predominant languages are English (the official national language) along with Fijian and Fiji-Hindi.

Primary school enrolment in Fiji is almost universal and 40% of 18-year-olds are enrolled in secondary school. Although 40% is a low figure, it represents a significant improvement across several decades. There are no gender differences in enrolment rates; adult literacy is 94%, as estimated from recent census data.[30,32]

Over a number of decades there have been significant improvements in child health, although recently progress has slowed due to political instability, economic downturn, and other factors.[32] Estimated mortality rates for infants and children under five-years are 15.2 and 23.2 per 1000 live births respectively, and have halved since the 1960's.[32,33] Due to improved child survival in Fiji, there is increasing focus on causes of childhood morbidity including developmental disabilities and the long-term sequelae of major childhood illness.

The Fiji Newborn Integrative Care Initiative is a collaborative project of the Fiji Ministry of Health and the University of Melbourne. Its aims are to establish strengthened systems of developmental surveillance and early intervention for graduates of Neonatal Intensive Care Unit (NICU). As a first step in this process, we are currently undertaking research to assess the long-term health and developmental outcomes for a cohort of NICU graduates and "control" newborns in Fiji.

Currently, developmental screening using a non-validated milestone checklist occurs as part of routine maternal and child-health checks during infancy. Nevertheless, once the checklist is completed, there is no standardised process of referral to (the very limited) locally-available early intervention services. This system has not been formally assessed and there are anecdotal concerns amongst health workers about its effectiveness.

Epidemiological data that accurately describe the needs of high-risk newborns in Fiji is lacking. In order to address this research gap in a systematic and standardised manner, an important first step for our research project has been the selection, translation and piloting of appropriate developmental screening tools. The following is a brief description of challenges experienced in this work to date.

Tool Selection

For the purposes of our research, we required a general developmental screening tool that was appropriate for a medically "high risk" population that could be used from birth to primary school-age. An initial question in selecting an appropriate tool was whether to use an instrument that had been developed and standardised in a high-income setting or to further develop a novel tool specifically developed for resource-limited settings.

After reviewing available published literature, we considered several tools that had been developed specifically for resource-limited settings.[34-37] Perceived advantages of these tools included the feasibility of instruments which are low-cost, readily available, and easy to administer in settings where resources are few, as well as greater emphasis on prevalent health conditions relevant to child development in resource-limited settings (e.g. undiagnosed sensory impairments, seizures, malnutrition).

Nevertheless, in many cases such tools were still in a development phase or were incompletely standardised and validated. In other cases, tools that had been validated and normed were specific to a particular context and could not be easily adapted to another 'resource-limited' but otherwise completely different setting.[34-37] Since any tool used would clearly need to be adapted to the local context, we decided to consider tools which are psychometrically robust, even if they had previously been normed and standardised in 'high-income' settings.

We then reviewed measures with adequate psychometric properties, as detailed in the American Academy of Pediatrics algorithm for developmental surveillance, and attended particularly to those used internationally as well as in follow-up of NICU populations. In discussion with local paediatric staff, several potentially relevant screening tools were selected for informal piloting with patients on the general paediatric wards.

Piloting

A small team of junior medical and nursing staff were then trained in the use of the *Ages and Stages Questionnaire, Brigance Screens, Parents' Evaluation of Developmental Status (PEDS)* and *PEDS Developmental Milestones (PEDS:DM)*. It was clear during this informal piloting that several aspects of the health systems context were especially important in tool selection. In particular, we wanted a measure that could be easily implemented by nurses and junior medical staff in a busy paediatric outpatient department. Key pragmatic considerations also included limited time requirements for training, administration and scoring, low cost and need for minimal, easily replaceable materials.

Of the tools piloted, *PEDS* and the *PEDS:DM* were selected for further use and exploration within our research project. Local health staff who piloted developmental screening tools perceived as advantageous the simple structure of these tools, their ease and speed of administration. Other tools were excluded primarily due to the need for multiple questionnaires, need for expensive photocopying, and a perceived emphasis on formal pre-academic skills that were less applicable in the local context.

Translation

Although English is the official language in Fiji, Fijian and Fiji-Hindi are widely spoken and the preferred languages of many families.[38] Therefore, we decided to translate *PEDS* and the *PEDS:DM* into each of these languages. This was a challenging task given limited resources, lack of linguistics background, together with awareness of the many different dialects of Fijian and Fiji-Hindi. Pragmatic guidelines produced by the *PEDS Tools* publishers in multiple prior translations of the tools provided a useful guide for this process.[39]

Translations were undertaken by several experienced paediatric nurses as well as a research nurse with extensive prior experience interviewing families. Discrepancies and variations between translators were settled by discussion and mutual agreement, and from this, a working translation was developed, which is now being further assessed. A similar process is being undertaken to develop a Fiji-Hindi translation. Nevertheless, there were initial problems with this translation due to an inappropriately high language and reading level. This alerted us to the need to find personnel with practical experience with families, i.e., someone who could translate accurately and appropriately for the target parent audience.

Other specific issues arising from the translation of *PEDS* included questions about the cultural responses to the use of the word "concerns" when asking parents about their children's development. Cappiello et al highlighted the importance of empowering disadvantaged parents in low-income settings to express concerns about their children's development.[40] Although a working Fijian translation of *PEDS* has been developed, we await the results of our ongoing research to compare the effectiveness of general questions regarding parental concerns with more specific milestones-based questions.*

Other items in both *PEDS* and the *PEDS:DM* were identified as potentially needing adaptation, and we are exploring this further through our current research project. Examples include items focused on pre-academic skills, use of store-bought toys, dressing, particular linguistic concepts or types of play. Some of these translation challenges have been managed by substituting similar tasks (e.g. replacing the requirement to draw with a 'crayon' for drawing with a 'pen' or 'stick' or mentioning 'blocks' as well as 'small objects'). Others items require further cultural and linguistic exploration (e.g., concepts of independent play in a traditional culture, appropriate linguistic substitutes for use of plurals and pronouns). The *PEDS Tools* research team advised us along the way. For example when a bright 4-year-old stated, when we asked him to point to something purple, "That's the color of sea-urchin blood." He was correct, in a way, but we had to debate whether his was the term Fijians use to identify purple. It wasn't! So this child's answer demonstrated good receptive understanding of color words, but not the higher-level expressive skill of naming colors (at least not in conventional terms). So, we will continue to compare performance of *PEDS/PEDS:DM* tasks with comprehensive developmental assessments as a baseline for further adaptation of culturally-divergent items.

Testing Procedures

Many cultural and procedural issues which are likely to impact assessment of children's development are emerging during the piloting process. For example, many children travel long distances by boat and bus to reach hospital-based clinics, and are hungry and exhausted by the time they arrive. Children are often apprehensive about the hospital, strange toys and 'games,' and foreign doctors whose speech and appearance are different. These issues may well impact adversely the children's performance. In this context, community screening undertaken by local nurses known to the family and who travel to the children's homes or villages clearly has many potential advantages, although the human resource costs of sustaining outreach programs are a major challenge.

Validation, Standardisation and Adaptation

A key part of establishing our research involved consideration of what processes and tools for developmental screening and surveillance will be reliable, feasible and culturally appropriate in the local setting. Our work to date has focused on selection and translation of developmental screening tools. We are now in the process of validating these screening tools against comprehensive developmental assessments in our study population.

We realise that establishment of a system of developmental surveillance for high-risk newborns in Fiji will require further adaptation and local standardisation of established tools and procedures. We hope our preliminary research will serve as a platform for such work. Nevertheless, given resource limitations, there is a strong need for international collaboration and support to apply lessons learned to other vulnerable subgroups of children in our region and internationally.

(See Chapter 19 for translation guidance)

PREVENTION AND EARLY IDENTIFICATION IN NORWAY

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Norway is a Scandinavian country with about 5 million inhabitants. Due to enormous oil and gas resources Norway has become one of the richest nations in the world. Health is given high priority in the national budget each year. According to Organisation for Economic Co-operation and Development, Norway is second in the world when it comes to per capita spending on health. Norway is repeatedly ranked among the top 10 of 164 countries on the Save the Children Annual Mothers' Index (*www.savethechildren.org*). The top 10 countries attain very high scores for maternal and child health, education and economic status.

Prevalence of Mental Health Problems and Disorders Among Children

Studies using both checklists and diagnostic interviews found noticeably lower prevalence of symptoms and disorders among preschool and school-age children in Norway and other Scandinavian countries, than in many other western countries, including the US. Two recent studies conducted in Norway suggest that the prevalence of disorders among pre-schoolers and young school-age children is 7% (excluding encopresis).[41,42] There are no prevalence rates available on psychiatric disorders among adolescents in Norway as yet. By combining results from several large scale studies in Norway, it is estimated that 15% to 20% of children and adolescents between 0 to 18-years have reduced functioning due to mental health problems.[43] The lower prevalence of disorders among preschool and school-age children in Norway is not fully understood. However, there are obvious reasons to believe that low prevalence is related to socioeconomic factors such as the minmal poverty rates, a comparatively generous government-financed social security scheme, low rate of unemployment, one year paid maternity/paternity leave, and the existence of high quality center-based daycare for all children above the one-year of age. Although the average Norwegian enjoys good health, there are increasing social inequalities. Two Norwegian studies found emotional and behavioral disorders were more common among children whose parents did not live together or who had low socioeconomic status.

The Norwegian Health Care System

The Ministry of Health and Care Services (HOD) has the overall responsibility for government policy on healthcare services. HOD is responsible for providing equitable quality healthcare services. The ministry directs these services by means of comprehensive legislation and annual budgetary allocations through various governmental institutions. The Norwegian Directorate of Health sets national guidelines in accordance with areas of high priority. These professional guidelines communicate what is considered to be good practice with advice based on current scientific knowledge. The guidelines are not legally binding to healthcare providers, but play a substantial role in shaping their decisions.

The public health system in Norway provides free antenatal care for pregnant women and free medical and dental services for children 0 to 18-years of age. Primary medical care for children and families is mainly provided by general practitioners (GPs). Pediatricians provide specialist medical care for children through referrals from GPs. Local government health authorities provide the municipalities with child health clinics and school health services. These are important low-threshold programs available for all children and youth, and are free of charge and mandated by law.

National Strategies

From 1999 to 2008 HOD had a national strategy focused on mental health.[44] The overall aim was to improve services in municipalities and hospitals for all individuals with mental illness. According to an evaluation report from the Norwegian Research Council,[43] the majority of main goals were reached, although areas for improvement were identified: (a) the need to expand and further develop low-threshold services in municipalities by increasing the availability of psychological help, including having more psychologists at health centers and GP offices; and (b) the need for better coordination centered on patients' concerns, including better follow-up for patients who require long-term services via the establishment of Assertive Community Treatment Teams. A new health services reform was presented in the ongoing evaluation report from the Minister of Health and Social Affairs.

The current national strategy focuses on prevention and early intervention. The national healthcare plan is built on a vision that states, "Healthcare services should be located as close as possible to where people actually live." Municipalities will be given greater responsibility for citizens' health, and will play a new and more central role through the new Public Health Act. One of the aims is to strengthen local health promotion so that municipalities will be better able to carry out health monitoring, cross-sectoral cooperation, prevention and early intervention. Today many different organizational models are being tried out to co-locate family-related health services under the same roof. With one main entrance families with children can more easily get access to services such as the children's health center, child physiotherapists, psychologists, child welfare and open daycare. Some municipalities have also included the Norwegian Labour and Welfare Service under the same roof. The hope is that co-localization will lead to more coordinated services for the benefit of clients.

Child Health Clinics and the School Health Service

Although child health clinics and the school health service are important low-threshold schemes, the expanded mandate on health prevention and intervention raises concerns about whether there are adequate personnel who are sufficiently trained. The child health clinics are used by almost 100% of parents with infants and toddlers. The average number of consultations is eight during the first year of the child's life. Each visit lasts 20 - 30 minutes. Regular checkups are offered when children are 1½-, 2- and 4-years of age. Clinicians are mostly public health nurses and GPs. The GPs examine children at 6-weeks, 6- and 12-months. In most clinics, physiotherapists are available for consultation if needed. There are still very few psychologists located at children's health centers or in municipalities. Despite frequent health checkups, experience from research and clinical practice shows that too few at-risk children are identified early. The majority of children with symptoms of developmental problems and mental health disorders are first identified at school-age when problems have become more complex and serious.

The School Health Service is mainly staffed by public health nurses. Some have supplementary training in child and adolescent mental health. In addition to vaccination and contraceptive counseling for youth, an increasing number of nurses offer support groups for children with divorced parents, and individual counseling for those with mild to moderate mental health problems. Further, nurses help with referrals to child and adolescent outpatient clinics (CAOC) in severe cases or to drug treatment clinics. Some communities have tested a model where psychologists from the CAOC have office hours at the school health service once or twice per week. The result of this alternative organization was that the psychologists received a large increase in the referrals of young patients. It was also found that the severity of the problems identified in school sessions were similar to those of the young patients treated in treatment in outpatient clinics.[45]

The Municipal Health Services Act §1-4 states that the municipal health service should maintain an overview of community health status and the factors that influence it. Staff at children's health centers in Norway currently work in accordance with the National Guidelines for Antenatal Care[46] and the Guidelines for Children's Health Centers.[47] There is clear guidance about the themes requiring attention, but advisors have said little about which methods should be used in surveying and evaluating children's development, health and well-being. This causes the content and frequency of consultations to vary greatly from health center to health center and from provider to provider. Without national guidelines it is difficult to fulfill this new act. It is also challenging to make high quality comparisons among municipalities.

The Norwegian Knowledge Centre for the Health Services published a report compiled by a multi-disciplinary clinical team focused on developmental, behavioral and emotional screening tools for children birth to six-years of age. Regional differences and seemingly random selection among tools were noted, as were insufficient evidence for: (a) determining optimal choices across measures; (b) use of screening tools to prevent or reduce the progression of mental health or developmental disorders; and (c) service availability if use of screens increases detection rates. Although a governmental appointed committee recommends use of evidence-based screens for detecting social, emotional and behavioral problems in children attending kindergarten or preschool, Norwegian health authorities remain reluctant to recommend use of any particular screening tool in child health clinics or school health services.[48] Debates are ongoing.

Four Regional Centres for Child and Adolescent Mental Health (RBUPs) and the Department of Infant Mental Health

In the late 1980s and 1990s, the Ministry of Health and Health Care Services established four regional centers (RBUPs) focused on research and postgraduate training in child and adolescent mental healthcare. The initiative was propelled by several white papers illustrating the need to strengthen services and ensure professional competence. Subsequent research lead to the establishment, in 2006, of the Department of Infant Mental Health via a national mandate from the Directorate of Health in collaboration with the Ministry of Children, Equality and Social Inclusion. One of the main objectives of the Department of Infant Mental Health is to develop and validate scientific findings with relevance to mental health practitioners. The research aims of the RBUP are:

1. Contribute to the development of scientific, practice-relevant, multi-professional and evidence-based knowledge related to child and adolescent mental health;

2. Emphasize development of knowledge and competence that promotes prevention, treatment and consumer participation in the work with child and adolescent mental health;

3. Cooperate with other institutions about the tasks;

4. Disseminate knowledge and conduct educational activities.

The clinical aims of the Department of Infant Mental Health are to conduct research and education promoting the mental health of infants and preschoolers. The focus is translating research into practice, including validation of clinical measures, treatment methods, and training professionals. Training in

use of screening and assessment tools involves community preparation to make sure there are sufficient hospital and outpatient services staffed with professionals prepared to prioritize children and families with special needs. By the end of 2011 we collaborated with one-third of all municipalities in Norway and arranged frequent follow-up seminars to learn from and help further providers in practice.

The Department of Infant Mental Health selected five screening tools for use in the child health clinic beginning with the *Ages & Stages Questionnaires (ASQ)* and *The Ages & Stages Questionnaires: Socio-Emotional (ASQ:SE)*. The *ASQ* is translated into Norwegian and Norwegian norms were established in 2003.[49] To identify vulnerable parents we recommended the *Edinburgh Postnatal Depression Scale (EPDS), TWEAK (Tolerance, Worried, Eye opener, Amnesia, Cut down of alcohol use)* and the *PSS (Parental Stress Scale)*. The majority of the municipalities decided to take one step at a time by starting with the *Edinburgh*. Public health nurses are trained in the use of the *EPDS* and taught counseling skills based on empathic listening. As a rule, mothers with moderate symptoms of depression are offered a maximum of four counseling visits. Mothers with more severe or long-lasting symptoms are referred to the specialist level or a psychologist if available in the municipality. Via local training groups, public health nurses are regularly supervised by a psychologist during the first year after training.

Testing of a Three-Step Screening and Assessment Model in the Child Health Clinics in Five Municipalities

The aim of the project is to improve early (and accurate) identification rates and treatment enrollment of infants and families at risk by implementing screening tools in the well-baby clinics that focus on infants' development and well-being, as well as parents' well-being. To be useful, first-level screening assesses the total population with a goal of identifying the relatively few infants and families who require more extensive evaluation, and completing all screens within 10 – 14 days of the initial visit. The second step is a collaborative meeting at the healthcare clinic that includes other relevant staff (e.g., child psychologists, medical doctors, physiotherapists) depending on the problem. If the conclusion is that the infant or parents need more specialized evaluation or treatment, the third step is to invite specialist professionals to discuss and prepare a detailed report and specific referrals.

Study Methods. About 1500 infants and families from five municipalities will participate. The infants will be followed from birth to 2-years of age. To strengthen parents' empowerment, all the selected screening tools are designed to be completed by primary caregivers. All infants will be systematically screened over time by the use of the *ASQ* and the *ASQ:SE*. Parents will be asked to fill in the *EPDS*, the *TWEAK*, and the *PSS* at several occasions, and the information gathered from these screening tools will be included in a dialogue with the parents. Data collection commenced in Spring 2011. Home visitors' and parents' satisfaction with the screening tools will be part of the evaluation of this project. This study will also validate *ASQ* and *ASQ:SE* using the *Bayley Scales of Infant development (Bayley-III)* and the *Infant-Toddler Social Emotional Assessment (ITSEA)*.

Future Directions

All nations must strive to improve developmental-behavioral care for children and families. Norway, despite its wealth and careful service delivery systems, is no exception. We view our initiatives as "works in progress" because ongoing efforts to improve health and well-being are needed and invaluable.

EARLY CHILD DEVELOPMENT AND DETECTION IN SOUTH AFRICA

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Worldwide, approximately a third of 200 million children less than 5-years of age fail to develop up to

their potential because of multiple risk factors (including poverty, malnutrition/stunting, poor health and psychosocial deprivation). Sixty-one percent of these children are resident in sub-Saharan Africa.[28,50] South Africa is a country with huge disparity between its richest and poorest citizens as reflected in household and child statistics and in the Gini coefficient which estimates income distribution.[51,52] For South Africa this is estimated at between 0.66 and 0.68, placing it among the most unequal countries in the world.[52] The apartheid system (wherein health, education, and social welfare systems and their bureaucracies were racially segregated at all levels) has left a legacy of inequality which remains a daily reality for many living in South Africa, even 20 years after the first democratic elections. Writing an overview of early child development (ECD) in a country where there is such extreme variation between the services accessible to different sectors of the population, remains a task which is unlikely to adequately achieve a representative picture. This summary attempts to describe the situation in the broadest strokes.

As a result of South Africa's complex social and political history, the most economically disadvantaged communities often have access to only the poorest quality services, both in healthcare provision and in ECD programs. Predictably, this has deleterious effects on the general health, nutritional status, and the developmental trajectories of the majority of children. In South Africa, 64% of children live in families with a per capita income of less than $3 a day and are likely to experience food insecurity. In 2005, 4.5% to 18% of children aged 1- to 9-years were stunted, underweight or wasted.[53] Children suffering from chronic malnutrition fail to reach their developmental and growth potential.

South African children attending the best schools receive an excellent education, but considering the country as a whole, basic education achievement is extremely poor. Literacy and numeracy testing of grade 3 learners revealed pass rates of 36% and 35%, respectively.[54,55] These figures indicate three things: Many South African children are inadequately prepared for school; many schools are not providing quality teaching and learning environments; and existing strategies for support of learners experiencing difficulties do not effectively address the problems in the Reception Year and the Foundation Phase (the first four years of formal schooling).

Beyond the disadvantage of poor nutritional status and socioeconomic background, South African children also feel the impact of the HIV/AIDS epidemic. South Africa has the largest absolute number of children living with HIV. In 2009, there were 280,000 children with HIV under 15-years of age, and 59,000 newly infected children with HIV. In a 2008 national household survey conducted by the Human Sciences Research Council, the prevalence of HIV in children aged 2- to 14-years was 2.5%—although this was slightly lower than the 3.5% found in 2005 (*http://childrencount.ci.org.za*).

Nevertheless, children may be affected by the epidemic in a number of ways other than that of direct infection, though often more than one of these categories applies: Children may be infected themselves; they may be living in households within which carers and/or other members have HIV or are already ill with AIDS-related diseases; they may have lost caregivers to AIDS (and as a result may have been fostered by relatives or others, been placed in residential care or may be living in child-headed households). Many children infected with HIV-1 are born into poor socioeconomic circumstances and suffer multiple health risks that lead to greater impact on neurobehavioural function.[56]

The South African Policy Framework

In South Africa the term Early Child Development (ECD) is defined as the period comprising a child's development from birth to 9-years. Services are broken down into 3 phases/strata:

1. Birth to 5-years (Health and Social Services lead with the ECD curriculum designed by Education);
2. Reception Year (grade R): 5- to 6-years (Education is the lead Department);
3. Compulsory Grade 1: 6- to 7- years (Education is the lead Department).

The following discussion will concentrate on the first phase, as this is the area for which there is, at present, less formal provision and where insults to health and development can also potentially have long lasting impacts.[28,57] Nevertheless, the full benefits of ECD are only likely to be realised if children

also experience high quality education throughout the school years.[58]

It is widely recognised that access to quality ECD services form the backbone of subsequent performance in the formal schooling system, with knock-on effects on success in social and economic spheres in adult life.[59] The elements of "quality" in this context are well-established and determine the likely extent of the benefit resulting from ECD programmes.[60] Establishing a strategy for supporting Early Child Development across South Africa has been recognised as a policy priority.[61,62]

The Children's Act is a critical piece of legislation that seeks to promote children's welfare and development in South Africa. Nevertheless, the clearest acknowledgement of the importance of ECD in practical policy came in the form of the National Integrated Plan for Early Childhood Development (NIP) in 2005.[62] The NIP recognizes key threats to early health and psychological development, and outlines a range of commitments to improving services to children under five-years of age.[63] The NIP specifically targets the poorest and most vulnerable children for intervention, recognizing that it is this sector of the child population that requires the most support. The NIP emphasizes a holistic approach to improving child well-being, strengthening human capital outcomes, and reducing threats to healthy development. At the provincial level the Western Cape Integrated Provincial ECD Strategy has been updated for the period 2011-2016, and includes as three of its 24-key indicators for outcome measures of its strategy: Universal developmental screening under 1-year; increased access to screening and referral services; and access for learners with special educational needs.[64]

To date, strong policies have not yet resulted in improved learner performance as measured by numeracy and literacy in the schooling system. There remains a significant lag in effective implementation of these ECD policies. It is evident that in some places, services are being measured (and found wanting) against high policy standards, well before the strategies to improve the services have had an opportunity to provide requisite support.[64,65] In addition, specific strategies to identify children with disabilities remain vague.[66]

Detection of Developmental Disabilities

Accurate figures in South Africa on the proportion of children with disabilities are not available at present. The estimated prevalence of moderate to severe disability (including physical and intellectual disabilities) in South African children is between 3.3% and 8.4%.[67]

There is a lack of structured and consistent screening policy for developmental disabilities amongst infants and preschool children in South Africa. Families who can afford privately funded healthcare have access to paediatricians, and many practices have screening programmes. Even within these relatively well-resourced communities, programmes are not standardised and no consistent strategy exists for referral lines or interventions when problems are identified. Additional concerns in our context include the ethics of identifying developmental problems without the capacity to intervene appropriately. With the exception of families in the larger urban centres in the country, many children are not accessing even basic ECD facilities, and facilities for additional support are rarely available.[55]

A comprehensive hand-held health record was rolled out in South Africa early in 2011. Every child born in a public or private facility receives one of these documents at birth. Included in this record is a brief screening tool aimed at infants attending their scheduled immunisation visits. No clear strategy for referral has been developed to accompany this screening tool, and its impact on the identification of developmental disabilities is yet to be seen.

Therefore, for the vast majority of the population, recognition of a child with a disability relies on the parents or caregivers identifying a problem and presenting to medical facilities. In a country where levels of parental education are low, access to even the most basic health services is poor, and the burden of acute diseases high. This situation leaves many children with special needs unrecognised and hence without appropriate intervention.

In a national audit of ECD facilities in 2000, it was recorded that 11,585 (1% of children) enrolled at

ECD facilities had disabilities. Of these (where detailed information was available), 31% were 7-years or older. According to the national education policy, children of this age should be in the formal schooling sector or specialised educational facilities.[62] This figure reflects a failure in service integration and inter-departmental collaboration on provision of integrated ECD services. Viewed another way, the reported proportion of disabled children attending these centres suggests that most children with disabilities, whether mild or severe, are not accessing ECD.

Screening for sensory disabilities such as congenital hearing and visual impairment is inconsistently carried out even across high-risk groups. Sound evidence is available for the value of early identification and intervention for these specific disabilities.[68-70] Furthermore, specialized assessment for more complex developmental disabilities such as autism is a protracted process, and the lack of formal screening programmes inevitably results in long delays in achieving a diagnosis and hence appropriate interventions.

Future Directions

Developing a sustainable model for broad screening and surveillance should be considered a critical aspect of developing a sustainable and far-reaching ECD strategy. Initiatives which have emerged in the last ten years have included a combination of Non-Governmental Organizations (NGO)-driven and government subsidised community and centre-based programmes. For example, the Department of Social Development created a training package of 11 sessions focused on capacity-building and on helping parents/primary caregivers support young child development. A number of trainers located in NGOs and ECD representative structures were trained with the intention that they would in turn cascade this program and use it flexibly for their different constituencies as weekly sessions or as a block of training.

Exciting new initiatives that show promise include targeted programmes aimed at particularly vulnerable groups of children with ongoing medical needs (such as HIV-positive children). Harnessing a model of linking developmental follow-up and stimulation to medical care visits integrated with nutritional and social support seems to be achieving anecdotal success in some communities. As a global strategy, targeting families and/or communities solely on the basis of psychosocial or biomedical risk is not justified from a scientific or ethical standpoint. A universal or whole-population programme must be the core of any reliable and effective early intervention strategy. The targeting of risk is most effective when it is done from a strong base of universal services that are not only accessible but actually accessed by all children and families. Models such as the one described above can provide a exampe for multi-sector collaboration which must be the future strategy.

In a country such as South Africa, where significant proportions of young children are challenged by impoverished environments, risks to health, under-nutrition, compromised care and stimulation, programmes should attend to children's physical, social and emotional needs, as well as providing developmental support. Successful management of children's physical health and developmental trajectories will continue to require firm political and financial commitment across many sectors.

TRAINING PROGRAMS ON PSYCHOSOCIAL NEEDS OF CHILDREN IN DISASTERS: HAITI, THAILAND, PAKISTAN AND INDIA

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Both natural and man-made disasters increased significantly in the past twenty years. In every disaster more than half of displaced persons are women and children. On any given day, there are approximately 8 million children who are displaced because of disasters, and many displacements last for years. Children suffer both physically and emotionally. They are at risk for poor short-term and long-term health outcomes because of their limited judgment, inability to advocate for themselves, lack of physical

strength, and limited biologic reserves. Children are also likely to suffer from the stress and trauma generated by disasters; the effects may be long-lasting and irreversible. Although many studies have documented the acute and long-term psychosocial consequences of disasters for children, there remains a great need for training relief workers to recognize and address the special needs of children.[71,72]

Beginning in 1996 a group of faculty volunteers at Case Western Reserve University developed problem-based training courses on the special needs of children in disasters. Five-day annual courses in Cleveland have addressed a range of problems, including infectious diseases, nutrition, child trafficking, school issues, unaccompanied minors, and psychological problems.[73] These courses have been presented in fifteen countries. Several of the overseas workshops focused on psychosocial issues only. More than 3,000 professionals have been trained to date.

Workshops on Psychosocial Needs of Children in Disasters

The topics addressed in any given workshop vary somewhat depending on the location, culture, and available time. The workshops include short lectures and case histories based on real events discussed in small groups, using a problem-based format. Three or four topics and case histories are discussed each day. Child developmental differences and changes are emphasized in the training. Decision-making about interventions depend significantly on a child's developmental state.

Thailand After the 2005 Tsunami

In collaboration with Thai pediatricians and psychologists, we organized a two-day workshop on psychosocial needs of children after the tsunami. Participants were Thai teachers who taught school in the devastated areas, psychologists and psychiatrists. Training focused primarily on school-age children and also addressed stress issues of teachers. Thai colleagues who had already trained with us several years prior to the tsunami joined the teaching faculty and led efforts to facilitate long-term psychosocial recovery for children in Thailand's affected areas.

Pakistan After the 2006 Earthquake

In collaboration with Pakistani pediatricians, child psychiatrists and child psychologists, we organized two 5-day workshops and two psychosocial workshops in Peshawar and Islamabad in 2006. The topics for these workshops included review of developmental changes in children from birth to adolescence, long-term psychological effects of disasters on children, diagnostic signs and symptoms of emotional trauma in children, the Return to Happiness program for children post-disaster, child abuse during disasters, and planning and implementing specific programs for children in Pakistan. Discussion of case histories used problem-based learning strategies with emphasis on the need to consider developmental differences in evaluating and helping children after a disaster. Evaluations were excellent and we have maintained connections with the Pakistani faculty over the past seven years.

Mumbai, India After the November 2008 Attack: A Five-Day Psychosocial Workshop

After the Mumbai attack, Indian mental health professionals, including developmental-behavioral pediatricians, general pediatricians, child psychologists and psychiatrists, noticed that children under their care prior to the attack were traumatized by accounts of the event. Aware of articles written on pre-event personality and temperament of children as predictors of their reaction to disasters, professionals saw the need for special training on the psychosocial recovery of children after a disaster.[74,75] In collaboration with an Indian developmental-behavioral pediatrician and her colleagues, we organized a five-day workshop in Mumbai. The topics included personal preparedness for working in a disaster, rapid epidemiological assessment, special needs of children in various stages of development, psychosocial triage, death and bereavement, school issues, stress relief for caretakers and mental health workers, media issues, legal and ethical issues, gender-based violence, unaccompanied children with developmental disabilities, and child protection. The workshop received excellent evaluations, and participants used information to develop interventions in their workplaces.

Haiti After the 2011 Earthquake

The Haitian Pediatric Society requested that we offer a psychosocial workshop in Port-au-Prince to educate child professionals on how to alleviate suffering and foster resilience in children who experienced the earthquake. We implemented a five-day workshop in March 2011. Faculty included Haitian child health professionals who had previously completed our workshop in Cleveland. This was the first multidisciplinary training program in Haiti that focused on post-disaster psychosocial issues. The lectures and case histories related to the needs and resources of Haiti's children. Participants were provided information on *PEDS*, a developmental-behavioral screening tool, translated by the publisher in accordance with International Test Commission guidelines, and shared without costs for this project. Child health professionals were encouraged to share and learn from one another's experiences in the aftermath of the earthquake. The problem-based methodology was enthusiastically adopted by Haitian faculty.

Summary of Psychosocial Needs of Children in Disasters

There is a continuing need for emphasis on the psychological issues, both acute and long-term for children who experience either natural or manmade disasters. Improved logistics can rapidly address issues of shelter, food, safe water, and medications in most parts of the world. Neverthelss, the psychosocial needs of children, including those with disabilities or chronic diseases, require much more attention. Our experience indicates that problem-based learning workshops are an effective means of training, which can be adapted to a wide range of culturally diverse areas in the world.

DEVELOPMENTAL-BEHAVIORAL HEALTHCARE SERVICES IN BHUTAN

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Bhutan, the Land of the Thunder Dragon (Druk Yul), is a Buddhist country nestled in the Eastern Himalayas. It shares borders with India and Tibet. Bhutan is a small country geographically, of little more than 38,000 square kilometers, but widely varied in its landscape and climate zones. Altitude ranges from 590 feet in the southern region to greater than 24,000 feet above sea level in the North and Northwest border.

According to 2009 census statistics, the population is greater than 691,000. It is estimated that 32% live below the poverty line and 53% of the population is literate. Literacy rates are improving as attendance in government and private schools expands. English and Dzongkha, the national language of Bhutan, are taught as compulsory languages.

Bhutan is governed through a constitutional monarchy with elected Ministers and representatives. His Majesty, Jigme Khesar Namgyel Wangchuk, continues to be highly revered and has much decision-making authority in governmental and societal affairs. The third main authoritative body is the Dratshang Lhentshog, the Commission for the Monastic Affairs of Bhutan. The highest official for this organization is the Je Khenpo or Chief Abbot of Bhutan.

The capital of Bhutan is Thimphu that houses the densest population in the country, approximately 100,000. This is also the location of the National Parliament, the Royal Palace of His Majesty the King, all government ministries including the Ministries of Education, Health, and the Royal Institute of Health Sciences that is responsible for medical and nursing education and training. Thimphu is also the location of the Jigme Dorje Wangchuck (JDW) National Referral Hospital, named after the fourth king of Bhutan and funded with the support of India.

Bhutan's Buddhism is a blend of Tibetan Buddhist (the Kagyu or Whispered Transmission school) and ancient local spiritual beliefs. There is a small population of Hindus and Christians. Because of Bhutan's unique geography, religions are dispersed regionally as are languages, beliefs and culture. There is a deeply spiritual blend of the secular and religious in daily life. From the presence of over 2,000

monasteries, to chortens and prayer wheels at almost every street corner, Buddhist beliefs dominate. Even the national flag symbolizes the sharing of the religious and secular authority.

One needs to appreciate and take this duality of beliefs into account to understand its influence on healthcare for the Bhutanese. The current healthcare system is based upon a centralized referral hospital system in different geographic regions of the country. There are smaller regional hospitals, treatment centers, and Basic Health Units, which provide primary- and secondary- level care. The notion of a modern healthcare system did not emerge until 1961.

The current health system provides primary healthcare, acute care with limited triage, and even more limited specialty care. Currently there is one National Referral Hospital for tertiary diagnostic evaluations and care, 29 smaller hospitals throughout Bhutan, over 170 Basic Health Units (small community health dispensaries manned by non-physician healthcare workers), and over 500 outreach clinics (providing immunizations, de-worming). There are also 25 Traditional Medicine units and a National Traditional Medicine College and treatment center in Thimphu.

The healthcare system in Bhutan is directed through both the Ministry of Health and the Royal Institute of Health Sciences. There are "eight essential elements" of the entire Bhutan healthcare system summarized as follows:

1. Health education;
2. Nutrition programs (e.g., salt iodization, Vitamin A dispensary clinics, nutrition counseling for protein-calorie malnutrition);
3. Maternal and Child Health (e.g., antenatal care clinics, reproductive health and prevention of STD/HIV education programs);
4. Water and sanitization for the populace;
5. Immunization programs targeting prevention of TB, diphtheria, pertussis, tetanus, polio, measles;
6. Infection control programs for STD/HIV prevention and treatment, leprosy control, decreasing diarrheal diseases and treating acute respiratory infections;
7. Treatment of common illnesses and injuries. In 2006, the "top 10 diseases" treated at the hospitals and Basic Health Units included common upper respiratory tract infections, skin infections, diarrhea, peptic ulcer disease, pharyngitis/tonsillitis, conjunctivitis;
8. Essential drug programming. This includes adequate procurement and dispensing of medications for inpatient and outpatient use.

Annual Health Bulletin, 2011: Ministry of Health, Royal Government of Bhutan

There are additional core features of healthcare planning for Bhutan that included mental health services begun in 1997. It is now recognized that mental health morbidity is increasing, both for adults and pediatric populations. For adults these include alcohol-related disorders such as liver disease, epilepsy, depression, and anxiety. For children and adolescents these include ADHD, autism, anxiety, neurologic disabilities (e.g., cerebral palsy, epilepsy, and neurodevelopmental disorders including language delays, learning disabilities and cognitive impairments).

A recently completed study analysed elementary school children using the *10 Questions Screen*.[76] This was the first attempt at a national needs assessment to determine rates of children with disabilities. The results indicate that the prevalence of any disability among children in the age group 2- to 9-years-old based on identifying difficulty in at least one functional domain is 21.3%. The prevalence of mild disability is 18.6%; moderate disability is 2.1%; severe disability is 0.7%. Cognitive disorders were the most prevalent at 15.1%, followed by behavioral disorders at 5.6% and motor disorders at 5.5%. The prevalence of children living with a single disability is 13.8%; multiple disabilities is 7.6%. The ratio of male:female was close to 1:1 (no interpretation offered given most international data sets reporting a 3:1 male:female ratio). The prevalence for any disability among younger children aged 2- to 5-years is 26.8%

compared to 15.3% for children aged 5- to 9-years. Disability rates also vary by region, though with large overlapping confidence intervals. The disability prevalence is higher among poor children with 26% for the lowest quintile and 14% for the highest. The disability prevalence rates also vary for those children living in rural areas (23.1%) compared to those living in urban areas (14.1%). The mother's education also has an impact on children's disability rates: mothers with no education have children with a 22.8% prevalence rate, versus 13.5% when mothers have a secondary education or more.

Ministry of Health Services Programs to Detect and Address Disabilities

In 1997, the Ministry of Health approved a community-based rehabilitation mission. The stated vision is "all persons with disabilities are able to attain their fullest potential, become self-reliant within their limitations and be active contributors in nation-building to the extent possible." This was implemented on a community-based model integrated with educational programming and directives. Currently these include a few pediatric physiotherapy units, the main one at the JDW National Referral Hospital with others scattered throughout the country.

While there are stated screening and assessment programs sponsored through the Ministries of Health and Education, in actuality these have not yet been successfully developed or implemented. There is only one adult-focused speech-language specialist at the National Referral Hospital to provide receptive-expressive language screening on a referral basis only. Neither full pediatric speech-language assessments nor ongoing speech therapy exists yet in Bhutan. Child audiology assessments are on a referral basis only. As is common in developing countries, there does not yet exist an infant hearing screening program nor routine audiology screening for neonates discharged from the NICU, despite the successful management of a large population of premature infants, and high elevations of bilirubin seen in infants at the regional hospitals and BHUs throughout the country.

There are as yet no pediatric neurodevelopmental clinics, although there are current plans underway for the first neonatal follow-up clinic in Bhutan at the JDW National Referral Hospital in Thimphu. We hope this will soon be followed by the creation of a child development referral clinic. These clinics will be jointly managed by the Department of Pediatrics and the Department of Pediatric Physiotherapy.

Currently there is an active Pediatric Physiotherapy clinic at the JDW National Referral Hospital, directed by two dedicated pediatric physiotherapists. They currently assess and treat a wide range of children referred for intervention including cerebral palsy, autism and cognitive impairment, congenital brain malformations, brain damage secondary to hypoxic-ischemic changes, post-meningitis/encephalitis, or elevated neonatal bilirubin levels. There are also children seen with a panoply of genetic (non-confirmed) disorders.

Ministry of Education: Responsibilities and Initiatives

The Ministry of Education is responsible for the planning and administration of all public education in Bhutan. It has grown exponentially over the past four decades and now educates greater than 160,000 children each year. It is structured around a primary cycle (beginning at age 6 for seven years) and four years of secondary education. Two additional years of higher secondary education are offered after which some students may then enter tertiary education such as college and professional studies.

The Ministry of Education houses both the Department of Special Education and the Department of School Education. Global public education within Bhutan is continually being developed and modified: There are as yet no national standards or curricula for primary and secondary education. It is an inclusive design with a government commitment to achieve the Education for All Act by 2015. The intent is to provide an "inclusive education for children with physical, intellectual and sensory impairment."

Nationally, there is one school for the deaf in Paro, and a separate school for the blind in Khaling. There is a special education classroom integrated into a general education setting at the Changankha Lower School. The teachers (two) are credentialed in general elementary education and have received some form of additional training in special educatio. This special education classroom has a mixed population

of students of all ages, learning profiles and cognitive abilities. Some children are non-communicative. There are as yet no additional supportive services such as speech-language therapy or occupational therapy. Teachers attempt to develop "IEPs" to take individual learning and behavioral profiles into account; a differentiated national curriculum for children with special needs does not yet exist. The education staff in the classroom are indeed quite hard-working and also supportive to parents.

There is an established vocational training program for older children and young adults with more severe disabilities. This is the Drak-Tsho Training Centre for Special Children and Youth, located in Thimphu and more recently, in the Trashigang district. Their stated objectives are to train youth with special needs in art and other vocational skills (e.g. weaving). The program also plans to assist in vocational placement, provide parent support groups, and outreach to the greater Bhutan community about the integration of children and adults with special needs (*www.draktsho-bhutan.org*).

The Ability Bhutan Society, began in November, 2012, and was initiated by Ms. Beda Giri, the Director of Pediatric Physiotherapy at the JDW National Referral Hospital. The goal of this new society is to "create an environment that supports and promotes early intervention and integration of individuals with disabilities and enhances their quality of life." The focus through fund-raising and foundation-grant support is to create services for direct intervention for children with special needs, program development, and advocacy.

Charitable Efforts

There are currently two foundations with a focus on children with special needs: The Bhutan Foundation (*www.bhutanfound.org*) and the Bhutan Youth Development Fund (*www.bhutanyouth.org*). The Bhutan Foundation is a private American non-profit organization that partners with government and non-governmental organizations within Bhutan to support various initiatives including "educational and training opportunities for children with special needs." They are currently funding a program for designing special education programs within the public schools in partnership with the Ministry of Education and the Bhutan Youth Development Fund.

In a short period of time Bhutan has emerged from a third-world status to a developing nation. This rapid growth has led to both tensions and opportunities for future development. There are now mandates and proposals for identification, education and intervention for all children with special needs.

EARLY DETECTION IN AUSTRALIA

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Geographically, Australia is the world's sixth largest country. It is ranked number two on the Human Development Index.[77] With an area of 7.7 million sq. km, a large amount of the country is flat and sparsely populated. Most of the population resides on the eastern coastal plain and on the south-eastern coast.[78] The estimated population of Australia in 2011 was 22,620,600: 27% of the population was born overseas (6.0 million people). Indigenous people represent approximately 2.5% of the total Australian population. English is considered the national language of Australia. Apart from English and Indigenous languages, more than 160 other languages are also spoken in the home.[79]

In general, children are very healthy. Infant mortality rates are low (4.2/1000 live births), but substantially higher in the indigenous population (10.3/1000 live births).[80] In the 2007 UNICEF Report Card on children in wealthy countries, Australia ranked 13th on Material Wellbeing, 14th on Health and Safety, and 7th on Educational wellbeing, out of approximately 21 countries.[81] In 2009, the *Australian Early Development Index* (an adaptation of the Canadian Early Development Instrument) was completed for all children starting school (N = 261,147). This population measure showed that 23.4% of Australian children were developmentally vulnerable (scoring in the lowest 10th percentile) for one or more developmental domains, and 11.8% for two or more.[82]

The Australian Healthcare System

Australia has a healthcare system that is both pluralistic and complex. It involves many providers whose source of funding stretches across public and private sectors, as well as the divided responsibilities across levels of government, including Federal, State and Local. Most medical, dental and a number of other professional services, such as optometrists, are provided by private practitioners who charge a fee for service and receive their payments through a mixture of universal insurance via Federal funding (Medicare) and consumer co-payments. Primary medical care for children and families is provided by general practitioners (GPs). Paediatricians provide specialist medical care for children through referral from GPs.

State and Territory governments have responsibility for the provision of public health services including the public and psychiatric hospital systems, and community and public health services. Government responsibilities include: Mental health programs; dental health services (mainly community dental services, not private dentists); child, adolescent and family health services; health promotion; rehabilitation services; and regulation, inspection, licensing and monitoring of premises, institutions and personnel.

Local government generally has the responsibility for environmental control and a range of community-based and home-care service. The Federal government is also responsible for the universal benefits scheme for private medical services (Medicare) and for Pharmaceuticals (Pharmaceutical Benefits Scheme). In addition, State and Local government health authorities are active in early intervention and prevention, and provide services such as the maternal and child health centres, antenatal clinics, and community health centres.

Table 18-2. Examples of Relevant Australian National and State Policies

- Investing in the Early Years: *A National Early Childhood Development Strategy*, July, 2009. This strategy focuses on how Australia's early childhood development system will engage with and respond to the needs of young children and their families to provide the best possible start in life. The strategy aims to link the role of communities, non-government organisations and government in shaping children's early childhood development (*www.coag.gov.au*).

- *Australia: The Healthiest Country by 2020, National Preventative Health Strategy—The Roadmap for Action*, prepared by the Preventative Health Taskforce, September, 2009 (*www.preventativehealth.org.au*).

- *A Healthier Future for All Australians*, Final Report of the National Preventative Health and Hospitals Reform Commission, June, 2009 (*www.health.gov.au*).

- *Building a 21st Century Primary Health Care System—Australia's First National Primary Health Care Strategy*, Department of Health and Aging, 2010 (*www.yourhealth.gov.au*).

- *The Report of the Maternity Services Review*, Commonwealth of Australia, including the reparation of collaborative antenatal care guidelines, February, 2009 (*www.health.gov.au*).

- National nutrition and physical activity initiatives such as the *Australian National Breastfeeding Strategy* 2010-2015, released in November 2009, and *Healthy Eating and Physical Activity Guidelines for Early Childhood Settings*, October, 2009 (*www.health.gov.au*).

- *Protecting Children is Everyone's Business—A National Framework for Protecting Australia's Children* 2009-2020, an initiative of the Council of Australian Governments, April, 2009 (*www.coag.gov.au*).

Early Detection Systems in Australia

There are a number of universal service platforms including healthcare delivery (antenatal care, child and family health services), school education and early childhood education and care. Children receive curative primary healthcare through general or family practitioners who then refer to specialists (e.g. paediatricians) as required. Preventive services and well-child care are generally provided by community-based nurses although the distribution, qualifications and service-delivery models vary between states.

The mechanisms for early detection (e.g., screening) from these services have come under scrutiny. In 2002, the Centre for Community Child Health undertook a critical review of screening for the National Health and Medical Research Council. As a result there were only a limited number of conditions that fulfilled the World Health Organization (WHO) criteria for a screening test and a screening program.[83] It was apparent that while developmental and behavioural problems were prevalent, it was not possible to find screening tools that were sufficiently robust against these WHO criteria to form the basis of a screening program independent of clinical practice.

The review noted that children's developmental problems are unlikely to be picked up with a single test delivered at a single point in time; rather reviewers recommended that developmental monitoring should occur over time, requiring professionals to build relationships with parents (family-centred practice) in order to address many of the other psychosocial problems that compound children's developmental issues. This systems approach to early detection placed greater emphasis on the availability of referral pathways into assessment facilities or to appropriately qualified professionals. It was recognised that this is a challenging issue, especially where resources are scarce.

In building a quality early detection system, a number of core principles were suggested. These support a universal service platform that has the capacity to engage with parents over time and link them to other local services. Rather than "seek and refer," the ideal system has the capacity to "seek and respond" with resources and training available to address a number of problems. Such a system might include addressing issues such as mild behavior and developmental problems (e.g., tantrums, toileting, eating and sleeping difficulties). In this way, the system supports families, responds to needs, and refers children most likely to require additional assessment or therapies. The principles include:

- Universal access and participation for all children;
- Development of partnerships with families, communities and other service providers;
- Providing referral pathways into services for children and families, recognising a continuum of need;
- Focusing on evidence-based prevention, promotion, early detection and early intervention to address the health and well-being of children (a seek and respond system);
- The need to monitor performance through a population-health approach that focuses on outcomes.

These principles have informed the review of the Victorian Maternal and Child Health Service as outlined below. It should be noted that while there is a desire for a national early detection system in Australia, in reality each State and Territory has a somewhat different approach.

The Victorian Maternal and Child Health Nursing Service: An Example of Building a State-Wide Early Detection Approach to Developmental Surveillance

The Victorian Maternal and Child Health Nursing Service has provided free public health universal nursing to Victorian infants and children since 1926, based on the principles of well-child care. Although the Service initially focused on infant weight and nutrition, over time it has broadened its practice to align with the "new morbidities."[84] This effort includes engaging parents (particularly mothers) about their own health as well as the health and development of their children. In Victoria, the Service is funded jointly by state and local governments to provide ten visits to all children in the first 5-years of life. Not dissimilar to many other well-child care services around the world, these are designed to align with developmental opportunities and "teachable moments." The Service is highly regarded by families and well utilised. In 2009 - 2010, 99.8% of Victorian infants had a home visit soon after birth, with 80.6% of children still participating at 12-months and 63.1% at 3½-years.[85]

In 2004, the State Government released *Future Directions for the Maternal and Child Health Service*, as an opportunity to consider how best to position the service in the future.[86] This process paralleled increasing policy interest in providing an evidence-based service, and instigated an entire review of

the content and approach of the key age and stage visits—the core of the service. Although evidence to support the number of visits is scarce, evidence to support the principles of early detection and intervention, healthcare promotion and prevention was considered strong. It was on this basis that the Victorian Service began the process of reorienting each visit from a prescribed set of "topics" to a visit that was centred around a series of core activities designed to be family centred, evidence-based and focused on early detection, prevention and promotion. Each visit then became an opportunity for parent engagement and developmental surveillance, and included:

- Elicit and respond (through counselling or referral) to parental concerns about the health and development of their children, with parents and families using a systematic approach. In Victoria, New South Wales, Tasmania and Western Australia, *PEDS*[87] is used as the first-line parent engagement tool with the *Brigance Screens*[88] or *Ages and Stages Questionnaire*[89] as a secondary screen. Children's needs are then addressed by a nurse or a referral is made to the local general practitioner and/or the local early childhood intervention service, which may be a publicly or privately run program. There are few fully coordinated assessment centres in Victoria. Brief intervention training has been provided to nurses (e.g., smoking cessation, infant sleep problems, domestic violence, postnatal depression). It is expected that even if children enter into the secondary or tertiary service healthcare system that ongoing well-child care continues to be provided;

- Deliver a limited number of evidence-based promotion and prevention activities that are developmentally appropriate (e.g., brushing teeth at 12- to 18-months);

- Provide responsive and consistent written information for parents [using the Raising Children Network (*www.raisingchildren.net.au*), a national peer-reviewed website for parents on child health and development];

- Enter data for population health monitoring (e.g., rates of smoking, breastfeeding) and service delivery indicators (e.g., numbers and demography of children seen).

The final framework also included a set of outcomes that were either directly or indirectly related to the Service. These outcomes and associated indicators were also directly linked to the Victorian Child and Adolescent Monitoring System, as an attempt to create a more integrated approach to determining outcomes (*www.eduweb.vic.gov.au*).[90]

The review and reform process engaged stakeholders, particularly lead nurses, followed by a pilot study to address any substantive issues regarding implementation. The 2009 State-wide implementation was supported by: (a) the development of practice guidelines and standards; (b) a central help-line for nurse queries; and (c) a tailored training program, delivered State-wide, focused on the core functions i.e., developmental screening and surveillance. A concurrent process and impact evaluation is underway along with an ongoing quality improvement program to review training and consider how to best connect across service.

Conclusion: Early Detection and Intervention in Australia

Healthcare systems contribute most to improving health and health equity when the institutions and services are organised around the principle of universal coverage, and when the system is organised around primary healthcare.[91] Improving child health and development should be based on universal and equitable systems of care that enable efficient and effective targeting of services and supports for children identified as at risk for developmental difficulties. Such efforts decrease inequalities in outcomes. Implementing universal early detection systems is the first step in ensuring early intervention and prevention for improved outcomes for Australia's children.

WORLD WIDE INITIATIVES: A FEW VIBRANT EXAMPLES

The World Health Organization (WHO) and the **United Nations Children's Fund (UNICEF)** promulgate early childhood development and intervention for those with disabilities. Most international agencies focus on the challenges faced by developing nations and the elimination of disease burdens that contribute to delays (e.g., malnutrition, iron and iodine deficiency, malaria, environmental toxins, and exposure to violence), but also on such psychosocial issues as inadequate stimulation or learning opportunities, parental depression, exposure to violence, neglect, lack of attachment (e.g., children in orphanages), etc. For example, WHO and UNICEF encourage nations to develop family-friendly social policies that support family health and teach parenting skills. The Commission on Social Determinants of Health outlines the tenets of the WHO and UNICEF initiatives in multiple languages (*www.who.int*). The report also includes helpful tools for identifying problems and tracking progress. UNICEF's website (*www.unicef.org*) has helpful benchmark data along with a downloadable Early Childhood Resource Pack.

The Gates Foundation (*www.gatesfoundation.org*) promotes health and literacy (both within the United States and in other developing nations) and focuses on improving agricultural, sanitation, and economic development, libraries, and advocacy for public policy surrounding families and children.

Partners in Health (*www.pih.org*) is devoted to "breaking the cycle of disease and poverty" by collaborating with governments (in twelve countries) on disease prevention, education, access to health care, and training local healthcare workers.

Chapter Comments: *The many international initiatives presented in this chapter are remarkable in diverse ways. Many nations use public health models to focus initiatives (e.g., place-based services), while others work from the ground up. Most involve a learning collaborative for all involved and thus continually build and refine approaches to helping children and their families. All international initiatives clearly reach out to other nations to find out what works. In so doing, they capitalize and improve on existing models. Some have created entirely new approaches that have gained enormous traction in the United States— where our own diversity and population size have many researchers and interventionists searching for optimal approaches. Sometimes great models are beyond our borders.*

Americans sometimes think that families facing economic crises, wars or environmental catastrophes are so busy with their woes that their children's development and well-being are far from their minds. This is clearly not the case: Even in nations with far fewer resources than the US, there is abundant interest in improving child development, educational opportunities, health care, and parenting skills. Just as with many other countries, the US is a nation with enormous differences in wealth. As in other countries with huge land masses, families must often traverse long distances when seeking health and developmental care. Even within large cities with vast populations (e.g., Los Angeles, New York City), transportation to clinics can involve multiple subway stops and bus transfers, i.e., hours of family time. Increasingly all countries embrace diverse cultures and languages. So all across our planet, we do best by children and parents if we share our ideas and learn from each other.

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Chapter 19: Test Construction and Psychometrics, Quality Improvement and Other Research in Developmental-Behavioral Screening

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CHAPTER HIGHLIGHTS

Within we cover a wide array of issues helpful for researchers and those planning clinical care protocols. Topics include:

- **I.** Creating new items for clinical care and research projects;

- **II.** How to translate items into other languages;

- **III.** Test construction and the proof required for psychometric support;

- **IV.** Guidance for researchers on variable selection, research metrics, study designs, adapting existing measures for use in other nations and issues in needs-assessment and survey research;

- **V.** Quality Improvement and Maintenance of Certification projects;

- **VI.** Resources for bench-marking, literature reviews, use of established datasets for analysis, etc.

I. CREATING NEW ITEMS

Researchers, trainers, program evaluators and clinicians often need to create questionnaires with items focused on results of interest. Of all the various types of writing (e.g., expository, narrative, persuasive), item-and direction-writing are the most challenging. Over-explaining generates confusion. Vocabulary and sentence length have an enormous impact on intelligibility. Simplicity of wording is essential especially when eliciting information from parents. Response options for multiple-choice questions also need careful attention. Suggestions for those who need to generate questionnaires, post-tests, or research protocols are shown in Table 19-1 with the special consideration of item-writing for parents (shown in Table 19-2).

Table 19-1. Item-Writing Guidance

> (a) Start with a thorough review of existing literature with a careful eye to the questions asked;
>
> (b) If the exact wording of questions is not included in published research, write the authors to see if they will share a successful protocol [and also ask for comments on the questions used (e.g., which ones were discarded and why)];
>
> (c) Vary question types (e.g., multiple-choice, true-false, fill-in-the-blank, open-ended). This improves attention to the question asked and the quality of answers provided;
>
> (d) Vary the placement of correct or desirable answers within multiple-choice response options, i.e., place only some correct answers at the beginning or end of the list;
>
> (e) Avoid response patterns [meaning a long series of questions for which the probable answer is the same (e.g., *"No"*)]. In such cases, parents or other test-takers may fail to pay careful attention to questions;
>
> (f) For training and program evaluation items, begin with open-ended questions such as, *"What did you hope to learn today?"* End with open-ended questions such as, *"What did you like best about....,?", "What did you like least?"*;
>
> (g) For training questionnaires, use "The Harvard Question" at the very end (e.g., *"How will you use the information you've acquired today?"*). This question is known to encourage attendees to actually implement new learning;
>
> (h) When rating the success of a program, average responses to all rating scale items, and consider removing the two extreme scores, i.e., overall results that are extremely positive and extremely negative. In each audience, there is almost always one 'curmudgeon' and one excessive 'enthusiast.' Removing the two extreme scores provides a better measure of central opinion. Nevertheless, make use of all suggestions;
>
> (i) Provided in Appendix B (and downloadable at *www.pedstest.com/TheBook/AppendixB*) is a sample of questions to trainees about child development, early detection and intervention that demonstrates principles of item-writing, i.e., varied types of questions and response requirements, including a combination of multiple-choice, matching, open-ended, etc.

Table 19-2. Special Considerations When Writing Questions for Parents

(a) Consider what is known about parents' understanding of specific vocabulary. For example, *"development"* is only understood by 50% of parents.[1] Terms such as *"expressive language"* and *"gross motor"* are not meaningful to most parents.[2] So either use family-friendly terms or pair unfamiliar words with commonly understood synonyms;

(b) When writing items use short sentences to enhance intelligibility;

(c) Make sure items are readable at the 4th grade level or lower (see the Resources Section for websites offering readability checks);

(d) Avoid binary response options (e.g., yes/no). These may force parents into socially desirable answers and may not capture what parents actually observe or do with their children. A better approach is to add a *"sometimes"* type answer or a 3 – 5 point Likert rating scale. Analytic techniques can be used to determine whether, for example, *"sometimes"* actually means *"rarely"* or *"often;"*[3,4]

(e) After drafting items, conduct a small pilot study in which colleagues and staff comment on newly written items and provide suggestions to improve clarity of questions and response options;

(f) Be sure to include a social worker on your professional team. Social workers can often advise on how to simplify wording and vocabulary, given their skills at interviewing parents of diverse backgrounds;

(g) Next, pilot questions with families but have a researcher present to conduct *"cognitive testing,"* i.e., asking families what they thought about when answering. This process helps determine whether parents understood the questions and how they interpreted it. Capturing verbatim comments is useful for qualitative studies and helps enormously in clarifying quantitative results;[3]

(h) Conduct additional pilot studies as needed until confident that parents are answering questions in a way that reflects the content and intent of the items.

II. CREATING AND WORKING WITH TRANSLATIONS

Translations are often needed (e.g., for clinic intake forms, for working with a clinic translation service, for effective encounters with parents, for research protocols and studies of whether published measures work with non-English speaking families or when working with test publishers on creating new translations). Imbedded within the recommendations below are case examples (shown in italics) that illustrate lessons learned the hard way and how to avoid such mistakes in your own work. The focus in this section is the creation of translations, and research on their use within the US. Adapting measures for other nations and establishing psychometric support is described further along in this chapter.

- If you are dealing with copyrighted material such as a standardized test, first check with publishers on what translations are available. You will need to seek permission to translate and to use your translation. In many cases publishers will help you along the way, put you in touch with others interested in a particular translation, may pay for translations, and are willing to distribute them. See Chapter 4 for links to publishers' websites.

- It is not enough to translate and back-translate. Translations need to be vetted with several bilingual providers as well as families to make sure they work well. Word choices may have very different meanings in other languages. *For example, in translating PEDS into Chinese, the word "concerns" also means "care" (as in "do you care about your child?"). Of course Chinese and all other parents care about their children and so we found inordinately high rates of Chinese parents expressing concerns. Researchers had to substitute a far stronger word, "worries," in order to obtain appropriate response rates. Meanwhile, in English, the word "worries" does not work well.[5]* All this means that words have different connotations across languages. Testing and refining translations are needed.

- If working on a new translation, the initial translator should have a background in child development, social work or nursing, and thus skills in communicating effectively with parents. Translators need to be fully bilingual in order to understand the meaning of questions and discuss wording options.

- Translators need to use the simplest and briefest possible language (see Table 19-1 on item-writing).

- Slang should be avoided because it may not be understood by all speakers of a language, and varies by dialect and nation of origin. For example, Spanish, the most commonly understood language in the world (there are far more Chinese speakers but they cannot always understand each other except in writing), has many vocabulary differences across Spanish-speaking backgrounds. *For example, American-Spanish uses words like "carro" for car, and "chicos" for children, but these words are not understood by all Spanish-speakers within or outside the United States. A question such as "Can your child extend his index finger to poke at a cube?" may deploy words that have "dirty" connotations in some countries (e.g., "empujar" and "caja").* So collaboration among translators speaking a single language but who have different national backgrounds is needed.

- Recognize that some languages, Arabic, for example, can be read by all literate Arabic speakers. But spoken Arabic differs substantially from written Arabic (as does Chinese). When anticipating limited literacy, interview versions may need to be developed.

- When creating a translation for recent refugees, study the political climate in the nation of origin. *In our first attempt at a Somali translation of PEDS in America, the translator, who was a long-time ex-patriot, did not realize the word "concern" was used in political slogans by warlords, i.e., "we are concerned about you" appeared on many billboards in Somalia. Families who had recently fled the country did not respond much, as you might imagine (e.g., only about 2% of Somali families raised concerns as compared to about 40% of English-speaking Americans). So, questions in Somali had to be reworded. The phrase, "Do you have concerns about.....?" is now rendered as "Do you have feelings about your child's .....?" Such wording would not work in English but it worked very well with Somali families.*

- Per recommendations from the International Test Commission (*www.intestcom.org/guidelines*), check and recheck your translation by sending it to other professionals, not only to vet wording, but also to correct typos. This is most important if you aren't fluent in the language being translated on your behalf. *For example, in our first Spanish translation of PEDS, when asking "How old is your child?", we failed to notice that "años" (meaning years) was typed as "anos"—meaning that we were actually asking parents how many anuses their child had. Giggling in the waiting room was not exactly the desired response!*

- If translation support is needed for clinical care, make sure translators (whether working in person within clinics or via a telephone translation service), have fully vetted translations of tools. Although professional translators are bilingual, questions about child development and behavior are delicate (*as you can tell by the messes described above*) and need to be very carefully written, vetted, and tested to make sure they work. Ad hoc translations are often problematic, ineffective and may be marred, even within the same language, by dialectical differences between translators and families.

- When studying the effectiveness of translations with standardized measures, compare incidence rates from existing research (meaning the percent with probable or actual problems) to the incidence found in your sample. *For example, Dr. Marie Leiner, noticed that the Pediatric Symptom Checklist detected far fewer mental health problems in children of Spanish-speakers than in English-speakers, and also that even English-speakers of limited socioeconomic status had lower than expected detection rates (even in the face of increased psychosocial risk). Dr. Leiner and colleagues[6] improved the Spanish translation but also added pictograms to both the English and Spanish versions to facilitate comprehension (very helpful for groups where literacy may be limited). Thus they created the Pictorial Pediatric Symptom Checklist (Pictorial-PSC) and found that the Pictorial-PSC improved detection rates in lower SES families whether they spoke English or Spanish.*

III. HOW TESTS ARE CONSTRUCTED: A BASIC GUIDE TO PSYCHOMETRY

An understanding of test construction is helpful for: (a) Clinicians using existing tools (who perhaps wonder why results should be trusted); (b) committees selecting tests for early detection initiatives or deciding among diagnostic options; and (c) researchers constructing new tests, measuring outcomes or adapting tools for use in other nations. Although tests vary by complexity, depth, and measurement method, all quality tools are constructed via an arduous psychometric process involving multiple studies of standardization, reliability, validity/accuracy, and, ideally, feasibility:

STANDARDIZATION

Test standardization (also known as "norming") is a fundamental part of the psychometrics required for quality test construction. Standardization involves administering the test in exactly the same way to a large sample of children so that each child's performance can be compared confidently to that of other children. Standardization identifies the distribution of performance and shows that a test can be used effectively with children from diverse socioeconomic and language backgrounds. Standardization also offers performance parameters for those working with low-, moderate- or high-risk children, i.e., the probability of greater or fewer problems in light of differences in psychosocial risk factors. The process of standardization involves these steps:

1. **Identify national demographics.** When standardizing a test, we create a nationally representative sample that reflects the characteristics of an entire country. In the US, Census Bureau data (*www.census.gov*) is used to determine population percentages for variables essential in test norming. These include ethnicities, levels of education, primary languages spoken at home, poverty rates, and locations (meaning rural versus urban, and also geographic regions such as North, South, East, Mid-west, etc.). Including children with disabilities and giftedness is also needed and depends on projections from the Centers for Disease Control (*www.cdc.gov)* aided by IDEA statistics (*www.ideadata.org*). While it may be surprising to include children with exceptionalities when standardizing a test, all are part of the overall population and their presence in a sample ensures that norms capture the complete spectrum of performance and thus contribute fully to the meaning of average. The percentages assigned to the above critical variables establish proportions to be emulated in creating the standardization sample for each test.

2. **Select settings that mirror where a test will be administered** (e.g., if a primary care screen, then settings should be mostly primary care clinics). Such settings also serve children with exceptionalities—in likely proportion to their presence in the general population of children.

3. **Ensure naturalist sampling and eliminate selection/spectrum bias.**[7] Avoid norming on clinic-referred children, i.e., those with probable problems, because this skews the meaning of average (downward) and may, when it comes to accuracy studies (described below) result in improbable sensitivity and under-referrals. Similarly, simply adding in a group with known disabilities is not wise, because the "shades of gray" representing the spectrum of delays will not be captured. Nevertheless, exceptions are needed when tests focus only on unique populations (e.g., to answer research questions such as, "How does this extremely low birth-weight child compare to others with this condition?").

4. **Administer the test to the nationally representative sample.** You may end up over-sampling some groups (e.g., a disproportionate percentage of white children). Options for honing your sample are: (a) Using a sampling program that can randomly select and eliminate over-represented cases; or (b) bootstrapping to boost the numbers of under-sampled groups by replicating/weighting their presence in a data set. Nevertheless, bootstrapping should be used judiciously and preferably not at all because replicating a minimal sub-sample can compound distortions in the performance of subgroups. A better plan is to oversample groups of interest (e.g., Hispanics, African-Americans,

American Indians) and save some of these cases for further analysis, i.e., for determining how a test performs with unique groups as compared to the normative sample.

5. **Ensure a sufficient sample size.** With a milestones-type measure, scoring usually changes in one-month increments in the first year of life, in two-month increments in the second year of life, etc. A minimum of 75 – 200 children for each age group/scoring change is recommended. With the advent of web-based data collection, it is not uncommon to see tests with thousands of children per age-range/scoring change. 'More is better' with standardization because it ensures you have captured representative performance for each group.

6. **View collective performance** for your sample in order to determine what is *probably* average and what is not. Typically this is done by computing standard scores (e.g., quotients or percentiles for each age) and then plotting these on a histogram/bar graph. When these scores are "smoothed," they will take ideally the predictable shape of a bell curve—with most children scoring in the standard deviations on either side of the mean, and fewer children scoring at the extremes. Note that standardization is not validation—the meaning of average, below average, or above average requires careful comparison with other measures. But, standardization is essential for viewing performance ranges. Figure 19-1 shows a typical graph of performance distribution on standardized results, and Table 19-3 explains the meaning of various kinds of scores.

7. **Determine the performance of specific groups** (e.g., those who are Spanish-speakers, have psychosocial risk, etc.). Performance studies on unique populations should reflect that: (a) Measures work equally well in each language tested; and (b) children at risk score less well overall than do children without risk factors. Note: It is unwise to create separate norms for children at risk (e.g., enrolled in Head Start, on Medicaid, etc.). Such norms lower the definition of average and lead to under-detection. The purpose of testing is to decide who needs help well before kindergarten enrollment. It is only by comparing children at risk to the performance attained by the majority of age-mates, that we can see who needs intervention. Nevertheless, subgroup standardization analyses provides valuable information on what providers can expect when working with discrete populations [e.g., families who receive Medicaid; families in crisis who are unable to pay utility bills, facing eviction, lacking the income needed to feed their children; children of parents who are highly educated and have few, if any, psychosocial risk factors; families with diverse ethnic backgrounds; those residing in (or recently immigrated from) other nations; those who speak languages other than English, etc.].

8. **Update standardization on a regular basis.** The American Educational Research Association together with the American Psychological Association, and the National Council on Measurement in Education recommend re-norming tests at least every ten years.[8] Demographics change (e.g., the Latino population is growing rapidly, languages other than English are increasingly common, etc.). In addition, test stimuli become dated. For example, many tests had to be recalled because children, when shown a rotary dial telephone, could not name it correctly!

Table 19-3. A Guide to Test Scores

> **Raw Scores** are a simple count of the numbers of correct answers. When broken out by age, differences in raw scores are used in standardization research to generate other scores such as quotients or percentiles. For many tests, raw scores reflect the number of skills mastered (e.g., within a curriculum) and are thus helpful for charting progress. Raw scores will have a range from all items passed to all items failed. Although we can view the mean number of items passed or failed (or better still, the median—meaning the middle of the range), raw scores do not tell us much about how scores are dispersed, i.e., where do most children score and what are the frequencies of extreme scores.
>
> **Standard Deviations** offer a better way to look at how frequently scores vary from average (with average defined by the age or grade of the child). Standard deviations reflect dispersion (also called variance) and provide a consistently recognized way to view frequencies of scores as they depart from the mean. As shown in Figure 19-1, more than 68% of children score within 1 standard deviation above or below the mean (i.e., $\pm$ 1 σ) with far fewer scoring 2 standard deviations above or below the mean. Scores 3 standard deviations above or below the mean are even more rare and thus asymptotic.

<div align="right">table continues…</div>

Table 19-3. Cont'd

Standard Scores are attached to standard deviations but flesh out the score ranges in between. Standard scores are used with all diagnostic measures, but tests results may be expressed with different scales. Nevertheless, all standard scores, despite differences in metrics, express the same variance in test performance:

Quotients are the most familiar standard score and assign a mean of 100 and a standard deviation of 15. So in viewing the Weschler Scales of Intelligence in Figure 19-1, we can see that most children receive scores of 100 ± 15 points. Quotients generally have the following meanings but must be considered in terms of relative performance (e.g., quotients in the average-range may be below average in a rigorous private school):

< 74	Very poor
77 - 84	Poor
85 - 90	Below Average
91 - 114	Average
115 - 120	Above Average
121 - 130	Superior
> 130	Very Superior

Quotients usually remain roughly the same over time. If so, this means a child is continuing to learn skills at the same rate (but also see comments on Flynn effect* below). Dropping or rising quotients mean a child is learning more slowly or more quickly than prior testing predicted. For quotient changes to be considered significant, a difference of 6 or more points is needed. As a consequence of the somewhat invariant nature of quotients, age-equivalents or raw scores offer a more responsive metric for outcome studies and often enable a wider range of statistical techniques.

Figure 19-1. Graph of Typical Performance Ranges on Standardized Tests
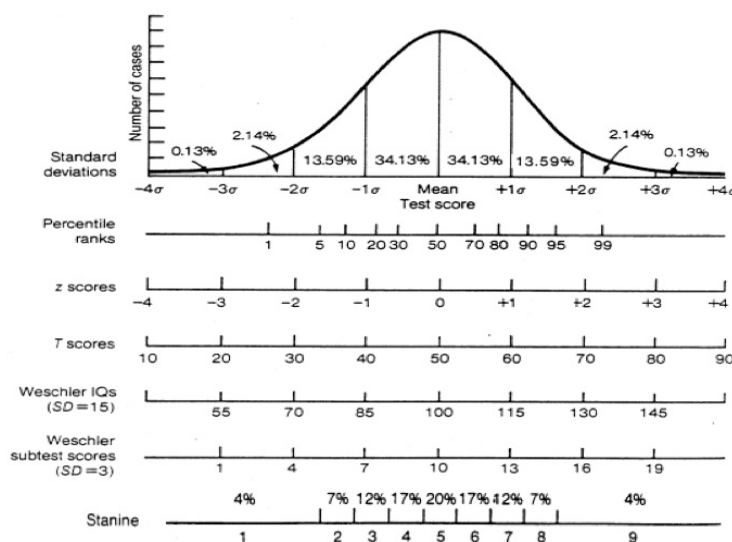
©Anastasi A. Psychological Testing (3rd edition). Toronto, Ontario: The MacMillan Company, 1968. Used with permission.

Scaled Scores are often used to describe performance on subtests of diagnostic measures. For example, on the Weschler Scales, there are ten to twelve subtests each producing a scaled score of 10 with a standard deviation of 3.

T-Scores are yet another way of expressing standard scores but have a mean of 50 and a standard deviation of 10.

Percentiles also known as percentile ranks, are another type of standard score into which age (or grade placement) is factored. Percentiles have a range between 0.1 and 99.9. A percentile of 20 means that a student performed in the lowest 20%. In contrast, a percentile of 86 means that a student performed in the top 86% of all children. Percentiles should not be confused with percentage which is just a way of expressing a number (e.g., correctly answered items) as a fraction of 100. So for example, a child can get 80% of items correct but if all other children do better, then the percentile rank could be < 1st percentile.

Percentiles are helpful for expressing relatively fine differences in performance within the broad range of average. Percentiles cluster heavily in the standard deviations just above and below the mean, but they do less well at defining how high- and low-functioning students are performing. In contrast, quotients on the very low end of the spectrum can be expressed as 65, 55, 45, 35, etc. while the comparable percentile ranks for these quotients only renders < 1. Unlike quotients or age-equivalent scores, percentile ranks, because they are a uniquely uneven metric, should not be averaged.

The interpretation of percentiles changes according to variables measured (e.g., the 16th to 25%th percentiles are fine for height, weight, and head circumference but are always concerning when it comes

table continues...

Table 19-3. Cont'd

to development: the handwriting is on the wall for school failure). Percentiles, as with all standard scores, need to be evaluated in light of the performance of students' actual peers and immediate performance demands.

Age-Equivalent Scores/Grade-Equivalent Scores, like raw scores, are non-standardized and usually created by viewing the average raw score for each age-group or grade. Even if tied to standard scores, age/grade-equivalent scores remain an uneven metric due to swift changes in skills (see Figure 19-2). There is an enormous difference in skill sets between a child who is 1-year, 1-month of age versus a child who is 1-year, 9-months of age. The latter is, we hope, talking and walking, the former is usually not. Similarly, a first grader who, at the end of the school year where we'd hope most children are performing at the 1st grade, 9-month level, but who instead performs at the 1st grade, 1-month level is a child who is failing miserably at the tasks at hand.

Age/grade-equivalents offer some practicality as an ever-changing continuous variable that is enormously responsive to developmental changes and interventions. Similarly age/grade-equivalents are also helpful for selecting instructional materials or age-appropriate toys. Nevertheless, the metric is often confusing to both parents and professionals. For example, a 10-year-old working at a 5-year level is not the same as a 5-year-old working at a 5-year-old level. The former child will have trouble with abstract thinking and problem-solving while the latter child will not.

Age-equivalent scores are expressed as "year–month" (e.g., 2-year plus 3-month = 2–3). Grade equivalents are expressed as "grade.month" (e.g., 2nd grade, 3rd-month = 2.3). As with percentiles, when tests produce a range of age/grade-equivalent scores, averaging this into a single result may be less than meaningful, especially if there are substantial strengths and weaknesses in skills.

Figure 19-2. Unevenness of Equivalence Scores (Showing Age-Equivalents in Years and Months)
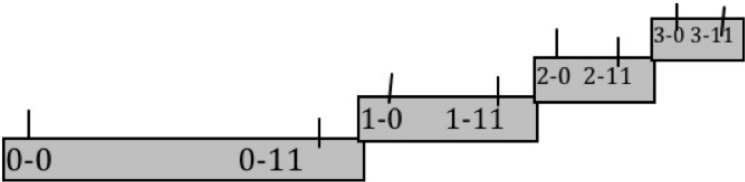
Cutoffs (also a non-standardized score) are used almost exclusively with screening and sometimes assessment-level measures (not diagnostic tools). Cutoffs are usually created by comparing raw scores to the diagnostic findings from validation studies (expressed as the presence or absence of a disability). Cutoffs are designed to be the optimal balance between detecting problems and detecting typical development with minimal over- or under-detection. Some screens are designed to detect not only children at risk but also those with disabilities. With the former, cutoff scores will hover around 1 standard deviation below the mean, i.e., quotients of 85 or less/at or below the 16th percentile. For screens identifying only disabilities, cutoffs will be closer to 2 standard deviations below the mean, i.e., quotient of 70 or less/at or below the 2nd percentile. Some screens offer a choice of cutoffs, i.e., 1 standard deviation below the mean; 1½ standard deviation below the mean; 2 standard deviations below the mean (which is helpful because States have differing criteria for IDEA eligibility). Note that screening test cutoff scores have different names according to the test used (e.g., suboptimal/optimal, milestones met/unmet, high-risk/low-risk, pass/fail) but in any case we are talking about various binary results in relation to the reference standard battery. How to establish cutoff scores and understand their meaning is discussed further in the section on Accuracy.

*Flynn effect refers to the fact that quotients, most particularly intelligence scores, tend to rise over time (e.g., 3 - 5 points per decade). Despite efforts of test authors and publishers to adjust for this when re-standardizing measures, differences in performance across test editions remain. Some studies of the Bayley-III's scores found them to be almost one standard deviation higher than those rendered by the Bayley-II.[9,10] This creates headaches for longitudinal studies using different versions of measures over time (e.g., NICU follow-up and for re-evaluation of IDEA eligibility).

To date, there are no clear methods to adjust for Flynn effect. It is tempting to simply subtract 1 standard deviation from existing results, but until large scale samples are evaluated, we don't know whether Flynn effect is operational at all levels of performance. For example, Flynn may not be as strong at 2 – 3 standard deviations above and below the mean. Drs. Aylward and Aylward provide a technical review of Flynn effect including a report from the publisher of the Bayley-III (www.pearsonassessments.com) suggesting that Bayley-II scores might have been depressed compared to the Bayley-I or Bayley-III.[9] This review also covers Flynn effect with the latest edition of the Weschler Scales and the Preschool Language Scale-4. So while this debate continues, diagnosticians and researchers are urged to keep up with this issue and consider using additional measures when diagnosing cognitive and language delays, and for determining IDEA eligibility.

RELIABILITY

Test construction involves at least three broad types of reliability tests. For example, an informal milestone item often used in primary care age-specific encounter forms may include "Recognizes colors." What exactly does that mean? Points to colors when named? Names colors when asked? How many colors and which colors at which age? Consider the fact that without standardized instructions, different providers might use very different stimuli and very different scoring criteria. Standardized tests eliminate such vagaries via consistent presentation of test stimuli (e.g., identical cubes of varying colors), clear directions such as *"Tell me what color this is?"* along with definitive scoring criteria (e.g., 5 of 7 colors at five-years of age). In so doing, standardized tests enable measures to be administered the same way every time, even by different examiners—enabling us to confidently compare a child's performance to others of the same age. But first we have to prove that a standardized administration elicits virtually identical performance from children if they are retested by the same person, and also that different examiners can retest and obtain close to the same results. Researchers usually conduct studies of reliability before taking a measure into standardization. Reliability indices involve:

(a) Test-Retest Reliability determines that a child performs the same way when tested again by the same examiner (usually one to two weeks later). To express agreement, some authors use correlations and some use the Kappa statistic (although standards for correlations and Kappa are fuzzy because it accounts for chance agreement and lacks a consensus among statisticians for rating its significance).[11] Hence most psychometricians prefer to express test-retest reliability as a percentage of agreement (e.g., a range of 90% to 100% with a mean of 95%).

(b) Inter-Rater Reliability demonstrates that two different examiners when testing the same child can render the same results. Inter-rater reliability studies should also scrutinize multiple methods of test administration if available. For example, if a test can be administered by interview versus parent-self-report versus hands-on, inter-rater studies should be conducted to test agreement across measurement approaches.

(c) Internal Consistency demonstrates that related items "hang together" and measure cohesively, the same domain. For example, if motor items are highly correlated with language items, that probably means directions for motor tasks place too many demands on receptive language skills, and thus penalize a child with good motor ability but poor language comprehension. Internal consistency also shows which items are so highly inter-correlated as to be duplicative and thus safely removed to shorten the test. Analysis of differential item functioning is a typical method for identifying an optimal set of questions and eliminating redundant ones.

(d) Stability indicates that scores are consistent over long intervals of time (e.g., across three months to six years). For example, if children perform in the above-average range at Time 1, we expect (and hope) to see above-average performance at Time 2. Standards for stability coefficients are not well established, which is understandable given the rapid changes in young children's skills (especially given the brevity of screening tests), but significant correlations in performance administered over time suggest that measures tap meaningful predictors of outcomes. Another way to view stability is by viewing agreement for the standard deviation in which a child performs at Time 1 and then at Time 2 (e.g., if performing 2 standard deviations below the mean at Time 1, to what extent is performance within the same standard deviation at Time 2). Identifying likely de-stabilizers such as the presence of psychosocial risk factors and absence of resilience or intervention is much needed to interpret stability indices.

VALIDITY

There are many types of validity studies required for quality test construction:

(a) Content/Face Validity does not involve statistical analysis but instead professional opinion that items are likely to tap the domains of interest (hence why lots of item vetting is wise).

(b) **Concurrent (sometimes called Convergent) Validity** is a comparison between the test under study to "gold standard" or reference tests (meaning tests that are well-established, proven, effective, and diagnostic). Concurrent validation should involve a test battery that samples the same range of developmental tasks measured by the test under study (e.g., if motor, language and academic skills are measured in the research test, then the criterion measures should include tests of motor, language and academics). Concurrent validity studies are usually expressed as correlations and ideally the correlations show close relationships between "like subtests," i.e., language items correlate with language items on the reference tests.

(c) **Construct Validity** is much like internal consistency but focuses on whether a test has meaningful factors (e.g., a cluster of subtests or items that clearly reflect verbal versus non-verbal performance). Established factors are often used to generate separate scoring (e.g., a different set of cutoffs or quotients for verbal versus non-verbal factors). Such scores are useful to test users who, when interpreting a child's performance, are best assisted by indicators of broad strengths and weaknesses. Unlike internal consistency, construct validity compares a test's factors to performance on reference measures.

(d) **Discriminant Validity** determines the strengths and weaknesses of measures in detecting various conditions. Ideally, there will be unique performance patterns associated with unique disabilities. To conduct these studies, disability according to type versus the absence of disabilities (as diagnosed by reference tests) are grouped as dependent variables. Next, items or subtests from the experimental measure are used as predictor variables. Statistical techniques typically involve logistic regression, discriminant function analysis or factor analysis. An example of desirable results is that language items on the measure under study are highly associated with the presence or absence of a language disorder, motor items predict motor coordination disorders, and overall, that children with common conditions such as learning disabilities or autism spectrum disorder have distinct patterns of results. Discriminant validity studies are most helpful when they report accuracy in detecting various conditions, i.e., the percent of children with cerebral palsy correctly identified. Such information is useful for determining whether a measure has limitations in detecting certain conditions (and thus whether alternative tests should be used).

(e) **Predictive Validity** views how well a test measures enduring and meaningful dimensions of child development. Such research involves measuring children (Time 1) and then repeating testing, along with diagnostic measures later in life (Time 2). Time-frames vary in studies and can be as little as three months or more than two decades. Because child development is complex and ever-changing, there are no defined standards for predictive validity but in general, a statistically significant correlation with outcome measures signifies a predictive relationship. Accuracy indicators such as sensitivity and specificity (described below) are sometimes used but achieving the levels demanded for concurrent tests should not be expected. It is worth noting that in predictive validity studies, it is not uncommon to find certain items or subtests that were not concurrent indicators, but have instead a long-term association with outcomes. Essential for longitudinal studies are creative exploration of results, careful tracking of families over time, obtaining information about any interventions and changes in psychosocial risk between Time 1 and Time 2 because these might alter predictions/outcomes. Finally, copious funding is necessary to minimize subject (and researcher) attrition.[12]

(f) **Criterion-Related Validity,** also known as accuracy, is required for screening tests, and is described below.

CRITERION-RELATED VALIDITY: SCREENING TEST ACCURACY

Studies of accuracy are considered the "acid test" for how well screens work in detecting probable problems versus the probable absence of problems. Accuracy research determines optimal cutoff scores for screens in relation to the reference standard measure(s), i.e., the criterion battery, which is often

referred to, informally, as the "gold standard." The steps in establishing accuracy are:

Identify the Performance Criteria to be applied to the reference standard measures. For starters, we are placing children into two categories, i.e., those with actual problems and those who do not have problems. Presence or absence of eligibility for special services is a practical way to categorize results, but it is important to note that developmental status is not a binary phenomena. We also have children with delayed development but who are not so far behind as to qualify for special services and instead need other kinds of help (e.g., parent education, Head Start, etc.). All this means that we should look at developmental status in different ways and often "lump" and "re-lump" the two categories in order to identify a range of cutoff scores on a screen.

Determine Optimal Cutoff Scores on Screens. Having established one (and preferably more than one) way to categorize reference tests into a binary result, the next step is to determine optimal cutoff scores for the screen. The goal for setting cutoffs is to detect the greatest number of children with problems with also correctly identify the greatest number of children without problems. The Receiver Operating Characteristic (ROC) is often used to plot scores on screens (e.g., number of items passed) against the binary categories for capturing performance on the "gold standard."[13] Again, more than one categorization approach for the reference standard should be tested if appropriate for the goal of the screening test. ROC analyses help identify the optimal cut-point for maximizing test accuracy, and some researchers spend vast amounts of journal space reporting "the area under the curve." But a simple comparison of continuous scores on screens against each binary categorization of reference measures more readily answers "in the trenches questions" such as, "My patient passed a screen but what is the chance that the screen missed a problem?" And conversely, when faced with a problematic result, a clinician may well wonder, "What is the chance my patient truly has a problem?" Figure 19-3 is an example that defines the various parameters for determining test accuracy followed by clinical questions and a description of the analyses required to provide relevant answers.

Figure 19-3. Terms for the Intersection of Diagnostic and Screening Test Results

	Diagnosis		
Screening Test	NO	YES	
Pass	70 (co-negatives/ true-negatives)	4 (false-negatives)	74
Fail	10 (false positives)	16 (co-positives/ true positives)	26
	80	20	___ /100

Legend

Note: That the term "positive" means a problematic result.

True/co-positives: Out of the total number of children with problematic results (N = 20), true/co-positives are the number of children who had both problematic screening scores and problematic results on diagnostic testing (N = 16).

True/co-negatives: Out of the total number of children identified as typical on diagnostic testing (N = 80), true/co-negatives are the number who also passed screening (N = 70).

False-positives: The number of children found to be typically developing on diagnostic testing who nevertheless failed the screening test (N = 10).

False-negatives: The number of children with problematic results on diagnostic testing who nevertheless passed the screening test (N = 4).

Computation of Screening Test Accuracy

Given diagnostic and screening test results on the same children, there are a number of computations required and each has its own terminology:

Sensitivity (co-positivity). This analysis answers the question, what percentage of children found to have problems on the diagnostic battery were detected by a screen? The computation involves dividing the numbers of true/co-positives by the sum of true positives/co-positives+false-negatives. In this case, 16 of 20 children diagnosed also performed poorly on screens, but 4 of the 20 diagnosable children passed the screen. So sensitivity is 16/20 = 75%.

Ideally, all children with disabilities would score below cutoffs on a screen and thus be identified as needing referrals for further evaluation/special services. In reality, detection of disabilities is imperfect due to behavioral noncompliance, psychosocial malleability, age-related skill changes in development, imperfections in reference tests (hence the reason for the term co-positivity), and ultimately the necessary brevity of screens. So basic standards for sensitivity are 70% to 80%. While this figure may seem low, many tests fail to attain this level of accuracy. Higher sensitivity may be found if using stringent performance criteria on the reference battery (e.g., 2nd percentile or lower), but such criteria are not appropriate if a screen is designed to identify not only children who probably need IDEA services, but also those with milder delays who need services such as Head Start or quality day care (e.g., < 16th percentile). Nevertheless, because screening tests should be re-administered over time wherein information gleaned from surveillance activities can also be brought to bear especially on negative (meaning passed) screens, detection rates will improve given repeated measurement.

Specificity (co-negativity). This analysis answers the question, what percentage of children found to have typical development on diagnostic measures also passed the screen? The computation involves dividing the number of true/co—negatives divided by the sum of true/co-negatives+false-positives. In this example, 80 children had typical development on diagnostic testing, 70 passed the screen, but 10 did not. So specificity is 70/80 = 88%.

As with our wish to identify all children with problems (100% sensitivity), we would also prefer that all typically developing children pass a screening test (100% specificity). But the messy realities of child development and its measurement do not accord such accuracy. So 70% - 80% specificity is a basic standard, but within that range, closer to 80% or higher is desirable because there are many more typically developing children than not: For each decrement in specificity, there is a geometric increase in over-referrals. Thus the balance of sensitivity and specificity needs to be tipped toward specificity, if at all possible, while still keeping sensitivity in the 70% - 80% ballpark for screening test standards. Again, typical development needs to be carefully defined, often in multiple ways (e.g., is "normal" defined as children not eligible for special services or does it also include the non-eligible but delayed, such as those scoring below the 16th percentile?).

Negative Predictive Value. This term answers the question, if a child passes a screen, what is the chance that he or she does not have an actual problem? The computation involves dividing the number of true/co-negatives by the sum of true/co-negatives+false-negatives. In this case, 70 out of 74 children with a passed screen were not found to have problems on diagnostic testing. So the negative predictive value is 70/74 = 95%.

Under-Referral Rate. This term answers the question, what percentage of children did a screening test fail to detect correctly? The computation divides the number of children without problems on screens by the total number without problems on diagnostic testing. In this case, 4 children who passed screening were found to have a problem on diagnostic evaluations, so 4/74 = 5%. This computation is the same as subtracting negative predictive value from 100% and so in this example, 100% minus the 95% = 5% under-referral rate.

Positive Predictive Value: This term answers the question, if a child fails a screen, what is the

chance that he or she truly has a problem, i.e., what percentage of problematic screening results are actually associated with problems on diagnostic measures? The computation involves dividing the number of true/co-positives by the sum of true/co-positives+false-positives. In this example, 16 of 26 children who failed the screen also had problems on diagnostic testing, but 10 of the 26 children who failed the screen did not have a problem on diagnostic testing. So positive predictive value is 16/26 = 62% but see the over-referral rate discussion below.

Over-Referral Rate. This term answers the question, what percentage of children were over-referred for seemingly unnecessary evaluations? The computation involves dividing the false-positives (those who did poorly on screens but did not have a problem on diagnostic tests) by the total number of positive screening results. In this case, 26 children had positive results but 10 children were false-positives. So the over-referral rate is 10/26 = 38%. This computation is the same as subtracting positive predictive value from 100%. In this example, 100% minus the positive predictive value of 62% = 38% over-referral rates.

It is important to note that the 38% over-referral rate in the above example doesn't reflect 38% of all patients, but rather only 10% (10 out of 100 patients). Even so, clinicians are often alarmed at over-referral rates and may be reluctant to refer as a consequence. Should they be? No! In one study (of four different screening tests compared to a reference standard battery), approximately 70% of over-referred children had numerous psychosocial risk factors and scores well below the 25th percentile on diagnostic measures of intelligence, language, and academic achievement (the point below which regular classroom instruction is less than optimally effective).[14] So over-referrals often identify children who don't qualify for IDEA but still need other interventions (e.g., Head Start, Title I public school services, parent-training, quality daycare, social services, mental health programs, etc.). Although we should report the positive predictive value on screens, it is important to parse the "broad range of normal" into those eligible for IDEA versus those not eligible but in need of other services.

The long-term costs/benefits are also an important consideration with regard to false-positive rates. Assuming that all children with positive screens are referred for diagnostic testing at a cost of approximately $1000 - $1500, these costs are substantially less than the cost of under-treatment, [a life-time loss to the child and society of more than $100,000 (in 1997 dollars) when needed early intervention is not offered.[15] The costs of subsequent evaluations can be reduced considerably if less expensive measures such as assessment-level tools are deployed between screening and diagnosis (see Chapter 13 for additional information].

Hit-Rates—An Accuracy Indicator to Avoid. Hit-rates are simply the total number of children for whom a screening test gave accurate information when compared to diagnostic measures. Co-positives and co-negatives are added together and then divided by the entire sample (co-positives+co-negatives+false-positives+false negatives). But hit rates are an extremely misleading statistic because the preponderance of results are co-negatives—meaning that specificity carries excessive weight. For example, a high hit-rate (e.g., 91%) could mean that 99% of typically developing children were correctly detected (e.g., 89 out of 90) but only 20% of children with problems were correctly detected (e.g., 2 out of 10). So hit-rates can mask serious flaws in accuracy (and most especially serious flaws in sensitivity).

UTILITY

Utility (also called feasibility) covers the practicality of tools, meaning how well specific measures work in real life. How do parents respond to tools? Do providers find measures efficient and are they willing to use them? So ideally, when constructing or studying a measure, authors/researchers should address such questions as:

(a) What are the material costs of a screening (e.g., the price of protocols or, if an option, the cost of photocopying)?

(b) How long does it take to score a measure (and what is the clinic expense for time spent scoring)?

(c) If a percentage of parents can't complete a measure on their own, how long does it take to administer a measure by interview or hands-on, and what are the associated costs?

(d) Is training information freely available or does training incur a cost? Training support, requisite time-frames, and self-training resources should be evident within test manuals or publishers' websites (e.g., links to videos, slide shows, and training exercises).

(e) Are clinicians and researchers satisfied with the measurement methods and scores offered?

(f) Are the directions easy to understand and readily visible? To give a test in a standardized and efficient manner is critical. Having directions stand out is important, especially when testing very young and active children.

(g) Is scoring clear? Are scoring supports such as CD-ROMs needed and workable in each setting where the tool will be used?

(h) If measures require stimuli (e.g., toys, spoons, etc.) is the kit easy to use? Can examiners find materials within? Are lost materials easily replaceable?

(i) What is the readability for parent- or youth self-report measures? Readability should be lower than the fifth-grade level for self-report measures, across all items and response options. Is there guidance for working with families who have limited literacy, i.e., how to administer a measure by interview?

(j) Are needed translations available? If not, is the publisher willing to help develop new ones?

(k) Can tools be administered by paraprofessionals when parents cannot complete screens on their own or when hands-on measures are needed?

(l) Is there guidance on interpreting results and selecting among referral options? Is there clinician/researcher buy-in about taking action when results are problematic?

(m) Is there a longitudinal tracking form so that results can be concatenated over time?

(n) Are electronic applications needed, available, and helpful? Tests have various electronic offerings from parent portals (where parents take measures before an encounter but don't see results) to live interviews with scoring and interpretation support, and in some cases generating parent summary reports and referral letters. Some electronic applications also offer Spanish language support.

(o) Is there guidance on how to bill and code for optimal reimbursement, depending on the type of test used?

(p) Is there published research on implementation of tools? What do colleagues who have used tools have to say? Are they able to consistently use tools or are administration rates (e.g., at well-visits) lower than established goals? If so, should a different measure be deployed?

Comment on Utility: There is an increasing body of research, including studies by Alison Schonwald and colleagues at Harvard University, offering objective information on the feasibility of detecting and addressing developmental-behavioral issues in primary care (e.g., time, practice expenses/benefits, provider and parent satisfaction, referral uptake, etc.).[16,17] Conducting practice-based research aimed at improving care is now a requirement for members of most medical specialty boards (and discussed in Section V of this chapter). Such studies will surely add to what is known about making early detection and intervention work well in primary care. A few resources and pertinent questions include:

• The table of tools in Chapter 4 provides an analysis of time and materials, i.e., practice expenses according to administration methods, training options, etc.

• Time and motion studies show that screening tools focused on parents' concerns shave several minutes off well-visit encounters by reducing "oh by the way" disruptions (thus leaving time for the more important tasks of counseling parents and making any needed referrals).

- Clinic cost/benefit studies on screens have yet to be conducted but might focus on the amount of time and money spent on inefficient or ineffective methods (e.g., eliciting informal milestones, dictating, typing, proofing reports, searching for resources or locating billing/procedure codes, etc.). Establishing a practice-expense benchmark offset by reimbursement or the price of provider time, can then be compared to the costs of deploying quality screens (e.g., online with automated scoring and report-writing via a parent portal) and then changes to clinic expense or reimbursement.

IV. GUIDANCE FOR RESEARCHERS

Whether designing new projects or evaluating existing measures, keep these key recommendations in mind for a successful project:

1. Identify your research hypothesis, and preferably keep it in front of you (e.g., on a post-it note stuck to your computer) to reduce the inevitable "cognitive drift" that occurs when exploring data and reviewing related literature.

2. Be sure to also state a null hypothesis, i.e., that any point you think provable, may turn out to be insupportable. Empiricists must strive to both prove and disprove their hypothesis.

3. Conduct a thorough literature search, keeping an eye on the research methods and authors working on your topic of interest. Authors, not professional librarians, tend to be the source for key words and may not list all relevant terms. So for an initial review, use a variety of search terms, author names, and embrace more than simply the last few years.

4. When searching for studies, use a wide range of databases. MEDLINE does not cover thoroughly instrumentation research or studies in other nations. See the Resources section below for suggestions.

5. Recognize that not all information about specific tests is published in journals and that most exists within test manuals. So if using a test in research or studying test performance, be sure to acquire and read manuals carefully.

6. Read the prior sections of this chapter on how tests are constructed, and become familiar with psychometric constructs and the statistical methods deployed. If needing to create new items or translate existing items for your study, refer to our guidance on how to write (and translate) these.

7. Conduct a pilot study to ensure items are working well.

8. Add open-ended questions to both your pilot study and final research protocol. Answers will enhance the interpretability and meaningfulness of your findings—even if such items are not expected to become part of your final set of questions.

9. If conducting outcomes studies focused on the effectiveness of a specific intervention, consider whether measures under consideration have been researched and are known to show changes over time. Some tests have enjoyed research demonstrating 'response to intervention' (RTI) but some measures have not. This does not mean that a measure you've selected would not work well but caution is advised, especially if considering use of screens as an outcome measure because the item sets are slender.

10. Consider test metrics carefully. If conducting outcomes studies, screens [with their often binary results (e.g., pass/fail)] are unlikely to be helpful since scores may not change. Consider using measures that produce a range of scores such as age-equivalents or better still, raw scores, because a more continuous metric enables a wider range of statistical methods. See Chapter 13 for information on assessment-level tools that may be helpful in outcomes studies.

11. If studying existing screens that do not produce binary results, research still needs to answer the clinical question, i.e., on this very day, do we refer or do we not refer? [For example, the Denver-II

produces several categories of results, and so in one study researchers tested various combinations of results in order to view optimal sensitivity and specificity: (a) combining "normals" with "questionables" versus the combination of "abnormals" and "untestables;" (b) comparing "normal" alone versus the combination of "questionables+abnormals+untestables;" and (c) sensitivity and specificity with the above combinations by age-group and domain.[18] Although a parsimonious solution was not found, it was not due to lack of research effort but rather to problems in the test itself. Similarly, another researcher compared children receiving an "untestable" score to diagnostic testing and provided the helpful conclusion that these children were more likely than not to be "abnormal" and thus in need of referral.][19]

12. Recognize that psychosocial risk can often eclipse the impact of health or other conditions under study. Be sure to capture variables such as parents' level of education, ethnicity, marital status, number of children in the home, social support, poverty (easiest if just presence or absence of Medicaid or free/reduced school lunch because Americans are usually reluctant to disclose income), etc. Include psychosocial risk variables in regression equations as independent variables along with results from criterion measures.

13. Read about statistical methods and how to select techniques appropriate for the questions asked.[20,21] When advice from a statistician is needed, seek someone with a background in child development research.

14. Establish a project advisory board and seek mentors (e.g., from the Society for Developmental-Behavioral Pediatrics, the Ambulatory Pediatric Association).

15. If cross-validating a measure, be sure to compare it appropriately, i.e., select a concurrent battery that fully measures the content of the test under study. For example, most screens and assessment level measures sample a wide range of skills. Comparing such tools only to an IQ test is not reasonable because an IQ test does not measure self-help, academic skills, etc. Avoid "comparing apples and oranges."

16. Match the cutoffs used for the criterion battery to those of the measure you are studying (e.g., if a screen identifies children at risk, such as those who perform at or below the 16th percentile, compare the criterion battery to the 16th percentile or below).

17. Avoid a study design in which one screen is compared directly to another. Screens often measure different dimensions of child development and all contain error. Over- or under-referrals may compound rather than overlap, and so it is wise, when studying multiple screens, to compare each screen to reference measures.

18. Apply practical, real-life criteria to the reference battery for determining disability status. For example, when sorting children into disability categories on the basis of criterion measures, use standards such as eligibility for IDEA programs. Given that IDEA eligibility varies across States, it is best to test several different eligibility criteria in order to ensure generalizability of research findings.

Research Issues with Needs Surveys, Quality of Care, and Use of Existing Data Sets

The American Academy of Pediatrics, the National Survey of Childhood Health (NSCH), First Five California (CHIS), the Medical Expenditure Panel Survey (MEPS) and other initiatives have constructed (usually telephone) surveys of child development focused on how well providers address developmental-behavioral issues including screening and referring, disparities in care, parents' perceptions of quality of care, etc.[22,23] In many cases, these and other data sets are available to researchers for post-hoc analyses. Often test publishers with online applications can make available anonymized data sets (see the Resources section below and *www.pedstest.com/TheBook/Chapter19*). Below we include highlights of

studies on child development based on population surveys:

National Telephone Surveys on Child Development

National surveys provide an opportunity to gather critical information on health and developmental issues on large population samples. Although surveys do not indentify individuals or assist clinicians in day-to-day work and decision-making with patients, survey data not only describes a nationally representative group, but also enables a focus on the issues of specific groups (e.g., Hispanics, Asians). The invaluable information gathered often functions as a needs-assessment and is thus useful for formulating national, State or local policies focused on allocating resources to improve overall public health. Survey studies also provide prevalence estimates for specific conditions or events (such as access to care) and thus function as something of a census for developmental and other problems.

The California Health Interview Survey (CHIS) and Cultural Issues. CHIS provides a model for addressing patterns of developmental delays in a diverse population, including specific Asian subgroups. CHIS is the largest among State health surveys as befits the population of California. The survey uses a random-digit-dialing telephone survey method of data collection and collects information on a wide range of health and health-related behaviors, and is designed to track health status and disparities among the State's heterogeneous populations. It provides both Korean and Vietnamese oversamples, producing representative estimates for these and most other Asian subgroups.

In order to capture the linguistic diversity of the population, the survey conducts interviews in multiple non-English languages including Korean, Vietnamese, Mandarin and Cantonese. A multicultural technical advisory committee consults on the selection of survey languages, suggests multicultural health topics, and recommends measures designed to provide insight into multicultural health issues, including acculturation and discrimination in healthcare settings. In addition to translations, CHIS develops questions that are linguistically simplified and strives to attain the English equivalence if translated into a non-English language. Cultural adaptation reviews and cross-cultural cognitive testing identify whether survey questions are appropriate and culturally unbiased so that offensive or problematic language and concepts are excluded. Finally, behavioral coding of the field-interviewers' verbal interactions with respondents identifies potential cultural and linguistic barriers to the administration of survey questions.

In the 2003, 2005, and 2007 CHIS surveys, parents of children ages 4-months to 5-years were asked age-specific questions (in English or the respondent's native language) about perceptions concerning their child's emotional or behavioral development using an close-ended, twelve-question version of *Parents' Evaluation of Development Status* called *Survey PEDS* which was adapted without additional validation but standardized separately (see updates at *www.pedstest.com/research*).[24] Studies on *Survey PEDS* showed that risk levels were comparable to those of the open-ended clinical version of *PEDS*. In CHIS, depending upon the age of the child, parents were asked how "concerned" they were about their child's developmental progress in eight domains including fine motor, gross motor, expressive language, receptive language, self-help, social-emotional, preschool and school skills. Parents were also asked questions about specialist referrals for any development, speech and language problems for their children. Analysis of the data revealed some unexpected findings for the Asian subgroups captured in CHIS.

According to parents' responses, Asian children had the highest proportion of risk for developmental delays compared to Latino, African-American and white children. Yet among all children at high risk, Asian children had the lowest rates of professional referrals for any type of developmental delay. We found these survey results counter-intuitive for several reasons. Because developmental delays are often associated with lower socioeconomic status, single-parent households, and lower educational attainment, we did not expect Asian families to be the group at highest risk for developmental delays. Additionally, we expected higher referral rates for children whose parents express the greatest concern for their children's developmental and behavioral status. Asian children, in contrast, did not reflect such patterns in this survey. Even after accounting for income and language differences, Asian parents continued to express far more concerns than other groups. Taken together, these unexpected findings provide insight into the cultural, translational and linguistic challenges in working with Asian parents

in the survey setting.

The nuanced complexity of Asian languages and/or cultural interpretation of the questions suggest that the word "concern" may have been interpreted by parents as other than the intended meaning. Specifically, instead of capturing perceptions of worry or special needs regarding their children's behavioral or developmental skills, we suspect that Asian parents were inclined to report concern based on the concepts of "care for" or "interest in" the child's particular health or developmental milestones. This in turn elevated risk scores among Asian children regardless of clinical need or true risk of developmental delay. Asian cultural values regarding parental accountability may lead to interpretation of these questions of "concern" as obligatory involvement in the child's development. Challenges with cultural translations and interpretation of the questions may be amplified among different Asian populations including those those interviewed in English versus Asian languages, as well as immigrant and non-immigrant groups.

Similar challenges were found with Spanish translations of National Survey of Child Health in which Spanish speakers reported far fewer concerns than predicted given elevated psychosocial risk.[23-25] Translation problems were a likely contributor, although actual access to health care is surely a major issue. We then worked with the author of *PEDS* who provided us better, i.e., thoroughly vetted translations to use in future administrations of CHIS. We offer several suggestions for future population-based surveillance of child development and behavior risk in a population:

- Testing of survey screening tools is needed, either through cognitive interviews or focus groups, to ensure that both the translated questions and their concepts are accurately administered and understood across cultures. Self-reports often lead to interpretation biases; therefore parental questions regarding their children's health or development must also take into account the cultural values that are linked to specific survey item responses.

- Recognize that integration into mainstream society may affect the ways in which parents who are ethnic minorities view concerns, professional referrals or their child's overall development. Language and/or cultural assimilation can affect the interpretation of questions. Recent immigrants may retain linguistic or cultural norms not shared by their non-foreign born counterparts.

- Telephone surveys should consider the immigrant status of the targeted population when designing and implementing screening tools for the detection of developmental and behavioral problems among children in a community.

- Open-ended questions are invaluable tools to gauge additional thoughts or concerns that may not have been captured using close-ended response options—and to ensure that parents are actually answering the question asked. Research using open-ended questions about parents' concerns reveal these take an average of 2 minutes and so can be used readily in population surveys.[25,26]

- Consider using online screening services for those sections of surveys devoted to early detection. These services offer a degree of accuracy in scoring that is not possible otherwise, and in many cases provide interview-style questions, as well as quality and thoroughly vetted translations.

There are many other examples of national surveys yielding invaluable information on families' developmental-behavioral needs, quality of care, etc. We've listed these in the Resources section of this chapter with information about national data sets that can be used for further studies.

Adapting Tests for Other Nations

Researchers all over the world, whether working in developed or developing nations, are engaged in projects requiring measures of children's development, parenting, and psychosocial risk. Chapter 17 and 18 describe American as well as international initiatives in early detection and intervention. Meanwhile, a preponderance of tests are developed in the United States. Many other nations, because they lack their own standardized tools, need to adapt measures developed in Western, English-speaking countries. While translation guidance is essential, this is not sufficient for ensuring cultural relevance

and applicability. Stimuli may need to be changed, psychosocial risk factors differ, parents' tolerance for children's behavior and understanding of child development vary across cultures, and ultimately, entrance standards for kindergarten (and the age of kindergarten entrance) are often diverse. Below are some issues to consider when adapting Western measures for use in other nations:

1. Within Western, English-speaking nations, complete revalidation of measures may be unnecessary because performance differences are usually miniscule. Nevertheless, because there are curricular differences, it is still helpful to at least conduct a standardization study to determine whether performance patterns are similar (e.g., frequency of risk levels, similarity of age-equivalent or raw scores, etc.). In developing or non-English-speaking nations, restandardization is always needed.

2. If adapting tools focused on milestones, recognize that some items will need to be changed, replaced, deleted or added. For example, self-help skills may differ substantially (e.g., mastery of chopsticks doesn't occur until 4-years of age, while use of a spoon is mastered by much younger children). The various self-help skills children need to know vary by culture, particularly in rural versus urban areas (e.g., preschoolers living on farms may be expected to feed the chickens or mash palm hearts into oil, while urban preschoolers need to master crossing a street safely and respond correctly to national safety signs). Images of people, their skin color and clothing may need to be changed, and different responses may need to be accepted (e.g., there are no snakes in Iceland and so "worms" becomes a correct response).

3. Explore normative behavior qualitatively and with many types of professionals, including teachers. For example, what prerequisite skills does a 6-year-old need to know in order to be successful in school? This information helps guide standardization, adds meaning to results, and, as with needed changes to stimuli and children's expected skill sets, provides direction for adding or altering test items.

4. Explore parents' understanding of child development and culturally-driven for tolerance (or impatience with) children's behavior. For example, ADHD is less of an issue in cultures where the typical energetic behavior of young children is better tolerated than in many Western nations.

5. Recognize that psychosocial risk factors vary. Consider current events that may have a dramatic impact on well-being (e.g., witness to violence and post-traumatic stress, in both children and parents). Health and environmental issues differ and will have an impact on measuring development. For example, a study in Tanzania conducted during a malarial outbreak found that parents were so worried about their children's development (as well they should be) that most scored in a very high-risk category on screening.[27] All this means that unique and current national circumstances as well as different psychosocial risk factors need to be taken into consideration when evaluating the performance of measures.

6. Despite differences in types of psychosocial risk, anticipate that multiple risk factors will have an adverse impact on child development. For example, children who are poor, rural and whose families have limited education, will usually do less well than children who have wealthy and educated parents. A discussion of risk factors is presented in Chapter 10.

7. Recognize that citizens in different nations may be more or less sensitive to questions about psychosocial risk factors. Even across Western nations, questions about ethnicity, nation of origin, and income, may be considered invasive in some countries but less so than others. Thus, somewhat oblique methods of determining income may be helpful (e.g., in the US, eligibility for Medicaid, free/reduced school lunch). In other nations, different approaches to questions are needed (as is a thorough understanding of social services). Parents' level of education can also serve as a proxy for income and is easier data to gather.

In any case, researchers need to identify common ethnicities, languages spoken, levels of education and other socioeconomic and demographic variables essential for standardization research. Most nations have something comparable to the US Census Bureau for determining population

demographics. See the Resources section in this chapter for links. With population parameters in hand, refer to the guidance presented earlier in this chapter regarding sample sizes and other considerations for standardization.

9. A viable translation, thoroughly vetted, is essential (see translation guidelines presented earlier in this chapter). Dialectical differences within nations need to be carefully considered and multiple variants of translations may be needed. In some nations and across nations with a common written language (e.g., China and much of the Middle East), separate interview translations may need to be created for families who do not read well.

10. One of the biggest challenges ever is working with languages that are not written down. [In studies of Aboriginal people in Australia where only three of their 100 languages exist in print (and where many people speak combinations of several different languages), use of tape recorded versions of screens were needed (after the sort of vetting required for any translation).] Telephony and talking touch-screens may be options for parents with limited literacy (although offline access may be needed). Note also that pictograms used in Western nations (e.g., to convey concepts like "Wait," or "Go") do not always translate into other countries. So take note of conventional signage and make use of these, especially if using measures that tap common safety words, street and store signs. Similarly, hand gestures (sometimes required for test directions) require scrutiny—these are not universal and in some cases Western gestures and body language may be downright offensive!

11. When standardizing a test in other nations, administer more items than needed, i.e., ones originally designed for older or younger children including those outside the age-range of the original test. Anticipate that new norms might change or expand the age-range appropriate for the test.

12. If there are diagnostic or assessment-level instruments already normed in a nation, administer these during the standardization process, at least to a random sample of children. If there are no previously normed measures, administer an assessment-level measure alongside screens. That way it is easier to determine cutoffs after adjusting norms for the validation measure used.

13. After you've gathered data, view the typical performance of children at each age level. Then consider whether items from the original norming studies need to be shifted to older or younger ages (e.g., motor skills items may be mastered by younger children, alphabet naming may be mastered by older children).

14. Explore different performance patterns as well as probable predictors of problems. For example, parents' concerns about self-help skills, while not a predictor of disabilities in Western populations, were associated with problems in India and elsewhere.[28]

15. Consider standardizing tests with simultaneous administration methods (hands-on, in writing by parents, and by interview). That way, you've ensured that a range of approaches are grounded in evidence, and workable across families with varying degrees of literacy and professionals of varying qualifications. Be sure to compare the results of administration methods so that you determine the reliability (e.g., between parents versus providers) of your revised measure.

16. Seek support from test authors and publishers because they have experience with test norming, translations, item changes, etc. Publishers may be able to put you in touch with other clinicians and researchers with ongoing projects in the same language or nation.

V. PLANNING AND CONDUCTING A QUALITY IMPROVEMENT PROJECT

The American Board of Medical Specialties (ABMS) (*www.abms.org*) assists the twenty-four approved medical specialty boards in establishing standards for evaluation and certification of physicians. Member societies include the American Boards of: Pediatrics; Family Medicine; Preventive Medicine; Emergency Medicine; Psychiatry and Neurology; Medical Genetics; and Physical Medicine and Rehabilitation. We single out these groups because all (including Emergency Medicine with its focus on disaster preparedness and the well-being of children and parents, along with everyday work with the health and developmental consequences of psychosocial risk) tend to focus on various aspects of developmental-behavioral issues as part of certification/re-certification requirements.

The ABMS and its constituent boards require Maintenance of Certification (MOC). MOC embraces four goals: (1) Professional standing and licensure; (2) Life-long learning and self-assessment; (3) Building cognitive expertise; and (4) Identifying/rectifying gaps in quality of care. Goals 2 and 3 embrace ongoing continuing medical education (e.g., attending conferences offering CME, reading journal articles and answering post-test questions, etc.—see the Resources section for CME opportunities).

Goal number 4 is generally referred to as a Quality Improvement Initiative (QI). In pediatrics, residents and fellows are required to conduct a QI project during their training. Pediatric nursing societies require CME and the National Association of Pediatric Nurse Practitioners (NAPNAP) encourages participation in MOC including offerings from the American Academy of Pediatrics. QI initiatives can be one of two types:

1. Participating in existing approved projects involving physician teams collaborating across practice sites and/or institutions to implement strategies carefully designed to improve care. Experienced coaches guide these multi-practice clinical improvement projects.

2. For individual providers/clinics, there are web-based, self-paced, expert-developed quality improvement activities that physicians complete within their own practice settings.

For provider teams wanting to develop their own QI initiatives, accreditation involves:

- An improvement in practice that fulfill aims of the Institute of Medicine, i.e., safe, effective, efficient, equitable, timely, and patient-centered;[29]

- Provider participation in planning, and progress evaluation with appropriate changes to implementation as suggested by results;

- Evidence of direct physician action with their own patients via chart reviews; and

- A project duration of at least 3 months and taking at least 10 hours.

QI BASICS

Quality Improvement initiatives are research projects but go beyond a literature search and a testable hypothesis. Instead, QI also deploys Plan-Do-Study-Act (also known as the Compass Model), which begins by defining a clinical problem (such as limited use of quality tools, limited referrals or referral uptake by parents).[29-31] Next up is collecting baseline information, i.e., benchmark rates, by collecting data for review, usually over a month-long time frame. During or following this process, planning meetings focus on further refinement to the central question (e.g., what are the obstacles to implementation of screens, to referring, to referral uptake, etc.). From these meetings, goals are established (e.g., 90% of well-visit patients receive quality screening; 100% of those with probable problems are referred; 90% of those referred receive evaluations). In addition, an initial implementation plan is defined and then trialed (usually another month or two of data collection). Both baseline, initial trials and subsequent trials are concatenated for comparison (and usually referred to as "run-charts"). Along the way,

providers are asked to keep a list of comments on their 'daily hassles' and ideas for improvements. Further meetings identify successes, challenges and revisions to the plan, i.e., "a rinse-repeat (in new ways) cycle" is needed to figure out next approaches for solving the identified problem. At the end, a debriefing meeting is needed to finalize the optimal plan. QI is "a work in progress" but one that leads to viable answers on how to improve care.[30,31] The implementation form in Chapter 16 (downloadable at *www.pedstest.com/TheBook/Chapter16)* provides a helpful list of considerations for assisting QI projects in planning, reaching, and sustaining targeted goals in early detection challenges.

QI Example #1: The AAP's Bright Futures Training Intervention Project (BFTIP)[32]

Methods and Benchmarks: *BFTIP faculty trained providers in fifteen different practices on the abiding philosophy of Bright Futures. Each clinic was required to review twenty consecutive charts with an eye toward which goals had been addressed and which goals needed attention.*

Progress Tracking/Outcomes: *Practices were provided monthly feedback via charting of progress and monthly conference calls on progress toward all Bright Futures goals. Most practices (87%) decided to establish a recall/reminder system (focused on early detection methods, referral tracking and follow-up with families who missed appointments), and 80% established a community linkage system (e.g., a regularly updated referral resource list, referral information, and referral coordination methods including regular two-way communication with services).*

Conclusions, Issues, Next Steps: *Providers recommended that subsequent QI research start with selection of quality screening/surveillance tools including measures of family risk and resilience. Next step recommendations were to introduce a preventive service prompting-system (e.g., well-visit forms and problem/process checklists that reminded clinicians of what to do and when). The BFTIP project participants also noted the arduous task of implementing new processes while clinicians were also in the ever-busy midst of providing care (implying that different times of the year might be better for starting up a QI). While providers' sense of 'do-ability' was critical to uptake, the usual barriers were found: the challenges of introducing new forms, competing demands on staff time, lack of familiarity with specific methods of screening, lack of agreement with Bright Futures recommendations, and disbelief that outcomes would be influenced by a structured approach to screening. So all issues are fascinating topics for further QI projects and for scrutinizing implementation suggestions (see Chapter 16).*

QI Example #2: AAP's Developmental Surveillance and Screening Policy Implementation Project (D-PIP).[33]

Methods and Benchmarks: *D-PIP was designed to view the feasibility of the AAP's 2006 policy statement on early detection.[34] In this study seventeen diverse practices (including teaching hospitals, community health centers, and private pediatric clinics) in fifteen US States, volunteered to trial implementation of measures over a nine-month time frame. None were using validated measures prior to the study. All were then exposed to a range of measures from which they could choose. Of the seventeen practices, fifteen opted to use screens relying on information from parents, i.e., PEDS and/or ASQ, often in combination. Both qualitative and quantitative analyses were deployed to view screening rates over time and to capture providers' issues regarding implementation.*

Progress Tracking/Outcomes: *In the final four months of the study, screening rates averaged 80% across practices (although variability was wide: 33% to 100%). Problematic performance on screens varied by the screen used. Referral rates, as determined by chart review, varied by time of year (far fewer during flu season), but averaged 61% during the course of the study (although again there was a wide range across practices: 27% to 100%).*

Conclusions, Issues, Next Steps: *Nearly all practices recommended an office-wide implementation system dividing responsibility across staff and clinicians for administering, scoring, interpreting, and making referrals based on screening test results. Honing the implementation process to make sure that screening was offered consistently was a common issue and required clinics to repeatedly trial the process*

until establishing one that was consistent. Many providers found that using screening/surveillance only at certain visits created problems—implying that a routine process is easier. Tracking referrals was a common challenge and included issues with families, clinics, and referral services failing to follow-up, although nine of the seventeen practices felt referral uptake was much improved via more effective communication of test results to/from early intervention services. Ultimately, next step recommendations focused on both clinic implementation issues and better coordination with referral sources.

Comment on Creating QI Projects: Implementation and referral follow-up are a consistent theme in American Academy of Pediatrics' initiatives. The challenges uncovered are surely generalizable to other settings and thus to new QI projects in developmental-behavioral care. Capitalizing on what is known and working from there is much advised. Chapter 16 covers methods and research in effective implementation and the many considerations for ensuring a QI project works well. Chapter 5 covers the many issues in referral coordination. We hope the above examples and the guidance offered in this book become starting points for projects focused on overcoming challenges, and delving further into creating workable solutions.

QI projects are easier if using electronic resources for screening. Online screening services circumvent administration errors via automated scoring. Some also create measurable time-savers by generating referral letters and parent summaries and some report billing/procedure codes (useful if QI efforts focus on practice cost-benefits). All establish digital databases that provide enormous help for benchmarking and for progress-tracking. All this means that new QI projects should ideally focus on an increasingly digital world and how this helps us do better with developmental-behavioral issues. Note that it is not necessary to have an electronic healthcare record in order to use online services (although EHRs are definitely helpful for tracking the progress of individual patients).

Online screening services offering quality tools and databases include the *ASQ Pro*, (*www.brookespublishing.com*), *PEDS Online* (*www.pedstest.com/online*), and *CHADIS* (*www.chadis.com*). *CHADIS* offers particularly rich support for QI and MOC efforts via run-charts for monthly review, "point of care" learning (via prompts related to the clinician's own patient-specific issues) as well as e-chapters providing layered, bulleted references with links to current research abstracts. All such web-based data collection options provide decision-support that enables clinicians and practices to turn the process of quality improvement into a means of both life-time education and professional/practice improvement, i.e., by taking on targets for new evidence-based care even beyond the requirements for re-certification.

VI. RESOURCES FOR QUALITY IMPROVEMENT AND OTHER RESEARCH PROJECTS

This list of resources (with live links at *www.pedstest.com/TheBook/Chapter19*) is not exhaustive. We will keep the website updated and encourage you to send suggestions on new QI projects, data sets available for analysis, etc. via *www.pedstest.com/ContactUs*.

QUALITY IMPROVEMENT AND CME RESOURCES

1. For providers wishing to work on a clinic-level quality improvement project, the American Board of Pediatrics (*www.ABP.org*) has well-defined performance improvement modules (PIMs) including ones on adolescent depression, vision screening, and early detection using quality screening tools. The modules provide detailed procedures, requisite forms, and demonstration videos (e.g., (*http://pim.abp.org/development_screening/global/demo.php*).

2. For multiple-setting clinics, the American Board of Pediatrics' site lists collaborative projects. In addition, many approved projects can be found at AAPs EQIPP/PediaLink site (*http://pedialink.aap.org*). The *CHADIS* initiative can be found at *www.chadis.com*. Most of the ABP and AAP projects are also endorsed by NAPNAP but is not clear whether members of other medical specialty boards can participate and receive credits.

3. The Vermont Child Health Improvement Program (VCHIP) (*www.uvm.edu/medicine/vchip*) offers QI projects (e.g., improving rates of detection in autism spectrum disorder) but also technical assistance on QI (e.g., raising national literacy rates). VCHIP also sponsors the National Improvement Partnership Network (NIPN) (*www.uvm.edu/medicine/nipn*) and its many QI projects embracing over fifteen States and regions.

4. The National Association of State Health Policy's ABCD projects (all devoted to improving early detection, referral rates, and collaboration with IDEA) provide MOC/QI projects for participating providers (*www.nashp.org*). States and regions working with Help Me Grow can receive QI support for completing the American Board of Pediatrics' developmental screening performance improvement module (*www.helpmegrownational.org*).

5. Many journals and e-journals (such as *Contemporary Pediatrics, Pediatrics in Review, Medscape Pediatrics,* NAPNAP's *Journal of Pediatric Health Care* and the AAFP's *Family Physician,* offer continuing medical education credits for reading collections of articles on early detection, and answering questions.

6. Reach Out and Read (ROR) offers a CME course focused on background information and tools to promote children's developmental skills and later school success. For more information, visit *www.bumc.bu.edu/cme.*

7. The National Institute for Children's Health Care Quality (*www.nichq.org*) has a range of projects for which credits are offered, including follow-up on infant hearing-screening, autism spectrum disorders, ADHD, and establishing a medical home.

8. The Continuity Research Network of the Academic Pediatrics Association (CORNET) (*www.ambpeds.org*) provides training, collaborative QI projects and support for faculty and residents in continuity care clinics. Among the many ongoing projects are initiatives focused on mental health and decreasing aggressive behavior in children via the "Play Nicely" program (described in Chapter 7).

Sources for Literature Reviews

1. The National Library of Medicine (MEDLINE) (*www.ncbi.nlm.nih.gov*) focuses on peer-review biomedical literature and includes full-text articles for selected journals, and abstracts for others.

2. Health and Psychosocial Instruments (HaPi) (*www.ebscohost.com*) provides information about behavioral measurement instruments abstracted from journals covering health and psychosocial sciences, and research-review databases such as the Buros Mental Measurement Yearbook. Records provide information on questionnaires, interview schedules, vignettes/scenarios, coding schemes, rating and other scales, checklists, indices, tests, projective techniques, etc. The HaPi data base is often adopted by libraries and shown alongside MEDLINE.

3. The PsycINFO database from the American Psychological Association (*www.apa.org/psycinfo*) includes more than 3 million records for peer-reviewed literature in the behavioral sciences and mental health, and is often available via online university libraries.

4. ERIC is The Education Resources Information Center provided by the US Department of Education (*www.eric.ed.gov*). ERIC provides free access to education literature to improve practice in learning, teaching, educational decision-making, and research including long-term outcomes studies.

5. EMBASE (*www.embase.com*) includes all MEDLINE records but also millions of international journals. Carried by most university libraries (although often only with abstracts, not full-text papers), EMBASE enables researchers interested in identifying studies in other nations to find comparable work. Exploration of this data should proceed with a recognition of English spelling differences when searching, (e.g., "behaviour," "immunisation"), and that terms for ethnic

minorities vary substantially (e.g., in Great Britain, "Asian" usually refers to those from the subcontinent of India and Pakistan).

6. Collections of review papers in developmental-behavioral pediatrics are often available. Examples are the Cochrane Collaboration (*www.cochrane.org*) and its extensive summaries of research on a range of topics. The *Journal of Developmental and Behavioral Pediatrics* (*www.sdbp.org*) has an ongoing series on measurement issues in child development.

7. RAND (*www.rand.org*) is designed to assist the US government with scientific research, analysis, and development. RAND's Child Policy staff have published over 1300 omnibus research reviews on such topics as homelessness, mental health, adjustment issues in military families, how to evaluate the quality of childcare programs, etc. The organization also hosts post-graduate training and summer internships.

8. The Center for Mental Health in Schools (*www.smhp.psych.ucla.edu*) recognizes that most mental health services for children are provided by the public schools. Initiated by the University of California at Los Angeles, the school mental health project houses a listserv, a quarterly newsletter, links to journals focused on child psychiatry and psychology, and creates research reviews such as "Mental Health in Schools: Engaging Learners, Preventing Problems, and Improving Schools."

9. The University of California at Los Angeles' Center for Healthier Children, Families & Communities (*www.healthychild.ucla.edu*) provides publications and a listserv focused on building effective communities and services around families' psychosocial needs.

National/International Demographics and Performance Indicators

1. If it is difficult to find statistics bureaus for other countries, see *www.unstats.un.org* and *www.who.int/research/en.* With population parameters in hand, refer to guidance above on sample sizes and other considerations for standardization. The Wikipedia *(www.wikipedia.org)* has detailed articles about nations, languages spoken, and links to sites within countries for further demographic information.

2. Several agencies have compiled abundant rankings of US States embracing a wide range of variables relevant to developmental-behavioral pediatrics. Examples are:

    (a) Annie E. Casey Foundation's Kids Count (described in detail in Chapter 17 on National Initiatives) publishes a regularly updated State- and local-level data book, special reports, issue briefs, fact sheets focused on high school dropout rates and teen births, proportions of children born with low birth-weights, living in single-parent or low-income families, etc. (*www.kidscount.org*).

    (b) The Agency for Healthcare Research and Quality provides a range of quality indicators in preventive health care (*www.qualityindicators.ahrq.gov*) including measures and software for data analysis.

    (c) Child Trends (*www.childtrends.org*) focuses on improving developmental and health outcomes for children. Its database publishes information on the effectiveness of various initiatives (e.g., after-school programs, book sharing, etc.).

    (d) The Commonwealth Fund (*www.commonwealthfund.org*) hosts the Health Systems Data Center within which is an interactive comparison map on such variables as numbers of children receiving annual developmental-behavioral screening, mental health screening and treatment, etc. [It is not clear whether this service is currently updated.]

The Offord Centre for Child Studies (*www.offordcentre.com*) conducts population surveys on developmental-behavioral status and psychosocial risk. Developed in Canada and used in several nations, the Offord Centre provides mapping software showing families' needs in relation to available services.

Existing Data Sets for Further Analysis

For researchers interested in working with existing data there are many options. For requests to analyze existing data (these must be HIPAA compliant and fully de-identified), approval from a university Internal Review Board (IRB) is still needed. Among the many IRB protocols, the appropriate form is "Research Not Subject to FDA or Common Rule"—often (and somewhat oddly) referred to as Non-Human Subjects Research. Suggestions for locating data sets include:

1. The Data Resource Center for the Child and Adolescent Health Measurement Initiative (CAHMI) (*www.childhealthdata.org*). The site offers data from the National Survey of Children's Health and the National Survey of Children with Special Health Care Needs together with national and State indicators established from prior studies.

2. Large multi-site/State collaborative investigations may have data sets available for research. See CORNET (*www.ambpeds.org*) and the AAP's Pediatric Research in Office Settings (PROS) projects (*www2.aap.org/pros*) that each have studies focused on developmental-behavioral issues (e.g., child behavior problems, child abuse recognition, and violence prevention).

3. Online screening services (see Chapter 4 for current options) may be able to share anonymized data sets. For example, the verbatim concerns of 47,000 parents accessing *PEDS Online* in primary care (*www.pedstest.com*) is being analyzed by researchers interested in viewing the content and changes in parents' concerns according to well-visit ages. Additional studies focus on specific parental concerns associated with child behavior/social-emotional problems, possible autism spectrum disorder and other developmental disabilities. *CHADIS* (*www.Chadis.com*) is able to provide large data sets and recently worked on new standardization for the *Pediatric Symptom Checklist*.

Miscellaneous Research Resources

1. If writing items, test the readability of questions with a variety of reading formulas—each has strengths and weaknesses. The website, *www.readingformulas.com,* explains how each formula works, what information they provide, and enables input of text for analysis. Be sure to test questions separately from response-options because some formulas use sentence length as part of the criteria, and so including choices for answers such as, "yes" or "sometimes," can falsely lower the results.

2. If translating items and particularly for international studies, see the recommendations provided in this chapter and also the International Test Commission's Guidelines for adapting tests (*www.intestcom.org*). The site also includes guidance on internet/computer applications and quality control in scoring and interpretation, etc.

3. Helpful resources for a basic understanding of statistical methods include *Reading Statistics and Research* for the essentials of univariate techniques including non-parametric tests (with websupport at *www.readingstats.com*).[20] *Using Multivariate Statistics* provides a clear (and actually fun) discussion of multivariate methods.[21] Manuals for the various statistical packages are useful, but at least for the Statistical Package in the Social Sciences (SPSS), earlier versions are more informative about metrics.

4. The University of California at Berkeley has a helpful glossary of statistics terms and concepts (*http://statistics.berkeley.edu*).

Chapter Comment: *There are many unanswered questions worthy of exploration especially when it comes to detecting and addressing developmental-behavioral issues in primary care. Issues include:*

How well do screens identify specific problems such as cerebral palsy? Can a single broad-band screen effectively detect a variety of problems and thus can we dispense with narrow-band tools?

- *Does screening itself confer a benefit to families (an important consideration in the US Preventive Services Task Force recommendations) leading to questions such as, do parents learn something about child development from screening, and do parents of children with problematic screening results work harder to build skills prior to engaging formal intervention?*

- *What are the limitations and impact of developmental-behavioral promotion in primary care, given the few minutes we have to spend in well-visits?*

- *Do we actually need so many physical exams at well-visits or would some of that time best be directed toward counseling parents on child-rearing issues?*

- *How well can we detect and prevent future problems before they even start (e.g., with tools that capture both developmental-behavioral status as well as psychosocial risk and resilience)? Can screening/surveillance become less of a tertiary intervention and more of a primary intervention (meaning detection and intervention of occult factors)?*

- *What is the economic health of practices using quality screens (e.g., do quality measures using parent-report save staff time and increase clinic revenues)?*

- *What rates of screening test failures can we expect in different settings so that providers know what to anticipate in terms of referral rates if working with families in crisis, Medicaid populations, etc?*

- *What encourages providers to persist with evidence-based screening and surveillance? Does improved communication with referral sources make a difference in providers' willingness to use good tools and to refer when results are problematic? Are practice cost/benefits a compelling reason? How can we best help clinicians surmount obstacles to implementation?*

- *Why do some providers continue to use early detection methods associated with under-identification?*

- *How can we best encourage early detection and intervention in developing nations?*

These are but a few issues worthy of investigating. Complex indeed is measuring child development, child and family outcomes, parent satisfaction and needs, improvements to providers' delivery of developmental-behavioral care, and coordination of referrals. We have not done justice to the increasingly sophisticated statistical techniques available to researchers, but instead addressed the fundamentals required for quality measurement. The fundamentals begin with research aims that are not simply ornamental, but are instead functional and useful. Because screening and surveillance are real-world issues, we encourage researchers to aim study goals in a way that translates science into practice.

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Chapter 20: The Clinician-Advocate: Supporting Children with Disabilities and their Families

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INTRODUCTION*†

Approximately 1 in 6 children in the United States, ages 3- to 17-years, has a developmental disability.[1,2] Developmental disabilities range from mild to severe and include language impairment, learning disabilities, attention deficit disorder, cerebral palsy, intellectual disability (formerly mental retardation), autism spectrum disorders, vision and/or hearing impairments, and many others. Clinicians who care for children are uniquely trained to promote health and wellness. This expertise can make providers powerful advocates for children with disabilities and their families.

Advocacy can become an important role for clinicians. Advocacy can occur on an individual level with a child and family, at the local level within the community, and at the State or even Federal level. Busy clinicians serve as advocates every day when they talk to a teacher or connect a family with a community group. Many clinicians advocate in their community by serving on local boards or helping with community projects. While many clinicians are working regularly at the Federal level, a busy clinician does not have to make a trip to Washington, DC to be an effective and important advocate in the life of a child with a disability. This chapter considers advocacy at four levels: clinical, community, legislative and within systems-of-care, and provides examples of how clinicians can help families at the individual, local, State or Federal levels. At the end of this chapter are links to advocacy resources.

ADVOCATING THROUGH CLINICAL CARE

The Medical Home

Clinicians can support patients in many ways. The American Academy of Pediatrics (AAP) recommends that every child have a medical home that is "accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective."[2] Providing a quality medical home is particularly important for children with disabilities or chronic medical conditions.[3,4] When providing carefully coordinated, family-centered care, the various professionals working with children should collaborate in the promotion of healthy outcomes and quality of life improvements.

There are many adaptations to improve care experiences for families, as well as for clinic personel. Some practices "flag" charts so that office staff know to schedule additional time for children with complex medical conditions or disabilities. Larger practices should provide case management for complicated patients. Although appropriate and quality clinical care for patients with disabilities can be time consuming, organizational adaptations help maintain efficiency within clinics.

Action Steps:
- Some children are very sensitive to chaotic or loud environments. These patients might be better served by having the first or final appointment of the day;

- Minimize exposure to an over-stimulating and possibly germy waiting room by taking the child to an exam room when they arrive or bringing children through a back entrance to avoid the waiting room altogether;

- Review office procedures and environment and adapt to accommodate the needs of children with disabilities and their families;

- Understand what it takes to provide a medical home for children with disabilities and their families. (*www.medicalhomeinfo.org*)

Early Identification

Note that most children with disabilities and delays are not identified as early as they could be. Outcomes are worse for children with problems whose detection is delayed. Clinicians can support children and families by advocating for early identification, and prompting referrals to appropriate intervention services.

Action Steps:
- Know referral sources in your community for diagnostic and early intervention services;

- Use public awareness campaigns such as "Learn the Signs. Act Early." to increase parental awareness about the need to take action on their concerns.[5]

Anticipatory Guidance

Anticipatory guidance is a part of every well-child check. In addition to typical recommendations addressing topics such as nutrition and safety, families are supported by information on how disabilities may be associated with difficulties in sleep, feeding, toileting, communication, and behavior. Parents who are informed about potential problems and have resources for support and information are better prepared to handle challenging situations.

Clinicians can encourage parents to help their child participate in extra-curricular activities in their communities. There are sports organizations supporting children with disabilities or options for participating in existing sports teams. Clinicians should ensure that appropriate medical precautions are taken. Such activities are beneficial to children's development, family well-being, and to the community as a whole.

Action Steps:
- Encourage families of children with disabilities to engage in community activities;

- Advocate that sports programs and other recreational activities include children with disabilities or help create programs for children with disabilities.

Transition

As children with disabilities grow, they and their families will need to learn how to navigate transitions from one service system to another. The first transition occurs within the educational system at age 3-years when children move from Part C, Birth to Three Early Intervention to the local school system where they will receive special education services (either as individual therapies or as part of other educational programs). For children enrolled in IDEA Part C, transition planning begins six to nine months prior to the third birthday. During transition planning, parents receive information about options including preschool special education, Head Start, and other community-based programs. The National Association of Child Care Resource and Referral Agencies' website has tools to help parents find quality care (*www.naccrra.org*). The National Early Childhood Transition Center investigates and validates practices that promote successful transitions between infant/toddler programs, preschool programs, and public school services for young children with disabilities and their families (*www.hdi.uky.edu*).

Other transitions occur at kindergarten and whenever there is a change to a different school, and finally between the ages 18- to 22-years when children finish their secondary education. Anticipating and planning for these transitions is important from a financial and emotional point of view. With each transition, there is a need to reflect on what changes will fulfill the needs of the child, family, and maintain the highest quality of life. Parents often struggle emotionally as they move through these transitions because each transition is a reminder that children with disabilities have extra needs that typical children do not. Financial planning is essential for children's transition out of the educational system to adult services.

Action Steps:

- As children transition to adulthood they also need different medical providers. Many children's hospitals do not serve those beyond 18-years of age. Preparing ahead of time is important because it can be difficult to find healthcare providers for adults with disabilities. The National Health Care Transition Center website has tools, tips and other resources for professionals, families, and youth with special needs as they transition from pediatric to adult health care (*www.gottransition.org*);

- As children become adolescents and eventually adults, it is important to teach and guide them to become self advocates. By early adolescence, if able, students should begin to keep track of medications, become an integral part of medical decision making, and begin advocating for their own needs. Many school systems encourage student participation at IEP meetings;

- New AAP guidelines include materials and practices designed to make transitions more successful for children with special healthcare needs;[6]

- In addition to anticipatory guidance around transition, children with disabilities often have need specific medical updates. For example, in a child with Down syndrome, there may be additional medical tests required at certain ages. Guidelines published by the American Academy of Pediatrics and other organizations indicate condition-specific issues at certain ages. These guidelines can be kept in patients' charts and referred to during well-visits to ensure that additional preventive services are performed as needed.

Advocating Within Systems of Care

Clinicians can help families navigate various systems because integration is often lacking. Public health and educational systems play a vital role in the support of children with disabilities. Nevertheless, these systems use different languages and are often not well-coordinated with each other.

Children with disabilities and their families interact with many different service systems in the community, often on a daily basis. These systems are complex, and clinicians need a general understanding of the systems used in order to be an effective advocate. A child with a disability is likely to receive services across many components of the medical system: home health agencies, hospitals, doctors' offices, and other specialists. Coordinating care can be especially challenging for families.

Action Steps:

- Providers do not need to understand the detailed workings of every organization, but require knowledge of community contacts in order to help families navigate service systems and obtain the support they need for their children.

- Providers should capitalize on parents' knowledge and experiences with services.

- A step as simple as coordinating two appointments on the same day to take advantage of an already planned trip to a tertiary care center can be beneficial to the patient and family.

- By facilitating such arrangements, clinicians also make hospitals or other entities aware of the importance of coordinated care.

Education

The reauthorization in 2004 of the Individuals with Disabilities Education Act (IDEA) entitles all children ages 3- to 21-years to a free and appropriate public education. IDEA legislation, under Part C (Early Intervention), serves children birth to 3-years of age in early intervention programs. The lead agency can be the public health department, department of education or another agency depending on the State. Eligible families of children with disabilities are involved in designing an Individualized Family Service Plan (IFSP) and will often qualify for services including a variety of therapies and educational programs.

Children ages 3- to 21-years are served by their local school districts via an Individualized Education

Plan (IEP). Children with disabilities can receive services, therapies and special education that help a child succeed. The IEP is developed by a team that includes teachers, therapists and the child's family to ensure that appropriate educational goals are set for the child, and reviewed annually to measure progress and revise goals. Families may request anyone they wish to be present in an IFSP or IEP meeting. Procedural safeguards and complaint resolution provided under IDEA protect families' rights. Many States have online resources informing families of their rights. The National Early Childhood Technical Assistance Center has many useful resources for parents and professionals, including a mapfinder tool to locate State contact information for early intervention and early childhood special education programs (*www.ectacenter.org*).

In most states there are Federally funded parent resource programs such as Family Voices and Parent-training and Information Centers (*www.parentcenternetwork.org*) that provide support to families as their children grow. They work with families to help them understand their child's disability and also to help them navigate complicated education and healthcare systems and identify resources available to their child.

In some communities, there are active disorder-specific and general disability organizations such as United Cerebral Palsy, Autism Society of America, Epilepsy Foundation, Easter Seals and many others that can offer support to families. These organizations often have local chapters that offer a range of supports such as camps and scholarships, respite, educational programs, social and recreational activities, and sibling and grandparent programs.

Action Steps:
- It is important to make families aware of the services provided under IDEA;

- Obtain information from the school, such as current classroom observations and teacher impressions, as well as requesting a copy of the child's IEP can be helpful in the medical care of the child. For example, a teacher might communicate to the clinician that a child is falling asleep in the classroom, which could influence the clinician's decision regarding dosage or timing of a medication;

- Collaborate with children's schools by communicating with teachers and school professionals when appropriate and reviewing children's IEPs annually. It is also helpful for clinicians or other health professionals to attend IEP meetings;

- Refer children with developmental disabilities or suspected developmental disabilities age 0 to 3-years to the local early intervention program and children age 3- to 21-years to the local school district;

- When families have questions about systems and resources, refer them to an organization like Family Voices—an excellent resource for clinicians, and families;

- Encourage families to contact local chapters of national family support organizations and advocacy programs for families of children with special needs.

Financial Assistance

Children with developmental disabilities may qualify for public assistance such as funding from the Social Security Administration. Eligibility is determined based on type of disability and family income (*www. Socialsecurity.gov*). There are usually State Medicaid services that can provide additional assistance. Eligibility criteria for Medicaid waiver programs vary from State to State. Some waivers are based on income and others on disability. One example is the Katie Beckett waiver that provides financial assistance for families who have children with significant needs (*www.familyvoices.org*). Obtaining a determination of eligibility can be a lengthy and confusing process for families. Because of long waiting lists and lengthy application processes, clinicians should encourage families to apply early for such help. In addition, States have Federally-funded programs through Children with Special Health Care Needs

(*http://mchb.hrsa.gov/programs*) that may provide additional resources for children and families.

Action Steps:
- Understand public assistance programs available in your State and community;
- Encourage families to apply for Social Security Disability benefits.

Children At-Risk

Children with disabilities are a vulnerable population and at elevated risk for maltreatment. It is sometimes difficult to place a child with a disability in a foster home or other temporary situation. Care should be taken to make sure that if a child moves from one home to another, that his/her medical record and list of medications is available. Children with disabilities or those who have been abused or neglected, may require a Guardian ad Litem to investigate and advocate for each child; ensuring that needs are met.

Bullying is widespread in the US, affecting children with and without disabilities. And a higher incidence of bullying is reported for children with special healthcare needs.[7,8] Bullying can be verbal (teasing, name-calling, rumor-spreading), physical or electronic.[9] Clinicians caring for children with disabilities should converse with parents about friends and social relationships at well-child visits. The National Bullying Prevention Center website has resources focused on education, advocacy, and community awareness (*www.pacer.org/bullying*).

Action Steps:
- Clinicians should have social services contact information available for when abuse or neglect is suspected.
- Providers also need a handy list of services and information on bullying.

Advocating for Community Awareness

Clinicians are in a unique position to talk about disabilities on the individual- and community-level. Clinicians' unique perspectives can help community childcare providers, and other healthcare professionals understand the importance of identifying children with disabilities as soon as possible. A campaign at the Centers for Disease Control and Prevention (*www.cdc.gov/actearly*), "Learn the Signs. Act Early." helps parents learn developmental milestones and urges prompt action when delays are noticed. Free materials can be ordered or downloaded, displayed in practices, and shared with families and professionals.

Action Steps:
- Educate your community about developmental disabilities and the importance of acting early when professionals or parents have concerns.
- Work with local community resources for children and youth with special needs, consult their websites, and collaborate on regional early identification efforts and resource-building.

Advocating at the State and National Level

Some clinicians support children with disabilities through legislative advocacy. There are many bills in State legislatures addressing issues of reimbursement for medical and therapeutic services. On the State level the American Academy of Pediatrics plays an important role by assisting AAP State chapters in advocacy. The AAP Division of State Government Affairs provides clinician-advocates with up-to-date resources and materials to assist in advocacy at the State level (*www.aap.org*).

Clinicians often advocate on the national level (*www.aap.org*). Federal legislative activities have a broader focus and may relate to specific disorders, such as autism or motor disability or to overall healthcare

services. The AAP Department of Federal Affairs serves as the link for the AAP to Washington, DC, and provides clinicians with tools and information needed to be effective child advocates. The Association of University Centers on Disability Action Center provides legislative alerts and online resources (*www.aucd.org*). The Association of Maternal and Child Health Programs generates an annual policy agenda to inform legislators and policy-makers through advocacy training resources, webinars and issue briefs (*www.amchp.org*).

Action Steps:
- Stay informed about legislation that impacts children with disabilities and their families;

- Get involved with your state chapter of the American Academy of Pediatrics and related professional organizations.

Table 20-1. Ten Action Steps for the Clinician-Advocate

1. Learn how to provide a "Medical Home" and implement its precepts in your clinic.

2. Review office procedures and environment, and adapt these to accommodate the needs of children with disabilities and their families. Keep condition-specific preventive guidelines in patients' charts.

3. Help families and children with disabilities stay engaged in their communities by advocating for inclusive sports and other recreational activities.

4. Know community resources for diagnostic and early intervention programs, and how to refer. Use public health awareness campaign materials to increase parental awareness about the importance of acting early on their concerns.

5. Provide guidance to families so they can anticipate and prepare for transitions across educational and medical settings.

6. Encourage families of children with disabilities to contact local chapters of family support organizations.

7. Collaborate with teachers and therapists, communicate with school personnel, and review children's IEPs regularly. Refer children with suspected or known developmental disabilities for evaluations and services available under IDEA.

8. Understand eligibility and application processes for financial assistance programs. Encourage families to apply for available benefits.

9. Educate your community about disabilities and the importance of acting early. Get to know State/local contacts for national family support and advocacy programs.

10. Stay informed about legislation that effects children with disabilities and their families. Stay involved with the State chapters of your professional organizations.

Chapter Summary: *As child experts, clinicians can effectively advocate and support children with disabilities and their families on many levels. Whether it's working with a child and family individually to improve quality of life, educating the local community or advocating at a State or national level on legislation and policy, every clinician can make a difference in the lives of children with disabilities.*

ADVOCACY RESOURCES

The sites described below are also shown as live links on *www.pedstest.com/TheBook/Chapter20*. Also see other chapters in this book and its website, on national initiatives and advocacy resources for researchers.

Association of Maternal and Child Health Programs (AMCHP) *www.amchp.org*
AMCHP is a national partner and advocate for State public health leaders and others working to improve the health of women, children, youth and families, including those with special healthcare needs. Members include academic, advocacy and community-based health professionals, as well as families themselves.

Catalyst Center *www.catalystctr.org*
The Catalyst Center is dedicated to improving healthcare coverage and financing for Children and Youth

with Special Health Care Needs (CYSHCN).

Centers for Disease Control and Prevention: National Center on Birth Defects and Developmental Disabilities *www.cdc.gov/ncbddd*
NCBDDD's mission is to identify the causes of birth defects and developmental disabilities, help children to develop and reach their full potential, and promote health and well-being among people of all ages with disabilities. The CDC's focus is on research, partnerships and prevention and education programs.

US Department of Education *www.ed.gov*
The Department of Education promotes student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access. Its major activities include: establishing policies related to Federal education funding, distributing of funds and monitoring their use; collecting data and overseeing research on America's schools; identifying and focusing national attention on the major issues in education; and enforcing Federal laws prohibiting discrimination in programs receiveing Federal funds.

Family Voices and Family-to-Family Health Information Centers (F2F) *www.familyvoices.org*
Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Via a national network, F2F provides families with tools to make informed decisions; advocates for improved public and private policies; builds partnerships among professionals and families, etc.

National Dissemination Center for Children with Disabilities *http://nichcy.org*
NICHY is a central source of information on disabilities in infants, toddlers, children, and youth. Here, you will also find easy-to-read information on IDEA and State-by-State resource sheets listing disability agencies and organizations.

National Health Care Transition Center (*Got Transition?*) *www.gottransition.org*
Got Transition? is a national resource for healthcare professionals, families, youth, and State policy-makers focusing on the transition from pediatric to adult health care. This site is an information exchange focused on youth with special healthcare needs.

The Early Childhood Technical Assistance (ECTA) Center *www.ectacenter.org*
The Early Childhood Technical Assistance Center is supported by the US Department of Education's Office of Special Education Programs (OSEP) under the provisions of IDEA. In addition to providing links to IDEA services, the ECTA Center compiles and analyzes data on outcomes. Information on collaborative initiatives (e.g., Head Start, Zero to Three) are posted on its website, along with conferences and webinars.

The Council for Exceptional Children (CEC) *www.cec.sped.org*
A central voice for special and gifted education, the CEC summarizes evidence-based research on effective teaching methods, defines standards of practice and accreditation, provides guidance on professional training, and publishes more than twenty subspecialty journals and newsletters focused on various exceptionalities.

National Institutes of Mental Health (NIMH) *www.nimh.nih.gov*
The mission of NIMH is to transform the understanding and treatment of mental illnesses through basic and clinical research, paving the way for prevention, recovery, and cure.

Parent to Parent-USA (P2P) *www.p2pusa.org*
Offers parent-to-parent support through a one-to-one match, wherein experienced parents provide emotional support to families and assist them in finding information and resources.

State Health Insurance Program (SCHIP) *www.insurekidsnow.gov*
The Children's Health Insurance Program (CHIP) provides free or low-cost health coverage for children up to 19-years of age. CHIP covers US citizens and eligible immigrants and is known as SCHIP when referring to US States. CHIPRA is the program within SCHIP providing performance bonuses for States facilitating enrollment and retention in health coverage programs.

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Chapter 21: Advocacy for Developmental Screening

a Front-Line Look at Improving Federal, State and Local Policies

Margaret Dunkle

INTRODUCTION

From the Editors: This chapter covers policy and advocacy from a personal perspective—that of Margaret Dunkle, who is a research scientist in public policy at the George Washington University. She has effectively worked in Washington with multiple Administrations (both Democratic and Republican), testified before Congress, met with Senators and Representatives to educate them on early intervention issues, created fascinating State and national initiatives, and established large grass-roots, cross-sector collaborations. Below, Ms. Dunkle talks about many of her experiences and explains what worked as well as what did not. Along the way, she offers guidance about how to improve public policy with regard to early detection and intervention. In recognition of her work on behalf of women, children and families, Ms. Dunkle was awarded the American Academy of Pediatrics' Dale Richmond Award and was inducted into the Maryland Women's Hall of Fame in 2012.

Good public policy—like good medicine—is part science and part art. The best practitioners excel at both.

Public policy decisions matter to providers as well as to children and their families. Why? Because policy decisions set priorities and allocate resources, such as funding, services and benefits. For example, policy decisions determine who gets paid and by whom, for a specific service or intervention.

- It is policy—not a doctor's discretion—that determines when children are eligible for Early Intervention services and when they are not.

- Policy sets the standards for who can review children's health and educational records and who cannot.

- And policy provides rewards and punishment for doing or not doing, something—from legislatively-created grant programs to encourage the use of specific interventions, to civil rights provisions that carry sanctions if there is illegal discrimination based on race, ethnicity or gender.

This chapter describes why and how policy can matter for the one in every six children who has a developmental issue along the way. The examples are specific to the author's personal experience and involvement at all levels of government—Federal, State, and local. The discussion begins with basic information to demystify "policy:" what policy is, where it happens, and how to set policy priorities.

- First is a "Cliff Notes" description of a vehicle—the Early Identification and Intervention Collaborative for Los Angeles County (EII Collaborative)—used to launch and nurture many of the policy initiatives described in this chapter. As founder and Director of this coalition that promotes early screening and effective intervention across the board, I well know its history and inner workings.

- Going from the top to the bottom of the policy food chain, starting with the Federal level, next comes a description of two successful efforts to improve Federal policies affecting young children with disabilities and developmental delays—a new Congressional requirement that all children enrolled in Head Start and Early Head Start must have evidence-based developmental screenings, and getting a dollar amount associated with developmental screening so that physicians can bill health insurance when they provide this service. Described is an "almost-win"—engaging the Federal Social Security Administration to support early screening as a way to cut long-term disability costs.

- The discussion of State-level efforts describes how the EII Collaborative—supplemented by complementary projects I took on—worked to ensure that updated California Child Health and Disability Prevention guidelines on developmental screening reflect the latest science in order to nudge California pediatricians to regularly use good screening tools.

- At the local level, the venue is Los Angeles County, where multiple examples illustrate initiatives to improve policies and promote promising screening practices. One important initiative is described

in detail—the EII Collaborative's efforts that directly led to a 211LA County project to test conducting evidence-based developmental screening over the phone. Other efforts are described to show the catalytic effect of the work of the EII Collaborative; creating and spinning off ideas and projects to other entities.

UNDERSTANDING PUBLIC POLICY AND ADVOCACY

Policy is not rocket science, but it is not dumb luck either. Crafting good policy requires study and strategy—understanding the players and processes, the rules and the rhythms of the policy formation, setting clear and realistic goals based on your values and beliefs, and also being sufficiently flexible to take advantage of unexpected opportunities.

Advocacy is putting strategies into action to achieve a specific goal. Successful advocacy requires a healthy dose of pragmatism, not letting the perfect be the enemy of the good. Advocacy efforts that insist on perfection or that attempt to solve 100 problems in one fell swoop typically fail. Successful advocacy in our democracy is most often incremental—aiming for the best possible results at a particular moment, based on a candid assessment of the political climate, resources, players, and competing priorities. There will always be another day, a next legislative session, a new crop of legislators or a new mayor, governor or president. With each change, there will be new opportunities for progress.

> ### What is Policy?
> *Policy is the process of setting priorities and allocating resources, such as funding, services and benefits.*

Policy improvements—from funding to well-crafted program design—are often the missing link between a successful pilot project and one that can go to scale locally, Statewide or nationally. Lisbeth Schorr, a well-known social scientist and insightful researcher on programs affecting children, wrote an inspiring book, *Within Our Reach*, highlighting successful and promising pilot programs. As she ruefully noted a decade later, most of these programs did not survive, much less flourish:

> *Most of the successful programs I reported on in 1988 in my first book, <u>Within Our Reach</u>, were no longer in existence or not being built upon just five years after the book came out. . . . After several years of traveling the country, looking at both successes and failures, I am convinced that the reason we haven't been able to build upon success on any significant scale is that we have ignored the mismatch between the attributes of effective programs and the gravitational pull of prevailing systems.[1]*

In other words, successful programs can only flourish when systems and policies are put in place to nurture and grow them. Most of the exemplary pilot programs stumbled because they did not develop those policy legs.

Where Policy Happens

Policy is more than legislation. In fact, sometimes passing a lofty-sounding law is the easy part. And, if a law promises much, but lacks the resources, funding or clout to deliver on its promises, it is a hollow victory. Policy must include funding decisions, i.e., appropriations.

Policy also includes Executive Branch actions, such as regulations, guidelines and standards, that can turn a rough legislative blueprint into an effective program or initiative or alternately, into a sorry bureaucratic exercise that doles out dribbles of funding to projects, States, and localities, but doesn't make much difference at the end of the day. These Executive Branch actions are often excruciatingly dense, laden with convoluted procedures, acronyms, obscure cross-references, and mind-numbing lists of definitions. But decoding these seemingly boring documents and finding and influencing the important provisions (even if they are buried in a footnote amidst 50 pages of fine print) can make the difference between a successful and unsuccessful program or initiative. And, of course, the judiciary makes policy as it interprets laws and regulations.

Public policy happens at all levels of government—Federal, State and local.

- At the Federal level, policy change can happen in all three branches of government—through Congress, the President and his Administration (and all of the Departments, from Health and Human Services to Education), and the judiciary.

- At the State level, the State legislature, the Governor and State agencies, and State courts all make policy decisions.

- At the local, city, county, and community level, mayors, county executives, city councils, county boards of supervisors or commissioners, and the local governmental agencies they administer all make policy decisions. Sometimes these entities make decisions directly and sometimes through a designated agency, such as a local school board.

Of course, the policy picture is not quite this tidy. Many Federal and State policies and programs trickle down to the local level—sometimes working well, sometimes not. For example, Head Start programs are Federally-funded and governed, but run locally. And local special education and Early Intervention programs are a result of Federal requirements through IDEA, but administered through a State governmental agency. These programs also typically have significant State and local, as well as Federal funding.

In addition, complementary policy initiatives can and do happen at all levels of government simultaneously. For example, programs funded at the Federal and State level, under IDEA Part C (Early Intervention) may also seek funding for local services through which they trial effective ways "to do good" (e.g., evidence-based developmental screening in nontraditional settings—such as in childcare, Head Start centers, WIC programs or online).

Finally, the private, nonprofit, philanthropic, and business communities set many of their own policies and priorities. They also often work to influence Federal, State, and local governmental policies. For example, a foundation may support a promising pilot program, seek to prove it is successful, and then work to get legislators to create a Federal- or State-funded program to replicate this model on a larger scale.

Setting Policy Priorities

Over the years, working on a range of issues, I have developed a simple set of three criteria to identify what policy action to take and when.

The first and most important criterion is **impact**. The simple questions to ask are: Will the policy change make the difference we want? For early screening and intervention, this question becomes, Will these policy changes increase the number of young children who receive high-quality developmental screening and, if they need it, effective follow-up and intervention? If the answer is "yes," then move on to the next criterion. If "no," stop and come up with another policy idea or strategy.

The second criterion is **opportunity**. Is there a window of opportunity—a "moving policy train" to jump onto? A "moving train" might be a related effort already underway, a law about to be revamped ("reauthorized") by Congress, a State or local legislature or an issue where there is already strong public will or that suddenly makes front-page news. To look at "opportunity" from another perspective, few things annoy a policymaker more than to have someone approach him with even a

Criteria for Policy Action
• Impact
• Opportunity
• Partners

great idea immediately after he has voted or acted on that very issue and the deal is done.

Sometimes an opportunity can be created from whole cloth, as was done with the effort to put a billable dollar value on developmental screening described below. More often, the trick is to identify an opportunity that is already there and then use it to make progress.

The third criterion is **partners**. Are there ready allies? Is opposition minimal or at least manageable? If there are only a few others on your side, and the other side is well-armed and resourced, you are facing

an uphill battle.

As all three criteria suggest, policy priorities and strategies shift as the political climate changes, new leaders and knowledge emerge, and funding is more or less available.

The Early Identification and Intervention (EII) Collaborative for Los Angeles County

The Early Identification and Intervention Collaborative for Los Angeles County, locally called the EII Collaborative, has applied the three criteria—**impact**, **opportunity**, and **partners**—to improve most of the developmental screening policies described in this chapter.

I founded the EII Collaborative, almost by accident, in the Fall of 2003. After working on policy issues in Washington, DC, for many years, I moved to Los Angeles and had just completed a project to identify policy issues associated with autism detection. Both the research and my personal observations confirmed that many children on the spectrum were identified much later than need be (often well into elementary school), with the result that these children fell further behind at just the time when early intervention services could have done the most good. Sadly, children who were low-income and ethnic or racial minorities were the last to be identified and helped.

While giving an autism-specific screen to every child every year is a good idea, it is unlikely to happen when today's pediatric visits last only about fifteen minutes and are packed with physical exams, vaccinations and other "must-do's." And even if a pediatrician administered a separate autism screen, how likely was it that he/she will also administer the many other condition-specific tools—each of which takes time, training, and record-keeping—to detect possible problems with gross or fine motor skills, speech, social-emotional development or cognition?

My answer to this policy quandary was that the best way to detect autism was to promote broad-band, evidence-based developmental screens on all young children. Broad general screening most quickly flags children with autism and also flags children with other developmental concerns—from cerebral palsy to attention deficit disorder to social-emotional problems. A win-win. In addition, routine screening for all children carries no stigma. Finally, primary care screening is most efficient when using tools relying on information from parents, and such tools engage parents across the socioeconomic and racial-ethnic spectrum in an effective and respectful way.

The EII Collaborative Mission

The purpose of the EII Collaborative is to ensure that every child in Los Angeles County gets developmental screenings—early, often and with high-quality tools—and that any child needing help receives it at the earliest possible moment.

The EII Collaborative is a catalyst, a partner and a leader for improving public policy, systems, and local practices.

As I explored this issue, I invited a group of ten colleagues—experts in the fields of education, early intervention, health, mental health, philanthropy, and advocacy—to join me for an informal lunch in September of 2003 to talk about developmental screening. This lunch-table discussion quickly turned into something between a request and an expectation for me to convene regular Countywide meetings to make a reality of the vision that every child in Los Angeles County would get developmental screenings—early, often, and with a high-quality screening tool—and that any child needing help would receive it at the earliest possible moment.[2]

The best policy to detect autism is to promote broad, evidence-based developmental screens on all young children.

An early decision was to be very specific about what it would take to achieve the EII Collaborative's mission. Fuzzy goals with no way to measure progress are typically ineffective goals. So using the best research, complemented by a healthy dose of common sense and feedback from the field, the Collaborative began to advocate strongly for three specific screening tools: the *Ages and Stages Questionnaires (ASQ), Parents' Evaluation of Developmental Status (PEDS)*, and *PEDS: Developmental Milestones (PEDS:DM)*. These tools

covered all developmental domains and were accurate, short, low-cost, appropriate in multiple settings, billable to health insurance, and easy to administer and score. They also made use of information from parents, are available in multiple languages, and are culturally appropriate—all requirements in a community as large, complex, and diverse as Los Angeles County.

During its earliest days, the Collaborative pursued—often successfully—many policy opportunities, starting with attaching a dollar figure to the diagnostic code for developmental screening, described later. Structure followed action, with a logo and Steering Committee in 2006, a Strategic Plan in 2007, and a revamped mission statement and formal Charter in 2010.

Over the years, the EII Collaborative grew into a coalition that includes more than 350 different organizations and agencies across many sectors, including childcare and early childhood, child welfare, disability, early intervention, education, law enforcement, social services, and health. Participants come from governmental, community-based, academic, philanthropic, nonprofit and advocacy groups, and include family members of children with disabilities and developmental delays.[3]

Involving multiple sectors was essential. Figure 21-1 illustrates the enormous range of services required by a toddler with undiagnosed regressive autism. No single sector holds all of the information, answers or services for this child or his family.

Figure 21-1. An Example of Sector Service Use for a Child with Undiagnosed ASD

Education
- Public Schools
- ESEA, Title I
- School Lunch & Breakfast
- Head Start
- IDEA
- After-School Programs
- Textbook Funding
- Tests & Achievement
- Teacher Issues
- GED

Health & Food
- Medi-Cal – EPSDT
- Healthy Families Parent Expansion
- Child Health & Disability Program
- Expanded Access Primary Care
- Trauma Case Funding
- Co-payments for ER Services
- Child Lead Poisoning Prevention Program
- HIV/AIDS Prevention & Education
- Breast Cancer Screening
- Food Stamps
- WIC

Social Services
- TANF
- GAIN, CAL Learn, Cal WORKS, etc.

Child & Family Services
- Child Care – CCDBG, SSBG, Cal WORKS Child Care, etc.
- After-School Programs – 21st Century Learning Centers, etc.
- Promoting Safe & Stable Families
- Child Abuse & Neglect Programs
- Foster Care – Transition, Independent Living, Housing, etc.
- Adoption Assistance, Adoption Opportunities

Mental Health & Probation
- School-Based MH Services for Medi-Cal Kids
- Probation Officers in Schools
- Cardenas-Schiff Legislation
- Health Care Through Probation
- Mental Health Evaluations
- Juvenile Halls

Understanding How Programs & Services Affect a Child with a Developmental Delay, Disability or Other Problem

Margaret Dunkle

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Baby 1 1/2

TIPS FOR EFFECTIVE CROSS-SECTOR COALITIONS ON EARLY INTERVENTION

Communicating and cooperating across sectors, as the EII Collaborative does, takes more than good intentions. It also requires understanding the points of view and priorities of the different sectors and being able to describe the issues and options in language that addresses the varying perspectives of each partner agency.

One way to do this is to focus on what programs mean for children and families—how programs and services, in combination with one another, can strengthen families. For example, it is better to use generic terms like "child," "family," and "parents," rather than sector-specific terms such as patient (health), student (education), client (social service and child welfare) or slot or enrollee (job training).

Additional tips to facilitate good cross-sector communication include:

- Be sure your coalition's mission resonates with many partners and is not loaded down with words or references that reflect one sector only. For example, the health professionals often talk about "children with special healthcare needs" while educators talk in terms of addressing issues to increase school readiness. But these and other terms all refer to the same kids. When in doubt, use language that your Mom would understand if you were explaining to her what you do.

- In meetings, insist on a simultaneous translation of jargon and acronyms—IFSP, EPSDT, CAPTA, Part C, Commissioner, IDEA, MCH, HIPAA, FERPA, Section 504, etc. Jargon and acronyms that roll off the tongue of people from one sector are often totally incomprehensible to someone from another sector. There's a lot to be said for plain English. It is also worth a chuckle when the person using the acronym or jargon stumbles when they are called on to define or untangle it on the spot. Chapter 1 includes a glossary of the more common terms.

- Structure meetings so that even introverts can comfortably share their best ideas. For example, the EII Collaborative often starts its meetings with self-introductions and a one-sentence answer to an "inkblot question" such as, "What would make you leave this meeting today saying it was really useful to you?" It is important to enforce the one-sentence limit, starting with the very first person. Otherwise, this potentially useful exercise will consume your whole meeting.

- Don't become so focused with planning that you don't actually do anything. Some of the best coalitions are created ad hoc to tackle an urgent problem. They later develop the structure needed to remain viable and successfully take on the next challenge. As Frank Lloyd Wright said, "Form follows function."

FEDERAL EFFORTS TO IMPROVE EARLY SCREENING

With these tips in mind, the EII Collaborative plunged into the policy arena—building on both local knowledge of the problems and issues facing children and families together with my knowledge of DC and the policy process. Two successes (Head Start and physician-payment for developmental screening) are described below, along with another "almost-win" (engaging the Social Security Administration to support developmental screening).

Creating a New Requirement: Head Start Programs Must Do Good Developmental Screening

It took almost five years of work to get the law changed so that developmental screening with a good tool became a requirement for every child enrolled in Head Start and Early Head Start.

In 2003 conversation with Bill Christeson, Research Director at *Fight Crime/Invest in Kids*, we discussed how Head Start provisions concerning developmental screening were vague and toothless—with no quality standard. This is not surprising because developmental screening has matured substantially since the 1960s when the Head Start program was created. But the upcoming reauthorization of Head

Start provided an opportunity to catch up with the science of developmental screening, and for the law to make realistic requirements of programs that would not have been possible 40 to 50 years ago.

This meeting was important because it raised a solvable policy problem and reminded me that the timing for change was right. It was also important because *Fight Crime* quickly became our essential 'Inside the Beltway' partner in this effort.

In an effort to follow up, in 2004 I almost literally hijacked two colleagues—test-developer and developmental expert, Frances Page Glascoe of Vanderbilt University, and Los Angeles developmental screening practitioner, Cynthia Landes, who thought she was coming to DC for a vacation—to traipse around Capitol Hill with me to speak about the importance of developmental screening. Because improving screening in Head Start was so timely, we targeted committee staff—both Republicans and Democrats—charged with drafting the Head Start bill.

> ### Rating This Initiative on the Three Criteria for Policy Action
>
> **Impact:** <u>High</u>. Head Start reaches many high-risk children and is seen as the "gold standard."
>
> **Opportunity:** <u>High</u>. Congress was in the process of reauthorizing the Head Start law.
>
> **Partners:** <u>High</u>. The DC-based group, Fight Crime/Invest in Kids, was our strong partner and DC voice as Congress considered, debated, and voted on various Head Start bills.

Because of my previous work in DC (which included running Capitol Hill seminars on issues affecting children and families), I knew and was able to get personal meetings with these busy staffers. I had researched and written extensively about which Congressional Committees control which laws, so it was also relatively easy for me to identify the specific staffers responsible for the Head Start bill. When I told them that I wanted to discuss an idea that would improve Head Start and help it better meet its goals, they believed me and agreed to meet.

In discussions such as these, it is important to know whom to contact (who can pull the policy levers), to have something worth saying that is also timely, and to have a track record of providing solid and useful information so that the staffers take your suggestions seriously. It is also important to listen carefully to concerns raised and to address these concerns, even if these were not initially your issues.

Trust, and a track record for providing solid and useful information, matter. And these relationships are not created in an instant. That is why constituents who drop in every other year for a "lobby day" in conjunction with a DC convention are unlikely to have a legislative impact unless they also stay in touch between visits and understand the legislative calendar.

There was keen interest across the political spectrum. The main criticism staff raised was that they needed standards, not just the names of specific evidence-based tools, to craft legislative language to do what we wanted: make high-quality developmental screening for every child a Head Start requirement.

Armed with this information, I enlisted the aid of both LA colleagues and Federal experts at the Centers for Disease Control in Atlanta to develop a short but tough definition of what constitutes a high-quality developmental screening tool. While I recognized that even the half-page definition we developed (see box below) was too long for final statutory language, the plan was to provide enough detail to inform the legislative history and Congressional reports, so that the Head Start office would eventually write regulations and standards requiring first-rate tools. This definition also provided Congressional staff with enough details to answer questions that might be raised.

I kept Capitol Hill staffers on both sides of the aisle in the information loop along the way. Months passed before the legislative process picked up again. Then, one week I received separate calls from both Republican and Democratic staffers asking if the language they had put in the bill was OK. (When I answered the phone, I thought I had died and gone to heaven: they called me!) Because Republicans were in the majority, the Republican staffer has primary drafting responsibility—and good developmental screening language was included in what is called the 'Chairman's Mark' (this is the generic name for a bill introduced by the Committee Chairman, and typically used as a template that is then "marked up" by other committee members with amendments and changes).

Congress couldn't agree on a Head Start bill during that particular session, so our initial version of the bill died. But we knew it would be reborn in the next session of Congress because of the statutory need to reauthorize the program. During this process, we also started to work more closely with 'Fight Crime's' talented and savvy legislative director, Miriam Rollin. She lead the way on many Head Start issues and became a strong advocate for the developmental screening provisions through the many meetings, drafts, discussions, and negotiations with both powerful Capitol Hill staffers and other advocates.

With the next legislative session, the House flipped leadership and the Democrats were in the majority — calling the shots and chairing the committees. Because we had worked closely with both parties from the outset, the strengthened developmental screening provisions stayed in the bill and stayed in the 'Chairman's Mark,' even though the Committee Chairman was now a Democrat rather than a Republican.

More time passed. Eventually, in late 2007 Congress enacted the Head Start Act of 2007 (HR 1429—P.L. 110-134). This law requires that Head Start and Early Head Start programs must meet quality standards:

> *Use research-based developmental screening tools that have been demonstrated to be standardized, reliable, valid, and accurate for the child being assessed, to the maximum extent practicable.*

While brief, this new statutory requirement alluded to the exact criteria we had suggested—standardization, reliability, validity, and accuracy—even in the same order as our definition from three years earlier.

All that effort for just a few words. But it was worth it. This new requirement has already made a huge difference in identifying and helping children in Head Start and Early Head Start programs who have disabilities, developmental delays and other problems. For example, when the EII Collaborative surveyed Los Angeles' Head Start programs before the new law passed, most were either not using any tool at all or using a poor-quality tool. Now, they are all using good developmental screening tools. This in itself is significant progress: LA County has more people than 43 States, and the largest Head Start program in the country.

While I have not seen a study of Head Start compliance with the new developmental screening requirements, I hear anecdotally that high-quality developmental screening is now firmly integrated as a programmatic standard nationwide.

"HIGH-QUALITY DEVELOPMENTAL SCREENING INSTRUMENT" DEFINED

High-quality developmental screening tools are those that are standardized, reliable, valid, and accurate (that is, both sensitive and specific, correctly detecting children with and without problems).

- *For **standardization**, this means that the screening tool was standardized on a large nationally representative population (not a referred population) and with at least 100 subjects per age range.*
- *For **reliability**, this means correlations of 0.85 or above for internal consistency, inter-rater consistency, and test-retest reliability.*
- *For **validity**, this means correlations of 0.70 or higher for concurrent validity and discriminate validity, and, if possible, evidence of predictive validity.*
- *For **accuracy** (also known as "criterion-related validity") this means:*

  Sensitivity of 70% to 80% for all age ranges. That is, the screen correctly identifies 70 - 80% of children with delays and disabilities.

  Specificity of at least 70% and hopefully 80% or higher for all age ranges. That is, the screen correctly identifies 70 - 80% of children without disabilities or delays.

*In addition, high-quality developmental screening tools have been **rigorously peer-reviewed** to assure that their standardization, reliability, validity, sensitivity and specificity are accurately reported – including publication in refereed professional journal.*

Early Identification & Intervention Collaborative for LA County
May 2004

Putting a Dollar Value on Developmental Screening

One of the first policy projects of the EII Collaborative, as it was being formed in 2003, was to take pediatricians at their word that their offices could not be expected to do developmental screening if they were not paid for this procedure, just as they are paid for other services they perform.

The goal of this policy effort was to get a reasonable dollar amount associated with the developmental screening code, so that pediatricians would be fairly compensated and incentivized to make developmental screening of young children the rule rather than the exception.

We partnered with Los Angeles Congressman Henry Waxman, who was the senior Democrat on the Energy and Commerce Committee (which controls major federal health laws including Medicaid). The Congressman and a bipartisan group of colleagues had urged Secretary of Health and Human Services Tommy Thompson to put the process in motion to establish a dollar value for the 96110 developmental screening billing code.[4] Meanwhile, the American Academy of Pediatrics was also lobbying with Congress and the Centers for Medicare and Medicaid Services (CMS).

As this process moved ahead, I submitted, as did the AAP, strong comments to support giving the developmental screening code a specific dollar value. We were also able to get the influential Director of the Los Angeles County Department of Health Services and the Director for Public Health to write CMS supporting adequate insurance reimbursement for developmental screening. Drs. Garthwaite and Fielding concluded their letter, *"Our goal is for every young child in Los Angeles County to receive high-quality developmental screening, and for those who need early intervention to receive it at the earliest possible moment."*

These comments were important in two ways. They provided CMS with substantive arguments for reimbursement for developmental screening and showed significant community support for this action. The comments also provided an immediate way for the EII Collaborative to speak and act jointly, and to become well-known in the Los Angeles community.

The full impact of this billing improvement is still not clear. On the positive side, it was an early win for the EII Collaborative, the AAP, and the Congressional instigators when CMS adopted improved reimbursement so that physicians could now bill a child's health insurance for quality developmental screening. But this victory has had only moderate success in increasing the number of pediatricians who actually regularly use a good developmental screening tool. Between 2002 and 2009, the percentage of pediatricians who said they always or almost always use a developmental screening tool rose from 23% to just under 48% (although use of problematic tools continues to predominate).[5]

This is progress. But doubling a very low percentage is modest progress at best. Seven years later and in the wake of a strong American Academy of Pediatrics statement recommending annual developmental screenings, the majority of pediatricians still do not routinely screen infants and toddlers for developmental issues. Further, the recent AAP study speculates that the actual developmental screening rate is likely lower than the 48% reported, since their data are from physician- (not parental-) reports.[5] Because the most commonly cited measure is one that has only minimal sensitivity and cannot be completed in the time frame of well-child visits, it is likely that pediatricians may not properly administer certain screens. The AAP study did not track whether children with problematic screening results actually received appropriate follow-up diagnoses and services.[6]

> ### Rating This Initiative on the Three Criteria for Policy Action
>
> **Impact:** <u>High</u>. *Lack of insurance reimbursement was a major reason pediatricians said they did not use a developmental screening tool.*
>
> **Opportunity:** <u>High</u>. *Our Congressional partners knew just how to create this opportunity.*
>
> **Partners:** <u>High</u>. *A powerful LA Congressman was perfectly positioned to help and had already been looking at screening issues. Also, key LA County officials lent their support.*

A Federal "Almost-Win"—Engaging the Social Security Administration

The two examples above can be counted as Federal "wins." But not every effort is successful. Some are lost. And some are, as the saying goes, "rained-out."

An example of a rained-out Federal initiative was our campaign to actively engage the Social Security Administration (SSA) on screening issues. The idea was to encourage developmental screening and effective intervention as a positive way to prevent long-term dependence on the Supplemental Security Income Program (SSI). Some children, as they become adults, are headed towards long-term dependence on SSI. With earlier detection and intervention they would more likely become taxpayers (with a huge savings for other tax-paying citizens).

I approached a long-time colleague who was then SSA Deputy Commissioner, closely working for several years with him and his staff to make this case. This work was the catalyst for SSA to issue an innovative 2007 Request for Proposals (RFP) for a risk-management project to prevent long-term dependence on the SSI Program through early identification and intervention of young children with disabilities and developmental issues. This RFP, slated to fund only two projects, generated unexpectedly intense interest and many proposals from across the country. But, alas, when there was a leadership change at SSA, this promising project was scrapped and has yet to be resuscitated.

As these examples illustrate, the Federal government can do much to improve developmental screening and effective intervention. States and localities also have important roles to play.

What is SSI?

SSI provides financial support to low-income people with serious disabilities. While most people think of the Social Security Administration as cash support for the elderly, SSA programs also provide monetary support to people with serious disabling conditions.

Rating This Initiative on the Three Criteria for Policy Action

Impact: Potentially high, *because the SSI program is huge and nationwide.*

Opportunity: This was an opportunity that we created.

Partners: High, then low. *The original SSA Deputy Commissioner was a strong partner, but his successor was not.*

STATE-LEVEL ACTION

For many programs, State-level decisions are critical. For example, each State must come up with its own standards for how seriously disabled an infant or toddler must be to qualify for Early Intervention services. While these programs were created in response to requirements in Part C of IDEA, Federal law establishes only a floor for which children under age 3-years qualify for services. Each State sets its own ceiling or cut-off for eligibility. In contrast, for children age three-years and older, IDEA eligibility is Federally determined and is similar across all States. State actions can be statutory—passing a new or reauthorized law; or they can be administrative or regulatory—writing rules, regulations, standards or guidelines.

Improving the California Child Health and Disability Prevention Guidelines for Developmental Screening

In 2005, the EII Collaborative learned that the State of California, through its Department of Health Care Services' initiative 'Child Health and Disability Prevention' (CHDP), was planning a much-needed update of its Health Assessment Guidelines (inelegantly referred to as "HAG") on developmental screening. These Guidelines are important because many children are affected. In Los Angeles County alone, there are more than 1,000 CHDP sites, involving 1,800 clinicians.

With encouragement from the Los Angeles County CHDP leadership and input from EII Collaborative participants, I drafted recommendations and goals to improve the CHDP Guidelines on developmental screening, specifically:

- Use of high-quality tools for developmental screening—tools that are standardized, reliable, valid, accurate, and appropriate for children from a wide range of racial, ethnic, linguistic, and cultural backgrounds;

- Increase awareness of the value and efficiency of tools making use of information from parents (including specific examples);

- Inclusion of infant/child health issues including vision/hearing along with developmental screening;

- Improve physician-training concerning developmental screening and referral;

- Creation of a list of evidence-based developmental screening tools in the guidelines;

- Enhanced payment for physicians who do high-quality developmental screening;

- Make it easier for pediatricians to use good developmental screening tools by, for example, providing them with copies of good tools, negotiating Statewide licensing agreements to cut costs, training physicians and their staff to interpret screening results, and help families navigate the complicated service systems;

- Revise the billing report to document when screening with a good tool is done, which tool was used, and whether a more thorough assessment specified any diagnoses or indicated developmental areas in which screening produced "red flags" (e.g., communication, gross- and fine-motor, social-emotional, and cognition).[7]

> **Rating This Initiative on the Three Criteria for Policy Action**
>
> **Impact:** <u>High</u>. The CHDP guidelines outline best practices for thousands of California pediatricians.
>
> **Opportunity:** <u>High</u>. The guidelines were slated to have a much-needed revamping.
>
> **Partners:** <u>High</u>. In addition to all of the EII Collaborative partners, the LA County CHDP program leadership was very supportive.

Many of these recommendations were ultimately adopted. For example, the final HAG Guidelines recommended high-quality and parental-report tools, included mental health/behavioral issues, recommended a list of evidence-based tools, and discussed physician reimbursement for screening with a good tool.[8] In a complementary activity, the State also negotiated the recommended Statewide licensing agreements with key test developers who responded with a Statewide discount during the project's start-up phase.

The process to get to these results was not speedy. It took more than four years, with final HAG Guidelines issued in December of 2009. Along the way, there was much turnover in the staff charged with this revision process, each of whom faced steep learning curves.

During these intervening years, a State screening collaborative was also formed, staffed by personnel from the Maternal, Child, and Adolescent Health Program of the California Department of Public Health. The coordinator of this effort frequently flew from Sacramento to Los Angeles to participate in meetings of the EII Collaborative, and I also participated in the State screening collaborative efforts.[9]

In addition, this State project commissioned me as a consultant to develop a chart summarizing the best developmental screening tools—including a description, the developmental domains covered, the age-range, administration time, how to purchase, and obtain additional information. This chart and its summary introduction were included as an appendix in the final Guidelines. Similarly, the Guidelines also included a second summary chart I developed—this one describing highly accurate developmental screening tools that identified likely problems in specific areas: social-emotional and behavioral development, autism, language and cognition, and motor coordination.[8] This project also supported my work with a cross-agency Statewide committee to develop user-friendly algorithms that outlined which young children to screen (answer: all young children), and what to do when a child was flagged as having a possible developmental issue.

IMPROVING LOCAL POLICY: A LOS ANGELES COUNTY PERSPECTIVE

The local level is where policy hits reality. The local level is typically where services are delivered to individual children and their families. Below are examples of local-level efforts by the Early Identification and Intervention (EII) Collaborative to improve policies and programs.

A Pilot Project with Policy Potential: Over-the-Phone Developmental Screening Through 211LA

The idea behind this project is to use web-based technology to administer a valid developmental screen over the phone to parents of young children who call 2-1-1, the health and human services helpline that is now active in more than 80% of North America. Operators at 211LA use *PEDSONLINE*, and get Google-quick results as they type in what parents say. They then provide the parent the results, and if there is a developmental red-flag, help the parent take the next steps to determine if their child needs early intervention.

How the Idea Began in the EII Collaborative

The seed for the 211LA Developmental Screening Project was planted at the September 2003 inaugural lunch of what became the EII Collaborative. The ten participants strategized about systems change, the need to identify promising pilot projects, and how to promote developmental screening in multiple settings, not just in pediatricians' offices. Soon the idea of doing accurate developmental screenings over the phone became a recurring pilot-project theme at Collaborative meetings.

Discussions continued in 2004 and 2005, including a hopeful but ultimately unproductive meeting with Nexcare, the contractor that had a large project with First 5 Los Angeles to provide phone-based support to parents of young children. (First 5 Commissions are the California county-based entities that fund projects for children under age six-years with tobacco-tax money.)

By the fall of 2005, the EII Collaborative had created a committee to explore how 211LA could promote developmental screening, co-led by Judy Higelin of the Los Angeles County Office of Education and me. The timing was right: First 5 LA had switched contractors, dropping Nexcare and instead funding 211 Los Angeles County to provide phone-based support services to parents of young children. Around the same time, 211LA County was renamed and revamped—changing from being called "Infoline" to using the 211LA name and dialing code that was becoming the standard nationwide. At the same time *PEDSONLINE* was launched as a web-based screening service.

> ### Rating This Initiative on the Three Criteria for Policy Action
>
> **Impact:** *High, since 211 callers are typically the hardest-to-reach and the least likely to have the resources and knowledge to navigate the complicated care systems.*
>
> **Opportunity:** *High, once the EII Collaborative developed the idea and engaged the local 211 agency.*
>
> **Partners:** *High, since 211LA County quickly became an enthusiastic advocate for developmental screening.*

The EII Collaborative Partners with 211LA

Discussions continued and gained momentum through 2005 and into 2006. 211LA Executive Director Maribel Marin heard of these discussions through both the Collaborative's newsletters and from 211LA staff she had sent to EII Collaborative meetings. In June of 2006, she was a surprised and very welcome participant at a regular EII Collaborative meeting. She clearly wanted confirmation that the Collaborative could back up its claims that good developmental screening could be done over the phone (we could) and to meet the people who were advocating for this project.

The Collaborative welcomed Maribel, and the partnership between the EII Collaborative and 211LA began. 211LA was a strong partner with capacity and technical skills that complemented the mission and broad membership of the Collaborative. The agency serves more than 600,000 families each year,

mostly for basic human needs. It has a database of almost 50,000 programs, and provides assistance in more than 140 languages and for the hearing-impaired.

But actually doing developmental screening would be a new—and untested—activity for a 2-1-1 program. The Collaborative's vision for this initiative went far beyond the information-and-referral function that was normal for 2-1-1 programs. At the same time, the 211LA leadership was intrigued with the idea of piloting a developmental screening project to see if this was a viable service.

Also important was that 211LA reached high-risk children and families. A 2010 survey found that 28% of callers had preschool-aged children. Further, these callers were often single parents (41%), unemployed (50%), Latino (65%) or African-American (25%), either publicly insured through Medicaid (51%) or uninsured (29%), and low income (with 52% having monthly incomes of $1,000 or less, and 85% having monthly incomes of $2,000 or less). Most (62%) had a high school education or less and only a third had full-time jobs. Two out of five (39%) spoke Spanish as their primary language. Almost half (45%) did not have use of a car. And a third reported having been victims of domestic violence.

Around the same time, a long-time EII Collaborative participant, Patricia Herrera, was moving on from working at a large local disability agency (called a Regional Center in California) that ran an IDEA Early Intervention program (called Early Start in California). Because Patricia had just the right mix of skills, training, knowledge, and enthusiasm that the 211 Developmental Screening Pilot Program would need to be successful, I recommended her to Maribel, who quickly engaged Patricia as a consultant to work to develop the project.

I continued as volunteer consultant, introducing Patricia and 211LA staff to *PEDS*' author, Frances Page Glascoe, drafting proposals along with Patricia, and making connections to build local support and partnersips. Once funding was secured, I became an official consultant with a focus on engaging the EII Collaborative to build support, provide feedback, and identify problems, barriers, and resources for referral, as well as grant writing and proposal development.

After many false starts, including rejected proposals, we wrote a successful proposal that secured three-year funding at $300,000 from the W.M. Keck Foundation, which launched the 211LA Developmental Screening Project. This was followed by $500,000 from the Robert Wood Johnson Foundation Local Funding Partners Program, approval for up to $300,000 in matching grant funds from First 5 LA, and several smaller grants.

Looking to the Future

Early results are promising. 211LA appears to be a successful way to identify children, especially those who are low-income and at-risk, whose parents have developmental concerns.[10] (See the description of this initiative in Chapter 17, "North American Models," for detailed data concerning screening results and follow-up.)

The Developmental Screening Project is currently dependent on grant funding. As with many pilot projects, generating policy initiatives to sustain this effort have been put on the back burner, as the 211 Developmental Screening Project has focused on immediate concerns: direct service to callers, integrating developmental screening into the larger 2-1-1 context, hiring and training staff, creating a data system and collecting data, and looking for additiional grant funding. Future policy activities include exploring funding from health, disability, child welfare, and educational funding sources that have or could have, developmental screening and effective early intervention as a goal and fundable activity.

The First 5 LA Early Developmental Screening and Intervention Project

The First 5 LA Early Developmental Screening and Intervention Project is an example of the catalytic effect of the work of the EII Collaborative as it was just getting off the ground. One of the strengths—and challenges—of the Collaborative's "Johnny Appleseed" approach is to plant promising seeds and then step back and watch with an encouraging eye as new entities assume the care and feeding of initiatives.

First 5 Los Angeles and First 5 Commissions in other California counties were established by a 1998 ballot initiative to use tobacco-tax money to fund programs that benefit children from birth through age 5-years. In the early 2000s, before the EII Collaborative was formed, I worked closely with First 5 LA through my association with the then-influential Los Angeles Children's Planning Council. In that capacity, in the spring of 2003, I brought the issue of screening for developmental, learning, mental health and behavioral problems to the attention of First 5 LA's Healthy Kids Advisory Committee. I was a member of this committee, which recommended using First 5 LA funds to expand health insurance coverage to children in families with incomes just above the Medicaid cutoff limits.

Because of what I was learning about autism and developmental issues, I repeatedly raised developmental screening and early intervention as a service that should be paid for by this new health insurance program. After many discussions and conference calls, the Committee agreed that early and often ("periodic" in Medicaid parlance) screening was very important and that there was a leadership role for First 5 LA in this area.[11]

While the timing was not right to incorporate standards for early screening into the First 5 LA Healthy Kids health insurance program (it seemed that the contract with the insurance provider had already been drafted), understanding and support for early screening and intervention rapidly gained traction, and skeptics turned into advocates. Indeed, just a few months later, in September 2003, the meeting that launched the EII Collaborative occurred.

These issues gained momentum as the EII Collaborative moved ahead to become a broadly representative coalition with a policy focus—drafting policy changes, promoting improvements in local practice, and educating the public as well as practitioners. In the meantime, First 5 LA staff became active participants in the EII Collaborative, both enriching discussions and learning about the value of effective early intervention for children, parents, and providers alike.

This learning curve paid off. Less than a year later, in May of 2004, the First 5 LA Commission voted to create an Early Developmental Screening and Intervention project, funded with $5.5 million that was originally slated to support the Healthy Kids (insurance) Initiative. A year later, in May of 2005, First 5 LA issued a request for proposals for this five-year project, which became operational later that year.

Other Los Angeles County Initiatives of the EII Collaborative

Many other initiatives to improve both policy and practice were fueled by the EII Collaborative and its growing list of partners. Some were conceived in the Collaborative and then fully adopted by new partners, much as the 211LA County project began in the EII Collaborative and then was happily adopted as an integral part of 211LA.

Other examples of local EII Collaborative activities and impact include:

- Helping LA public television station, KCET, identify programming to address early identification and intervention in its innovative program, "A Place of Our Own," for caregivers of young children;

- Working with the Los Angeles County Education Foundation as it chose early identification and intervention as a primary strategy to improve school readiness;

- Providing support and suggestions as several local clinics in Los Angeles County incorporated developmental screening into their practice. Here results were mixed. One moment there were signs of success, but when the screening champions moved on or were reassigned, these efforts faltered;

- Providing the inspiration—and informal but intense technical assistance—for including "Identification and Inclusion of Children with Special Needs" as one of six core standards for the County of Los Angeles' Steps to Excellence Program (STEP) Quality Rating System for Child Care Programs, developed by the Policy Roundtable for Child Care. This new standard has been fully embraced by the Roundtable, which has followed up with excellent training and outreach on screening issues;

- Strengthening the LA Education Coordinating Council's "Blueprint for Raising the Educational Achievement of Foster and Probation Youth," making "assuring early identification and intervention for children with disabilities, developmental delays and other problems" one of two major recommendations of the Council's Early Childhood Work Group. While the Work Group recommendations were excellent, follow-up activities focused primarily on older children in the foster care system, not the ever-increasing number of infants and toddlers;

- Including an early intervention indicator in the core set of County-wide school readiness indicators. This was an important conceptual victory. The 2005 report, "Shaping the Future," was excellent, and the 15 school readiness indicators, including the one on early intervention, were officially endorsed by the powerful Los Angeles County Board of Supervisors. But, as is too often the case with data and indicators, the report ended up sitting on the shelf rather than being used by policymakers and leaders to make decisions and allocate resources;

- Working with the Los Angeles County Department of Public Health to do a major study of "Children with Special Health Care Needs in Los Angeles County." This 2005 report was excellent, and showed that the lowest-income sections of Los Angeles County also had, surprisingly, the lowest reported rates of children with special healthcare needs. The Department of Public Health is now working on an updated report.

As you can see, some of these efforts—such as incorporating developmental screening into local child care standards and the County report mentioned in the last bullet—were wildly successful. Others less so. And it is often difficult to predict just how influential a specific local effort will eventually become when it first presents itself.

Conclusion

The consequences of policy stagnation are serious. Childhood developmental issues now affect one in every six children. Autism rates have increased dramatically. We have excellent tools to identify and help young children with developmental issues. But these readily available tools are, sadly, often unused. Of course, as a society, we also need to get to the bottom of and address the causes of increasing disability rates.

Policy improvements are one critical way to do this, both building on the initiatives described and pursuing new strategies and approaches. With the goal of inspiring and educating others to pick up this mantle, this chapter has provided a front-line description of multiple efforts to improve Federal, State, and local policies affecting early screening and effective intervention for children with disabilities and developmental delays.

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Chapter 22: Taking Off Into Sunny Skies

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INTRODUCTION

After all the exposition lobbed in prior chapters, we yearn for the poetic and metaphorical. So within this final chapter, we highlight important issues in this book and share our recommendations. Please fasten your seatbelts!

"Experiencing Turbulence"

In the 1970s, the US had the world's highest rate of high school and college graduation. Soaring into 2013, the US has slipped to No. 21 in high school completion and No. 15 in college completion, as other countries have surpassed us in the quality of their primary and secondary education. Today only about 7 out of 10 ninth-graders will receive high school diplomas, and among many minorities, rates are closer to 5 out of 10. Lower graduation rates correlate with higher unemployment rates, with an increased number of families struggling with psychosocial stressors and adverse health outcomes. So what can primary care providers do about this?

"Review Your Pilot's Manual"

Recall that developmental-behavioral problems are the most common conditions of childhood and adolescence—16% - 18% of children have a developmental disability and 21% have a mental health disorder. Swiftly instituted intervention well prior to kindergarten entrance often averts difficulties and always ameliorates disabilities. Recall that investing in early intervention has huge pay-offs to children with problems, their families, our State and national economies, and the well-being of our society.

But in the US, the reality is that early intervention depends most heavily on the early detection efforts of primary care providers. Do not rely on the educational or social welfare sector to systematically seek out early intervention for every child in your practice who needs it. Do not rely on parents whose children appear to have problems to self-refer to IDEA or other services. Assume responsibility for your critically important role in early detection. But also acknowledge that "it takes a village" to build a better system. If you are lucky, system-wide care coordination networks are being built throughout your community that can help you get your most vulnerable families to their destination (e.g., a high school diploma, productive tax-paying citizenship, and healthy adulthood). Nevertheless, many US communities are still without support networks and many parents and practitioners feel as though they've been stranded in the terminal.

"Check Instruments"

While more complex than most anthropomorphic measurements (e.g., temperature, body mass index, blood pressure), development and behavior are quantifiable, even if a moving target. Still we are more likely to have far better aim if we use quality instruments. A recurring theme throughout this book is that failure to use evidence (e.g., informal approaches to eliciting parents' concerns or measuring children's milestones, such as "yes/no" checklists extrapolated from lengthier measures) contribute to the low detection rates of developmental-behavioral problems. If you are currently using such checklists on your well-child visit encounter forms including those in electronic medical records, please consider the lack of accuracy within and the hazardous impact on quality decision-making. Quality measurement matters!

The periodic and preferably routine use of accurate developmental-behavioral screening tools helps practitioners optimize early identification. Screening over time equals surveillance, but surveillance with evidence. Evidence-based measurement vastly improves referral rates and also helps us identify and hone the types of referral resources needed.[1] Before boarding the plane together, recall the importance of preparing families for the early detection process and then, carefully navigate them towards the appropriate interventions—lest children and parents become lost in the Bermuda Triangle of "no follow-up," and heightened parental anxiety due to inaction.

To achieve a screening tool's reported reliability and accuracy it is essential that screening tools be administered and thoughtfully interpreted as described in users' manuals or official websites. It's not just the quality of your tool but how you employ it! Careful attention to proper implementation and interpretation of screening tools leads to more collaborative conversations between parents and practitioners. Throughout this book, this has been a consistent take-home message. When screening results are problematic, proper administration and same-day interpretation ensure that IDEA and other community referrals occur in a manner that is: (1) safe; (2) equitable; (3) effective, i.e., accurate; (4) timely; (5) parent-/patient-centered; and (6) efficient. These are the six quality aims of the Institute of Medicine. And by timely, we not only mean that referrals are made swiftly, but that early detection and follow-up continues throughout all our encounters with families. Problems emerge well beyond 24- to 30-months of age and we need to continually search for them and intervene promptly.

"Monitor Radar"

We not only want to detect and intervene with existing problems but also try our best to prevent them. Many problems can be averted if we attend carefully to the "yellow alerts" of psychosocial risk before they turn into the "red alerts" of actual delays. Toward that end, we have emphasized careful measurement of psychosocial risk and the importance of intervening with risk factors to prevent "a collision" that adversely affects developmental status—meaning that screening instruments may indicate "systems on go" but "radar" suggests problems ahead. Different tools are needed for viewing psychosocial risk and resilience, but can be staggered across visits. In combination with developmental-behavioral screens, we can prevent many problems.

Most critical to the task of prevention is developmental-behavioral promotion in primary care, and keeping an eye on its effectiveness. Dr. Mitch Blair and Sir David Hall, the authors of Great Britain's healthcare plan for children, argue compellingly that the greatest value in preventive health visits is to encourage appropriate parenting skills, i.e., resilience.[2] Research on *"Reach Out and Read," "Play Nicely," "Healthy Steps," "Bright Futures,"* and many other parenting interventions provide strong evidence that brief parent-training in developmental-behavioral promotion has an enormous positive impact on family well-being and children's developmental status. The work we do with families during clinic visits is invaluable. But, we still need to keep an eye on the "radar" as to whether our brief in-office advice works or whether more intensive preventive services are needed (e.g., *Triple P, Incredible Years, STEP*).

"Air Traffic Control"

"Checking instruments" and "monitoring radar" mean that primary care providers are tasked, not only with early detection, making referrals and prevention, but also with monitoring—the inordinate challenges of viewing the effectiveness of developmental-behavioral promotion, whether families follow through with recommendations and referrals or whether alternative programs are needed, i.e., diversion to a different "runway." Much collaboration and communication with other services is required for follow-up and referral coordination. Primary care providers and families very much need a "grand movement planner." Clinic-level efforts are important to a smooth "take-off"—such as having a care coordinator (as exemplified in the *American Academy of Pediatrics' Medical Home Initiative* and *Healthy Steps*) or by hiring a nurse practitioner, developmental or mental health specialist to help.

There is invaluable care-coordination assistance from national and Statewide programs devoted to the task of making sure that families get to needed services (and in finding alternatives when children are ineligible for IDEA). Sometimes IDEA programs can monitor and divert families to other programs. Sometimes they cannot. We've highlighted several initiatives within this book including Help Me Grow and the National Academy for State Health Policy (*www.nashp.org*), who along with the Commonwealth Fund, established the ABCD initiative for training and collaboration across healthcare and State departments of human services and education (most recently Oklahoma's *Preventive Services Reminder System* to help foster care workers collaborate effectively with healthcare providers).

At the State level, many AAP Chapters (e.g., Illinois) established referral networks, clinic training, mandates for using quality screens, while also ensuring appropriate payment for early detection in primary care. Other States, such as Delaware via the State's Division of Public Health, along with many other agencies (e.g., Nemours Foundation, State IDEA, private payers), offered to all healthcare providers, freely available online screening services along with two-way consent forms across health and other services. We hope such efforts grow and grow and grow. We encourage you to participate in local, regional, State or Federal networking initiatives whenever possible.

We also encourage you to view quality screens as the often unsung heroes in the task of linking families to services. Good measures function as policy initiatives in their own right by providing clinicians' optimal decision-support. Quality screens shape, in positive ways, how we interact with families and other professionals.

"Ceiling Unlimited and Sunny Skies"

To get us all to a better place for helping families with needs, it is crucial to ensure adequate funding for mandated early intervention programs including parent-training, (Early) Head Start, and IDEA. We, as a society, save enormous sums by spending on early childhood and parenting services. But economic arguments are only a part of the compelling reasons to invest in children and families. Quality of life is vastly improved via reductions in incarceration, high school dropout, and unemployment rates, among the many other social benefits. These benefits accrue not just to the families who receive services, but to all citizens. Thus we have fiscal, legal as well as moral and ethical imperatives for ensuring early detection, intervention, and parenting support.

Economic and social benefits accrue over a long time-frame—often 20 years or more. But our elected officials are only in office long enough to worry about short-term costs—not long-term benefits. This means advocacy, repeated across years and years, is crucial. Advocacy has many forms:

- **Top-down** (e.g., the placed-based initiatives in Australia and Canada in which national public health mapping efforts help identify clusters of need and appropriate locations for services). Top-down advocacy is also visible in the work of our various professional societies, government agencies, researchers, and policy-makers. Far more funding is needed to sustain effective programs such as Reach Out and Read, Head Start, etc;

- **Side-to-side** where agencies and programs communicate and coordinate their efforts at early detection and intervention, minimize barriers to services, and reduce redundant expenses. Side-to-side advocacy is also evident in "grass roots" initiatives that help local services get to know each other, create service directories, streamline community collaboration, and collectively advocate for appropriate funding;

- **Looping**—meaning the work of clinician-researchers who recognize that s*cience does not always speak for itself* and so work toward applying policy and science into real-world applications (e.g., create accurate measures, figure out how best to implement them, find time to train and inspire others, etc.);[3]

- **Ground up**—meaning clinic-level work with families focused on developmental-behavioral promotion, early detection, referral and follow up.

So in the sunnier skies, far above clouds and turbulence, we all need to implement as well as lobby for policies and procedures that work. We need to encourage inter-agency care coordination, careful follow-up with families and uninterrupted healthcare... so that children and families can truly "lift off" into a sunnier future.

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Appendix A: Evidence-Based Age-Specific Encounter Forms for Preventive Health Visits

KEVIN P. MARKS

INTRODUCTION

Screening and surveillance activities may sound decidedly overwhelming. But the process is a longitudinal one. This means that not everything has to be done at once. In this appendix we provide well-child visit (WCV) templates to facilitate optimal prevention, early detection, referral and monitoring – one well-child visit at a time. The templates are downloadable at www.pedstest.com/TheBook/AppendixA as modifiable Word documents so you can add your clinic letterhead, space for patient information regional risk factors, etc. An explanation of content, abbreviations, and process is included here.

The WCV templates serve as crucial reminders of the various tasks of surveillance and screening. These forms have been used successfully in busy practices (e.g., at PeaceHealth Medical Group in Eugene, Oregon) in an effort to improve quality of care at well visits. The "lesson learned" was that busy pediatric practitioners need reminders on their clipboard (or computer screen) and concrete guidelines about the content of each well-visit. Per research from the Bright Futures Training Intervention Project, "recall/reminder systems" for pediatric providers are the most effective and most frequently adopted office system change i.e., 87% of practices in 9 States and are known to improve preventive and developmental care in primary care practices.[1]

Caveats and Admonitions

Note that these forms do not provide a list of milestones. Unlike accurate screens, evidence for informal checklists shows they do not detect most children with deficits [e.g., those provided in the AAP/Bright Futures (3rd edition pocket guide/toolkit), Reach Out and Read's checklist, the CDC's Act Early questionnaire, etc.)][1-3] Informal items are usually rooted in the 50th percentile meaning half of all patients will not do well—essentially giving you nothing to go on. Thus you will flounder for what to do with results, meaning most likely, under-refer. You are encouraged to remove milestones checklists on your own well-child encounter forms and replace them with the results of viable screening tests as shown in the various age-specific encounter forms (and described further in Chapter 16 Implementation). The same issue applies to eliciting parents' concerns. Informal questions to parents are fine as conversation starters (e.g., "What have you been doing since I saw you last?"), but are not thorough probes for the issues families want to discuss (and for making decisions based on parents' concerns). Evidence-based questions are essential.

Directions, Abbreviations, Mnemonics and Definitions

The WCV templates are meant to be used with the content of Chapter 5 (screening and surveillance for children 0 to 6-years of age) and with Chapter 9 (screening and surveillance with children 6 years and older). Illustrated are the tasks required and the age at which they are required. Each WCV templates has two columns on the first page. At the top left are identifiers with these abbreviations:

WCV = well-child visit
Age_mo = age in months
CG's name = caregiver's name

Within the two columns are 15 headers. We list these headers below, in order of appearance, along with a description of needed input by providers, and definitions for the many abbreviations and mnemonics—either listed on the forms or commonly inserted by providers.

In addition, the 8 specific tasks required for an Early Periodic Screening Diagnosis and Treatment (EPSDT) visit (listed and numbered at the top of the WCV forms) are explained below. A few common abbreviations used throughout the forms (or used by providers to document findings) include:

HPI = history of the present illness
HX = history
Tx = therapy

qd = every day
qid = 4 times a day
BID or 2x qd = twice a day
TID = three times a day
PO = per os (by mouth)
IU = International Units
Mg = milligrams
Kg = kilograms [*clinicians usually describe a child's weight in kilograms. If you need to convert these to pounds (lbs) this website is helpful: www.metric-conversions.org*]
OV = office visit
SIDS = sudden infant death syndrome

Patient History (EPSDT Task #1)

Includes space to list prior health/growth concerns as well as ongoing issues. Medical problems such as congenital hypothyroidism, PKU, iron deficiency anemia, or lead poisoning negatively affect a child's developmental-behavioral trajectory (i.e., are serious biological or environmental risk factors).

Interval Hx (Hx = history) is space to comment on prior visits and parents' answers to such questions as: Since the child's last well visit, what has (or has not) happened? Any illnesses, office visits or trips to the emergency room? Any sub-specialty consultation visits or interventions? Any missed well visits? Any missed appointments for previously recommended follow- up or consultation appointments?

Nutrition/Activity (EPSDT Task #1)

This section includes a number of prompts regarding what a child eats. There is space in this section to comment on physical activity. Providers sometimes write:

5-2-1-0 = 5 servings of vegetables & fruits per day, 2 hrs or less of screen time per day, 1 hr of physical activity per day, 0 sweetened drinks & 0 trans fats per day
or
5-4-3-2-1-0 Go!... which is mostly the same as above but includes 4 cups of water & 3 cups of lowfat milk per day. It is usually more helpful to tell parents and kids what to eat, rather than always rambling on about what not to eat. Other abbreviations are:

Fe = iron
MTV w/ iron = multivitamin with iron
BM = bowel movement

Development/Behavior/Learning (EPSDT Task #1)
and Abbreviations for Screening Tools

Under **Dev./Behav./Learning** is space to identify which screening measures were administered and the results. Abbreviations for commonly used measures are listed here:

ASQ = Ages & Stages Questionnaire
ASQ:SE = Ages & Stages Questionnaire: Social-Emotional
ASD = Autism Spectrum Disorder
*CRAFFT Screen= Car, Relax, Alone, Forget, Family or Friends, Trouble
*ESP = Eating disorder Screen of Primary Care
IEP = Individualized Educational Program
M-CHAT = Modified Checklist of Autism in Toddlers
PEDS = Parents' Evaluation of Developmental Status
PEDS:DM = PEDS: Developmental Milestones
PSC = Pediatric Symptom Checklist
Pictorial PSC = Pictorial Pediatric Symptom Checklist (shown in full in Chapter 9)

Y-PSC = Youth self-report Pediatric Symptom Checklist
*HEEADSSS (HEADS) = Home, Education (and/or Employment), Eating, Activities, Drugs, Safety, Sex, Suicidality/mental health
*items and scoring are shown at the end of Appendix A and on the back of the downloadable WCVs at www.pedstest.com/TheBook/AppendixA.

Dental (EPSDT Task #8)

This section reminds practitioners to ask about oral health issues and help prevent them. Boxes should be checked when prevention-based procedures are accomplished (e.g., tooth brushing twice a day, fluoride varnish, dental appointments, etc.).

Sleep Counseling

The acronym "BEARS" is the most efficient way to document sleep issues. BEARS stands for:

Bedtime Problems: Does your child have any problems going to bed? Falling asleep?
Excessive daytime sleepiness: Does your child seem overtired or sleepy a lot during the day? Does she still take naps?
Awakenings during the night: Does your child wake up a lot at night?
Regularity and duration of sleep: Does your child have a regular bedtime and wake time? What are they?
Snoring: Does your child snore a lot or have difficulty breathing at night?

Past Medical History, Medication and Allergies (PMH)

Past medical history, medications, and allergies should be updated in the problem checklist which is typically housed in the front of the patient chart. Certain medical conditions (e.g., obstructive sleep apnea) and medications (e.g., anti-seizure meds) can increase the risk of a developmental delay or other future developmental-behavioral problem. At every visit, update your problem and medication lists. The large majority of clinics are now using EMR systems to track pertinent medical conditions and all medications. Many practices have a process where a qualified nurse is responsible for updating the EMR medication list for you. In other practices, pediatric providers feel strongly about updating the medication list themselves.

IDM = infant of a diabetic mother
IUGR = in utero growth retardation
LGA = large for gestational age
LBW = low birth weight
SGA = small for gestational age

Abbreviations for Tools To Gather Family and/or Social History

*FPS = Family Psychosocial Screen
*BPCIS = Brigance Parent Child Interaction Scale
PSQ = Parent Screening Questionnaire

*Critical depression screening and parent observation items and scoring (for the FPS and BPCIS) are shown at the end of Appendix A and on the back of downloadable WCVs at www.pedstest.com/TheBook/AppendixA.

Family History (Family Hx)

At the time of new patient intake (which is often at birth) consider use of an evidence-based tool such as the FPS (shown in full in Chapter 10 and downloadable at *www.pedstest.com/ TheBook/Chapter10*). The FPS probes for a wide range of psychosocial risk factors including depression, substance abuse, parent education, employment status, social support, parents' history of abuse as a child, guns in the home, domestic violence, etc. The FPS also includes questions about family medical status (e.g., "high blood pressure," "lung problems/asthma," "nerve problems," "diabetes," "heart problems," and "smoking in the home) but additional questions are needed to probe for history of speech-language deficits, autism,

hearing loss, vision problems, and genetic disorders.

Social History (Social Hx)

The space for social history is used to update significant family issues found at new patient intake, along with response to recommended interventions [e.g., tobacco exposure, domestic violence (which is noted as DV on the templates)]. The AAP also recommends rescreening for post-partum depression in the 1st and 2nd year of life. For this task, selected items from the FPS or PSQ are brief and useful. Included on the back of the WCV for the 1 month and 12 month visits are the 3 FPS items for depression screening along with scoring directions.

Even at the earliest well-visits, we should encourage parents to promote development by talking with their baby, sharing books, taking him/her places and teaching new things, etc. At 6 months and again at 15 months, we need to affirm that our advice is working. The BPCIS is helpful for capturing (either by parent-report or by examiner observation) critical resilience/protective factors (e.g., whether parents are providing an enriched language environment, enjoy child-rearing, etc.). The BPCIS is shown in full in Chapter 10 and downloadable at *www.pedstest.com/TheBook/Chapter10* in both its parent report and examiner observation versions (in English and Spanish). The 8 critical observation items are shown on the back of the downloadable 6 and 15 month WCVs along with scoring and referral recommendations.

Medical Screening (EPSDT Task #3)

This section is used to capture results of any medical screens administered. Certain medical screening recommendations (e.g., lead screening) often vary based on the population served but, in general, the friendly reminders within these WCV forms diligently follow the AAP/Bright Futures recommendations and the advice of up-to-date, peer-reviewed research articles. Whenever a child is identified with a suspected developmental-behavioral disorder, consider an early return office visit to reassess the child more thoroughly. Part of this assessment may include laboratory tests to screen for an iron deficiency anemia, elevated blood lead level, genetic or metabolic disorder, etc.

To detect iron deficiencies, hemoglobin (Hgb) screening should always be used in combination with a focused dietary history. If the dietary history is highly suggestive of an iron deficiency, some experts recommend a complete blood count (CBC), ferritin and CRP (to make sure that the ferritin is not falsely elevated). Other tests, such as reticulocyte hemoglobin content, may someday prove to be more reliable measures of an iron deficiency. If your physical exam confidently detects a neuromotor delay, then a creatinine kinase (CK) and thyroid stimulating hormone (TSH) should be considered for children with low or normal muscle tone and a brain magnetic resonance imaging (MRI) should be considered for children with increased tone/spasticity. But for the other, more routine medical screening recommendations, please refer to Bright Futures.[1] Abbreviations on the WCV forms are as follows:

CBC = complete blood count
CRP = c-reactive protein
Hgb = hemoglobin
NB = newborn
OGTT = oral glucose tolerance test
TMA = transcription-mediated amplification
TB = tuberculosis
TST = TB skin test

Physical Exam (PE) Sensory Screening (EPSDT Tasks #5 and #6)

Vision and hearing screening recommendations are presented on these WCV forms in a planned and periodic manner as recommended by the AAP/ Bright Futures and EPSDT guidelines. Based on the recommendations of AAP policy statements, peer-reviewed articles and national experts, specific methods or tools have been suggested to enhance your ability to identify (and refer) children with vision and hearing problems. Whenever a child is identified with a suspected developmental-behavioral

disorder, you should also consider a vision or hearing screening as part of that child's assessment at an early return office visit. There is space to check off problems with cover tests, corneal light reflex, response to sounds.

ALGO = brand name device for newborn hearing screening
OAE = otoacoustic emissions
dB = decibels
Hz = hertz

Physical Exam (PE) (EPSDT Task #2)

It is crucial to remember that the large majority of children with developmental-behavioral problems will not have any overt dysmorphology. To identify medical conditions that contribute to developmental-behavioral problems, the results of your developmental-behavioral and family psychosocial screens are essential. Your unclothed (per EPSDT guidelines) physical examination should include attention to the child's growth parameters (including head circumference and shape), facial and other body dysmorphology, eye findings (e.g., cataracts in various inborn errors of metabolism), vascular markings, and other signs of neurocutaneous disorders (e.g., café-au-lait spots in neurofibromatosis, hypopigmented macules in tuberous sclerosis), muscle strength, tone, presence of abnormal reflexes, and disturbance of movement.

Blood pressure screening is an important part of the AAP/Bright Futures health supervision guidelines. Unfortunately, physicians and nurses frequently under-identify children with an elevated blood pressure in their well visit notes The blood pressure cut-offs provided in the vitals section of these WCV forms represent the lower limits for abnormal blood pressure ranges, according to age and gender. Any blood pressure reading equal to or greater than these values represent blood pressures in the prehypertensive, stage 1 hypertensive, or stage 2 hypertensive range and should be further evaluated by a physician. Blood pressure should also be diligently monitored whenever children are prescribed medication for Attention Deficit Hyperactivity Disorder (ADHD) and other psychiatric conditions.

The term "parent-child interactions" is bolded in order to remind practitioners to routinely observe and document parent-child interactions. Although this may have been accomplished with the BPCIS, when doing a physical exam on a child who has a history of being abused and/or neglected, parent-child interactions should alert you that something is seriously wrong with the family dynamics. "Other" is space to note additional findings. Abbreviations include:

Wt = weight
Ht = height
HC = head circumference
BMI = body mass index
T (C) = temperature (Celcius)
HR = heart rate
RR = respiratory rate
BP = blood pressure
HEENT = head, ears, eyes, nose & neck, throat
CV = cardiovascular
ABD = abdomen
GU = genital-urinary
SMR = sexual maturity rating
MSK = musculoskeletal
Neuro = (see Chapter 5 for details)

Assessment

This section summarizes findings including history of growth, weight gain (or lack thereof) in light of developmental/behavioral problems uncovered. Thou cannot treat what thou cannot identify! These WCV forms intentionally guide practitioners away from routinely labeling children with the overly

used terms, "well child" or "normal growth and development." Also commonly used is "WNL," meaning "Within normal limits," a term that often stands for "Would Not Look!" Many a child is not a "well child" (i.e., free of any health, developmental or behavioral conditions). Falsely reassuring labels along with a plan to just "wait and see" are ill-advised. Treating promptly is the most beneficial approach.

Developmental delays, family psychosocial risk factors and other conditions such as hypertension are commonly under-identified in WCV notes too. By encouraging periodic screening, these WCV forms guide practitioners to more reliably and accurately identify developmental-behavioral conditions such as a "suspected developmental delay," "higher risk for autism," "suspected social-emotional/mental health disorder," or "exposure to domestic violence."

Whenever a child was previously suspected to have a developmental-behavioral problem, it is helpful to review previous referral reports while tracking the child's early intervention (EI) and special education eligibility status longitudinally over time.

Act promptly on health-related issues. For these reasons, check boxes are provided to identify common conditions such as "overweight" (BMI > 85th and < 95th %tile), "obesity" (BMI > 95th %tile), "underweight" (BMI < 5th %tile), etc.

Abbreviations include:
AGA = appropriate for gestational age
BW = birth weight
FTT = failure to thrive

A Special Note about Gathering a History and Assessing the Health Risk of Adolescents (11- to 21-years). HEEADSSS (or HEADS on the well-visit forms) is a mnemonic used to structure the history gathering segment of the adolescent well-visit. Evidence-based measures such as the Eating Disorder Screen for Primary Care (ESP), CRAFFT questionnaire, Pediatric Symptom Checklist-Youth Report (Y-PSC) and 2 evidence-based, suicide-specific questions are embedded into the HEEADSSS format as pre-visit screens to reduce the length of the adolescent interview and leave more time for counseling. Most adolescent morbidity and mortality are related to behavior problems or unhealthy decision-making and, as such, are preventable. The home environment, especially parental involvement and attitudes also affect adolescent behavior and health outcomes and so, these issues are incorporated into the HEEADSSS interview or questionnaire.

Plan

This section is meant to work in conjunction with the "Guidance" section that follows. The Plan section includes space to indicate individualized recommendations for services, topics of advice given (e.g., specific information handouts, etc.). The check-off boxes that follow include some of the more common health, developmental-behavioral promotion activities, and service recommendations. (See Chapters 5 and 7 for more information).

For children 6 months to 5 years, strongly consider incorporating Reach Out and Read (ROR) into your practice through which a developmentally age-appropriate book is given at every well-child visit. Although ROR's milestones checklist is not a substitute for accurate screening, it is a helpful guide to observing parent-child interactions (e.g., it is exciting to walk into an exam room and see parents and children reading together).

Common abbreviations are:
EI = Early Intervention
HS/EHS = Head Start/Early Head Start
ECE = early childhood program (usually daycare or preschool)
IU = International Units
MTV = multivitamin
PO = per os (Latin for "by mouth")
ROR = Reach Out and Read

Guidance (EPSDT Task #4)

This section is meant to work in conjunction with the "Plan" section above and focuses on the most common topics for anticipatory guidance and routine advice to parents given the age of the child.

Immunizations (EPSDT Task #7)

Check boxes are provided to remind practitioners to give vaccine counseling services (and to code appropriately for reimbursement). Parents of children with developmental disabilities (e.g., autism) tend to intentionally decline immunizations and are therefore, at greater risk of vaccine-preventable illnesses. Appropriate vaccine counseling is commonly needed for parents of children with developmental disabilities (or a positive family history of developmental disabilities).

A box can be checked off whenever the "AAP Refusal to Vaccinate" form has been signed. For parents who intentional decline vaccinations as recommended by the AAP and Center for Disease Control (CDC), practices should consider having parents sign this form. Abbreviations include:

EMR/EHR = electronic medical record/electronic health record
CDC = Center for Disease Control

Follow-Up/Return

This section also asks practitioners to decide (i.e., "check the box") if a routinely scheduled visit versus an early return office visit is indicated. For example, in children 0 to 4-years, if a broad-band developmental screen like the ASQ is found to be problematic, then practitioners should consider administering a supplemental social-emotional screening tool like the ASQ:SE. An alternative combination of measures capturing both developmental and social-emotional status is to use a combination of PEDS and the PEDS:DM at an early return office visit (or referring to IDEA services for more detailed assessment). Similarly, when the M-CHAT is found to be positive/problematic, a practitioner should make sure the M-CHAT follow-up interview is completed—either during the current visit, via an early return office visit or most commonly by referral to IDEA programs. If parents do not follow-up with a referral to Early Intervention, then the M-CHAT Follow-up Interview should be conducted at the next return office visit. Follow-up visits, between routinely scheduled well-child encounters, are also needed for monitoring medical conditions (e.g., elevated blood pressure, asthma, etc.).

Abbreviations include:
OV = office-visit
SE = social-emotional
ASD = autism spectrum disorder

Implementation

Ideally, clinic staff should help parents/caregivers complete measures in advance and enter results into your electronic record or paper encounter form. Staff can also help gather parent/patient information hand-outs and referral information so that it is ready for you before you enter the exam room. A pre-visit screening implementation system helps you to properly interpret screening tool results after your history and physical exam. For information on explaining findings and treatment plans to parents, please see Chapter 8.

*Items and Scoring for Screens Shown on the Back of Age-Appropriate Downloadable Well-Visit Templates

Several of the well-visit templates shown in Appendix A refer to very brief, narrow-band measures used for screening parental depression, adolescent substance abuse, parent-child interactions, etc. The items and scoring are shown below and are also included on the back of the downloadable well-visit forms at the appropriate ages (*www.pedstest.com/TheBook/AppendixA*).

FPS Depression Scale
Target Ages: 1-month and again at 12-months

1) How often in the last week have you felt depressed? 0   1-2   3-4   5-7 days

2) In the past year, have you had two weeks or more during which you felt sad, blue, or depressed, or lost pleasure in things that you usually cared about or enjoyed?   yes   no

3) Have you had two or more years in your life when you felt depressed or sad most days, even if you felt okay sometimes? yes   no

FPS Scoring
Positive answers are: (1) 5 – 7 days,(2) yes and (3) yes.
Two or more positive answers are considered a positive screen.

BPCIS (Critical Examiner Items)
Target Ages: 6-months and again at 15-months

Directions: Please circle the answers that correspond to your observations. You will need to use clinical judgment about some items (including asking parents questions). Note that item numbers correspond to the complete examiner version and its scoring (shown below). The parent report version of the BPCIS in English is shown in Chapter 10 and downloadable in English and Spanish atwww.pedstest.com/TheBook/Chapter10.

1. Parent plays with child and shows him or her things about toys.
      Not likely/Not often   Sometimes   Often/ Likely

3. Parent talks to child mostly when child is crying.
      Often/ Likely   Sometimes   Not likely/Not Often

4. Parent helps child learn new things.
      Not likely/Not Often   Sometimes   Often/ Likely

5. Parent reads children's books to child.
      Not likely/Not Often   Sometimes   Often/ Likely

8. When child looks at or touches a toy or object, parent talks to him/her about the toy.
      Not likely/Not Often   Sometimes   Often/ Likely

15. When child looks at or touches something, parents' first response is "No."
      Often/ Likely   Sometimes   Not likely/Not Often

19. Parent faces child when talking with him or her.
      Not Likely/Not Often   Sometimes   Often/ Likely

20. Parent brings food, toys, diapers or other helpful child-support materials to the encounter.
      Insufficient for child's needs   Sufficient

BPCIS Scoring
Indicators of Resilience are:
Two or more of the following: Items 1, 4, 5, 8, answered with "often/likely" ("a menudo"), "mostly true" "(es bastante cierto")

Indicators of Risk are:
Fewer than 2 positive answers from the above set of items/responses and/or two or more of these answers:

(a) Items 3 and 15 answered as "often/likely" ("a menudo") or "sometimes" ("a veces")
(b) Item 19 answered as "not likely/not often" ("No muy seguido") or "sometimes" ("a veces")
(c) Item 20 answered as "insufficient" ("insuficiente")

HEEADSSS, CRAFFT and EPS Questionnaire and Scoring
Target Ages: 15-years and older

HOME

Do you think that your parent(s) or guardian(s) listen to you and take your feelings seriously?   ☐ No   ☐ Yes

Are you permitted in your home to make independent decisions?   ☐ No   ☐ Yes

Has you or anyone in your family ever been in counseling or had a mental health problem?   ☐ No   ☐ Yes

Do you ever have family conversations at the table about how to cope with stress?   ☐ No   ☐ Yes

Does anyone in your household smoke (including smoking outside)?   ☐ No   ☐ Yes

How many guns are in your home? ☐ None ☐ >1
    If >1, do you know how to get to the gun and its ammunition?   ☐ No ☐ Yes

Who do you talk to when things are not going well?_____

EDUCATION

School_____Grade _____
Are you eligible for special education services? ☐ No   ☐ Yes
    If Yes, Do you have an IEP or 504 behavioral plan? ☐ No   ☐ Yes

Any academic or homework concerns?_____

Have you ever skipped classes or missed school? ☐ No   ☐ Yes

Is anybody concerned about your behavior or attention span? _____

EATING Eating Disorder Screen for Primary Care (ESP), >2 (+) items in bold = (+) screen

    1. Are you satisfied with your eating patterns?
        ☐ **No**   ☐ Yes

    2. Do you ever eat in secret?
        ☐ No   ☐ **Yes**

    3. Does your weight affect the way you feel about yourself?
        ☐ No   ☐ **Yes**

    4. Have any members of your family suffered with an eating disorder?
        ☐ No   ☐ **Yes**

    5. Do you currently suffer with or have you ever in the past suffered with an eating disorder?
        ☐ No   ☐ **Yes**

ACTIVITIES

Getting at least 1 hour of physical activity per day?	☐ No	☐ Yes
Screen time (except for homework) less than 2 hours per day?	☐ No	☐ Yes
Have friends, interests or participating in community activities?	☐ No	☐ Yes
Any parental concerns about internet safety?	☐ No	☐ Yes

DRUGS: *After first assuring confidentiality (with the parents outside the exam room)…*

Do you currently smoke cigarettes? ☐ No   ☐ Yes
    If yes, how many cigarettes do you smoke per day? _____packs per day

SUBSTANCE ABUSE SCREENING (CRAFFT)

    1. Drink any <u>alcohol</u> (more than a few sips). Do not count religious or family events.   ☐ No   ☐ Yes

    2. Smoke any <u>marijuana or hashish</u>?   ☐ No   ☐ Yes

    3. Use any thing else to get high (e.g., illegal drugs, OTC or prescription drugs, things that
       you sniff or "huff")?   ☐ No   ☐ Yes

4. Ever ridden in a CAR driven by someone (including yourself) who was "high" or had been using
    alcohol or drugs?   □ No □ Yes

Then if "No" to items 1 - 4, then STOP. If "Yes" to ANY then ask:

5. Do you ever use alcohol or drugs to RELAX, feel better about yourself, or fit in?   □ No □ Yes

6. Do you ever use alcohol/drugs while you are by yourself, ALONE?   □ No □ Yes

7. Do you ever FORGET things you did while using alcohol or drugs?   □ No □ Yes

8. Do your family or FRIENDS ever tell you that you should cut down on your drinking or drug use? □ No □ Yes

9. Have you gotten into TROUBLE while you were using alcohol or drugs?   □ No □ Yes

Give 1 point for every "Yes" answer.

Interpretation

□ **CRAFFT score 0 or 1** ➔ brief advice   □ No signs of acute danger or addiction ➔ Brief negotiated interview to stop

□ **CRAFFT >2** ➔ brief assessment ➔   □ Signs of addiction / **CRAFFT >5** / daily or near daily use ➔ Refer to treatment

                              □ Signs of acute danger ➔ Make immediate intervention & contract for safety

SAFETY

Do you feel you live in a safe place?   □ No   □ Yes _____

In the past year, have you ever felt threatened in your home or a relationship?   □ No   □ Yes

How often do you use a seatbelt?   □ Never   □ Rarely   □ Sometimes   □ Often □ Always

Any history of impaired (e.g. alcohol, marijuana, etc.) or distracted driving
(e.g. texting or talking on phone) ?   □ No   □ Yes

SEX

Are you attracted to (circle answer):   males,   females,   both,   not sure

Are any of your friends sexually active?   □ No   □ Yes

Have you ever had any sexual experiences? (circle if: oral, vaginal, anal)   □ No   □ Yes

SUICIDALITY/ <u>Mental health (PSC or Y-PSC) screening</u> *(Note: scoring is on the PSC or Y-PSC questionnaire)*

PSC or Y-PSC score:_____ □ **(-)** □ **(+)** (+) Subscales: □ **Internalization** □ **Externalization** □ **Attention**

Do you ever see or hear things that aren't there?   □ No   □ Yes

<u>**Suicide-specific screening**</u> >1 (+) items are in **bold** = (+) screen

1. During the past 3 months, have you thought of killing yourself?   □ No   □ **Yes**
2. Have you ever tried to kill yourself?   □ No   □ **Yes**

REFERENCES

1.   Hagan JF, Shaw JS, Duncan PM, eds. Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents. 3rd ed. Elk Grove Village, IL: American Academy of Pediatrics, 2008.

2.   Reach Out and Read. Literacy Milestones. *www.reachoutandread.org.*

3.   Centers for Disease Control. Learn the Signs. Act Early. *www.cdc.gov/ncbddd/actearly/index.html.*

4.   Kaelber DC, Pickett F. Simple table to identify children and adolescents needing further evaluation of blood pressure. *Pediatrics*. 2009;123:e972-974.

5.   Lannon CM, Flower K, Duncan P, Strazza Moore K, Stuart J, Bassewitz, J. The Bright Futures Training Intervention Project: Implementing Systems to Support Preventive and Developmental Services in Practice. *Pediatrics*. 2008;122(1):e163-e171.

Well-Child Visit: 1st Week   Age:_____days

CG's Name: [_____]

EPSDT
❶ Hx/Nutr/Devel
❷ Unclothed PE
❸ Labs
❹ Health Educ
❺ Vision Screen
❻ Hearing Screen
❼ Immunizations
❽ Dental Referral

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History ①

Who is at the WCV?
☐ Mom   ☐ Grandparent
☐ Dad   ☐ Foster parent
☐ Sibling(s)   ☐ Other Caregiver

Health or feeding concerns? _____
_____
_____
_____
_____

Nutrition / Activity ①

☐ **Breastfeeding** q _____hrs, _____min/side

Position/ Latch & Suck? ☐ Appropriate ☐ Problematic
Nipple soreness?   ☐ Yes   ☐ No

_____

Breast pumping?_____X qd (~10 min after every feeding, q 2 hrs or 8-10X daily?)

☐ **Formula** = _____

_____ oz q _____ hrs or _____ oz/day

Elimination: BMs:_____ Voids:_____

Past Medical History (Dev-Behav. Risk Factors) ①

☐ Prenatal, delivery & neonatal history reviewed; see EMR

(+) findings:_____

Gest. Age_____wks   Preterm? ☐ Yes ☐ No
☐ LBW   ☐ SGA   ☐ IUGR
☐ LGA   ☐ IDM
☐ In Utero Exposure to:_____

Administered: ☐ **AAP Pediatric Intake Form/ Family**
(per AAP)   **Psychosocial Screen (FPS)** or
    ☐ **Parent Screening Questionnaire (PSQ)**

Meds, Allergies Updated in EMR

Family Hx see FPS or PSQ_____

_____

Social Hx see FPS or PSQ_____
_____
_____

Tobacco exposure? ☐ Yes ☐ No   DV? ☐ Yes ☐ No

Medical Screening ③

1st newborn screen: ☐ Normal ☐ Results pending

PE: Sensory Screening ⑤⑥

Red reflex: ☐ Present bilaterally
Corneal light reflex: ☐ Symmetrical
Hearing behavior: ☐ Startles ☐ Calms to voice
Newborn OAE or ALGO ☐ Passed ☐ Refer on R &/or L side(s)

PE ②   Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp P_____ R_____ BP_____/_____

HC_____cm (_____%) Length _____cm (_____%)

Wt_____kg (birth wt _____kg) wt / ht ratio _____%

GEN _____
HEENT _____
Chest/Lungs _____
CV/Heart _____
ABD _____
GU _____
Skin _____
MSK/Spine _____
Neuromotor_____
Parent-Child Interaction _____
Other: _____

Assessment

Growth: ☐ Term   ☐ _____ weeks preterm
    ☐ AGA   ☐ LBW, SGA or IUGR ☐ LGA
    ☐ Breastfed ☐ Formula fed ☐ Both
    ☐ Feeding nl ☐ Feeding problems ☐ <10% BW

Development & Behavior:
    ☐ Typical   ☐ "At-risk"   ☐ Automatically EI-eligible

Icterus & Other: ☐ Typical ☐ Jaundice ☐ EMR problem list
        updated

Plan

_____
_____
_____

Newborn well baby handout (Bright Futures: Infancy)
☐ AAP SIDS Prevention handout
☐ Vitamin D 400 IU PO qd (with iron if premature)
☐ Electric breast pump
☐ **Lactation referral**_____

Guidance ④

- Breastfeeding promotion; AAP recommended goal is 12 months or longer but exclusive breastfeeding for the first 4-6 months is ideal; wait 4-6 weeks to introduce pacifier
- SIDS prevention: back to sleep position; firm mattress; no soft bedding, no pillows; sleep in same room as baby; smoke-free environment; crib w/ slats <2 3/8 inches apart
- Family readiness: community resources can help!
- Create nurturing routines; physical contact (holding, carrying and rocking) makes baby feel secure
- Smoke free home & vehicle; avoid others with cold & flu

Immunizations ⑦

☐ Hepatitis B vaccine given after birth; EMR updated

Follow up / Return

☐ Next routine well-child visit   ☐ Early return OV

EPSDT
❶ Hx/Nutr/Devel
❷ Unclothed PE
❸ Labs
❹ Health Educ
❺ Vision Screen
❻ Hearing Screen
❼ Immunizations
❽ Dental Referral

Well-child Exam: 2-4 weeks   Age:_____ days

CG's name: _____

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History ①

Who is at the WCV?
☐ Mom   ☐ Grandparent
☐ Dad   ☐ Foster parent
☐ Sibling(s)   ☐ Other Caregiver

Health or feeding concerns? _____
_____
_____
_____
_____

Nutrition / Activity ①

☐ **Breastfeeding** q _____ hrs, _____min/side

Position/ Latch & Suck?   ☐ good   ☐ problematic
Nipple soreness?   ☐ yes   ☐ no

_____

Breast pumping:_____X qd (q 3-4 hrs or 8-10X qd?)

☐ **Formula** = _____

_____ oz q _____ hrs or _____ oz/day

Elimination: BMs:_____ Voids:_____

Past Medical History (Dev-Behav. Risk Factors) ①

☐ Prenatal, delivery & neonatal history reviewed in EMR

(+) findings:_____

Gest. Age_____wks   Preterm? ☐ Yes ☐ No
☐ LBW   ☐ SGA   ☐ IUGR
☐ LGA   ☐ IDM
☐ In-Utero Drug Exposure:_____

Administered: ☐ **AAP Pediatric Intake Form/ Family**
                    Psychosocial Screen (FPS)
               ☐ **Parent Screening Questionnaire (PSQ)**

Meds, Allergies
Updated in EMR

Family Hx
see FPS or PSQ_____

Social Hx
see FPS or PSQ_____
_____

Tobacco exposure? ☐ Yes ☐ No   DV? ☐ Yes ☐ No

Medical Screening ③
1st NB Screen: ☐ nl ☐ pending

2nd NB Screen: ☐ Lab slip given

PE: Sensory Screening ⑤⑥

Red Reflex: ☐ Present bilaterally
Corneal light reflex:☐ Symmetric
Hearing behavior: ☐ Startles ☐ Calms to voice
OAE or ALGO: ☐ Passed ☐ Referred on R &/or L side(s)

PE ②
Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp P_____ R_____ BP_____/_____

HC_____cm (_____%) Length _____cm (_____%)

Wt_____kg (birth wt _____kg) wt / ht ratio _____%

GEN _____
HEENT _____
Chest/Lungs _____
CV/Heart _____
ABD _____
GU _____
Skin _____
MSK/Spine _____
Neuromotor_____
Parent-Child Interaction _____
Other: _____

Assessment

Growth: ☐ Term   ☐ _____ wks Preterm
           ☐ AGA   ☐ SGA or IUGR   ☐LGA
           ☐ Breastfed   ☐ Formula fed   ☐ Both
           ☐ Feeding typical ☐ Feeding problems ☐ FTT

Development & Behavior:
   ☐ Typical   ☐ "At-risk"   ☐ Automatically EI-eligible

Other: see updated EMR problem list

Plan

_____
_____
_____

2-4 wk WCV handout (Bright Futures: Infancy)
☐ **Positive parenting program & care coordination phone #**
Vitamin D 400 IU PO qd +/- iron (if breastfeeding or premature)
☐ AAP SIDS Prevention handout
☐ Electric breast pump
☐ **Lactation referral**_____

Guidance ④

❑ Breastfeeding: AAP recommended goal is 12 mo or longer; exclusive breastfeeding for the first 4-6 mo is ideal
❑ SIDS prevention; back to sleep position; firm mattress; no soft bedding, no pillows; sleep in same room as baby; smoke-free environment; crib w/ slats ≤2 3/8 inches apart
❑ Newborn transition; develop feeding & sleeping routines; calm baby w/ hushing, stroking head or gentle rocking
❑ Baby Blues: rest & sleep when baby sleeps; accept help from partner, family & friends; seek community resources
❑ Get infant car seats checked by a certified technician
❑ Hand washing, avoid crowds, buy a rectal thermometer

Immunizations ⑦

☐ AAP, CDC or other vaccine handouts given

Follow up / Return

☐ Next routine well-child visit
☐ Early return OV

EPSDT
❶ Hx/Nutr/Devel
❷ Unclothed PE
❸ Labs
❹ Health Educ
❺ Vision Screen
❻ Hearing Screen
❼ Immunizations
❽ Dental Referral

Well-Child Visit: 2 months   Age_____ mo

CG's name: [_____]

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History ①

Who is at the WCV?
☐ Mom   ☐ Grandparent
☐ Dad   ☐ Foster parent
☐ Sibling(s)   ☐ Other Caregiver

Health or growth concerns? _____
1._____
2._____
3._____
_____
_____

Nutrition / Activity ①

☐ **Breastfeeding** q _____hrs, _____min/side

Position/ Latch & Suck?   ☐ Appropriate   ☐ Problematic
Nipple soreness?   ☐ Yes   ☐ No
Pumping & Storing?   ☐ Yes   ☐ No

☐ **Formula** = _____

_____ oz q _____ hrs or _____ oz/day

Elimination concerns? ☐ Yes   ☐ No

Dev./Behav./Learning ①   Concerns?_____

_____

Administered: ☐ **ASQ**   ☐ **PEDS**   ☐ **PEDS:DM**

Interpretation: ☐ Typical/ observe   ☐ Atypical/ action needed

Domains: ☐ expr. lang.   ☐ recept. lang.   ☐ cognitive
of concern ☐ fine motor   ☐ gross motor   ☐ SE/ behavior
            ☐ self-help/ adaptive   ☐ other

☐ **Maternal mood disorder screen** *Circle if:* **(+) or (-)**
Mother's PCP, ob/gyn or midwife:

Sleep   _____

Daytime nap routine?_____
Awakenings/ night?_____

PMH, Meds, Allergies   Updated in Problem List / EMR

Family History _____

Social History _____

Tobacco exposure? ☐ Yes ☐ No   DV? ☐ Yes ☐ No

Medical Screening ③

1ˢᵗ Newborn Screen: ☐ Normal   ☐ Abnormal
2ⁿᵈ Newborn Screen: ☐ Normal   ☐ Abnormal

Sensory Screening ⑤⑥

Red Reflex: ☐ Present bilaterally
Corneal light reflex: ☐ Symmetric
Hearing: ☐ Startles   ☐ Calms to voice

PE ②   Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp   P_____   R_____   BP_____/_____

HC_____cm (_____%)   Length _____cm (_____%)

Wt_____kg (_____%) wt / ht ratio _____%

GEN _____
HEENT _____
Chest/Lungs _____
CV/Heart _____
ABD _____
GU _____
Skin _____
MSK/Spine _____
Neuromotor _____
Parent-Child Interaction _____
Other: _____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: see updated EMR problem list

Plan

_____
_____
_____
_____

2 mo WCV handout (Bright Futures: Infancy)
☐ Vitamin D 400 IU qd +/- iron (if breastfeeding or premature)
☐ EI referral & care coordination phone #
☐ **Refer to positive parenting/ other community resource**
☐ **Refer mother to mental health, PCP, ob/gyn or midwife**

Guidance ④

- Breastfeeding maintenance; pumping & storing if returning to work or school; 8-12 feedings/ day; exclusive breastfeeding for first 4-6 months is ideal
- Formula; prepare safely as directed; hold baby semi-upright; don't prop bottle; no bottle in bed
- Postpartum depression is common; take time for self & partner; maintain social contacts; engage others to help
- Talk with partner about family planning; discuss with PCP
- Choose quality child care; recognize separation is hard
- Tummy time while awake; strategies for fussy times
- Maintain a regular sleep & feeding routine
- Set home water temp<120° F; don't leave baby in tub!

Immunizations ⑦

Refer to EMR for vaccines administered, CDC handouts given
☐ Vaccine counseling
☐ Refusal to vaccinate AAP form signed

Follow up / Return

☐ Next routine well-child visit   ☐ Early return OV

EPSDT
❶ Hx/Nutr/Devel
❷ Unclothed PE
❸ Labs
❹ Health Educ
❺ Vision Screen
❻ Hearing Screen
❼ Immunizations
❽ Dental Referral

Well-child Exam: 4 months   Age:_____mo

CG's name: [_____]

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History ①

Who is at the WCV?   ☐ Mom   ☐ Grandparent
                      ☐ Dad   ☐ Foster parent
                      ☐ Sibling(s)   ☐ Other Caregiver

Health or growth concerns? _____

1._____

2._____

3._____

_____

_____

Interval Hx? _____

Nutrition / Activity ①

☐ **Breastfeeding** q _____hrs, _____min/side
Position/ Latch & Suck?   ☐ Appropriate   ☐ Problematic
Nipple soreness?   ☐ Yes   ☐ No
Pumping & Storing?   ☐ Yes   ☐ No

☐ **Formula** = _____

_____ oz q _____ hrs or _____ oz/day

Iron-fortified cereal or food? ☐ No ☐ Yes_____

Elimination concerns? ☐ No ☐ Yes_____

Dev./Behav./Learning ①   Concerns?_____

_____

Administered: ☐ **ASQ**   ☐ **PEDS**   ☐ **PEDS:DM**

Interpretation: ☐ Typical/ observe   ☐ Atypical/ action needed

Domains: ☐ expr. lang.   ☐ recept. lang.   ☐ cognitive
of concern   ☐ fine motor   ☐ gross motor   ☐ SE/ behavior
            ☐ self-help/ adaptive   ☐ other

☐ **Maternal mood disorder screen** Circle if: (+) or (-)
Mother's PCP, ob/gyn or midwife:

Sleep   _____

Daytime nap routine?_____

Awakenings/ night? _____

PMH, Meds, Allergies   Updated in Problem List / EMR

Family Hx   _____

Social Hx

_____

Tobacco exposure? ☐ Yes ☐ No   DV? ☐ Yes ☐ No

Medical Screening ③

1st Newborn Screen: ☐ normal   ☐ abnormal
2nd Newborn Screen: ☐ normal   ☐ abnormal

Sensory Screening ⑤⑥

Red Reflex: ☐ present bilaterally
Corneal light reflex: ☐ symmetric
Hearing: ☐ startles   ☐ calms to voice

PE ②   Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp P_____ R_____ BP_____/_____

HC_____cm (_____%) Length _____cm (_____%)

Wt_____kg (_____%) wt / ht ratio _____%

GEN _____
HEENT _____
Chest/Lungs _____
CV/Heart _____
ABD _____
GU _____
Skin _____
MSK/Spine _____
Neuromotor_____
Parent-Child Interaction _____
Other: _____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: See EMR problem list

Plan

_____

_____

_____

_____

_____

4 mo WCV handout (Bright Futures: Infancy)
☐ EI referral & care coordination phone #
☐ Positive parenting support group or counseling
☐ Vitamin D 400 IU qd +/- iron (if breastfeeding or premature)
☐ **Refer mother to post-partum mood d/o support group**
☐ **Refer mother to mental health, PCP, ob/gyn or midwife**

Guidance ④

☐   Exclusive breastfeeding during first 4-6 months is ideal
☐   Introduce iron-fortified cereal or food when baby is ready
☐   Rear-facing car seats; never put baby in front seat
☐   Take time for self & partner; maintain social contacts
☐   Make quality child care arrangements
☐   Quiet reading & singing; "tummy time"/ active playtime

Immunizations ⑦

Refer to EMR for vaccines given, CDC handouts given
☐ Vaccine counseling
☐ Refusal to vaccinate AAP form signed

Follow up / Return

☐ Next routine well-child visit
☐ Early return OV
☐ **SE (ASQ:SE) screening needed** (per AAP)

Well-Child Visit: 6 months   Age_____mo

CG's name: _____

History ①

Who is at the WCV?
☐ Mom   ☐ Grandparent
☐ Dad   ☐ Foster parent
☐ Sibling(s)   ☐ Other Caregiver

Health or growth concerns? _____

1._____
2._____
3._____
_____
_____

Interval Hx? _____

Nutrition / Activity ①

Breastfeeding: ☐ Yes, on demand   ☐ No
Formula: ☐ Yes   ☐ No

=_____ _____ oz/ feeding, _____X qd

Fe-rich cereal/ food 2x qd? ☐ Yes ☐ No
Stage 1 solids? ☐ Yes ☐ No
Fruit juice, sugars? ☐ Yes ☐ No

Elimination concerns? ☐Yes ☐ No

_____

Dev./Behav./Learning ① Concerns?_____

_____

Administered: ☐ ASQ ☐ PEDS ☐ PEDS:DM

Interpretation: ☐ Typical/ observe ☐ Atypical/ action needed

Domains: ☐ expr. lang. ☐ recept. lang. ☐ cognitive
of concern ☐ fine motor ☐ gross motor ☐SE/ behavior
☐ self-help/ adaptive ☐ other

☐ **Maternal mood disorder screen** *Circle if:* **(-) or (+)**

Mother's PCP, ob/gyn or midwife:_____

Dental ⑧ No bottle in bed • don't prop the bottle • avoid frequent breastfeeding qhs & over grazing • **fluoride drops**

Sleep Daytime routine?_____

Awakenings/ night? _____

PMH, Meds, Allergies Updated in Problem List / EMR

Family Hx _____

Social Hx ☐ BPCIS & discussed "resiliency" factors

_____

Tobacco exposure? ☐ Yes ☐ No   DV? ☐ Yes ☐ No

PE Sensory Screening ⑤⑥

Cover test: ☐ No motion   Corneal light reflex: ☐ Symmetric
Hearing: ☐ **OAE** *(administer routinely if possible)*
☐ **Pass** ☐ **Refer** *circle if on:* **R** and/or **L** side(s)

PE ② Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp   P_____   R_____   BP_____/_____

HC_____cm (_____%)   Length _____cm (_____%)

Wt_____kg (_____%)   wt / ht ratio _____%

GEN _____
HEENT _____
Chest/Lungs _____
CV/Heart _____
ABD _____
GU _____
Skin _____
MSK/Spine _____
Neuromotor_____
Parent-Child Interaction _____
Other: _____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: see EMR problem list

Plan

_____
_____
_____
_____

6 mo WCV handout (Bright Futures: Infancy)
ROR book & literacy counseling
☐ AAP Choking Prevention & Child CPR handouts
☐ "Healthy Habits"/ obesity prevention handout + counseling
☐ **EI referral & care coordination phone #**
☐ **Positive parenting support group or counseling**
☐ Fluoride 0.25mg PO qd + MTV w/ iron & Vit D 400 IU PO qd

Guidance ④

☐ Car seats rear-facing until maximally allowed weight
☐ Choking prevention; keep small objects & plastic bags away from baby; limit finger foods to soft bits
☐ Don't ever leave baby alone in a tub, high places
☐ Don't use an infant walker
☐ Set home water temp <120°F; avoid burn risk (stoves, heaters, hot drinks); barriers around space heaters
☐ Never leave baby alone in a tub or high places;
☐ Do home safety check: gates at stairs; lock up or re-shelve cleaning products; avoid infant walkers;
☐ Interactive & reciprocal play, talk & sing, read to baby daily

Immunizations ⑦

Refer to EMR for vaccines given, CDC handouts given
☐ Vaccine counseling
☐ Refusal to vaccinate AAP form signed

Follow up / Return

☐ Next routine well-child visit   ☐ Early return OV
☐ **SE (ASQ:SE) screening needed** *(per AAP)*

EPSDT
❶ Hx/Nutr/Devel
❷ Unclothed PE
❸ Labs
❹ Health Educ
❺ Vision Screen
❻ Hearing Screen
❼ Immunizations
❽ Dental Referral

Well-Child Visit: 9 months   Age_____ mo

CG's name: _____

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History ①

Who is at the WCV?
☐ Mom   ☐ Grandparent
☐ Dad   ☐ Foster parent
☐ Sibling(s)   ☐ Other Caregiver

Health or growth concerns? _____

1._____
2._____
3._____
_____

Interval Hx? _____ _____

Nutrition / Activity ①

Breastfeeding: ☐ Yes, on demand   ☐ No
Formula: ☐ Yes   ☐ No

= _____ _____oz/ feeding,_____Xqd
Fe-rich cereal 2x qd?   ☐ Yes ☐ No
Meats, fish, eggs, soy?   ☐ Yes ☐ No
Vegetables, fruits?   ☐ Yes ☐ No
Age-apropriate finger foods?   ☐ Yes ☐ No
Fruit juice, sugar?   ☐ Yes ☐ No

Elimination concerns? ☐ No ☐ Yes _____

Dev./Behav./Learning ①

Concerns?_____
Broad-band developmental screening *(AAP recommended)*
Administered: ☐ **ASQ**   ☐ **PEDS**   ☐ **PEDS:DM**

Interpretation: ☐ Typical/ observe   ☐ Atypical/ action needed

Domains: ☐ expr. lang.   ☐ recept. lang.   ☐ cognitive
of concern   ☐ fine motor   ☐ gross motor   ☐ SE/ behavior
☐ self-help/ adaptive   ☐ other

Dental ⑧
No bottle in bed • don't prop the bottle • avoid frequent breastfeeding qhs & over grazing • fluoride drops

Sleep

PMH, Meds, Allergies   Updated in Problem List / EMR

Family Hx _____

Social Hx _____
_____

Tobacco exposure? ☐ Yes ☐ No   DV? ☐ Yes ☐ No

Medical Screening ③

☐ **Cap Hemogram or HemoCue** (If Hgb<11 or if high-risk for iron deficiency, then venipuncture CBC, ferritin, CRP)
☐ **Blood lead level** (if (+) lead screening questionnaire)

Sensory Screening ⑤⑥

Cover test: ☐ No motion
Corneal light reflex: ☐ Symmetric
Hearing: ☐ Turns to voice ☐ Startles

PE ②   Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp   P_____   R_____   BP_____/_____

HC_____cm (_____%)   Length _____cm (_____%)

Wt_____kg (_____%)   wt / ht ratio _____%

GEN _____
HEENT _____
Chest/Lungs _____
CV/Heart _____
ABD _____
GU _____
Skin _____
MSK/Spine _____
Neuro _____
Parent-Child Interaction _____
Other: _____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: see EMR problem list

Plan

_____
_____
_____

9 mo WCV handout (Bright Futures: Infancy)
ROR book & literacy counseling
☐ AAP Home Safety Checklist given & reviewed
☐ "Healthy Habits" / obesity prevention handout + counseling
☐ **EI referral & care coordination phone #**
☐ **Positive parenting support group or counseling**
☐ Fluoride 0.25mg + MTV with iron & Vit D 400 IU qd PO qd

Guidance ④

❑ Home safety: review handout; be within arm's reach near water, pools, bathtubs; Poison Control # at each telephone; don't leave heavy objects or hot liquids/ soups/ oatmeal on tablecloth; rear facing car safety seat
❑ Positive discipline; use distraction; limit the use of the word "no"; be a good role model; ask for help if DV !
❑ Talk / Sing / Read to baby; play with cause and effect toys
❑ Avoid TV & Media, not beneficial for children under 3 yrs

Immunizations ⑦

Refer to EMR for vaccines given, CDC handouts given
☐ Vaccine counseling
☐ Refusal to vaccinate AAP form signed

Follow up / Return

☐ Next routine well-child visit
☐ Early return OV
☐ **SE screening (ASQ:SE) needed** *(per AAP)*

Well-Child Visit: 12 months   Age_____mo

CG's name: _____

History ①

Who is at the WCV?   ☐ Mom   ☐ Grandparent
   ☐ Dad   ☐ Foster parent
   ☐ Sibling(s)   ☐ Other Caregiver

Health or growth concerns? _____

1._____
2._____
3._____
_____
_____
_____

Interval Hx? _____

Nutrition / Activity ①

Breastfeeding   ☐ Yes   ☐ No
Cow's milk   ☐ Yes   ☐ No   Whole or 2%?_____ oz/day
Fe-rich cereal/ foods 2x qd?   ☐ Yes   ☐ No
Meats, fish, eggs, soy protein?   ☐ Yes   ☐ No
Vegetables, fruits?   ☐ Yes   ☐ No
Age-appropriate finger foods?   ☐ Yes   ☐ No
Fruit juice, sugar?   ☐ Yes   ☐ No

Elimination concerns?   ☐ Yes   ☐No _____

Dev./Behav./Learning ①
Concerns?_____
_____

Administered: ☐ ASQ   ☐ PEDS   ☐ PEDS:DM

Interpretation: ☐ Typical/ observe   ☐ Atypical/ action needed

Domains: ☐ expr. lang.   ☐ recept. lang.   ☐ cognitive
of concern   ☐ fine motor   ☐ gross motor   ☐ SE/ behavior
       ☐ self-help/ adaptive   ☐ other

Dental ⑧
Circle if: no bottle in bed • Brushing • Fluoride
    ☐ **Refer to dentist** *per AAP & ADA*
    ☐ **Fluoride varnish + handout**

Sleep _____

PMH, Meds, Allergies   Updated in Problem List / EMR

Family Hx _____

Social Hx _____
_____
_____

Tobacco exposure? ☐ Yes ☐ No   DV? ☐ Yes ☐No

Medical Screening ③

Cap Hemogram or HemoCue (If Hgb<11 or if high-risk for iron deficiency then venipuncture CBC, ferritin, CRP)
☐ Blood lead level
☐ TB Skin Test if at risk per TB questionnaire

Sensory Screening ⑤⑥

Red Reflex: ☐ Present bilaterally
Corneal light reflex: ☐ Symmetric
Hearing: ☐ Turns to voice   ☐ Startles

PE ②
    Vitals & Growth Parameters

T_____ °C/°F ax/rect/tymp   P_____   R_____   BP____/_____

HC_____cm (_____%)   Length _____cm (_____%)

Wt_____kg (_____%)   wt / ht ratio _____%

GEN _____
HEENT _____
Chest/Lungs _____
CV/Heart _____
ABD _____
GU _____
Skin _____
MSK/Spine _____
Neuro _____
Parent-Child Interaction _____
Other: _____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: See EMR problem list

Plan
_____
_____
_____
_____

12 mo WCV handout (Bright Futures: Early Childhood)
ROR book & literacy counseling
☐ "Healthy Habits" / obesity prevention handout + counseling
☐ **EI referral & care coordination phone #**
☐ **Positive parenting support group or counseling**
☐ Fluoride 0.25mg + MTV w/ iron & Vit D 600 IU PO qd

Refer to Dentist_____

Guidance ④

☐ Consistent, positive discipline; use distractions; be a role model; make time for self, partner, friends;
☐ Ask for help with domestic violence
☐ Parenting support or education groups; maintain or extend ties with community; parent-toddler playgroups
☐ Rear-facing car seats until maximum allowable weight
☐ Reminder to complete AAP home safety checklist
☐ Brush teeth 2x daily with soft toothbrush & water
☐ Bedtime routine w/ quiet time, singing, reading; 1 nap/day

Immunizations ⑦

Refer to EMR for vaccines given, CDC handouts given
☐ Vaccine counseling
☐ Refusal to vaccinate AAP form signed

Follow up / Return

☐ Next routine well-child visit
☐ Early return OV
☐ **SE (ASQ:SE) screening needed** *(per AAP)*

Well-Child Visit: 15 months   Age_____mo

CG's name: _____

History ①

Who is at the WCV?   ☐ Mom   ☐ Grandparent
☐ Dad   ☐ Foster parent
☐ Sibling(s)   ☐ Other Caregiver

Health or growth concerns? _____
1._____
2._____
3._____
_____
Interval Hx? _____

Nutrition / Activity ①

Breastfeeding ☐ Yes ☐ No
Cow's milk? ☐ Yes ☐ No   Whole or 2%? _____ oz/day
Fe-rich cereal 2x qd?   ☐ Yes ☐ No
Meats, fish, eggs, soy?   ☐ Yes ☐ No
Vegetables, fruits?   ☐ Yes ☐ No
Age-appropriate finger foods? ☐ Yes ☐ No
Fruit juice, sugars?   ☐ Yes ☐ No

Elimination concerns? ☐ Yes   ☐ No _____

Dev./Behav./Learning ①   Concerns?_____

_____
Administered: ☐ ASQ   ☐ PEDS   ☐ PEDS:DM

Interpretation: ☐ Typical/ observe   ☐ Atypical/ action needed
Domains: ☐ expr. lang. ☐ recept. lang. ☐ cognitive
of concern   ☐ fine motor   ☐ gross motor   ☐ SE/ behavior
               ☐ self-help/ adaptive   ☐ other

Administered: ☐ ASQ:SE *Circle if:* (+) or (-)

Administered: ☐ Parent mood d/o screen *Circle if:* (+) or (-)

Dental ⑧   *Circle if*: No bottle in bed ; Brushing; Fluoride
☐ Referred to dentist
☐ **Fluoride varnish + handout**

Sleep
_____

PMH, Meds, Allergies   Updated in Problem List / EMR

Family/Social Hx   ☐ BPCIS + discussed "resiliency" factors

_____
_____

Tobacco exposure? ☐ Yes ☐ No   DV? ☐Yes ☐ No

Medical Screening ③

☐ Cap Hemogram or HemoCue (If Hgb<11 or if high-risk for
iron defic. then venipuncture CBC, ferritin, CRP)
☐ Blood lead level
☐ TB Skin Test if at risk per TB questionnaire

Sensory Screening ⑤ ⑥

Cover test: ☐ No motion
Corneal light reflex: ☐ Symmetric
Hearing: ☐ Turns to voice ☐ Startles

PE ②   Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp P_____ R_____ BP_____/_____

HC_____cm (_____%) Length _____cm (_____%)

Wt_____kg (_____%) wt / ht ratio _____%

GEN _____
HEENT _____
Chest/Lungs _____
CV/Heart _____
ABD _____
GU _____
Skin _____
MSK/Spine _____
Neuro _____
Parent-Child Interaction _____
Other: _____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: see EMR problem list

Plan

_____
_____
_____
_____
_____

15 mo WCV handout (Bright Futures: Early Childhood)
ROR book & literacy counseling
☐ "Healthy Habits" / obesity prevention handout + counseling
☐ **EI referral & care coordination phone #**
☐ **Positive parenting support group or counseling**
☐ Fluoride 0.25mg + MTV w/ iron & Vit D 600 IU PO daily
☐ Refer caregiver to mental health provider or PCP

Guidance ④

❑ Praise for good behavior; using distractions; choices with
2 options; discipline for teaching/protecting (not punishing)
❑ Talk about what you see; use simple clear words &
phrases to describe pictures in books; read daily
❑ Anticipate "stranger anxiety" (reflective of cognitive gains)
❑ If night awakenings occur, reassure briefly & give stuffed
animal or blanket for self-consolation; no bottle in bed
❑ Review home safety:remove or lock up poisions, cleaning
supplies; set hot water <120°F; install smoke detectors;
keep hot liquids, lighters, matches out of reach

Immunizations ⑦

Refer to EMR for vaccines given, CDC handouts given
☐ Vaccine counseling
☐ Refusal to vaccinate AAP form signed

Follow up / Return

☐ Next routine well-child visit   ☐ Early return OV
☐ **SE (ASQ:SE) screening needed** *(per AAP)*

EPSDT
❶ Hx/Nutr/Devel
❷ Unclothed PE
❸ Labs
❹ Health Educ
❺ Vision Screen
❻ Hearing Screen
❼ Immunizations
❽ Dental Referral

Well-Child Visit: 18 months   Age_____mo

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CG's name: _____

History ①

Who is at the WCV?
☐ Mom   ☐ Grandparent
☐ Dad   ☐ Foster parent
☐ Sibling(s) ☐ Other Caregiver

Health or growth concerns? _____
1._____
2._____
3._____
_____

Interval Hx? _____

Nutrition / Activity ①

Breastfeeding ☐ Yes ☐ No
Cow's milk? ☐ Yes ☐ No   Whole or 2%? _____ oz/day
Fe-rich cereal 2x qd?   ☐ Yes ☐ No
Meats, fish, eggs, soy?   ☐ Yes ☐ No
Vegetables, fruits?   ☐ Yes ☐ No
Age-appropriate finger foods? ☐ Yes ☐ No
Fruit juice, sugars?   ☐ Yes ☐ No

Elimination concerns? ☐ Yes ☐ No _____

Dev./Behav./Learning ①

Concerns?_____
_____

General developmental & ASD screenings *(per AAP)*
Administered: ☐ ASQ   ☐ PEDS   ☐ PEDS:DM

Interpretation: ☐ Typical/ observe   ☐ Atypical/ action needed
Domains: ☐ expr. lang. ☐ recept. lang. ☐ cognitive
of concern   ☐ fine motor   ☐ gross motor   ☐ SE/ behavior
                ☐ self-help/ adaptive   ☐ other

Administered: ☐ **M-CHAT** *circle if:* **(+) or (-)**   ☐ **Other**

Dental ⑧

Circle if: No bottle in bed ; Brushing; Fluoride
☐ Referred to dentist
☐ **Fluoride varnish + handout**

Sleep
_____

PMH, Meds, Allergies   Updated in Problem List / EMR

Family Hx _____

Social Hx _____
_____

Tobacco exposure? ☐ Yes ☐ No   DV? ☐Yes ☐ No

Medical Screening ③

☐ Cap Hemogram or HemoCue (If Hgb<11 or if high-risk for
iron defic. then venipuncture CBC, ferritin, CRP)
☐ Blood lead level
☐ TB Skin Test if at risk per TB questionnaire

PE: Sensory Screening ⑤⑥

Cover test: ☐ No motion
Corneal light reflex: ☐ Symmetric
Hearing: ☐ Turns to voice   ☐ Startles

PE ②   Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp   P_____   R_____   BP_____/_____

HC_____cm (_____%) Length _____cm (_____%)

Wt_____kg (_____%) wt / ht ratio _____%

GEN _____
HEENT _____
Chest/Lungs _____
CV/Heart _____
ABD _____
GU _____
Skin _____
MSK/Spine _____
Neuro _____
Parent-Child Interaction _____
Other: _____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: see EMR problem list

Plan

_____
_____
_____
_____

18 mo WCV handout (Bright Futures: Early Childhood)
ROR book & literacy counseling
☐ "Healthy Habits" / obesity prevention handout + counseling
☐ **EI referral & care coordination phone #**
☐ **Positive parenting support group or counseling**
☐ **Refer for multi-speciality dev-behav. evaluation**
☐ Fluoride 0.25mg + MTV w/ iron & Vit D 600 IU PO daily

Guidance ④

☐ Praise for good behavior; consistent, calm, immediate
   discipline; choices with 2 options; reinforce limits
☐ Talk about what you see; use simple words to describe
   pictures in books; teach words about feelings; read daily
☐ Anticipate anxiety/clingy behavior in new situations
☐ No bottle in bed; consistent bedtime & waking up routine
☐ Home safety: stair gates; operable window guards if ≥2nd
   story room; prevent burns; install smoke detectors

Immunizations ⑦

Refer to EMR for vaccines given, CDC handouts given
☐ Vaccine counseling
☐ Refusal to vaccinate AAP form signed

Follow up / Return

☐ Next routine well-child visit
☐ Early return OV
☐ **SE (ASQ:SE) screening needed** *(per AAP)*
☐ **ASD assessment/ M-CHAT Follow-up Interview needed**

EPSDT
❶ Hx/Nutr/Devel
❷ Unclothed PE
❸ Labs
❹ Health Educ
❺ Vision Screen
❻ Hearing Screen
❼ Immunizations
❽ Dental Referral

Well-child Exam: 24 – 30 months   Age_____mo

CG's name: _____

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History ①

Who is at the WCV?
☐ Mom   ☐ Grandparent
☐ Dad   ☐ Foster parent
☐ Sibling(s) ☐ Other Caregiver

Health or growth concerns? _____

1. _____
2. _____
3. _____

_____
_____

Interval Hx _____

Nutrition / Activity ①

Breastfeeding? ☐ Yes ☐ No
Cow's milk? ☐ Yes ☐ No Whole or 2%? _____ oz/day

Other calcium-rich foods?   ☐ Yes ☐ No
Fe-rich cereal 2x qd?   ☐ Yes ☐ No
Meats, fish, proteins?   ☐ Yes ☐ No
Vegetables, fruits?   ☐ Yes ☐ No
Fruit juice, sugar?   ☐ Yes ☐ No

Elimination concerns? ☐ No ☐ Yes _____

Dev./Behav./Learning ①

Concerns _____
General developmental & ASD screenings *(per AAP)*
Administered: ☐ ASQ   ☐ PEDS   ☐ PEDS:DM

Interpretation: ☐ Typical/ observe   ☐ Atypical/ action needed

Domains: ☐ expr. lang. ☐ recept. lang. ☐ cognitive
of concern   ☐ fine motor   ☐ gross motor   ☐ SE/ behavior
              ☐ self-help/ adaptive   ☐ other

Administered: ☐ M-CHAT *circle if* (+) or (-)   ☐ Other

Dental ⑧
Circle if: brushing 2x daily • Fluoride • Flossing
☐ **Fluoride Varnish + handout**

Dentist ☐ referred to ☐ has seen:_____

Sleep
_____

PMH, Meds, Allergies   Updated in Problem List / EMR

Family/ Social Hx _____

_____

Tobacco exposure? ☐ Yes ☐ No   DV? ☐ Yes ☐ No

Medical Screening ③

☐ Cap Hemogram or HemoCue (If Hgb<11 or if high-risk for iron deficiency then venipuncture CBC, ferritin, CRP)
☐ Blood lead level

E: Sensory Screening ⑤⑥

Color test: ☐ no motion
Corneal light reflex: ☐ symmetric
Hearing: ☐ turns to voice   ☐ startles

PE ②   Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp P_____ R_____ BP_____/_____

Ht_____cm (_____%) Wt_____kg (_____%)

BMI _____%

GEN _____
HEENT _____
Chest/Lungs _____
CV/Heart _____
ABD _____
GU _____
Skin _____
MSK/Spine _____
Neuro _____
Parent-Child Interaction _____
Other: _____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: see EMR problem list

Plan

_____
_____
_____
_____

2 yr WCV handout (Bright Futures: Early Childhood)
ROR book & literacy counseling
☐ "Healthy Habits"/ obesity prevention handout + counseling
☐ **El referral & care coordination phone #**
☐ **Positive parenting support group or counseling**
☐ **Refer for multi-speciality dev-behav. evaluation**
☐ Fluoride 0.25mg PO qd + MTV w/ iron & Vit D 600 IU qd

Guidance ④

❑ Model appropriate language, praise good behavior
❑ Read every day, go to the library
❑ Limit TV/Media to 1-2 hrs/ day, be active as a family
❑ Smoke detectors on every level, test monthly & check batteries annually; fire escape plan; matches out of sight
❑ Stay within arms reach near water, pools, bathtub, toilet
❑ Supervise outside around cars, in streets
❑ Prevent burns; smoke detectors, sensible sun exposure
❑ Toilet training guidance; begin when child can be dry x 2 hrs, knows difference b/t/n wet & dry, can pull pants down & up, can indicated bowel movement

Immunizations ⑦

Refer to EMR for vaccines given, CDC handouts given
☐ Refusal to vaccinate AAP form signed
☐ Vaccine counseling

Follow up / Return

☐ Next routine well-child exam   ☐ Early return OV
☐ **SE (ASQ:SE) screening needed** *(per AAP)*
☐ **ASD assessment/ M-CHAT Follow-up Interview needed**

EPSDT
❶ Hx/Nutr/Devel
❷ Unclothed PE
❸ Labs
❹ Health Educ
❺ Vision Screen
❻ Hearing Screen
❼ Immunizations
❽ Dental Referral

Well-child Exam: 3 years   Age_____ mo

CG's name: _____

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History ①

Who is at the WCV?
- ☐ Mom   ☐ Grandparent
- ☐ Dad   ☐ Foster parent
- ☐ Sibling(s)   ☐ Other Caregiver

Health or growth concerns? _____

1._____
2._____
3._____

Interval Hx _____

Nutrition / Activity ①

Healthy portion sizes?	☐ Yes ☐ No
Fruits & Veggies: 5 servings / day?	☐ Yes ☐ No
Dairy or calcium-rich foods: 800 mg day?	☐ Yes ☐ No
Meats, leafy greens, iron-rich cereals?	☐ Yes ☐ No
Foods high in sugar, trans & saturated fats?	☐ Yes ☐ No

Elimination concerns? _____

Screen time / day? _____

Dev./Behav./Learning ①   Concerns?_____

_____

Administered: ☐ ASQ   ☐ PEDS   ☐ PEDS:DM

Interpretation: ☐ Typical/ observe   ☐ Atypical/ action needed

Domains: ☐ expr. lang.   ☐ recept. lang.   ☐ cognitive
of concern   ☐ fine motor   ☐ gross motor   ☐ SE/ behavior
     ☐ self-help/ adaptive   ☐ other

Dental ⑧   *Circle if:* Brushing 2x daily • Fluoride • Flossing

Dentist ☐ referred to   ☐ has seen:_____

Sleep
Bedtime problems • **E**xcessive daytime sleepiness
•**A**wakenings in pm • **R**egularity & duration of sleep • **S**noring

"BEARS"_____

PMH, Meds, Allergies   Updated in Problem List / EMR

Family Hx   _____

Social Hx

_____

Tobacco exposure? ☐ Yes ☐ No   DV? ☐ Yes ☐ No

PE: Sensory Screening ⑤⑥③   *(2-4 yrs per EPSDT, AAP)*

Vision: R_____/_____   *Stereopsis (Random Dot E*
Monocular   *or stereogram)* ☐ Pass ≥ 4/5
distance acuity   L_____/_____   ☐ Fail ≤ 3/5

☐ Pass   ☐ Refer   ☐ Uncooperative

Hearing: *(OAE indicated if (+) risk assessment per AAP)*

AOE ☐ Pass   ☐ Refer on *Circle if* R and/or L side(s)

PE ②　　　Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp   P_____   R_____   BMI _____%

Ht_____cm (_____%)   Wt_____kg (_____%)

BP_____/_____   **90th%tile: M 100/59   F 100/61**

GEN _____
HEENT _____
Chest/Lungs _____
CV/Heart _____
ABD _____
GU _____
Skin _____
MSK/Spine _____
Neuro _____
Parent-Child Interaction _____
Other: _____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: See EMR problem list

Plan

_____
_____
_____
_____

3 yr WCV handout (Bright Futures: Early Childhood)
ROR book & literacy counseling
☐ "Healthy Habits" / obesity prevention handout + counseling
☐ **ECSE referral + care coordination phone #**
☐ **Positive parenting support group or counseling**
☐ **Head Start/ other high-quality preschool recommended**
☐ Flruoride 0.5mg PO qd + MTV w/ iron & Vit D 600 IU qd

Guidance ④

- ☐ Enroll in high-quality preschool or Head Start program
- ☐ Encourage pretend play games with appropriate toys
- ☐ Show affection; handle anger constructively; reinforce limits; model appropriate behavior; time for self & partner
- ☐ Talk about pictures in books; encourage child to talk
- ☐ Limit TV/Media to 1-2 hrs/ day; no media in bedroom
- ☐ Car seat until max allowable wt & ht; ride in back seat
- ☐ Supervise closely near streets & driveways
- ☐ Remove guns from home or store unloaded and locked

Immunizations ⑦

Refer to EMR for vaccines given, CDC handouts given
☐ Vaccine counseling
☐ Refusal to vaccinate AAP form signed

Follow up / Return

☐ Next routine well-child visit
☐ Early return OV
☐ **SE (ASQ:SE) screening needed** (*per AAP*)

EPSDT
❶ Hx/Nutr/Devel
❷ Unclothed PE
❸ Labs
❹ Health Educ
❺ Vision Screen
❻ Hearing Screen
❼ Immunizations
❽ Dental Referral   © Kevin Marks MD, 2012; Last Revised 2-17-2012

Well-child Exam: 4 years   Age_____yrs

CG's name:[_____]

History ①

Who is at the WCV?   ☐ Mom   ☐ Grandparent
Health or Growth Concerns? ☐ Dad   ☐ Foster parent
☐ Sibling(s) ☐ Other Caregiver

1._____

2._____

3._____

Interval Hx _____

Nutrition / Activity ①

"5-2-1-0"

5: Fruits & Veggies: 5 servings / day?   ☐ Yes ☐ No
2: Less than 2 hrs of screen time/ day?   ☐ Yes ☐ No
1: Activity/ exercise >1 hr/ day   ☐ Yes ☐ No
0: Zero servings per day of sweetened drinks? ☐ Yes ☐ No
   Dairy or calcium-rich foods: 800 mg day?   ☐ Yes ☐ No
   Meats, leafy greens, iron-enriched cereals? ☐ Yes ☐ No
   Foods high in sugar, trans & saturated fats? ☐ Yes ☐No

Elimination concerns? _____

Dev./Behav./Learning ①

Concerns?_____
"**Kindergarten readiness**" **screening** *(per AAP)*

Administered: ☐ **ASQ** ☐ **ASQ:SE** ☐ **PEDS** ☐ **PEDS:DM**

Interpretation: ☐ Typical/ observe   ☐ Atypical/ action needed
Domains: ☐ expr. lang. ☐ recept. lang. ☐ cognitive
of concern ☐ fine motor   ☐ gross motor   ☐ SE/ behavior
        ☐ self-help/ adaptive ☐ pre-math ☐ pre-reading

Sleep

Bedtime problems • **E**xcessive daytime sleepiness
•**A**wakenings in pm • **R**egularity & duration of sleep • **S**noring

"BEARS"_____

Dental

Circle if: Brushing 2x daily • Fluoride • Flossing

Dentist ☐ referred to ☐ has seen:_____

PMH, Meds, Allergies   Updated in Problem List / EMR

Family Hx _____

Social Hx _____

_____

Tobacco exposure? ☐ Yes ☐ No   DV? ☐ Yes ☐ No

PE: Sensory Screening ③ ⑤⑥

Vision: R_____/_____   *Stereopsis (Random Dot E*
Monocular   *or stereogram)* ☐ Pass > 4/5
distance acuity L_____/_____   ☐ Fail < 3/5

☐ **Pass**   ☐ **Refer**   ☐ **Uncooperative**

Hearing: R_____@ _____db L _____@ ____ db
(pure tone audiometry, 500 to 4000 Hz)

☐ **Pass** ☐ **Refer** ☐ **Uncooperative so OAE needed**

PE ②   Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp P_____ R_____ BMI _____%

Ht_____cm (_____%) Wt_____kg (_____%)

BP_____/_____   90th%tile: M 102/ 62
               F 101/ 64

GEN _____
HEENT _____
Chest/Lungs _____
CV/Heart _____
ABD _____
GU _____
Skin _____
MSK/Spine _____
Neuro _____
Parent-Child Interaction _____
Other: _____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: see EMR problem list

Plan

_____
_____
_____
_____

4 yr WCV handout (Bright Futures: Early Childhood)
ROR book & literacy counseling
☐ "Healthy Habits" / obesity prevention handout + counseling
☐ Fluoride 0.5mg + MTV w/ iron & Vit D 600 IU PO qd
☐ **ECSE referral + care coordination phone #**
☐ **Head Start/ other high-quality preschool recommended**

Guidance ④

❑ Kindergarten readiness: encourage high-quality preschool/
   Head Start; pre-math, pre-reading, writing skills at home
❑ Reading daily; encourage letter and word recognition
❑ Calm bedtime ritual; mealtimes should be without TV
❑ Expect child to be curious about their body; use correct
   terms, answer the child's questions
❑ Saftey: ride in back in car safety seat until child reaches
   highest weight or height allowed by manufacturer, then
   switch to a belt-positioning booster seat
❑ Limit TV/ media 1-2 hrs qd; no TV in bedroom

Immunizations ⑦

Refer to EMR for vaccines given, CDC handouts given
☐ AAP "Refusal to Vaccinate" form signed
☐ Vaccine counseling

Follow up / Return

☐ Next routine well-child visit
☐ Early return OV
☐ **SE (ASQ:SE) screening needed** *(per AAP)*
☐ **Follow-up ADHD assessment needed**

Well-child Exam: 5 - 6 years   Age_____yrs

CG's name: _____

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History ①

Who is at the WCV?

☐ Mom ☐ Grandparent
☐ Dad ☐ Foster parent
☐ Sibling(s) ☐ Other Caregiver

Health or growth concerns? _____

1._____

2._____

3._____

_____

_____

Interval Hx _____

Nutrition / Activity ①

"5-2-1-0"

5: Fruits & Veggies: 5 servings / day?   ☐ Yes ☐ No
2: Less than 2 hrs of screen time/ day?   ☐ Yes ☐ No
1: Activity/ exercise >1 hr/ day   ☐ Yes ☐ No
0: Zero servings per day of sweetened drinks?   ☐ Yes ☐ No
   Dairy or calcium-rich foods: 800 mg day?   ☐ Yes ☐ No
   Meats, leafy greens, iron-enriched cereals?   ☐ Yes ☐ No
   Foods high in sugar, trans & saturated fats?   ☐ Yes ☐ No

Elimination concerns? _____

Dev./Behav./Learning ①

Concerns?_____
Social-Emotional/ mental health screening *(per AAP)*

Administered: ☐ **ASQ:SE** ☐ PEDS ☐ PEDS:DM
Interpretation: ☐ **Typical**   ☐ **Atypical/ action needed**

Sleep

Bedtime problems • **E**xcessive daytime sleepiness
•**A**wakenings in pm • **R**egularity & duration of sleep • **S**noring

"BEARS"_____

Dental ⑧   Brushing 2x daily • Fluoride • Flossing

Dentist ☐ referred to ☐ has seen:_____

PMH, Meds, Allergies   Updated in Problem List / EMR

Family Hx _____

Social Hx _____

_____

Tobacco exposure? ☐ Yes ☐ No   DV? ☐ Yes ☐ No

PE: Sensory Screening ③

Vision: R_____/____   *Stereopsis (Random Dot E*
Monocular   *or stereogram)* ☐ Pass > 4/5
distance acuity   L_____/_____   ☐ Fail < 3/5

☐ **Pass**   ☐ **Refer**   ☐ **Uncooperative**

Hearing: R_____@ ____db L_____@ ____ db
(with pure tone audiometry, 500 to 4000 Hz)

☐ **Pass**   ☐ **Refer**   ☐ **Uncooperative so OAE needed**

PE ②   Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp   P_____   R_____   BMI _____%

Ht_____cm (_____%) Wt_____kg (_____%)

BP_____/_____   **90ᵗʰ%tile: M 104-105/ 65-68**
                                 F 103-104/ 66-68

GEN _____
HEENT _____
Chest/Lungs _____
CV/Heart _____
ABD _____
GU _____
Skin _____
MSK/Spine _____
Neuro _____
Parent-Child Interaction _____
Other: _____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: see EMR problem list

Plan

_____

_____

_____

5-6 yr WCV handout (Bright Futures: Middle Childhood)
ROR book & literacy counseling (ends at 5 yrs)
Child "Healthy Habits" / obesity prevention handout
☐ Fluoride 0.5mg PO qd + MTV w/ iron & Vitamin D 600 IU qd
☐ **ECSE referral + care coordination phone # (needs IEP?)**
☐ **Mental health community referral**

Guidance ④

- Prepare for kindergarten/ school; tour school; attend back to school events; be sure after-school care is safe, positive; talk school experiences; teasing is not ok
- Reading nightly; word recognition, simple sentences
- Use discipline for teaching, not punishing
- Saftey: teach safe street habits, bike helmets, pads
- Saftey: swimming lessons, supervise around water
- When to switch to a booster seat, ride in back seat
- Teach 3 safety rules around adults: (1) no adult should tell a child to keep a secret from parents, (2) no adult should be interested in private parts, (3) no adult should ask a child for help with his/her private parts (but explain to the child what "privates" means)
- Limit TV/ Media to 1-2 hrs qd; no TV in bedroom

Immunizations ⑦

CDC handouts given, refer to EMR
☐ Vaccine counseling
☐ AAP refusal to vaccinate form

Follow up / Return

☐ Next routine well-child visit
☐ Early return OV
☐ **Follow-up ADHD assessment needed**

EPSDT
❶ Hx/Nutr/Devel
❷ Unclothed PE
❸ Labs
❹ Health Educ
❺ Vision Screen
❻ Hearing Screen
❼ Immunizations
❽ Dental Referral

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Well-Child Visit: 7 – 8 years   Age_____yrs

CG's name: _____

History ①

Who is at the WCV? ☐ Mom   ☐ Grandparent
☐ Dad   ☐ Foster parent
☐ Sibling(s)   ☐ Other Caregiver

Health or growth concerns? _____

1._____
2._____
3._____
_____

Interval Hx _____

Nutrition / Activity ①

"5-2-1-0"

5: Fruits & Veggies: 5 servings / day?   ☐ Yes ☐ No
2: Less than 2 hrs of screen time/ day?   ☐ Yes ☐ No
1: Activity/ exercise ≥1 hr/ day   ☐ Yes ☐ No
0: Zero servings per day of sweetened drinks? ☐ Yes ☐ No
    Dairy or calcium-rich foods: 800 mg day?   ☐ Yes ☐No
    Meats, leafy greens, iron-enriched cereals? ☐ Yes ☐ No
    Foods high in sugar, trans & saturated fats? ☐ Yes ☐ No

Elimination concerns? _____

Dev./Behav./Learning ①

Concerns?_____
Mental health (PSC) screening *(per AAP) (but use the Pictorial PSC for low SES or Spanish-speaking populations)*

Administered: ☐ PSC or PPSC Score:_____ ☐ (-) ☐ (+)
(+) PSC subscales: ☐ Internaliz. ☐ Externaliz. ☐ Attention

☐ PEDS ☐ PEDS:DM ☐ SWILS ➔ ☐ Typical ☐ Atypical

School:_____Grade____th **IEP? ☐ Yes ☐ No**

Dental ⑧

Brushing • flossing • fluoride tabs or rinse

Dentist ☐ referred ☐ has seen_____

Sleep

Bedtime problems • **E**xcessive daytime sleepiness
•**A**wakenings in pm • **R**egularity & duration of sleep • **S**noring

"BEARS"_____

PMH, Meds, Allergies

Updated in Problem List / EMR

Family/ Social Hx

_____

Tobacco exposure? ☐Yes ☐ No   DV? ☐ Yes ☐ No

Medical Screening ③

☐ Lipid screening as indicated
☐ GlycoHgb A1C and OGTT

PE: Sensory Screening ⑤⑥

Vision: R_____/_____   ☐ **Pass**

L_____/_____   ☐ **Refer**

Bilat. _____/_____   ☐ **Uncooperative**

Hearing: R_____@_____db L_____@_____db
(with pure tone audiometry, 500 to 4000 Hz)
☐ **Pass** ☐ **Refer** ☐ **Uncooperative so OAE needed**

PE ②

Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp P_____ R_____ BMI _____%

Ht_____cm (_____%) Wt_____kg (_____%)

BP_____/_____   **90ᵗʰ%tile: M 106-107/ 70-71
F 106-108/ 69-71**

GEN _____
HEENT _____
Chest/Lungs _____
CV/Heart _____
ABD _____
GU/SMR _____
Skin _____
MSK/Spine _____
Neuro _____
Parent-Child Interaction _____
Other: _____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: see EMR problem list

Plan

_____
_____
_____

7-8 yr WCV handout (Bright Futures: Middle Childhood)
"Healthy Habits" / obesity prevention handout
☐ Fluoride 1mg + MTV w/ iron & Vit D 600 IU PO qd
☐ **Mental health community referral**

Guidance ④

❑ **Obesity prevention:**
  o Limit candy, soda & high-fat snacks/ processed food
  o 5+ servings per day of veggies & whole fruits
  o Eat a healthy breakfast & meals away from the TV
  o 2 cups low-fat milk or other dairy per day
  o Physical activity 60 min per day; play outside
  o Screen time <1-2 hrs qd; no TV/ media in bedroom
❑ Positive roll model; teach affection & respect; do not hit or let others hit; discuss rules & consequences
❑ Talk about school experiences; any bullying, name calling or teasing in the classroom, hallways or playground?
❑ Safety: swimming lessons; safety equipment; teach safe street habits; teach safety rules around adults
❑ Safety: remove guns from home or gun must be unloaded & locked w/ ammunition stored separately

Immunizations ⑦

Refer to EMR for vaccines administered, CDC handouts given
☐ Vaccine counseling
☐ Refusal to vaccinate AAP form signed

Follow up / Return

☐ Next routine well-child visit
☐ Early return OV
☐ **Follow-up ADHD assessment needed**

EPSDT
❶ Hx/Nutr/Devel
❷ Unclothed PE
❸ Labs
❹ Health Educ
❺ Vision Screen
❻ Hearing Screen
❼ Immunizations
❽ Dental Referral

Well-child Exam: 9 - 10 years   Age_____yrs

CG's name: _____

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History ①

Who is at the WCV?
☐ Mom   ☐ Grandparent
☐ Dad   ☐ Foster parent
☐ Sibling(s)   ☐ Other Caregiver

Health or growth concerns? _____

1._____
2._____
3._____

_____
_____
_____

☐ Sports pre-participation form for_____

Menarche: Age _____yrs   Regularity_____

Nutrition / Activity ①

"5-2-1-0"

5: Fruits & Veggies: 5 servings / day? ☐ Yes ☐ No
2: Less than 2 hrs of screen time/ day? ☐ Yes ☐ No
1: Activity/ exercise ≥1 hr/ day ☐ Yes ☐ No
0: Zero servings per day of sweetened drinks? ☐ Yes ☐ No
   Dairy or calcium-rich foods: 800 mg day? ☐ Yes ☐ No
   Meats, leafy greens, iron-enriched cereals? ☐ Yes ☐ No
   Foods high in sugar, trans & saturated fats? ☐ Yes ☐ No

Elimination concerns? _____

Dev./Behav./Learning ①

Concerns? ☐ Yes ☐ No

Mental health (PSC) screening *(per AAP)* *(but use the Pictorial PSC for low SES or Spanish-speaking populations)*

☐ **Administered PSC or PPSC**   Score:_____ ☐ (-) ☐ (+)
(+) PSC subscales: ☐ Internaliz. ☐ Externaliz. ☐ Attention

School:_____Grade____th **IEP? ☐ Yes ☐ No**

Dental ⑧

Circle: Brushing 2x qd • Flossing • Fluoride rinse

Dentist ☐ referred ☐ has seen_____

Sleep

"**BEARS**"_____

PMH, Meds, Allergies

Updated in Problem List / EMR

Family Hx
_____

Social Hx
_____

Tobacco exposure? ☐ Yes ☐ No   DV? ☐ Yes ☐ No

Medical Screening ③

☐ Lipid screening as indicated
☐ GlycoHgb A1C & OGTT

PE: Sensory Screening

Vision: R_____/_____ ☐ **Pass** ☐ **Refer**

L_____/_____ ☐ **Evaluated by optometrist or**

Bilat. _____/_____ **ophthalm. in last ____ mo**

Hearing: R ____@____db L ____@ ____db
(with pure tone audiometry, 500 to 4000 Hz)

☐ **Pass** ☐ **Refer** ☐ **Uncooperative so OAE needed**

PE ②

Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp P_____ R_____ BMI _____%

Ht_____cm (_____%) Wt_____kg (_____%)

BP_____/_____   **90th %tile: M 109-111/ 72-73**
                            F 100-112/ 72-73

GEN _____
HEENT _____
Chest/SMR _____
Lungs _____
CV/Heart _____
ABD _____
GU/SMR _____
Skin _____
MSK/Spine _____
Neuro _____
Parent-Child Interaction _____
Other: _____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: See EMR problem list

Plan
_____
_____
_____

9-10 yr WCV handout (Bright Futures: Middle Childhood)
 "Healthy Habits" / obesity prevention handout
☐ Cleared for participation in sports
☐ Fluoride 1mg + MTV w/ iron & Vitamin D 400 IU PO qd
☐ **Mental health referral**

Guidance ④

☐ Obesity prevention:
  o Nutritious foods; 5+ servings vegetables & fruits daily
  o Physical activity 60 min per day; play outside
  o Limit TV/ media to 1-2 hrs daily, no TV in bedroom
☐ Show interest in school & activities
☐ If any concerns, ask teacher about extra help
☐ Promote independence & self-responsibility; assign chores
☐ Answer questions about puberty & sexuality
☐ Use safety equipment (helmets & pads)
☐ Back seat is safest; switch to safety belt when ht ≥ 4 ft 9 in
☐ Remove guns from home vs. gun must be unloaded & locked with ammunition stored separately

Immunizations ⑦

Refer to EMR for vaccines administered, CDC handouts given
☐ Vaccine counseling
☐ Refusal to vaccinate AAP form signed

Follow up / Return

☐ Next routine well-child visit   ☐ Early return OV

EPSDT
❶ Hx/Nutr/Devel
❷ Unclothed PE
❸ Labs
❹ Health Educ
❺ Vision Screen
❻ Hearing Screen
❼ Immunizations
❽ Dental Referral

Well-child Exam: 11-14 years

CG's name: _____

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History ①

Who is at the WCV? ☐ Mom ☐ Grandparent ☐ Dad ☐ Foster parent
Health, growth concerns? ☐ Sibling(s) ☐ Other Caregiver

1._____
2._____
3._____
_____

☐ Teen & parent intake forms ☐ Sports pre-participation form

Menarche: Age _____ Regularity _____

Nutrition / Activity ①

"5-2-1-0" & **"HEADS"** on back
5: Fruits & Veggies: 5 servings / day? ☐ Yes ☐ No
2: Less than 2 hrs of screen time/ day? ☐ Yes ☐ No
1: Activity/ exercise >1 hr/ day ☐ Yes ☐ No
0: Zero servings per day of sweetened drinks? ☐ Yes ☐ No
   Dairy or calcium-rich foods: 800 mg day? ☐ Yes ☐ No
   Foods high in sugar, trans & saturated fats? ☐ Yes ☐ No

Elimination concerns? _____

Dev./Behav./Learning ①

*See **"HEADS"** on back

Concerns?_____

Mental health & substance abuse screening *(per AAP)*

Administered: ☐ **PSC or Y-PSC** *circle if:* **(-)** or **(+)**
(+) Subscales: ☐ Internaliz. ☐ Externaliz. ☐ Attention

Administered: ☐ **CRAFFT** circle if: **(-)** or **(+)** *see back*

Dental ❽

Brushing 2x daily • Flossing • Fluoride rinse

Dentist ☐ referred ☐ has seen_____

Sleep

"**BEARS**"_____

PMH, Meds, Allergies

Updated in Problem List / EMR

Family/ Social Hx

_____
_____

*See teen & parent intake forms + **"HEADS"** on back side

Medical Screening ❸

☐ Lipid screening as indicated
☐ GlycoHgb A1C and OGTT as indicated
☐ Hemogram or HemaCue as indicated (after puberty)
☐ Urine Chlamydia TMA if sexually active

PE: Sensory Screening ❺❻

Vision: R_____/_____ ☐ **Pass** ☐ **Refer**
   L_____/_____ ☐ **Evaluated by optometrist**
   Bilat. _____/_____ **or ophthalm. in last _____ mo**

Hearing: *(only needed if (+) risk per AAP)* ☐ **Pass** ☐ **Refer**
R _____@___ db L _____@___ db
(pure tone audiometry, 500 to 4000 Hz)

PE ❷

Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp P_____ R_____ BMI _____%
Ht_____cm (_____%) Wt_____kg (_____%)
BP_____/_____ 90th%tile: M 113-120/ 74-75
   F 114-119/ 74-77

GEN _____
HEENT _____
Chest/SMR _____
Lungs _____
CV/Heart _____
ABD _____
GU/SMR _____
Skin _____
MSK/Spine _____
Neuro _____
Behavior & hygiene_____
Parent-Child Interaction _____
Other_____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: see EMR problem list

Plan

_____
_____
_____

11-14 yr WCV handout (Bright Futures: Early Adolescence)
☐ Healthy Habits" / obesity prevention handout + counseling
☐ AAP "Calcium and You" handout + MTV w/ iron & Vitamin D
☐ AAP "Tips for Parents of Adolescents"
☐ AAP "The Internet & Your Family" handout
☐ **Mental health referral**
☐ **Tobacco/ drug/ alcohol/ substance abuse referral**
☐ Actively suicidal/ emergency

Guidance ❹

❑ Puberty & sexuality: get accurate info from a trusted adult or clinician; youth go through puberty at different times
❑ 5 servings daily of fruits/veggies, whole grain, low-fat dairy; limit candy/chips/soda; physical activity 60 min/day
❑ Limit media: TV, video games, internet use, cell phone use
❑ Clearly communicate rules/ family responsibilities
❑ Parents should get to know their child's friends
❑ Independently taking responsibility for schoolwork
❑ Talk about tobacco/ alcohol/ drugs/ inhalants/ sex
❑ Plan for situation where child feels unsafe riding in car

Immunizations ❼

Refer to EMR for vaccines administered, CDC handouts given
☐ Vaccine counseling
☐ Refusal to vaccinate AAP form signed

Follow up / Return

☐ Next routine well-child visit ☐ Early return OV

Well Visit: 15-17 years   Age_____yrs

CG's name: [_____]

History ①
Who is at the WCV?   ☐ Mom   ☐ Grandparent
Health, growth concerns?   ☐ Dad   ☐ Foster parent
   ☐ Teen alone   ☐ Other Caregiver

1._____
2._____
3._____
_____

☐ Teen & parent intake forms   ☐ Sports pre-participation form

Menarche? Age _____   Regularity _____

Nutrition / Activity ①   **"5-2-1-0"** & **"HEADS"** on back
5: Fruits & Veggies: 5 servings/ day?   ☐ Yes ☐ No
2: Less than 2 hrs of screen time/ day?   ☐ Yes ☐ No
1: Activity/ exercise ≥1 hr/ day   ☐ Yes ☐ No
0: Zero servings per day of sweetened drinks?   ☐ Yes ☐ No
   Dairy or calcium-rich foods: 800 mg day?   ☐ Yes ☐ No
   Foods high in sugar, trans & saturated fats?   ☐Yes ☐ No

Elimination concerns? _____

Dev./Behav./Learning ①   See **"HEADS"** on back

Concerns?_____

Mental health & substance abuse screening *(per AAP)*

Administered: ☐ **PSC or Y-PSC** *circle if:* **(-)** or **(+)**
(+) Subscales: ☐ Internaliz. ☐ Externaliz. ☐ Attention

Administered: ☐ **CRAFFT** *circle if:* **(-)** or **(+)** *see back*

Dental ❽   *Circle:* Brushing 2x qd • Flossing • Fluoride rinse

Dentist ☐ referred   ☐ has seen _____

Sleep   "**BEARS**" _____

PMH, Meds, Allergies   Updated in Problem List / EMR

Family/ Social Hx   See teen & parent forms + "**HEADS**"

_____
_____

Tobacco exposure? ☐ Yes ☐ No   DV? ☐ Yes ☐ No

Medical Screening ❸
☐ Lipid screening as indicated
☐ GlycoHgb A1C and OGTT as indicated
☐ Hemogram or HemaCue as indicated after puberty
☐ Urine Chlamydia TMA if sexually active

PE: Sensory Screening ❺❻

Vision: R_____/_____   ☐ **Pass**   ☐ **Refer**
   L_____/_____   ☐ **Evaluated by optometrist or**
   Bilat. _____/_____   **ophthalm. In last _____ mo**

Hearing: *(only needed if (+) risk per AAP)* ☐ **Pass** ☐ **Refer**

R_____@ _____ db   L_____@ _____ db
(pure tone audiometry, 500 to 4000 Hz)

PE ❷   Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp   P_____   R_____   BMI _____%

Ht_____cm (_____%)   Wt_____kg (_____%)

BP_____/_____   **90ᵗʰ%tile: M 120/ 76-80**
                             F 120/ 78

GEN _____
HEENT _____
Chest/SMR _____
Lungs _____
CV/Heart _____
ABD _____
GU/SMR _____
Skin _____
MSK/Spine _____
Neuro _____:_____
Behavior & hygiene_____
Parent-Teen Interaction _____
Other: _____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: See EMR problem list

Plan
_____
_____
_____
_____

15-17 yr WCV handout (Bright Futures: Middle Adolescence)
☐ "Healthy Habits" / obesity prevention handout
☐ AAP "Tips for Parents of Adolescents"
☐ AAP "The Teen Driver"
☐ AAP "Calcium and You" handout + MTV with iron & Vit D
☐ **Mental health referral**
☐ **Tobacco/ drug/ alcohol/ substance abuse referral**
☐Actively suicidal/ emergency

Guidance ❹

☐   Find positive ways to deal with stress; recognize signs of depression/ anxiety (irritability, change in sleep habits, etc)
☐   Physical activity 60 min/day; healthy food choices
☐   Don't smoke, drink, "huff", use drugs—listen & counsel
☐   If sexually active, protect against STIs & pregnancy
☐   Wear a safety belt, helmet, protective gear
☐   Never ride with a driver who has used alcohol/drugs
☐   Healthy relationships are built on respect
☐   Manage stress & conflicts in a safe, non-violent manner

Immunizations ❼

Refer to EMR for vaccines administered, CDC handouts given
☐ Vaccine counseling
☐ Refusal to vaccinate AAP form signed

Follow up / Return

☐ Next routine well-child visit   ☐ Early return OV

EPSDT
❶ Hx/Nutr/Devel
❷ Unclothed PE
❸ Labs
❹ Health Educ
❺ Vision Screen
❻ Hearing Screen
❼ Immunizations
❽ Dental Referral

Well Visit: 18 - 21 years   Age_____yrs

CG's name: [_____]

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History ①

	☐ Mom ☐ Grandparent
Who is at the WCV?	☐ Dad ☐ Foster parent
Health concerns?	☐ Patient only ☐ Sibling or friend

1._____

2._____

3._____

_____

_____

☐ College form for_____

Menarche: Age _____   Regularity _____

Nutrition / Activity ①

"5-2-1-0" & **"HEADS"** on back

5: Fruits & Veggies: 5 servings / day?   ☐ Yes ☐ No
2: Less than 2 hrs of screen time/ day?   ☐ Yes ☐ No
1: Activity/ exercise $\geq$1 hr/ day   ☐ Yes ☐ No
0: Zero servings per day of sweetened drinks?   ☐ Yes ☐ No
    Dairy or calcium-rich foods: 800 mg day?   ☐ Yes ☐ No
    Foods high in sugar, trans & saturated fats?   ☐ Yes ☐ No

Elimination concerns?_____

Dev./Behav./Learning ①   *See **"HEADS"** on back

Concerns?_____

Mental health & substance abuse screening *(per AAP)*

Administered: ☐ **Y-PSC** *circle if:*   **(-) or (+)**
(+) Subscales: ☐ Internaliz. ☐ Externaliz. ☐ Attention

Administered: ☐ **CRAFFT** *circle if:* **(-) or (+)** *see back*

Dental ⑧   *Circle:* Brushing 2x qd • Flossing • Fluoride rinse

Dentist ☐ referred   ☐ has seen

Sleep   "**BEARS**"_____

PMH, Meds, Allergies   updated in Problem List / EMR

Family/ Social Hx   see intake forms & **"HEADS"** on back

_____

_____

Tobacco exposure? ☐ No ☐ Yes   IPV? ☐ No ☐ Yes

Medical Screening ③

☐ Lipid screening as indicated
☐ GlycoHgb A1C and OGTT as indicated
☐ Urine Chlamydia TMA if sexually active

PE: Sensory Screening ⑤⑥

Vision: R_____/_____   ☐ **Pass**   ☐ **Refer**

          L_____/_____   ☐ **Evaluated by optometrist or**

          Bilat. _____/_____   **ophthalm. in last _____ mo**

Hearing: *(only needed if (+) risk per AAP)* ☐ **Pass** ☐ **Refer**

R_____@ ____ db L _____@ ____ db
(Pure tone audiometry, 500 to 4000 Hz)

PE ②   Vitals & Growth Parameters

T_____°C/°F ax/rect/tymp   P_____   R_____   BMI _____%

Ht_____cm (_____%) Wt_____kg (_____%)

BP_____/_____   **90th %tile: M or F 120/ 80 ($\geq$ 18 yrs)**

GEN _____
HEENT _____
Chest/SMR _____
Lungs _____
CV/Heart _____
ABD _____
GU/SMR _____
Skin _____
MSK/Spine _____
Neuro _____
Behavior & hygiene_____
Other_____

Assessment

Growth: ☐ typical ☐ obese ☐ overweight ☐ underweight/ FTT
Development & Behavior: see above
Other: See EMR problem list

Plan

_____

_____

_____

_____

_____

_____

18-21 yr WCV handout (Bright Futures: Late Adolescence)
☐ "Healthy Habits" / obesity prevention handout + counseling
☐ MTV with iron & Vitamin D 600 IU PO qd
☐ **Mental health community referral**
☐ **Tobacco/ drug/ alcohol/ substance abuse referral**
☐ Actively suicidal/ emergency

Guidance ④

☐   Don't use tobacco/ alcohol/ drugs/ steroids/ diet pills
☐   Never ride with a driver who has used alcohol/drugs
☐   Find positive ways to deal with stress & manage conflicts
☐   When sexually active, protect against pregnancy & STIs
☐   Wear safety belt, helmet, protective gear, life jacket
☐   Consider college/ future education & work plans

Immunizations ⑦

Refer to EMR for vaccines administered, CDC handouts given
☐ Vaccine counseling
☐ Refusal to vaccinate AAP form signed

Follow up / Return

☐ **Transition care to Family Practice/ Adult PCP**
    Special health care needs? ☐ No ☐ Yes

Follow up with Dr._____in_____months

Appendix B: Judging the Effectiveness of Training: Pre- and Post-Tests

FRANCES PAGE GLASCOE

INTRODUCTION

When training others, you'll need information on what trainees want and need to learn, how well content has been mastered, what participants will do with the information you've provided, and any suggestions they have for improving your presentation. Questions in this Appendix (and downloadable at *www.pedstest.com/TheBook/AppendixB*) are designed to be a learning experience requiring trainees to think in a variety of ways, affirm what they've learned, and allow trainers to discern what content has been mastered or not.* Many of the items can be used for both pre- and post-testing but some focus on: (a) pre-testing, i.e., items designed to identify in advance what trainees need and want to know; (b) post-testing to determine whether trainees demonstrate sufficient knowledge and functional skills in understanding development, policy, services, and screening test administration, and potentially train others; and (c) presentation feedback and questions to help trainees implement what they have learned. A scoring guide is shown at the end of this Appendix and on the website.

The entire set of items requires about 30 – 45 minutes to complete but all may not be needed. So you can download a copy (in Word) and delete items not covered in your presentation. We ask that you keep the copyright and permissions notice on each page of your questionnaire. If you create new questions you wish we'd included, please send them to us (*www.pedstest.com/ContactUs*) so we can add them to the website to share with others. Finally, if you are applying for continuing education credits for your course, you will undoubtedly need to share (your adapted version of) this questionnaire with the sponsoring university or agency.

Note: Performance criterion (e.g., 80%, 95%) is a decision you will need to make based on whether you expect participants to demonstrate mastery of skills (e.g., in test administration) or also have the background skills to train others for which a higher level of competence is needed. Please see Chapter 15 for additional ideas (such as requiring independent practice with test scoring before offering certification). Included on the website for this chapter is a downloadable version of this pre- and post-test and a downloadable sample certificate (in PowerPoint) that can be modified to show course completion, mastery, etc.

The topics covered are:

- Knowledge of child development and its domains;

- Meaning and prevalence of delays and disabilities;

- Policy, service mandates, and the rationale for these;

- The value of early intervention and developmental promotion;

- Psychosocial risk, resilience, and parenting issues including best methods for explaining results;

- Knowledge of referral options;

- Specifics about measurement including administration, scoring and interpretation of various screens;

- Implementation and collaboration issues;

- Questions for program evaluation including pre- and post-course feedback.

*Thanks to Drs. Glen Aylward and Jane Squires for contributing questions about the BINS, ASQ and ASQ:SE.

PRE-PRESENTATION QUESTIONS

What do you hope to learn from today's presentation?

What methods of early detection are you currently using?

What challenges, successes, and worries do you have about your current approaches?

Any other comments about what you'd like to learn today?

POST-PRESENTATION QUESTIONS

I. SERVICES

1. **What does IDEA stand for?** (circle all that apply)
    a) Irksome Developmental Efforts and Annoyances
    b) International Development and Education Association
    c) Individuals with Disabilities Education Act
    d) Intervening in Development is Effective Act of 1976

2. **IDEA services:** (circle all that apply)
    a) are rarely available
    b) are expensive and involve lengthy waiting lists
    c) exist in every county and State
    d) must be provided within approximately 40 days of referral

3. **How is early intervention beneficial?** (circle all that apply)
    a) reduces the impact of psychosocial risk factors
    b) reduces drop-out rates
    c) increases chance of employment and school success
    d) decreases teen pregnancy and violent crime
    e) saves society money
    f) increases likelihood of owning a home
    g) increases chance of graduating from high school

4. **List three services for children with delays who do not qualify for IDEA programs:**

II. AAP Policy and Billing/Coding

1. **What are the components of the American Academy of Pediatrics' policy statements on screening and surveillance for mental health, developmental-behavioral problems, and autism spectrum disorder?** (circle all that apply)

   a) encourages providers to detect and address psychosocial risk factors

   b) discourages use of screening tests

   c) confirms clinical judgment as the primary detection method

   d) encourages watchful waiting rather than prompt referral

   e) emphasizes prompt referrals to early intervention

   f) encourages frequent use of screening tests

   g) confirms the value of informal milestones checklists

2. **Why does American Academy of Pediatrics' policy state, in effect, *"We hope the combination of surveillance and screening sets up a pattern of practice that extends to well-visits beyond the 24- to 30-month age-range"?*** (circle all that apply)

   a) developmental-behavioral problems are still developing

   b) language impairments and other disabilities or delays aren't always visible before 24- to 30-months

   c) clinical observation, judgment, and informal milestones checklists are not an effective early detection method

   d) psychosocial risk factors may not have yet adversely impacted children's development

   e) early intervention continues to be effective after 24- to 30-months of age

   f) This is unnecessary because detection at 24- to 30-months will pick up most children with problems and so additional screening/surveillance is not needed

3. **Should we stop screening after 24- to 30-months of age: Why or why not?** (in your own words):

4. **What is meant by developmental surveillance?** (circle all that apply)

   a) eliciting and addressing parents' concerns at each visit

   b) measuring milestones at each visit

   c) identifying and intervening with psychosocial risk factors

   d) promoting development and educating parents

   e) exclusive reliance on provider judgment to identify children with problems

   f) determining families' needs for various types of services

   g) maintaining child and family medical history

   h) conducting a thorough physical exam

   i) monitoring parental well-being

   j) longitudinal use of accurate screening tools
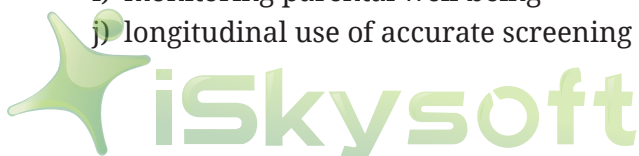
5. **AAP policy recommendations for screening and surveillance:**
   a) Require different tools for surveillance than for screening
      ___True ____False
   b) Can be accomplished by using the same tools for both surveillance and screening
      ___True ____False
   c) Can be accomplished by clinical judgment and informal age-specific milestones
      ___True ____False

6. **When coding for developmental screens in primary care and public health, you may, depending on payer requirements/denials:** (circle all that apply)
   a) attach the -25 modifier to the preventive service code and then add 96110
   b) show next to 96110 the number of screens administered (e.g., X 3)
   c) expect to receive about $8.00 per screen (unless in a Federally Qualified Rural Health Center)
   d) need to help families appeal claims denied by private payers
   e) use the -59 modifier but typically only with denied claims
   f) expect separate payments for 96110 in States with enhanced reimbursement for well-visits
   g) need to ask for help from the American Academy of Pediatrics
   h) have each clinic's coordinator check with each payer for specific coding details

7. **If you are (wisely) screening at well-visits beyond 24- to 30-months and your payer denies claims, you should:** (circle all that apply)
   a) sigh deeply and let it go
   b) appeal the claim to the payer
   c) point out to the payer that the AAP encourages screening at all well-visits
   d) appeal to the AAP

III. Child Development, Disabilities, Delays and Prevalence

1. **Of the various domains of development during the preschool years, which are the best predictors of future school success?**

2. **Identify each of these statements as true or false:**
   a) Developmental-behavioral problems are usually innate, genetic or congenital and present at birth.
      ____True ____False

   b) Most children with developmental-behavioral problems have dysmorphic features (e.g., unusual eye shape or hairlines) or observable deficits (e.g., gait problems, floppy tone, etc.).
      ____True ____False

3. **What is the prevalence of disabilities in the birth through 18-year age-range? (**Circle one)

    a) 6% – 8%

    b) 16% – 18%

    c) 8% – 12%

    d) 23% – 27%

    e) 28%

4. **If working with low-income families, professionals should expect incidence rates to be higher than national prevalence.**

    ___True   ___ False

5. **The national prevalence rates (in the middle column) do not match the age groups (shown in the left column).** Please write in the left hand column the letter assigned to the correct prevalence for each age group.

Age Group (in years)	Prevalence	Letter for correct Prevalence by Age Group
0 - 2	A. 6%	
0 - 3	B. 12%	
0 - 4	C. 8%	
0 - 6	D. 16%	
0 - 8	E. 4%	
0 - 18	F. 16 - 18%	

6. **Which new (or previously undiagnosed) developmental-behavioral problems might we expect to discover in children 8-years and older?** (circle all that apply)

    (a) speech-language impairment

    (b) learning disabilities

    (c) cerebral palsy

    (d) mild autism spectrum disorder

    (e) slow learning (e.g., IQ < 85)

    (f) mental health problems

    (g) none of the above

7. **Indicate True or False for the following statements regarding differences in developmental delays versus disabilities:**

    a) **Developmental delay is the diagnosis typically used in IDEA birth to 3-year programs.**

        ___True ____False

    b) **Developmental delay is uniformly defined across US States' IDEA programs.**

        ___True ____False

    c) **Beyond the birth to 3-year age-range and outside of IDEA programs, developmental delay refers to children who are behind age-mates and are likely to fail once they reach kindergarten.**

        ___True ____False
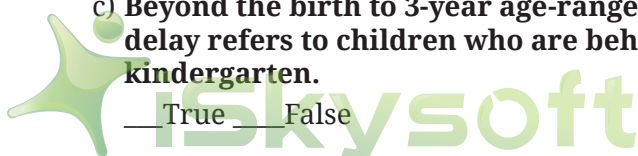
d) **Developmental delay is the sole diagnosis used by IDEA programs serving children 3-years of age and older.**

___True ___False

e) **ADHD is a disability that consistently qualifies children for IDEA programs.**

___True ___False

f) **Family psychosocial risk factors often contribute to developmental delay.**

___True ___False

g) **Children with delays always qualify for IDEA programs.**

___True ___False

h) **Developmental delay means that children will always catch up with time.**

___True ___False

i) **Developmental disorders are disabilities characterized by age-appropriate skills but problematic application (e.g., four-word utterances with excessive repetition, lack of communicative intent, odd syntax, difficulty with pronouns).**

___True ___False

8. **Children with disordered development may talk, walk, even read on time. They may not always exhibit delays on milestones-type screening tests. This means that providers should:** (check all that apply)

a)___ consider the quality of performance on milestones tasks

b)___ listen carefully to parents' observations and concerns

c)___ wait and see

d)___ refer only children with obvious delays

9. **Assign a number to the common disabilities of early childhood in order of prevalence (with "1" being most frequent):**

___ intellectual disabilities

___ attention deficit hyperactivity disorder

___ specific learning disabilities

___ speech-language impairment/delays

___ autism

___ cerebral palsy and other physical impairments

10. **Childrens with disabilities and delays are difficult to detect by clinical judgment. Reasons include:** (circle all that apply)

a) most such children seem typically developing in the first two years of life

b) psychosocial risk factors take a slow toll on developmental outcomes that may not be visible until 3- to 4-years of age

c) the limits of the "broad range of normal" are too broad in the absence of criteria/cutoffs

d) all of the above

e) a and c above

IV. Parenting, Psychosocial Risk and Explaining Results

1. **When explaining screening results to families, it is wise to:** (circle all that apply)

    a) describe the more potentially adverse future outcomes

    b) explore what families already know

    c) affirm the potential value of their concerns

    d) allow time for questions and expression of emotions

    e) discuss the negative impact on siblings

    f) suggest out-of-home placements

    g) explain risk/prevalence in several ways

    h) give news over the telephone

    i) offer a follow-up meeting with other family members

    j) offer global reassurance (e.g., likelihood that a problem may not exist)

    k) present early intervention in a positive light

    l) provide a diagnostic label (if you have not administered diagnostic measures of development and behavior)

    m) use everyday language (e.g., "seems behind")

    n) provide a take-home summary of results/recommendations

    o) sit behind a desk or stand to deliver information to families

    p) avoid giving difficult news because it is uncomfortable for parents and providers

2. **List four appropriate activities for parent-child interactions when children are 6- to 12-months of age.**

    a) _____

    b) _____

    c) _____

    d) _____

3. **Match parenting styles with their definitions by placing the definition number in the space next to parenting style:**

Parenting Style	Definition
Permissive____	1. both demanding and responsive; disciplinary methods are supportive rather than punitive
Authoritarian ____	2. indulgent, avoiding confrontation, more responsive than demanding
Authoritative ____	3. low in both responsiveness and demandingness; often uninvolved and depressed
Neglectful _____	4. highly demanding and directive, but not responsive; often intrusive and punitive

4. **Psychosocial risk factors include:** (circle all that apply)

    a) a permissive parenting style

    b) authoritarian or uninvolved parenting style

    c) two parents with stressful full-time jobs

    d) single parent

    e) parents with < a high school education

    f) frequent household moves

    g) first born/only child

    h) 4 or more children in the home

    i) limited social support

    j) parental mental health problems such as depression

    k) minority status

    l) limited parental literacy

    m) teen motherhood

    n) limited two-way communication between parent and child

5. **Psychosocial risk factors:** (check all that apply)

    a) cause declines in intelligence, language and academic skills

    b) are associated with being held back in school

    c) increase the likelihood of dropping out of high school

    d) are associated with teen pregnancy, criminality and unemployment

    e) are rarely changeable and thus not an effective target for intervention

    f) often have a greater adverse impact on child development than prematurity

6. **Children with psychosocial risk factors for developmental problems:** (circle all that apply)

    a) are unlikely to have emerging disabilities

    b) may need to be enrolled in Head Start

    c) often have numerous psychosocial risk factors

    d) are likely to be over-referred by screening tests

    e) may not qualify for IDEA services

    f) will benefit from quality preschool or Head Start

    g) have parents who may need to be taught parenting skills

    h) have parents who may need social work services for assistance with housing, food, job training, etc.

    i) have parents who may have depression, anxiety or other mental health problems needing treatment

7. **Parents sometimes ask for parenting advice and suggestions for age-appropriate parent-child activities. Please name three or more sources for information you can share with parents:**

_____

_____

_____

_____

_____

_____

_____

V. Measurement Principles In Early Detection

1. **Accurate screening tests typically identify what percent of children with disabilities prior to kindergarten enrollment?** (circle one)
   - a) 5%
   - b) 15%
   - c) 30%
   - d) 60%
   - e) 70% to 90%

2. **Primary care providers using clinical judgment and informal milestones typically identify what percent of children with disabilities prior to kindergarten enrollment?** (circle one)
   - a) 5%
   - b) 15%
   - c) 30%
   - d) 60%
   - e) 70% to 90%

3. **What is meant by "developmental screening?"** (circle all that apply)
   - a) use of informal milestones checklists
   - b) use of selected items from lengthier screens such as the Denver
   - c) use of measures that are standardized and reliable
   - d) use of measures that are validated, sensitive and specific
   - e) trigger or informal questions to parents

4. **Specificity is the:** (circle all that apply)
   - a) percentage of children without disabilities correctly detected by a screen
   - b) percentage of children with disabilities correctly detected by a screen
   - c) the percentage of children with failing screening test scores who actually receive a diagnosis

5. **Sensitivity is the:** (circle all that apply)
   - a) percentage of children without disabilities correctly detected by a screen
   - b) percentage of children with disabilities correctly detected by a screen
   - c) the percentage of children with failing screening test scores who actually receive a diagnosis

6. **Minimal but acceptable standards for screening test accuracy are:** (circle all that apply)
   - a) sensitivity and specificity of 70% to 80%
   - b) sensitivity and specificity of 60% to 70%
   - c) sensitivity and specificity of 50% to 60%
   - d) sensitivity and specificity of 80% to 90%

7. **Over-referrals on screening tests:** (circle all that apply)
   - a) are discovered when children do not qualify for IDEA
   - b) can be minimized by using more than one screen
   - c) are best met with "watchful waiting" to see if problems persist
   - d) require monitoring but should not result in recommendations for additional services
   - e) are children who tend to perform below average and have risk factors for school failure
   - f) should lead to referrals such as Head Start, quality preschool programs, parenting training etc.

8. **The Denver-II:** (circle all that apply)
   a) takes longer to administer than the average well-visit/parent-teacher conference
   b) was never validated by the authors
   c) is inaccurate and misses children with developmental-behavioral problems
   d) leads to use of selected items that lack scoring criteria
   e) does a good job detecting academic problems in older children
   f) does a good job detecting developmental problems in young children

9. **Milestones checklists, even if items are drawn from validated tools, are problematic because:**
   (circle all that apply)
   a) items are often ambiguously worded (e.g., "Knows Colors?" How many colors? Which colors? Should colors be named or is pointing to colors an acceptable response?)
   b) items are usually set at the 50th%tile and so about half of all children will fail
   c) milestones do not provide referral criteria
   d) informal milestones checklists lead providers to refer only about 30% of children with delays, and so they miss 70% of children with problems
   e) neither lend credibility to a referral recommendation nor generate reimbursement for billable services
   f) (a) and (d) above

10. **List two reasons why it is better to use a quality screening test than a milestones checklist or selected items from longer measures?**
   _____
   _____
   _____

11. **Validated screening tools relying on parents' concerns or report about specific skills are:**
   (circle all that apply)
   a) as accurate than other tools
   b) enhance provider-parent collaboration
   c) save providers time and money
   d) may require interview for some parents
   e) take more time than my usual approach to early detection
   f) less accurate than commonly used milestones checklists

V. (A) Specific Questions About Using Parents' Evaluation of Developmental Status (Peds)

1. **PEDS measures which of the following domains:** (circle all that apply)
   a) social-emotional/behavioral/mental health
   b) expressive language
   c) fine motor
   d) self-help
   e) academic skills
   f) receptive language
   g) gross motor
   h) cognitive
   i) health/family issues
   k) b, c, d, f, g
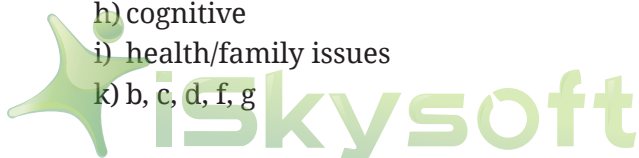
2. **PEDS is for children:** (circle one answer)
   a) 4-months to 6-years of age
   b) birth to 17-years
   c) birth to 8-years
   d) birth through 8-years

3. **If parents complete the PEDS Response Form on their own you must:** (check all that apply)
   a) make sure they have written something on the Response Form
   b) administer by interview if only "yes," "no" or "a little" boxes are circled
   c) follow up their answers with additional questions about developmental milestones
   d) make sure they've been asked first, "Would you like to go through this on your own or would you like someone to go through it with you?"
   e) make sure you've given them the correct foreign language translation if they do not speak English at home
   f) give them the Score Form so they can mark the categories of their concerns

4. **When scoring PEDS:** (circle all that apply)
   a) correct for prematurity for children 2-years and younger and born 3 or more weeks early.
   b) categorize comments in response to the intent of the question asked.
   c) read all responses, view the Brief Guide showing the types of concerns, and then mark the appropriate box on the Score Form
   d) score the global/cognitive category for any response to Question 1 on the PEDS Response Form

5. **Match the category of concern in the left column with the number assigned to the examples in the right-hand column:**

Category	Examples
_____ Global/Cognitive	1. *He can't sit still... won't concentrate... disobeys... may have ADHD... bites... tantrums*
_____ Receptive Language	2. *She won't listen... acts like he doesn't understand even though I think he really does... gives me blank looks when I ask him to do something... Can't follow a two-step command*
_____ Self-help	3. *She can't say her "r's"... Most people other than me can't understand her... He can't ask for what he wants... She doesn't point to things she wants—just takes my hand and puts it on things*
_____ Behavior	4. *He just ignores other people and acts like they aren't there....She's very shy and won't talk around others.... He likes to watch other kids but won't join in.... He's easily frustrated and gets angry fast.*
_____ School	5. *I don't think he hears....She is a picky eater....He doesn't sleep well at night....I wonder if she has asthma*
_____ Gross motor	6. *She's slow... I think he has autism...She's regressing and losing skills.... He can't do what other kids can do.... She is learning but it takes her lots longer and she needs lots of extra practice.*
_____ Expressive Language	7. *We're having trouble even getting him interested in toilet.... He won't even try to get dressed*
_____ Fine Motor	8. *He can't read as well as other children.... She hates math.... He can't write clearly.*
_____ Other/Health	9. *He falls a lot. ...She's really clumsy.... Can't run well. ...She's only four months old and can stand for hours*
_____ Social-Emotional	10. *She does funny flapping things with her hands.... He holds his fork oddly.... Just scribbles... Can't write her name*

6. **If a parent marks "No" to all PEDS questions, but writes the following, in what category of concerns would you place such comments:** *" She's doing about as well as any other child. Occasional meltdowns but that's typical for her age and we can deal with it."* (circle one)

    a) behavior

    b) other/health

    c) social-emotional

    d) all of the above

    e) none of the above

7. **How would you categorize comments such as,** *"My other kids could do lots more at the same age.... His friends are much better at learning, talking, and taking care of themselves"... "She's struggling with everything."* (circle one)

    a) global/cognitive

    b) other/health

    c) school skills

    d) self-help

    e) expressive language

8. **When parents have concerns about self-help skills such as using utensils to eat, trouble with fasteners, what other domain should be marked on the PEDS Score Form:** (circle one)

    a) other/health

    b) gross motor

    c) global/cognitive

    d) fine motor

9. **If a parent says, "She won't listen to me," this should be scored as:** (circle all that apply)

    a) receptive language

    b) behavior

    c) social-emotional

    d) other/health

10. **When parents mark they are "a little" concerned, this should be:** (circle one)

    a) ignored as not a real issue for the family

    b) considered an area of concern

    c) not marked as a concern on the PEDS Score Form

11. **When parents make statements such as** *"I used to be worried about his speech but now I think he's doing better...." "I don't know what a 6-month-old should be saying,"* **the Score Form box for expressive language:** (circle all that apply)

    a) does not need to be marked as a concern for the parent

    b) should be marked as an area of concern

    c) should be explored further with an additional screen before making a decision about what to do next.

12. **Sometimes parents describe concerns that do not appear to professionals to be especially problematic or predictive of problems. In such cases professionals should check the PEDS Score Form for the type of concern raised.**

    __True __False
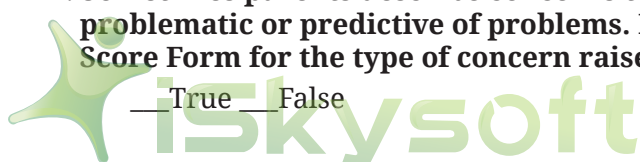
13. **Sometimes professionals notice delays or are troubled by a child's development but the parent does not express concerns. In these cases you could:** (circle all that apply)

   a) use an informal milestones checklist to consider developmental status

   b) add your concerns to the PEDS Response Form

   c) explain your concerns to the family and the need for additional screening

   d) check the box on the Score Form to note your own concern and/or place the child on Path A or Path B

   e) assume the parent is correct and ignore your clinical observations

   f) administer an additional screen such as PEDS: Developmental Milestones or the ASQ

14. **PEDS screens for the following possible conditions:** (circle all that apply)

   a) learning disabilities

   b) speech-language impairments

   c) autism spectrum disorders

   d) orthopedic impairments for which special education eligibility is likely

   e) developmental delay/intellectual disabilities

   f) giftedness/academic talent

   g) typical/normal development

   h) behavioral/social-emotional/mental health problems

15. **Assign the numbers for each Risk Level in the right-hand column to PEDS Paths:**

PEDS Path	Risk Level
Path B (health-focused)_____	1. High Risk: needs referral for diagnostic testing (e.g., speech-language, psychoeducational, etc.)
Path A ____	2. Moderate Risk: needs additional screening to determine whether there is a likely problem
Path C ____	3. Moderate Risk: needs health screens, (e.g., growth chart, re-explanation of prior medical problems now resolved, hearing, vision, lead screening, etc.)
Path B (developmental-focus)____	4. Low Risk: for developmental problems, but elevated risk for emotional/behavioral/mental health problems
Path E ____	5. Moderate Risk: difficulty communicating with families due to language barriers or other issues
Path D ____	6. Low Risk: needs reassurance and routine monitoring.

16. **PEDS is known to:** (circle all that apply)

   a) help parents learn to think about development like professionals do—as a range of domains

   b) encourage parents to observe their children closely

   c) increase parents' worries about their children's development

   d) teach parents that development and behavior are a part of health care

   e) increase parents' willingness to come back for well-child visits and other appointments.

   f) increase positive parenting practices such as time out, instead of spanking

   g) open the door to parent-provider/teacher discussions about child-rearing

   h) make parents less willing to follow through with referrals to other services

   i) lengthen well-visit time frames

17. **When children receive a Path C result:** (circle all that apply)
    a) they should be promptly referred for mental health services
    b) providers should give parents' advice about child-rearing and follow-up in a few weeks
    c) if concerns persist, mental health screening is needed and if failed, children should be referred for mental health/behavioral interventions
    d) professional advice should be tailored to the challenges parents' describe
    e) the effectiveness of professional advice should be monitored in a few weeks to determine if other services are needed
    f) providers can rescreen at the next visit and assume child and family are doing well

18. **Some parents don't raise concerns on PEDS when they actually have worries. Reasons often include:** (circle all that apply)
    a) a belief that providers will notice problems and shouldn't be influenced by parents' concerns
    b) parental anxiety and lack of confidence in their observations
    c) lack of awareness that providers are interested in developmental-behavioral issues
    d) lack of education, poverty, stresses at home
    e) limited ability to read
    f) limited understanding of the language in which PEDS was administered (in writing or by interview)
    g) informal translations of PEDS
    h) asking only a few of the PEDS questions

19. **Why do parents of infants and toddlers need to be asked the PEDS' question about school skills:** (circle all that apply)
    a) parents don't need to be asked that and frankly, shouldn't be asked that question
    b) because it informs providers about parents' understanding of what is developmentally appropriate
    c) it helps providers get an idea of what parents are doing with children at home in terms of teaching children new things
    d) it alerts providers that parents may not be aware of what to teach young children

20. **Parents' concerns are sometimes vague or developmentally off-target (e.g., "*I don't know what a 6-month-old should be doing?*"; "*She's 9 months old but not talking yet*"). Please explain why such comments may or may not be useful to providers in terms deciding on an optimal response.**

21. **Parents' concerns:** (circle all that apply)
    a) always reflect the domains in which children have developmental delays
    b) can be significant predictors of disabilities
    c) should consistently be met with reassurance and watchful waiting
    d) may suggest the need for in-office counseling and monitoring
    e) all of the above

22. **Parents with limited education are:** (circle all that apply):
    a) as likely to have concerns about their children's development as more educated parents
    b) less likely to raise concerns spontaneously
    c) less likely to notice problems in their children
    d) less likely to know that healthcare providers are interested in child development
    e) all of the above

23. **The value of using PEDS to elicit parents' concerns in their own words is:** (circle all that apply)
   a) reduces "oh by the way" concerns at the end of visits
   b) saves time during visits
   c) enables providers to figure out in advance exactly what families need to know
   d) creates a collaborative relationship between professionals and parents
   e) helps parents know that providers are interested in development and behavior
   f) helps providers know when to look further at children's skills
   g) helps providers view disordered development (e.g., age-appropriate two-word utterances that are too repetitive and non-communicative)
   h) enhances reimbursement for services

24. **In your own words, why is it critical to refer frequently to the PEDS Brief Guide or to use PEDS Online when scoring PEDS?**

25. **PEDS Online offers:** (circle all that apply)
   a) Modified Checklist of Autism in Toddlers
   b) PEDS
   c) PEDS:Developmental Milestones
   d) automated scoring
   e) a diagnosis for various kinds of disabilities
   f) referral letters when needed
   g) a summary report for parents
   h) academic screens for children 8-years and older
   i) screens of parental mental health
   j) procedure codes for billing/coding

26. **In your own words why should we routinely elicit parents' concerns?**

V. (B) Specific Questions About Using Peds: Developmental Milestones (PEDS:DM)

1. **PEDS:DM items are tied to which performance cutoff:** (circle one)
   a) 10th percentile
   b) 16th percentile
   c) 25th percentile
   d) 50th percentile
   e) 75th percentile
   f) 90th percentile

2. **Performance below the 16th (or even the 20th to 25th) percentile is worrisome because:** (please state in your own words)
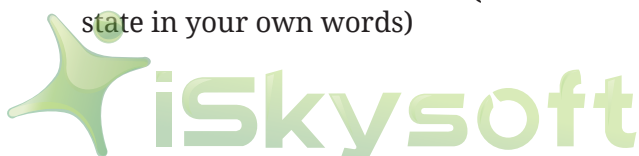
3. **If a child does not meet a milestone on the PEDS:DM it means that he or she:** (circle all that apply)

    a) simply needs watchful waiting and rescreening

    b) is probably well behind same-age peers in that domain of development

    c) needs further evaluation

    d) has a diagnosable problem that can be identified by the PEDS:DM

4. **Scores on the PEDS:DM are defined as:** (circle all that apply)

    a) milestones met or unmet

    b) pass or fail

    c) optimal or suboptimal

    d) disabled or not disabled

5. **PEDS:DM measures development in which areas:** (circle all that apply)

    a) expressive language

    b) self-help

    c) social-emotional

    d) fine motor

    e) receptive language

    f) health, vision, hearing

    g) gross motor

    h) behavior

    i) academics in math and reading

6. **The PEDS:DM detects probable delayed development as well as probable disabilities.**

    ___ True ___ False

7. **Please explain why measures such as the PEDS:DM or the ASQ, even though they detect developmental delays, may not identify children with disordered development:**

8. **When making referrals on the basis of PEDS or the PEDS:DM:** (circle all that apply)

    a) early intervention/public school services should be the first consideration

    b) a diagnosis is needed before early intervention services can be initiated

    c) it is not necessary to refer if a child fails to meet milestones on the PEDS:DM. Instead, watchful waiting is the optimal response

    d) professionals should consider, based on observations of family functioning, medical history, etc., whether social work, mental health, parent training or other services are needed in addition to IDEA

    e) a teaching hospital or private diagnostic evaluation clinic should be consulted prior to referring to IDEA

    f) providers should be prepared to make referrals to Head Start or other services

9. **The PEDS:DM can be administered in various ways.** (circle the administration methods that apply):

    a) interviewing parents

    b) administration by parents

    c) professional hands-on administration with children

    d) observation only (for younger children)

    e) professional opinion about the presence or absence of skills

10. **Please rate these statements as true or false:**

    a) it is acceptable to probe the extent of unmet milestones on the PEDS:DM by administering lower-level items

      ____ True ____ False

    b) if a child is suspected of advanced development it is NOT acceptable to administer higher-level items and note these on the PEDS:DM Recording Form.

      ____ True ____ False

V. (C) Specific Questions About Using The Ages And Stages Questionnaire-Third Edition (ASQ-3)

1. **The ASQ-3 can be administered repeatedly for developmental surveillance, monitoring.**
____True ____False

2. **If a child receives a perfect score on the ASQ-3 they are considered above average.**
____True ____False

3. **Answers on the ASQ-3 should be provided by parents either in writing or by interview.**
____True ____False

4. **The ASQ-3 tells you if a child has a probable delay or disability.**
____True ____False

5. **All items must be answered on the ASQ-3 for it to be valid.**
____True ____False

6. **Alternative materials and phrasing may be used when completing the ASQ-3.**
____True ____False

7. **It is acceptable for providers to complete the ASQ by observation and without parent-report.**
____True ____False

Please circle the best answer/s for questions 8 - 12

8. **The beginning of the *dark shaded* "cutoff" area on the ASQ-3 summary sheet represents:**

    a) the mean/average score

    b) 1 standard deviation below the mean

    c) 1.5 standard deviations below the mean

    d) 2 standard deviations below the mean

9. **The beginning of the *light shaded* "monitoring" area on the ASQ-3 summary sheet represents:**

    a) the mean/average score

    b) 1 standard deviation below the mean

    c) 1.5 standard deviations below the mean

    d) 2 standard deviations below the mean

10. **The ASQ-3 series of questionnaires covers the following age-range?**

   a) 4- to 36-months

   b) 2- to 66-months

   c) 0 to 60-months

   d) 2- to 48-months

11. **How many developmental domains and items in each are included on the ASQ-3?**

   a) 4 domains with 5 items each

   b) 6 domains with 6 items each

   c) 1 domain with 30 items

   d) 5 domains with 6 items each

   e) 10 domains with 2 items each

12. **Which domains are measured by the ASQ-3?**

   a) fine motor

   b) gross motor

   c) communication

   d) social-emotional

   e) problem-solving

   f) personal-social

13. **A child should be referred for further evaluation if they have the following ASQ-3 score?** (circle all that apply.)

   a) below the 2 sd cutoff score in all domains.

   b) parent or pediatric practitioner has significant concerns about the child's development but scores are only in monitoring zone (-1sd).

   c) below the 2 sd cutoff score in 1 domain.

   d) below the 2 sd cutoff score in communication only.

14. **Please explain why measures such as the PEDS:DM or the ASQ, even though they detect developmental delays and most disabilities, may not identify children with disordered development:**

15. **ASQ Online offers:** (check all that apply)

   a) Ages and Stages Questionnaire

   b) automated scoring

   c) a diagnosis for various kinds of disabilities

   d) referral letters when needed

   e) a summary report for parents

   f) academic screens for children 8-years and older

   g) mental health screens for parents

   h) procedure codes for billing/coding

   i) ASQ:SE

V. (D) Specific Questions About Using Ages And Stages : Social Emotional (ASQ:SE)

1. **ASQ-3:SE items answered as "Most of the Time" always receive 10 points.**
   ____True ____False

2. **If a child's score is above the cut-off on the ASQ:SE, he is considered typically developing.**
   ____True ____False

3. **The ASQ:SE may be completed by multiple caregivers.**
   ____True ____False

4. **The sensitivity and specificity of the ASQ:SE, i.e. agreement with professional evaluation, are above 78% and 94% respectively.**
   ____True ____False

5. **Children who score above the cut-off should always be referred for a mental health evaluation.**
   ____True ____False

6. **Cultural considerations should be considered when interpreting ASQ:SE scores.**
   ____True ____False

7. **Inter-rater reliability may not be high when looking at social-emotional behaviors.**
   ____True ____False

Please circle the best answer(s) for questions 8 - 10

8. **The graphed distribution of scores on the ASQ:SE looks like:**
   a) a bell curve
   b) scatter
   c) a negative skew
   d) a positive skew

9. **Cut-off scores on the ASQ:SE represent:**
   a) 2 standard deviations above the mean.
   b) the median for all scores
   c) the mode for the scores
   d) the best balance of sensitivity and specificity.

10. **Which of the following are considerations for making referrals even if scores are higher than the cut-off?** (circle all that apply)
    a) setting/time factors
    b) developmental factors
    c) health factors
    d) family/cultural factors
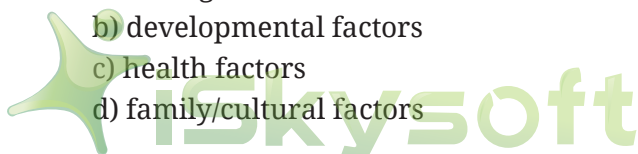
11. **Identify the areas screened by the ASQ:SE:**
    a) self-regulation
    b) communication
    c) adaptive behavior
    d) autonomy
    e) affect
    f) interaction with people
    g) parenting skills

V. (E) SPECIFIC QUESTIONS ABOUT USING THE BAYLEY INFANT NEURODEVELOPMENTAL SCREENER (BINS)

1. **The BINS is for infants:** (circle all that apply)
    a) birth to 48-months
    b) 3- to 24-months
    c) birth to 2-years
    d) 12- to 48-months

2. **The BINS is scored using:** (circle all that apply)
    a) a complications approach
    b) a critical items summary
    c) an optimality approach
    d) developmental milestones

3. **The same BINS items are given for all age groups.**
    ____True ____False

4. **In the case of infants born prematurely, the BINS item set selected for administration is based on chronological age.**
    ____True ____False

5. **The BINS scoring yields:** (circle all that apply)
    a) established, biological and environmental risk estimates
    b) number of failed items
    c) a neurodevelopmental index score
    d) low-, moderate- and high-risk groupings

6. **BINS neuromotor item administration and scoring are sometimes more difficult for psychologists and other professionals who lack training in neuromotor disabilities. When in need of training, examiners should:** (circle all that apply)
    a) rely on clinical judgment
    b) practice with infants from a variety of age groups to develop a point of reference.
    c) collaborate with occupational or physical therapists

V. (F) Specific Questions About Using The Modified Checklist Of Autism In Toddlers (M-CHAT)

1. **The M-CHAT identifies:** (circle all that apply)
      a) mild developmental delays and disabilities
      b) possible autism spectrum disorders
      c) mental health problems

2. **When parents complete the Modified Checklist of Autism in Toddlers (M-CHAT) and their children receive a failing score:** (circle all that apply)
      a) a referral to ASD specialists/developmental-behavioral clinics is the first best step.
      b) failed items should be readministered via the M-CHAT Follow-up Interview
      c) IDEA personnel can be asked to administer the M-CHAT Follow-up Interview
      d) If the interview is failed, referrals to both Early Intervention and an ASD specialist may be needed
      e) a diagnosis of autism spectrum disorders (ASD) can be made
      f) a failed M-CHAT means that a child may have ASD and/or other conditions such as intellectual disabilities or a significant language impairment
      g) If the broad-band screens are failed but the M-CHAT is passed, no referrals are needed.

3. **The M-CHAT should not be used as a stand-alone parent-report screen because:** (circle all that apply):
      a) the most common disabilities such as moderate language impairment, learning or intellectual disabilities are likely to be missed.
      b) the M-CHAT does not detect most developmental delays (e.g., children who are behind, don't qualify for IDEA services, but who need services such as Head Start or quality preschool/daycare programs)
      c) I disagree with the premise of this question: The American Academy of Pediatrics says the M-CHAT should be used at 18- and 24-months. The M-CHAT alone is sufficient for those visits.

V. (G) Specific Questions About Using The Safety Word Inventory And Literacy Screener (SWILS)

1. **The SWILS is standardized on children who are:** (circle all that apply)
      a) 4 ½- to 16-years
      b) 5 ½- to 10-years
      c) 6 ½-to 14-years
      d) 3- to 8-years

2. **The SWILS can be used to identify literacy and health literacy problems in older students and parents:**
      ___True ___False

3. **The SWILS identifies probable:** (circle all that apply)
    a) depression
    b) possible autism spectrum disorders
    c) learning disabilities
    d) mental health problems
    e) health literacy challenges
    f) academic problems

4. **If the examinee segments a word (e.g., "Volt-age" but does not self correct and say "Voltage," this answer is marked as correct.**
    ____True ____False

V. (H) Specific Questions About Using The Pediatric Symptom Checklist (PSC)

1. **The PSC identifies probable:** (circle all that apply)
    a) depression
    b) possible autism spectrum disorders
    c) conduct problems
    d) attention difficulties
    e) developmental deficits
    f) mental health problems

2. **In your own words, why should the PSC be administered before deciding to use a measure like the Vanderbilt ADHD Scales that focuses mainly on attention deficit hyperactivity disorder:**

3. **The Pictorial PSC is helpful for:** (circle all that apply)
    a) families who don't speak English
    b) families with limited literacy
    c) adolescents who may not read well
    d) all youth and their parents
    e) improving identification of mental health problems in families with low socioeconomic status

VI. Implementation Questions

1. **The following statements describe the process of preparing for use of quality screening tools in healthcare. Place them in logical order:**

   ____ Collaborate on selecting a quality instrument

   ____ Conduct training

   ____ Organize parent education materials

   ____ Provide a rationale for office staff

   ____ Consider any similar existing work flow (e.g., how other questionnaires "float" down the hall)

   ____ Plan training, gather training materials

   ____ Identify physicians or other staff heavily interested in the issue

   ____ Monitor implementation of screening

   ____ Allow staff to determine how the workflow steps will be executed

   ____ Gather a list of referral resources

   ____ Set a timeline

   ____ Trial implementation and decide on needed adjustments to the process

   ____ Encourage staff to take responsibility for defining the new work process

   ____ Work with the early intervention community to establish referral mechanisms, the kinds of reports you'd like to receive, times to communicate, preferred mechanisms for communication (e.g., email, fax, phone, surface mail)

2. Please identify your opinion about the following statements. **Collaboration with community services on referral processes:**

a)	Takes excessive amounts of time from primary care	___True ___Maybe ___False
b)	Helps identify community-wide needs	___True ___Maybe ___False
c)	Is problematic because services are rare or non-communicative	___True ___Maybe ___False
d)	Facilitates providers' awareness of service options	___True ___Maybe ___False
e)	Enables medical and non-medical providers to communicate and refer to/from each other	___True ___Maybe ___False
f)	Is usually confusing for families due to conflicting advice	___True ___Maybe ___False
g)	Enables further evaluation and reduces the need for health care providers to administer multiple screens	___True ___Maybe ___False
h)	Increases opportunities for care coordination	___True ___Maybe ___False
i)	Leads to turf battles and animosity among various types of providers	___True ___Maybe ___False
j)	Often leads to community-wide advocacy for the needs of children and families	___True ___Maybe ___False
k)	Is worth exploring to see whether it aids my work	___True ___Maybe ___False

Post-Training Course Evaluation Questions

How will you use the information you acquired during training?

What did you like most about your training experience?

What did you like least about your training experience?

What additional information did you wish had been covered?

What suggestions do you have for improving this presentation?

Which measures do you intend to use in your setting and why?

Are there existing forms or questions that provide a workflow template for your setting?

Please list your thoughts about use of online screening services in your setting.

SCORING GUIDE TO QUESTIONS

I. SERVICES

1. c

2. d

3. a – g

4. three among: Head Start, Early Head Start, quality daycare, parent-training, after-school tutoring, parent counseling, monitoring effectiveness of advice

II. AAP POLICY AND BILLING/CODING

1. a, e, f

2. a – e

3. desirable answers are any reasons to continue screening after 24- to 30-months

4. a – d, f – j

5. a) False; b) True; c) False

6. a – e, g, h

7. b – d

III. CHILD DEVELOPMENT, DISABILITIES, ETC.

1. language, preacademic skills, cognition

2. a) False; b) False

3. b

4. True

5. the order should be: E, A, C, B, D, F

6. a, b, d, e, f

7. a) True; b) False; c) True; d) False; e) False; f) True; g) False; h) False; i) True

8. a, b

9. the order should be: 4,2,3,1,5,6

10. a – c or d

IV. PARENTING, PSYCHOSOCIAL RISK AND EXPLAINING RESULTS

1. b – d, g, i, k, m, n

Section IV continues...

2. desirable answers include four or more among: book-sharing, talking about things the child is noticing, imitating the child's sounds/ word attempts, engaging in the child's self-initiated play, taking the child places and talking about what he/she sees, encouraging creative play such as block stacking, leggos, scribbling, showing the child new things including sounds, objects, etc.

3. the order should be 2,4,1,3

4. b, d – f, h – n

5. a – d, f

6. b – i

7. desirable answers are two or more among: parenting books, websites such as *www. kidshealth.com*, parenting information handouts plus orally delivered advice, parent training programs, parenting video series, etc.

V. MEASUREMENT PRINCIPLES

1. e

2. c

3. c, d

4. a

5. b

6. a

7. a, b, e, f

8. a – d

9. a – e

10. correct answers include two or more: proven accuracy in early detection, clear scoring criteria, higher levels of sensitivity and specificity, ability to detect more children with problems

11. a – d

V. (A) PEDS

1. a – i

2. c

3. a, b, d, e

Section V. (A) continues...
4. a, b, c
5. categories of concerns should be numbered in this order: 6, 2, 7, 1, 8, 9, 3, 10, 5, 4
6. a
7. a
8. d
9. a (and optionally b, but b alone is incorrect)
10. b
11. b, c
12. True
13. b – d, f
14. a – e, g, h
15. PEDS Paths should be numbered in this order: 3, 1, 4, 2, 6, 5
16. a, b, d, f, g
17. b, c, d, e
18. a – c, e – h
19. b – d
20. appropriate comments are: alerts us to the need for careful monitoring, developmental promotion, parent education, possible psychosocial risk
21. b, d
22. a, b, d
23. a – h
24. desirable answers are fidelity to scoring, accuracy of results, reduction of cognitive drift, adherence to administrative directions, etc.
25. a – d, f, g, j
26. desirable answers are: eases delivery of difficult news, enhances collaboration, focuses parenting advice on specific topics of interest, creates a teachable moment, reduces "oh by the way" concerns
V. (B) PEDS:DM
1

Section V. (B) continues...
2. acceptable answers mention: hazards of entering school already behind, having future difficulties in school, higher chance of being held back in grade, increased risk of dropping out, etc.
3. b, c
4. a
5. a – e, g – i
6. True
7. answers should focus on age-appropriate skills executed in problematic ways (e.g., expressive language that is repetitive and non-communicative; fine motor skills in which tremors or other neuromotor problems are present)
8. a, d, f
9. a – d
10. a) True; b) False
V. (C) ASQ-3
1. True
2. False
3. True
4. True
5. False
6. True
7. False
8. d
9. b
10. b
11. d
12. a – c, e, f
13. a – d
14. answers should focus on age-appropriate skills executed in problematic ways (e.g., expressive language that is repetitive and non-communicative; fine motor skills in which tremors or other neuromotor problems are present)

Section V. (C) continues...
15. a, b, d, i
V. (D) ASQ:SE
1. False
2. False
3. True
4. True
5. False
6. True
7. True
8. d
9. d
10. a – d
11. a – f
V. (E) BINS
1. b
2. c
3. False
4. False
5. d
6. b, c
V. (F) M-CHAT
1. b
2. b, c, d, f
3. a, b
V. (G) SWILS
1. c
2. True
3. c, e, f
4. False

V. (H) PSC
1. a, c, d, f
2. optimal responses focus on the need to determine whether symptoms of ADHD are instead, due to learning disabilities, language impairment, mental health problems
3. a – e
VI. IMPLEMENTATION
1. there is not right or wrong sequence here—this question is designed to help trainees consider a workable process although we'd prefer to see the process begin with engendering support among colleagues and recruiting their help in planning the work flow (e.g., 3, 5, 14, 1, 6, 4, 2, 11, 8, 12, 9, 10, 7, 13)
2. these items elicit opinion and provide presenters information on perceived obstacles to implementation—obstacles for which trainees may need further support and training to overcome. Ideally, you'll see these answers: a) False; b) True, c) False; d) True; e) True; f) False; g) True; h) True; i) False; j) True; k) True
POST-TRAINING EVALUATION AND TAKE-HOME PLANNING
These questions are designed to solidify learning and give presenters helpful feedback about topics requiring more emphasis, identify which trainees need further assistance, etc.

Appendix C: Milestones for Teaching and Learning Child Development

FRANCES PAGE GLASCOE

Table of Milestones: Birth to 5 Months

Chronological Age	Gross Motor	Fine Motor/ Writing	Self-Help	Cognitive/Academic	Social/Emotional	Receptive Language	Expressive Language
~ 1 month	Turns head in supine Chin up in prone	Hands fisted near face	Sucks well	Gazes at black-white objects Follows face	Discriminates mother voice Cries out of distress	Startles to loud noise	Makes sounds other than crying
~ 2 months	Chest up in prone Tries to steady head briefly when held	Hands unfisted 50% Retains rattle if placed in hand Holds hands together	Opens mouth at sight of breast or bottle	Follows large highly contrasting objects Recognizes mother	Reciprocal smiling - responds to adult voice & smile	Alerts to voice / sound	Coos (e.g., "oooh" and "aah") Social smile (6 wks) Gurgles when vocalizing
~ 3 months	Props on forearms in prone Rolls to side	Hands unfisted 50% Inspects fingers Bats at objects	Brings hands to mouth	Reaches for parent's face Follows objects moved in circle (when in supine) Regards toys	Expression of disgust (sour taste, loud sound) Visually follows person who is moving across a room	Regards speaker	Chuckles Vocalizes when talked to
~ 4 months	Sits with trunk support No head lag when pulled to sit Props on wrists Rolls front to back	Clutches at clothes Reaches persistently Plays with rattle Holds hands predominately open	Briefly holds onto breast or bottle	Mouths objects Stares longer at novel faces than familiar ones Shakes rattle Reaches for ring/rattle	Smiles spontaneously at pleasurable sight/ sound Stops crying at parent voice To and fro alternating vocalizations with others	Orients head in direction of a voice Stops crying to soothing voice	Laughs out loud Vocalizes when alone
~ 5 months	Sits with pelvic support Rolls back to front Parachute sits with arms supporting trunk (anterior protection)	Grasps cube using whole hand (palmer grasp) Transfers objects: hand-mouth-hand Holds hands together Reaches/grasps dangling ring	Gums/mouths pureed food	Turns head to look for dropped spoon Regards pellet or small cracker	Recognizes caregiver visually Forms attachment -relationship to caregiver	Begins to respond to name	Says "Ah-goo" (or other vowel +consonant combinations) Razz, squeal Expresses anger with sounds other than crying

Table of Milestones: 6 Months to 9 Months

Chronological Age	Gross Motor	Fine Motor/ Writing	Self-Help	Cognitive/Academic	Social/Emotional	Receptive Language	Expressive Language
~ 6 months	Sits momentarily propped on hands Pivots in prone (on belly) Prone—bears weight on one hand	Transfers hand-hand Rakes pellet Takes second cube - holds on to one Reaches with one hand	Feeds self crackers Places hands on bottle	Touches reflection and vocalizes Removes cloth on face Bangs & shakes toys	Stranger anxiety: recognizes familiar vs. unfamiliar people	Stops momentarily to "no" Gestures for "up"	Reduplicates babble with consonants "(e.g., "da-da-da") Listens then vocalizes when adult stops Smiles/Vocalizes to mirror
~ 7 months	Bounces when held Sits w/o support—Steady Puts arms out to sides for balance (Lateral protection)	Grasps using side of hand (radial-palmar grasp)	Refuses excess food	Explores different aspects of a toy Observes cube in each hand Finds partially hidden object	Looks from object to parent and back when wanting help (e.g., with a wind-up toy)	Looks toward familiar object when named Attends to music	Increasing variety of syllables Increased reduplicative babble — Repeats same syllables (e.g., "mamam-ama")
~ 8 months	Gets into sitting Commando crawls Pulls to sitting/ kneeling	Bangs spoon after a demo Grasps with all four fingers and side of thumb (Scissor grasp) Takes cube out of cup Pulls large peg out	Holds own bottle Finger feeds Cheerios or string beans	Seeks object after it falls silently to the floor	Lets parents know when happy vs. upset Engages in gaze monitoring: adult looks away and child follows adult glance with own eyes	Responds to "come here" Looks for family members when asked, "Where's Mama?...etc.	Says "Mama" (non-specific) Non-reduplicate babble (e.g., "wapa") Imitates sounds
~ 9 months	"Stands" on feet and hands Begins creeping Pulls to stand Crawls with all four limbs straightend (Bear walks)	Grasps with two fingers and thumb below (Radial-digital) Bangs 2 cubes together	Bites, chews cookie	Inspects parts of a bell Rings bell after demo Pulls string to obtain an attached toy out of reach	Uses sounds to get attention Separation anxiety Follows a point "Oh look at… " Recognizes familiar people visually	Enjoys gesture games Orients to name well Turns head upward and diagonally to view source of sound	"Mama" (non-specific) Increased non-redupli-cate babble (e.g. "wapa" +"mada") Imitates sounds Gestures (e.g., reaching, pointing)

Table of Milestones: 10 Months to 14 Months

Chronological Age	Gross Motor	Fine Motor/Writing	Self-Help	Cognitive/Academic	Social/Emotional	Receptive Language	Expressive Language
~ 10 months	Creeps well; Cruises around furniture—two hands; Stands—one hand held; Walks—two hands held	Clumsy release of cube; Grasps pellet with side of index finger and thumb (inferior pincer grasp); Isolates index finger and pokes	Drinks (not sucks) from cup held for him/her	Uncovers toy under cloth; Pokes at pellet in bottle; Tries to put cube in cup, but may not be able to let go	Experiences fear; Looks preferentially when name is called	Enjoys Peek-A-Boo; Waves "bye-bye" back	Says "Dada" (specific); Waves bye-bye; Adds new consonant sounds to babbling
~ 11 months	Walks—one hand held; Pivots in sitting; Cruises furniture holding on with one hand; Stands for a few seconds	Throws objects; Stirs with spoon	Cooperates in dressing	Finds toy under cup; Looks at pictures in book	Gives objects to adult for action after demonstration (lets adult know he needs help)	Stops activity when told "no"; Bounces to music	Says first word; Vocalizes to songs
~ 12 months	Stands well with arms high and legs splayed (Posterior protection); Independent steps	Scribbles after demo; Fine pincer grasp of pellet; Holds crayon; Attempts tower of two cubes	Cooperates in dressing; Finger feeds part of meal; Takes hat off	Rattles spoon in cup; Lifts box lid to find toy	Shows objects to parent to share interest; Points in order to get desired object (Proto-imperative pointing)	Follows 1-step command with gesture; Recognizes names of two objects–looks at each correctly when named	Points in order to get desired object (Proto-imperative pointing); Uses several gestures with vocalizing (waving, reaching, etc.)
~ 13 months	Walks with arms high and out (high guard)	Attempts to release pellet in bottle	Drinks from cup with some spilling	Dangles ring by string; Reaches around clear barrier to obtain object; Unwraps toy in cloth	Shows desire to please caregiver; Solitary play; Functional play	Looks appropriately when asked "Where's the ball?", etc.	Uses three words; Immature jargoning (Inflections without real words)
~ 14 months	Stands without pulling up; Falls by collapse; Walks well	Attempts to release pellet in bottle; Imitates back—forth scribble; Adds third cube to a two cube tower; Puts round peg in & out of hole	Removes socks/shoes; Chews well; Puts spoon in mouth typically turning it over	Dumps pellet out of bottle after demo	Points at object to express interest (e.g., to get parent to name it) (Proto-declarative pointing); Purposeful exploration of toys through trial and error	Follows one-step command without gesture (e.g., "give it")	Names one object; Points at object to express interest (e.g., to get parent to name it) (Proto-declarative pointing)

Table of Milestones: 15 Months to 20 Months

Chronological Age	Gross Motor	Fine Motor/Writing	Self-Help	Cognitive/Academic	Social/Emotional	Receptive Language	Expressive Language
~ 15 months	Stoops to pick up toy; Creeps up stairs; Runs stiff-legged; Walks carrying toy; Climbs on furniture	Builds 3-4 cube tower; Place 10 cubes in cup; Releases pellet into bottle	Uses spoon—some spill; Attempts to brush own hair; Fusses to be changed	Turns pages in book; Places circle in single shape puzzle ● △ □	Shows empathy (if someone else cries, child looks sad); Hugs adult in reciprocation; Recognizes without a demo that a toy requires activation and hands it to an adult if can't operate	Points to 1 body part; Points to 1 object of 3; Gets object from another room upon demand	Uses 3 - 5 words; Mature jargoning with real words
~ 16 months	Stands on one foot with slight support; Walks backwards; Walks up stairs—one hand held	Puts several round pegs in board (with urging); Scribbles spontaneously	Picks up and drinks from cup; Fetches and carries objects (same room)	Dumps pellet out without demo; Places circle in formboard; Finds toy observed to be hidden under layers of covers	Kisses by touching lips to skin; Periodically visually relocates caregiver; Self-conscious: embarrassed when aware of people observing	Understands simple commands "Bring to mommy"; Points to one picture when named	Uses 5-10 words
~ 18 months	Creeps down stairs; Runs well; Seats self in small chair; Throws ball—standing	Makes 4 cube tower; Crudely imitates vertical stroke	Removes garment; Gets onto adult chair unaided; Moves about house without adult	Matches pairs of objects; Re-places circle in formboard after it has been turned around (usually with trial and error)	Passes M-CHAT; Engages in pretend play with other people (e.g. tea party, birthday party); Begins to show shame (when does wrong) & possessiveness	Points to 2 of 3 objects when named; Points to 3 body parts; Points to self; Understands "mine"; Points to familiar people when named	Uses 10-25 words; Uses giant words (all gone, stop that); Imitates environmental sounds (e.g., animals); Names one picture on demand
~ 20 months	Squats in play; Carries large object; Goes up stairs held by one hand	Completes round peg board without urging; Makes 5-6 cube tower; Completes square peg board	Places only edibles in mouth; Feeds self with spoon—entire meal	Returns to search for object hidden under cloth after not finding it an adult's closed fists; Places square in form board ● △ ■	Begins to have thoughts about feelings; Engages in tea party with stuffed animals or dolls; Kisses with pucker	Points to three pictures; Begins to understand her / him / me	Holophrases ("Mommy?" and points at keys, meaning "These are Mommy's keys"); Two-word combinations; Answers requests wtih "no"

Table of Milestones: 22 Months to 2 Years, 6 Months

Chronological Age	Gross Motor	Fine Motor/ Writing	Self-Help	Cognitive/Academic	Social/Emotional	Receptive Language	Expressive Language
~ 22 months	Goes up stairs holding rail, putting both feet on each step Kicks ball with demo Walks with one foot on walking board	Closes box with lid Imitates vertical line Imitates circular scribble	Uses spoon well Drinks from cup well Unzips zippers Puts shoes on partway	Completes formboard with three shapes (● ▲ ■)	Watches other children intensely Begins to show defiant behavior	Points to 4 – 5 pictures when-named Points to 5 – 6 body parts Points to 4 pieces of clothing when named	Uses 25-50 words Asks for more Adds 1-2 words per week
~ 24 months	Walks down stairs holding rail, both feet on each step Kicks ball without demo Throws overhand	Makes a single-line "train" of cubes Imitates circle Imitates horizontal line	Opens door using knob Sucks through straw Takes off clothes without buttons Pulls off pants	Sorts objects Matches objects to pictures Shows use of familiar objects	Parallel play Begins to mask emotions for social etiquette	Follows two-step command Understands me / you Points to 5-10 pictures 2 word sentences (noun+verb) Telegraphic speech 50% intelligibility Refers to self by name Names 3 pictures	Uses two-word sentences (noun+verb) Telegraphic speech 50 + words in vocabulary 50% intelligibility Refers to self by name Names 3 pictures Adds new consonant sounds (e.g., "g", "h")
~ 2 years, 4 months	Jumps from bottom step, one foot leading Walks on toes after demo Walks backward 10 steps	Strings large beads (awkwardly) Unscrews jar lid Turns paper pages (often several at once)	Holds self and/or verbalizes toilet needs Pulls pants up with assistance	Matches shapes Matches colors	Reduction in separation anxiety	Understands "just one"	Repeats 2 digits Begins to use pronouns (I, me, you) Names 10-15 pictures
~ 2 years, 6 months	Goes up stairs with rail, alternating feet Jumps in place Stands with both feet on balance beam Walks with one foot on balance beam	Makes an 8 cube tower Makes "a train" of cubes and includes a stack	Washes hands Puts things away Brushes teeth with assistance	Re-places circle in formboard after it has been turned around (little or no trial and error) Points to small details in pictures	Imitates adult activities (e.g., sweeping, talking on phone, pretending to hunt animals)	Follows 2 prepositions: "Put block in . . .on box" Points to objects by use: "ride in" … "put on feet" . . . "write with"	Echolalia and jargoning gone Names objects by use Refers to self with correct pronoun Recites parts of well-known story/fills in words

Table of Milestones: 2 Years, 9 Months to 4 Years, 6 Months

Chronological Age	Gross Motor	Fine Motor/Writing	Self-Help	Cognitive/Academic	Social/Emotional	Receptive Language	Expressive Language
~2 years, 9 months	Walks swinging arms opposite of legs (synchronous gait)	Makes 9-10 cube tower Puts 6 square pegs in pegboard Imitates cross	Toilet trained Puts on coat unassisted	Points to self in photos Points to body parts according to function ("what do you hear with…?")	Begins to take turns Tries to help with household tasks	Understands three prepositions Understands dirty, wet	Gives first and last name Counts to 3 Begins to use past tense Enjoys being read to (short books)
~3 years, 0 months ~3 years, 6 months	Balances on one foot for 3 seconds Goes up stairs, alternating feet, no rail Pedals tricycle Walks heel to toe Catches ball—arms stif	Copies circle Cuts with scissors: side to side (awkwardly) Imitates bridge of cubes Strings small beads well	Eats independently Pours liquid Puts on shoes without laces Spreads with knife Unbuttons	Draws a 2 – 3 part person Understands big/small, more/less Knows own gender Knows own age Matches letters/numerals	Starts to share with/without prompt Fears imaginary things Imaginative play Uses words to describe what someone else is thinking ("Mom thought I was asleep")	Points to parts of pictures (nose of cow, door of car) Understands action words: "playing…washing…blowing" Names body parts when functions described Understands negatives Groups objects (foods, toys) Understands long/short	Uses 200+ words 3 word sentences Uses pronouns correctly 75% intelligibility Acquires new consonant sounds (e.g., "f", "t", "j", "s") Uses plurals Names body parts by use Asks to be read to
~4 years, 0 months ~4 years, 6 months	Balances on one foot 4-8 sec Hops on one foor 2-3 times Standing broad jump 1-2 ft Gallops Throws ball overhand 10 ft Catches bounced ball	Copies square Imitates making a complex gate with cubes Ties single knot Cuts 5 inch circle Uses tongs to transfer Writes part of first-name Works from left to right, top to bottom	Goes to toilet alone Wipes after BM Washes face / hands Brushes teeth alone Buttons Uses fork well	Draws a 4 – 6 part person Can give amounts (usually less than 5) correctly Completes simple analogies: (e.g., dad /boy: mother/ ???, Ice /cold: fire / ???, Ceiling /up: floor/ ??? Points to 5 - 6 colors Points to letters/numerals when named Rote counts to 4 "Reads" several common signs/store names	Deception – interested in "tricking" others, and concerned about being tricked by others Has a preferred friend Labels happiness, sadness, fear and anger in self Group play	Follows three step commands Points to things that are the same versus different Names things when actions are describe (e.g., it swims in water, you cut with it, it's something you read, it tells time.)	Repeats 4 – 6 syllable sentence Uses 300-1000 words Tells stories May repeat words in sentences (e.g., ("Mom, Mom, … I, I want….") 100% intelligibility with few articulation errors Uses "feeling" words Uses words that tell about time

Table of Milestones: 5 Years, 0 Months to 8 Years

Chronological Age	Gross Motor	Fine Motor/ Writing	Self-Help	Cognitive/Academic	Social/Emotional	Receptive Language	Expressive Language
~ 5 years, 0 months	Walks down stairs, alternating feet, without using rail; Balances on one foot for > 8 sec; Hops on one foot 15 feet; Skips	Copies triangle; Builds stairs from model; Puts paper clip on paper; Can use clothespins to transfer small objects; Cuts with scissors; Writes first name	Spreads with knife; Independent dressing; Bathes independently	Draws an 8 – 10 part person; Gives amounts (< 10); Identifies coins; Names letters/numerals out of order; Rote counts to 10; Names 10 colors; Uses letter names as sounds to invent spelling (e.g. NDN); By end of kindergarten:Knows sounds of lconsonants and "short vowels"; Reads 25 words	Has a group of friends; Apologizes for mistakes; Responds verbally to good fortune of others	Knows right and left on self; Points to different one in a series; Understands "er" endings, (e.g.,(batter, skater). Understands adjectives:bushy, long, thin, pointed; Enjoys rhyming words and alliterations; Produces words that rhyme; Points correctly to "side", "middle", "corner"	Repeats 6 – 8 syllable sentence; Defines simple words; 2000 words; Knows telephone number; Responds to why questions; Retells stories with clear beginning, middle, end; Word repetitions in sentences wane (single sound repetitions e.g., s-s-s-s-, absent)
~ 5 years, 6 months	Running broad jump 2-3 ft; Walks backward heel-toe; Jumps backward						
~ 6 years, 0 months	Tandem walks; Skips	Builds stairs from memory; Draws diamond; Copies flag; Writes first and last name; Creates and writes short sentences; Forms letters with down-going and counterclockwise strokes	Ties shoes; Combs hair; Looks both ways at street; Remembers to bring belongings	Draws a 12-14 part person; Number concepts to 20; Simple addition/subtraction; Understands seasons; Sounds out regularly spelled words; Reads (by end of first grade) 250 words	Has best friend of same sex; Plays board games; Distinguishes fantasy from reality; Wants to be like friends and please them; Enjoys school	Asks what unfamiliar words mean; Can tell which words do not belong in a group	Repeats 8 – 10 word Sentences; Describes events in an orderly way; Masters sounds of "r" and "l"; Knows days of the week; 10,000 word vocabulary; Masters pronunciation of consonant digraphs (e.g., "st-", "dr")
~ 6 years, 6 months							
~ 7 - 8 years	Rides bicycle independently; Bats ball placed on cone; Does somersaults	Writing rate increases; Stays on line when writing; Spaces between words; Size of letters becomes uniform; Letter reversals disappear	Sticks with tasks (with TV off) for up to 20 minutes; Pays attention to teacher when in a group; Completes homework on own; Answers and delivers phone messages; Completes household chores (with reminders)	Knows sounds of consonant digraphs (e.g., "ch", "sh"); Knows sounds of voweldipthongs (e.g., "oo", "ou"); Reads words with r-controlled vowels (e.g., "bird", "burn"; Starts "reading to learn" not just "learning to read"; Two-place addition and subtraction; Enjoys reading independently; Remembers spelling words	Avoids hurting others in play; Learns from mistakes; Helps younger children; Strong notions about what is fair; Takes turns in conversations; Delays gratification and waits to take turn; Interested in the opinions of peers	Understands "opposites" and word analogies; Answers "who", "why", "when", "where" and "how" questions; Knows right from left on others; Understands days and months	Masters "r" sound in speech; Tells time; Uses complex and compound sentences; Talks about a range of topics