Pritchard MA, Colditz PB, Beller EM; Queensland Optimising Preterm Infant Outcomes Group. Parents' evaluation of developmental status in children born with a birthweight of 1250 g or less. J Paediatr Child Health. 2005 Apr;41(4):191-6.

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OBJECTIVE: To evaluate the agreement between parental reporting of development of children born very preterm using the Parents' Evaluation of Developmental Status (PEDS) questionnaire and professional assessment by a paediatric developmental team in the detection of sensorineural disability. METHODS: A cross-sectional cohort study of 362 children born in Queensland with a birthweight < or = 1250 g, who were surviving at 2 and 4 years of age corrected for prematurity, was conducted. Parents completed the PEDS questionnaire prior to their child receiving a neurodevelopmental assessment. The level of agreement for sensorineural disability between the neurodevelopmental assessment and the parents' score on the PEDS questionnaire was measured using the kappa statistic, and screening test characteristics were calculated. Logistic regression was used to investigate factors that might affect agreement. RESULTS: Two hundred and eighty-three (78%) of the eligible children were located and contacted. Of these, 216 (76%) agreed to participate in the study (110, 2-year-olds; 106, 4-year-olds). Agreement between the two forms of rating sensorineural disability (developmental quotient > -2SD (standard deviation), cerebral palsy, bilateral blindness and deafness requiring aids) for the 4-year age group children was fair (kappa = 0.27, P = 0.001). PEDS accurately identified 69% (11 of 16) of disabled children and 72% (65 of 90) non-disabled children. The test characteristics for these children were similar to Glascoe's norming sample with a PPV 31% (95% CI: 14-48%), specificity 72% (95% CI: 62-81%), but lower sensitivity 69% (95% CI: 62-81%) and higher false-negative rate 31% (95% CI: 11, 59). Agreement for the 2-year age group was fair with poor test characteristics. Other comparisons for both age groups (PEDS A and B compared using a disability status with DQ > -1SD) showed poor agreement and test characteristics. Gestation age < 27 weeks and maternal education at or below grade 10 in the 2-year age group were the only factors independently affecting agreement. CONCLUSIONS: The agreement between parental evaluation of sensorineural disability status using PEDS and paediatrics developmental assessment in children born very preterm at 4-years corrected age for prematurity compares favourably with Glascoe's norming sample. The lower agreement seen in the 2-year age group limits the utility of PEDS to be used as a screen for disability at an age when early intervention may be useful. The PEDS questionnaire is designed and normed for the general paediatric population, and it is not clear if parents of children born very preterm may have interpreted the PEDS questionnaire in relation to their satisfaction with their child's developmental progress rather than their child's functional ability.

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Letters to the Editor
28 February 2005

Dear Editor,

RE: PARENTS' EVALUATION OF DEVELOPMENTAL STATUS

The article by Drs Pritchard, Colditz and Beller entitled, '*Parents' Evaluation of Developmental Status*' (PEDS) in children born with a birthweight of 1250 g or less (*J. Paediatr. Child Health* 2005; **41**: 191–6) involved use of a screening and surveillance tool I authored, known informally as PEDS.1 I congratulate the authors on a potentially helpful study and offer several suggestions for explaining their findings and planning additional analyses:

1. The authors attempted to view whether PEDS identified children with cerebral palsy. Although this is valuable, PEDS is designed, in contrast, to identify children eligible for special education.2 In the USA, cerebral palsy alone is not sufficient for placement in special classes. Rather, children qualify under the category of physical impairment only if they show motor disabilities in addition to deficits in intelligence, adaptive behaviour and/or academic/preacademic skills, that is, their difficulties must interfere with school success or its likelihood. As a consequence, parental concerns about communication and cognition have stronger predictive value than do gross motor concerns. If the criteria for special education placement are different in Australia, then Drs Pritchard *et al*. are encouraged to consider whether a different constellation of parental concerns as elicited by PEDSwould perform more effectively.

2. If detection of cerebral palsy with or without other developmental deficits is, in fact, a goal for Australian children, it might be wise to evaluate whether parents of children with cerebral palsy describe motor development in a way that could be discerned from parents with motor concerns but whose children are developing in a typical fashion. For example, statements such as, '*my four month old is very strong and can stand for hours*'; '*she holds her body in an odd way*';

'*she keeps her legs stretched out and crossed all the time*'; '*he's like a rag doll*', all might be clues to the presence of spasticity, scissoring, persistence of primitive reflexes, hypotonicity etc. Drs Pritchard *et al*. are encouraged to make use of their rich dataset to consider secondary, qualitative analyses of the concerns of parents whose children have cerebral palsy.

3. It may be unnecessary to point out that screening tests do not need to be deployed with children with previously identified disabilities. In the US validation studies, 25% of families whose children were already enrolled in special education, did not raise concerns on PEDS. Drs Pritchard *et al*. speculate sagely that satisfaction with services may reduce or eliminate the parental concerns. It is also likely that parents whose children have known disabilities come to view their child's development in a relativistic and incremental manner – comparing current progress, however slow, only to past performance – and not, as most parents do, by comparing their child to other children. This would make for an interesting longitudinal study and one that is also encouraged. Some evidence for marked early differences in the perspective of parents whose children have known disabilities is found in a study in which parents of 2-year-old children were asked to predict adult outcome. Parents of non-disabled children consistently predicted quite exalted futures, a phenomenon the researchers dubbed, 'Presidential syndrome'. In contrast, parents of children with cerebral palsy and/or mental retardation, simply predicted their child would become an average, normal adult.3 Although both sets of predictions may be unlikely, they do suggest early and significant differences in the views of parents whose children have disabilities.

4. Finally, PEDS is not only a screening test, it is also a surveillance tool. As such, it calls for, when making referral decisions, provider input including results of a physical exam, medical history, observations and/or knowledge of the family. The *PEDS Brief Guide to Scoring and Administration* states, '*If parents have no concerns or nonpredictive concerns but clinical judgment suggests the presence of a problem, follow Path A or B*' (the two planks of the PEDS algorithm denoting increased risk and need for additional assessment (p. 6)). Had the authors followed this recommendation, their sensitivity findings would have been substantially higher.

I am happy to assist the authors with additional analyses of their and in formulating hypotheses for future research.

REFERENCES

1 Glascoe FP. *Parents' Evaluation of Developmental Status (PEDS)*. Nashville, TN: Ellsworth & Vandermeer Press, 1997.

2 Glascoe FP. *Collaborating with Parents: Using Parents' Evaluation of Developmental Status to Detect and Address Developmental and Behavioral Problems*. Nashville, TN: Ellsworth & Vandermeer Press, 1998; l.

3 Shapiro DM, Ostroff JS, Howe GW. *Parents' beliefs about the severity and permanence of their child's handicap*. In: Proceedings of the 19th Annual Gatlinburg Conference on Research and Theory in Mental Retardation and Developmental Disabilities; 13–15 March 1986, Gatlinburg, TN.

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REPLY

We thank Professor Glascoe for her comments that clarify issues and highlight the purpose of our study. Our aim was to evaluate the agreement between PEDS and paediatric developmental assessment in the detection of *sensorineural disability (developmental quotient <2 SD below the mean, cerebral palsy, bilaterial blindness or hearing impairment requiring aids) in children born preterm with a birthweight ≤1250 g*. Professor Glascoe rightly points out that PEDS was designed to be used

to identify children eligible for special education. We, however, chose to examine whether PEDS could be used as an effective screening tool to identify global disability in these children in Queensland which is a large geographical area where universal assessment by neurodevelopmental teams is difficult. Glascoe reported that 79% of children with a PEDS score A have a disability where the prevalence is 2.9%. In our study the prevalence of disability was between 15% and 22% for 2- and 4-year-old children born very preterm and we, therefore, anticipated better test results than our study showed.

Professor Glascoe offers sound advice suggesting modifying the PEDS motor question to better reflect cerebral palsy and indeed this should greatly improve its use in the very preterm population. Likewise she highlights the fact that our delivery of the questionnaire to parents without any contextual explanation did prompt some parents with children with problems to say they had no concerns because of their heightened awareness of potential disability and their use of early intervention services. These parents may have inappropriately viewed PEDS more as a quality audit than a developmental screening tool.

We agree that PEDS could be modified in the light of our findings and Professor Glascoe's comments to provide a useful standardized approach for general practitioners and child health practitioners in their routine childhood screening and surveillance assessments of children born very preterm and also for tertiary neonatal centres for families who cannot be formally assessed.

One of our aims in undertaking this study was to identify the areas where the current PEDS tool could be improved for use in these populations. We look forward to working with Professor Glascoe to further explore the possibility of developing a version of PEDS optimized for screening for disability in infants born very preterm.

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