Systems of early detection in Australian communities: the use of a developmental concern questionnaire to link services

AUTHORS

Marcia F. Armstrong
RN, RM, MCHN, BNurs, PGradDipNursEd, PGradDipAdNursPaedICU, MHealthMg, International Board Certified Lactation Consultant (IBCLC), Maternal and Child Health Nurse Coordinator, City of Wodonga, Victoria, Australia.
marmstrong@wodonga.vic.gov.au

Sharon Goldfeld
MBBS, FRACP, GradDipEpiBio, PhD,
Paediatrician and Senior Fellow, Centre for Community Child Health, Murdoch Children's Research Institute, Royal Children's Hospital, Parkville, Victoria, Australia.

KEY WORDS

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ABSTRACT

Objective
To establish the Parents' Evaluation of Development Status (PEDS) questionnaire as an acceptable and feasible communication and developmental screening tool to use with parents and providers of maternal and child health centres, childcare centres, preschools and primary schools.

Design
This was a cross sectional study designed to evaluate the utility and uptake, satisfaction level, referral patterns and impact of the PEDS on services and parents. Methods included provider and parent completed questionnaires and semi structured interviews.

Subjects
The PEDS questionnaire was utilised by maternal and child health nurses, childcare workers, preschool teachers, primary school teachers and primary school nurses in the regional city of Wodonga in 2003. There were 246 parents who completed the PEDS questionnaire.

Results
The PEDS proved to have high utility and be relatively cheap. The majority of parents (99.4%) found the questionnaire easy or very easy to complete and would use it in the future, particularly in relating to health and education professionals. Those least educated found it the most helpful. Similarly, over 80% of providers felt confident in using the PEDS, agreeing that it was a positive addition to their practice especially to facilitate routine visits, and periods of transition. Costs were estimated at $1.80 per child based on conservative estimates.

Conclusions
The PEDS was found to be a useful and acceptable tool for screening, facilitating parent discussion, and communication between service providers. It increased attention on children's developmental progress and helped to create a coordinated early years service framework that focused on child development, early detection and prevention.

INTRODUCTION

International evidence highlighting the importance of the early years of life is now having a significant influence on governments across Australia as they consider the best approach to developing systems that lead to improving outcomes for children (Western Australian Department of Community Development 2004; Commonwealth Taskforce on Child Development, Health and Wellbeing 2003; Department of Human Services 2002; Office for Children and Young People 2002; National Research Council IoM 2000). In parallel, a report by the National Health and Medical Research Council (NHMRC), summarising the evidence for a number of child health screening and surveillance programs has highlighted the importance of systems of early detection (Centre for Community Child Health 2002). The report supports an integrated and coordinated approach to the early identification of problems, rather than stand alone activities, with subsequent provision of evidence based interventions. Finally, the seemingly growing number of children with developmental difficulties and behavioural problems (some reports have estimated as high as 20% of children) suggest that a new approach to early detection and intervention is required if there is to be a shift in children's developmental trajectories and improved outcomes for children and their families (Glascoe 1994; Yeargin-Allsopp et al 1992; McCue-Horwitz et al 1992).

Given this evidence, the City of Wodonga, a regional city in Victoria, undertook a project to test the feasibility of establishing a questionnaire that could act as a communication tool between providers, and between providers and parents, as well as have sufficient psychometric properties to enable its use as a developmental screening tool in the context of services and professionals that were already providing a system of care. Previous community consultation with parents of young children and service providers revealed that childcare, preschools and primary schools provided a ready platform for early identification of developmental and behavioural problems in children. The same consultations also suggested that a suitable tool for maternal and child health nurses (MCHN), childcare, preschool and primary school staff to use in identifying problems was necessary.

This paper reports on the results of a community based project that aimed to establish the Parents' Evaluation of Developmental Status (PEDS) questionnaire as an acceptable and feasible communication and developmental screening tool for use with parents and providers of maternal and child health services, childcare services, preschools and primary schools to identify, address and appropriately refer developmental and behavioural problems in children aged birth to eight years.

METHODS

This project was a cross sectional study of children recruited and enrolled through child care centres, preschools, maternal and child health centres and primary schools in the City of Wodonga in 2003. Parents who agreed to participate completed the PEDS and a questionnaire which included questions relating to the PEDS as well as demographic information. Professionals completed questionnaires that explored the utility of the PEDS within their practice. Six focus groups with parents and providers were also undertaken. The study measured the process, impact and cost of using the PEDS across a range of service providers. Simple bivariate analyses were undertaken utilising chi squared to estimate significance. Ethics approval was obtained from the Ethics in Human Research Committee, Royal Children's Hospital, Melbourne.

Measures

Parents' Evaluation of Developmental Status (PEDS)

The PEDS is a 10-item parent completed questionnaire designed to systematically elicit parents' concerns regarding their children's (birth to eight years of age) health, development and behaviour. It has been shown to be as accurate as any of the previously developed screening tests (Glascoe 1997). However it has the distinct advantage of taking less time, needing no specialised equipment and has a strong emphasis on parental involvement

(Glascoe 1999; Christopherson 2002). The PEDS has been shown to have a high sensitivity and identifies 74% to 80% of children with disabilities, similar to the accuracy of other screening tests which take much longer to administer. The PEDS also has a high specificity in that 70%-80% of children without disability are identified as developing normally. Certain groupings of concerns have found to be significant predictors of the risk (low, medium or high) of developmental disability for certain age categories. The PEDS has been adapted for Australia to ensure cultural appropriateness (Coghlan 2003).

Brigance Screen

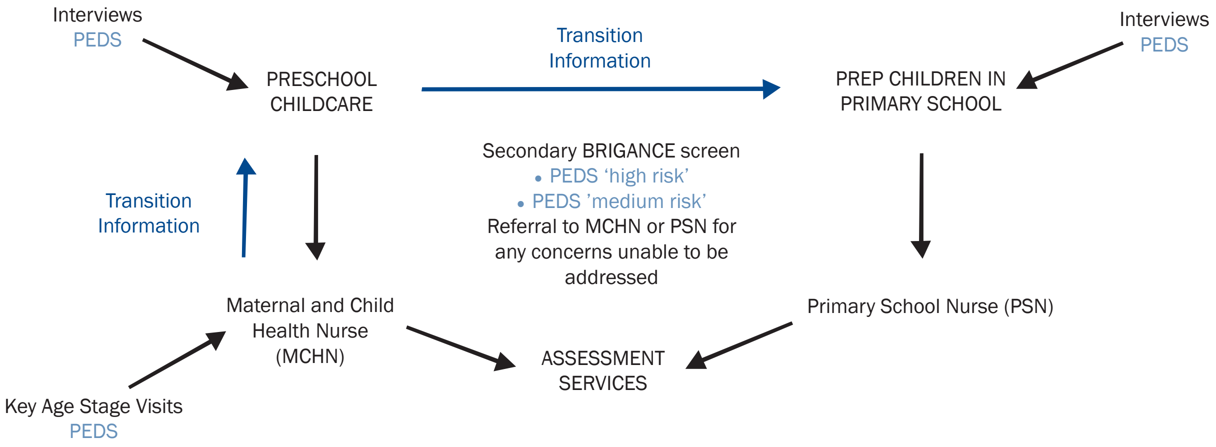
The use of the Brigance as a secondary developmental screen increases the specificity of the PEDS to over 82% (Glascoe 1998). In this study, children under school age with 'high-risk' and 'medium-risk' of disability were referred to the MCHN for the secondary Brigance screen while school age children were referred to the primary school nurse (PSN).

The Brigance screen helps the professional decide whether further assessment and referral is warranted. By increasing the specificity (ie excluding those with normal development who were false positives on the PEDS) the professional can then decide who to refer and who not to refer, thus potentially decreasing the number of children who may be on waiting lists for intervention services.

Developing an early years intersectoral framework

Using the PEDS and Brigance, an early years intersectoral framework was established (see figure 1). Concerns raised through PEDS could then be addressed by primary care providers who could prevent further problems through early intervention and anticipatory guidance and also act as appropriate triage for referrals.

Figure 1: PEDS within an inter-sectoral communication and referral framework around child development and behaviour (Wodonga Early Years Service Coordination Framework)



RESULTS

Sample size

A total of 380 parents were approached for recruitment to the project. Of these 246 parents completed the PEDS questionnaire (including information about gender and age) with regard to their child and consented to be part of the project. However only 162 (65.8%) returned a completed questionnaire on the ease of use/acceptability of the PEDS and demographic data. A total of 26 service providers participated in the project. These service providers included maternal and child health nurses, primary school nurses, childcare workers, and preschool and primary school teachers.

Demographics

One hundred and sixty two parents responded to the written parent questionnaire. Most were mothers (93.8%) and the remainder were fathers. The average

age of the parent was 33.13 years with the majority of parents (94.4% n=153), born in Australia. The majority of parents were either married (79.6%) or living in a de-facto relationship (8.6%). Seven percent reported being single or never married, with 4.3% separated, divorced or widowed. Respondents reported having an average of 2.31 children in their family.

Forty-three percent of responding parents were either not in paid employment or attended home duties, while 82.2% of the spouses of responding parents were reported to be in full time employment. Thirty-two percent of responding parents reported being in part time employment, while only 6.8% of responding parents and 1.3% of spouses of responding parents reported being a pensioner.

Fifty percent of parents had a high school education (16.3% < Year 10 and 33.8% Year 11 or Year 12) and 49.4% of parents had post secondary qualifications (19.4% trade or diploma and 30.0% tertiary degree). Less than one percent of parents did not respond. Table 1 presents sample characteristics for the children and parents.

Parent report on utility of the PEDS

The majority of parents (99.4%) found the PEDS questionnaire easy or very easy to complete and would use it in the future. Most parents (96.0%) felt the PEDS would be helpful or very helpful for health and educational professionals. This varied with parental educational levels; 62.5% of parents with a tertiary level education rated the PEDS questionnaire as very helpful compared with 74% of those with an educational level of year 11-12 and 83% of those with an educational level of Year 10 or lower.

During the focus groups parents were asked about the best time to use the PEDS, and they agreed that the key stage visits were appropriate at maternal and child health centres and suggested on enrolment at other services such as childcare, preschool and school. Parents also reported that it would be beneficial to use the PEDS at parent interviews during the year at childcare, preschool and primary school.

Table 1: Sample characteristics of the respondents to the Parent's' Evaluation of Developmental Status (PEDS) questionnaire

Characteristic	n (%)[†]
Responding parent (n=162)	
Sex	
Female	152(93.8)
Male	10(6.2)
Age of parent (years; mean ± SD)	33.13 ± 5.64
Education	
≤ Year 10	26(16.3)
Year 11-12	54(33.8)
Trade/Diploma	31(19.4)
Tertiary	33(30.0)
Australian born	153 (94.4)
Speak English at home	160 (98.8)
No. of children (mean ± SD)	2.31 ± 0.09
Marital status	
Single/never married	12 (7.4)
Married	129 (79.6)
De facto	14 (8.6)
Separated/divorced/widowed	7 (4.3)
Employment of responding parent	
Employed/self employed full time	26 (16.0)
Employed /self employed part time	52(32.1)
Not in paid employment/home duties	70 (43.2)
Pensioner	11(6.8)
Other	3(1.9)
Employment of spouse of responding parent	
Employed/self employed full time	131(82.2)
Employed /self employed part time	7(4.4)
Not in paid employment/home duties	4(2.5)
Pensioner	2(1.3)
Other	2(1.3)
Doesn't apply	13(8.2)
Child (n=246)	
Sex	
Female	106 (43.1)
Male	140 (56.9)
Age	
< 18 months	49 (19.9)
18 months - < 3 years	49 (19.9)
3 years - < 4.5 years	67 (27.3)
≥ 4.5 years	81 (32.9)
Birth weight (kg; mean ± SD)	3443.56 ± 654.83
Provider	
Maternal and Child Health	85(34.5)
Childcare	85(34.5)
Preschool	26(10.7)
Primary School	50(20.3)

[†] Percentages might not add up to 100 because of missing data

Parents suggested that transition information be passed on by both parents and service providers with the child health record should be the carrier of this information.

Provider feedback

The PEDS was thought to be an easily used tool by all providers from schools, childcare and maternal and child health, with over 80% of providers feeling confident in using the PEDS and agreeing that it was a positive addition to their practice and they would be interested in using the PEDS in the future.

Service providers in childcare, preschool and primary school agreed the most appropriate time to use the PEDS was on enrolment and possibly repeated in an interview during the year. MCHN agreed at key stage visits from 8 - 12 months onwards. Both the MCHN and PSN liked the Brigance screen and found it an easy tool to use.

The PSN acknowledged that if all schools used the PEDS on enrolment, it would identify early those children requiring further assessment and referral. The PSN reported they would need to adjust their current practice in order to meet the potential increased demand at the beginning of the year to provide secondary screenings to those children at high and medium risk of disability on the PEDS. The nurse also commented that the PEDS had the ability to provide a triage system, whereby those children who are at 'high-risk' or 'medium-risk' of disability, are seen by the PSN as a priority. Children, whose parents have non significant concerns or no concerns could be reviewed at a later date. This would mean a change in the service provision of the PSN program.

Cost per child

The true cost of sustaining this model is the purchase cost of the PEDS forms and photocopies of the transition information. These costs are based on purchasing only small quantities of the PEDS. Costs would be reduced with bulk purchases. There was no additional time necessary by the providers as the PEDS simply reshaped current practice rather than being an additional load. These costs are summarised in table 2.

Table 2: Summary of sustainability costs

Item	Cost per child
PEDS forms initial	$1.10
PEDS forms ongoing	$0.55
Photocopy of PEDS for referral	$0.05
Photocopy of transition information	$0.10
Total	$1.80

Developmental concerns and referral pathways

Twenty-eight children (11.4%) were classified as being at 'high-risk' of disability and 54 (22.0%) were classified as being at 'medium-risk' of disability. Thirty-nine children (15.9%) were classified as non-significant concern only, mostly on behavioural and social emotional domains. Around half the parents (50.8%) reported no developmental concerns and required no further follow up.

Table 3 provides detail on the risk of disability and referral outcomes. Of the 28 children (11.4%) considered at 'high-risk' of disability following the PEDS questionnaire, 60% were new referrals to outside services and 28.6% had been previously referred. Three (10.7%) were not referred to outside services as the concerns identified by these parents were unrealistic for the child's age. The nurse had no professional concerns regarding these children and counselled and reassured the parents on normal developmental progress. Of the 54 (22.0%) children considered at 'medium risk' of disability, 26 (48.1%) were referred to outside services and six (11.2%) had been previously referred. Twenty-two (40.7%) of children were not referred to outside services as the issues identified were able to be addressed by the provider. Thirty-nine (15.9%) children were considered at 'low-risk' of disability following the PEDS questionnaire and concerns were mainly managed directly by the provider. However three (7.7%) were referred to outside services and one (2.6%) had been previously referred. Thirty-five (89.7%) were not referred to outside services. Of those children who were previously referred across risk groups, most (73%) were three years of age and over. One hundred and twenty-five (50.8%)

children were at 'low-risk' of disability following the PEDS questionnaire with their parents reporting no concerns. Only one (0.8%) child was referred to an outside service and this was related to a professional concern regarding the child's speech development. The parent was unaware the child's speech was delayed for their age.

Table 3: Risk of developmental disability and referral

PEDS Path n (%)		Referral n (%)		
		Yes	No	Previously Referred
High-risk	28 (11.4)	17 (60.7)	3 (10.7)	8 (28.6)
Medium-risk	54 (22.0)	26 (48.1)	22 (40.7)	6 (11.1)
Low-risk (non significant concerns)	39 (15.9)	3 (7.7)	35 (89.7)	1 (2.6)
Low-risk (no concerns)	125 (49.2)	1 (0.8)	124 (99.2)	0 (0)
Total				246 (100.0%)

Overall, 47 (19.1%) children were referred to outside services as a result of their parents completing the PEDS. Of the 47 children referred to outside services, the majority of referrals were made to speech therapy, followed by multiple referrals and then 'others'. Those children at 'high-risk' of disability (who were referred to outside services) had a higher referral rate to multiple services (42.9%) compared to 'medium-risk' (7.4%), 'low risk' (2.6%) and those with no concerns (0%). Children with 'medium-risk' and 'low-risk' were more likely to receive a referral to a single service provider and this was significantly different (p=0.029).

DISCUSSION

Evidence would suggest that any system of early detection (and hence early intervention) will rely on a more coordinated service system (that crosses traditional sectoral boundaries) as well as tools that help detect developmental and behavioural problems early and assist professionals to engage with parents during the early years of their children's lives (Centre for Community Child Health 2006). This includes better use of the available service platforms in order to ensure a universal approach (ie those most in need do not miss out) and the capacity to engage with parents recurrently over time. The additional benefit is the prevention of 'bottlenecks' at the secondary and tertiary level with more appropriate and triaged referrals for children with more complex needs, and prevention and early intervention strategies implemented through primary care providers.

This small but significant study demonstrated that the PEDS can successfully form an integral part of a service coordination framework. The Wodonga Early Years Service Coordination Framework used the PEDS to facilitate a focus on child development, family centred practice, early detection and prevention and assist in transition information between services. Given the provider change process that was necessary for this project, the PEDS was still thought to be an easily used tool by a range of providers. Interestingly over 80% of professionals felt confident using the PEDS regardless of where they were located (schools, childcare or maternal and child health). All agreed the PEDS was a positive addition to their practice and had interest in using it in the future. As importantly, parents found it useful, particularly those with the least amount of education. While the PEDS is a useful tool for more educated parents; its greatest benefit may lie in its capacity to empower parents who have previously not been able to voice their concerns.

The PEDS also provided a process whereby those children most at risk were identified and appropriate anticipatory guidance and referrals could be implemented by providers. Those children with 'high-risk' of disability required more referrals than those with 'medium-risk'. Children with non significant concerns required minimal referral. Of those with 'no risk factors', only one (0.8%) was referred to an outside service. These results would suggest that the PEDS and the framework facilitated appropriate gate keeping. Concerns raised through PEDS can be addressed by primary care providers and prevent further problems through early intervention and anticipatory guidance.

Despite the small size of this study, it supports the findings (proportion of children at risk of disability) from the USA (Glascoe 1999) and Melbourne, Australia (Coghlan 2003) research. This study is particularly unique within the current PEDS literature as it captures both parent and provider feedback across sectors. The overwhelmingly positive utility (cost and practice) of the PEDS within a framework designed to coordinate services would suggest this model may be robust enough to test more widely across Australia. With the increasing adoption of the PEDS in primary care and universal services within Australia, there is a real opportunity to test this model further and ultimately improve service delivery and outcomes for children.

CONCLUSION

This study has demonstrated that PEDS is a feasible, acceptable and cost effective way of engaging with parents, promoting family centred practice and addressing parental concern. Within a service coordination framework or model, the PEDS has the potential to be used across service providers to coordinate early detection and intervention for developmental and behavioural concerns. The full report of this project titled *Good beginnings for young children and families: a feasibility study* can be found at www.wodonga.vic.gov.au and www.rch.org.au/ccch/peds.

REFERENCES

Australia. Commonwealth Taskforce on Child Development, Health and Wellbeing. 2003. *Toward the development of a national agenda for early childhood.* Canberra: Commonwealth of Australia.

Australia. Department of Human Services, Victoria, Policy and Strategic Projects Division. 2002. *Best Start program overview.* Melbourne: Department of Human Services, Victoria.

Australia. Office for Children and Young People. 2002. *Families First: a support network for families raising children.* Sydney: NSW Government.

Australia. Western Australian Department of Community Development. 2004. *Early years strategic framework 2003-2006.* Perth: Western Australian Department of Community Development.

Centre for Community Child Health. 2002. *Child Health Screening and Surveillance: a critical review of the literature.* Canberra: National Health and Medical Research Council.

Centre for Community Child Health. 2006. *Services for young children: an integrated approach.* Melbourne: Centre for Community Child Health.

Christopherson, E. 2002. Collaborating with parents: using Parent's Evaluations of Developmental Status to detect and address developmental and behavioural problems. *Archives of Pediatrics and Adolescent Medicine,* 156(6):627-628.

Coghlan, D., Kiing, J.S.H. and Wake, M. 2003. Parents' Evaluation of Developmental Status in the Australian day-care setting: developmental concerns of parents and carers. *Journal Paediatric Child Health*, 39(1):49-54.

Glascoe, F.P. 1999. Using parents' concerns to detect and address developmental and behavioural problems. *Journal of the Society of Pediatric Nurses,* 4(1):24-28.

Glascoe, F.P. 1998. *Technical Report for the BRIGANCE Screens: Infant and Toddler, Early Preschool, Preschool, and K and 1 Screens.* Massachusetts: Curriculum Associates.

Glascoe, F.P. 1997. Parents' concerns about children's development: prescreening technique or screening test? *Pediatrics*, 99(4):522-526.

Glascoe, F.P. 1994. It's not what it seems: the relationship between parents' concerns and children's cognitive status. Clinical *Paediatrics,* 33(5):292-298.

McCue-Horwitz, S., Leaf, P.J., Leventhal, J.M., Forsyth, B. and Nixon-Speechley, K. 1992. Identification and management of psychosocial and developmental problems in community based, primary care paediatric practices. *Paediatrics,* 89(3):480-85.

National Research Council (Institute of Medicine). 2000. *From neurons to neighbourhoods.* Washington: National Academy Press.

Yeargin-Allsopp, M., Murphy, C.C., Oakley, G.P. and Sikes, R.K. 1992. A multiple-source method for studying the prevalence of developmental disabilities in children: the Metropolitan Atlanta Developmental Study. *Paediatric*s, 89(4 Pt.1):624-630.