

Use of parents and caregivers as accurate assessors of young children's development

Utilidad de padres y cuidadores como evaluadores certeros del desarrollo en niños menores

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Effective early intervention/early childhood special education (EI/ECSE) and services for children with disabilities and at risk for disabilities are highly dependent upon early identification of potential delays and appropriate referral for young children with and at risk for disabilities. Fundamental to early identification are effective strategies to find and refer children. The acceptance of this important premise necessitates the development of valid and reliable screening tests that identify a range of children accurately and economically and can be used by a variety of providers in diverse settings. Thus, developmental-behavioral screening during the preschool years is an essential component of an early detection/child find system. Furthermore, there exists a strong case supported by data that early and timely identification and referral to quality services produces better outcomes for children and families¹⁻³.

A solution that we have studied centers on the use of parents and caregivers as primary assessors of their child's development. The tools that I have developed with a team of researchers include the Ages & Stages Questionnaires (ASQ)^{4,5} and the Ages & Stages: Social Emotional Questionnaires (ASQ:SE)^{6,7} and their associated support materials (e.g., User's Guides, activities). Extensive psychometric data have been collected on the ASQ with positive results both in the US⁸⁻¹⁰ and internationally¹¹⁻¹³. Overall, the ASQ-3 has strong validity, 86.7% for sensitivity overall and 85.6% specificity and 86% agreement with standardized assessments;

robust reliability including test-retest reliability (92%), inter-rater reliability (93%) and internal consistency (0,51-0,87). The ASQ-3 has been translated into over 65 languages and used successfully around the world including in China¹¹, Brazil¹⁴, Korea¹⁵, as well as Chile¹⁶.

Parents can be accurate observers of their child's development, if current, observable behaviors are included and simple, straightforward language is used. These tools, together with several additional measures (e.g., MacArthur Bates, Brief Infant Toddler Social Emotional Assessment), comprise a class of screening tools called *parent-completed* screening tests, that have greatly contributed to early identification efforts internationally especially during the last 10 years¹. Parent-completed screening tests have been shown in research to be valid, reliable, economical to use, and readily adapted to large scale screening systems^{1,5}.

The value and usefulness of screening measures such as the Ages & Stages Questionnaires^{4,5} lies in their ability to provide a dependable and cost effective strategy for early identification of children who may require further assessment and who may benefit from some form of intervention. These measures were designed to be used in flexible, community-based multidisciplinary systems by a wide variety of professionals, paraprofessionals, parents, and caregivers to assist in early identification and timely entry into specialized services.

Among advantages of using parents and other primary caregivers to assist with screening are many. First, parents and caregiver possess a wealth of information about their children that is not accessible to professionals during a brief examination of visit. By using parents, a more complete picture of the child's behavioral repertoire can be obtained. Second, using parents to screen their child is cost-effective. If parents can accurately assess their child's development, professional resources can be used elsewhere, such as on administering more comprehensive assessments to children (such as the Bayley Scales of Infant Development, Peabody Motor Scale) identified with potential delays during the screening process, or on screening those children for whom parent-completed questionnaires are not appropriate. Third, parents' knowledge about child development and specifically about their child's development may be enhanced as a result of completing questionnaires⁴. Parents may glean ideas about activities and games that they can use to encourage certain behaviors emerging in their child's developmental repertoire. Fourth, involving parents with their child's evaluations and education early on may enhance parental participation throughout the assessment and education processes. They may feel empowered by participating in screening and motivated and confident that they can continue to contribute during subsequent events and years.

Fifth, parent-completed questionnaires have great flexibility and can be put to use in a variety of systems, with diverse families and children. For example, parents can complete screening questionnaires in a waiting room prior to an office visit, on line and then email to their pediatrician, at immunization clinics, in child protective service offices. Screening questionnaires can be completed as part of home visits by nurses and social workers, by classroom teachers in partnership with parents during conferences, and at community events and activities such as children's museums and book fairs. The flexibility of how and when parent-completed questionnaires are used may help in screening diverse children who may not attend regular well child visits.

Finally, parent-completed questionnaires may benefit early intervention professionals, particularly medical personnel, by pinpointing parents' concerns and focusing further evaluations towards highlighted problems. Completion of screening tests such as the ASQ can serve as a scaffold on which important conversations and concerns about child development can be discussed and followed during the child's early years. Parents report that completing the ASQ makes them feel more empowered and allows them to voice their worries about behaviors or skills that are of concern to them.

Issues related to the accuracy of parent-completed developmental screening questionnaires

Although the majority of parents are able to complete developmental questionnaires on their child's behavior accurately, some parents may need more support than others. For example, parents with low literacy or who do not speak the language in which the questionnaires are written will need an office assistant or home visitor as partners in the completion process. It is important that a "cultural broker" or someone who is familiar with the family's cultural values and practices assist in questionnaire completion. New foster parents may need to wait for several weeks before they know their child well enough to accurately assess his/her skills and some young teen age parents may need assistance. Finally, some parents such as those with substance abuse issues or who are abusing alcohol or drugs may not be accurate with questionnaire completion.

Also important is that serious consideration is given to cultural adaptations and careful translation processes when parent-completed questionnaires are translated into another language or dialect^{14,15}. Guidelines and standards for translations should be carefully followed and native speakers should act as translators and back translators to confirm that the original intent of items is preserved while allowing for cultural adaptations¹³. These processes as well as careful psychometric studies will be needed to assure validity and reliability of translated versions of the ASQ and other screening questionnaires.

Predictive validity of screening instruments is always a thorny issue when assessing very young children. As Schonhaut and colleagues have found, predicting child behaviors from infant and toddler skills is difficult. Intervening environmental variables such as acute illness and traumatic events such as natural disasters, as well as supportive and therapeutic interventions, may halt or accelerate developmental trajectories. Given the limitations, Schonhaut et al.¹⁷ found that ASQ results from infant/toddler years had excellent specificity in predicting cognitive development in these same children at 6-9 years of age. That is, the ASQ was able to predict the cognitive outcomes of typically developing children. However, it was less successful in predicting children with delays or at-risk outcomes in their elementary school years. This finding suggests on-going screening and assessment of infants/toddlers with at-risk cognitive skills until well into their school years.

A final issue related to validity and reliability of the ASQ and other developmental questionnaires relates to method of completion. As mentioned, there is great flexibility in completion of the ASQ, including

web-based completion, in the waiting room, and during a home visit. Overall, few differences were found between web-based and pencil-paper completion¹⁸. Further research is needed, however, to measure which on line conditions and formats (for example, addition of video clips illustrating targeted skills, oral presentation of test items) yield most accurate completion by parents.

Most important to questionnaire completion is that parents have time to try items with their children when they are not sure whether their child has a target skill. For example, if a parent isn't sure if their child can draw a straight line from the top to bottom of a paper, they should give their child a piece of paper and pencil and see if he/she can draw this line. If parents guess whether their child has a skill, they will not be as accurate as when they see their child display the target

skill. Toy kits and a quiet space away from the noise and bustle of a waiting room may be necessary when asking parents to complete an ASQ before an office visit. Home visitors also may want to carry a toy kit so that materials for warm-up play and trying of specific skills are available.

In summary, early identification of young children in order to optimize outcomes and academic success remains a collective goal for those concerned about young children and families. Including parents in this process may increase the numbers of children who can be assessed, as well the effectiveness of these systems in improving the quality of life for these young children and families. Continued research, feedback from parents, and systems improvement are necessary for ongoing improved developmental screening through input from families, caregivers, and the community.

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