

Table 4. Principles of an ICF aligned developmental assessment^a

1. An integrated and functional model of child development—one that informs how best to help an individual child—must be central to any assessment and provide a strengths-based framework for the integration of gathered data.
2. Multiple sources of information about the child's strengths and weaknesses (past and present) must be solicited during the assessment.
3. The assessment should have a predictable sequence that plays to the child's strengths and taps his or her weaknesses. This process begins first by building alliances and a relationship with parents, obtaining a strength-based developmental history, observing child in optimal play, and functionally assessing areas of weakness.
4. To achieve optimal performance, the child must participate only in an assessment with his or her most trusted caregivers.
5. The timing of child development and the factors that affect the variation of this timing should be well known by the multidisciplinary assessment team.
6. An optimal assessment should identify the child's strengths and weaknesses that the child brings to the next developmental challenge and form the basis for potential intervention efforts if needed.
8. An optimal assessment should not upset the child or place the child in a deficit-dominated or vulnerable position.

^aAdapted from Greenspan and Meisels (1996).

information about the long-term stability and sensitivity of this early diagnostic process (Charman et al., 2005; Zwaigenbaum et al., 2006). It is not known which of these factors plays the dominant influence in the unmet needs experienced by children with ASD.

Our clinical experience has often reminded us that the primary healthcare provider is frequently the first to identify and respond to a family's developmental concern, and it is critical they understand and play a central role in overseeing the family's successful negotiation of the evaluation process. Equally important, the primary healthcare provider plays an integrative and educational role for the family after the diagnostic assessment is completed and when follow-up with the referral source is limited.

Based on the work of Meisels and the Zero to Three Work Group on Developmental Assessment, the principles of an optimal developmental assessment that best serve the family and primary care provider have been summarized in Table 4 (Greenspan & Meisels, 1996; Meisels & Atkins-Burnett, 2000; Meisels & Shonkoff, 1990; Shonkoff & Meisels, 2000).

The best practice components of a developmental assessment for young child with delays in communication, social skills, and developmental competencies should first contain multiple sources of information about the child's developmental progress and functional capacities. This requires that not only the parents but also the healthcare provider's and, possibly, the day care provider's concerns and description of the child's strengths and weaknesses be part of the diagnostic process. A primary healthcare provider should be alarmed on behalf of the family when the referral diagnostician does not solicit or accommodate the developmental history and primary care perspective of the child from the previous well child visits in the diagnostic assessment.

Second, primary healthcare providers shoulder the responsibility for increased mandates for developmental screening for ASD (Council on Children With Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, & Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2006). This responsibility and role increases

the primary care provider's part in the developmental assessment process because collaborative and sequential assessments are central to any high-quality autism early identification, assessment, and family support management program.

Third, as primary care providers and systems of care become increasing adept in providing a medical home for children with ASD and other special healthcare needs, they need to join with the parents in identifying the child's current competencies and strengths as well as the skills the child needs to develop to continue with his or her developmental progression. Providing tips for "surviving your child's developmental assessment" (*Seven Tips for Surviving Your Child's Developmental Assessment* assessed at http://www.zerotothree.org/site/PageServer?pagename=ter_screen_tips) is one way the primary care provider can remain connected to parents as they embark on the developmental diagnostic process for their child and strive to manage the child's lifelong condition after the diagnostic assessment.

Finally, the ultimate goal of developmental and diagnostic assessments appropriate for the ICF strength-based model and the medical home is that no parents will suddenly face as part of the diagnostic process the reality of uncovering a problem that they did not suspected. When primary care fulfills its ideal role, parents are heard and supported up to, during, and after any referral multidisciplinary assessment. In addition, the primary care provider plays an important role for the parents who have difficulty in relating the initial behavioral or developmental concerns with the outcome of a diagnosis of ASD. Keeping the child and the child's behavior as the central focus of the parent's concern and the focus of the diagnostic process helps parents recognize their child's personhood in the diagnosis process. The primary care provider's facilitation of parental observations after the diagnostic process and understanding the terms of the diagnosis of ASD is an invaluable support as parents adjust their internal view of their child (Baird et al., 2000).

Even when parents perceive the initial diagnosis of ASD as unwarranted and premature, primary care providers can adopt the "working diagnosis" perspective and join with the family to refine the diagnosis over time. It is in this context that the National Academy of Science recommendations are most pertinent. This committee recommended that all children with any ASD, regardless of label or level of severity, be eligible for special education services that comprehensively address social, cognitive, communicative, and learning skills. The therapeutic nature of this supported diagnostic process for parents should not be underestimated (Parker & Zuckerman, 1990) because it allows the introduction of structured services and for the priority of early intervention services to address communication and social skill challenges without driving parents to risky and unproven alternative treatment (Hyman & Levy, 2005).

CAUTION ABOUT NONTRADITIONAL THERAPIES

Parents of children with autism are bargained with promises of miracle cures, drug therapies, and nontraditional therapies to cure their child (Nickel, 1996; Tanguay, 2000). Many times, caregivers are willing to try anything to help their child. Nonethical promoters of nonscientific therapies use common ploys to seduce desperate parents into trying their treatments. Some common approaches include exploiting the natural fear of disease, preying on the uncertainty about traditional medical care, promising painless and natural treatments, and claiming miraculous scientific breakthrough and developmental cures.

One promise of a scientific breakthrough was the use of secretin to cure autism. A case study was reported in the literature that 1 dose of intravenous secretin costing more than \$1000 successfully eliminated symptoms in a child with autism (Horvath et al., 1998). Several scientific studies have been conducted since the original case study. One undertaken by Coniglio et al. (2001) involved children aged 3 to 10 years diagnosed

using *DSM-IV* criteria for autism. The goal was to determine whether a single dose of intravenously administered secretin could improve communication and socialization skills in children with autism. Subjects were randomly divided into treatment and placebo groups. The Childhood Autism Rating Scale and Preschool Language Scale-3 (PLS-3) were administered at baseline, 3 weeks, and 6 weeks after treatment. In addition, caretakers completed the Parent Perception Survey and the Gilliam Autistic Rating Scale and were asked several study-specific questions including "Do you believe your child received secretin? Have you noticed any changes in your child's symptoms?" Results showed that children who did not receive secretin made more communicative, behavioral, and developmental progress using these standardized outcome measures.

In another study, Sandler et al. (1999) randomly assigned 60 children aged 3 to 14 years to either a single treatment secretin group or a placebo control group. *DSM-IV* criteria were used to diagnose autism (Sandler et al., 1999). If autism criteria were not met, PDD was diagnosed. Subjects were administered the Childhood Autism Rating Scale and the Autism Behavior Checklist at baseline and at a 4-week follow-up. Again, the children assigned to the placebo treatment improved on these behavioral measures more than the secretin group. To date, there have been several other secretin trials involving more than 700 children with autism (Dunn-Geier et al., 2000; Lightdale et al., 2001; Owley & Steele, 1999; Roberts et al., 2001). In no trial was secretin a miracle cure. However, in all trials, improvement occurred over time in all children with ASDs, thus demonstrating that all children with ASDs learn. Despite the lack of evidence for secretin's therapeutic use and even after being presented the study's negative results, parents continued to ask the study doctors for ongoing secretin treatment.

Primary care professionals need to embrace the passion parents demonstrate in their search for supports to their afflicted child. Rather than a punitive remark or avoiding a

discussion about an alternative treatment, primary healthcare professionals can play a positive role by providing families valuable information to evaluate any alternative treatment. We have found some useful Web sites and handouts to offer to families when contemplating the complex issue of and risks associated with alternative treatments.

1. <http://www.asatonline.org/> (Association for Science in Autism Treatment, n.d.)
2. <http://www.autismresearchnetwork.org/AN/default.aspx> (National Institutes of Health Autism Research Network, 2007)
3. Parent handouts have been developed by The Autism Program. These include:
 - a. *Current Interventions in Autism—A Brief Analysis* at <http://www.theautismprogram.org/autismtreatments.asp> (The Autism Program, n.d.-a)
 - b. *Tips for Working With Children With Autism Spectrum Disorders* at <http://www.theautismprogram.org/tips.asp> (The Autism Program, n.d.-d)
 - c. *Top 10 Things to Remember When Working With Children With Autism Spectrum Disorders* at <http://www.theautismprogram.org/top10.asp> (The Autism Program, n.d.-e)
 - d. *Tips for Daily Life—Visiting the Dentist* at <http://www.theautismprogram.org/dentist.asp> (The Autism Program, n.d.-b)
 - e. *Tips for Daily Life—Toilet Training* at <http://www.theautismprogram.org/toilet.asp> (The Autism Program, n.d.-c)

ADMINISTRATIVE AND FUNDING REALITIES

The primary healthcare provider, as the central figure in the medical home and because of his or her unique training, interest, and commitment, is perfectly positioned to

understand and support the special family circumstances that each family brings with a child who has developmental differences. Unfortunately, Medicaid and private party payers do not value this expertise or commitment with their reimbursement schemes. Primary healthcare providers, pediatricians, and nurse practitioners and family practice specifically are best positioned to involve family members in planning the evaluation of a child's development. They also foster respectful communication between parents, referrals to subspecialty physicians, and allied healthcare and educational professionals. Helping families integrate the different pieces of an assessment for ASDs (genetics, hearing, neurologic, and educational) is one valuable mandate of the medical home.

The American Academy of Pediatrics, and its national medical home initiative (American Academy of Pediatrics: The National Center of Medical Home Initiatives for Children With Special Needs, n.d.), has advocated a model of primary care delivery that keeps the primary healthcare professional central to the process of identification, family understanding, professional referrals, and diagnostic assessment for children with developmental differences. At the same time, this initiatives at the American Academy of Pediatrics endeavors to find political and legal avenues to address the negative financial setbacks that most primary care providers risk when they choose to maintain this central role for their patients and families. The American Academy of Pediatrics has a toolkit as well as updated brochures to enhance the primary care provider's skills (see www.aap.org). In addition, the National Medical Home Autism Initiative at the University of Wisconsin and the Maternal and Child Health Bureau (MCHB) is evidence, in part, of the way national organizations and federal agencies are promoting and providing technical assistance to pediatric healthcare providers who desire to work with other partners in the community to serve children with autism (Fig. 1).

Adopting the ICF model with a strengths- and supports-based framework for describing

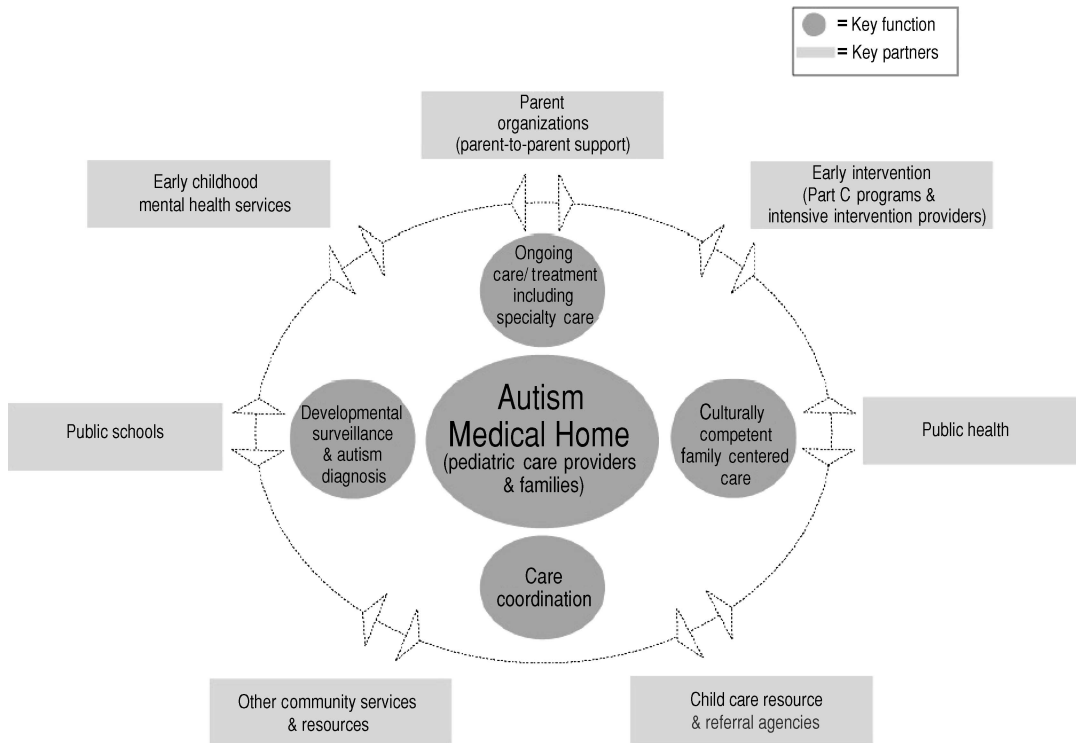
preschool children with ASD is a perfect match for primary healthcare professionals. In collaboration with the larger community of providers, the key goal is to provide comprehensive coordinated and compassionate care for children and families faced with the challenges of ASDs.

Building on the ICF framework of enablement, primary care providers will have the structure to communicate with sensitivity and mutual respect information about the developmental diagnosis, explain current medical understanding of autism to families, and provide ongoing family support. Only then will families have the confidence to increase their requests to primary care providers for guidance about the range of traditional and non-traditional autistic-specific treatments available. In addition, this framework allows the physician to prioritize interventions that promote child functioning and enhance family well-being.

The blending of the ICF framework within the primary care structure of the medical home can serve to reveal the added value of decreasing fears and stresses through efficient parent-professional partnerships. This added value reflects the teamwork of professional and nonprofessional office staff toward family-centered care management and enhanced communication. These models also recognize the wide range of differences in challenges families of children with autism face and the increased time and effort required for the ongoing monitoring of the child's progress and family adaptation.

CONCLUSION

The major need for families is to feel that their primary healthcare professional listens to their concerns and understands the multi-threaded information required for a diagnostic assessment. Parents also need to be continually supported in accessing comprehensive systems of early intervention and preschool education on behalf of their child. It is most important to view ASD as a developmental disorder whereby interventions to enhance



*Adapted from: Halfon, N., Regalado, M., McLearn, K., Kuo, A., Wright, K. (2003). Building a Bridge from Birth to School: Improving Developmental and Behavioral Health Services for Young Children. The Commonwealth Fund

Figure 1. National Medical Home Autism Initiative: Key functions and partners (Waisman Center, 2006).

communication, promote adaptive skills, and build on the child’s strengths occur. It is a dangerous practice to assume that there is a magic bullet that will dramatically cause the child to be suddenly typical. Unfortunately, the complexity of human language and the developmental neurobiology of autism do not allow for cures with injections of miracle drugs or nutrition supplements (Coury & Nash, 2003; Ozonoff et al., 2003; Volkmar & Pauls, 2003). Instead, ASD allows us to understand how all children can benefit from comprehensive and quality supports that enhance communication, adaptive skills, and functional independence at home and in the community. If the parent or the child experience challenges that are too demanding or out of control, they will not understand the current behavior and educational technologies that can make a

difference (Rogers, 1998; Siegel, 1996, 2003; Smith, Eikeseth, Klevstrand, & Lovaas, 1997; Wetherby & Prizant, 2000; Wing, 2001). The role of the physician is not to be an expert on all educational practices but to know the hard task of parenting children who are motorically able but communicatively challenged and behaviorally unpredictable. Attention to family stresses and daily management supports can make a difference at home, school, and in the community. In this way families can undertake the multidimensional management strategies that promote functional, communicative, social, and adaptive skills. They then can celebrate with professionals the strengths of their child’s unique way of experiencing the world and set goals that promote steps to independence, and when challenges persist, know they will not be abandoned.

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