There is increasing public and healthcare provider awareness about the early signs and developmental challenges of children with autistic spectrum disorders (ASDs). Healthcare professionals are guided by several major policy statements regarding the diagnosis and management of autism. There remain substantial gaps between these guidelines and families’ needs during the diagnostic process. This article provides a developmental and behavioral perspective for the professionals who desire to find guideposts in tasks of supporting families throughout the diagnostic process of autism. We illustrate the diversity of the ASDs using the International Classification of Functioning, Disability and Health Model and describe developmental and behavioral perspectives about the autism diagnostic process. Our overall goal is to enhance parent and professional collaboration in promoting the establishment of medical homes, accessing the highest quality developmental assessments, and implementing comprehensive supports for parents of children with ASDs.

Key words: autistic spectrum disorders, counseling, family supports, functioning

There is increasing awareness about the early signs and developmental challenges of children with autistic spectrum disorders (ASDs) (Chakrabarti & Fombonne, 2001; Fombonne & Chakrabarti, 2001). Major policy statements by the American Academy of Pediatrics and the National Academy of Sciences have provided a template for widely disseminated state-of-the-art strategies for diagnosis and management (Committee on Children With Disabilities, 2001a; National Research Council Committee on Educational Interventions for Children With Autism, 2001). However, there remain substantial gaps between these guidelines and families’ goals of feeling supported and accessing quality and comprehensive early childhood services (Anders & Gardner, 2003; Renty & Roeyers, 2006). The purpose of this article is to provide developmental and behavioral pediatric perspectives for healthcare professionals on ASDs with respect to communicating the developmental diagnosis, explaining medical advances to families and ongoing family supports. We build on the International Classification of Functioning, Disability and Health (ICF) framework of enablement, functional assessment, and child and family well-being (World Health Organization, 2001). In approaching the developmental diagnosis of
Communication About Autism

autism, we strive to begin a dialogue about the process of developmental diagnosis in the setting of a child's strengths and challenges while addressing the complex hopes, fears, stressors, and typical lack of family supports. In addition, we discuss some of the strengths of a developmental diagnostic approach that emphasizes a spectrum of outcomes and possibilities as well as some of the pitfalls of a categorical diagnosis, particularly when families in desperation try complementary interventions that may have adverse effects. Our goal is not to review the complexity of accepted and/or alternative treatments, as this has been recently done by the National Academy of Sciences (National Research Council Committee on Educational Interventions for Children With Autism, 2001) and Hyman and Levy (2005), but to highlight how the primary care provider positively impacts the diagnostic process and how ongoing family supports can be provided as families negotiate the complexity of management in the birth-to-3 and early preschool years. In this way, we begin to develop both problem-solving strategies and approaches essential to optimizing health, development, and functional competencies.

ADVANCES IN PEDIATRICS AND DEVELOPMENTAL MEDICINE

Major advances in pediatrics, child development, and developmental neurosciences have enhanced our understanding of children with autism (Bristol, McIlvane, & Alexander, 1998). These advances have included the prevention of neurodevelopmental sequelae in children with phenylketonuria (PKU). PKU is an inborn error of metabolism whereby children fed milk or natural proteins develop autism and developmental disabilities. Through specialized nutritional interventions, requiring both metabolic formulas and biochemical monitoring, children are severely restricted in their natural protein intake. Children with PKU cannot drink cow or soy milk or eat cookies, crackers, hamburgers, ice cream, pizza, cheese, hot dogs, cold cuts, or cake. The special protein formula provides the equivalent of a liver transplant and dialysis machine. In all 50 states, screening for PKU takes place in newborns whereby, after confirmatory biochemical analysis, a specialized biochemical formula is started.

Major progress in immunizations has led to the near elimination of congenital rubella, measles encephalitis, and Haemophilus influenzae meningitis and resulting postinfectious developmental disabilities including ASDs (Fombonne & Chakrabarti, 2001; Goldston, Gruenberg, & Lewis, 1986; Halsey, 2001; Halsey, Hyman, & Conference Writing Panel, 2001). Prior to these vaccines, substantial numbers of children developed intellectual disability as well as neurological disorders.

Neurodiagnostic advances have included the early detection of visual and hearing disorders, communicative and social developmental screening tools for evaluating parental initial concerns, and specific assessment scales for communication, play, social behaviors, and adaptive skills (Ozonoff, Rogers, & Hendren, 2003). Molecular genetic advances have included detection of fragile X syndrome, expanded banding karyotypes and FISH analysis for regional hot spots especially on chromosomes 15 and 7, and the genetic markers for the Rett syndrome and the tuberous sclerosis complex. The former is an X-linked dominant disorder whereby the MECP mutation impacts on a girl's ability to learn purposeful hand skills and communicative skills. The latter is an autosomal dominant neurogenetic syndrome with complex seizures, difficulty learning language, and social skills, and with more than half of the children meeting criteria for ASDs. Despite these molecular advances, most children with other neurodevelopmental disorders including autism cannot be given an exact etiologic explanation.

Research networks have been established by National Institutes of Child Health and Human Development and the Centers for Disease Control and Prevention to understand the epidemiology, genetic and environmental
Table 1. Stressful myths and autism

<table>
<thead>
<tr>
<th>Myth</th>
<th>Reality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism is caused by immunization of</td>
<td>Children not immunized with rubella, measles, mumps, hemophilic influenza,</td>
</tr>
<tr>
<td>vulnerable children.</td>
<td>pneumococcal, and pertussis vaccines have high rates of developmental</td>
</tr>
<tr>
<td></td>
<td>disabilities including deafness, blindness, cerebral palsy, epilepsy,</td>
</tr>
<tr>
<td></td>
<td>and autistic spectrum disorders.</td>
</tr>
<tr>
<td>Autism is a mental illness.</td>
<td>Autism is a developmental disability impacting on understanding and use of</td>
</tr>
<tr>
<td></td>
<td>language, complex learning, and social communication</td>
</tr>
<tr>
<td>Autism is caused by problems during</td>
<td>Prematurity and neonatal complications have not been scientifically</td>
</tr>
<tr>
<td>labor and delivery.</td>
<td>linked to autism.</td>
</tr>
<tr>
<td></td>
<td>Major known etiologies associated with autism include phenylketonuria,</td>
</tr>
<tr>
<td></td>
<td>tuberous sclerosis, congenital rubella, fragile X syndrome, chromosomal</td>
</tr>
<tr>
<td></td>
<td>disorders, and severe retinopathy of prematurity.</td>
</tr>
<tr>
<td>Children with autism cannot learn.</td>
<td>Children with autism have strengths in motor skills, fine motor</td>
</tr>
<tr>
<td></td>
<td>manipulative skills, nonverbal intelligence, and basic adaptive skills.</td>
</tr>
<tr>
<td></td>
<td>There is a range of communicative, cognitive, and complex adaptive</td>
</tr>
<tr>
<td></td>
<td>abilities. All children with autism learn.</td>
</tr>
<tr>
<td>Autism is caused by poor parenting.</td>
<td>Autism is a neurobiological disorder whereby brain systems integrating</td>
</tr>
<tr>
<td></td>
<td>language, complex learning, and social communication are underdeveloped.</td>
</tr>
<tr>
<td>Experimental alternative medical treatments</td>
<td>Autism is not caused by food, allergies, or malabsorption. The best</td>
</tr>
<tr>
<td>involving specialized diets, megavitamins,</td>
<td>treatments for autism are special education programs that build on a</td>
</tr>
<tr>
<td>and natural therapies can cure autism.</td>
<td>child’s strengths, provide family supports, and comprehensively address</td>
</tr>
<tr>
<td></td>
<td>communicative, learning, and behavior challenges. Children with autism</td>
</tr>
<tr>
<td></td>
<td>with gastrointestinal concerns should receive competent pediatric care.</td>
</tr>
<tr>
<td>There is no role for pediatric medicine</td>
<td>All children require a medical home that monitors growth and development,</td>
</tr>
<tr>
<td>for children with autism.</td>
<td>identifies sensory, neurological, and health conditions that can interfere</td>
</tr>
<tr>
<td></td>
<td>with progress, helps set comprehensive goals that optimize adaptive</td>
</tr>
<tr>
<td></td>
<td>functioning, and advocates for proactive community programs that provide</td>
</tr>
<tr>
<td></td>
<td>quality family supports.</td>
</tr>
</tbody>
</table>

etiolgies, and developmental processes involved in children with autism (Tager-Flusberg, Joseph, & Folstein, 2001). In addition, clinical research networks of multidisciplinary professionals and specialized university-affiliated centers of excellence have developed to explore advances in psychopharmacology, communicative and developmental interventions, and alternative medicine treatments (Arnold et al., 2000; Levy & Hyman, 2002; Rogers, 1998). This systemic collaboration offers the promise for scientific advances, but has not quieted several common misconceptions that exist regarding children with autism. Table 1 provides a list of some of the most frequent myths and the evidence-based reality that defines sources of family uncertainty.

There is also another major myth that there is an explosive epidemic of autism due to childhood immunizations (Nelson & Bauman, 2003; Murch et al., 2004; Offit & Jew, 2003). This leads to both suspicion of medicine and failure to understand that the preponderance of evidence supports the benefit of immunizations for the prevention of illness in children with autism and preventing both autism and severe disabilities in young children. For example, without rubella vaccine, the United States would experience
epidemics of congenital rubella. Prior to this vaccine, as many as 11,000 fetal deaths and 2000 neonatal deaths occurred because of congenital rubella. In addition, more than 20,000 newborns were affected with the congenital rubella syndrome (Goldston et al., 1986). The sequelae of this syndrome include blindness in 10%, deafness in 50%, autism in 25%, as well as mental retardation, epilepsy, and cerebral palsy (Chess, 1978). Rubella vaccination prevents these epidemics. Prior to measles vaccine, significant numbers of children died from measles pneumonia and measles encephalitis. In 1923, more than 10,000 deaths were reported in 1 year because of measles. Between 1950 and 1962, almost 500 children per year died of measles (Goldston et al., 1986). In 1982, after a decade of immunization control efforts, there were 2 deaths. Approximately 1 in 1000 children with measles develops measles encephalitis and more than 50% have devastating long-term sequelae including autism (Benda, 1952). In an era where the promise of neuroscience has not yet brought new restorative treatments, immunizations are the best way to prevent both autism and other developmental disabilities.

A MODEL FOR ASSESSING ENABLEMENT AMONG CHILDREN WITH ASDs

The World Health Organization (2001) proposed a strengths- and supports-based model framework for describing individuals with disability. The ICF model describes a child’s health and well-being in terms of 4 components: (1) body structures, (2) body functions, (3) activities, and (4) participation. Body structures are anatomical parts of the body, such as organs and limbs, as well as structures of the nervous, sensory, and musculoskeletal systems. Body functions are the physiological functions of body systems, such as digestion and respiration, and also include psychological functions such as attending, remembering, and thinking. Activities are tasks done by children, including learning, communicating, walking, carrying, feeding, dressing, toileting, and bathing. In older children, these tasks include reading, preparing meals, shopping, and washing clothes. Participation means involvement in community life, such as relationships with peers, going to school, and recreational activities.

The ICF model accounts for contextual factors in a child’s life, including environmental and personal factors. Environmental factors include policy, social and physical facilitators and barriers, positive and negative attitudes of others, legal protections, and discriminatory practices. Personal factors include age, gender, interests, and sense of self-efficacy. A variety of preschool scenarios using the ICF model are illustrated in Table 2 for preschool children with ASD. These scenarios include a 1-year-old girl with infantile spasms secondary to tuberous sclerosis complex, 2-year-old boy who is nonverbal with autism, a 3-year-old girl with blindness and developmental regression, and a 4-year-old boy with fragile X syndrome, challenging behaviors, and autism. The ICF model explicitly measures functional strengths, social role activity, community participation, and environmental facilitators.

THE SPECTRUM OF AUTISM AND RELATED PERVERSIVE DEVELOPMENTAL DISORDERS

Over the past 50 years, autism has been diagnosed using different labels and criteria. We currently support the term “ASD” to encompass the formal categorical diagnoses of autistic disorder, pervasive developmental disorder—not otherwise specified (PDD-NOS), and Asperger’s syndrome. Currently, the 2 standardized criteria for diagnosing these ASDs, DSM-IV and ICD-10, are similar (Volkmar & Pauls, 2003). Core diagnostic features include impairments in communication and social interaction coupled with restrictive and stereotyped patterns of behavior, interests, and activities. Onset is in the preschool years, with delays in language understanding and use, delays in joint attention and nonverbal skills, symbolic play...
### Table 2. Dimensions of functioning and participation

<table>
<thead>
<tr>
<th>Dimension: Definition</th>
<th>1-y-old girl with seizures and autism</th>
<th>2-y-old boy with autism</th>
<th>3-y-old girl with autism and visual disability</th>
<th>4-y-old boy with autism</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pathophysiology:</strong> Molecular or biochemical mechanisms interfering with cellular function</td>
<td>Infantile spasms at 6 mo, tuberous sclerosis complex</td>
<td>“Presumed” miswiring of neurological systems involved in language, development, and complex behavioral regulation</td>
<td>750 g, 26-wk completed gestation, and severe retinopathy of prematurity</td>
<td>Initially with hypotonia and communication delays</td>
</tr>
<tr>
<td><strong>Impairment:</strong> Loss of organ structure or function</td>
<td>Recurrent seizures</td>
<td>Cognitive, communicative, and neurobehavioral dysfunction. No seizures, no evidence of fragile X syndrome</td>
<td>Visual, cognitive, communicative, and neurobehavioral dysfunctions</td>
<td>Fragile X syndrome diagnosed at age 4</td>
</tr>
<tr>
<td><strong>Functional challenges:</strong> Difficulty performing an activity</td>
<td>Lack of developmental progress, unable to walk or talk</td>
<td>Difficulty with receptive and expressive language transitions, repetitive play, dietary rigidity</td>
<td>Difficulty with running, restricted visual fields, nonverbal, self-injurious behavior</td>
<td>Difficulty with activity, eye contact</td>
</tr>
<tr>
<td><strong>Functional strengths:</strong> Performing activities such as running, dressing, communicating, playing</td>
<td>Transfers toys, rolls, laughs</td>
<td>Loves playground and music activities</td>
<td>Climbing</td>
<td>Cartoon watching, loves Thomas the Tank</td>
</tr>
<tr>
<td><strong>Disability:</strong> Difficulty performing activities typical for peers</td>
<td>Unsteady in sitting, unable to crawl</td>
<td>Unable to go to relatives</td>
<td>Special education supports, low-vision aids, bilateral ankle-foot orthoses, intense behavior management program</td>
<td>Quality preschool services and behavioral management</td>
</tr>
<tr>
<td><strong>Participation:</strong> Age appropriate roles, chores, hobbies, and sports</td>
<td>Mother has to take offf from work frequently because of child’s seizures</td>
<td>Loves swimming with father at YMCA</td>
<td>Horseback riding</td>
<td>YMCA playgroup</td>
</tr>
<tr>
<td><strong>Societal limitations:</strong> Attitudinal, legal, policy, and architectural barriers</td>
<td>Health maintenance organization will not allow magnetic resonance imaging or referral to a pediatric epilepsy center</td>
<td>Fragmentation between early interventionists and explicit deliverables to enhance communication. Lack of full-day extended 3-y-old quality programs</td>
<td>Lack of respite services and weekend supports</td>
<td>Because mother works outside the home, she cannot attend genetic support groups</td>
</tr>
<tr>
<td><strong>Contextual factors:</strong> Environmental barriers</td>
<td>No out-of-home day care available for child with frequent seizures</td>
<td>Failure to have communications strategies for nonverbal children</td>
<td>Church members request that child be kept at home during services</td>
<td>Denied life insurance policy</td>
</tr>
</tbody>
</table>
difficulties (ie, pretend play), and difficulty with social interactions with parents and peers. Although current reviews mandate a medical evaluation for autism (Committee on Children With Disabilities, 2001b; Filipek et al., 2000), many children do not have an associated or causative medical condition (Fombonne, 1999). The medical differential diagnosis of autism includes global developmental delay, developmental language disorders (DLDs), and severe sensori-neural hearing impairments. There are also many rare neurogenetic disorders that impact on higher cortical functions including abstraction, problem solving, understanding viewpoints of others, information processing, and regulation of attention (eg, too short, too long, too inflexible) (Rapin, 1997). In addition, among a subset of children with language regression, a specific epilepsy pattern is present and called the Landau-Kleffner syndrome (Rapin & Katzman, 1998).

Some uncommon medical etiologies associated with autism include untreated PKU, tuberous sclerosis complex, retinopathy of prematurity, congenital cytomegalovirus infection, and fragile X, Lesch Nyhan, and Moebius syndromes. In addition, several genetic disorders such as Down, Prader-Willi, Angelman, and Williams syndromes and Duchenne muscular dystrophy have higher risks for ASDs. The lesson is not that all children with Down syndrome or Duchenne muscular dystrophy manifest behaviors consistent with ASD, but that among individuals with developmental and genetic vulnerability (ie, Down syndrome or Duchenne muscular dystrophy), higher rates of classical autism are found than the population prevalence of 1 to 2 per 1000 (Yeargin-Allsopp et al., 2003) and the ASD prevalence of 4 to 6 per 1000 (Szatmari, 2003; Yeargin-Allsopp et al., 2003).

**Epidemiology of Preschool Childhood Disabilities**

There are improved tools for early recognition and increased awareness of the preschool presentation of children with ASDs. With expanded definitions of the autistic spectrum, there are more individuals who do not have the classical comorbidities of mental retardation/intellectual disability. By including Asperger’s disorder in the autism spectrum, there is increased awareness of the social skill and motor coordination impairments that impact on school-aged children with learning disorders. Lastly, including preschool children with challenging behaviors and communicative and attention disorders as children with autistic spectrum disorder (PDD-NOS) substantially increases the number of children eligible for accommodations (504 Plans) and special education services (individualized education programs). Thus, to understand the changing epidemiology of preschool communicative, developmental, and neurobehavioral disorders, one must understand the background prevalence of communicative and cognitive disorders in early childhood.

Communicative impairments associated with developmental disabilities can be classified in terms of severity (high, low) and prevalence (high, low) (Accardo, 2007). Impairments with high severity and low prevalence include classical (Kanner’s) autism (1–2 per 1000) and significant intellectual disabilities (IQ < 50–55) with a prevalence of 5 per 1000. Those with low severity and high prevalence include mild intellectual disabilities (30 per 1000), language disorders (100 per 1000), and learning disabilities (70–100 per 1000). It is because of these latter categories that as many as 20% of school-aged children may qualify for special education accommodations. Mild intellectual disabilities are defined as an IQ of 55 to 70, with adaptive skills more than 2 SDs below the mean, and are often detected in kindergarten and early elementary grades. These children are independent in communication skills and all activities of daily living. Reading and writing skills usually advance to a fifth-grade level before leveling off. Children with moderate intellectual disabilities ultimately have IQs of 40 to 55 and present with preschool language delay that later is diagnosed as a more complicated disability. These children are
Table 3. Language skills among children with communicative disorders

<table>
<thead>
<tr>
<th></th>
<th>Developmental language disorder</th>
<th>High-functioning autistic disorder</th>
<th>Low-functioning autistic disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single words(^d)</td>
<td>18 (8.5)</td>
<td>17 (10.5)</td>
<td>20.4 (13.1)</td>
</tr>
<tr>
<td>Phrases(^e)</td>
<td>27.2 (9.4)</td>
<td>29 (11.7)</td>
<td>36 (16.3)</td>
</tr>
<tr>
<td>Intelligibility</td>
<td>30 (10.8)</td>
<td>29 (12.3)</td>
<td>30.6 (16.3)</td>
</tr>
<tr>
<td>1-Step commands(^e)</td>
<td>23.4 (9.4)</td>
<td>33 (12.5)</td>
<td>37.4 (14.7)</td>
</tr>
</tbody>
</table>

\(^a\)Values represent age in months with (SD).
\(^b\)Nonverbal IQ > 80.
\(^c\)Nonverbal IQ < 80.
\(^d\)Significant difference between groups \(P < .05\).
\(^e\)Significant difference between groups \(P < .001\).

Independent in all activities of daily living and eventually able to communicate basic needs to a caregiver. The major sequelae of this group of disorders are difficulty in complex academics, especially in reading paragraphs and writing book reports. A key question is: What are the differences in diagnosis and developmental outcomes among children with cognitive, language, and ASDs?

Rapin led a multisite multidisciplinary project whose purpose was to investigate the neurobiologic basis of ASD and related communication disorders, provide a basis for rational interventions, and improve the training of professionals who educate and care for these children (Rapin & Autism and Language Disorders Nosology Project, 1996). The cohort involved 487 children aged 3 to 7 years. Developmental language disorder (DLD) was present in 41%, ASDs were present in 36%, and intellectual disability without autism was present in 23%. The children were further divided into high-functioning autistic disorders (HADs; \(n = 51\)) and low-functioning autistic disorders (LADs; \(n = 125\)). The high-functioning group had nonverbal IQs greater than 80, whereas the low-functioning group had nonverbal IQs lower than 80. All children received a comprehensive assessment of neuropsychologic processes including language, nonverbal intelligence, adaptive behaviors, academic abilities, and neuromotor skills. Detailed histories of prenatal, perinatal, and postnatal events; childhood illnesses; family illnesses; developmental milestones; and growth, physical, and expanded neurologic examinations were noted.

Several findings were reported. The presence of developmental disabilities in parents and siblings was generally not a significant predictor for DLDs or ASDs. However, in families where one child had an ASD, there was an increased risk for other children to have either DLDs or intellectual disability. In a smaller number of families with one child with ASD, there was a second child with this disorder. Neonatal problems were generally not predictive of ASD or significantly different between the DLD and the ASD.

With respect to early developmental milestones, no child with a DLD or an ASD was a late walker, defined as not walking independently at age 18 months. Late walking was present in 25% of children with global developmental delay. Difficulty with pretend play at 36 months occurred in 25% of children with DLDs, 49% of children with global developmental delay, and 71% of children with ASDs. By age 4, only 5% of children with DLDs could not engage in pretend play whereas 1 in 6 (>15%) of high-functioning children with autistic disorders and 1 in 6 children with global developmental delays continued to struggle with these play skills.

Table 3 illustrates that delays in communicating in phrases and following 1-step
commands significantly differentiated children with ASD from children with DLD. These findings also highlight why concerns about communicating in words and phrases and following requests without gestures are key first signs for the early recognition of autism. Overall, children with DLDs performed better in both receptive and expressive language skills than children with ASD and low nonverbal intelligence. These findings also suggest that enhancing communication skills is one of the key requirements for preschool interventions.

Rapin concluded that most prenatal, perinatal, and postnatal events did not differentiate between DLDs, high-functioning ASD, autism with intellectual disability, and mental retardation. Developmentally, 31% of the intellectual disability group and 56% of the autism group with nonverbal IQ less than 80 had significantly low IQ scores (IQ < 50). This study replicated findings from the multicenter Collaborative Perinatal Project that perinatal events do not play a strong causative role in autism, intellectual disability, and DLDs (Nelson, 1991).

A DEVELOPMENTAL AND BEHAVIORAL PERSPECTIVE

The role of healthcare professionals

Autism and ASDs have received a lion’s share of public and media attention. There is also increased recognition that has contributed to higher clinical and administrative prevalence rates over the past 2 decades. Although families and research scientists may differ on the root-causal pathways for this increase in prevalence (Baird et al., 2000; Fombonne, 2003) of children either diagnosed or currently receiving specialized treatment for ASDs, it is timely that the primary healthcare professional assumes a leadership role in guiding and supporting families during the early diagnostic process.

Primary healthcare professionals, however, face several obstacles. First, they are increasingly called upon to screen for autism and other developmental disorders as part of the “well child” visits without adequate infrastructure for time and reimbursement considerations (Dosreis, Weiner, Johnson, & Newschaffer, 2006). Second, although national initiatives at the Center for Disease Control and Prevention (Autism Information Center) and policy statements (Committee on Children With Disabilities, 2001b; Filipek et al., 2000) have recommended specific autism screening tools and diagnostic standards (ICD 10, DSM IV), so far very few publications have addressed the effectiveness of the implementation of these strategies. Finally, because there is no laboratory or blood test for autism, the diagnosis remains open for subjective interpretation of even formal diagnostic standards. However, consensus exists that expert clinical judgment is more reliable than algorithm diagnosis in the youngest of children (Charman & Baird, 2002). These factors separately or in combination all serve to add obstacles and confuse the role pediatricians and primary care providers play in the diagnosis and management of ASDs (Committee on Children With Disabilities, 2001b).

PRINCIPLES OF THE DIAGNOSTIC ASSESSMENT

Primary care providers can find guideposts in this changing landscape by beginning with the ICF strength-based framework and reviewing the principles of the early childhood diagnostic assessment. One goal of this review is to provide a bridge for the primary care provider as the information about the prevalence, diagnosis, and optimal management of ASDs evolves.

Four converging factors regarding the diagnosis of ASD highlights the importance of this review. Improved ability to diagnose ASDs at earlier ages (Lord, 1995; Moore & Goodson, 2003) is linked with pressure to meet early intervention or school-based special education eligibility requirements and fueled by emerging information about the effectiveness of early identification and treatment (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993; Sheinkopf & Siegel, 1998). However, at the same time, there is emerging and conflicting
Table 4. Principles of an ICF aligned developmental assessment

<table>
<thead>
<tr>
<th>Principle</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
</tr>
<tr>
<td>2. Multiple sources of information about the child’s strengths and weaknesses (past and present) must be solicited during the assessment.</td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td>4. To achieve optimal performance, the child must participate only in an assessment with his or her most trusted caregivers.</td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td>8. An optimal assessment should not upset the child or place the child in a deficit-dominated or vulnerable position.</td>
</tr>
</tbody>
</table>

*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 barraged 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.

3. Parent handouts have been developed by The Autism Program. These include:

**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 ASDis (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 ASDis.

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
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.

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


assessments of infants and young children (pp. 11-26). Washington, DC: Zero to Three.
Communicating About Autism


