Caring for Children With Autism Spectrum Disorder, Part II: Screening, Diagnosis, and Management

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Recent emphasis on the importance of early identification and intervention for children with autism spectrum disorder (ASD) highlights the need for nurses in the community and primary care settings to learn to screen for ASD in children. In addition, given that ASD now affects 1 in 150 children, it is probable that nurses in a variety of settings, at all practice levels, will encounter children with ASD. Nurses need to be able to support families, educate parents, manage basic issues relevant to ASD, and advocate for these children and their families.

Key words: Autism; ASD; Pervasive developmental disorders

AUTISM SPECTRUM DISORDER (ASD) refers to a group of pervasive developmental disorders that are now reported to affect 1 in 150 children. This group of disorders includes autism, Asperger's disorder (AD), and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS; Kutscher, 2006; National Institute of Mental Health [NIMH], 2007). ASD is characterized by impairments in three domains: social interaction, communication, and restricted or repetitive behaviors and/or interests. ASDs are collectively described as a spectrum of disorders because the symptoms can occur in a variety of combinations and present with varying degrees of severity (Autism Society of America [ASA], 2006). ASD is frequently profiled in the national media, and it is common for families to either have a child or know someone with a child on the spectrum. Pediatric nurses at all practice levels, regardless of the setting in which they work, are frequently asked about issues related to the health of children. Nurses are in a position to partner with children and families so that they can help advocate for, educate, and adequately manage the care of children with ASD.

Early identification of ASD is important because educational planning and the initiation of intervention as soon as possible result in better outcomes for these children (Filipek et al., 1999; NIMH, 2007; National Research Council, 2001). Despite knowing that early intervention can reduce symptoms and improve a child's ability to learn new skills, the NIMH estimates that "only 50% of children are diagnosed before kindergarten" (NIMH, 2007, p. 4). Pediatric nurses and pediatric nurse practitioners (PNPs) can play an instrumental role in assisting with developmental assessment, autism screening, and possibly the formal diagnosis of children with ASD. They can address parental concerns and observe children diligently (even in an everyday nonclinical setting) once they have a basic knowledge of the developmental deficits associated with ASD. In the clinical setting, they can use specific screening instruments for ASD to address concerns. Knowing when to consider a more formal developmental assessment, specifically for ASD, is critical.

ASD SCREENING AND DIAGNOSIS

The emphasis on early identification and mobilization of resources has led to improvements in how children are behaviorally assessed in primary care

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settings. The development of valid screening tools, coupled with improvements in comprehensive assessment after referral to a specialist, has led to the development of standardized guidelines for ASD screening (Filipek et al., 2000). Screening tools are becoming more readily available. Although some of these instruments are in the beginning stages of development, or continue to have limitations in their use, the increased circulation of tools has supplemented an increased awareness of ASD in children and helps clinicians identify and monitor changes over time in the child with suspected ASD.

Parents often express frustration because their initial "instincts" are not always heard, or they have been told "not to worry" by providers (Crais, Watson, Baranek, & Reznick, 2006). Harrington, Patrick, Edwards, and Brand (2006) found that 75% of parents of children with ASD expressed little or no confidence in their primary care physician's ability to recognize autism and that a perceived delay in diagnosis might contribute to their reported confidence level. Nurses in the pediatric primary care setting should be sensitive to parental concerns, ask specific questions, and advocate for children. They can use the time allotted for checking children in, and getting them settled into a room, to ask basic developmental questions and probe for parental concerns.

The American Academy of Pediatrics (AAP) recommends general developmental surveillance and screening at all well-child visits (AAP, 2006). Their recently published algorithm on developmental screening advocates that primary care providers use well-established screening tools to assess development at the 9-, 18-, and 24-month visit. The 2006 AAP policy provides descriptions of general developmental screening tools, language and cognitive screening tools, motor screening tools, and autism screening tools. The 2007 AAP Clinical Report on the identification and evaluation of children with ASD specifically addresses screening for ASD and provides guidance on when this should occur (Johnson, Myers, and the AAP Council on Children with Disabilities [AAP CCD], 2007). They state that ASD screening needs to be integrated into general developmental screening and that even if parents do not express any concerns, children need to be formally screened for ASD at the 18- and 24-month visit. Specific screening tools available to assess for ASD in children are discussed in detail later. Although developmental surveillance includes asking parents whether they have any concerns, if no concerns are expressed, the impetus is on the health care providers to astutely assess and document whether children seem to be at the appropriate developmental level.

Early Identification

The *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*; American Psychiatric Association, 1994) criteria for autism require the presence of core features before the age of three. The features described in the *DSM-IV*, however, are often difficult to measure in children before they are about 3 years old. The challenge has been to determine how the social, communicative, and behavioral features manifest themselves in children younger than 3 years and to determine how early one can accurately predict the development of ASD. Prior to the recent surge in interest, and call for earlier diagnosis of autism (National Research Council, 2001), most children were evaluated after parents mentioned their concerns to a primary care pediatrician. Historically, the most common parental concern first reported to a pediatrician involved language development. Parents would report that their child was not speaking like other children or that they had begun to speak and suddenly stopped. Most parents (90%), following formal diagnosis, can retrospectively report that they began to notice abnormalities before 24 months of age (De Giacomo & Fombonne, 1998). It is now recognized that the time lag between initial concern and formal evaluation leads to a later initiation of intervention and the loss of precious time (Crais et al., 2006; Osterling, Dawson, & Munson, 2002). The charge to health care providers is to screen for and recognize manifestations of autism earlier.

There are difficulties with early diagnosis, however, and many experts debate how early one can make a definitive statement regarding ASD. In addition, because infant and child development is rapid, dynamic, and variable from one child to another, it is challenging to identify very specific manifestations that directly indicate the child has or will develop ASD. Despite challenges, there are some specific indicators that have been identified with somewhat strong predictive value. Parental concerns to note, if expressed at a doctor's visit, include reports that they do not think their child can hear, their child does not point or show them things, their child stopped talking, or that their child does not respond to his or her name. Table 1 summarizes these common concerns and lists various behaviors that health care providers should document if observed in infants and toddlers.