

The Role of Nurses in Screening for Autistic Spectrum Disorder in Pediatric Primary Care

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This article addresses the issue of integration of routine screening for autism spectrum disorder (ASD) in pediatric primary care. The relationship between screening and patient outcome is discussed. The ASD screening recommendations of the American Academy of Pediatrics and practical issues associated with their application are then reviewed. Finally, data from a pilot project to prepare nurses to conduct ASD screening during routine pediatric health visits are presented. The authors discuss the role of nurses in establishing systems within pediatric primary care to identify and refer children at risk for ASD.

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AUTISTIC SPECTRUM DISORDERS (ASDs) are an often-disabling continuum of disorders affecting between 2 and 6 of 1000 children (Bryson, 1996; Fombonne, 2001; Yeargin-Allsopp et al., 2003). These disorders have a core set of defining features that include impaired verbal and nonverbal communication and restricted and repetitive patterns of behavior (Volkmar, Cook, Pomeroy, Realmulto, & Tanguay, 1999). The etiology of autism is uncertain. As yet, the disorder can be defined only by related behaviors (Wing, 1997). Twin studies have provided evidence of a strong genetic component, and multiple genetic loci have been identified with no relationship to specific phenotypes (Folstein & Rosen-Sheidley, 2001). Specific environmental factors such as maternal rubella have been associated with autism (Dykens & Volkmar, 1997). Other hypothesized causes, such as parenting practices (DeMyer et al., 1972) and vaccines (DeStefano & Chen, 2000), have been discredited.

Monitoring children for developmental disability including ASD or pervasive developmental disorder (PDD) as part of routine pediatric care is now mandated by the American Academy of Pediatrics (Committee for Children with Disabilities, American Academy of Pediatrics [CDD/AAP], 2001). Systematic screening will result in children being diagnosed at a younger age, when intervention has its maximum benefit (Butter & Mulick, 2003). Standardized screening techniques for children with

ASD have improved over the last 10 years such that, according to clinical research studies, ASD can now be reliably and validly detected in children as young as 18 months using standardized screening techniques. This age may be further reduced to 14 months (Lord, 1995; Squires, Nickel, & Eisert, 1996). However, the practical application of innovations in screening and diagnostic techniques has lagged far behind the research. The average age of diagnosis is reported to be between 3 and 6 years (Howlin & Moore, 1997; Shevell, Majnemer, Rosenbaum, & Abrahamowicz, 2001) with significant differences based on ethnicity and socioeconomic status (Mandell & Pinto-Martin, 2002).

This article addresses the importance of routine screening for ASD in pediatric primary care. The recently published recommendations of the AAP

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0882-5963/03/\$ - see front matter

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doi:10.1016/j.pedn.2005.01.004

for screening for ASD are reviewed and practical issues associated with their application are discussed. Data from an ongoing pilot project to prepare nurses (i.e., PNPs, RNs, and LPNs) in pediatric offices to conduct screening for ASD are presented. The authors consider the importance of the role of nurses in establishing the necessary systems within pediatric primary care to identify and refer children at risk for ASD at an early age.

EARLY SCREENING FOR AUTISM SPECTRUM DISORDER AND PATIENT OUTCOMES

Developmental screening has been defined as the “brief, formal evaluation of developmental skills applied to a total population of children, which is intended to identify those children with suspect problems who should be referred for a complete diagnostic assessment” (Squires et al., 1996, p. 420) and “the prospective identification of unrecognized disorders by the application of specific tests or examinations” (Baird et al., 2001, p. 468). As such, screening instruments should be efficient, quick, and relatively inexpensive to administer. For relatively rare disorders such as ASD, with recently reported prevalence rates ranging from 4 to 6 cases for every 1000 (Fombonne, 2001; Yeargin-Allsopp et al., 2003), screening instruments may trade specificity for sensitivity to maximize positive predictive value (Clark & Harrington, 1999). This tradeoff in favor of sensitivity is justified because early screening for ASD is critical for at least 4 reasons.

First, parents require genetic counseling regarding the risks to future children who may inherit a genetic predisposition or genetic alteration associated with ASD or its behavioral phenotypes (Baird et al., 2001; Simonoff, 1988). Specifically, the probability of having a second child with ASD is 1 in 20, compared with a general community prevalence of 1 in 500 (Bolton et al., 1994). The risk of having a second child with some broader communication or cognitive deficit is even higher (Le Couteur et al., 1996).

Second, there are a number of behavioral and educational interventions for children with ASD that may improve outcomes for children (Matson, Benavidez, Compton, Paclawskyj, & Baglio, 1996), and there is increasing agreement that these interventions are more effective with younger children (Campbell, 1996; Rapin, 1997; Volkmar et al., 1999). Lord (1995) suggests that early treatment

will optimize long-term prognosis, whereas others estimate that the gains in functioning associated with early treatment may result in considerable cost savings to both the family and the health, education, and early intervention systems in which children with ASD are served (Jacobson & Mulick, 2000; Jarbrink & Knapp, 2000).

Third, the Individuals with Disabilities Education Act (PL 105-17) specifies that starting at birth, children with disabilities are eligible for public special education and related services (U.S. Department of Education, 2001). ASD was identified as a separate category of disabling condition in 1990 under PL 101-476. Children with ASD must be identified early so that the public education system can plan for and provide the “free, appropriate public education” to which these children are entitled (Jacobson & Mulick, 2000, p. 586).

Finally, parents and siblings of children with ASD are psychologically and socially affected by the child’s disorder and its related behavioral and developmental symptoms (Gray, 2001). Families often struggle to understand and cope with the “disordering effects of ASD on family life” (Gray, 2001, p. 1248). Early identification through screening, followed by psychosocial support and education about the disorder and treatment options can help families to adjust and cope.

RECOMMENDATIONS ON EARLY SCREENING FOR AUTISM SPECTRUM DISORDER

In 1998–1999, a Consensus Panel comprised of 13 organizations including the Child Neurology Society, American Academy of Neurology, and liaisons from the National Institutes of Health was formed. The panel analyzed 2500 related research articles and formulated a practice parameter for the screening and diagnosis of ASD (Filipek et al., 2000). The resulting Practice Parameter for the Screening and Diagnosis of Autism calls for a two-level approach. At the first level, screening is conducted for atypical development as part of routine well-child care, followed by an ASD-specific screen for those children who screen positive on the more general developmental screening test. Children who score positive on the ASD-specific screen or who have evidence of other abnormalities, move to the second level, which includes a developmental and health history and neurological assessment to determine the developmental profile and a formal diagnostic evaluation by

an experienced clinician (Filipek et al., 2000). These recommendations have been endorsed by the CDD/AAP (2001). The implementation of these guidelines across pediatric practices is now a priority of primary care.

The parameters outlined by the Consensus Panel are one of several sets of guidelines that have been proposed by various pediatric organizations for either general or condition-specific developmental screening. There is a considerable body of evidence, however, suggesting that these principles and guidelines are often not followed in practice (Dearlove & Kearney, 1990; Dobrez et al., 2001; Dobos, Dworkin, & Bernstein, 1994; Glascoe & Dworkin, 1993; Glascoe, 2001; Minkovitz, Mathew, & Strobino, 1998; Rossiter, 1993; Scott, Lingaraju, Kilgo, Kregel, & Lazzari, 1993).

CURRENT SCREENING PRACTICES

Only a few studies in the research literature have described developmental screening practices among primary care providers. Although methods vary, most rely on surveys of physicians to determine practice patterns. Results have been relatively consistent. For example, in an urban sample of physicians, Minkovitz et al. (1998) found that 50% of pediatricians conducted routine developmental screening during well child visits. In a survey of Australian physicians, Rossiter (1993) found that only 41% used any standardized developmental screening measure, and many physicians used them incorrectly. In a 1993 survey of pediatricians in Virginia, Scott et al. (1993) reported that 97% of respondents reported that they regularly conducted developmental screening, but only 58% used standardized screening instruments during well-child visits. Dobos et al. (1994) surveyed Connecticut physicians and found that only 20% reported using formal developmental screening instruments.

Several studies have found that when given a choice, most physicians rely on clinical judgment to detect potential developmental problems (Dobos et al., 1994; Dobrez et al., 2001). This practice has been shown to identify fewer than half of children with developmental delay (Glascoe & Dworkin, 1993). Research also suggests that pediatricians tend to control the flow of conversation and fail to elicit concerns about developmental issues from parents, who are the principal source of empirical data on the child's developmental needs (Raimbault, Caichin, Limal, Eliacheff, & Rappaport, 1975).

Barriers to Standardized Screening

Although there are reliable and valid tools for screening for both general developmental screening and ASD-specific screening, there are practical barriers to the uniform use of these tools. One of the primary barriers to routine formal screening is reimbursement concerns and limited staff. The costs of screening are estimated to be from \$11 to \$82 per screening implementation (Dobrez et al., 2001). In addition, many providers, and especially those with practices in urban environments, report difficulties in attempting to sequentially assess development in their patients because of larger patient volume, diminishing reimbursement for in-office behavioral services, failure of at-risk patients to attend well-care appointments, and the length of screening tools (Dobos et al., 1994; Goldstein, Dworkin, & Bernstein, 1999). Another barrier is the variety of screening tools from which to choose (Clark & Harrington, 1999) and the lack of uniformity among tools with regard to validity, sensitivity, and specificity. These variables may confuse practitioners and may make choosing one difficult (Glascoe, 2000). Finally, practitioners rarely receive formal training in the administration and scoring of developmental screening tools (Scott et al., 1993).

Eliminating Barriers

If developmental screening is to be universal, these practical barriers must be addressed. Principal among these barriers is the time it takes for a physician or nurse to complete the standardized screening tool. Given the hectic pace of pediatric offices, other options must be considered. First, nurses can be instructed to administer the tools. Training to complete the standardized tools is straightforward and nurses can complete the assessment in conjunction with performing other tasks such as weighing and measuring the child.

With limited physician and nurse practitioner time and lack of adequate insurance reimbursement for time spent in formal screening for developmental problems, the use of parent-completed report tools has also been recommended (Squires, 1996). Parent-completed reports can be used in conjunction with clinical observation to reduce the time required for screening assessments and to produce a more complete and valid report of the child's typical range of behaviors (Glascoe, 2000). Parent-completed screening tools can facilitate communication between parents and providers on developmental issues of concern. Hickson,

Altemeir, and O'Connor (1983) report that although 70% of mothers had concerns about their child's development, only 28% reported discussing these concerns with their pediatrician. Currently, children with behavior problems are underidentified by primary care physicians (Lavigne, Binns, & Christoffel, 1991). The use of a parent-completed report tool allows a parent to identify issues of concern about their child's development before seeing the pediatrician or nurse practitioner and allows for longitudinal monitoring of the individual child so that data can be gathered and followed for changes over time (Meisels & Provence, 1989). Squires et al. (1996) have shown that asking parents to complete a standardized evaluation of their child's development aids in the timely and appropriate referrals for diagnosis and early intervention.

Available Screening Technology

Parent observations and reports of behavior are one important method for screening for ASD. Observations may suffer from poor reliability and validity as compared with a biologic measurement. However, there are a few tools that can provide relatively accurate assessments of the risk of ASD as early as 18 months of age. To date, only one screening instrument for ASD has been thoroughly tested in the general population: The Checklist for Autism in Toddlers (CHAT).

The CHAT was developed to screen children 18 months of age and includes items to evaluate social orienting behaviors such as pretend play, joint attention, and protodeclarative pointing (Baron-Cohen, 2000; Klinger & Renner, 2000). The CHAT relies on behavioral observations of five activities by the health provider and nine questions answered by the parent or caregiver. There is no formal training required for its use. Children who fail five key items relating to protodeclarative pointing, pretend play, and joint attention are considered at high risk for developing ASD. Children who fail only two of the key items (which measure protodeclarative pointing) are predicted to be at medium risk. All other children are considered at low risk (Baron-Cohen, 2000).

This instrument has been studied extensively in the South Thames region of the United Kingdom where 16,235 of the total population of 40,818 toddlers (39.8%) were screened (Baron-Cohen et al., 1996). The positive predictive value was found to be 83% for ASD and PDD and 75% for ASD alone. The specificity was 100% and the negative predictive value was 99.7%. However, the sensitivity of

the instrument was only 18%. In other words, 82% of children who were later identified as having ASD were not identified using the CHAT (Baird et al., 2001; Baron-Cohen, Allen, & Gillberg, 1992). Preliminary results found the CHAT most effective for children in the 18- to 24-month developmental range. Baron-Cohen et al. (1996) were looking for toddlers who met strict criteria for autistic disorder rather than the wider population of children with ASD or PDD. Over the past decade, a shift of the conceptualization of the autism spectrum has made this tool insensitive.

In an effort to improve the sensitivity and practical use of the CHAT, Robins (2001) developed the Modified Checklist for Autism in Toddlers (M-CHAT). The developers of the M-CHAT were concerned that atypical development might be missed in a single behavioral observation session. Therefore, the modified checklist includes a parent-completed report of behavior. Data collection on the psychometric properties of the M-CHAT is ongoing. The M-CHAT is being tested on children 24 months of age, whereas the CHAT was tested among children at 18 and 24 months. The authors report the properties of the M-CHAT as follows: sensitivity, 87%; specificity, 99%; positive predictive value, 80%; negative predictive power, 99%. They conclude that the M-CHAT is an accurate method of detection, correctly classifying 33 of 38 children with ASD/PDD and 1188 of 1196 children who did not have ASD/PDD. The six items with the best predictive ability were joint attention (protodeclarative pointing, following a point, bringing objects to show parent), social relatedness (interest in other children and initiation), and communication (responding to name) (Robins, 2001).

The M-CHAT, incorporating the original 9 questions from the CHAT, has improved the sensitivity to 87% by asking 14 additional questions and screening children at 24 months instead of 18–24 months. However, the authors caution physicians and nurse practitioners against screening solely based on parent report. Some parents are poor observers of their children's behaviors, particularly if they have limited interactions with other toddlers or are overwhelmed with family needs (Robins, 2001). Therefore, health providers who have concerns about a child's development should refer a child for a diagnostic evaluation despite a passing score on the M-CHAT. Health providers' observations remain key to adequate screening.

TRANSFERRING RESEARCH TO PRACTICE: TEACHING STAFF TO SCREEN FOR AUTISM SPECTRUM DISORDER

The Pennsylvania Center for Autism and Developmental Disabilities Research and Epidemiology is conducting an ongoing study to assess the feasibility of integrating early screening for ASD into routine pediatric care. This pilot study has received Institutional Review Board approval from The University of Pennsylvania and the Children's Hospital of Philadelphia. Although the long-term goal of this project will be to improve developmental screening in general, this pilot study is focused on screening specifically for ASD. The screening protocol uses the parent-completed (23 item) M-CHAT, modified to a third-grade reading level, as well as the five clinical observations from CHAT described above. Informed consent is obtained from parents and from health-care providers.

Initially, all personnel (including PNs, RNs, pediatricians, medical assistants, and LPNs) at one busy, urban pediatric site were trained by a pediatric nurse practitioner on the purpose and use of the CHAT/M-CHAT. Instruction and role modeling of a developmental screening protocol were provided to these health-care providers during the 18- and 24-month well-child visits.

To date, of the 50 toddlers scheduled for their 18- to 24-month routine health visit, data have been collected on 21. Twenty parents with children scheduled for routine health visits did not keep their appointments and nine parents chose not to participate in the study. The participating children ranged in age from 17 to 26 months, with a mean age of 21.6 months. Ten toddlers were boys and 11 were girls; there were 18 African Americans, 1 Japanese, 1 Bangladeshi, and 1 Caucasian. Of the 21 children screened, 3 were positive, 1 on the CHAT alone, 1 on the M-CHAT alone, and 1 on both. The first two children were already identified as at-risk and were receiving services for developmental delay. The third child has been referred for diagnostic evaluation to the Regional Autism Center.

This ongoing study has uncovered several challenges to the implementation of developmental screening in an urban pediatric practice. First, because this was a research project that required informed consent, some parents refused to consent or were confused by the language presented on the HIPAA authorization form. Some health-care providers also refused to participate. In this primary care clinic, a large population of children and families who receive care reside in the Philadelphia

Shelter system. Often, these families rely on the transportation available from the shelters to travel to the clinic. As a result, families often arrive at the same time despite appointments that are staggered. This results in delays throughout the process, from registration to entry into the examination room. Therefore, additional responsibilities such as screening tools can be burdensome to the staff. Because of the numerous stressors faced by these families, parental report of a child's developmental milestones maybe less than accurate, emphasizing the need for both parental report and clinical observation to capture delayed development.

Although the focus of this pilot project is on ASD-specific screening, the long-term goal includes improving developmental screening practices in general. Phase 2 of this pilot study will incorporate general developmental screening, followed by ASD-specific screening when it appears warranted. Data from this pilot project will be used to evaluate the best practice for administration, collection, and synthesis of screening data in a busy urban pediatric practice.

DISCUSSION

Preventive health care through the screening and early detection of children at risk for developmental disability is a mandate in pediatric primary care that is embraced by providers in theory. However, the need for timely and consistent developmental surveillance is a health-care service issue that is not easily addressed. Valid and reliable tools exist for the screening and diagnosis of ASD, but the current system of pediatric care allows limited time to implement routine screening at each well-child visit. Health-care providers continually struggle to meet competing demands on their time and are searching for methods of secondary prevention that are rapid, accurate, and easy to administer. Nurses can quickly learn to conduct routine developmental screening and autism-specific screening while performing other necessary duties during the visit.

This pilot project has demonstrated that nurses working in the practice are ideally situated and have opportunity to make the observations required by the CHAT to assess risk for ASD. The CHAT observations can be easily completed while weighing and measuring children and settling them in the examining rooms. An educational program can be designed for a group of providers with mixed skill levels, for example, licensed practical nurses, medical assistants, nurse practitioners, physicians,

and registered nurses. The team of providers can be informed about the importance of developmental screening and each can be involved according to their level of expertise and scope of practice. For example, nurses may perform the five observations of the CHAT, and medical assistants may ensure that the M-CHAT is completed by the parent.

An ideal model of ongoing developmental assessment would begin with a general developmental screening at each well-child visit. Asking parents to complete a tool designed for general developmental screening will encourage them to focus on developmental milestones for their child

and facilitate communication between providers and parents around developmental issues. This, in turn, will identify potential problems and determine those children who require evaluation for ASD or other developmental delay. "Bright Futures" is one successful model currently in use that trains PNPs and physicians to integrate developmental assessment into pediatric primary care. The physician and nurse practitioner's role in developmental assessment and referral for early intervention is greatly supported by such collaborative initiatives. Children will be the principal beneficiaries.

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