



Autism Spectrum Disorder: The Nurse's Role

Evidence-based support for early screening and intervention.

ABSTRACT: Autism spectrum disorder (ASD) is the most common and fastest-growing developmental disability in the United States, affecting approximately one in 54 children nationwide. Early intervention for ASD produces the best outcomes—and developmental surveillance and screening are prerequisites to intervention. Although screening has been strongly recommended for two decades, the majority of U.S. children are not screened for ASD. Here, the authors discuss ASD epidemiology, screening, and diagnosis, as well as appropriate early actions nurses can take when ASD is suspected.

Keywords: autism spectrum disorder, early detection, early intervention, screening

“**W**hat’s the scoop with our autism screening?” a concerned mother asked the nurse upon realizing that the autism spectrum disorder (ASD) screening questionnaire she had completed wasn’t addressed during her daughter’s well-child visit. (This case scenario is a composite based on our experience.) The nurse brought the mother’s concern to the primary care provider, who replied, “Don’t worry, I only look at screenings if I think there’s a problem. I can spot autism during a patient visit.”

While the literature refutes the primary care provider’s assumption, it is not uncommon for parents and nurses to witness similar practices on the part of primary care providers and to find incomplete, unscored ASD screenings across clinical settings, revealing unanswered questions and potential health inequities.

The American Academy of Pediatrics (AAP) has recommended universal developmental screening of infants since 2001 and expanded this recommendation in 2016 to include ASD-specific screening.¹ However, a cross-sectional analysis of the 2016 National Survey of Children’s Health, an initiative

of the Health Resources and Services Administration, found that only 30.4% of infants ages nine to 35 months received a parent-completed developmental screening and only 37.1% received developmental surveillance in which the parent or caregiver reports to the health care provider any developmental concerns about the child.¹

Nurses can become the change agents that interrupt this pattern by educating and supporting their patients’ families, community members, and other members of their health care teams regarding the importance of early ASD detection and treatment. While the Centers for Disease Control and Prevention advises caregivers to bring any ASD-related concerns about their child to the child’s primary care provider,² the first health care provider a parent and child are likely to encounter is a nurse; and since the prevalence of ASD has increased over the past several years, nurses can expect to see increasing numbers of patients with ASD.³ Across all areas of clinical practice, academics, and policy, nurses empowered with the knowledge of ASD risk factors, signs, and current best practices for screening and early intervention may refer caregivers to



Cassandra Burgess-Alex and her son Diallo, who is on the autism spectrum. Because Diallo has run away from home so many times, his mother keeps the windows and doors bolted, except for the front door that she locks and unlocks with the key she wears on a lanyard around her neck. Photo by Paul Kitagaki Jr. / Sacramento Bee / ZUMA Wire.

appropriate help before valuable treatment time is lost. This article summarizes what is known about ASD epidemiology, describes recent advances in ASD screening and diagnosis, and discusses how nurses can advocate for early identification of ASD as well as early, appropriate intervention.

EPIDEMIOLOGY OF ASD

ASD is a neurodevelopmental disorder characterized by impaired social communication; diminished social interactions; unusual responses to sensory stimuli; and restrictive or repetitive behaviors, interests, or activities.⁴ Along the autism spectrum, both abilities and effects vary widely. Regardless of where a child falls on the spectrum, early intervention yields the best outcomes.²

ASD reportedly affects 1% to 2% of the world's population. In the United States, the incidence of ASD has steadily increased, with one in 54 children affected in the most recent epidemiological reports.⁵

Sex differences in ASD diagnoses. ASD occurs within all ethnic, racial, and socioeconomic groups, though diagnosis is four times more common in boys than girls. It's been suggested, however, that

this disparity in ASD prevalence may result from a "camouflage effect" in which girls with ASD are better able than boys with ASD to conceal social impairments on performance-based measures, resulting in an underdiagnosis of ASD in girls.⁶

From four different ASD clinical and research sites in the United States, researchers identified an initial sample of 816 school-age children who had intelligence quotient (IQ) scores above 70 and had been diagnosed with ASD by a trained clinician on the basis of gold standard diagnostic measures and criteria outlined in the *Diagnostic and Statistical Manual of Mental Disorders*, fourth and fifth (DSM-5) editions.⁶ Parent reports of autistic traits and adaptive skills had been collected for all the children. From the initial sample, the researchers assembled a final age- and IQ-matched sample of 114 girls and 114 boys. Data analysis revealed no significant sex differences in ASD diagnostic data, indicating similar levels of autistic traits among the boys and the girls. However, parent-reported measures of adaptive behavior and social functioning in real-world settings indicated that the girls were more severely affected than the boys, suggesting

that in order to meet the ASD diagnostic criteria, the girls may have had to demonstrate a greater degree of autistic traits.

Adding to this research, a multisite integrative analysis of sex differences in scoring on gold standard measures of autism recently published by Kaat and colleagues provides perspective on potential sex differences in autism and autism diagnoses.⁷ The study, which combined several databases to create the largest sample to date of girls with ASD diagnoses, found few sex-related differences beyond known ASD severity indicators. After taking into account age, nonverbal IQ, and language level, boys' scores, as determined by both parent report and direct observation, indicated more severe ASD manifestation than girls' scores in the area of restricted and repetitive behaviors, a finding that is consistent with previously published reports. In terms of social responsiveness during adolescence, however, girls' scores indicated more severe deficits, a finding that contradicts previously published reports in which girls were determined to have fewer deficits in this area. According to the investigators, this may suggest that parents have higher social expectations of girls than boys.

ably diagnosed by age two, most children are not diagnosed until after age four,⁹ radically reducing the period during which intervention may be most effective.

The economic burden of delayed intervention.

A 2014 literature review estimated that ASD represented a substantial aggregated annual economic burden in the United States of \$61 billion to \$66 billion for children and \$175 billion to \$196 billion for adults, depending on whether assumed prevalence of intellectual disability is 40% or 60%, respectively.¹⁰ This significant economic burden represents multiple associated costs. For children with ASD, these include medical care, special education, and lost parental productivity; for adults with ASD, they include residential accommodation, medical care, and productivity loss. Early intervention is projected to improve long-term health outcomes and thereby substantially reduce lifetime costs associated with ASD.¹¹ Children with ASD who receive early intervention are more likely to have fewer symptoms, incur fewer health care costs, enroll in mainstream educational programs, and enjoy greater employment opportunities than those who do not.

Contrary to popular belief, ASD can be neither diagnosed nor excluded through having a simple exchange with a child.

Although these findings suggest sex-specific ASD scoring may not be necessary, the investigators note that previous sex-based comparisons of scores on standardized ASD screening tools have produced inconsistent results, possibly due to the small sample sizes in these studies and the fact that girls constitute only about 20% of all pediatric ASD diagnoses. They note, however, that in some girls and women ASD may manifest differently than in men and boys and stress that future research should explore potential sex differences in ASD diagnoses.

IMPORTANCE OF EARLY INTERVENTION

Although it is never too late for ASD intervention, in order to achieve optimal individual developmental trajectories, ASD-specific treatment should begin as early as possible—ideally, before the age of two, which is a period of tremendous neuroplasticity and accelerated brain growth.⁸ While ASD can be reli-

SCREENING FOR ASD

Research suggests that both genetic and environmental factors contribute to the development of ASD. Known risk factors for ASD include having any of the following:

- a sibling with ASD²
- older parents²
- neonatal complications, including low birth weight,¹² birth injury,¹² or preterm birth¹³

Developmental screening. The AAP recommends that clinicians perform developmental screening using a validated tool during well-child visits conducted at nine, 18, and 24 or 30 months of age, noting any subtle red flags in infants who have a sibling with ASD.

ASD-specific screening. The AAP further recommends that clinicians perform ASD-specific screening using a validated tool at both 18- and 24-month well-child visits and at any subsequent visit in

which concerns about ASD are raised.^{14,15} Single-point screening prior to age two often fails to identify a subpopulation of children with ASD who appear to achieve normal development before regressing and demonstrating symptoms of ASD at around 20 months of age.¹⁶

REFERRAL FOR EVALUATION AND INTERVENTION

Nurses should ensure patients are evaluated for ASD when

- primary care provider or parent concerns remain after a negative screen.
- there are two or more ASD risk factors.
- a screen is positive.

In such cases, referral for formal ASD evaluation (to be completed by a developmental pediatrician, child neurologist, child psychologist or psychiatrist) is highly recommended, as is early intervention if deemed appropriate.¹⁵ Both developmental and ASD-specific screening combined with surveillance promote early ASD diagnosis,¹⁷ increasing the likelihood of appropriate intervention.

Nurses can simultaneously direct families to early intervention services in their state to request a free evaluation, which requires neither a provider referral nor a medical diagnosis.

- **Parents of children under age three** should contact their local early intervention services (see state-specific contact information at <https://ectacenter.org/contact/619coord.asp>).
- **Parents of children ages three years or older** should contact their local public school.

SCREENING AND SURVEILLANCE IN THE UNITED STATES

Overall, U.S. rates of developmental screening and surveillance are low. There is, however, considerable variation among states, with more than a 40% difference between the two states with the lowest and highest rates: Mississippi (with a 17.2% screening rate and a 19.1% surveillance rate) and Oregon (with a 58.8% screening rate and a 60.8% surveillance rate).¹

States can dramatically improve developmental screening and surveillance rates, however, as Oregon has demonstrated. In 2007, Oregon had one of the lowest rates of developmental screening in the country. Since that time, it has achieved the nation's highest rates of developmental surveillance and screening, nearly doubling the national average in both categories. It has been suggested that Oregon's success may be due to tracking and incentivizing quality improvement through performance incentives.¹

Common barriers to improving access to early ASD screening, diagnosis, and intervention include¹⁸

- inefficient systems of care (educational, health, and social services systems, as well as intersystem communication).

How Electronic Capability Affects Screening Rates

A key component of successful screening in 2020 is electronic capability, a need that has been exacerbated by the coronavirus disease 2019 (COVID-19) pandemic. While numerous validated autism spectrum disorder (ASD) and developmental screening tools are available in paper format or may be accessed online for free or at low cost, these tests do not communicate with electronic health records (EHRs) and the workarounds function as a proprietary lock as, in order to enable communication between the screening tools and the EHRs, health care systems are required to either purchase costly subscriptions from the developers or pay developers royalties per completed screening. Since tools that communicate with the EHRs are more likely than paper tools to be completed in a timely manner and with fewer scoring errors, this may be a previously unpublished factor contributing to low developmental and ASD screening rates.

Easy access. To increase the number of complete screenings, parents should be able to access screenings electronically from a phone, computer, tablet, or office electronic station prior to their child's appointment, with immediate results connecting directly to the EHR. This streamlined process would not only improve screening rates but also alert nurses and other providers of failed screenings in advance of the appointment, increasing opportunities for further developmental probing while children and parents are with providers.

Financial assistance resulting from the current pandemic may be available for health care systems to allocate to electronic screening. If improved community outcomes are to be realized, ASD screening tools must be made immediately accessible to patients and families in the most useful format. In a COVID-19 world, every moment matters for the taxed primary care front line. The time to improve the process for use of valid ASD screening tools has never been more critical. Nurses across practice settings can help ensure that barriers to electronic evidence-based screening are scaled back.

- difficulty engaging families.
- provider attitudes (based on time limitations, little access to diagnostic and treatment services, or long wait times).
- organizational culture (specifically, unwillingness to adopt new innovations).

To read about the role of electronic tools in reducing barriers to screening, see *How Electronic Capability Affects Screening Rates*.

Demographic factors. In addition to regional differences, some demographic characteristics, including primary household language, family structure, highest household educational level, household income, past-year preventive visit, child's special health care needs, and having a medical home were significantly associated with whether developmental screening was performed.¹ However, the only demographic characteristic significantly associated with receiving both developmental screening and surveillance was having at least three components of a medical home,¹ which the AAP

defines as an approach to providing care that may be characterized as accessible, family centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.¹⁹

In their cross-sectional analysis, Hirai and colleagues found that the aspects of a medical home most strongly associated with developmental screening were a usual source of care (accessibility), a personal physician or nurse (continuity), and family-centered care (in which all medical decisions are made in partnership with the family).¹

Unfortunately, many children with ASD do not receive family-centered, coordinated care. In a 2014 survey of 371 parents or caregivers of children with ASD, fewer than one-third of respondents reported that their child received coordinated care and fewer than half reported that their child received family-centered care.²⁰

ASD SCREENING INSTRUMENTS

In 2016, 81% of pediatricians reported using a formal screening tool to detect ASD; most often, it was the Modified Checklist for Autism in Toddlers (M-CHAT).²¹ A later revision, known as the Modified Checklist for Autism in Toddlers, Revised with Follow Up Interview (M-CHAT-R/F), was validated for use in children ages 16 to 30 months.²² The M-CHAT-R/F with scoring instructions is available for download at no cost (see <https://mchatscreen.com>) and the M-CHAT may be taken online for free (see <https://m-chat.org>).

ASD risk, as determined by scoring, and with appropriate follow-up, is outlined below^{22,23}:

- Scores of 0 to 2: Low risk; no further action is required unless other risk factors are present.
- Scores of 3 to 7: Moderate risk; a follow-up interview must be performed to clarify all at-risk responses. If the final score is greater than 3, referral is indicated.
- Scores of 8 or higher: High risk; refer the child for immediate diagnostic evaluation and early intervention.

Other potentially useful ASD screening instruments include the Infant-Toddler Checklist (ITC), the Social Communication Questionnaire (SCQ), and the Screening Tool for Autism in Toddlers and Young Children (STAT).

The ITC is a component of the Communication and Symbolic Behavior Scales Developmental Profile, a 24-item parent questionnaire validated for use on infants and toddlers ages nine to 24 months.²⁴ In a feasibility study in which 10,479 infants were screened using the ITC at the 12-month well-child visit, the tool showed promise in detecting ASD, as well as language delay and developmental delay.²⁵ The ITC questionnaire and scoring instructions are available for download at no cost (see <https://brookespublishing.com/wp-content/uploads/2012/06/csbs-dp-itc.pdf>).

The SCQ, formerly known as the Autism Screening Questionnaire,^{26,27} is a 40-item caregiver questionnaire based on the much longer Autism Diagnostic Interview–Revised (ADI-R),^{27,28} described below. The SCQ may be used to screen patients ages four years and older.²⁷ It comes in two forms—“Lifetime” or “Current”; Lifetime is based on a person’s entire developmental history, whereas Current focuses on behavior over the past three months.²⁹ The SCQ may be purchased online at www.wpspublish.com/store/p/2954/scq-social-communication-questionnaire or www.parinc.com/Products/Pkey/393.

STAT, originally known as the Screening Tool for Autism in Two-Year-Olds, was developed for children who are in referral settings and between the ages of 24 and 35 months. It is administered by a trained professional.^{30,31} The tool may be purchased online at <http://stat.vueinnovations.com/about>.

PROBLEMS WITH REAL-WORLD SCREENING

In a data analysis of 18- and 24-month pediatric visits made by 36,233 children between 2013 and 2016, in which the M-CHAT was used to screen for ASD, only 10 of the 20 practices followed the recommended scoring guidelines and only one typically administered the follow-up interview intended to reduce false positives.³² Nearly 73% of the children included in the analysis were screened at one of those visits and more than 54% were screened twice. Hispanic children were less likely to be screened than the children of all the other ethnic groups included (non-Hispanic white, non-Hispanic Black, and Asian or Pacific Islander). Furthermore, the researchers found many false negatives in this analysis, suggesting that children should continue to be closely monitored for signs of ASD even after receiving a negative screen and rescreened as needed. The investigators stress the importance of administering ASD screening tools as intended, and of promptly referring at-risk children for evaluation and intervention.

DIAGNOSING ASD

Contrary to popular belief, ASD can be neither diagnosed nor excluded through having a simple exchange with a child. At the very least, an ASD evaluation should be made and consider the child’s

- developmental history and current developmental level.
- functional language abilities (not speech articulation).
- functional social communication.
- functional play.
- presence or absence of sensory issues.
- presence or absence of repetitive behaviors, interests, or activities.

The DSM-5 criteria for ASD (see *DSM-5 Diagnostic Criteria for ASD*⁴) can act as a scaffold for the diagnostic evaluation, though the AAP

DSM-5 Diagnostic Criteria for ASD⁴

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):
1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation, to reduced sharing of interests, emotions, or affect, to failure to initiate or respond to social interactions.
 2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication, to abnormalities in eye contact and body language or deficits in understanding and use of gestures, to a total lack of facial expressions and nonverbal communication.
 3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts, to difficulties in sharing imaginative play or in making friends, to absence of interest in peers.

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior.

- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):
1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
 4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior.

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

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Table 1. Absolute Indications for ASD Diagnostic Evaluation Referral^{15,46}

Behavior Indicator	Referral Time Frame
No gesturing (waving bye-bye and pointing)	By 12 months
No babbling	By 12 months
No single words (excluding echolalia or labeling)	By 16 months
No spontaneous two-word phrases (excluding echolalia)	By 24 months
Any loss of language or social skills (regression)	Any age

recommends standardized, validated diagnostic instruments to quantify the clinical diagnosis.^{14, 33}

Such standardized diagnostic tools might include the Autism Diagnostic Observation Schedule, second edition (ADOS-2), the ADI-R, and the Childhood Autism Rating Scale, second edition (CARS-2).

The ADOS-2 is a behavioral observation instrument that consists of five modules. The Toddler Module provides ranges of concern for children ages 12 to 30 months, while Modules 1 through 4 provide cutoff scores for diagnoses of autism and ASD classifications for those ages 30 months

CARS-2, a diagnostic instrument based on history and direct observation, is available in two forms: the standard version, CARS-2-ST, which, like the first edition, is designed for use with children ages two through six years, or older than six with an estimated IQ below 80; and the high-functioning version, CARS-2-HF, designed for use with verbally fluent people ages six and older who have IQ scores above 80. Both may be purchased online at www.wpspublish.com/cars-2-childhood-autism-rating-scale-second-edition.

The AAP has published a series of recommendations for ASD practice and research,^{33, 36-38} and ASD diagnostic instruments have been extensively reviewed.^{39, 40}

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through adulthood, based on comparisons with same-age peers. The ADOS-2 may be purchased online at www.wpspublish.com/ados-2-autism-diagnostic-observation-schedule-second-edition.

The ADI-R²⁸ is a modified version of the Autism Diagnostic Interview, which had been developed in 1989 primarily for use in research.³⁴ The ADI-R contains 93 items that focus on three domains: language and communication; reciprocal social interactions; and restricted, repetitive, stereotyped behaviors or interests. The ADI-R may be purchased online at www.wpspublish.com/adi-r-autism-diagnostic-interview-revised. Combined, the ADOS and the ADI-R are considered the gold standard for data collection used in ASD research.³⁵

PROMOTING SAFETY IN CHILDREN WITH ASD

Anderson and colleagues surveyed parents in the Interactive Autism Network who had a child with ASD between the ages of four and 17 years about wandering behavior in their children.⁴¹ A total of 1,367 families completed the survey; the study sample included 1,218 children with ASD and 1,076 of their siblings without ASD. Survey results indicated that 49% of respondents reported at least one attempt by their children over age four to wander away from safe areas. From ages four through seven, 46% of the children with ASD had wandered off compared with 11% of the siblings without ASD, and from ages eight through 11, 27% of the children with ASD had wandered off compared with 1% of the siblings without ASD.

Nearly one-third of reported ASD wandering cases in the United States are either fatal or require medical attention, with the majority of deaths attributed to accidental drowning, followed by traffic injury. Wandering may be an attempt to explore or to depart from unpleasant stimuli. For children under age five, wandering ends in death 58% of the time.⁴²

Nurses can thoughtfully guide families toward accident prevention by encouraging close supervision of children with suspected ASD and teaching families to take the following precautions:

- Use fencing barriers, safety locking car seats, identification bracelets, Global Positioning System tracking devices, temporary tattoos, and window and door alarms (at home and when traveling).
- Enroll children in water safety classes early.
- Ensure all potentially hazardous materials are inaccessible.

Nursing action is needed to address critical safety issues concerning this growing population.

NURSING ADVOCACY

Awareness of evidence-based recommendations for ASD screening can help nurses advocate for patients with ASD, ensuring that ASD is identified early so that appropriate intervention is initiated. Despite the growing prevalence of ASD and its lifelong consequences, nursing faculty are often uncomfortable teaching nursing students about ASD screening and intervention. A survey of faculty in associate's degree, baccalaureate, or accelerated RN programs found that fewer than 5% of the 295 respondents described their knowledge of ASD as at the expert level, 33% felt they had "good" knowledge of ASD, 20% reported they were not very knowledgeable in this area, and 75% reported having "very low" or "only some" knowledge of best practices for nursing care of this patient population.⁴³ Nursing faculty are challenged to incorporate ASD course content and their own clinical experiences with ASD into nursing curricula and to call attention to the health care inequities affected patients often face.

It's important that nurses not dismiss any parental concerns related to child development that could be attributed to ASD. Parental reports of unusual behaviors have been found to be significant predictors of later ASD diagnosis.⁴⁴ Nurses should also be aware that denial and grief may deter parental reporting of ASD concerns or diagnostic pursuit. Race, too, can influence such parental reporting. In a study of parental reports of developmental concerns, Black parents reported significantly fewer ASD concerns than

white parents—specifically, social concerns related to social interest, attention, play, and reciprocity and concerns related to restricted and repetitive behavior.⁴⁵ Race did not, however, affect the number of non-ASD concerns that parents reported, such as those related to motor difficulties, temperament, medical conditions, general development, feeding, or disruptive behavior. The investigators suggest that one possible factor in this disparity may be knowledge of and access to information about ASD. These findings support the need for consistent ASD screening and developmental surveillance for all children, especially those at high risk for ASD, as well as the need for all clinicians to be familiar with the absolute indications for diagnostic referral, regardless of ASD risk or screening status (see Table 1^{15,46}).

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Resources

For more information, visit the following websites and share them with your patients' families:

American Academy of Pediatrics: www.aap.org (search for autism or ASD)

Autism Speaks: www.AutismSpeaks.org

- First Concern to Action Tool Kit: www.autismspeaks.org/tool-kit/first-concern-action-tool-kit
- Five Things to Do While Waiting for an Autism Evaluation: www.autismspeaks.org/blog/five-things-do-while-waiting-autism-evaluation
- 100 Day Kit for Young Children: www.autismspeaks.org/tool-kit/100-day-kit-young-children

Centers for Disease Control and Prevention:

www.cdc.gov (search for autism or ASD)

- Learn the Signs. Act Early. www.cdc.gov/ncbddd/actearly
- ASD Recommendations and Guidelines: www.cdc.gov/ncbddd/autism/hcp-recommendations.html

National Autism Association: *Be REDy Booklets*, wandering prevention resources for caregivers, first responders, and teachers: <http://nationalautismassociation.org/resources/aware-wandering-be-redy-booklets>

Nurses can promote early consideration of ASD risk by

- learning to recognize the risk factors for and early signs of ASD.
- promptly communicating parental developmental concerns to other health care team members.
- determining whether system- and site-specific screening and early action practices are aligned with current AAP recommendations—and if not, challenging those practices.
- encouraging the use of health information technologies, automated screening, surveillance, and action reminder systems.
- reviewing with caregivers the safety precautions for those at risk for ASD.
- referring families to local early intervention providers and public education assessment services, or if such services are not locally available, working with social service agencies and legislators to obtain funding for this purpose.
- verifying completion of all specialist referrals, including any additional referrals addressing family support and education, such as for social work.
- reminding families to bring all previous medical, therapeutic, and individualized education program (IEP) reports to diagnostic appointments with all specialists.
- teaching families and other practitioners the importance of intervening at the earliest time to help children at risk for ASD.
- ensuring that children identified as being at risk for ASD undergo appropriate follow-up appointments as soon as possible.

Long-standing stigmas associated with ASD are beginning to fade as research has progressed, revealing short- and long-term progress made possible through early intervention. Universal screening and surveillance remain critical to the detection of children at risk for ASD. While qualification for early intervention services is not dependent on a formal ASD diagnosis, a good understanding of ASD symptoms can help parents focus treatment goals on the unique qualities and needs of their children with ASD. For a list of online resources nurses can share with patients' families, see *Resources*. ▼

For three additional continuing nursing education activities on the topic of autism, go to www.nursingcenter.com.

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REFERENCES

1. Hirai AH, et al. Prevalence and variation of developmental screening and surveillance in early childhood. *JAMA Pediatr* 2018;172(9):857-66.
2. Centers for Disease Control and Prevention. *What is autism spectrum disorder?* 2020. <https://www.cdc.gov/ncbddd/autism/facts.html>.
3. Stokes D. Empowering children with autism spectrum disorder and their families within the healthcare environment. *Pediatr Nurs* 2016;42(5):254-5.
4. American Psychiatric Association. Autism spectrum disorder. In: *Diagnostic and statistical manual of mental disorders: DSM-5*. 5th ed. Washington, DC; 2013. p. 50-9.
5. Centers for Disease Control and Prevention. *Data and statistics on autism spectrum disorder*. 2020. <https://www.cdc.gov/ncbddd/autism/data.html>.
6. Ratto AB, et al. What about the girls? Sex-based differences in autistic traits and adaptive skills. *J Autism Dev Disord* 2018;48(5):1698-711.
7. Kaat AJ, et al. Sex differences in scores on standardized measures of autism symptoms: a multisite integrative data analysis. *J Child Psychol Psychiatry* 2020 Apr 20. Online ahead of print.
8. Bradshaw J, et al. Feasibility and effectiveness of very early intervention for infants at-risk for autism spectrum disorder: a systematic review. *J Autism Dev Disord* 2015;45(3):778-94.
9. Christensen DL, et al. Prevalence and characteristics of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *MMWR Surveill Summ* 2018;65(13):1-23.
10. Buescher AV, et al. Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatr* 2014;168(8):721-8.
11. Horlin C, et al. The cost of autism spectrum disorders. *PLoS One* 2014;9(9):e106552.
12. Gardener H, et al. Perinatal and neonatal risk factors for autism: a comprehensive meta-analysis. *Pediatrics* 2011;128(2):344-55.
13. Schieve LA, et al. Comparison of perinatal risk factors associated with autism spectrum disorder (ASD), intellectual disability (ID), and co-occurring ASD and ID. *J Autism Dev Disord* 2015;45(8):2361-72.
14. Hyman SL, et al. Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics* 2020;145(1).
15. Johnson CP, et al. Identification and evaluation of children with autism spectrum disorders. *Pediatrics* 2007;120(5):1183-215.
16. Werner E, Dawson G. Validation of the phenomenon of autistic regression using home videotapes. *Arch Gen Psychiatry* 2005;62(8):889-95.
17. Martinez M, et al. Family experiences with the diagnosis of autism spectrum disorder: system barriers and facilitators of efficient diagnosis. *J Autism Dev Disord* 2018;48(7):2368-78.
18. Broder Fingert S, et al. Implementing systems-based innovations to improve access to early screening, diagnosis, and treatment services for children with autism spectrum disorder: an Autism Spectrum Disorder Pediatric, Early Detection, Engagement, and Services Network study. *Autism* 2019;23(3):653-64.
19. American Academy of Pediatrics. *What is medical home?* 2020. <https://www.aap.org/en-us/professional-resources/practice-transformation/managing-patients/Pages/what-is-medical-home.aspx>.
20. Farmer JE, et al. The relationship between the medical home and unmet needs for children with autism spectrum disorders. *Matern Child Health J* 2014;18(3):672-80.

21. Coury D, et al. Screening of young children for autism spectrum disorders: results from a national survey of pediatricians. Presented at the Pediatric Academic Societies Annual Meeting, San Francisco, 2017.
22. Robins DL, et al. Validation of the modified checklist for autism in toddlers, revised with follow-up (M-CHAT-R/F). *Pediatrics* 2014;133(1):37-45.
23. Robins DL, et al. *The modified checklist for autism in toddlers, revised, with follow-up (M-CHAT-R/F)*; 2018. <https://mchatscreen.com>.
24. Wetherby AM, et al. Validation of the Infant-Toddler Checklist as a broadband screener for autism spectrum disorders from 9 to 24 months of age. *Autism* 2008;12(5):487-511.
25. Pierce K, et al. Detecting, studying, and treating autism early: the one-year well-baby check-up approach. *J Pediatr* 2011;159(3):458-65.e1-e6.
26. Berument SK, et al. Autism screening questionnaire: diagnostic validity. *Br J Psychiatry* 1999;175:444-51.
27. Eaves LC, et al. Screening for autism spectrum disorders with the social communication questionnaire. *J Dev Behav Pediatr* 2006;27(2 Suppl):S95-S103.
28. Lord C, et al. Autism Diagnostic Interview-Revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *J Autism Dev Disord* 1994;24(5):659-85.
29. Interactive Autism Network. *The social communication questionnaire (SCQ)*. n.d. https://iancommunity.org/cs/ian_research_questions/social_communication_questionnaire_scq.
30. Stone WL, et al. Psychometric properties of the STAT for early autism screening. *J Autism Dev Disord* 2004;34(6):691-701.
31. Stone WL, et al. Use of the Screening Tool for Autism in Two-Year-Olds (STAT) for children under 24 months: an exploratory study. *Autism* 2008;12(5):557-73.
32. Carbone PS, et al. Primary care autism screening and later autism diagnosis. *Pediatrics* 2020;146(2):e20192314.
33. Zwaigenbaum L, et al. Early screening of autism spectrum disorder: recommendations for practice and research. *Pediatrics* 2015;136 Suppl 1:S41-S59.
34. Le Couteur A, et al. Autism diagnostic interview: a standardized investigator-based instrument. *J Autism Dev Disord* 1989;19(3):363-87.
35. Zander E, et al. The added value of the combined use of the Autism Diagnostic Interview-Revised and the Autism Diagnostic Observation Schedule: diagnostic validity in a clinical Swedish sample of toddlers and young preschoolers. *Autism* 2015;19(2):187-99.
36. Zwaigenbaum L, et al. Early identification and interventions for autism spectrum disorder: executive summary. *Pediatrics* 2015;136 Suppl 1:S1-S9.
37. Zwaigenbaum L, et al. Early intervention for children with autism spectrum disorder under 3 years of age: recommendations for practice and research. *Pediatrics* 2015;136 Suppl 1:S60-S81.
38. Zwaigenbaum L, et al. Early identification of autism spectrum disorder: recommendations for practice and research. *Pediatrics* 2015;136 Suppl 1:S10-S40.
39. de Vaan G, et al. A critical review of screening and diagnostic instruments for autism spectrum disorders in people with sensory impairments in addition to intellectual disabilities. *J Ment Health Res Intellect Disabil* 2016;9(1-2):36-59.
40. Vlasaliu L, et al. Diagnostic instruments for autism spectrum disorder (ASD). *Cochrane Database Syst Rev* 2016(1).
41. Anderson C, et al. Occurrence and family impact of elopement in children with autism spectrum disorders. *Pediatrics* 2012;130(5):870-7.
42. National Autism Association. *Mortality and risk in ASD wandering/elopement 2011-2016*. Portsmouth, RI; 2017 Mar. <https://nationalautismassociation.org/wp-content/uploads/2017/04/NAAMortalityRiskASDElopement.pdf>.
43. Gardner MR, et al. Survey of nursing faculty preparation for teaching about autism spectrum disorders. *Nurse Educ* 2016;41(4):212-6.
44. Hedley D, et al. The relationship between clinicians' confidence and accuracy, and the influence of child characteristics, in the screening of autism spectrum disorder. *J Autism Dev Disord* 2016;46(7):2340-8.
45. Donohue MR, et al. Race influences parent report of concerns about symptoms of autism spectrum disorder. *Autism* 2019;23(1):100-11.
46. Filipek PA, et al. Practice parameter: screening and diagnosis of autism: report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology* 2000;55(4):468-79.

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