

Screening and Surveillance



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Abstract Within the context of typical development, it is not unusual for a child to show a slight delay in reaching a developmental milestone. Healthcare providers and parents may adopt a wait-and-see approach for some delays with little consequence to the child's outcome. In the case of early signs of autism spectrum disorder (ASD) that often manifest as developmental delays, however, acting early to evaluate the child's development and provide early intervention is key to better outcomes. Early identification is defined as having a comprehensive developmental evaluation of possible ASD symptoms no later than age 3, but a growing body of research has shown identification can be accurate and stable at younger ages. Navigating the differences between minor delays and signs of ASD is best conducted by combining forces between parents and health or other early childhood care providers using both ASD screening and developmental surveillance. This chapter outlines guidelines and resources for both screening and surveillance from professional organizations, ASD researchers, and healthcare agencies.

Early Identification of Autism Spectrum Disorder

The first 3 years of life are characterized by tremendous brain growth and skill development. These are also the years in which symptoms of autism spectrum disorder (ASD) become apparent (Guthrie, Swineford, Nottke, & Wetherby, 2013; Zwaigenbaum et al., 2013). Developmental theorists and scientists have provided ample evidence for typical developmental trajectories and timeframes within early childhood development (Centers for Disease Control [CDC], 2019), allowing both parents and providers to monitor development. In addition to gains in height, weight, and head

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circumference, development in cognitive, motor, social–emotional, language, and adaptive skill domains may be tracked and noted in personal and medical records. Collaboration across healthcare disciplines, early childhood care, and education is key to early identification of ASD. While primary care providers (PCPs) have consistent access and play a substantial role in early identification (Baio et al., 2018), parents and other providers can join with PCPs as a team to recognize early signs and act on delays or differences at the earliest opportunity (Glascoe, 1999).

As will be discussed below, over the last 20 years, researchers have focused efforts on identifying the earliest signs of ASD. Prospective studies examining the development of infants and toddlers at risk for ASD have led to an increased understanding of the social communication, language, and motor delays that may be observed in this population. Further, research has shown that screening for ASD can result in earlier diagnosis (Chlebowski, Robins, Barton, & Fein, 2013; Miller et al., 2011; Robins et al., 2014).

Social and Communication Development

First smiles, cooing, and eye contact are among the earliest social milestones expected in typical development (CDC, 2019). If vision and hearing are intact, and a child does not achieve these social milestones, parents and providers can begin to work on identifying possible delays through early intervention referrals and increasing interventions aimed at developing social interaction skills (Fein, Holt, Brennan, & Barton, 2015). Communication entails verbal and/or nonverbal interactive exchanges between people. Deficits in communication are a core feature of ASD and include impairments in both verbal and nonverbal communication forms (DSM-5; American Psychiatric Association [APA], 2013). Infants and toddlers later diagnosed with ASD have been found to show decreased use of a range of prelinguistic communication skills including eye gaze, facial expressions, sharing attention and enjoyment, communicative vocalizations, and gestures (e.g., Shumway & Wetherby, 2009; Veness et al., 2012; Wetherby et al., 2004; Wetherby, Watt, Morgan, & Shumway, 2007). In relation to gesture, studies of infants at increased genetic risk for ASD (due to having an older sibling diagnosed with the disorder) indicate that reduced gesture use is present in infancy (Mitchell et al., 2006) and persists over time (Iverson et al., 2018). Parents and providers can be watching for these social communication skills to develop, paying special attention to the frequency of use as well as the purpose for which the communication is used. For example, how clear is the communicative intent? Does the child integrate different forms of communication, such as pairing a gesture with eye gaze? Is the communication directed to another person? Does the child communicate for a variety of purposes—to request, comment, etc.? Reduced frequency of communication as well as the variety of communicative intent may point to an important area for targeted intervention.

Language Delays

While communication deficits are a core feature of ASD, a delay in language is not specific to ASD. Even so, language delay is among the first concerns most commonly reported by parents of children later diagnosed with ASD (Matheis et al., 2017) and language impairment is common enough to warrant status as a specifier of ASD in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (APA, 2013). In addition to expressive language delays, early delays in receptive language are also often present in infants and toddlers later diagnosed with ASD, and these delays have a substantial impact on social communication development and learning opportunities (Camarata, 2014). The American Academy of Pediatrics (AAP) recommends hearing evaluation as a first step when communication delays are observed in order to rule out the presence of hearing loss, even temporary hearing loss, which can impact language development (Johnson & Myers, 2007).

Motor Development

Esther Thelen's work in early development focused on the underlying brain capability for motor movement requiring dynamic sub-systems of interplay between body systems, tasks, and environment (Thelen, 1995). While not diagnostic of ASD, early deficits in motor skills have been found in young children later diagnosed with ASD. For example, an association has been identified between low muscle tone, or hypotonia, in infancy and later symptoms of ASD (Serdarevic et al., 2017). Head lag has been shown to be another early indicator of deviation from typical development in children later diagnosed with ASD (Flanagan, Landa, Bhat, & Bauman; 2012). Differences in gait symmetry have also been found in toddlers with ASD (Esposito, Venuti, Apicella, & Muratori, 2011). Emerging research points to prolonged retention of primary reflexes (e.g., grasping, rooting, and sucking) beyond the normal developmental period as impacting motor development in children later diagnosed with ASD (Chinello, Di Gangi, & Valenza, 2018). Importantly, early motor delays have been linked with subsequent social communication, expressive language, and adaptive developmental delays in children with ASD (Bhat, Galloway, Landa, 2012; LeBarton & Iverson, 2013; Provost, Lopez, & Heimerl, 2007).

Age of Identification of ASD

The first few years of life are a sensitive developmental period (Uylings, 2006), so researchers continue efforts to identify ASD at earlier ages (Jones & Klin, 2013; Ozonoff et al., 2010). The majority of ASD diagnoses made by 2 years of age are stable over time (Chawarska, Klin, Paul, Macari, & Volkmar, 2009, Guthrie et al.,

2013; Zwaigenbaum et al., 2013), and the target for early identification of ASD is before 3 years of age (Baio et al., 2018; Johnson & Myers, 2007). Other factors involved in determining this target include United States federal law, the Individuals with Disabilities Education Improvement Act (IDEA, 2004), whose Part C specifies a mandate for Child Find activities for children with disabilities from birth to three years for the express purpose of providing early intervention services, primarily in home settings. Part C or Early Intervention (EI) services are generally provided at low or no cost to families with the intention of equalizing access to care regardless of socioeconomic status.

Although 3 years or younger has been identified as the target age for early identification of ASD, according to data collected over the past decade or more in the United States, the average age of diagnosis ranges from 3 years, 11 months for children with severe symptomatology to 4 years, 9 months for children with ASD who have milder symptoms including age-appropriate cognitive and language abilities (Maenner et al., 2020). Although developmental concerns are often documented by 3 years of age in the majority (85%) of children with ASD, only 42% have been reported to have completed a comprehensive evaluation (including measures of cognitive, adaptive, language, and behavioral development) by age 3 years. Recent studies of 4-year-olds with ASD show 84% have evaluations before 36 months, however (Shaw et al., 2020). While a formal medical diagnosis of ASD is not required to receive EI services, a comprehensive developmental evaluation is typically performed as part of EI eligibility determination. A study of enrollment in EI services for all disabilities found a wide disparity across states between the estimated number of eligible infants and toddlers and those that are enrolled in EI services (Rosenberg, Robinson, Shaw, & Ellison, 2013). Improving the implementation of best practices in surveillance and screening could help to close this gap, providing earlier entry into EI services and additional therapies as needed. For more information regarding EI and transition services, please see the chapter “[Transition to Early Schooling for Children with ASD](#)”.

Conversations About Developmental Concerns

Although pediatric care providers, including family practice providers, have the most consistent professional access to children in the first 3 years of life, any professional who works with this population should be aware of early signs of developmental delays, including those specific to ASD, to ensure early identification. Extensive specialty training is not required for the wide range of early childhood professionals to identify possible signs of delays. However, awareness of the importance of developmental monitoring and understanding what to do if signs of ASD or other delays are present are needed to connect parents with resources for assessment (including experts with specialty training) and early intervention options. One example of reaching out to the broader range of early childhood professionals is the research that has been done to integrate surveillance and ASD screening into the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) in some areas

(First5LA, 2011; Guerrero, Inkelas, Whaley, & Kuo, 2013; Zuckerman, Chavez, & Reeder, 2017).

Trajectories Versus Timeframes

Developmental trajectories are stable and consistent in humans, but the exact timeframes for developmental milestones may vary slightly. Parents may be concerned about potentially minor delays in reaching developmental milestones, which could be indicative of the variability seen in typical development. In contrast, parents may be unaware of more significant delays if similar age infants or toddlers are not consistently available for comparison. Either way, professionals need to take action if they or the parents have concerns. Parent concerns can be the most valuable source of early detection of ASD risk, as the brief observation available during a pediatric visit may not be a reliable sample of behavior (Gabrielsen et al., 2015). Conversations about development are an established part of well-child visits with the child's pediatric care provider (AAP, 2019), although less is known about how these conversations occur and how best to assess parent concerns. Recognizing that diversity of culture, language, education, and family circumstances can all affect the reporting of parent concerns is critical (Donohue, Childs, Richards, & Robins, 2019). While a wait-and-see approach may seem like a logical response to parent concerns given the variation within typical development, in the case of developmental concerns related to ASD risk, early action is strongly recommended over wait-and-see approaches (CDC, 2019; Hyman, Levy, Myers, & Council and Children with Disabilities, 2020; Johnson & Myers, 2007).

Gender Differences

Differences in symptom presentation between females and males are important to note both in surveillance and screening. In the past, females identified with ASD were usually severely affected, with intellectual disability and language disorder profiles. In contrast, current research suggests that females with ASD may have better social communication skills than males with ASD, may imitate social behavior better (Ormond, Brownlow, Garnett, Rynkiewicz, & Attwood, 2017), and may have restricted or repetitive interests that are more focused on animals or people than objects (Lai, Lombardo, Auyeung, Chakrabarti, & Baron Cohen, 2015). Thus, it is critical to consider that concerns may be reported less often or interpreted as less urgent when the child is female. However, research has yet to provide specific information to guide parents and providers when considering early developmental profiles specific to females with ASD. Some screening research suggests that a focus on social communication and interaction deficits or differences may be useful (Evans, Boan, Bradley, & Carpenter, 2019).

Cultural Differences

ASD is generally thought to be equally present across cultures and genetic groups globally, but prevalence rates (and therefore identification rates) vary widely (Norbury & Sparks, 2013). Given the longstanding delays in the identification of children from ethnic or racial minority groups (Maenner et al., 2020; Baio et al., 2018), provider outreach and communication with culturally diverse families is critical to early identification. Latino families have reported that the stress of the diagnostic process, lack of parent knowledge about ASD, and lack of understanding the medical system are the leading barriers to receiving a timely diagnosis and appropriate intervention (Zuckerman et al., 2017). Other studies suggest that cultural influences on the way caregivers discuss behaviors with a provider might obscure ASD symptoms for a provider who is listening for typically White, Western cultural behavior descriptions (Norbury & Sparks, 2013). Both screening and surveillance can help to mitigate these barriers (Begeer, El Bouk, Boussaid, Terwogt, & Koot, 2009; Dawson, 2016). Please see the chapters “Clinical and School Identification and Intervention for Youth with ASD: Culturally and Linguistically Responsive Interdisciplinary Considerations” and “International Perspectives in Coordinated Care for Individuals with ASD” for more information regarding culture and ASD.

Education About Developmental Milestones

Each state in the United States (U.S.) has a federally funded *Learn the Signs, Act Early* Ambassador to coordinate early identification efforts within their state. For more information and to find your state’s ambassador, see: <https://www.cdc.gov/ncbddd/actearly/ambassadors-list.html>. Supporting local efforts are the nationally accessible training modules and resources for both parents and providers available from the Centers for Disease Control (see Table 1). Although these efforts are aimed at identifying ASD in the early years, developmental milestone monitoring is useful for all developmental delays or other conditions affecting development. Resources range from developmental milestone handouts to milestone tracker apps for parents. Provider resources include training, most notably the *Autism Case Training (ACT)* and *Watch Me!* online training modules with continuing education credit available. Materials are adapted for various professional settings (e.g., healthcare, WIC, home visitors, Head Start). All are free downloads, with options to order hard copies (e.g., books, pamphlets, charts, magnets).

ASD-specific educational resources can also be accessed through the extensive resource, *Autism Navigator*® (Autism Navigator, LLC, 2019), listed in Table 2. Among the many resources available through the *Autism Navigator*®, perhaps the most illustrative is the Video Glossary, which shows side-by-side video examples of typical development and delays that may be seen in ASD in the toddler years. Intervention options are also shown in the Video Glossary, making it a rich source of information for both parents and providers.

For professionals across disciplines, the *Birth to 5 Watch Me Thrive!* website from the U.S. Department of Health and Human Services (2017) contains extensive data

Table 1 Learn the signs act early resources for early identification of ASD. All available from <https://www.cdc.gov/ncbddd/actearly/index.html>, free, and available in English and Spanish unless otherwise noted

Audience	Online training/educational awareness resources	Developmental milestones
Parents	<ul style="list-style-type: none"> • Milestones in action: photos and videos • If you're concerned (steps to take) • How to get help for your child 	<ul style="list-style-type: none"> • Milestones tracker app • Milestones checklist (<i>Arabic, Brazilian Portuguese, Haitian Creole, Chinese, Somali, Vietnamese</i>) • Milestones moments booklet (<i>Chinese, Korean</i>) • Baby's busy day: Being one is so much fun! (Book) • Where is bear? A terrific tale for 2-year-olds (Book) • Amazing me: It's busy being 3 (Book) • How to help your child tipsheets and how to talk to your doctor tipsheets (<i>Vietnamese, Korean, Haitian Creole</i>) • Milestone brochure (<i>Spanish, Vietnamese, Korean, Haitian Creole</i>) • Flyers (first tooth, almost walking, watch me) • Growth charts (grow up healthy and milestones) • Developmental monitoring and screening fact sheet
Providers or educators	<ul style="list-style-type: none"> • Health care providers primer • Early childhood educators primer • WIC program staff primer • Early head start and head start program primer • Home visiting program primer • Child find program primer • Narrated PowerPoint presentation for health care providers (English only) • Narrated PowerPoint presentation of parents of young children • Watch me! celebrating milestones and sharing concerns (1-hr training with credit available) • Autism Case Training (ACT) online (English Only) • ACT in-classroom curriculum (English only) 	<ul style="list-style-type: none"> • Milestone tracker app, milestones matter posters • Web button (English only) • Videos to share on website (English)

Table 2 Autism Navigator® early identification resources available in English, Spanish, and Creole, all available through <https://autismnavigator.com/>

Audience	Free educational resources	Fee-based resources
Parents	A seamless path for families <ul style="list-style-type: none"> • 16 by 16™ LookBooks • Social communication growth charts About autism in toddlers <ul style="list-style-type: none"> • 3-hr course for anyone ASD video glossary (English only)	A seamless path for families <ul style="list-style-type: none"> • Social communication video growth charts How-to guide for families (8-hr course) <i>Some fee-based resources could be free for families if providers or families are enrolled in research or have a group rate</i>
Professionals	What is ASD? (Handout) Early red flags of autism (poster)	Autism Navigator® for primary care (8-hr course)

Table 3 Birth to Five, Watch Me Thrive! <https://www.acf.hhs.gov/ecd/child-health-development/watch-me-thrive> (available in English and Spanish unless otherwise indicated)

Developmental and behavioral screening practices	Screening measures
<ul style="list-style-type: none"> • Early child care and educator guide • Early intervention service and early special education provider’s guide • Primary Care Provider’s Guide • Community guide (English only) • Child welfare caseworker’s guide (English only) • Home visitor’s guide • Behavioral Health Provider’s Guide (English only) • Housing and homeless shelter provider’s guide (English only) • Developmental screening passport 	Compendium of screening measures (2014) reviews of commonly used measures. <ul style="list-style-type: none"> • Ages and Stages Questionnaire (ASQ) • Brigance • Developmental Assessment of Young Children (DAY-C) • Learning Accomplishment Profile-Diagnostic Screens (LAP-D) • Early Screening Profiles • Parents’ Evaluation of Developmental Status (PEDS) • FirstSTEP • Infant developmental inventory • Survey of Well-Being of Young Children (SWYC)

for developmental surveillance, including a *Compendium of Screening Measures* (See Table 3). The website also offers links to resources in each state for early identification and intervention.

Ongoing Professional Surveillance

In the 2020 AAP Clinical Report aimed at offering guidance to clinicians providing pediatric care to individuals with ASD, developmental surveillance for ASD is defined as talking with caregivers about concerns about their child’s development or

behavior, making informal observations, and monitoring of symptoms in the context of routine health supervision (Hyman et al., 2020). This Clinical Guide is an excellent resource for all care providers, as it provides excellent care information from early identification through treatment, and is freely available online at <https://pediatrics.aappublications.org/content/145/1/e20193447>.

The Bright Futures National Center has been developing guidelines over several decades by and for multidisciplinary pediatric care professionals, currently involving the AAP, the Maternal Child Health Bureau, Health Resources and Service Administration, and the Centers for Medicare & Medicaid Services. Although overall health is the focus of Bright Futures, some of their resources include guidelines for ongoing surveillance of development (Table 4). A brief summary of the timing of surveillance activities is provided in the Bright Futures/AAP Periodicity Schedule within the Guidelines. The Schedule indicates ages for surveillance and screening of developmental and behavioral health, beginning with Newborn visits through age 21 years. Developmental screening is indicated at 9, 18, and 30 months, and ASD-specific screening at 18 and 24 months, consistent with the AAP recommendations (Hyman et al., 2020; Johnson & Myers, 2007; Lipkin, Macias, & Council for Children with Disabilities, 2020).

Surveillance begins with a family history of developmental delays, including ASD. Asking open-ended questions about concerns as well as age-specific questions about developmental milestones constitute ongoing surveillance. General developmental screening tools, such as those described in the Compendium of Screening Resources (see Table 3) are an important part of surveillance, but the conversations between providers and parents about development and concerns are critical for

Table 4 American Academy of Pediatrics and Bright Futures guidelines and resources <https://brightfutures.aap.org/materials-and-tools/Pages/default.aspx>

Audience	Free resources	Fee-based or subscription resources
Parents		Patient education handouts for ASD (AAP) (in English and Spanish) <i>Many handouts are available for care across the lifespan, only surveillance handouts are listed here</i> <ul style="list-style-type: none"> • What is your one-year old telling you? • Is your toddler communicating with you?
Providers	<ul style="list-style-type: none"> • Bright futures guidelines • Periodicity table • Pocket guidebook • Developmental, behavioral, psychosocial, screening, and assessment forms (links) • Presentation templates for education • Clinical practice tools 	<ul style="list-style-type: none"> • Bright futures: guidelines for health supervision of infants, children and adolescents, 4th edition (print and e-book) • Bright futures toolkit (AAP) • AAP autism toolkit (English only) https://shop.aap.org/autismtoolkit/

early identification of ASD, as provider observation alone is not likely to provide a comprehensive picture of development (Gabrielsen et al., 2015).

The AAP surveillance and screening algorithm specific to ASD outlined in the 2007 guidelines (Johnson & Myers, 2007) has recently been expanded to include a broader range of neurodevelopmental disorders and behavioral and emotional problems, titled “Promoting optimal development: Identifying infants and young children with developmental disorders through developmental surveillance and screening.” (Lipkin et al., 2020). The new algorithms are freely available online through the *Pediatrics* portal (<https://pediatrics.aappublications.org/content/pediatrics/145/1/e20193449.full.pdf>). At health supervision visits, Bright Futures’ developmental and ASD-specific screening previously described are supplemented by specific actions to take if screens are positive and/or surveillance reveals concern for motor development specifically, for developmental concerns, or for any unaddressed concerns. The algorithm indicates that surveillance should continue throughout childhood, and extends from early concerns through the initiation of chronic conditions management (Lipkin et al., 2020).

The AAP Policy Statement and Technical Report regarding identification and evaluation of ASD first published in 2007 describes surveillance as a “. . . ‘moving picture’ of the child’s unfolding development, [and] screening represents ‘snapshots’ of the child’s development at specific times.” (p. 1195, Johnson & Myers, 2007). Although developmental screening is important, general screeners may not be sensitive to social symptoms associated with ASD, requiring ASD-specific screening tools to maximize the chances of identifying ASD early (Hyman et al., 2020).

Universal Screening for ASD

The AAP recommendations for ASD screening are for universal screening of children for ASD at their 18- and 24-month well-child visits, *or at any time there is a parent or provider concern* (Hyman et al., 2020; Johnson & Myers, 2007; Lipkin et al., 2020). Universal screening is slowly being adopted in the U.S., with recent surveys indicating that 17% (Self, Parham, & Rajagopalan, 2015) to 65% of pediatricians report using a formal screener to screen for ASD (Coury et al., 2017). While this is encouraging, universal screening is not without controversy (Al-Qabandi, Gorter, & Rosenbaum, 2011; Charman & Gotham, 2013). In 2016, the United States Preventative Services Task Force (USPSTF) finalized their report on universal screening for ASD, stating there is currently insufficient evidence to directly connect better outcomes to universal screening. The report clearly states that screening is not harmful, and that screeners with satisfactory performance data do exist, but that without more research on outcomes from universal screening, they could not endorse screening on a universal basis (Siu et al., 2016). Similar recommendations were published in Canada and the United Kingdom (Allaby & Sharma, 2011; Canadian Task Force on Preventative Health, 2016).

One of the flaws in the standard methodology employed by recommendation bodies, such as the AAP or the USPSTF, is that treatment outcomes are the only outcome of interest, whereas many would argue that age of identification could be justified as an outcome (Coury, 2015; Pierce, Courchesne, & Bacon, 2016). There is a well-established body of research tying early intervention to favorable outcomes, as well as some large studies showing that screening results in earlier identification (Chlebowski, Robins, Barton, & Fein, 2013; Robins et al., 2014). However, because these two bodies of literature are not connected, the gap in the literature between screening and treatment outcomes has become a barrier to the endorsement of universal screening. Although many have been concerned about excessive false positive results based on screening research to date (Charman & Gotham, 2013), newer research with longitudinal follow-up is documenting risk for false negative results as well (Beacham et al., 2018; Carbone et al., 2020; Guthrie et al., 2019). The USPSTF judged that adequate evidence exists that screening tests can detect ASD in children aged 18–30 months (Siu et al., 2016), and prominent ASD researchers urge continuation of universal screening as the benefits (including earlier detection of ASD in underserved populations) outweigh the concerns raised (Dawson, 2016).

In 2015, a large group of ASD researchers published a report titled *Early Screening of Autism Spectrum Disorder : Recommendations for Practice and Research* (Zwaigenbaum et al., 2015). The report is publicly available in *Pediatrics* and may be found at: https://pediatrics.aappublications.org/content/136/Supplement_1/S41. A selection of screening measures discussed in the report for universal screening of toddlers (Level 1) and more targeted at-risk screening measures (Level 2) are listed in Table 5. Other screening measures commonly used in the U.S. and available to the public are also provided.

Not included in the table are screeners often used in research, but not readily available except through contacting the authors, e.g., the First Year Inventory (FYI: Baranek, Watson, Crais & Reznick, 2003; Lee et al., 2019) for 12-month-olds, from the Program for Early Autism Research, Leadership and Service (PEARLS), at the University of North Carolina School of Medicine. In addition, some measures with additional screening options, such as the Autism Spectrum Rating Scales (ASRS: Simek & Wahlberg, 2011; Goldstein & Naglieri, 2009), were not included because the short form of the ASRS (derived from the long form's 15 most highly predictive items) has extremely limited psychometric data available regarding its performance as a screener. Broad developmental measures with limited research on effectiveness for ASD screening (Dolata, Sanford-Keller, & Squires, 2019) were also not included as ASD screeners, e.g., Ages and Stages Questionnaires: Social-Emotional, Second Edition (ASQ:SE; Squires et al., 2015) and the Brief Infant-Toddler Social and Emotional Assessment (BITSEA: Briggs-Gowan & Carter, 2006; Gisman Kiss, Feldman, Sheldrick, & Carter, 2017). (See Table 3 for general developmental screeners.) Finally, measures commonly used in diagnostic or educational classification decision-making (Level 3 evaluation measures) were not included in the table as screeners. See the chapter "[Interdisciplinary Evaluation of Autism Spectrum Disorder](#)" for interdisciplinary evaluation measures.

Table 5 Commonly used ASD-specific screening and broadband developmental measures by age range

Age range	Measure copyright	Availability	Psychometrics	Level 1—Universal or Level 2—At Risk
*9–24 months	<i>Infant Toddler Checklist (ITC)—Part of the Communication and Symbolic Behavior Scales Developmental Profile</i> (Wetherby & Prizant, 2002, Brookes Publishing)	Parent Questionnaire Free download https://brookspublishing.com/product/csbs-dp-itc/ Scoring information https://firstwords.fsu.edu/pdf/Checklist_Scoring_Cutoffs.pdf Spanish available https://firstwords.fsu.edu/pdf/infant-toddler_Spanish.pdf	*Not recommended for < 9 months. PPV (for all delays, not specifically ASD) PPV = 0.42 – 0.79; NPV = 0.87 – 0.99 ¹	Level 1 Broadband needs ASD follow-up measure for Level 2
9–24 months	<i>Early Screening for Autism and Communication Disorders (ESAC) and SmartESAC</i> (Autism Navigator, LLC)	Autism Navigator® product https://firstwordsproject.com/screen-my-child/ Parent questionnaires online—can connect with providers, fees for providers	Extremely limited evidence available publicly. Preliminary field-testing indicated sensitivity from 0.84 to 0.86 and specificity from 0.83 to 0.85 for a total of 47 items ²	Level 1 or Level 2
16–30 months	<i>Modified Checklist for Autism in Toddlers™—Revised with follow up (M-CHAT-R/F)</i> (Robins, Fein, & Barton, 2009)	Parent Questionnaire Free https://mchatscreen.com/mchat-rf/ Multiple languages and a picture version	Strong evidence for use PPV 0.475 for ASD, but if all developmental disorders are included PPV = 0.946 ¹	Level 1 (Questionnaire) and Level 2 (follow-up interview)

(continued)

Table 5 (continued)

Age range	Measure copyright	Availability	Psychometrics	Level 1—Universal or Level 2—At Risk
18–35 months	<i>Parents' Observations of Social Interactions (POSI)</i> (Perrin, et al., 2016)	Parent questionnaire Free Part of the Survey of Well-being of Children www.TheSWYC.org Multiple languages	Very limited evidence in referred populations only—early comparisons with MCHAT are favorable, but PPV has not been provided. ^{3,4}	Level 1
24–36 months	<i>Screening Tool for Autism in Toddlers and Young Children (STAT™)</i> (Stone Coonrod, & Ousely, 2000, Vanderbilt Univ.)	In-person interactive observation measure Kit, protocols, and online training (required) ⁵ available through https://stat.vueinnovations.com/	Strong evidence for use, 24–35 mos. Promising for 14–23 mo. ¹	Level 2 in-person measure
Ages 4 + years ASD Lower cutoff for ages 2–4	<i>Social Communication Questionnaire (SCQ)—Current version</i> <i>Lifetime version</i> (Rutter, Bailey & Lord, 2003, WPS)	Parent Questionnaire (can be completed by others) Purchase from WPS Multiple languages Available in hard copy and online versions Lifetime Version is phrased for children older than 5 years, but some have advocated it for children younger than age 4 (consider the last 12 months) because of more stable psychometric properties than the Current Version. ⁶	Metanalysis shows acceptable accuracy AUC = 0.827–0.885, sensitivities 0.47–0.96, specificities 0.52–0.99. ⁶ Cutoff of 12 (rather than 15) overall showed high sensitivity of 0.82, but lower specificity of 0.56. ⁷ A lower cutoff score of 11 has better psychometrics for children 2–4. ^{8,9}	Level 2

(continued)

Table 5 (continued)

Age range	Measure copyright	Availability	Psychometrics	Level 1—Universal or Level 2—At Risk
2.5 years and up ASD	<i>Social Responsiveness Scales-Second Edition (SRS-2)</i> (Constantino & Gruber, 2012, WPS)	Parent/Teacher Questionnaire Purchase from WPS Available in hard copy and online versions Spanish available	Norms separated by gender (in school age version only). Sensitivity 0.45–1.00 Specificity 0.73–0.83 PPV = 0.33–0.60 NPV = 0.71–1.00 AUC = 0.59–0.93 ¹⁰	Level 2

PPV = Positive Predictive Value. NPV = Negative Predictive Value. WPS = Western Psychological Services. MHS = Multi-health Systems Assessments, Inc.
¹Evaluation of adequacy and psychometric data are quoted from Zwaigenbaum et al., 2015

²Wetherby et al., 2009

³Salisbury, Nyce, Hannum, Sheldrick & Perring, 2018

⁴Smith, Sheldrick, & Perrin, 2013

⁵Requires formal training on administration and coding

⁶ Chesnut, Wei, Barnard-Brak & Richman, 2017

⁷ Corsello et al., 2007

⁸ Wiggins, Bakeman, Adamson & Robins, 2007

⁹ Allen, Silove, Williams & Hutchins, 2007

¹⁰ Dovekot, van der Ende, Verhulst & Greaves-Lord (2015), Dutch version of SRS, deemed equivalent in raw scores to SRS-2 because questions were the same. The addition of a Teacher Report to the Parent Report increased the psychometric properties of the SRS. Results were similar to previous studies by the authors, Constantino & Gruber, 2012, and other external validation studies (Boltje et al., 2011 and Charman et al., 2007)

Next Steps for Referral

When screening and surveillance efforts result in a decision to pursue evaluation, there are several options to consider, and all can be pursued simultaneously to find the option that will result in the earliest evaluation. Comprehensive evaluations for ASD are time-consuming and may take place over multiple days and/or multiple visits. As early intervention efforts are symptom dependent rather than diagnosis dependent, for children under 3 years of age, the first and typically fastest path to an evaluation is to refer to the local Early Intervention agency (<https://ectacenter.org/contact/ptccoord.asp>). For children over age 3, contact the local school for an evaluation. These evaluations are low or no cost and may result in access to intervention if the child meets eligibility criteria for services (which vary by state). These evaluations typically cover multiple domains of development; however, they may not include ASD-specific assessment measures.

In some cases, access to therapies at the level of intensity desired by families, or access to specialist assessment may be beyond the school system capabilities (Irvin, McBee, Boyd, Hume, & Odom, 2012). Families may wish to supplement school-based services with private assessment and/or therapies. Health insurance mandates for ASD services are now in place throughout the U.S., providing many families with insurance coverage for Applied Behavior Analysis (ABA) services, which along with speech-language and occupational therapy services, are the most commonly prescribed intensive treatments for ASD in the early years (Bitterman, Daley, Misra, Carlson, & Markowitz, 2008). Medical diagnoses are required for insurance coverage, so evaluations outside of the education system may be necessary to access the intensity of treatment services desired. Medical diagnoses for ASD are generally given by physicians or PhD-level psychologists. In cases where neither of these professionals with appropriate ASD expertise are available, and/or there is a speech-language pathologist (SLP) with significant ASD training and experience available, an SLP may diagnose ASD. Note, however, that not all insurance companies accept an SLP diagnosis for ASD-specific services, such as ABA therapy.

In the 2020 Clinical Report Guidance, the primary care provider is charged with both discussing the importance of assessment and assisting the family in navigating the assessment process, including connecting families with community resources, with extra support required for families with low income or language barriers (Hyman et al., 2020). This charge applies to other community providers as well, given that pediatricians may not always be the first point of contact when a concern is discussed.

Waitlists for medical diagnoses from specialists can be long, but ASD specialty clinics in many states have been trying novel approaches to reduce the wait in order to provide diagnoses earlier (Austin et al., 2016; Gordon-Lipkin, Foster, & Peacock, 2016; Rotholz, Kinsman, Lacy, & Charles, 2017). Most states have ASD specialty clinics associated with a university medical center or large healthcare system or hospital, and specialty clinics exist independently as well. See the chapter “[Interdisciplinary Evaluation of Autism Spectrum Disorder](#)” for more details. When specialist waitlists are long, and if general pediatricians and child psychologists are experienced

and comfortable with the application of the DSM-5 criteria, they can make an initial clinical diagnosis to begin eligibility for services (Hyman et al., 2020).

Case Examples

There are many pathways and approaches to screening, early identification, and early intervention for very young children with ASD. The following case examples illustrate the benefits of screening and surveillance used together to improve outcomes.

Case 1 male: Surveillance by the pediatrician identified significant ASD concerns at age 12 months, including possible seizures and speech delay. The parents were unaware of ASD symptoms or anything about ASD but sought community-based gross motor play therapy. Physical therapists discussed multiple developmental concerns with parents, leading to follow-up with the pediatrician. ASD-specific screening was failed at age 27 months, which prompted parents to seek evaluation and more intensive intervention. Evaluation resulted in an ASD diagnosis, followed by enrollment in EI services, special education preschool, and a specialized preschool for ASD. Other family members, including extended family, have subsequently received ASD diagnoses.

Case 2 female: Although parents were not concerned, the pediatrician identified concerns with weight at 18 months. Some severely restricted feeding behaviors were initially attributed to reflux. At 23 months, pediatrician concerns about low weight resulted in a referral to EI services for feeding difficulties. ASD screening was also failed at 23 months, with subsequent evaluation confirming ASD. She was able to enroll in EI services for speech/language, feeding, and ASD, then an ASD specialty preschool with Medicaid funding. Parents report she is doing very well.

Case 3 male: Parents were concerned about speech development, which was monitored by the pediatrician from 18 months to 24 months. Recommendations at that time were to do at-home speech enrichment activities. The child's extended family had no concerns, commenting that he had some well-developed routines that were enjoyable for all every day and they thought he was fine. His mother had been taking courses in child development, which raised her level of concern about ASD specifically. At his 24-month well-child visit, an ASD screen result was borderline failed by parent report, but the pediatrician urged further action because of the mother's concerns. Subsequent evaluation confirmed significant ASD symptoms. He enrolled in EI services, his mother attended seminars on various treatment options to help with decision-making, and he transitioned into an intensive special education preschool in his school district.

Summary

There is no single perfect approach to identifying ASD, so multiple efforts are required. Parents and providers across disciplines (healthcare, speech and language, education, early childhood care, and early intervention), working together to coordinate surveillance and screening can result in earlier identification of ASD, which is the key to early intervention access. For example, concerns regarding social interaction or play skills may first be noted by early education and/or childcare providers, while differences in nonverbal communication may be more apparent to speech therapists. Communication with parents and among providers about concerns is key to taking earlier action. Improved outcomes for ASD rely on early intervention, so the importance of combining ASD screening with surveillance cannot be understated. Given the importance of early identification, redundant systems and methods are required for the best outcome (e.g., screening in healthcare, early intervention, and early childhood care centers). Surveillance of development requires that all early childhood care providers have conversations with parents, and that both professionals and parents are educated about development. Fortunately, many resources are available for no or low cost to improve education about developmental milestones and red flags for ASD. Considerations of culture, language, and gender differences within these conversations are important to avoid missing identification of ASD at the earliest opportunities. Screening measures are available at low or no cost and in multiple languages, improving identification across cultures and languages. Finally, although universal screening for toddlers has not yet been fully adopted in the U.S., use of ASD-specific screening measures for children with and without significant concerns has been shown to improve early identification of ASD (Baio et al., 2018; Chelbowski et al., 2013; Oosterling et al., 2010; Robins et al., 2014), giving families options for earlier treatment and better outcomes.

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