# Chapter 1: Screening and Diagnosis

How Can We Improve Identification of Autism?

# Introduction

Aspirational Goal: Provide a timely diagnosis for people on the autism spectrum, so they can be linked to appropriate interventions, services, and supports to maximize positive outcomes.

Observational studies of infants with a high likelihood of developing ASD reveal that, although timing of the emergence of ASD features is variable, subtle signs can be detected within the first few years of life. Experienced clinicians who are trained to use validated diagnostic tools can diagnose ASD by 18-24 months of age. Still, the median age of diagnosis in children in the U.S. is four years, with disparities in diagnosis related to socioeconomic factors, geographic location, and race/ethnicity<sup>1</sup>. Given the unprecedented growth and organization of the brain during the first three years of life, behavioral interventions initiated in autistic toddlers within this time period are most likely to maximize positive outcomes. However, due to the lag in diagnosis, many children miss the opportunity to receive treatment during this critical period of brain development. This chapter reviews the state of knowledge about screening and diagnostic tools, as well as the current state of service delivery and challenges families face when trying to access screening and diagnostic services.

# Screening and Diagnostic Tools

Researchers have developed several tools for identifying children with ASD. These include screening tools that identify developmental delays and issues of concern, and diagnostic tools, which are fuller evaluations designed to provide a definitive indication of autism in an individual. The American Academy of Pediatrics <u>recommends</u> that children should be screened for ASD at ages 18 and 24 months during well-baby visits. The AAP also recommends that children should be screened for general developmental delays at 9, 18, and 30 months of age. By identifying children with potential traits of autism at these stages, it is possible to connect them to diagnostic and early intervention services as soon as possible.

## Screening Tools

The most commonly used parent-report screening tools are the *Modified Checklist for Autism in Toddlers* (M-CHAT) and its two revised versions, *Modified Checklist for Autism in Toddlers, Revised* (M-CHAT-R) and the *Modified Checklist for Autism in Toddlers, Revised, with Follow-Up* (M-CHAT-R/F). The M-CHAT and other similar screening tools are brief, making them ideal to be administered in primary care settings. In recent years, researchers have leveraged technology to administer screening instruments on digital platforms<sup>2,3</sup>. These studies have shown that a full administration of the M-CHAT-R/F) on a computer tablet not only resulted in greater and more accurate documentation of the screening results within electronic medical record system, but also reduced some of the time constraints involved in screening for ASD during well-baby visits<sup>4,5</sup>.

While the M-CHAT instrument and its revisions have many strengths, there are some challenges associated with their use. In particular, large-scale studies examining the efficacy of screening

demonstrate that the M-CHAT/F is less accurate in community settings than in clinical settings<sup>6</sup>. Many cases of ASD may be missed, especially in children younger than 24 months. This may be due to many factors, including: the accuracy of the screening tool, ability of parents to notice and report early signs of autism, readiness of parents to act on a positive autism screen, and the heterogeneity in symptom presentation at this young age. Recent studies have developed new screening tools designed for children as young as 12 months<sup>7</sup>,<sup>8</sup>. This and other screening instruments may reduce some of these detection issues and be better suited to individuals of particular age groups or populations. In the future, it will be important to further characterize and develop new screening tools to ensure that there are appropriate instruments for use across the full spectrum of autistic individuals and across the lifespan.

#### **Diagnostic Tools**

Once autism is suspected in an individual, they are typically referred for a diagnostic assessment. There are many diagnostic tools available, but the gold standard is to conduct a parent interview using an instrument such as the Autism Diagnostic Interview-Revised (ADI-R), and a clinician assessment of the individual using the activity-based Autism Diagnostic Observation Schedule-Second Edition (ADOS-2)<sup>9</sup>. The combination of these 2 instruments allows clinicians to get an accurate view of an individual's behaviors. The ADOS-2 includes 5 different modules that are targeted to different age groups (toddlers-adults) and verbal communication abilities<sup>10</sup>. Similar to screening tools, it is important to identify which existing diagnostic tools work best in individuals across the spectrum and across the lifespan.

## Telehealth Evaluation Tools

There are significant delays between when an individual first screens positive and when they are able to receive a diagnostic evaluation for ASD. These delays are largely due to a lack of developmentalbehavioral pediatricians or other providers trained to perform this assessment; in many cases families must wait months for an appointment and travel long distances from their homes to meet with an available provider. The COVID-19 pandemic has exacerbated these issues. Several studies have explored the use of telehealth methods to conduct diagnostic assessments for ASD<sup>11,12</sup>. One team of researchers has developed the TELE-ASD-PEDS tool, specifically in response to the COVID-19 pandemic, that mediates remote diagnostic evaluation of children with signs of autism<sup>13</sup>.

Surveys of clinicians using tele-assessment tools identified benefits and challenges of conducting assessments for autism remotely<sup>14,15</sup>. Benefits included increased child comfort and increased caregiver involvement. Some of the stated challenges include difficulty adapting to the absence of an in-person assessment, technological challenges, suitability of the child's home environment for assessment, and difficulty assessing older children or those with more subtle signs of autism. In some cases, clinicians report reduced confidence in their assessments made remotely rather than in person. In the future, it will be necessary to continue to enhance tools for remote assessment so that they can be better adapted to differing home environments and a wider range of individuals, including older children and adults. It will also be important to improve the training of clinicians on the use of these tools.

#### Universal Screening for ASD

Studies consistently report that screening using validated autism-specific parent-report tools can result in ASD detection as young as 12-18 months<sup>16</sup>, these tools are only used systematically within about 50% of primary care settings<sup>17</sup>. Reliance on using a standardized screening tool has even been shown to be more effective than pediatrician clinical judgment alone<sup>18</sup>. Thus, the American Academy of Pediatrics (AAP) has <u>recommended</u> universal ASD screening using standardized tools as the gold standard for detecting ASD and recognizes screening as a critical service need to improve early access to care. Barriers that prevent widespread uptake of parent-report and other screening tools within primary care settings include: lack of education and understanding of ASD, lack of familiarity with screeners, uncertainty about where to send a toddler with a test-positive screen, lack of effective and timely means of connecting families of individuals with ASD to available resources, and the extra time and resources required to utilize standardized screening tools<sup>19,20,21,22,23</sup>.

Although engagement in early treatment has been associated with a range of positive changes including increases in social orienting, language ability, and overall IQ<sup>24,25,26,27</sup>, no study has directly examined if children with ASD detected by early screening have better outcomes than those detected by other means, (e.g., parent or provider concern) an issue highlighted by the US Preventive Services Task Force (USPSTF) report on universal early screening<sup>28</sup>. However, such a study would require large representative samples from across the country to be randomly assigned to either a screening or nonscreening condition, and then followed to determine long-term outcomes and societal costs<sup>29</sup>. As an alternative to this type of study, the NIMH-funded ASD Pediatric, Early Detection, Engagement, and Services (ASD PEDS) Network investigated several new strategies to improve early access to screening, diagnosis, and treatment of autism among toddlers (ages 12-24 months). Preliminary findings from these five research projects suggest that routine universal early screening reduces the age of detection, increases early access to services, and is most beneficial for families from historically marginalized populations<sup>30,31</sup>. In addition, researchers in the NIMH Intramural Research Programs (IRP) collaborated on field testing an autism-specific early screening tool for children 12 to 36 months of age<sup>32</sup>. The collective results of this projects increase the evidence base for the benefits of universal screening, however, additional studies are still needed.

## Implementation of Screening and Diagnostic Tools and Services

While early detection is an essential step in the health care process for autism and deserves more research attention, it is just one step on the path to identification and eventual intervention. Families must actually follow through with subsequent diagnostic evaluation, then identify and engage with quality interventions. In order for screening to be effective, ample evaluation centers must be available with appropriate ASD diagnostic expertise. Indeed, uncertainty regarding where to send a toddler for an evaluation is a barrier to screening noted by over 75% of pediatricians<sup>33</sup>. Therefore, an increase in the number and accessibility of evaluation centers is necessary, based on population and expected rates of autism. Likewise, significant enhancement of the screening and evaluation system is meaningful only if high-quality treatment providers are available, accessible, and affordable. Some efforts have been made, such as "<u>Birth to Five: Watch Me Thrive!</u>", which is a coordinated Federal effort to raise awareness about the importance of universal early behavioral and developmental screening. This

resource offers a collection of research-based screening tools for children under the age of 5. However, there is still a need to investigate more cost-effective modes to deliver screening tools, such as those that are either partially or fully deployed by parents. Additional research is needed to identify key factors that must occur following a screen for ASD to increase the likelihood for successful engagement with intervention and services.

Potential improvements to early screening and diagnostic services will also call for the need to standardize policies regarding eligibility for IDEA Part C services, the Federal program that funds intervention services for children showing delays, including autism, from birth through 2 years of age. Generally, toddlers must first qualify for basic Part C services by exhibiting a particular state-mandated level of delay (usually a 25% delay in two or more areas), which often provides for just a few hours of speech or occupational therapy. Although autism is an automatic eligibility category, a child must be identified as either ASD or showing signs of ASD in a separate evaluation visit in order to be eligible to receive ASD-specific treatment. Currently, there are no guidelines mandating that all toddlers receiving Part C services should be examined for possible ASD. Even once a child is referred for an in-depth ASD evaluation, there are no policies regarding specific diagnostic and other evaluation tools that should be used to determine if a child is eligible for ASD-specific services. Unsurprisingly, many toddlers already receiving Part C services for a developmental delay have not been properly evaluated for ASD. Even more concerning, the vast majority of toddlers with ASD (at least 75%) who will go on to qualify for special education at school-age are still not identified in time to receive early intervention. Providing clear guidelines regarding ASD detection and subsequent treatment eligibility through Part C will help to eliminate these deficiencies.

# Early Signs and Biomarkers

In order to enable early linkages to services and interventions, it is critical to identify ASD at the earliest age possible, to enable early intervention and better long-term outcomes<sup>34</sup>. Studies have demonstrated that differences in brain development and function (e.g., eye gaze patterns, brain growth, and how different parts of the brain develop connections)<sup>35,36,37,38</sup> as well as some subtle behavioral differences (e.g. social communication and attention), emerge in the first months of life, before ASD symptoms begin to appear<sup>39,40,41,42</sup>. Many of these early signs were found in infants with a higher likelihood of developing ASD (e.g., having at least one sibling with ASD). There is a need to determine whether these early signs are also evident for infants who are not categorized as high likelihood for ASD. Thus, further studies to develop and validate new ASD screening methods that can be used on infants and toddlers will be important. Large-scale studies are examining methods to identify likelihood of ASD within the first year of life, to test strategies for universal screening, expedited diagnosis, and engagement with intervention. In addition, ongoing research is aimed at translating early screening methods for infants into practical, efficient, and inexpensive tools that could be implemented in the general population and within community settings. For example, a recent study has developed a screening tool that uses computer vision analysis to analyze toddler facial expressions or eye gaze patterns while they use a mobile device<sup>43</sup>,<sup>44</sup>. Another group has identified "digital biomarkers," patterns of previous medical encounters in electronic health records, that are predictive of a later autism diagnosis<sup>45</sup>.

Researchers are also considering the potential of pre-symptomatic intervention, which is starting intervention before signs of autism are fully apparent<sup>46</sup>. The goal in any such intervention would be to target brain development during the period when it is most adaptable to change. The identification and characterization of early biomarkers will be critical for any efforts in this realm. Given the potential ethical, social, and legal implications, the concept of pre-symptomatic interventions may be somewhat controversial. Therefore, it will be crucial to fully engage the autism community during the development of any such interventions.

# Disparities in ASD Screening and Diagnosis

Research has demonstrated several disparities in the process of ASD screening and diagnosis, based on factors such as race/ethnicity, primary language spoken, maternal education, and private vs. public insurance<sup>47,48,49,50,51,52</sup>. In addition, economic challenges, geographic distance between families and service providers, reduced professional resources and capacity, and characteristics impacted by cultural knowledge, such as stigma often contribute to diminished service availability and utilization in rural, minority, or other disadvantaged communities<sup>53,54,55,56</sup>. Examining and understanding these differences will be critical in reducing disparities in screening and diagnosis.

## Disparities in ASD Screening

The barriers that limit screening during well-child visits have immediate service access implications for children from diverse backgrounds. Overall, ASD screening rates during primary care visits vary greatly among primary care settings; some of the variability in use of standardized screening is based on children's sociodemographic characteristics. Research has shown that children from minority backgrounds are diagnosed on average more than a year later than their White peers<sup>57,58</sup>. However, it has been demonstrated that universal screening for ASD following a standardized protocol, including immediate referral for screen-positive cases, drastically reduces disparities in age of diagnosis<sup>59,60,61</sup>. Therefore, access to screening for all children, regardless of sociodemographic characteristics, is crucial to reduce existing disparities that may impact life-long outcomes. Dedicating more resources to early screening in underserved communities, with a corresponding increase in funding for evidence-based diagnostic evaluations, will avoid lengthening waitlists and thereby link individuals to interventions and services more quickly.

## Culturally-Competent Screening Instruments

A number of studies have examined ASD screening tools in different languages and cultural settings within the US and across the world<sup>62,63,64,65,66</sup>. The variability of results from these studies indicate that there is a need for additional research to adapt tools that will be valid (i.e., demonstrate adequate sensitivity and specificity) in diverse populations. Factors including low educational attainment, language/literacy, rural versus urban locale, race, and ethnicity also impact screening reliability and validity as well as screen-positive rates. Studies examining medical or state records for specific mention of ASD screening and diagnosis would be helpful in documenting disparities and also in tracking improvements based on policy changes or improved access to care.

It will be critical to evaluate the quality of screening instruments and programs in diverse samples of individuals, including long-term outcomes. Implementation studies examining the translation from research settings to community settings with diverse populations, including examining fidelity of adhering to screening protocols, also is a critical gap in the existing literature<sup>67,68,69</sup>.

#### Disparities in Access to Diagnostic Services and Age of Diagnosis

Differences both in prevalence rates and age of diagnosis by sociodemographic characteristics likely relate to disparities in access to expert services. While the most recent prevalence data of 8-year-old children from the Centers for Disease Control and Prevention's (CDC) Autism and Developmental Disorders Monitoring (ADDM) Network suggests that rates of ASD diagnosis are similar among White, Black, Hispanic, and Asian/Pacific Islander children, there was still some variability among racial/ethnic groups based on the presence of an intellectual disability<sup>1</sup>. In the CDC's recent expansion of prevalence monitoring to 4-year-old children, they found that rates of ASD diagnosis were higher in Black, Hispanic, and Asian/Pacific Islander children than in White children<sup>70</sup>. Additionally, there are still disparities in age of diagnosis for racial/ethnic minorities <sup>71</sup>.

A primary barrier to ASD early diagnosis is the limited availability of diagnostic clinics with providers trained in ASD diagnosis, leading to long waiting lists and poor reimbursement for comprehensive diagnosis<sup>72</sup>. This limited availability is especially pronounced in resource-poor and rural areas, with many children not diagnosed until entry into the school system. In addition, family level variables such as insufficient financial resources, lack of insurance coverage, language barriers, geographic isolation, and limited knowledge of or experience with complex healthcare systems, may be barriers to the timely diagnostic evaluation of a child<sup>73</sup>. Overall, there is limited research that documents these systemic- and individual-level barriers that exist from early ASD screening to appropriate diagnosis to early intervention. While recent prevalence data from the CD ADDM Network has demonstrated that universal screening can reduce disparities in prevalence<sup>74</sup>, it is still important to demonstrate that universal screening can subsequently reduce disparities in long-term outcomes for individuals with ASD.

Practitioner efforts that can help to reduce disparities in diagnosis include increasing psychoeducation to raise awareness and reduce stigma, building external professional networks, promoting continuing education programs, using alternative service delivery models when appropriate (e.g., telehealth, web-based, community health workers) or settings (e.g., schools, child care centers, mobile clinics) for screening/diagnosis, and providing wraparound services that address additional stresses (e.g., chronic illness, unemployment, lack of insurance) often faced by individuals in underserved communities. Finally, it is clear that children are not often well-tracked from the time of ASD screening to receipt of services, these tools are dependent on reliable internet service which is often unattainable for low-income and geographically isolated families<sup>76</sup>. It is imperative to have a system in place that can assure children and families adequate, timely, and appropriate services as they move through the identification, referral, and treatment process.

## Validity of Diagnostic Instruments Across Special Populations

There is general agreement that the best approach to ASD diagnosis includes both parent interview and an observational assessment of the child, such as the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS-2). The ADI-R has been translated into 17 languages, and a small number of studies have examined the validity of the ADI-R in different countries with varying results<sup>77,78,79,80</sup>. With respect to validation studies with diverse populations in the US, researchers found that the sensitivity and specificity of the ADI-R with a US-based Spanish-speaking population of parents of children with ASD were lower than values previously reported for mostly White, middle-class respondents<sup>81,82</sup>. The communication domains were found to be especially problematic for parents whose primary language was Spanish when reporting on children who spoke mainly English. Little is known about the validity of the ADI-R among low-income families in the US. The ADOS-2 has been translated into 19 different languages; however, cross-cultural validation studies of the ADOS-2 have not been identified.

The development of screening and diagnostic tools has largely been accomplished using data from boys, which might put other underserved populations of ASD at a disproportionate risk of not receiving a clinical diagnosis. Based on recent literature, there appears to be a diagnostic gender bias, which means that girls are less likely than boys to meet diagnostic criteria for ASD at comparatively high levels of autistic-like traits<sup>83,84</sup>. Girls may also exhibit different symptoms from boys, which may make current screening and diagnostic tools more likely to miss ASD in girls<sup>85,86,87</sup>. It is important that future research addresses the gender differences in ASD, both biological and behavioral, in the development of diagnostic tools.

Also at risk of being underdiagnosed are individuals with ASD that have other co-occurring developmental conditions. About one-third of children with ASD also have an intellectual disability<sup>1</sup>, and many individuals with ASD have a dual diagnosis of attention-deficit/hyperactivity disorder (ADHD); having multiple conditions often leads to a misdiagnosis or a delayed ASD diagnosis<sup>88</sup>. While research is necessary to develop tools that account for the overlap in symptomology, health providers must consider multiple diagnoses during evaluation.

In addition, increasing numbers of adults are presenting to clinics for first-time diagnoses of ASD, and recent studies suggest that many adults with ASD may be unidentified and living in the community without appropriate supports<sup>89,90</sup>. There is a need to improve diagnostic tools that are specific for adults; this will be discussed in more detail in Chapter 6: How can we meet the needs of people with ASD as they progress into and through adulthood?

# Workforce

The increased prevalence of diagnosed ASD cases has led to a need for a larger workforce trained in the identification and diagnosis of these disorders, including psychologists, psychiatrists, developmental pediatricians, neurologists, and speech and language pathologists. Early detection of ASD will require training those professionals who come in regular contact with young children, including primary care

providers and child care providers, to incorporate effective screening and referrals in their daily practice patterns.

Evidence demonstrates that healthcare professionals are less likely to detect ASD using developmental surveillance without the use of screening tools. Even experienced professionals may miss or misjudge symptoms during a brief observation<sup>91</sup>. However, primary care providers face barriers to implementing screening that include the time necessary to identify ASD, the cost of conducting screening and the reimbursement for this work, and having appropriately trained personnel in their offices or referral networks. Also, practitioners may lack the technical training to review and compare complex psychometric information on the quality of developmental screening tools. Training for this workforce is needed to improve their ability to screen effectively, recognize ASD symptoms, communicate clearly with parents, and refer appropriately for evaluation and intervention services.

Parents may not recognize signs of developmental delay, or they may have concerns about their child's development but do not know how or when to act on those concerns. There is a need to raise public awareness of the early signs of ASD, to encourage parents to observe and track their child's development, and to encourage them to discuss their concerns with their child's doctor, teachers, and other care providers. The "Learn the Signs. Act Early." campaign developed by CDC, and the <u>Autism</u> <u>Navigator</u> project developed by researchers at Florida State University, and the <u>Baby Siblings Research</u> <u>Consortium</u>, are examples of resources can be used to raise awareness and facilitate parent-provider collaborations. However, there is still a critical research gap on understanding how parent concerns can impact parent engagement in acting on referral for diagnosis and early intervention.

Addressing gaps in our understanding of how healthcare professionals can best reach families from underserved communities continues to be a challenge. There is an opportunity to improve the identification of ASD through materials prepared in languages spoken by target groups within these communities, but even more important are efforts to implement culturally competent practices and engage a workforce with greater cultural diversity in order to better address the needs of culturally diverse populations. For example, outreach activities held in places of worship and other community gatherings where families feel more comfortable may improve parent-provider partnerships and lead to increased identification of ASD.

Some important service initiatives to address screening and diagnosis training are ongoing, but there is a need for additional efforts. The AAP supports universal screening for ASD and provides training to pediatric providers through several formats (publications, webinars, and face-to-face conferences). Leadership Education in Neurodevelopmental and Related Disabilities (LEND) and the University Centers of Excellence in Developmental Disabilities (UCEDDs) also provide training to practitioners from over a dozen healthcare disciplines. Despite the recommended guidelines for utilizing these resources, the professional community is not reaching most of the families and children in need of early intervention. Therefore, service-relevant policies need to make professional development and training more available as well as dedicate more resources in order to expand the workforce to address unmet needs for early screening and diagnostic services, including access to care. Furthermore, there is a need for improved

policies to facilitate the collaboration of community-based programs and social supports with professional services.

# Systems Navigation

It is critically important that children with ASD are identified early so they can be referred to intervention programs that address their individual needs. Eligibility criteria and the lead agency for early intervention vary by state (health agencies in some states, and child welfare or education agencies in other states). Similarly, some states or regions have more comprehensive insurance coverage and/or more coordinated systems of healthcare than others. Even in better-resourced areas, families are often faced with many complex steps from screening to diagnosis to treatment. As a result, many infants and toddlers with ASD miss the opportunity to engage in early intervention services while they are age-eligible. There is a need to improve access to early screening and to increase the accuracy of screening tools because these are the gateway to early intervention services. Coordination of a care team that includes healthcare and childcare providers is critical to address gaps in screening, begin to bre ak down barriers for families to act on screening results, and support family engagement in intervention services.

Currently, families must navigate different sectors of service in terms of information, provision, and funding (e.g., medical providers, local government, education) all within a very short period of time (from noted concern to early intervention age eligibility cut-offs). The different service sectors often are not well-coordinated and do not communicate with each other, particularly across health and social service agencies. Systematic barriers for families include considerable differences in the type and amount of services supported by insurance plans, geographic differences in type and amount of services available, and inequities and disparities existing across counties and states. Several studies have highlighted the importance of systems navigation, which assists individuals and their families with accessing and coordinating diagnostic and intervention services. In one study, core components of the Family Navigation model were identified that were essential to families seeking autism services<sup>92</sup>. Importantly, use of this model was shown to reduce racial/ethnic disparities in the length of time to diagnostic evaluation<sup>93</sup>.

There are remaining systemic issues to be addressed in order to improve the screening and diagnosis process for all individuals. For example, some insurance plans do not cover quality interventions, such as applied behavior analysis (ABA), or may place limits on essential behavioral, medical, or other healthcare. Nearly half of children with ASD have private insurance; most others have insurance provided by Medicaid or the state-based <u>Children's Health Insurance Program (CHIP)</u>, or dual private and public coverage<sup>94</sup>. However, over one-third of families of children with ASD report that their insurance coverage is inadequate to meet their myriad of complex needs and costs. As noted earlier, reimbursement for ASD screening may improve screening rates and more readily become a standard procedure in practices. In addition, systems do not take into account families' concerns about stigma, the reluctance of professionals to make a diagnosis or share concerns about red flags of ASD in very young children, missed or false positive diagnoses, and the need for earlier evaluations and re-evaluations of very early assessments as symptoms are unfolding. It is critically important for researchers and service providers to address these issues in order to improve accessibility and equity.

# Summary

Significant advances have been made toward early identification of individuals with ASD, so they can be linked to appropriate interventions, services, and supports in as timely a manner as possible. However, gaps still remain. There is a need to validate tools in diverse settings, particularly in community primary care practices in low-resource areas. There is a need to evaluate the effectiveness of universal screening for improving outcomes in autistic individuals. There is a great need to understand the disparities in access and/or utilization of screening and diagnostic tools, and entry into intervention services. In addition, research is needed to develop, adapt, and validate tools that will improve detection of autism in special populations, including children with intellectual disabilities, girls, and adults. The challenges and barriers include gaps in the evidence base for the benefits of early detection in diverse populations and settings; an insufficient workforce with expertise in ASD diagnosis and intervention; lack of medical home for families of children on the autism spectrum; the need for continued insurance reform; disparate and uncoordinated service sectors; and the lack of an infrastructure to track children and families in order to evaluate the efficacy of service systems. There have been important strides in the area of early detection of autism features and in demonstrating the impact of early intervention. Yet, there are significant challenges and barriers to implementing screening, diagnostic, and treatment services broadly and reducing disparities in access and utilization.

# Objectives

## OBJECTIVE 1: Support research on how early detection of autism influences outcomes.

Examples:

- Implement innovative designs to evaluate the benefit of universal screening for autism.
- Conduct studies focusing on the differences and needs of special populations such as girls and women, underrepresented minorities, individuals with intellectual disabilities, and adults.
- Conduct research to better understand and develop strategies to address reasons for lack of compliance with screening recommendations; address barriers to universal screening.

## **OBJECTIVE 2: Reduce disparities in early detection and access to services.**

## Examples:

- Improve family engagement and help build an awareness of healthy developmental milestones and signs of concern.
- Demonstrate the validity of different screening and diagnostic tools for culturally diverse communities.
- Increase services in underserved and under-resourced regions; improve inclusion of these populations in research.

- Address differences in state policy requirements for Medicaid and the requirement of a diagnosis to receive services.
- Develop a culturally competent and more culturally diverse workforce.

# OBJECTIVE 3: Develop and improve tools, methods, and service delivery models for detecting autism in a variety of populations, including strategies that engage caregivers.

Examples:

- Increase coordination and personalization of screening, diagnosis, and early intervention services through use of the medical home model, person-centered planning, or other service models.
- Analyze the impact of insurance reform and national policy on coverage for screening, diagnosis, and intervention for autistic individuals and their families.
- Evaluate innovative service delivery methods (e.g., use of technology) to improve detection methods and increase access.
- Continue research on the potential translation of biomarker findings into valid and reliable screening or diagnostic tools.
- Develop cost-effective methods to deploy biomarker-mediated screening and diagnostic tools in community settings.

#### References

<sup>1</sup> Maenner MJ, Shaw KA, Bakian AV, Bilder DA, Durkin MS, Esler A, Furnier SM, Hallas L, Hall-Lande J, Hudson A, Hughes MM, Patrick M, Pierce K, Poynter JN, Salinas A, Shenouda J, Vehorn A, Warren Z, Constantino JN, DiRienzo M, Fitzgerald RT, Grzybowski A, Spivey MH, Pettygrove S, Zahorodny W, Ali A, Andrews JG, Baroud T, Gutierrez J, Hewitt A, Lee LC, Lopez M, Mancilla KC, McArthur D, Schwenk YD, Washington A, Williams S, Cogswell ME. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. MMWR Surveill Summ. 2021 Dec 3;70(11):1-16. [PMID: 34855725]

<sup>2</sup> Campbell K, Carpenter KLH, Espinosa S, Hashemi J, Qiu Q, Tepper M, Calderbank R, Sapiro G, Egger HL, Baker JP, Dawson G. Use of a Digital Modified Checklist for Autism in Toddlers - Revised with Follow-up to Improve Quality of Screening for Autism. J Pediatr. 2017 Apr;183:133-139.e1. [PMID: 28161199]

<sup>3</sup> Steinman KJ, Stone WL, Ibañez LV, Attar SM. Reducing Barriers to Autism Screening in Community Primary Care: A Pragmatic Trial Using Web-Based Screening. Acad Pediatr. 2022 Mar;22(2):263-270. [PMID: 33901728]

<sup>4</sup> Campbell K, Carpenter KL, Espinosa S, Hashemi J, Qiu Q, Tepper M, Calderbank R, Sapiro G, Egger HL, Baker JP, Dawson G. Use of a Digital Modified Checklist for Autism in Toddlers - Revised with Follow-up to Improve Quality of Screening for Autism. *J Pediatr*. 2017 Apr;183:133-139.e1. [PMID: 28161199]

<sup>5</sup> Major S, Campbell K, Espinosa S, Baker JP, Carpenter KL, Sapiro G, Vermeer S, Dawson G. Impact of a digital Modified Checklist for Autism in Toddlers-Revised on likelihood and age of autism diagnosis and referral for developmental evaluation. Autism. 2020 Oct;24(7):1629-1638. [PMID: 32466674]

<sup>6</sup> Guthrie W, Wallis K, Bennett A, Brooks E, Dudley J, Gerdes M, Pandey J, Levy SE, Schultz RT, Miller JS. Accuracy of Autism Screening in a Large Pediatric Network. Pediatrics. 2019 Oct;144(4):e20183963. [PMID: 31562252]

<sup>7</sup> Wetherby AM, Guthrie W, Hooker JL, Delehanty A, Day TN, Woods J, Pierce K, Manwaring SS, Thurm A, Ozonoff S, Petkova E, Lord C. The Early Screening for Autism and Communication Disorders: Field-testing an autism-specific screening tool for children 12 to 36 months of age. Autism. 2021 Oct;25(7):2112-2123. [PMID: 33962531]

<sup>8</sup> Meera SS, Donovan K, Wolff JJ, Zwaigenbaum L, Elison JT, Kinh T, Shen MD, Estes AM, Hazlett HC, Watson LR, Baranek GT, Swanson MR, St John T, Burrows CA, Schultz RT, Dager SR, Botteron KN, Pandey J, Piven J; IBIS Network. Towards a Data-Driven Approach to Screen for Autism Risk at 12 Months of Age. J Am Acad Child Adolesc Psychiatry. 2021 Aug;60(8):968-977. [PMID: 33161063]

<sup>9</sup> Huerta M, Lord C. Diagnostic evaluation of autism spectrum disorders. *Pediatric Clinics of North America*. 2012; 59(1), 103-111.

<sup>10</sup> Lord C, Rutter M, DiLavore PC, Risi S, Gotham K, Bishop SL. Autism Diagnostic Observation Schedule. 2nd. Torrance, CA: Western Psychological Services; 2012. <sup>11</sup> Alfuraydan M, Croxall J, Hurt L, Kerr M, Brophy S. Use of telehealth for facilitating the diagnostic assessment of Autism Spectrum Disorder (ASD): A scoping review. PLoS One. 2020 Jul 23;15(7):e0236415. [PMID: 32702017]

<sup>12</sup> Berger NI, Wainer AL, Kuhn J, Bearss K, Attar S, Carter AS, Ibanez LV, Ingersoll BR, Neiderman H, Scott S, Stone WL. Characterizing Available Tools for Synchronous Virtual Assessment of Toddlers with Suspected Autism Spectrum Disorder: A Brief Report. J Autism Dev Disord. 2022 Jan;52(1):423-434. [PMID: 33606157]

<sup>13</sup> Wagner L, Corona LL, Weitlauf AS, Marsh KL, Berman AF, Broderick NA, Francis S, Hine J, Nicholson A, Stone C, Warren Z. Use of the TELE-ASD-PEDS for Autism Evaluations in Response to COVID-19: Preliminary Outcomes and Clinician Acceptability. J Autism Dev Disord. 2021 Sep;51(9):3063-3072. [PMID: 33125622]

<sup>14</sup> Wagner L, Weitlauf AS, Hine J, Corona LL, Berman AF, Nicholson A, Allen W, Black M, Warren Z. Transitioning to Telemedicine During COVID-19: Impact on Perceptions and Use of Telemedicine Procedures for the Diagnosis of Autism in Toddlers. J Autism Dev Disord. 2022 May;52(5):2247-2257. [PMID: 34085153]

<sup>15</sup> Gibbs V, Cai RY, Aldridge F, Wong M. Autism assessment via telehealth during the Covid 19 pandemic:
 Experiences and perspectives of autistic adults, parents/carers and clinicians. Res Autism Spectr Disord.
 2021 Oct;88:101859. [PMID: 34512797]

<sup>16</sup> Zwaigenbaum L, Bauman ML, Fein D, Pierce K, Buie T, Davis PA, Newschaffer C, Robins DL, Wetherby A, Choueiri R, Kasari C, Stone WL, Yirmiya N, Estes A, Hansen RL, McPartland JC, Natowicz MR, Carter A, Granpeesheh D, Mailloux Z, Smith Roley S, Wagner S. Early Screening of Autism Spectrum Disorder: Recommendations for Practice and Research. *Pediatrics*. 2015 Oct;136 Suppl 1:S41-59. [PMID: 26430169]

<sup>17</sup> Arunyanart W, Fenick A, Ukritchon S, Imjaijtt W, Northrup V, Weitzman C. Developmental and Autism Screening: A Survey Across Six States. *Infants and Young Children*. 2012;25(3):175-187.

<sup>18</sup> Miller JS, Gabrielsen T, Villalobos M, Alleman R, Wahmhoff N, Carbone PS, Segura, B. The each child study: systematic screening for autism spectrum disorders in a pediatric setting. *Pediatrics*. 2011 May;127(5):866-871. [PMID: 21482605]

<sup>19</sup> Fenikilé TS, Ellerbeck K, Filippi MK, Daley CM. Barriers to autism screening in family medicine practice: a qualitative study. *Prim Health Care Res Dev*. 2015 Jul;16(4):356-366. [PMID: 25367194]

<sup>20</sup> Elder JH, Brasher S, Alexander B. Identifying the Barriers to Early Diagnosis and Treatment in Underserved Individuals with Autism Spectrum Disorders (ASD) and Their Families: A Qualitative Study. Issues *Ment Health Nurs*. 2016 Jun;37(6): 412-420. [PMID: 27070190]

<sup>21</sup> Dosreis S, Weiner CL, Johnson L, Newschaffer CJ. Autism spectrum disorder screening and management practices among general pediatric providers. *J Dev Behav Pediatr*. 2006 Apr;27(2 Suppl):S88-94. [PMID: 16685190]

<sup>22</sup> Carbone PS, Norlin C, Young PC. Improving Early Identification and Ongoing Care of Children With Autism Spectrum Disorder. *Pediatrics*. 2016 Jun;137(6). [PMID: 27244841]

<sup>23</sup> Van Cleave J, Morales DR, Perrin JM. Pediatric response to court-mandated Medicaid behavioral screening in Massachusetts. *J Dev Behav Pediatr*. 2013 Jun;34(5):335-343. [PMID: 23751887]

<sup>24</sup> Wetherby AM, Guthrie W, Woods J, Schatschneider C, Holland RD, Morgan L, Lord, C.
 Parentimplemented social intervention for toddlers with autism: an RCT. *Pediatrics*. 2014
 Dec;134(6):1084-1093. [PMID: 25367544]

<sup>25</sup> Dawson G, Rogers S, Munson J, Smith M, Winter J, Greenson J, Donaldson A, Varley J. Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. *Pediatrics*. 2010 Jan;125(1):e17-23. [PMID: 19948568]

<sup>26</sup> Brian JA, Smith IM, Zwaigenbaum L, Roberts W, Bryson SE. The Social ABCs caregiver-mediated intervention for toddlers with autism spectrum disorder: Feasibility, acceptability, and evidence of promise from a multisite study. *Autism Res. 20*16 Aug;9(8):899-912. [PMID: 26688077]

<sup>27</sup> Miller M, Iosif AM, Young GS, Hill M, Phelps Hanzel E, Hutman T, Johnson S, Ozonoff S. School-age outcomes of infants at risk for autism spectrum disorder. *Autism Res.* 2016 Jun;9(6):632-42. [PMID: 26451968]

<sup>28</sup> Siu AL, Bibbins-Domingo K, Grossman DC, Baumann LC, Davidson KW, Ebell M, García FA, Gillman M, Herzstein J, Kemper AR, Krist AH, Kurth AE, Owens DK, Phillips WR, Phipps MG, Pignone MP. Screening for Autism Spectrum Disorder in Young Children: US Preventive Services Task Force Recommendation Statement. *JAMA*. 2016 Feb 16;315(7):691-696. [PMID: 26881372]

<sup>29</sup> Dawson G. Why It's Important to Continue Universal Autism Screening While Research Fully Examines Its Impact. JAMA Pediatr. 2016 Jun 1;170(6):527-8. [PMID: 26882277]

<sup>30</sup> Pierce K, Gazestani VH, Bacon E, Barnes CC, Cha D, Nalabolu S, Lopez L, Moore A, Pence-Stophaeros S, Courchesne E. Evaluation of the Diagnostic Stability of the Early Autism Spectrum Disorder Phenotype in the General Population Starting at 12 Months. JAMA Pediatr. 2019 Jun 1;173(6):578-587. [PMID: 31034004]

<sup>31</sup> Sheldrick RC, Carter AS, Eisenhower A, Mackie TI, Cole MB, Hoch N, Brunt S, Pedraza FM. Effectiveness of Screening in Early Intervention Settings to Improve Diagnosis of Autism and Reduce Health Disparities. JAMA Pediatr. 2022 Mar 1;176(3):262-269. [PMID: 34982099]

<sup>32</sup> Wetherby AM, Guthrie W, Hooker JL, Delehanty A, Day TN, Woods J, Pierce K, Manwaring SS, Thurm A, Ozonoff S, Petkova E, Lord C. The Early Screening for Autism and Communication Disorders: Field-testing an autism-specific screening tool for children 12 to 36 months of age. Autism. 2021 Oct;25(7):2112-2123. [PMID: 33962531]

<sup>33</sup> Carbone PS, Norlin C, Young PC. Improving EarlyIdentification and Ongoing Care of Children With Autism Spectrum Disorder. Pediatrics. 2016 Jun;137(6):e20151850. [PMID: 27244841]

<sup>34</sup> Towle PO, Patrick PA, Ridgard T, Pham S, Marrus J. Is Earlier Better? The Relationship between Age When Starting Early Intervention and Outcomes for Children with Autism Spectrum Disorder: A Selective Review. Autism Res Treat. 2020 Aug 3;2020:7605876. [PMID: 32832154]

<sup>35</sup> Girault JB, Donovan K, Hawks Z, Talovic M, Forsen E, Elison JT, Shen MD, Swanson MR, Wolff JJ, Kim SH, Nishino T, Davis S, Snyder AZ, Botteron KN, Estes AM, Dager SR, Hazlett HC, Gerig G, McKinstry R, Pandey J, Schultz RT, St John T, Zwaigenbaum L, Todorov A, Truong Y, Styner M, Pruett JR Jr, Constantino JN, Piven J; IBIS Network. Infant Visual Brain Development and Inherited Genetic Liability in Autism. Am J Psychiatry. 2022 May 26:appiajp21101002. [PMID: 35615814]

<sup>36</sup> Emerson RW, Adams C, Nishino T, Hazlett HC, Wolff JJ, Zwaigenbaum L, Constantino JN, Shen MD, Swanson MR, Elison JT, Kandala S, Estes AM, Botteron KN, Collins L, Dager SR, Evans AC, Gerig G, Gu H, McKinstry RC, Paterson S, Schultz RT, Styner M; IBIS Network, Schlaggar BL, Pruett JR Jr, Piven J. Functional neuroimaging of high-risk 6-month-old infants predicts a diagnosis of autism at 24 months of age. Sci Transl Med. 2017 Jun 7;9(393):eaag2882. [PMID: 28592562]

<sup>37</sup> Hazlett HC, Gu H, Munsell BC, Kim SH, Styner M, Wolff JJ, Elison JT, Swanson MR, Zhu H, Botteron KN, Collins DL, Constantino JN, Dager SR, Estes AM, Evans AC, Fonov VS, Gerig G, Kostopoulos P, McKinstry RC, Pandey J, Paterson S, Pruett JR, Schultz RT, Shaw DW, Zwaigenbaum L, Piven J; IBIS Network; Clinical Sites; Data Coordinating Center; Image Processing Core; Statistical Analysis. Early brain development in infants at high risk for autism spectrum disorder. Nature. 2017 Feb 15;542(7641):348-351. [PMID: 28202961]

<sup>38</sup> Shen MD, Kim SH, McKinstry RC, Gu H, Hazlett HC, Nordahl CW, Emerson RW, Shaw D, Elison JT, Swanson MR, Fonov VS, Gerig G, Dager SR, Botteron KN, Paterson S, Schultz RT, Evans AC, Estes AM, Zwaigenbaum L, Styner MA, Amaral DG, Piven J, Hazlett HC, Chappell C, Dager S, Estes A, Shaw D, Botteron K, McKinstry R, Constantino J, Pruett J, Schultz R, Zwaigenbaum L, Elison J, Evans AC, Collins DL, Pike GB, Fonov V, Kostopoulos P, Das S, Gerig G, Styner M, Gu H, Piven J; Infant Brain Imaging Study Network. Increased Extra-axial Cerebrospinal Fluid in High-Risk Infants Who Later Develop Autism. Biol Psychiatry. 2017 Aug 1;82(3):186-193. [PMID: 28392081]

<sup>39</sup> Ozonoff S, Young GS, Landa RJ, Brian J, Bryson S, Charman T, Chawarska K, Macari SL, Messinger D, Stone WL, Zwaigenbaum L, Iosif AM. Diagnostic stability in young children at risk for autism spectrum disorder: a baby siblings research consortium study. *J Child Psychol Psychiatry*. 2015 Sep;56(9):988-998. [PMID: 25921776]

<sup>40</sup> Plumb AM, Wetherby AM. Vocalization Development in Toddlers with Autism Spectrum Disorder. *J* Speech Lang Hear Res. 2013 Apr;56(2): 721-34. [PMID: 23275403]

<sup>41</sup> Zwaigenbaum L, Bauman ML, Stone WL, Yirmiya N, Estes A, Hansen RL, McPartland JC, Natowicz MR, Choueiri R, Fein D, Kasari C, Pierce K, Buie T, Carter A, Davis PA, Granpeesheh D, Mailloux Z, Newschaffer C, Robins D, Roley SS, Wagner S, Wetherby A. Early Identification of Autism Spectrum Disorder: Recommendations for Practice and Research. *Pediatrics*. 2015 Oct;136 Suppl 1:S10-40. [PMID: 26430168] <sup>42</sup> Jones W, Klin A. Attention to eyes is present but in decline in 2-6-month-old infants later diagnosed with autism. Nature. 2013 Dec 19;504(7480):427-31. [PMID: 24196715]

<sup>43</sup> Carpenter KLH, Hahemi J, Campbell K, Lippmann SJ, Baker JP, Egger HL, Espinosa S, Vermeer S, Sapiro G, Dawson G. Digital Behavioral Phenotyping Detects Atypical Pattern of Facial Expression in Toddlers with Autism. Autism Res. 2021 Mar;14(3):488-499. [PMID: 32924332]

<sup>44</sup> Chang Z, Di Martino JM, Aiello R, Baker J, Carpenter K, Compton S, Davis N, Eichner B, Espinosa S, Flowers J, Franz L, Harris A, Howard J, Perochon S, Perrin EM, Krishnappa Babu PR, Spanos M, Sullivan C, Walter BK, Kollins SH, Dawson G, Sapiro G. Computational Methods to Measure Patterns of Gaze in Toddlers With Autism Spectrum Disorder. JAMA Pediatr. 2021 Aug 1;175(8):827-836. [PMID: 33900383]

<sup>45</sup> Onishchenko D, Huang Y, van Horne J, Smith PJ, Msall ME, Chattopadhyay I. Reduced false positives in autism screening via digital biomarkers inferred from deep comorbidity patterns. Sci Adv. 2021 Oct 8;7(41):eabf0354. [PMID: 34613766]

<sup>46</sup> Grzadzinski R, Amso D, Landa R, Watson L, Guralnick M, Zwaigenbaum L, Deák G, Estes A, Brian J, Bath K, Elison J, Abbeduto L, Wolff J, Piven J. Pre-symptomatic intervention for autism spectrum disorder (ASD): defining a research agenda. J Neurodev Disord. 2021 Oct 15;13(1):49. [PMID: 34654371]

<sup>47</sup> Zuckerman KE, Mattox K, Donelan K, Batbayar O, Baghaee A, Bethell C. Pediatrician identification of Latino children at risk for autism spectrum disorder. *Pediatrics*. 2013 Sep;132(3):445-53. [<u>PMID:</u> <u>23958770</u>]

<sup>48</sup> Robins DL, Fein D, Barton M. The Modified Checklist for Autism in Toddlers (M-CHAT). Self-published. 1999; <u>http://mchatscreen.com/</u>

<sup>49</sup> Robins DL, Fein D, Barton M. The Modified Checklist for Autism in Toddlers, Revised, with Follow-up (M-CHAT-R/F). Self-published. 2009; <u>http://mchatscreen.com/</u>

<sup>50</sup> Khowaja MK, Hazzard AP, Robins DL. Sociodemographic Barriers to Early Detection of Autism: Screening and Evaluation Using the M-CHAT, M-CHAT-R, and Follow-Up. *J Autism Dev Disord*. 2015 Jun;45(6):1797-808. [PMID: 25488122]

<sup>51</sup> Bethell CD, Kogan MD, Strickland BB, Schor EL, Robertson J, Newacheck PW. A national and state profile of leading health problems and health care quality for US children: key insurance disparities and across-state variations. *Acad Pediatr*. 2011 May-Jun;11(3 Suppl):S22-33. [PMID: 21570014]

<sup>52</sup> Yingling ME, Ruther MH, Dubuque EM. Trends in Geographic Access to Board Certified Behavior Analysts Among Children with Autism Spectrum Disorder, 2018-2021. J Autism Dev Disord. 2022 Jan 5:1–8. [PMID: 34985719]

<sup>53</sup> Khowaja MK, Hazzard AP, Robins DL. Sociodemographic Barriers to Early Detection of Autism: Screening and Evaluation Using the M-CHAT, M-CHAT-R, and Follow-Up. *J Autism Dev Disord*. 2015 Jun;45(6):1797-808. [PMID: 25488122]

<sup>54</sup> Kiani R, Tyrer F, Hodgson A, Berkin N, Bhaumik S. Urban–rural differences in the nature and prevalence of mental ill-health in adults with intellectual disabilities. *J Intellect Disabil Res*. 2013 Feb;57(2):119-27. [PMID: 22292906]

<sup>55</sup> Janvier YM, Harris JF, Coffield CN, Louis B, Xie M, Cidav Z, Mandell, DS. Screening for autism spectrum disorder in underserved communities: Early childcare providers as reporters. *Autism*. 2016 Apr;20(3):364-73. [PMID: 25991845]

<sup>56</sup> Bates BR, Graham D, Striley K, Patterson S, Arora A, Hamel-Lambert J. Examining antecedents of caregivers' access to early childhood developmental screening: Implications for campaigns promoting use of services in appalachian Ohio. *Health Promot Pract*. 2014 May;15(3):413-21. [PMID: 23479038]

<sup>57</sup> Esler AN, Sample J, Hall-Lande J, Harris B, Rice C, Poynter J, Kirby RS, Wiggins L. Patterns of Special Education Eligibility and Age of First Autism Spectrum Disorder (ASD) Identification Among US Children with ASD. J Autism Dev Disord. 2022 Feb 25. [PMID: 35212866]

<sup>58</sup> Daniels AM, Mandell DS. Explaining differences in age at autism spectrum disorder diagnosis: a critical review. Autism. 2014 Jul;18(5):583-97. doi: 10.1177/1362361313480277. Epub 2013 Jun 20. PMID: 23787411; PMCID: PMC4775077.

<sup>59</sup> Herlihy L, Brooks B, Dumont-Mathieu T, Barton M, Fein D, Chen C, Robins DL. Standardized screening facilitates timely diagnosis of autism spectrum disorder in a diverse sample of low-risk toddlers. *J Dev Behav Pediatr*. 2014 Feb-Mar;35(2):85-92. [PMID: 24509053]

<sup>60</sup> Yingling ME, Ruther MH, Dubuque EM. Trends in Geographic Access to Board Certified Behavior Analysts Among Children with Autism Spectrum Disorder, 2018-2021. J Autism Dev Disord. 2022 Jan 5:1–8. [PMID: 34985719]

<sup>61</sup> Sheldrick RC, Carter AS, Eisenhower A, Mackie TI, Cole MB, Hoch N, Brunt S, Pedraza FM. Effectiveness of Screening in Early Intervention Settings to Improve Diagnosis of Autism and Reduce Health Disparities. JAMA Pediatr. 2022 Mar 1;176(3):262-269. [PMID: 34982099]

<sup>62</sup> Khowaja MK, Hazzard AP, Robins DL. Sociodemographic Barriers to Early Detection of Autism: Screening and Evaluation Using the M-CHAT, M-CHAT-R, and Follow-Up. J Autism Dev Disord. 2015 Jun;45(6):1797-808. [PMID: 25488122]

<sup>63</sup> Garía-Primo P, Hellendoorn A, Charman T, Roeyers H, Dereu M, Roge B, Baduel S, Muratori F, Narzisi A, Van Daalen E, Moilanen I, de la Paz MP, Canal-Bedia R. Screening for autism spectrum disorders: state of the art in Europe. *Eur Child Adolesc Psychiatry*. 2014 Nov;23(11):1005-21. [PMID: 24913785]

<sup>64</sup> Soto S, Linas K, Jacobstein D, Biel M, Migdal T, Anthony BJ. A review of cultural adaptations of screening tools for autism spectrum disorders. *Autism*. 2015 Aug;19(6):646-61. [PMID: 25008216]

<sup>65</sup> Scarpa A, Reyes NM, Patriquin MA, Lorenzi J, Hassenfeldt TA, Desai VJ, Kerkering KW. The modified checklist for autism in toddlers: Reliability in a diverse rural American sample. *J Autism Dev Disord*. 2013 Oct;43(10):2269-79. [PMID: 23386118]

<sup>66</sup> Windham GC, Smith KS, Rosen N, Anderson MC, Grether JK, Coolman RB, Harris S. Autism and Developmental Screening in a Public, Primary Care Setting Primarily Serving Hispanics: Challenges and Results. *J Autism Dev Disord*. 2014 Jul;44(7):1621-32. [PMID: 24408091]

<sup>67</sup> Charman T, Baird, G Simonoff E, Chandler S, Davison-Jenkins A, Sharma A, O'Sullivan T, Pickles A. Testing two screening instruments for autism spectrum disorder in UK community child health services. *Dev Med Child Neurol*. 2016 Apr;58(4): 369-75. [PMID: 26303216]

<sup>68</sup> Yama B, Freeman T, Graves E, Yuan S, Campbell MK. Examination of the properties of the Modified Checklist for Autism in Toddlers (M-CHAT) in a population sample. *J Autism Dev Disord*. 2012 Jan;42(1):23-34. [PMID: 21373956]

<sup>69</sup> Pierce K, Carter C, Weinfeld M, Desmond J, Hazin R, Bjork R, Gallagher N. Detecting, studying, and treating autism early: the one-year well-baby check-up approach. *J Pediatr*. 2011 Sep;159(3): 458-465.e1-6. [PMID: 21524759]

<sup>70</sup> Shaw KA, Maenner MJ, Bakian AV, Bilder DA, Durkin MS, Furnier SM, Hughes MM, Patrick M, Pierce K, Salinas A, Shenouda J, Vehorn A, Warren Z, Zahorodny W, Constantino JN, DiRienzo M, Esler A, Fitzgerald RT, Grzybowski A, Hudson A, Spivey MH, Ali A, Andrews JG, Baroud T, Gutierrez J, Hallas L, Hall-Lande J, Hewitt A, Lee LC, Lopez M, Mancilla KC, McArthur D, Pettygrove S, Poynter JN, Schwenk YD, Washington A, Williams S, Cogswell ME. Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. MMWR Surveill Summ. 2021 Dec 3;70(10):1-14. [PMID: 34855727]

<sup>71</sup> Constantino JN, Abbacchi AM, Saulnier C, Klaiman C, Mandell DS, Zhang Y, Hawks Z, Bates J, Klin A, Shattuck P, Molholm S, Fitzgerald R, Roux A, Lowe JK, Geschwind DH. Timing of the Diagnosis of Autism in African American Children. Pediatrics. 2020 Sep;146(3):e20193629. [PMID: 32839243]

<sup>72</sup> Shattuck PT, Grosse SD. Issues related to the diagnosis and treatment of autism spectrum disorders. *Dev Disabil Res Rev*. 2007;13(2):129-35. [PMID: 17563895]

<sup>73</sup> Zuckerman KE, Sinche B, Cobian M, Cervantes M, Mejia A, Becker T, Nicolaidis C. Conceptualization of autism in the Latino community and its relationship with early diagnosis. *J Dev Behav Pediatr*. 2014 Oct;35(8):522-32. [PMID: 25186120]

<sup>74</sup> Sheldrick RC, Carter AS, Eisenhower A, Mackie TI, Cole MB, Hoch N, Brunt S, Pedraza FM. Effectiveness of Screening in Early Intervention Settings to Improve Diagnosis of Autism and Reduce Health Disparities. JAMA Pediatr. 2022 Mar 1;176(3):262-269. [PMID: 34982099]

<sup>75</sup> Daniels AM, Mandell DS. Explaining Differences in Age at Autism Spectrum Disorder Diagnosis: A Critical Review. Autism. 2014 Jul;18(5):583-97. [PMID: 23787411]

<sup>76</sup> Zwaigenbaum L, Bishop S, Stone WL, Ibanez L, Halladay A, Goldman S, Kelly A, Klaiman C, Lai MC, Miller M, Saulnier C, Siper P, Sohl K, Warren Z, Wetherby A. Rethinking autism spectrum disorder assessment for children during COVID-19 and beyond. Autism Res. 2021 Nov;14(11):2251-2259. [PMID: 34553489]

<sup>77</sup> Papanikolaou K, Paliokosta E, Houliaras G, Vgenopoulou S, Giouroukou E, Pehlivnidis A, Tomaras V, Tsiantis I. Using the Autism Diagnostic Interview-Revised and the Autism Diagnostic Observation Schedule-Generic for the diagnosis of autism spectrum disorders in a Greek sample with a wide range of intellectual abilities. *J Autism Dev Disord*. 2009 Mar;39(3): 414-20. [PMID: 18752062] <sup>78</sup> Tsuchiya KJ, Matsumoto K, Yagi A, Inada N, Kuroda M, Inokuchi E, Koyama T, Kamio Y, Tsujii M, Sakai S, Mohri I, Taniike M, Iwanaga R, Ogasahara K, Miyachi T, Nakajima S, Tani I, Ohnishi M, Inoue M, Nomura K, Hagiwara T, Uchiyama T, Ichikawa H, Kobayashi S, Miyamoto K, Nakamura K, Suzuki K, Mori N, Takei N. Reliability and validity of autism diagnostic interview-revised, Japanese version. *J Autism Dev Disord*. 2013 Mar;43(3):643-62. [PMID: 22806002]

<sup>79</sup> Lampi KM, Sourander A, Gissler M, Niemelä S, Rehnström K, Pulkkinen E, Peltonen L, Von Wendt, L. Brief report: validity of Finnish registry-based diagnoses of autism with the ADI-R. *Acta Paediatr*. 2010 Sep;99(9):1425-8. [PMID: 20412100]

<sup>80</sup> Becker MM, Wagner MB, Bosa CA, Schmidt C, Longo D, Papaleo C, Riesgo RS. Translation and validation of Autism Diagnostic Interview-Revised (ADI-R) for autism diagnosis in Brazil. *Arq Neuropsiquiatr*. 2012 Mar;70(3):185-90. [PMID: 22392110]

<sup>81</sup> Vanegas SB, Magaña S, Morales M, McNamara E. Clinical Validity of the ADI-R in a US-Based Latino Population. *J Autism Dev Disord*. 2016 May;46(5): 1623-35. [PMID: 26742934]

<sup>82</sup> Lord C, Rutter M, Le Couteur A. 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 Oct;24(5):659-85. [PMID: 7814313]

<sup>83</sup> Dworzynski K, Ronald A, Bolton P, Happé F. How different are girls and boys above and below the diagnostic threshold for autism spectrum disorders? *J Am Acad Child Adolesc Psychiatry*. 2012 Aug;51(8):788-97. [PMID: 22840550]

<sup>84</sup> Loomes R, Hull L, Mandy WPL. What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. *J Am Acad Child Adolesc Psychiatry*. 2017 Jun;56(6):466-474. [PMID: 28545751]

<sup>85</sup> Mandy W, Chilvers R, Chowdhury U, Salter G, Seigal A, Skuse D. Sex differences in autism spectrum disorder: evidence from a large sample of children and adolescents. *J Autism Dev Disord*. 2012 Jul;42(7):1304-13. [PMID: 21947663]

<sup>86</sup> Hiller RM, Young RL, Weber N. Sex differences in autism spectrum disorder based on DSM-5 criteria: evidence from clinician and teacher reporting. *J Abnorm Child Psychol*. 2014 Nov;42(8):1381-93. [PMID: 24882502]

<sup>87</sup> Hiller RM, Young RL, Weber N. Sex differences in pre-diagnosis concerns for children later diagnosed with autism spectrum disorder. *Autism*. 2016 Jan;20(1):75-84. [PMID: 25717130]

<sup>88</sup> Miodovnik A, Harstad E, Sideridis G, Huntington N. Timing of the diagnosis of attention-deficit/ hyperactivity disorder and autism spectrum disorder. *Pediatrics*. 2015 Oct;136(4):e830-7. [<u>PMID:</u> <u>26371198</u>]

<sup>89</sup> Brugha TS, McManus S, Bankart J, Scott F, Purdon S, Smith J, Bebbington P, Jenkins R, Meltzer H.
Epidemiology of autism spectrum disorders in adults in the community in England. *Arch Gen Psychiatry*.
2011 May;68(5):459-65. [PMID: 21536975]

<sup>90</sup> Croen LA, Zerbo O, Qian Y, Massolo ML, Rich S, Sidney S, Kripke C. The health of adults on the autism spectrum. *Autism*. 2015 Oct;19(7):814-23. [PMID: 25911091]

<sup>91</sup> Gabrielsen TP, Farley M, Speer L, Villalobos M, Baker CN, Miller J. Identifying autism in a brief observation. *Pediatrics*. 2015 Feb;135(2):e330-8. [PMID: 25583913]

<sup>92</sup> Broder-Fingert S, Stadnick NA, Hickey E, Goupil J, Diaz Lindhart Y, Feinberg E. Defining the core components of Family Navigation for autism spectrum disorder. Autism. 2020 Feb;24(2):526-530. [PMID: 31311287]

<sup>93</sup> Feinberg E, Augustyn M, Broder-Fingert S, Bennett A, Weitzman C, Kuhn J, Hickey E, Chu A, Levinson J, Sandler Eilenberg J, Silverstein M, Cabral HJ, Patts G, Diaz-Linhart Y, Fernandez-Pastrana I, Rosenberg J, Miller JS, Guevara JP, Fenick AM, Blum NJ. Effect of Family Navigation on Diagnostic Ascertainment Among Children at Risk for Autism: A Randomized Clinical Trial From DBPNet. JAMA Pediatr. 2021 Mar 1;175(3):243-250. [PMID: 33427861]

<sup>94</sup> Child and Adolescent Health Measurement Initiative. National Survey of Children's Health (NSCH), 2020. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved 07/01/22 from www.childhealthdata.org.