

Question 1: How can I recognize the signs of ASD, and why is early detection so important?

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

Introduction

Observational studies of infants at risk for 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, most children are not diagnosed in the U.S. until four years of age, with disparities in diagnosis related to socioeconomic factors, geographic location, and race/ethnicity (Christensen et al, 2016). Given the unprecedented growth and organization of the brain during the first three years of life¹, behavioral interventions initiated in ASD toddlers within this time period result in a range of positive changes including increases in social orienting, language ability, and overall IQ²⁻⁴. However, due to the lag in diagnosis, many children miss the opportunity to receive treatment during this critical period of neuroplasticity. 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.

Implementation of ASD Screening and Diagnostic Tools

Although studies consistently report that screening using validated autism-specific parent-report tools can result in ASD detection as young as 12-18 months⁷, these tools are only used systematically within about 50% of primary care settings⁶. Reliance on using a standardized screening tool has even been shown to be more effective than pediatrician clinical judgment alone⁸. Thus, the American Academy of Pediatrics¹⁰ has embraced using universal ASD screening⁹ 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: a lack of education and understanding of ASD^{40, 41}, lack of familiarity with screeners^{40, 42}, uncertainty where to send a toddler with a test-positive screen⁴², lack of effective and timely means of connecting families of individuals

with ASD to available resources^{41, 43}, and the extra time and resources required to utilize standardized screening tools^{12, 40}.

Given that many parents take their child for well-baby visits within a primary care setting, recent research on improving screening has utilized this context. To accommodate the dynamic and busy environment of a primary care setting, parent-report screening tools are, by design, very brief and can often be completed in just 5 minutes. A new revision to the Modified Checklist for Autism in Toddlers, Revised, ([M-CHAT-R](#)), the most commonly used parent-report screening tool, shows that administration of follow up questions (M-CHAT-R/F) can increase the ASD diagnostic specificity to approximately 50% (50% of children who test positive are later diagnosed with ASD), and if all developmental delays are also considered a true positive, that estimate increases to >95% (more than 95% of children who test positive are diagnosed with either autism or some other type of developmental delay or disability)¹¹. Despite the important achievement of reducing false positives, administering follow-up questions in the M-CHAT R/F procedure can take anywhere from 5 to 30 minutes and as such does not overcome the barrier of time limits in primary care settings¹². Leveraging technology, recent 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 systems, but also eliminated the time barrier because parents answered the follow up questions directly on the tablet, thus bypassing the need to engage medical personnel¹³.

Large-scale studies examining the M-CHAT^{5, 50} and its revisions^{11, 51, 14}, compared to the estimated prevalence rates suggest that many cases of ASD may be missed using the screening tool, especially in 18 month olds. 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, suggesting that screening efforts may need to go beyond simple parent-report tools. One such approach is a 2-stage screening model that combines a general developmental screening tool based on parent report, [the Infant Toddler Checklist \(ITC\)](#)¹⁵, with subsequent observational ratings to screen for ASD. Using this approach, detection rates have been reported as 15.1 per 1,000 children at a mean age of 20.8 months,¹⁶ which is very close to the expected prevalence rates for ASD⁵. Children with a true positive on the M-CHAT R/F alone display a lower developmental level than children ascertained with the ITC and follow-up observational rating^{16, 17}, and lower developmental level than those evaluated in a prospective sample of younger siblings at familial risk for ASD¹⁸, suggesting that this tool may be better at detecting children at a lower developmental level and may sometimes miss less severely affected children. Continued improvement in screening approaches may be achieved by better understanding the psychometric features of parent-report screening tools in relation to observational measures^{17, 19}, and by examining the utility of different screening thresholds in relation to diagnostic

accuracy and cost effectiveness²⁰. Additional new innovations in parent report screening approaches include the incorporation of photographs into the questionnaire to illustrate items in a culturally unbiased manner²¹, combining multiple screening tools to improve sensitivity and specificity²², and free mobile applications (apps), such as “[ASDetect](#)” that augment descriptions of ASD characteristics with video examples and provide a video-led assessment of child behaviors. Studies are needed to validate the usability and accuracy of these apps, although there is empirical support demonstrating that the markers highlighted within the apps (e.g., pointing and showing) are predictive of an ASD diagnosis^{23, 24}.

A growing appreciation of ASD as a condition marked by unique behavioral, neural and genetic signatures that may precede overt clinical symptoms has resulted in a surge of prodromal and biomarker-seeking research which broadens the scope of future screening efforts. Of particular interest are potential biomarkers likely to facilitate gene-brain-behavior studies, diagnosis, or those that may act as prognostic markers. Observational studies continue to reveal that signs of ASD are subtle, but may emerge within the first year of life, particularly in the areas of social communication, attention, and motor development^{18, 25, 26}. Preliminary studies deploying eye-tracking technology to measure social visual engagement have demonstrated utility and accuracy in detecting markers of ASD in the first year of life^{27, 28}. For the first time, structural and functional magnetic resonance imaging (fMRI) studies of infants are beginning to predict later ASD diagnosis and core characteristics such as language outcome³³⁻³⁵ (+ *Emerson et al, 2017*). Additionally, RNA expression profiles can classify toddlers as ASD at levels exceeding 80% accuracy³⁶. While these findings suggest a future of exciting new tools for screening and diagnosis, they must be validated in other high-risk groups and in the general population, and they must be adjusted for broader use in order to be beneficial to the wider community.

The stability of an ASD diagnosis at 18-24 months is high for samples ascertained from community-based screening 1-2 years later^{16 39} and from familial-risk samples¹⁵. This underscores the importance of developmental surveillance and follow-up for children with early social communication delays. The heterogeneity in developmental unfolding of ASD features over the first two years of life makes diagnosis of ASD by 18 to 24 months challenging in community-based settings and a critical need for future research.

Although engagement in early treatment has been associated with a range of positive changes including increases in social orienting, language ability, and overall IQ²⁻⁴, 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 recent US Preventative Services Task Force (USPSTF) report⁹ on universal early screening. However, as noted by Dawson (2016)⁴⁴, such a study would require large representative samples from across the country to be randomly assigned to either a screening or non-screening condition, and then followed to determine long term outcomes and societal costs. Given

that early treatment for children under age 3 years has been shown to result in positive gains⁴⁵, and has even been associated with an increased potential to lose an ASD diagnosis altogether⁴⁶, such a study is not without controversy.

While a considerable investment of time and resources would be required to conduct new randomized controlled trial (RCT) studies to specifically address concerns raised by the USPSTF, there are opportunities and study designs that could be leveraged using existing resources in the short term. First, data could be examined from within sample cohorts that include clinical longitudinal data from toddlers detected via screening as well as toddlers detected via other means (e.g., parent or clinician concern). Second, exclusively within cohorts of screen detected toddlers, researchers could examine outcomes of children detected at identical early ages via screening but that contained a subgroup of toddlers who started treatment well beyond the screen-detected age. In this way, the impact of very early treatment engagement as afforded by screening could be more directly examined. In terms of new, future studies, in instances where a traditional RCT design (intervention versus no intervention) may not be feasible and the health impact is high, other complex forms of RCT models could be used as well as utilizing administrative data. Several states collect state-level data on youth who receive ASD screening and subsequent developmental outcomes. This may afford an opportunity to compare children with and without early screening in terms of variations in developmental outcomes.

While early detection, whether achieved through universal screening or by other mechanisms such as parent or clinician concern, is an essential step in the health care process for ASD and deserves more research attention, it is just one step on the path to identification and eventual treatment. Screening in and of itself does not determine if and when parents actually follow through with subsequent diagnostic evaluation and treatment engagement, nor does it determine the quality and benefits of such treatment. Another key gap in the field, then, is a paucity of studies examining the many important factors that follow *after* screening has occurred⁴⁷.

There is indeed a growing appreciation of the importance of implementation science methods to examine contextual factors (e.g., mode of screening delivery) that may impact successful screening uptake. Some studies are currently underway, performed by researchers funded through the NIMH [ASD Prevention, Early Detection, Engagement and Services \(ASD-PEDS\) Network](#). Another important factor is comprehensive tracking of treatment participation, which is essential to determine the long-term outcomes of children detected early by screening. To date, most studies do not report treatment engagement, and if it is reported, it is often at a very coarse level (e.g., number of hours).

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 pediatricians¹². Therefore, an increase in the number and accessibility of evaluation centers is necessary, based on population and expected rates of ASD. Likewise, significant enhancement of the screening and evaluation system is meaningful only if high-quality treatment providers are available and affordable once test-positive cases are identified. Investigation of more cost-effective modes of treatment delivery, such as those that are either partially or fully deployed by parents, are currently being examined².

An increase in the number of toddlers screened and identified as possible ASD (Nygren et al. 2012) also calls 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 two 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. It is thus unsurprising that 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%⁴⁹) 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.

Disparities in ASD Screening and Diagnosis

Disparities in ASD Screening

Evidence demonstrates that screening is a successful strategy to detect ASD in toddlers (e.g., Guevara et al., 2013; Robins et al., 2014), yet 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 range from 1-60% (Arunyanart et al., 2012; dosReis et al., 2006; Gillis et al., 2009); some of the variability in use of standardized screening is based on children's sociodemographic characteristics. For example, screening may occur less frequently among Spanish-speaking families compared to English-speaking families (Zuckerman et al., 2013). Families with low levels of maternal education exhibit higher screen positive rates on the Modified Checklist for Autism in Toddlers (M-CHAT(-

R); Robins et al., 1999, 2009), but are less likely to follow-up with diagnostic evaluation, suggesting that these families are at risk for being underserved (Khowaja et al., 2015). Additionally, consistent use of screening tools may depend on insurance reimbursement; children from low-income families may be more likely to be screened during check-ups since it is often reimbursed by Medicaid (Bethell et al., 2011), but may not be covered by private insurance.

Research has shown that children from minority backgrounds are diagnosed on average more than a year later than their White peers (Daniels & Mandell, 2014). However, it has been demonstrated that when physicians follow a standardized screening protocol, including immediate referral for screen positive cases, disparities in age of diagnosis are reduced to approximately one month (Herlihy et al., 2014). Therefore, access to screening for all children, regardless of sociodemographic characteristics, language spoken at home, and geographic locale, is crucial to reduce existing disparities that multiply from screening to early diagnosis to early intervention, cascading to impact life-long outcomes. In addition to dedicating more resources to early screening in underserved communities, a corresponding increase in funding adequate evidence-based diagnostic evaluations will avoid lengthening waitlists (Shattuck & Grosse, 2007).

Validity of Screening Instruments in Diverse Groups

A number of studies have examined ASD screening tools in different languages and cultural settings within the US and across the world (e.g. Garcia-Primo et al., 2014; Soto et al., 2014; Scarpa et al., 2013; Khowaja et al., 2015; Windham et al., 2014). 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 vs. urban locale, race, and ethnicity also impact screening reliability and validity (Scarpa et al., 2013) as well as screen positive rates (Khowaja et al., 2015; Windham et al., 2014). Evidence of ASD screening, including data that speak to disparities in access to these services, often relies on provider surveys. 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.

The recent USPSTF report on universal ASD screening (Siu et al., 2016) specifically highlighted the gaps in research on health outcomes of children detected through screening, particularly in those from minority and low-income families. It will be critical to evaluate the quality of screening instruments and programs in diverse samples of children, 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 (Charman et al., 2015; Yama et al., 2012, Pierce et al., 2011; Windham et al., 2014).

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. According to the most recent surveillance study by the Centers for Disease Control's (CDC) Autism and Developmental Disorders Monitoring (ADDM) Network study (Christensen et al., 2016), White children were 20% more likely to have indicators of ASD in their school and health records than Black children, 40% more likely than Asian and Pacific Islander children, and 50% more likely than Latino children. A variety of factors, including economic challenges (e.g. Khowaja, Hazzard, & Robins, 2015), geographic distance between families and service providers (Kiani et al., 2013), reduced professional resources and capacity (Janvier et al., 2015), and characteristics impacted by cultural knowledge, such as stigma (Bates et al., 2014) often contribute to diminished service availability and utilization in rural, minority, or other disadvantaged communities. A primary barrier to ASD screening and 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 (Shattuck & Grosse, 2007). 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 an at-risk child (Zuckerman et al., 2014). 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 (Kavanagh et al., 2012). Finally, and perhaps most importantly, there is a need for prospective studies that demonstrate that equal access to high quality screening, with immediate referral for positive screen cases to diagnostic evaluation and early intervention services, will reduce disparities in prevalence, as well as any disparities in long-term outcomes for children 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 (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 time of ASD screening to receipt of services (Daniels et al., 2014). 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 (Huerta & Lord, 2012), 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 such as Greece (Papanikolaou et al., 2009), Japan (Tsuchiya et al., 2013), Finland (Lampi et al., 2010), and Brazil (Becker et al., 2012) with varying results. 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 (Vanegas, Magaña, Morales, & McNamara, 2016) than values previously reported for mostly White, middle-class respondents (Lord, Rutter, & Le Couteur, 1994). The communication domains were found to be especially problematic for parents whose primary language was Spanish when reporting on children who spoke mainly English (Vanegas et al., 2016). 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 girls are less likely than boys to meet diagnostic criteria for ASD at comparatively high levels of autistic-like traits.^{1, 2} Girls may also exhibit different symptoms from boys, which may make current screening and diagnostic tools more likely to miss ASD in girls (Mandy, W. et al. 2012. Sex differences in autism spectrum disorder: evidence from a large sample of children and adolescents. *J Autism Dev Disord*, 42 (7), 1304-1313, Hiller, R.M., Young, R.L. & Weber, N. (2014) Sex Differences in Autism Spectrum Disorder based on DSM-5 Criteria: Evidence from Clinician and Teacher Reporting. *J Abnorm Child Psychol* (2014) 42:1381-1393., Hiller, R.M., Young, R.L. & Weber, N. (2015) Sex differences in pre-diagnosis concerns for children later diagnosed with autism spectrum disorder. *Autism*. 2015 Feb 25.)_ 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 developmental comorbidities. A third of children with ASD also have an intellectual disability (Christensen, 2016) 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 (Miodovnik et al, 2015). 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 suggests that many adults with ASD may be unidentified and living in the community without appropriate supports.^{3,33} 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?* as well as the implications of an adult diagnosis of ASD.

Topic 3: Workforce

The increased prevalence of diagnosed ASD cases over the past two decades 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. In response to this need, CDC developed a web-based education program, the [Autism Case Training](#), to inform healthcare providers on fundamental components of identifying, diagnosing, and managing ASD through real life scenarios. Promoting, refining, and delivering similar education programs is a critical factor in building a workforce that can effectively serve individuals with ASD and their families.

Families experience lengthy delays between initial referrals and diagnosis of ASD (CDC 2016 ADDM paper, Guinchat et al. 2012, Chawarska et al. 2007). The average delay was 13 months in a study of surveillance records (Wiggins, Baio, Rice, 2006). Parents may not recognize signs of developmental delay, or 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 “[16 Gestures by 16 Months](#)” series developed by the [First Words Project](#) are examples of strategies that can be utilized 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.

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 (Gabrielson et al., 2015). 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.

Lack of compliance with ASD screening recommendations in primary care clinics can be partially addressed through continued development of accurate screening instruments that are easily and efficiently implemented in busy primary care settings. [“Birth to Five: Watch Me Thrive!”](#) 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. Opportunities exist to leverage other forces to encourage change in these practice habits, such as using innovative technology and professional development to support collaboration between the medical home, the IDEA Part C early intervention system, families, and other members of the individual’s care team may offer a mechanism to improve developmental surveillance and monitoring of services (Adams & Tapia, 2013).

Early childhood, healthcare, and education 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.

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.

The workforce necessary for assisting all children to have healthy, meaningful lives is one that encompasses families, persons with autism, paraprofessionals, and health providers. Some important service initiatives are ongoing, but there is a need for additional efforts. The American Academy of Pediatrics (AAP) supports universal screening for ASD and provides training to pediatric providers through several formats (publications, webinars, and face-to-face conferences) and the University Centers of Excellence in

Developmental Disabilities (UCEDDs) also provide training to practitioners from over a dozen health care 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 should be considered to make professional development and training more available and to dedicate more resources in order to expand the workforce to address unmet needs for early screening and diagnostic services, and access to care. There is a need for improved policies to facilitate the collaboration of community-based programs and social supports with professional services.

Linkage to Intervention Services and Other Supports

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. Given that the vast majority of toddlers (at least 75%⁴⁹) who will go on to qualify for special education at school-age, are still not identified in time to receive early intervention (ages 0-3 years), there is a continued pressing need to improve access to early intervention services for this age group, in part through IDEA Part C. Additionally, the IDEA Annual Report to Congress⁴⁹ indicates a continued broader challenge of the under-identification of infants and toddlers with developmental delays, including ASD, who should be eligible for early intervention through IDEA Part C. This means that most infants and toddlers with a diagnosis of ASD miss the opportunity to receive early intervention services.⁴⁹ This service need is unmet to an even greater degree in children from minority backgrounds (Daniels & Mandell, 2014). 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, and begin to break down barriers for families to act on screening results and to support family engagement in intervention services.

Nearly half of children with ASD have private insurance; the other half have insurance provided by Medicaid or the state-based [Children's Health Insurance Program \(CHIP\)](#), or dual private and public coverage.⁴ However, about half 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. A systemic issue is that some insurance plans do not cover quality treatments, such as Applied Behavior

Analysis (ABA), or may place limits on essential behavioral, medical, or other health care. Additionally, family social service supports, which contribute greatly to meeting the needs of the child, are not covered. These limitations often leave families struggling in many ways, which results in significant financial and familial burdens. In fact, nearly half of families of children with ASD say their child's health condition has caused major problems for the family and in some cases bankruptcy and other family disruptions, such as divorce or job loss (Cidav, Marcus, Mandell, 2012; Heartly et al, 2010).

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 are not coordinated and often 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. Lastly, 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.

Summary/Progress towards Aspirational Goal

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 and populations. There is a need to evaluate the effectiveness of universal screening for improving outcomes in ASD. 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 enable detection of autism in 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 with ASD; 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 ASD 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. The way forward is reflected in the three Objectives proposed for Question 1.

Objectives:**Objective 1: Strengthen the evidence base for the benefits of early detection of ASD.**

- Implement innovative designs to evaluate the benefit of universal screening for ASD, including research that addresses the specific research gaps noted by the USPSTF report.
- To improve early detection there must be greater attention paid to special autism populations such as girls and intellectually delayed individuals.

Objective 2: Reduce disparities in early detection and access to services

- Improve family engagement and help build an awareness of healthy developmental milestones and warning signs of concern.
- Demonstrate the validity of different screening and diagnostic tools for culturally-diverse communities.
- Increase services in high poverty and under-served 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: Improve/validate existing, or develop new tools, methods, and service delivery models for detecting ASD in order to facilitate timely linkage of individuals with ASD to early, targeted interventions and supports.

- Continue research on the potential translation of biomarker findings into feasible and valid screening or diagnostic tools.
- 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.
- Conduct research to better understand and develop strategies to address reasons for lack of compliance with screening recommendations; address barriers to universal screening.
- Analyze the impact of insurance reform and national policy on coverage for screening, diagnosis and intervention for children with ASD and their families.
- Evaluate innovative service delivery methods (e.g., use of technology) to improve detection methods and increase access.

Q1 Draft References

Topic 1: Implementation of diagnostic and screening tools

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