Chapter 1: Screening and Diagnosis

How Can We Improve Identification of Autism?

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.

Introduction

For many autistic individuals and their families, engagement with autism-related services and supports begins with screening and diagnosis. Signs of autistic traits are often visible in the first two years of life. However, the median age of ASD diagnosis in children in the U.S. is four years, with disparities in diagnosis related to socioeconomic factors, geographic location, and race/ethnicity[1]. Many people on the autism spectrum are initially misdiagnosed with other health conditions, and in many cases they may not receive a correct autism diagnosis until adolescence or adulthood. Others may recognize traits of autism in themselves or a loved one but have difficulty accessing diagnostic services. The consequences of these delays are myriad, including missed opportunities to receive services and supports.

Given the immense growth 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 intervention and supports during this critical period of brain development. For older children and adults, lack of a proper diagnosis often results in unmet healthcare and service needs. Thus, it is critical that children and adults are able to access screening and diagnostic services for autism in a timely manner. Much investment is focused on developing and optimizing screening and diagnostic tools, particularly for special populations such as women, adults, non-native English speakers, and racial/ethnic minorities. 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 (AAP) recommends 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.

Current 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[2,3,4]. 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.

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[5]. 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 discern early signs of autism, the ease of accessing follow-up diagnostic services, 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[6,7]. These 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.

Current Diagnostic Tools

Once autism is suspected in an individual, they are typically referred for a diagnostic assessment. There are many diagnostic tools available; the gold standard is to conduct a parent interview (in children) 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)[8]. The combination of these two instruments allows clinicians to get a comprehensive view of an individual's behaviors. The ADOS-2 includes five different modules that are targeted to different age groups (toddlers-adults) and verbal communication abilities[9]. Similar to screening tools, it is important to identify which existing diagnostic tools work best in individuals across the spectrum and across the lifespan.

Technological Advances in Screening and Diagnosis

Early Signs and Biomarkers

In order to enable early linkages to services and interventions (and subsequently better long-term outcomes), it is critical to identify ASD at the earliest age possible[10]. Studies have demonstrated that differences in brain development and function (e.g., eye gaze patterns, brain growth, and some brain connectivity patterns)[11,12,13,14] as well as some subtle behavioral and motor differences (e.g. social communication and attention, ability to hold up head), emerge in the first months of life, before more overt ASD signs begin to appear, such as non-responsiveness to their name or difficulties with language development [15,16,17,18,19,20]. 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 who later

receive a diagnosis. 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 testing innovative strategies and technologies for diagnosis by age 12 months, universal screening, and expedited diagnosis and engagement with intervention. In addition, ongoing research is aimed at translating early screening methods for infants and toddlers into practical, efficient, and inexpensive tools that can be implemented in the general population and within community settings. For example, a recent study developed a screening tool that uses computer vision analysis to analyze toddler facial expressions or eye gaze patterns while they use a mobile device[21,22]. Another study used machine learning to identify "digital biomarkers," patterns of previous medical encounters in electronic health records, that are predictive of a later autism diagnosis[23]. In 2021, the FDA approved a digital diagnostic tool that allows caregivers to upload videos of a child and answer a questionnaire that can be evaluated by primary care physicians[24]. These tools may be helpful in reducing long waitlists for a diagnosis and make diagnosis more equitable across different communities.

Researchers and clinicians are considering the potential of pre-symptomatic intervention, which is beginning intervention before traits of autism are fully apparent[25]. 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, including autistic individuals and their families, researchers, clinicians, and policy experts, during the development of any such interventions.

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 developmental-behavioral 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 closure of facilities during the COVID-19 pandemic has exacerbated these issues. Several studies have explored the use of telehealth methods to conduct diagnostic assessments for ASD[26,27]. 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[28].

Surveys of clinicians using tele-assessment tools identified benefits and challenges of conducting assessments for autism remotely[29,30]. 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 traits of autism. In some cases, clinicians reported reduced confidence in their assessments that were made remotely rather than in person. Therefore, 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[31], and has been shown to be more reliable than clinical judgment alone[32]. However, many primary care providers do not routinely screen all children at these ages[33]. In 2007, the AAP first recommended 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 screening tools, 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[34,35,36,37,38].

Although early intervention has been associated with changes including increases in social orienting, language ability, and overall IQ[39,40,41,42], 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). This issue is highlighted by the US Preventive Services Task Force (USPSTF) report on universal early screening[43]. However, 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 years of follow-up to determine long-term outcomes and societal costs[44]. 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). 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[45,46]. 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[6]. 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 maximizing positive outcomes for autism, it is just one step on the path to 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 child for an evaluation is a barrier to screening noted by over 75% of pediatricians[37]. 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 diagnostic system is meaningful only if high-quality intervention services are available, accessible, and affordable. 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 services under the Individuals with Disabilities Education Act (IDEA) Part C, the Federal program that funds intervention services for infants and toddlers (ages 0-3 years) showing developmental delays, including autism. Generally, children 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.

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[47,48,49,50,51,52]. 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[50,53,54,55]. Examining and understanding these differences will be critical in reducing disparities in screening and diagnosis.

Disparities in ASD Screening

ASD screening rates during primary care visits vary greatly, with different levels of use of standardized screening tools. Some of this variability has been shown to be associated with children's sociodemographic characteristics (e.g. race/ethnicity, socioeconomic status, geographic location, language spoken at home). Research has shown that children from minority backgrounds are diagnosed on average more than a year later than their White peers[56,57]. 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[46, 52, 58]. 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 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[50,59,60,61,62]. The variability of results from these studies indicates 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 level of educational attainment, language/literacy, rural versus urban locale, race, and ethnicity also impact screening reliability and validity as well as screen-positive rates. Examination of medical or state records for specific mention of ASD screening and diagnosis in individuals representing diverse demographic groups would be helpful in documenting disparities and in tracking improvements based on policy changes or improved access to care.

It will be critical to evaluate the efficacy and effectiveness 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[63,64, 65,].

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 whether individuals also had an intellectual disability[1]. 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 in White children[66]. Additionally, there are still disparities in age of diagnosis for racial/ethnic minorities, with minority children often being diagnosed later[67]. This is often due to differences in the time from a positive screen to diagnostic evaluation for ASD, or an initial misdiagnosis.

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[68]. This limited availability is especially pronounced in underprivileged and rural areas, with many children not diagnosed until they have entered 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[69]. Overall, there is limited research that documents these systemic- and individual-level barriers that exist from early ASD screening to appropriate diagnosis to intervention. While recent prevalence data from the CDC ADDM Network has demonstrated that universal screening can reduce disparities in prevalence[46], it is still important to demonstrate that universal screening can subsequently reduce disparities in long-term outcomes for individuals with ASD.

Strategies to reduce waitlists include increasing the diagnostic workforce, increasing the efficacy of existing diagnostic tools, and developing new or adjunctive tools, such as technology-based screening

tools. Additional practitioner efforts that can help to reduce disparities in diagnosis include training to raise awareness and reduce biases/stigma, 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 and 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 often not well-tracked from the time of ASD screening to receipt of services[57]. While telehealth-mediated methods have the potential to increase access to screening services, these tools are dependent on reliable internet service which is often limited for low-income and geographically isolated families[70]. It is imperative to have a system in place that can assure children and families receive adequate, timely, and appropriate services as they move through the screening, referral for diagnosis, and intervention process.

Diagnosis of Individuals from Underserved Populations

The ADI-R and ADOS-2 have traditionally been viewed as the best available diagnostic tools for evaluating potential cases of ASD. However, these tools may have limitations in their ability to diagnose ASD in non-native English speakers, females, racial and ethnic minorities, adults, and other populations. 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[71,72,73,74]. 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[75,76]. 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 in studies where the subjects were predominantly boys, resulting in tools that may not identify girls/women and people from other underserved groups as accurately, putting them at risk of a missed 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[77,78]. Girls may also exhibit different signs and characteristics from boys, which may make current screening and diagnostic tools more likely to miss ASD in girls[79,80,81]. It is important that future research addresses the gender differences in ASD, both biological and behavioral, in the development of diagnostic tools.

Individuals with ASD that have other co-occurring developmental conditions are also at risk of being underdiagnosed. About one-third of children with ASD also have an intellectual disability[1], 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[82]. While research is necessary to develop tools that account for the overlap in traits, health providers must be better equipped to discern 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[83,84]. Many autistic individuals diagnosed as adults report being misdiagnosed with other mental health conditions initially, such as borderline personality disorder, generalized anxiety, or mood disorders such as depression or bipolar disorder[85, 86]. Others report receiving care for mental health conditions such as eating disorders while displaying traits of autism that were unrecognized or ignored by healthcare providers[87]. Thus, there is a need to improve diagnostic tools that are specific for adults. There is also a need to practitioner training to recognize traits of autism in adults.

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 childcare 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[88]. 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 appropriately trained personnel in their offices or referral networks. Also, practitioners may lack the technical training to assess and compare 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/caregivers, 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, the Autism Navigator project developed by researchers at Florida State University, and the Baby Siblings Research Consortium 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 identification of ASD through translation of materials to other languages, 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 reduce disparities in 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), DBP?, and the University Centers of Excellence in Developmental Disabilities (UCEDDs) also provide training to practitioners from several healthcare disciplines. Additional efforts are needed to increase availability of professional development and training opportunities that will help 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 individuals seeking screening, diagnostic, or intervention services are able to efficiently navigate the healthcare system to obtain these services. This task is often made more difficult by differences in insurance coverage for various services, inadequate linkages between systems, and a lack of clear instructions to guide individuals and family members through an exceedingly complex process. Currently, families must navigate different sectors of service in terms of information, provision, and funding (e.g., medical providers, local government, education), sometimes within a very short period of time to avoid age eligibility cut-offs. The different service sectors often are not always well-coordinated and may not communicate with each other, particularly across healthcare 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. 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.

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[89]. Importantly, use of this model was shown to reduce racial and ethnic disparities in the length of time to diagnostic evaluation[90]. Coordination of a care team that includes healthcare, educational, and/or childcare providers is critical to address gaps in screening, begin to break down barriers for families to act on screening results, and support family engagement in age-appropriate intervention services over time. In the future, it will be important to expand the availability of systems navigators, particularly those who specialize in assisting older autistic children, adolescents, and adults. It may be particularly beneficial for autistic individuals who have had success navigating these systems to serve as peer navigators to others who are earlier in the process.

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 or may

place limits on essential behavioral, medical, or other healthcare. Nearly half of children diagnosed with ASD have private insurance; most others have insurance provided by Medicaid or the state-based Children's Health Insurance Program (CHIP), or dual private and public coverage[91]. 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.

4In addition, systems do not take into account families' concerns about stigma, the reluctance of professionals to make a diagnosis or share concerns about traits 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, racial/ethnic minorities, 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 a data or administrative? 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.

Recommendations

RECOMMENDATION 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 underserved populations such as girls and women, racial and ethnic 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.

RECOMMENDATION 2: Reduce disparities in early detection and access to services.

Examples:

- Improve family engagement and help build an awareness of appropriate developmental milestones.
- Demonstrate the validity of different screening and diagnostic tools for culturally diverse communities.
- Increase services in underserved and low-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 services? workforce.

RECOMMENDATION 3: Develop and adapt screening and diagnostic tools, including tools that incorporate new technologies to increase efficiency, accuracy, and timeliness of identification

Examples:

- Continue research on the potential translation of biomarker findings into valid, reliable, and cost-effective 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.
- Evaluate innovative service delivery methods (e.g., use of telehealth and other technologies) to improve detection methods and increase access.

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