The Roadmap to Early and Equitable Autism Identification

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It has been almost 2 decades since the first study documenting disparities in diagnoses of autism spectrum disorder (ASD) was published.1 Although the prevalence of ASD has increased during this time,1 Black,2,3 Hispanic,4 and low-income children5 remain less likely to be identified early. In a recent study, researchers found that almost one-quarter of children with documented signs and symptoms of ASD are undiagnosed, a circumstance 1.7 times more likely for Black children and 1.6 times more likely for Hispanic children than for white children.6 The median age of diagnosis across groups is 52 months,1 well beyond the age at which ASD can be identified.7 As a result, many children are excluded from early ASD-specific interventions at a young age, when these secondary prevention interventions and related tertiary prevention activities that target ASD-related co-occurring conditions are most likely to be effective.8,9 Clearly, there is work to do to improve the equity of ASD diagnosis and to reduce the age of diagnosis.

Developmental surveillance beginning in infancy and ASD-specific universal screening at 18 and 24 months are recommended by Bright Futures for inclusion as part of routine preventive care.7,10 In addition, public health campaigns, such as the Centers for Disease Control and Prevention’s Learn the Signs, Act Early,11 reach out to clinicians, families, and early child educators to promote the early recognition of developmental delay and ASD to encourage early identification and treatment. Despite these efforts, disparities in diagnosis and treatment remain.

Although screening rates have increased, more than 1 in 4 pediatricians report that they do not regularly offer ASD screening. Even in practices with high screening rates, disparities persist in which children are not screened,12,13 which children are referred for a comprehensive ASD evaluation after a positive screen result,14–16 and which children ultimately receive intervention services.

It is critical to recognize that screening is a process, with benefits only occurring when there is follow-up for those with a positive screen result. With ASD screening, there are rate-limiting steps along the pathway to diagnosis and management (Fig 1). Along the diagnostic pathway, additional racial, ethnic, and income-related disparities exist related to access to ASD assessment services,17 early intervention services,18 and ASD-specific interventions.19–21 It is important to note that a young child with ASD can qualify for early intervention services through Part C of the Individuals with Disabilities Education Act,22 and...
he or she may also qualify for ASD-targeted behavioral interventions through medical insurance; providers should help connect families to these educational and medical services, respectively.

Even when follow-up services are received, the quality (eg, fidelity to evidence-based interventions) can be variable.23 Waitlists for ASD specialists are long, and Black, Hispanic, and low-income children with ASD are less likely to report having access to specialty medical care.4 However, in a study that examined differences in care for non-Hispanic white patients and patients of color as homogeneous groups may obscure important differences in access to care for other subgroups.

These previous studies, taken together, suggest that disparities in ASD evaluations and management likely compound along each step of the pathway, contributing to delays and disparate rates in diagnosis and service receipt. The reasons for these disparities are numerous, including a tradition of structural racism, as was recently highlighted in Pediatrics,25 which introduces several barriers to care.

Furthermore, for decades, ASD was considered a problem of white boys, and children of color tend to receive alternative diagnoses before confirmation of ASD.26 Expanding clinicians’ view that ASD can affect girls and people of color populations remains challenging but crucial.

Although many steps along the diagnostic and intervention process currently represent barriers to equitable care, each of these can also be considered an opportunity to mitigate and correct those inequities. Thus, researchers and clinicians can move beyond work that identifies disparities to interventions that intend to correct or bypass the systemic inequities that produced them.

Within existing systems, there are opportunities for identification to consider. Ongoing surveillance beyond screening age should continue to address possible ASD-related concerns for children who may have gone undetected at traditional screening ages. Identifying children who have already passed screening ages sooner may do little to impact the median age of diagnosis but may affect the mean age and have tangible impacts on individual patients and families. Clinically, health care organizations should put processes in place that treat cases of delayed diagnosis as medical errors worthy of analysis and improvement efforts, similar to what is done for other near-miss or adverse events. Each contact with the medical system can provide an opportunity for ASD concerns to be raised. When a child visits the emergency department, for example, clinicians may have unique opportunities to observe for social communication or behavioral concerns. Thus, ongoing education about ASD recognition and referral processes for all clinicians who work with children may add backstops for identification.

New strategies should be employed with an equity lens in mind to improve diagnosis for minoritized populations. Quality improvement efforts can be effective in expanding rates of ASD screening and referrals after a positive screen result;27 and these efforts should also examine the impact across groups. Clinicians can consider their thresholds for...
The majority of children who falsely screen positive for ASD or developmental delay are later diagnosed with another developmental condition and tend to score lower on achievement tests. Therefore, more children may benefit from additional attention to their developmental status, even if they ultimately do not meet criteria for ASD. More work is needed to understand how and why some children are referred after a positive screen result and others are not, the accuracy of those referral decisions, and the role that implicit bias may have on referral decisions for children with different sociodemographic characteristics (eg, sex, race, and family language). Clinicians can examine their own implicit biases and query their own decisions by mentally replacing their patient’s characteristics and asking if they would make a referral in that case (eg, considering whether they would refer if the child were white instead of Black).

Additionally, digital tools embedded within the electronic health record, such as clinical decision aids that rely on machine learning, are being tested to identify patterns of concerns or diagnoses that may signal ASD risk. These tools may alert and bring needed clinical attention to address developmental concerns. However, algorithms may identify risk in a biased way if the data they rely on are biased. Therefore, it is imperative that the machine learning uses large, diverse populations of children to more equitably recognize risk of ASD or other developmental concerns.

Not only should we consider interventions to improve the steps of the current diagnostic and intervention process (eg, making referrals more generously and equitably and improving access to diagnostic assessments and interventions), we should also think of ways to build off of this current roadmap to find alternate routes to diagnosis and management. Focusing efforts to improve ASD identification and care primarily in primary care settings may be myopic and fail to consider additional team members that serve young children that can potentially bolster these surveillance efforts. Given known disparities in access to patient-centered care and medical homes for minoritized populations, thinking more broadly about other systems of contact may allow us to meet young children with ASD risk where they are.

For example, improved coordination between the educational and medical systems may decrease barriers to care. In many states, children require separate medical and educational assessments to receive ASD-related services that are covered by medical insurance and by Early Intervention Part C systems or schools. This redundancy may add unnecessarily to waiting lists for assessments. Additionally, early child care providers observe children in social situations and can add unique insights into early signs and symptoms of ASD; improving communication and partnership between medical and educational professionals can shed light on early ASD concerns. Other novel settings, such as offices that provide Special Supplemental Nutrition Program for Women, Infants, and Children services, may be places where caregivers report developmental concerns; Special Supplemental Nutrition Program for Women, Infants, and Children staff can be trained to respond to those concerns to provide an additional layer of prevention. In total, these efforts would signal to families that multiple systems of care offer support to identify developmental and ASD-related concerns.

Addressing concerns in multiple settings would also be more responsive to diverse family needs and preferences for trusted sources of information.

Achieving equitable and early ASD identification and intervention requires quality improvement efforts, ongoing research into best practices and their implementation, and a consideration of the steps beyond screening and outside of primary care offices. The last 20 years have highlighted the problems. We can now be creative in redesigning the roadmap to achieve meaningful change.

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ABBREVIATION
ASD: autism spectrum disorder

REFERENCES


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