

Structural Racism and Autism

Sarabeth Broder-Fingert, MD, MPH,^a Camilla Mateo, MD, MPH,^b Katherine E. Zuckerman, MD, MPH^c

Significant racial inequities exist in access to services for youth with autism spectrum disorder (ASD). Multiracial children are diagnosed with ASD later than their white counterparts, report difficulty accessing treatment services, and ultimately experience worse health outcomes. Empirical data on the mechanisms of inequities are generally lacking, although traditional contributors (structural racism, prejudice, education, income) are certainly at play.

In this month's issue of *Pediatrics*, Constantino et al¹ found that among a large cohort of African American (AA) children, there was on average a 3-year delay between first parental developmental concern and ASD diagnosis. Moreover, nearly half of parents reported visiting multiple providers before receiving an ASD diagnosis, and 31.3% stated lack of available professionals contributed to this delay.

Given the pervasive history of racism and exclusion that exists across the United States, particularly in medical care and research, we first applaud the overall goal of Constantino's work to increase representation of AA children in ASD research. Next, we want to leverage this opportunity as a call to action for the field of ASD services. Specifically, how can these data be used to address existing inequities in an urgent and meaningful way?

We believe these data shed light on structural racism as a driver of inequity for children with ASD. In this study, many AA children experienced significant delays from first parental concern to ASD diagnosis, saw multiple providers before diagnosis, and

reported a lack of available providers as a barrier to obtaining a diagnosis. Although causality can be difficult to demonstrate, particularly with cross-sectional data, in this study, the confluence of findings are suggestive of structural racism leading to inequity. For example, although the causes of delays from first parental concern to ASD diagnosis are complex, they can result from a number of issues, including racial bias and discrimination experienced by families, a lack of diversity in health professionals (impacting patient-provider relationships), and/or concentration of specialists in geographic areas with fewer minority residents. Each of these issues can be linked to racism, both individual (health care workers behaving in an implicitly biased or discriminatory way) and structural (systems that support white families accessing care over AA families). For example, 31.3% of parents cited availability of professionals as a barrier to diagnosis. Workforce capacity has long been a major challenge in the field of ASD. This issue may be compounded for AA families who may be more likely than white families to live in areas with few ASD diagnostic specialists and also be more likely to rely on Medicaid. Medicaid may aggravate inequities because low rates of Medicaid reimbursement for diagnostic services can create challenges to supporting and maintaining a workforce. Thus, AA families may be suffering from a lack of available workforce related to where they live (as a result of structural racism in housing policy), whereas clinics serving these communities may be unable to expand capacity (because of structural racism in Medicaid



^aBoston University and Boston Medical Center, Boston, Massachusetts; ^bBoston Children's Hospital, Boston, Massachusetts; and ^cOregon Health and Sciences University, Portland, Oregon

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Address correspondence to Sarabeth Broder-Fingert, MD, MPH, Department of Pediatrics, Boston Medical Center, 801 Albany St, Boston, MA 02118. E-mail: sarabeth.broder-fingert@bmc.org

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reimbursement rates). These issues are likely exacerbated by additional issues on the provider level including a lack of cultural humility and workforce diversity. Notably, a recent workforce survey showed that only 2% of developmental-behavioral or neurodevelopmental pediatricians are AA.²

Thus, we feel these data, combined with previous work on inequity in ASD, necessitate an immediate evaluation of how issues of structural racism have impacted ASD diagnosis and, more importantly, an action plan to address inequity. To start, a robust response to issues of workforce capacity for ASD diagnosis is needed. This would include evaluating Medicaid reimbursement rates for ASD diagnosis, removing restrictions on who is qualified to make a diagnosis (as recommended in the new AAP clinical report),³ increasing adherence to evidence-based practices in autism screening and diagnosis (which may reduce racial bias), increasing workforce cultural humility, and recruiting a workforce that reflects the diverse communities they serve.

Finally, any study of racial inequity warrants discussion of racism and racial injustice in the United States, including the long-standing, complex system of oppression and exclusion that allocates and concentrates unfair advantage to white communities and disadvantages to multiracial communities. In addition, given that authors of this study report on the AA population, genetics, and IQ, we remind the reader that the Black community has endured centuries of unsubstantiated “scientific” claims used to suggest a genetic predisposition to lower intelligence or other undesirable attributes and that the genetic material of Black people unfortunately also has a long history of scientific misuse (eg, Henrietta Lacks).⁴ Contemporary researchers should be cautious in exploring genetics, race, and IQ and understand that any conclusions can have important ramifications for future families seeking autism care.

The work to eliminate inequities in ASD diagnosis is hard and complex, but addressing structural drivers of inequity, such as racism, and associated barriers to equitable care, including workforce capacity and

diversity, as well as timely access to diagnostic services is critical to making any meaningful change a reality. The question is, do we as an ASD clinical and research community have the will to achieve this goal?

ABBREVIATIONS

ASD: autism spectrum disorder
AA: African American

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