

Racial, Ethnic, and Sociodemographic Disparities in Diagnosis of Children with Autism Spectrum Disorder

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ABSTRACT: This special article uses a biosocial-ecological framework to discuss findings in the literature on racial, ethnic, and sociodemographic diagnostic disparities in autism spectrum disorder. We draw explanations from this framework on the complex and cumulative influences of social injustices across interpersonal and systemic levels.

(*J Dev Behav Pediatr* 42:682–689, 2021) **Index terms:** ASD, health inequities, systemic racism, disparities.

The prevalence of autism spectrum disorder (ASD) has increased dramatically in the past 2 decades, with current reported US prevalence rates of around 1 in 54 children.¹ Behavioral symptoms of ASD have been detected in children between 12 and 14 months of age,² and ASD can be reliably diagnosed by 2 years of age^{3,4}; however, parents often have to wait an average of 3 years between their first concerns and their child receiving an ASD diagnosis.⁵ The average age of diagnosis remains between 4 and 7 years,⁶ with this delay being more pronounced with children from lower-income, ethnic/racial minority, and rural backgrounds.⁷ Although the prevalence of ASD has been found not to differ across racial and ethnic groups, studies have found that White children and those of higher socioeconomic status are more likely to be both identified and diagnosed with ASD earlier compared with Black, Latinx, and Asian children, as well as children from low-income families.^{8,9} As a result, non-White and lower-income children are less able to capitalize on early autism-specific intervention services during important developmental windows when optimal neuroplasticity and synaptic proliferation occur.^{7,10}

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Received November 2020; accepted June 2021.

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Health equity is defined as “the state in which everyone has the opportunity to attain full health potential, and no one is disadvantaged from achieving this potential because of social position or any other socially defined circumstance.”¹¹ Unfortunately, significant racial inequities exist in diagnosis and treatment of children with ASD. In a recent study, Constantino et al.¹² found that the average age of diagnosis for Black children was over 5 years and over 3 years after parents' first concerns about their child's development. Although the study did not include a comparable sample of non-Latinx White children, this is consistent with research that has found delay in diagnosis to be more pronounced in children of color. In a study of over 260,000 children younger than 8 years of age, up to one-fourth of children were undiagnosed, with most of these children being Black or Latinx.¹³ Another study found that White children were 19% and 65% more likely to receive a diagnosis of ASD than Black and Latinx children, respectively.¹⁴ Sadly, the findings of Constantino et al.¹² mirror previous studies, some of which were published almost 2 decades ago and suggest little progress in equitable care and that health disparities for children of color with ASD persist. Although there are little empirical data on the mechanisms and causality of these inequities in ASD, a multitude of factors, including structural racism (i.e., a system of White dominance in which non-White individuals are excluded from equal access to societal resources),¹⁵ discrimination, education, and income, are undoubtedly involved and serve as co-occurring and interrelated operational drivers for maintaining disparities.¹⁶

The biosocial-ecological model is a useful framework to understand the complex processes that underlie the onset, perpetuation, and exacerbation of health disparities.^{17,18} This model is represented by a series of concentric circles and can simultaneously consider individual, family, service system, and cultural factors that result from the complex interactions within and across socioecological levels (i.e., intrapersonal, interpersonal, organizational, community, and policy levels).¹⁹ To bring to light health inequities in ASD, we use this framework to discuss findings in the

literature on diagnostic disparities in ASD and draw explanations from this framework on the complex and cumulative influences of social injustices across interpersonal and systemic levels.²⁰ We should note that studies have typically examined health disparity factors in an isolated manner and do not consider the collective influence of the socioecological contexts surrounding the individual level.

INDIVIDUAL, FAMILY, AND CULTURAL-LEVEL FACTORS

The reasons for the disparities in age of diagnosis for children of color with autism spectrum disorder (ASD) are multifactorial and may include intertwined sociodemographic influences related to financial and educational resources as well as language and cultural barriers.²¹ A lack of financial resources can in turn limit access to information, education, and access to quality health care.²¹ Historical practices such as redlining have led to cyclic and serial divestment in low-income neighborhoods of people of color and have resulted in limited access to community resources and stark inequality in the ability for upward mobility.²² Poverty rates are typically higher in communities of color, and studies in both the United States and other countries have found a positive socioeconomic status (SES) gradient in ASD prevalence, with prevalence increasing with higher SES indicators.¹⁴ Regardless of ethnicity, those with higher maternal education and ASD knowledge have increased access to care.²³ It is likely that these parents have a higher level of health literacy to recognize atypical child development and also a higher ability to pay for and better navigate existing health care systems and to advocate for care in the face of discrimination or other systemic obstacles.²¹

Discrimination, fear of stigma, and uncertainty regarding the diagnostic process and services also continue to negatively affect the receipt of early identification for children of color with ASD. One study found that compared with White parents, Black parents of children with ASD reported significantly fewer autism concerns and fewer social, restricted, and repetitive behavioral concerns, which may be due to lower ASD knowledge or differing perceptions of whether specific behaviors are concerning.²⁴ In addition, having low awareness of ASD and its symptoms as well as increased stress during the diagnostic process has been reported barriers for Latinx families accessing care.²⁵ In fact, in a subsample of Latinx families with limited English proficiency, more than 85% of families indicated a lack of knowledge about ASD.²⁵ This lower level of awareness of ASD symptoms may be in part due to systemic barriers to developmental education for parents of color but may also reflect a lack of research on the heterogeneity of symptoms in diverse populations. Indeed, most extant research and measurement development for the evaluation of ASD has relied heavily on White, middle-class samples, and thus, the traditional knowledge base of ASD symptoms may not accurately represent the experiences of families of color.

Given these findings, educational campaigns and community awareness activities are needed. The expansion of early ASD awareness campaigns such as “Learn the Signs. Act Early” or the Autism Speaks Early Access to Care and the Global Autism Public Health initiatives can help create greater ASD awareness in low-income and communities of color.²⁶ Educational community engagement efforts within communities of color can enhance awareness of the early indicators of delayed development consistent with ASD and can provide advocacy training and support for marginalized families. With increased knowledge and awareness, parents and providers are more likely to observe behavioral symptoms and whether these phenotypes are consistent with ASD. Parents, in turn, are better equipped to navigate the health care and social service systems to secure the services for their child. Pediatric providers should ensure that efforts to educate families about available resources and services be performed in a way that is targeted to diverse consumers, is culturally responsive, and is in languages accessible to community members.²⁷ Simple parent-focused ASD education programs that do not take into account cultural factors (e.g., community acceptance) may be inefficient and leave disparities intact.¹⁸ Diagnostic delays and misdiagnosis can have significant downstream effects on the care journey pathway. Racial and ethnic minorities with ASD have been found to have decreased access to treatment services because of language and logistic barriers (e.g., transportation, child-care, and job accommodations), as well as a lack of knowledge of existing services.²⁷ These challenges, coupled with cultural factors, ultimately lead to lower use of health care and treatment services (e.g., school-based services, occupational therapy, speech and language therapy, and recreational programs).²⁷

HEALTH SYSTEM-LEVEL FACTORS

Access to Care

An increase in the proportion of children with autism spectrum disorder (ASD) who receive a diagnostic evaluation by 36 months of age has been a part of the Healthy People 2020 federal prioritization. The percentage of children with an ASD diagnosis by 48 months has increased from 58% in 2014 to 71% in 2018.²⁸ However, a shortage of trained professionals, the time it takes for diagnostic evaluations, and reimbursement constraints all continue to contribute to delayed referral and increased evaluation wait times.⁷ The lack of available specialty services and limited workforce capacity have resulted in diagnostic bottlenecks for all children suspected to have ASD. This shortage of specialists is even more pronounced in low-income and communities of color that rely on Medicaid, thus leading to even greater delays for families living in these areas.¹⁶ Moreover, low rates of Medicaid reimbursement for diagnostic services can make it challenging to support and maintain or expand workforce capacity.¹⁶ Compared

with White children, Black and Latinx children have been found to have increased difficulty in accessing specialty care for developmental disabilities and ASD.^{29,30} Nearly one-third of respondents in the study by Constantino et al.¹² indicated that a lack of specialists contributed to a delay in a child being properly diagnosed, and another 35.6% reported significant wait times to see a specialist. Even when a child screens positive for ASD, a family often experiences long wait times for a subsequent diagnostic evaluation by a specialist, with reported wait times up to 12 months in some geographic locations.⁷ Those families from more marginalized backgrounds may not have the same financial and educational resources as others and face additional systemic and interpersonal discrimination; thus, these families have increased difficulty navigating the complex diagnostic and treatment process, particularly in light of extended wait times.

Time to Diagnosis

Black parents in the study by Constantino et al.¹² reported that the average age at which they first had concerns about their child's development was around 2 years. Nearly half of the children were evaluated by multiple providers before being diagnosed, and 14% were seen by at least 6 professionals before finally receiving a diagnosis. This resulted in costly delays, with children not receiving a diagnosis until, on average, over 3 years later. Similar findings have been reported with Latinx children who receive an ASD diagnosis after an average of 8 doctor visits.³¹ These delays likely further exacerbate health disparities by leading to increased stress and frustration for the parents, along with the increased monetary costs (e.g., health care visits, transportation, and time off from work) that come with having to be seen by numerous providers before finally receiving a diagnosis. The core and associated symptoms of ASD can also mirror other conditions, including attention-deficit/hyperactivity disorder (ADHD) or obsessive-compulsive disorder. Children of color with ASD are more likely to receive an initial diagnosis other than autism (e.g., ADHD, conduct disorder, and adjustment disorder) during their first specialty visit before receiving an accurate ASD diagnosis.¹³ This is likely due to the lack of provider training in recognizing ASD symptoms in children of color. In addition, provider implicit bias may negatively affect their communication with families and gathering of behavioral symptoms, which in turn can affect their judgments or assessment of presenting symptoms and ultimately lead to providers attributing ASD symptoms to behavior problems stereotypical of children of color.

Provider General Education

The American Academy of Pediatrics (AAP) recommends the implementation of universal developmental and ASD screening^{32,33}; however, a lack of knowledge, lack of familiarity with screening tools, and lack of con-

fidence in identifying ASD symptoms continue to serve as barriers for many providers to successfully implement these recommended screening practices.³⁴ With increased uncertainty, providers may resort to a “wait-and-see” approach that can perpetuate further diagnostic delays. Even then, not all children who screen positive are referred for a diagnostic evaluation because rates for referral for an ASD evaluation are low.^{35,36} In addition, given the nondiverse samples used to develop and validate screening and diagnostic instruments, these tools may function differently in populations of color and may not identify all clinical phenotypes equally.³⁷ In fact, the specificity and positive predictive value of the Modified Checklist for Autism in Toddlers Revised have been found to be lower in children of color and those from lower-income household, resulting in a higher rate of false positives^{35,38}; thus, more sensitive screening instruments are needed. Providers have also reported feeling less comfortable in identifying ASD risk with Spanish-speaking families.³⁹ To help address disparities in ASD screening, Harris et al.⁴⁰ recently validated a visually based ASD screening tool for those with low-literacy levels or with limited English proficiency. Even with universal screening practices, children who are of color, are from lower-income households, receive public insurance/Medicaid, and are exposed to a language other than English are more likely to be missed.³⁸ As a result, providers would benefit from tools to facilitate communication and shared decision-making with families.⁴¹ In addition to ASD-specific screening, providers should screen for important social determinants of health that are consequences of structural racism, including housing difficulties, lack of safety in their neighborhood, poverty, food insecurity, and connect them to appropriate resources.²²

Because additional education and training for ASD can be beneficial for providers in pediatric practice, there has been an emergence of research on strategies to improve access to timely diagnostic evaluations, including training of primary care providers (PCPs),⁷ creating integrated behavioral health practices to streamline assessment and diagnosis,^{42,43} and use of telemedicine to reach underserved areas.⁴⁴ For example, the Project Extension for Community Healthcare Outcomes Autism Screening Tool for Autism in Toddlers and Young Children pilot study was developed to train community-based PCPs in underserved areas in screening and diagnosis of ASD to accelerate early access to diagnosis and treatment.³⁴ This hub-and-spoke model allows for telemonitoring of primary care physicians to consult with specialists regarding diagnosis and management of ASD and has resulted in increased self-efficacy and increases in knowledge around timely diagnosis and management, although most recent data have not yet shown significant changes in ASD screening.⁴⁵ In addition, the REAL-START intervention has been found to increase ASD screening overall, provider adherence to screening guidelines, and rates of referral in Latinx communities.⁴⁶ Finally, some have recommended

that offering ASD screening at preschool well-child visits might lower the overall age of diagnosis, particularly for low-income and children of color.⁴¹

The AAP has also recently released updated guidance for the identification, evaluation, and management of children with ASD.³² This comprehensive clinical report discusses a standardized approach to screening and highlights the importance of more accurate and culturally sensitive screening practices. In addition, the AAP has also offered an online learning course titled “Identifying and Caring for Children with Autism Spectrum Disorder: A Course for Pediatric Clinicians” to complement this material and aid clinicians in identifying and caring for children with ASD, available at <https://shop.aap.org/identifying-and-caring-for-children-with-autism-spectrum-disorder-a-course-for-pediatric-clinicians/>. This training is only the first step toward competent ASD diagnosis and management and should be supplemented with additional education on culturally sensitive care and antibias training.

Patient-Provider Relationship

Children and their families benefit from increased awareness by providers of diverse cultural practices and racial biases. Given the frequency of contact with families during the first years of life, pediatric PCPs serve as a link of continuity and are uniquely positioned to build strong rapport and trust with families. For this reason, pediatricians are uniquely positioned to mitigate the consequences of racism and ensure that all families receive timely diagnosis, management, and referral for ASD.⁴⁷ Yet, there is a lack of diversity in health professionals in general, which can negatively affect patient-provider relationships.¹⁶ Providers must be comfortable with being uncomfortable and be willing to get proximal to the problems of racism and engage in self-education.²² In addition, pediatric providers must be aware of their own implicit biases, which can affect their judgments and clinical decision-making about patient care and negatively affect patient ratings of patient-centered care, including trust and interpersonal treatment (e.g., care, concern, and respect).^{48,49}

Studies have shown that health care providers have similar levels of implicit racial bias as the general population, and those with more implicit bias tend to have higher verbal dominance in communication with patients and lower ratings of patient-centered care.⁵⁰

Patient-Provider Communication

Compared with children with other developmental disabilities, families of children with ASD have been more likely to report that the doctor did not spend enough time with the child, did not listen, and was not sensitive to the families’ values and customs.²⁹ This is especially pronounced for Black families who report ongoing experiences of racism, marginalization, and dismissal of concerns in health care settings, including in the pursuit of an ASD diagnosis for their children.⁵¹ Caregivers of

Latinx children have reported that limited English proficiency, a lack of knowledge of ASD, and difficulty navigating the health care system as well as feeling their concerns were dismissed by the provider were all barriers to diagnosis.^{25,41} This resulted in caregivers normalizing their child’s early behaviors and losing trust in the medical system. Further research on provider attitudes, cultural competence, linguistic barriers, and provider communication in the pediatric literature is warranted to help bridge the disparity gap. This will require providers to identify and mitigate the effects of their own implicit bias on care with children and families and also work to ensure that care provided in culturally competent ways that is consistent with the families’ values.⁴⁸ Given that trust in providers has been found to be problematic in populations of color, employing bicultural and bilingual staff, using trusted brokers (e.g., community members and Latinx parents of children with ASD), having language concordant helplines, and incorporating family navigators may engender trust, decrease the stress of the diagnostic process, and assist families in accessing services.²⁵ Family navigation is a case management model that has been identified as a promising intervention to target low-income families and minoritized groups to improve the timely diagnosis of ASD⁵²; however, large evaluations have demonstrated variable outcomes and family experiences across different health care delivery systems.⁵³

APPROACHES TOWARD EQUITABLE CARE

The barriers to access autism spectrum disorder (ASD) assessment for underserved populations highlight the need for innovative approaches to ASD screening, evaluation, and diagnostic decision-making that can increase access to earlier detection and intervention of ASD for all children. There have been increased interest and a growing literature on the feasibility of using either Real-Time or Store-and-Forward telemedicine for ASD diagnostic assessments and interventions.⁴⁴ For example, Smith et al.⁵⁴ compared the use of Naturalistic Observation Diagnostic Assessment with the in-person evaluation and found high rates of both diagnostic sensitivity and specificity (84.5% and 94.4%, respectively). Using a real-time method, Reese et al.⁵⁵ found improved access to diagnostic services and high agreement between face-to-face and videoconferencing for the diagnostic assessment of children with suspected ASD. Overall, the use of telehealth in the field of ASD has been shown to be an effective, acceptable, and usable modality for both clinical evaluation and behavioral intervention⁴⁴ and represents a scalable alternative to traditional methods. Telehealth offers advantages for increasing access to diagnosis and care, expediting the diagnostic process and receipt of early intervention services, decreasing provider and patient costs, and increasing provider coverage area.⁴⁴ It is important to note, however, that educational, socioeconomic, language, and literacy factors may minimize the impact of telehealth services for

populations of color, who are more likely to suffer from the digital divide. Although not a panacea for health disparities, telemedicine can be a viable option for families in remote and underserved areas, which allows for extended and expanded access to quality services, including for children of color.

Some have noted that the use of data-driven methods that leverage advances in artificial intelligence (AI) and machine learning are promising approaches to augment the practicing physician's clinical decision-making for diagnostic evaluations.³⁸ As mentioned previously, factors contributing to disparities in ASD diagnosis and access to early intervention include ethnic/racial-minoritized parental underreporting of certain symptoms, physician bias in diagnosis and discrimination in interactions, and limited access to specialists because of insufficient numbers of clinicians and geographical barriers. Integrating AI-based technology into standards of practice in clinical care can address these root causes of disparity by decreasing reliance on parental report of symptoms and reducing the potential impact of physician bias. By integrating massive data sets, the AI algorithms can assess thousands of traits and features and build on the findings to assist clinicians in making an accurate, timely, and unbiased diagnosis. With the use of racial-conscious and ethnic-conscious data sets, researchers and AI developers can control for the influence of cultural biases and identify the most predictive traits that are commonly linked to ASD for different races and ethnicities. These AI-based technologies can also be implemented in primary care settings, thereby reducing reliance on specialists and increasing accessibility of diagnosis in underserved geographic areas. Ultimately, when coupled with provider education and technical assistance, AI-based tools can be used to address the bottlenecks in the diagnostic process by increasing efficiency and decreasing the demand on specialists, thereby allowing for a scalable process for assessing ASD in children.⁵⁶ AI is not without limitations, however, because an AI algorithm or model is only as good as the data from which it was derived. Stated differently, if the data used to derive the model or algorithm are biased or otherwise do not fully represent all potential groups of individuals, then the output will only further perpetuate these biases.⁵⁷

CALL TO ACTION

Kilbourne et al.⁵⁸ developed a 3-component model or roadmap for health services researchers, practitioners, and policymakers to guide health disparities research, including (1) detecting or identifying disparities, (2) understanding the determinants that underlie the disparities, and (3) developing strategies and interventions for reducing or eliminating these disparities. The literature for simply identifying disparities in autism spectrum disorder (ASD) has been well established over the past 2 decades. The time is now to systematically advance

health disparities research and for the field to progress toward identifying root causes (phase 2) and develop effective system-level and culturally sensitive approaches to close existing gaps and move toward more equitable care (phase 3). The dimensions of equity must be identified, addressed, and transformed through clinical care, education and training, research, mentoring, and service.⁵⁹ Furthermore, the construct of race must be better measured, carefully used, and potentially replaced to further advance research in pediatric health disparities.⁶⁰ This includes clearly defining race in a way that clearly references the sociopolitical nature of the concept and not genetic interpretations of race.⁶¹

Studies unfortunately have typically examined health disparities in isolation without consideration of other socioecological factors/levels.¹⁸ A more thorough understanding of how parent (e.g., beliefs and preferences, education, and race/ethnicity), provider (knowledge, attitudes, racial biases, and competing demands), clinical encounter (e.g., provider communication and cultural competence), and health care system (e.g., health services organization, financing, and organizational culture) factors interact warrants more empirical research and system change. Intervention and prevention efforts to reduce disparities should consider child-level, family-level, school-level, community-level, and policy-level influences and should seek to elevate the perspectives of the families being affected at every stage from intervention development to implementation.

As the growing literature on race, socioeconomic status, and ethnicity in ASD indicates, disparities persist, resulting in worse health outcomes for non-White and low-income children with ASD, and necessitate a call to action to address the systemic drivers of inequity.⁶² We cannot ignore the centuries of oppression experienced by marginalized groups, and change is needed. The need for action has currently been highlighted given the COVID-19 pandemic, the current sociopolitical climate, and events of racial injustice that reverberate throughout and have been thrust into the forefront of national media. The work to address the longstanding system of oppression and exclusion to eliminate inequities in a meaningful way will be both difficult and complex and will require a shared commitment and multifaceted approach.⁵⁹ This work is critical to make meaningful change to the structural drivers of inequity and associated barriers to equitable care.¹⁶ The solutions are not as simple as providing increased education, and the focus should shift from changing individuals to changing the structures and systems that surround individuals.⁶³ In fact, for some approaches, short-term interventions merely serve as a band-aid solution for addressing systemic, interpersonal, and historical racism.⁶³ Most child health interventions are focused at the individual level and not structural interventions at the system or policy level, which, in isolation, will likely only perpetuate inequalities.⁶³ More research is needed to develop and validate interventions that address both health disparities

and the core issue of racism.⁵⁹ For example, changing existing systems will necessitate dedication to increasing ethnic and racial diversity in both clinical and research roles by making education and training more accessible to communities of color and by making medical training more culturally responsive. In addition, examining reimbursement rates and removing restrictions on who is qualified to make a diagnosis are a needed step in the process.¹⁶ Health care systems can support economic growth in communities that have historically seen serial divestment in their neighborhoods and work to dismantle policies and structures that systematically drive social determinants of health (SDoH).⁴⁸

In a recent editorial, the *Journal of Developmental and Behavioral Pediatrics* expressed its commitment to fostering publications on the role of racism and discrimination as determinants of child health and well-being as well as at the interpersonal and structural/systemic level in health care.⁶⁴ Relatedly, Valdez²² put out a call for pediatric providers to engage in antiracism and social justice for children through self-education to increase racial awareness and comfort in discussing race with patients, partnering with community agencies and advocacy groups to lobby for structural community improvements, and screening patients for SDoH (e.g., housing difficulties and neighborhood safety) that are both social and economic consequences of structural racism. Pediatrics should be at the forefront of addressing racism, as a failure to do so will continue to undermine health equity for all children and their families.⁴⁷

The dimensions of equity must be identified, addressed, and transformed through a significant investment in clinical care, education and training, research, mentoring, advocacy, and service.⁵⁹ Developmental and behavioral specialists can help mitigate the social injustices that low-income and families of color face and work together toward ameliorating the oppressive forces that limit access to timely evaluation and treatment services. This will require engaging in efforts to optimize clinical care, workforce development, professional education, systems engagement, and research.⁴⁷ Although there is a shortage of pediatric specialists overall, a recent workforce survey showed that only 2% of developmental-behavioral or neurodevelopmental pediatricians are Black.⁶⁵ To recruit a workforce that reflects the diverse populations served, the Academic Pediatric Association has created the New Century Scholars, a mentorship program aimed at increasing the workforce diversity in academic pediatrics that spans educational, research, and clinical care and at increasing the representation of underrepresented minorities.⁶⁶ In addition to diversifying the workforce, increasing cultural humility and a self-reflection and commitment to unpacking internalized or implicit racial biases and discriminatory practices will also be needed. Drawing from social psychology, health care educational interventions designed to reduce implicit bias have typically included both an approach to identify and increase awareness of one's own implicit biases and an instruction on how to reduce the activation of these biases or control how they influence

judgment and behavior. Unfortunately, only a few studies have examined the effectiveness of these steps in isolation or together with health care providers. Regarding ASD, more research is needed to provide direct evidence on the processes at work in provider bias with the diagnosis and management in children of color.

Further advancement is needed to meet federal initiatives aimed at eliminating disparities for low-income and children of color who present with developmental and/or behavioral concerns, including those with ASD. Eighteen years ago, the Institute of Medicine report titled *Unequal Treatment* highlighted the multifactorial disparities in health care quality received by individuals of color and provided a conceptual lens for identifying determinants to help understand and address the root causes of these disparities.⁶⁷ Despite this report, disparities persist into the present day and remain relatively unchanged, which can be explained, in part, by a failure to acknowledge that racism is at the root of these racial disparities.⁶² There has been an increased focus on diversity, equity, and inclusion in pediatrics over the past 10 years. Yet as a recent policy statement stated, pediatrics has yet to systematically address the influence of racism on child health outcomes and to prepare pediatricians to identify, manage, mitigate, or prevent the harmful impact of these inequities.⁴⁷ The collective call is loud and clear, and the time for change is now.

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