

## “They Don’t Know, Don’t Show, or Don’t Care”: Autism’s White Privilege Problem

Morénike Giwa Onaiwu, PhD<sup>1,2</sup>

WHEN I—AS A BLACK PERSON, as a woman, as an autistic adult, as the mother of black autistic children, as an advocate—think about the world of autism research and practice, the words of Doughboy come to mind. In a poignant ending scene from the late African American director John Singleton’s iconic debut film, *Boyz n the Hood*, Doughboy sadly remarks, “Either they don’t know, don’t show...or don’t care about what’s going on in the hood.<sup>1</sup>” Similarly, when it comes to autism, either they—or should I say you all—do not know, do not show, or do not care about black, indigenous, people of color (BIPoC) very much.

Perhaps “they”—society at large, particularly those who are more privileged—are uninformed of the realities of those whose lives are more laden with oppression than theirs (“they don’t know”). The typical “face” of autism tends to be that of a little white boy, regardless of autism’s actual prevalence in all racial, age, and gender groups. Moreover, autism continues to be widely depicted and perceived as a tragic childhood condition that devastates families and burdens communities and, therefore, requires urgent intervention.

A Google image search for the word “autism” yields a plethora of (mostly white) children, puzzle pieces, and colorful infographics bearing lists of symptoms, warning signs, graphs, and statistics. Like these images, the majority of autistic characters in popular media (e.g., *Atypical*’s Sam, *Parenthood*’s Max, *The Good Doctor*’s Shaun, and *Big Bang Theory*’s Sheldon) tend to be white and male. They bear little resemblance to Arnaldo Rios, Reginald “Levi” Latson, JT Torres, Kayleb Moon-Robinson, or David Ramos—all autistic individuals of color who were unjustly (and in most instances, violently) mistreated by U.S. police officers.<sup>2</sup>

In all of these cases, the intervening officers perceived these individuals’ mannerisms as aggression rather than characteristics of autism and responded with excessive force. Although the officers’ actions are clearly reprehensible, it begs the question: with such little recognition that autistic people of color even exist, should we truly be shocked by any of these incidents? Or by the recent deaths of Eyad Hallaq of Jerusalem or Elijah McCain of Colorado, both young men of color who displayed autistic characteristics and were killed by the police?<sup>3,4</sup>

In contrast to the limited perspective on autism shared by the general public, there are a significant number of individuals (and their respective organizations/institutions) who actually possess an understanding that grave inequities exist in communities of color with regard to autism.<sup>5</sup> Although the layperson might be largely uninformed, autism professionals and experts, including clinicians, investigators, service providers, and others who are privy to more in-depth information, cannot feign such ignorance; they “know” about it.

However, what they know is rarely, if ever, applied in a manner that could result in meaningful change to the disparities faced by people of color in the autism community. If knowledge is “power,” in this case that power is rendered dormant. These are the individuals and institutions within the autism community who “don’t show.” They do not adequately show what is going on with regard to the diagnostic, access, outcome, educational, psychosocial, economic, and other gaps between races.

This failure to call attention to and/or take action to right these imbalances is not necessarily malicious. Usually, it is not intentionally racist; in fact, most likely it seldom is. What it is, however, is self-serving. It is comfortable; it is familiar. It is lazy. And it is cowardly. For it is a lot safer to maintain the status quo, to “go with the flow” and to pretend not to notice. It takes courage and integrity to have to initiate difficult conversations. It takes time, and energy, and resources to make the efforts required to transform our spaces, our policies, and our practices to make them more inclusive. It takes self-awareness and strength to yield one’s privilege: to ask hard questions, to make space for others, to work toward restoration, and to unlearn and re-educate ourselves. Sadly, despite awareness of the plight of people of color in the autism community, many would rather not inconvenience themselves.

In addition to those who “don’t know” and those who know, but “don’t show,” there is, according to a more pessimistic hypothesis, a third possibility: those who simply “don’t care.” Like those who “don’t show,” those in society who “don’t care” are indeed aware of these issues. However, since personally they are not very impacted by these marginalizations, they largely disregard them. These very real

<sup>1</sup>Advocacy Without Borders, Sugar Land, Texas, USA.

<sup>2</sup>Center for the Study for Women, Gender, and Sexuality, Rice University, Houston, Texas, USA.

© Morénike Giwa Onaiwu, 2020; Published by Mary Ann Liebert, Inc. This Open Access article is distributed under the terms of the Creative Commons Attribution Noncommercial License (<http://creativecommons.org/licenses/by-nc/4.0/>) which permits any non-commercial use, distribution, and reproduction in any medium, provided the original author(s) and the source are cited.

\*Correction added on May 15, 2023 after first online publication of November 17, 2020: The author’s degree and affiliation has been updated.

discrepancies remain intentionally unaddressed because it is of little interest to them and because they see little to no benefit in getting involved. Essentially, “don’t show” and “don’t care” reside on a continuum. If you spend enough time as one who does not show, you will eventually evolve into someone who does not care.

Having read this, how are you feeling right now? Pretty crappy, I would assume. When racism within the autism community is brought up, it evokes a sense of discomfort so thick it is nearly tangible. White people seem to feel especially awkward about this topic. And I get that it is not exactly pleasant to think or talk about it. However, can you imagine what living it is like? I can, because unlike many of you, I do not have a choice.<sup>6</sup>

It is uncomfortable for me too. Sometimes (often) I feel as reluctant as Doughboy did to have to face that hurtful and ugly reality. I desperately want to believe that the structural racism within the collective world of autism, in both its subtle and more blatant manifestations, is merely a figment of my imagination (an imagination some would allege is essentially “nonexistent” since I am autistic). I would like nothing more than to feel assured that BIPoC autistic peers are valued as much as we seem to be in all of the rhapsodic and carefully curated “solidarity” and “Black Lives Matter” statements that have been issued in recent months. I wish the amalgamation of both the subjective (observations, personal experiences, and anecdotes from autistic BIPoC peers) and objective (“evidence-informed”) data did not collectively paint the same dismal picture of inequity. But wishing something does not make it true.

In *Boyz in the Hood*, neither Doughboy nor his brother Ricky lived long enough to have a fighting chance to change their circumstances. Their opportunity to experience better in this life ceased the moment their hearts ceased to beat. But if you are reading this, your heart, like mine, beats on. That means that we still have a chance to transform even this chaotic mess into something new that we can build together. It might seem amorphous, intimidating, maybe even impossible, but we must push past fear, doubt, ignorance, apathy, or whatever the obstacle is and seize the opportunity.

The problem is an enormous one; I am not going to lie to you nor myself about its scope. But present circumstances do not have to determine the final outcome. I believe that gradual progress is the ancestor of monumental change, and it starts with you and me. It starts today. I ask you, allies, families, fellow autistic people, *etc.* of all ages, genders, races, and backgrounds, to pledge to take the following steps toward a world where when it comes to autism and race: You will commit to doing the work to know what is happening. You will make concerted efforts to show these important concepts to others so they can be more informed. And, last but not least, through practical and consistent action, you will show that you do, indeed, care.

First, strive to continuously increase your knowledge of matters relevant to autism and race. A great way to start is by reading the intriguing roundtable discussion, moderated by a black autism researcher, in this issue of *Autism in Adulthood*. The discussion features several autistic and nonautistic panelists with diverse racial and ethnic backgrounds (Latinx, black, indigenous, and Pacific Islander) who create a thought-provoking dialogue about structural racism in autism research and practice.<sup>7</sup> In addition, you can follow BIPoC autism activists on social media; read the landmark autism and

race anthology, *All the Weight of Our Dreams: On Living Racialized Autism*<sup>8</sup>; or support efforts such as the grassroots Autistic People of Color Fund,\* which provides material support in the form of microgrants for those in need.

Second, plant seeds of change. Are you a clinician, researcher, or a service provider seeking to serve a more diverse population? First, assess yourself: Is your environment one that would be welcoming to and inclusive of such individuals? Your board? Your staff? If not, fix that first. Then seek out some strategic partnerships with minority serving institutions, professional and community organizations, multicultural fraternities and sororities (the Divine Nine, the National Association of Latino Fraternal Organizations [NALFO], *etc.*), faith-based institutions, and so on.

Mentoring others is another way to plant seeds of change. There is a critical need for greater racial diversity in autism research and practice; one way to help facilitate this is to increase the amount of BIPoC researchers and providers. To do so, we must ensure that we diversify our student population. One notable example, LoneStar Leadership Education In Autism and Neurodevelopmental Disabilities (LEND), places strong emphasis on the inclusion of racial and ethnic diversity as well as individuals with disabilities, including autism, among both its faculty and trainees; typically 50% or more of their annual fellows are people of color. By doing so, this interdisciplinary autism and neurodevelopmental training program in Texas is making tremendous progress toward its mission to develop and equip leaders to serve under-represented groups.

Third, use your privilege for good. All human beings have different identities, some that are more privileged in specific circumstances and some that are more marginalized. Do not get defensive about having privilege. Instead, flip it! If you have some influence in a certain sphere, take advantage of it. Use your position to share the ideologies and perspectives of those who are not as likely to have such a platform. Or share the platform. Or yield it to someone else! Do you *really* need to be the one to give that address or that interview, just because you were the one who was invited? And if so, who can you bring along who might be able to benefit from being present? Is there a person of color, or even better—an autistic person of color—with whom you can collaborate?

Fourth, do “what is right, not what is easy” with regard to autism research and practice. If you are a practitioner, perhaps you can find ways to accept new types of payment (e.g., other types of insurance, payment plans, and sliding scale fees)? Maybe you need to hire additional staff who are multilingual? Offer nontraditional hours of operation (some nights, some weekends, *etc.*)? If you are in research, perhaps you can also establish quotas to ensure your studies include participants of color. That might mean that it takes more time and effort to recruit, enroll, and retain study participants, but it will be worth the effort. Consider advocating for more diverse data sets. There is no rule that says you *must* use that same old tired sample wherein the vast majority of participants are white—even if that sample is “normed” or affiliated with some impressive entity.<sup>9</sup>

Lastly, not only “bloom where you’re planted,” but try to blaze a trail! A positive example is *Autism in Adulthood*. Rather than follow a “tried and true” template, this journal has taken a number of risks to remain true to its vision.

\*<https://autismandrace.com/autistic-people-of-color-fund>

And though, like everything in life, it is imperfect, I believe it has purposefully positioned itself to be an effective tool in our collaborative quest for racial equity in autism research and practice. From its carefully selected leadership team of autistic and nonautistic editors, its stance on the use of respectful nonstigmatizing language, its requirement for substantive plain language lay summaries, its use of traditional and community reviewers, and the purposeful composition of its editorial board (of which I am a proud member), *Autism in Adulthood's* commitment to meaningful inclusion is far from lip service.\* Believing diversity is not something that should be relegated to a “special interest” or ad-hoc group, our eclectic editorial board, consisting of advocates, researchers, clinicians, and community leaders, represents a diverse range of neurotypes, races, gender identities, nationalities, disciplines, ages, and organizations. We engage in open honest dialogue with one another, even when it is hard. In doing so, we continuously learn from one another, foster a sense of mutual respect and understanding, stimulate ideas for future research and exploration, and help build a forum for deep meaningful discussions on the issues that matter most to autistic adults.

Whoever you are and whatever you do, you can affect change right where you are. You can know, you can show, and you can care. It will require some innovation and some patience on your part, but it can be done. Seek opportunities to make progress, even if seemingly small or unconventional. There are so many possibilities!

## References

1. Durling R. *Boyz n the Hood*. Santa Barbara International Film Festival. <https://sbiff.org/boyz-n-the-hood/> (accessed October 1, 2020).
2. Autistic Self Advocacy Network. Research Overview on Autism and Safety. Autism and Safety Toolkit. <https://autisticadvocacy.org/wp-content/uploads/2017/11/Autism-and-safety-pt-1.pdf>
3. Agarwal R. Elijah McCain: Death By Injection. California Society of Anesthesiologists. July 15, 2020. <http://csahq.org/news/blog/csa-online-first/2020/07/15/elijah-mcclain-death-by-injectionwed> (accessed November 11, 2020).
4. Goldenberg T. Israel: Prime Minister: Killing of Palestinian with Autism a ‘Tragedy’. Associated Press. June 7, 2020. <https://apnews.com/article/75104c37fadeb37b993400c3b7182b3e> (accessed November 12, 2020).
5. Durkin MS, Maenner MJ, Baio J, et al. Autism spectrum disorder among US children: socioeconomic, racial, and ethnic disparities. *Am J Public Health*. 2017;107:1818–1826.
6. Bor J, Venkataramani AS, Williams DR, Tsai AC. Police killings and their spillover effects on the mental health of black Americans: a population-based, quasi-experimental study. *Lancet*. 2018;392:302–310.
7. Ellwood LJ, Garcia A, Johnson KR, et al. An expert discussion on structural racism in autism research and practice. Jones DR, Nicolaidis C, eds. *Autism Adulthood*. 2020; 2(4):273–341.
8. Brown LXZ, Ashkenazi E, Giwa Onaiwu M. *All the Weight of Our Dreams: On Living Racialized Autism*. Lincoln, NE: DragonBee Press; 2017.
9. West EA, Travers JC, Kempner TD, et al. Racial & ethnic diversity of participants in research supporting evidence-based practices for learners with autism spectrum disorder. *J Spec Educ*. 2016;50(3):151–163.

Address correspondence to:  
 Morénike Giwa Onaiwu, PhD<sup>†</sup>  
 Advocacy Without Borders  
 77 Sugar Creek Center Boulevard  
 Suite 600  
 Sugar Land, TX 77478  
 USA

Email: MGO@AdvocacyWithoutBorders.org

<sup>†</sup>**Correction added** on May 15, 2023 after first online publication of November 17, 2020: The author’s degree and affiliation has been updated.

\* *Autism in Adulthood*. Aims & Scope. New Rochelle, NY: Mary Ann Liebert, Inc. Publishers. <https://home.liebertpub.com/publications/autism-in-adulthood/646/overview#aims>