

## An Expert Discussion on Structural Racism in Autism Research and Practice

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### Introduction

**A**UTISM RESEARCH HAS a race problem. Despite improvements in screening and diagnosis, autism continues to be underdiagnosed in Black and Hispanic children,<sup>1</sup> and those who obtain a diagnosis often have limited access to support services.<sup>2</sup> Racial disparities persist during the transition to adulthood, with autistic adults from racial and ethnic minority groups experiencing a number of challenges, including lower rates of employment, social participation, and post-secondary education<sup>3</sup> compared with White autistic adults. Although these studies highlight the important intersection between race, ethnicity, and autism, people of color remain consistently under-represented in autism research,<sup>4</sup> and dialogues regarding the impact of racial and ethnic discrimination on autistic people of color have been limited.

With this roundtable discussion, we wanted to purposefully invite conversation from a group of interested stakeholders to discuss the unique experiences of autistic Black, Indigenous, and people of color (BIPOC), with an emphasis on Black, Indigenous, and Latinx adults, who have been historically under-represented in autism research. Our five panelists, all of whom are people of color, offer personal and professional insight on the critical issues impacting Black and Brown autistic people, and recommend ways to support the well-being of autistic and nonautistic people of color in the field of autism research. The following is a transcript of our discussion, with edits for clarity.

**Ms. Desiree R. Jones:** *Today, we have brought together five panelists with expertise on the experiences of autistic*

*people from marginalized racial and ethnic backgrounds. Their insight represents a number of different perspectives, including psychology, social work, occupational science, community advocacy, and lived experience. All of them are people of color, and three of them are autistic themselves.*

*Thank you all for joining us for this discussion, we really appreciate it. We are going to start with introductions.*

*I am a third-year doctoral student at the University of Texas at Dallas, working in the laboratory of Dr. Noah Sasson. My research focuses on how intrinsic factors, such as a person's social cognitive abilities, as well as extrinsic factors, such as exclusion or stigma, impact social outcomes in autistic adults.*

*As a Black woman in autism research, the topic of race and autism is really important to me. My thesis on stigma and autism has taught me a lot about race-based stigma, and I hope to use this knowledge to advocate for more inclusive environments and greater representation for Black autistic people and researchers.*

**Dr. Christina Nicolaidis:** Hello and welcome. I am here today in my role as the editor-in-chief of the journal. The editorial board and I are extremely grateful to have all of you join this round table discussion.

As to my own background, I am a professor in the School of Social Work at Portland State University. I am also a physician and practice and teach hospital-based internal medicine at Oregon Health and Science University. I have been conducting participatory research my entire career. I started doing participatory research in partnership with

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communities of color, but for the past 14 years or so, I have been primarily working in partnership with autistic adults.

**Ms. Lisa J. Ellwood:** I am an autistic, bipolar, multiply-disabled Lenape and Nanticoke Native American. I am a Black Native independent journalist, writer, and author currently living in the United Kingdom. I was finally diagnosed just before turning 48 years—and it should not have taken so long.

**Mrs. Arianne Garcia:** I am autistic and Latinx. I was diagnosed 4 years ago at age 25 years. I am also an editorial board member for Stairway to STEM, which is an online resource for autistic students transitioning from high school to college in STEM.

**Dr. Khalilah R. Johnson:** I am an assistant professor of occupational science and occupational therapy at the University of North Carolina School of Medicine. My research focuses on the institutionalization of people with intellectual and developmental disabilities (IDDs), including people with co-occurring autism, as well as the cultural and institutional mediators that impact how African Americans with IDDs participate in our vocational and health services system. All of my work is informed by 14 years of clinical experience as an occupational therapist (OT). My pronouns are she/her/hers, and I identify as Black.

**Dr. Kristina Lopez:** I am an assistant professor in the School of Social Work at Arizona State University, but I am dually trained in both social work and developmental psychology, having gone to the joint program at the University of Michigan. My research is focused on Latinx children with autism and their families, primarily looking at disparities in early diagnosis and subsequent intervention services, with a heavy emphasis on community integrated and culturally specific interventions, such as the use of *promotoras de salud*, or community health workers, in order for them to deliver the actual autism services.

I have also been living with epilepsy for the past 27 years, and being Latina myself, I have navigated many similar systems and have dealt with many of the same disparity issues, so my perspective also comes from a very personal stance.

**Dr. TC Waisman:** I am a 51-year-old Black, Indigenous, Pasifika and Nepalese, nonbinary person. I was diagnosed at age 48 years. Of course, once I learned I was autistic, I made it my laser focus and returned to formal education to obtain my doctoral degree studying autism and higher education.

My research was in defining ways in which higher education leaders, faculty, and professional staff can enhance services and outcomes for autistic students in higher education. I am on the board of *Autism in Adulthood* and am a cofounder of the Autistic Researchers Committee at the International Society for Autism Research (INSAR). I am also the primary author of a research project on autism and universal design training for faculty.

**Ms. Jones:** *Thank you all so much. Starting off, let us think about the intersection between autism, race, and ethnicity. Why is it important for us to talk about this, and how do you see racism playing out in your own domain, whether it is research, the clinic, or the community?*

**Ms. Ellwood:** This is so complicated that my answer will be really insufficient given the time constraints. For a start, the face of disability globally is still almost exclusively White, and autistic representation is still almost always White boys and men.

With racism, I had to fight to get my diagnosis, and even now, there are people—mostly White people—who refuse to accept it. Medical racism is something that I am always having to confront, even as an immigrant in the United Kingdom. Every aspect of trying to live, even just a bare minimum good life, is still a fight on both sides of the Atlantic.

**Mrs. Garcia:** There are huge geographic disparities and racial disparities, especially in America, for health and care and continuation of care, and most of the research is done on children. Doctors do not really know how to treat autistic adults, especially if there is racial bias, and then sometimes the doctors will not even take it seriously. I have had appointments where they completely miss the point of why I am there, and even though I say it as succinctly as I can, it is written off.

**Dr. Johnson:** Thinking about this in my own domain as an occupational scientist and therapist, one of the things that comes to mind is that we live in a racialized society. All of our experiences, whether we have autism or not, happen through the lens of race and racism.

In occupational therapy, we have become more intentional with talking about race explicitly, but not necessarily racism. We have done a better job with naming and framing on the research end, but not in ways that therapists can apply to practice.

Racism itself is inherent in all aspects of life, particularly in the American context, and by failing to recognize its impact on our clinical practice, our research, how we build community with autistic adults, and families who have children with autism, we continue to fall short with ameliorating the consequences of those systems of racism.

**Dr. Lopez:** I have been working with Black and Brown kids in special education since I was 17 years, and whenever I would focus on racial disparities, people would tell me “This is not really a thing.” But the intersection between race and autism was so clear to me. When I entered into my PhD program, I experienced the same thing because autism was and is still so White, and we look at it from a very White perspective. Even families and those seeking a diagnosis think of autism as something that only impacts White people. It is critical that we say, “No, this affects everyone. And the reason it looks like a White disorder is because we have only talked about it as a White disorder.”

Honestly, social work has a history of being embedded with racism. Now there is an interesting push for antiracist practice because of current racial tensions, and I am happy we are talking about it, but these things should have been discussed a long time ago.

**Dr. Waisman:** Building on what Dr. Lopez said, it is a very important subject matter not only given the times that we are living in, but also because it is the point of activism for those of us who live at the corner of the intersections of autism, race, and ethnicity.

In the postsecondary educational environment, which is my arena, I have experienced a fair amount of racism and ableism—intentionally through gatekeeping and being told directly that I have no place in academia because I do not fit the profile, and unintentionally through misinformation—for example, the assumption that Black people cannot be autistic, that autistic people cannot be in academia, and even being questioned as to why I would want to share that I am autistic, given that I am already a minority. Talking about this is important because we exist, we have a voice, and we deserve the space and respect given to others in our fields.

**Ms. Jones:** *Thank you for sharing your thoughts and experiences. You all brought up a number of important concerns regarding race, ethnicity, and autism. What do you think are the critical issues that impact the lives of Black and Brown autistic adults?*

**Dr. Waisman:** I am a Black and Brown and Indigenous autistic person, and I have experienced prejudice, as we all have, including daily street-level prejudice, medical prejudice, a lack of research regarding our particular health profile, and resource gatekeeping. These things have been impactful for me, and I still rarely see myself in autism research.

At a young age, my doctors never even thought to test me for autism because they were not looking for autism in someone like me. They were looking for behavioral issues. I missed out on resources other autistic kids might have received.

Frankly, as a Black and Brown and Indigenous person, I had bigger fish to fry. I was trying to keep under the radar of local police, and government agencies, who I saw take Black kids away from their parents. Becoming an expert camouflager was the best way I learned to survive, so I used the very skills that my neurology gave me. I cannot help but wonder now how many young kids like me are out there today using their autistic skills to survive, and as a result are flying under the diagnostic radar.

**Dr. Lopez:** That is an excellent point. I once attended an outreach event for the Black and Brown community in L.A. to discuss autism in these communities. So many of the families resonated with that exact statement of, “We are already trying to lay low because we do not want to be in trouble with the police because of the color of our skin, or because of the neighborhood we live in, or because we are at risk for deportation.” Then you lay autism on top of it? Oh, forget it.

The system sees that as, “Oh, they do not want services. ‘Those people’ are not showing up. ‘Those people’ are not answering their door.” So, there are multiple layers to all of these things that are happening with respect to the intersection of race, ethnicity, and autism.

**Ms. Ellwood:** There is one point that I need to make. Native Americans and Alaska Natives are the original people of the United States but are still very invisible. Most of the ideas that people have about us have to do with far history in the past<sup>7</sup> as opposed to recognizing that we are living breathing cultures that are still evolving. That is something of its own to navigate.

But when you are disabled and/or autistic, discrimination takes on a whole other level, because of the biases that even

medical professionals often have about us. If I go to the general practitioner (GP) or emergency room even here in the United Kingdom, the assumption is that I am faking whatever medical problem I have and just want drugs. That was something that I knew I was not going to leave behind once I left the United States, and it is still the case here.

When I come across somebody White my age who says, “Oh, yeah, I had my diagnosis when I was a teenager or younger,” I am fascinated by that, because I cannot help but wonder what my life would have been like if, instead of excusing what they were seeing away or possibly putting it on my upbringing, they had actually recognized, “Oh, this Black Native girl is actually autistic, and she is going to need support.”

**Mrs. Garcia:** I completely agree, and I just want to echo that and add to it. There is research that shows that Latinos report better quality of care with culturally competent providers, and doctors do not always make patients feel safe.<sup>6</sup> When they do not feel safe, they are less likely to divulge real concerns.

Mexican culture is not perceived as being inclusive or accepting of autism, and often parents have indications to cover up and hide their autistic children. When you have that insecurity and then the doctor is like, “Yeah, well, you know, there is nothing wrong, healthy child to me,” then children are diagnosed later.

Then what happens is exactly what Dr. Lopez said: they do not answer the door, they do not reach out for the services, and they will not even fight that it has been billed on the insurance, because they have, like TC was saying earlier, bigger fish to fry, such as staying alive.

**Ms. Jones:** Arianne, I agree. I think it is really important not just to have cultural sensitivity in researchers and clinicians, but to employ personnel from the communities you are working with—people who can actually relate to that experience.

In terms of the Black autistic community, studies have shown that Black parents bring their child to the doctor for first concerns of autism at around the same age as White children,<sup>7</sup> yet Black children are diagnosed much later.<sup>8</sup> Caregivers also report a lot of stigma from doctors,<sup>9</sup> such as racist assumptions about family structure. Things like that that can really impact diagnosis—an editorial just came out referencing how structural racism can contribute to these diagnostic disparities for Black autistic kids.<sup>10</sup> Because of this, it is important to have racial representation, not just in terms of people of color broadly, but focusing on under-represented or marginalized people. We should build trust and understanding, so we need Black and Brown researchers, Black and Brown autistic people, doing the research and working in clinics so we can actually help improve experiences for these communities.

**Dr. Johnson:** Desi, to your point, that is one of the big disconnects that we see, particularly in the Academy. Everybody was just talking about the erasure of Black and Brown autistic voices. I think about some of the disability activists whose work is fairly prevalent online, such as Imani Barbarin, Villissa Thompson, Alice Wong, and Edmund Asiedu, why are these activists not being brought to the table in the work that we do as researchers and as practitioners, right?

There is almost a need to call out as much as there is to call in. That is, we must bring critical attention to the issues while opening doors for others to collaborate in culturally affirming work—and I am saying the collective we, people who have platforms and influence over the situation—to first confront the fact that we, too, can take up and perpetuate these issues inadvertently because of our work, and to acknowledge the fact that we treat race in a way that is not conducive to really addressing the powers and structures that allow these issues to persist.

We treat race like it is the thing that causes disparities. We keep talking about that and admiring the issues over and over and over. I am 37 years. That is the only thing I have read since going to college at 17 years. You know? Let us get away from underintellectualizing, but also overintellectualizing race, and actually get to the issue of racism. And I do not think we can sufficiently do that until we treat our work inclusively like we say we do.

**Ms. Ellwood:** I cannot even think of any autism studies that have been done on Native Americans and Alaska Natives. In economic disparity polls, they will list every other race in the United States except for Indigenous people. And then when you ask, you get told, “Oh, well, there is just not enough of you.” Trust me, if you can find 100 people and extract a percentage from that, I am pretty sure you can find 100 Indigenous people as well and do the same. It is a poor excuse. Do not get me wrong, finding Indigenous autistic people to participate is challenging for a number of reasons, but the bare minimum is not even being attempted.

**Mrs. Garcia:** I just had a couple more things to add. Police violence toward autistic people is very real. Even though Elijah McClain<sup>11</sup> did not have a diagnosis, he showed a lot of autistic traits.

In a separate instance, a man called for help because he was having a mental health crisis in a public place. So, he called 911 because he needed help, and they ended up killing him.<sup>12</sup> There was a long period of time, the same thing as Elijah McClain before—he had already been killed for over a year before his family saw the video. So the question was, why was he killed when he was the one calling for help? Why are people still being attacked? As autistic people of color, we get discriminated on because of our behavior, when we are just being ourselves.

**Ms. Ellwood:** Elijah McClain was actually the first person that I thought of, because I still cannot think about him without getting upset. I am acutely aware that as a light-skinned Black Native woman, sometimes people can see me as “ambiguous,” but I am not ambiguous enough. When I was 10 years old, I was actually shot at in Virginia. I was just running around with my cousin outside of a church, and we were shot at by a racist farmer who did not want us in his field. But I am also aware that I have probably survived a lot, and definitely have not had nearly as many difficulties, because of my skin color and what I look like.

A Scottish autism organization came up with these two cards that I carry with me, and on one side it basically says, “Attention: I have an autistic spectrum condition.” And on the back, it lists a few bullet points like, “I am likely to be extremely anxious in unfamiliar situations. I may become

uncommunicative or nonverbal under stress.” And all I can think is, with the way that I look, somebody *might* actually give me the opportunity to take this card out. Elijah McClain? No. A dark-skinned Black or Indigenous person is just going to be shot, period.

Part of the conversation still has to be the fact that even as BIPOC, we do not all experience the same things in the same way, and we do have privileges. Yes, it may hurt to admit that you have certain privileges, but you do. I have my light-skin privilege. I am privileged with my education, my career, and especially privileged to have finally gotten my autism diagnosis. It would be disingenuous for me to ignore those facts.

**Dr. Lopez:** Could I say one thing on that note? I have been to a couple of different trainings about autism for police officers and one training that also included training autistic people how to interact with police and I always find them so aggravating, to be honest. They tell the people with autism to just comply, go to the police station, “Do not worry, it is all going to be figured out. That way you do not get hurt.”

I always ask, “But what if they are Black? What if they are Brown? How does this apply in that situation? Because you are coming from a very White lens of your state,” just like Lisa mentioned with the card, right? Just like you mentioned, you are not going to have the chance to pull that thing out of anywhere if you are the wrong color to that police officer.

I find it so frustrating. And I have been asked to help with one particular program called Be Safe to help to make it more culturally competent, but if we cannot even have the conversation about race, I do not know how we get to cultural competency, when no one will admit that this is still an issue.

**Ms. Jones:** *How are the issues that you discussed being addressed in your field? What resources are available for Black and Brown autistic adults? And then, if there are not any, what do you think should be done to support Black and Brown autistic adults and improve their experiences?*

**Ms. Ellwood:** Well, as a journalist, disability reporting is a minefield. Person-first language and perspectives are pushed against the wishes of most autistic people. I still see White and nondisabled perspectives dominating, including about disability language, like how we refer to ourselves. And I still feel like media prioritizes autism parents and people who are not neurodiverse, let alone actually autistic.

I have also had someone who quietly said to me, “I think you are the only professional journalist I have encountered who actually admits that they are autistic.” That was a few years ago. Things have probably changed since then. But I have not encountered anybody working in mainstream media who actually says, “Yes, I am an autistic journalist,” let alone somebody who might be a journalist of color and actually autistic. It still seems to me that the journalists who get the opportunity to write and speak about these issues are mostly White.

At any rate, BIPOC who are autistic and working in media are hard to connect to. Disability activists, such as Imani Barbarin and Alice Wong—yes, I have interacted with them online and supported things that they have done because I am a long-time disability activist myself. But outside of that, professionally in journalism, no.

**Dr. Waisman:** From the perspective of how this is being addressed in my field, in education, we are not doing enough to address BIPOC autistic issues. Those of us on the front line of disability and race are working hard to break down the barriers. But as other people have said in this roundtable, we are always working. We are constantly trying to educate.

Conversations like this bring awareness to the challenges that we face and create openings for our voices in policy and in governance and decision-making processes. But I think we need to challenge colleges and universities. I personally challenge colleges and universities to include our voices in meaningful ways, not just during the times of activism, as we are experiencing now, but as a regular course of action.

We are already here in our respective communities. We are already having an impact, and the people at this table are experts in our fields, so we can make a positive difference to the future of diversity and inclusion, and room needs to be made for our voices.

**Dr. Johnson:** Thinking about my own field of occupational science, race is something that you can find in the literature, but racism, absolutely not. If you tie that to the intersections of disability, then autism specifically, it does not exist. At every webinar I have done this year, I posed that same question, and I have yet to receive anything. So it just is not there. We have tons of toolkits to address workforce diversity, but there is nothing in place for therapists and educators and students who work with adults and children with autism to refer to at all.

Pertaining to how we move forward on something like this, I think opportunities like what we are doing right now, these transdisciplinary gatherings and efforts, are a great way to start. We must also address these issues as part of our educational standards, so that programs ensure that students are doing something about racism. When it is tied to that, then they also have to do it in their fieldwork, meaning that practitioners have to address it, as well. And if practitioners address it, then they demand that our national organizations make it a priority, so on and so forth.

And I hope the recent demands made by occupational therapy affinity groups—the pressure they are applying by keeping their feet on the necks of our parent organization—will help move this forward, because we keep *talking* about the need for action, but time for action is past due. So that is where I am sitting with occupational science and occupational therapy.

**Dr. Lopez:** At my academic institution, I am trying to make a push to integrate more autism training into the social work program, so when we have students who come in with great intentions and have excellent experience as behavioral therapists, they can be rerouted into doing the work that they have the skills in instead of ending up in child welfare and sort of the dropping the ball in the autism area.

We are not doing enough, but it is also because we are not traditionally seen as being in this area—in autism. That is more education. That is psychology. That is occupational therapy. But we are actively involved with kids who may have been missed this whole time and are in child welfare or in the criminal justice system or in all these different other places that have had a misdiagnosis. We could be doing more, but we need to have the conversation.

I also push to train our social work students and colleagues around antiracist practices, because just labeling ourselves as social workers does not make us antiracist, or very aware of our own biases and able to reflect about them. I think there is a lot of work we need to do, but there is also a lot of opportunity that we can capitalize on in the field.

Hopefully the few of us in this area can push for more integration of autism, but with a focus on the intersection of race and ethnicity with respect to autistic children and autistic adults.

**Dr. Nicolaidis:** I would actually love to push this a little further. I am a professor in a school of social work that, like any school of social work, is struggling with issues of racism and racial justice and is actively trying to focus on antiracist practice. I love that we are having these conversations. There is so much more work to do.

At the same time, when we talk about autism or disability, we use a very medical model, with very pathologizing language and a lot of really ableist ideas.

How do we talk about both? How do we take those hard-learned lessons from other civil rights movements and include those when we are talking about autism or disability, when so many people have come in with a very medical model of autism? They might recognize racial disparities in autism diagnoses—and I am glad they do—but at the same time, they do not think of autism itself as a marginalizing factor. They do not think that of the intersectionality here.

I would love to push fields such as social work—which sincerely try to use a social justice lens, but sometimes forget that autism or disability have anything to do with social justice.

**Ms. Ellwood:** Well, I am thinking about what you just said and what Kristina said. One thing that I keep harping about is the fact that when it comes to “wellness checks,” police should not be involved. And surely, we have enough experienced social workers, OTs, etc., who have this background who should be utilized as a resource rather than police—especially when it comes to BIPOC—we are more likely to end up dead than actually assisted. Despite making up small proportions of the U.S. population, Black, Native American, and Latinx peoples are most likely to have fatal police encounters<sup>13</sup>—Native Americans are actually more likely to be killed by the police than any other ethnic group in America.<sup>14</sup> There has been an uptick in mainstream media coverage of police violence in the past few years, but it still falls short because Native Americans and Alaska Natives are still largely invisible. We are still here and still fighting to survive state-sanctioned violence—there just is not significant coverage of these crimes of genocide outside of Indigenous media.<sup>15</sup>

What frightens me now as a Black Native woman is thinking about Black and Indigenous neurodiverse victims of police violence, including Elijah McClain, Jeanetta Riley,<sup>16</sup> and Paul Castaway<sup>17</sup>—even caregivers such as Charles Kinsey, a behavioral therapist, who have been shot with their autistic patients. It just seems like a really insurmountable mountain to climb, and especially in the current climate.

**Dr. Nicolaidis:** *Thanks to each of you for these really important insights. Is there anything else you want to add*

*based on racism and prejudice that has impacted you personally as leaders in the field? As a corollary to that, what can help autistic and nonautistic people of color succeed as researchers, clinicians, advocates, community leaders? What is going to make it better for people of color who are leaders in the field?*

**Dr. Lopez:** For me, one of the biggest things is that when I was in my PhD program, I was once outed for not speaking Spanish. A White person told me, “How do you ever think you are going to work with these Hispanic people? You do not even speak Spanish.” And then it became this recurring cycle of, “You do not speak Spanish. You do not speak Spanish.”

None of the families I have ever worked with have said, “I am not going to work with you because you do not speak Spanish.” They have always been grateful and just like, “Oh, my God, finally somebody who will talk to me and listen to me,” whether that means I bring in a student to help translate or interpret. It does not matter.

I still have Latina students now who come to me, and they will say, “Dr. Lopez, does it matter that I do not speak Spanish? I am sorry.” And I will tell them my story.

It is so interesting how even internalized oppression can impact how the pipeline gets stopped. Some students think that they are not Brown or Black enough or whatever enough to work with their own communities, because the system of Whiteness has told them, “You are still not good enough, even though you have worked this hard.”

**Mrs. Garcia:** Yes! The “You do not speak Spanish” thing is such a huge problem. They make it such a big deal outside of the Latinx community. Culturally sensitive does not mean “speaks Spanish,” that is super important for health care providers to understand.

**Dr. Waisman:** Also, some of us are not taught our language to save us from hearing the prejudice against us from our own community. In my case, I am Black, Brown, and Indigenous, and my dad did not teach me Hindi to protect me from the pain he experienced.

**Ms. Ellwood:** Gatekeeping is as much a problem in BIPOC communities as when it comes from White people. For me, cultural sensitivity means that the kinds of conversations we are having now and the kind of concerns that I have as a doubly neurodiverse multiply-disabled Black Native woman—that I can sit, and I can discuss them with you, and it is not going to turn into a debate where you systematically dismiss every concern that I have and who I am as a person.

A more recent example of that is here in Wales, the National Health Service piloted an integrated medical, social work, and psychiatric approach to health care, developed by Alaska Natives (NUKA<sup>18</sup>). The GP referred me to the provider, and I realized straightaway, “Uh-oh, I am going to be talking to a White Welsh woman to try and get support. Let’s see how this goes.”

I tried to have a conversation with this person, and one of the things that I said was to the effect of, “Well, you know, I am still struggling, even with having conversations with my folks about the fact that being autistic is not just a White thing.” She was so offended by the fact that I said that. It was

as if I had slandered her in some way. She just vanished into the ether, and I never heard from her again.

The only thing she actually did was refer me to the British Red Cross, and the person who turned up at my door was a Brown woman. We commiserated over that, and it felt like a weight was lifted from my shoulders, because even though she is Iraqi and I am a Black Native, we could have certain conversations, and she just got it. I could say, “Yeah, you know, the attitude is still like autism is this White thing that has nothing to do with us. And she did not get offended by it. It did not run her off.”

I still find myself absolutely astounded, because you just do not always have the freedom to be 100% yourself as an autistic BIPOC person with people who, in theory, are supposed to be able to put their issues to the side and support you in what you need. In my experience, racism and cultural insensitivity are problems everywhere.

**Ms. Jones:** Bouncing off Lisa’s comments, I think it is really important to create safe spaces where BIPOC can talk openly about these kinds of issues. Everyone can take action to support us, whether it is on a small scale in your laboratory or workplace, or at a broader institutional or organizational level. Everyone can play a part.

**Dr. Nicolaidis:** *Can I push you a little bit there? Because I think our audience may need some examples. What are the things that would make the workplace a safe space? What are the things that someone could do that would actually make a difference?*

**Ms. Jones:** In my own experience, especially in the current environment, it has been incredibly helpful to have mentors who are sensitive to the ways that their employees, friends, and coworkers from BIPOC communities are impacted by racism.

I have always appreciated a willingness to listen and learn. Sometimes well-meaning people can unintentionally say or do offensive things without realizing it. I have been fortunate to have relationships with mentors and professors where I could say, “Hey, I thought this was a little insensitive, this hurt me, this made me uncomfortable” and have a heart-to-heart about it—they would say, “I am so sorry,” and then work to understand. And not only that, they changed their behavior and took in that feedback, showed that they cared. It meant a lot to me.

So it is that listening and learning aspect. People often respond defensively when people of color address race and racism. If we are bringing this up, we are likely already feeling distressed. Please be sensitive and respectful, and do not attack us. We talk a lot about empathy in autism research,<sup>19</sup> but we as researchers need to work on being more empathetic.

**Dr. Lopez:** I was thinking, some examples could also include prioritizing the focus on this within INSAR, and not just leaving it to the diversity committee, and not just having the special meeting that happens the day before the conference actually starts. It has been beautiful to watch that meeting grow, but diversity should be embedded in the full conference. And at the board level, if you look at the board, who is on it? There certainly is not much diversity in any kind of way, shape, or form.

So things like that I think are critical. And that way, it trickles down also to what Desi is getting into when you talk about being a mentor on the ground, and you have a student who is coming into the field, and whether they are an undergrad or all the way up to a PhD student or a postdoc, when they see the INSAR board and they see the investment in BIPOC, that sets the stage for, “Okay, I am welcomed here.”

**Ms. Jones:** *Yes, exactly. I recently wrote an editorial about this issue of representation,<sup>20</sup> and I brought up the fact that we combed through INSAR’s conference archives and could not find a single Black keynote speaker. We went back to 2004!*

*However, I will say that I was actually approached by the INSAR Student and Trainee Committee because they are trying to increase representation, which is really cool—I am a member now because of this. But we need everyone to take action to increase diversity.*

**Dr. Waisman:** Returning to the main question, my best advice for BIPOC autistic and nonautistic people wanting to succeed, especially in research and advocacy, is, “Be yourself, because there is no one else out there with your particular voice. Pace yourself, because we all know it is a long process of educating others.”

Importantly, somebody told me this, “Love yourself, even when you do not see the community around you supporting you.” And lastly, I am going to say share yourself, because if you keep sharing your stories and you keep speaking up and making space, then we make room for our kids to stand on our shoulders and thrive in the spaces that we create.

**Dr. Johnson:** TC’s comments touched on something that I actually spoke with a mentor about yesterday. And that is for everybody who is on this call right now, we are probably either spending all of our time having to convince people that racism is real, or we are being bombarded with requests to provide free intellectual and emotional labor all the time in the name of listening and learning.

But in doing so, just being present and being someone who represents whatever your identities are, you are filling in the gap for someone. And although that might be exhausting and taxing, me being a Black female scholar-practitioner is helping someone else be able to see themselves in me. It will empower them to be the next up-and-coming activist or up-and-coming OT or whatever that is. And that, in and of itself, is so important. But take care of yourself in the process.

**Ms. Jones:** *Thank you. You have all shared such helpful advice that is relevant to autistic people, BIPOC, and autistic BIPOC.*

*Christina, you have been listening closely—would you like to share your thoughts and summarize today’s discussion?*

**Dr. Nicolaidis:** This has been an amazing discussion and I am truly grateful to each of you. The overarching theme I heard is that we live in a racialized society, where racism permeates everything. We should not just talk about race and racial disparities, when really, the issue is racism. Failing to

recognize the impact of racism on research, practice, and society makes it impossible to address the many negative consequences of racism.

Within this context of us living in a racialized society, I heard you discuss four main themes:

1. *“Invisibility”*: Many of you talked about feeling invisible, with the face of autism being that of a White boy. There is a desperate lack of research on autistic people of color, and even more so, of Indigenous people. And there is an equally great lack of representation of BIPOC autistic and nonautistic voices in clinical practice, journalism, academia, and society as a whole. This invisibility can result in late or missed diagnoses. And even when diagnosed, it can lead to autistic adults of color being dismissed or disbelieved.
2. *“Bigger fish to fry”*: You also talked about times where issues related to autism may be overpowered by issues related to racism. For example, TC talked about camouflaging their autistic traits as a survival skill, given the need to “stay under the radar” of police or government agencies. And Dr. Lopez discussed her observation of BIPOC families not seeking or accepting autism services in an effort to “lay low” and avoid contact with police or social service agencies.
3. *Multiplicative effect on discrimination*: Interactions with health care providers and police officers are already problematic for autistic adults, but racial bias greatly magnifies discrimination and risk. Moreover, some of the tools meant to help keep autistic people safe—for example, little wallet cards meant for police officers to understand the person is autistic—could potentially increase risk for an autistic person of color.
4. *Academia as an unwelcoming home*: It sounded like many of you—both as autistic and nonautistic autism scholars—were often made to feel like you do not belong in academia, at times even being actively discouraged from studying issues related to race. White mentors and colleagues seemed to overvalue language skills and undervalue cultural congruence. Finally, as Dr. Johnson summarized, BIPOC academics may be forced to expend a great deal of time and energy educating others about race without receiving any tangible reward.

Despite these enormous challenges, I also heard some real optimism about potential solutions to improve the lives of Black, Brown, and Indigenous autistic adults and families:

- Elevate and amplify the voices of Black, Brown, and Indigenous autistic adults.
- Challenge universities, health systems, and community and professional organizations to include autistic BIPOC voices in meaningful ways, not just when race is in the news, but also as a regular part of their work.
- Bring attention to racism, not just race, in trainings for health care providers, disability services professionals, and educators working with autistic people and families.

- Combine antiracist trainings with autism and neurodiversity training in professions such as social work, where autism is not regularly addressed, and where autism may not be seen using a social justice lens.
- Support collaborative partnerships between the police and qualified community members, such as social workers, OTs, and actual autistic people, to promote safety-first responses to wellness checks.
- Increase the number of BIPOC professionals, and especially autistic BIPOC professionals, including in journalism, clinical practice, and academia.

In terms of this last point, I heard some great ideas from all of you about how to make the world of autism research a more welcoming place for people of color:

- Encourage White mentors, supervisors, and colleagues to help create spaces where BIPOC students and faculty can talk openly about racism. Doing so means listening and believing people's experience of racism without becoming defensive. As Desi said, "We talk a lot about empathy in autism research, but we as researchers need to work on being more empathetic."
- Create affinity groups for people of color within professional organizations.
- Encourage INSAR to actively seek more racial diversity on their board, in the selection of keynote speakers, and on all committees, not just the Cultural Diversity Committee.

Finally, I heard you, as some of the foremost BIPOC leaders in our field, give wise advice to other emerging leaders of color, including the need to "love yourself," "pace yourself," and "share yourself," and the recognition that just being present and representing your identities helps someone else.

Again, I am extremely grateful to each of you. And I look forward to your help in making sure that our journal does all it can to address racism and improve the lives of Black, Indigenous, and Latinx autistic adults.

**Ms. Jones:** *Thank you, Christina. I have a final question for each of you. As Christina mentioned, we have covered many important themes today. What are you taking home from this discussion?*

**Dr. Waisman:** I just want to say this has been one of the most important discussions I have had, and I feel like crying. It just feels like there are not a lot of spaces to be able to speak this frankly, and I am super-grateful. Thank you.

**Ms. Ellwood:** Yeah, same. Oh, God. I am going to cry in a minute. I am sorry if I have spoken too much and too long, but I think it is mainly because I am so used to having to be quiet and to not being heard, even by people who I thought that I could be free with. To be in this environment right now is just—you just have no idea. I wish it could be like this all the time.

**Dr. Lopez:** I just want to highlight how powerful this is, and I have been through—and I am sure many of you have sat

through—many conversations pertaining to race and what we can do, but not with self-advocates, with BIPOC, with people who are really invested. And so thank you all, and thank you, Christina, and thank you, Desi, for organizing this, because there really has not been, like people are mentioning, a space to be able to do this up until today.

**Dr. Johnson:** I am sincerely grateful for the vision and intention demonstrated by Christina, Desi, and the *Autism in Adulthood* team to confront the impact of racism by bringing together self-advocates, practitioners, students, researchers, and educators of color. I hope other publications take note because this experience was transformative!

**Mrs. Garcia:** Thank you so much for organizing this discussion. I am thankful for the chance to talk about what I have read, seen, and been through. I am hopeful that this conversation can spur many more discussions about autism and racism and bring positive, institutional change.

**Ms. Jones:** *Thank you all so much for joining us and contributing to such a powerful emotional discussion. All of you are trailblazers in your respective fields, and your advocacy helps to pave the way for future dialogue on race, ethnicity, and autism. I hope that others in the field will use the themes from this discussion to guide changes in policy, research, and clinical practice and to improve the experiences of autistic adults from under-represented racial and ethnic groups.*

## References

1. Durkin MS, Maenner MJ, Baio J, et al. Autism spectrum disorder among US children (2002–2010): Socioeconomic, racial, and ethnic disparities. *Am J Public Health.* 2017; 107(11):1818–1826.
2. Thomas KC, Ellis AR, McLaurin C, Daniels J, Morrissey JP. Access to care for autism-related services. *J Autism Dev Disord.* 2007;37(10):1902–1912.
3. Eilenberg JS, Paff M, Harrison AJ, Long KA. Disparities based on race, ethnicity, and socioeconomic status over the transition to adulthood among adolescents and young adults on the autism spectrum: a systematic review. *Curr Psychiatry Rep.* 2019;21(5):32.
4. West EA, Travers JC, Kemper TD, et al. Racial and ethnic diversity of participants in research supporting evidence-based practices for learners with autism spectrum disorder. *J Spec Educ.* 2016. DOI:10.1177/00224669166632495
5. Eason AE, Brady LM, Fryberg SA. Reclaiming representations & interrupting the cycle of bias against native Americans. *Daedalus.* 2018. DOI:10.1162/DAED\_a\_00491
6. Zuckerman KE, Sinche B, Cobian M, et al. Conceptualization of autism in the latino community and its relationship with early diagnosis. *J Dev Behav Pediatr.* 2014; 35(8):522–532.
7. Jang J, Matson JL, Cervantes PE, Konst MJ. The relationship between ethnicity and age of first concern in toddlers with autism spectrum disorder. *Res Autism Spectr Disord.* 2014. DOI:10.1016/j.rasd.2014.04.003



8. Mandell DS, Listerud J, Levy SE, Pinto-Martin JA. Race differences in the age at diagnosis among medicaid-eligible children with autism. *J Am Acad Child Adolesc Psychiatry*. 2002;41(12):1447–1453.
9. Dababnah S, Shaia WE, Campion K, Nichols HM. “We had to keep pushing”: Caregivers’ perspectives on autism screening and referral practices of black children in primary care. *Intellect Dev Disabil*. 2018;56(5):321–336.
10. Broder-Fingert S, Mateo C, Zuckerman KE. Structural racism and autism. *Pediatrics*. 2020;146(3):e2020015420.
11. Thompkins L. Here’s What you need to know about elijah mcclain’s death. *The New York Times*. 2020.
12. Cramer M. A Tennessee man called police for help, then died in their custody. *The New York Times*. 2020.
13. Edwards E, Greytak E, Ofer U, Takei C, Fernandez P. *The Other Epidemic: Fatal Police Shootings in the Time of COVID-19*. New York, New York: American Civil Liberties Union; 2020.
14. Edwards F, Lee H, Esposito M. Risk of being killed by police use of force in the United States by age, race–ethnicity, and sex. *Proc Natl Acad Sci U S A*. 2019;116(34):16793–16798.
15. Schroedel JR, Chin RJ. Whose lives matter: the media’s failure to cover police use of lethal force against native Americans. *Race Justice*. 2020. doi:10.1177/2153368717734614
16. Revesz R. Native Americans most likely ethnic group to be killed by police. *The Independent*. 2016.
17. Hansen E. The forgotten minority in police shootings. *CNN*. 2017.
18. Gottlieb K. The Nuka system of care: Improving health through ownership and relationships. *Int J Circumpolar Health*. 2013;72:10.3402/ijch.v72i0.21118.
19. Nicolaidis C, Milton D, Sasson NJ, Sheppard E (Lizzy), Yergeau M. An expert discussion on autism and empathy. *Autism Adulthood*. 2019. DOI:10.1089/aut.2018.29000.cjn
20. Jones DR, Mandell DS. To address racial disparities in autism research, we must think globally, act locally. *Autism*. 2020;24(7):1587–1589.