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The Scholarly Neglect of Black Autistic Adults in Autism Research

Kayla M. Malone, MEd,¹ Jamie N. Pearson, PhD,² Kayla N. Palazzo, BA, Lonnie D. Manns, MEd,^{2,3}
Amelia Q. Rivera, MEd,^{2,3} and DeVoshia L. Mason Martin, MS^{2,3}

Abstract

Black autistic individuals, regardless of age, have not been centered in autism research. Instead, they often exist on the margins—on the periphery of autism research. In fact, Black autistic adults are largely absent from the literature. Most participants in autism research are majority-white autistic individuals and families. In this conceptual article, we use intersectionality and Dis/ability Studies and Critical Race Theory theories to contextualize Black autistic adults' experiences. Second, we argue that systemic disparities and methodological concerns are two contributors to the scholarly neglect of Black autistic adults in autism research. Third, we provide guidelines to support researchers in moving from neglect to inclusive research *with* Black autistic adults.

Keywords: autism, autism research, racial disparities, color blindness, Black autistic adults

Community Brief

Why is this topic important?

The experiences of Black autistic adults are not well represented in research. The lack of cultural responsiveness in autism research ignores the nuanced experiences of Black autistic adults, which limits the ability to understand their experiences and effectively meet their needs.

What is the purpose of this article?

The purpose of this article is to highlight the void in autism research concerning Black autistic adults. This article is a call to action for research that is inclusive of Black autistic adults. Specifically, we (1) use intersectionality and Dis/ability Studies and Critical Race Theory theories to contextualize Black autistic adults' experiences, (2) describe the systemic disparities (e.g., health care) that contribute to the scholarly neglect of Black autistic adults, and (3) provide guidelines to support researchers in moving from neglect to inclusive research with Black autistic adults.

What personal or professional perspectives do the authors bring to this topic?

The first author identifies as a white, non-binary, doctoral student in Applied Developmental Science and Special Education. The second author identifies as a Black, cisgender female, Assistant Professor of Special Education. The third author identifies as a white, non-binary, autistic autism researcher. The fourth author identifies as a Black, cisgender male, doctoral student in Educational Equity. The fifth author identifies as a black, cisgender female, doctoral student in Educational Equity. The sixth author identifies as a Black, cisgender female, dual-licensed special education teacher, and doctoral student in Educational Equity. Although

¹Applied Developmental Science and Special Education, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA.

²Special Education, North Carolina State University, Raleigh, North Carolina, USA.

³Educational equity, North Carolina State University, Raleigh, North Carolina, USA.

none of the authors embody the lived experience of being both Black *and* autistic, our research team is committed to supporting and advocating for Black autistic individuals through our ongoing professional development and dedication to strength-based, and identity-centered research.

What is already known about this topic?

Although we know about disparities in Black autistic children, little research has focused on the experiences of Black autistic adults. Most of what we know about autistic adults is based on the experiences of white participants.

What do the authors recommend?

First, we recommend that researchers work to understand how their own perspectives, values, and experiences shape their research (e.g., cultural reciprocity). Second, we recommend that researchers intentionally include the perspectives and experiences of Black autistic adults. This can include collaborating on research *with* Black autistic scholars and highlighting autistic and Black autistic led research. Finally, we advocate for systemic changes in institutions of higher education (e.g., reduce barriers to admission) and in communities (e.g., culturally responsive supports) to better address the inequities that impact the representation of Black autistic adults in autism research.

How will these recommendations help autistic adults now or in the future?

These recommendations will prepare researchers with strategies to effectively build partnerships with Black autistic adults in ways that honor their knowledge and contributions to the field. As a result, Black autistic adults will have more representation in autism research, both as participants and as leading scholars in the field. We hope that more inclusive representation of Black autistic adults will lead to more culturally responsive approaches in adult autism research.

Introduction

AUTISM IS HETEROGENEOUS (i.e., is experienced differently by different people) and idiosyncratic (i.e., specific to the person).^{1–3} For instance, Black autistic individuals' experiences cannot be characterized by racial identity alone. One might identify as autistic based on “medical diagnosis, personal choice and self identification, and even casual classification by outsiders,” however, group membership should always be self-determined by the individual and not those conducting research.^{3(p467)} Although there is no scientific consensus on autism, autistic people may embody different biological and sensory-perceptual experiences compared with their non-autistic peers (e.g., sensory sensitivities).^{2,4,5} In the United States, autism is most commonly diagnosed and validated based on medical professionals' observations and/or parent reports.^{6,7}

As a result, autism is most often situated within the medical model of disability, which emphasizes an individual's deficits and “impairment.”^{5–7} The traditional medical model of autism identification, however, often fails to account for culture, and it introduces concerns related to health care provider and measurement bias.^{8–14} For example, white children are consistently identified more efficiently and accurately than Black* and Latino children.^{9,10} Findings suggest that health care providers interpret autistic characteristics in Black children differently than in white children,¹¹ and they are more likely to dismiss the concerns of Black parents raising autistic children than white parents.¹²

As a result of identification biases, Black autistic children, adolescents, adults, seniors, and their families experience disproportionate systemic barriers to services and unmet mental health care needs compared with white peers.^{13,14}

Estimates suggest that there are nearly 5.4 million autistic adults living in the United States, yet Black autistic adults are largely missing from lifespan and disparities research.^{15–21} Researchers have begun to document disparities in Black autistic children; however, a few sources accurately capture how these disparities translate into adulthood. For example, Black autistic adults experience unmet employment support needs¹⁶ and experience higher unemployment than white autistic adults.²² This lack of scholarship—the neglect of Black autistic adults in autism research—contributes to limited knowledge about the strengths, celebrations, joys, barriers, and needs of Black autistic adults.^{21,23,24}

Therefore, the purpose of this article is to (1) use intersectionality and Dis/ability Studies and Critical Race Theory (DisCrit) theories to contextualize Black autistic adults' experiences, (2) describe the systemic disparities that contribute to the scholarly neglect of Black autistic adults, and (3) provide guidelines to support researchers in moving from neglect to inclusive research *with* Black autistic adults.

Scholarly Neglect

The exclusion of Black autistic voices exacerbates the misconception that autism is inherently white. Autism is most often characterized as a white male condition, despite evidence that autism occurs across racial and ethnic backgrounds.^{25,26} Whiteness “refers to a set of assumptions, beliefs, and practices” that centers the interests and perspectives of white people as the normative or universal

*We use “Black” to describe any descendant of the African diaspora (e.g., African American, Afro-Caribbean) who lives in the United States.

experience.^{27(p278),28} Black autistic adults have knowledge, lived experiences, and recommendations for the field that are often overlooked when they are excluded from research. This failure is best described by Morénike Giwa Onaiwu, a Black autistic adult and educator,

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.^{28(p270)}

Autism research that comprises majority-white samples fails to capture the needs of autistic people of color and the cumulative impact of racism, ableism, and systemic disparities on their quality of life.²⁹ The underrepresentation of Black autistic adults in published autism research can be best characterized as scholarly neglect.^{18,25,29} We define scholarly neglect as the assumption that findings from autism research applies to *all* groups and/or the failure of research teams to adequately recruit racially and ethnically representative samples. This scholarly neglect has material consequences—without racially and ethnically representative research, researchers cannot fully understand nor identify the needs of Black autistic adults.

Authors’ Positionality

Understanding the perspectives and experiences of researchers as central to the research process is critical, particularly among historically underrepresented groups (e.g., research with Black autistic persons).^{30,31} Researcher perspectives and experiences shape how we approach a topic and its socio-political context. Although our research team is racially, gender, and neuro-diverse, none of us embody the lived experience of being both Black *and* autistic—making all six researchers outsiders. Although researchers can sit in multiple places on the insider-outsider continuum, depending on which aspect of their intersecting identities is considered, outsiders can experience increased freedom from group expectations and loyalties, which can facilitate novel questions and challenges to accepted explanations.³²

The first author identifies as a white, non-binary, doctoral student in Applied Developmental Science and Special Education who has experience working with autistic individuals across the lifespan and expertise in Special Education. The second author identifies as a Black, cisgender female, Assistant Professor of Special Education with expertise in behavior analysis, parent-implemented autism interventions, and supporting Black families raising autistic children.

The third author identifies as a white, non-binary, autistic autism researcher, with experience advocating for, and working with autistic people. The fourth author identifies as a Black, cisgender male, doctoral student in Educational

Equity with interests in Special Education, critical theory, and critical literacy. The fifth author identifies as a black, cisgender female, doctoral student in Educational Equity with experience teaching autistic students in K-12 settings.

The sixth author identifies as a Black, cisgender female, dual-licensed special education teacher, and doctoral student in Educational Equity with interests in autism, teacher training, and racial disparities. Our research team is committed to supporting and advocating for Black autistic individuals through our ongoing professional development and dedication to strength-based and identity-centered research. Although we did not have a Black autistic adult on our team, we represent a broad range of diversity of lived experiences and expertise.

In the Intersectionality and DisCrit as Guiding Frameworks for Research, we situate our argument about the scholarly neglect of Black autistic adults in intersectionality and DisCrit theories. Then, we argue that systemic disparities and methodological approaches are two contributors to the scholarly neglect of Black autistic adults in autism research. In the final section, we provide three guidelines for moving from neglect to inclusion of Black autistic adults in autism research, and we identify critical next steps for the field as a whole.

Intersectionality and DisCrit as Guiding Frameworks for Research

We use intersectionality³³ and DisCrit³⁴ as guiding frameworks to guide our understanding of the experiences of Black autistic adults. Intersectionality does not see any category (e.g., race or gender) as more salient than another. Instead, intersectionality suggests that relationships between categories “continually and mutually constitute each other.”^{33,34} Identity categories can include dis/ability, race, ethnicity, gender, nationality, political affiliation, citizenship, or socioeconomic status. These identity categories merge to co-construct race, gender, class, and other statuses as systemic inequalities.³⁵

Race is a social construct that is typically based on appearance and subsequent cultural definitions applied to appearances. Race is different depending on the culture, geographic location, or time.^{33,36} There are no effects of race alone; race must always be read as gendered, sexualized, classed, etc.^{36,37} Intersectionality is important in autism research because as Cascio et al.³⁸ note, oftentimes participants are pigeonholed into a diagnosis and the complexity of their identities are not understood or explored in research. This is best described by Foster,[†] a Black autistic adult,

I am the sum of my parts, and any and all care I’ve received has fallen short because it’s attempted to treat my parts separately if it considers them at all... Picking two is telling me is unweaving the fraught, trauma-born tapestry of the person I am because I have too many colors of threads running through my story, instead of maybe considering that the space I exist in is just not colorful enough. Pick two: gender, race, autism, they tell me, and they don’t realize that they’re separating each

[†]*All the Weight of Our Dreams* is no longer in print because of racist content included in at least one chapter of the anthology. Because this is the only known text written by autistic people of color, we have carefully chosen to cite two contributors from the anthology, two of whom our team has collaborated with.

of these things from who I am in the process. I reject any suggestion that setting aside my race or disability or queerness is a viable compromise in order to receive the care and support I need. These things are not things that accompany my personhood: they *are* my personhood.^{39(p244)}

Identifying as disabled (e.g., autistic) is just one facet of intersectionality.^{40,41} Individuals who are both Black and autistic sit at the intersection of marginalized identities. Intersectionality describes the membership of multiple social categories such as “Black” and “autistic” that intersect to create new forms of oppression.^{40–42} For example, analyzing the oppression stemming from being “Black” and “woman” is not just a matter of analyzing blackness and womanhood because Black women experience a specific form of oppression called misogynoir.^{37,42}

Intersectionality helps us understand how “different systemic conditions vary in place, time, and circumstance” and work together to reproduce conditions of inequality.^{43(p77)} Autism research that explores the nexus of all identities is paramount. Understanding the impact of intersectional identities, such as disability, race, socioeconomic status, age, or gender, can inform more culturally responsive policy, research, and supports.

Intersectionality + DisCrit: Addressing Colorblindness in Adult Autism Research

The lack of focus on intersectional identities (e.g., race and gender) in adult autism research has led to the development of race-neutral, colorblind, or universal policies instead of policies that specifically address racism.^{44,45} However, universal policies predictably benefit a narrow category of beneficiaries (e.g., white cisgender males).⁴³ Colorblindness stems from the well-intentioned desire to appear as racially unbiased or to avoid racial bias.⁴³

Colorblind ideology suggests that not “noticing” race prevents prejudice and discrimination and that racial group membership should not be taken into account when decisions are made.⁴⁵ Scholars argue, however, that colorblind racial ideology justifies the “inaction that propels the system of racial inequities forward.”^{46(p155),47} Colorblind approaches to autism research have led to a body of research that does not fully identify or recognize the nuanced experiences of Black autistic adults.

DisCrit contends that both racism and ableism inform colorblindness because of perceived differences among individuals who deviate from “normal” (i.e., white, cisgender, able-bodied).⁴⁶ DisCrit highlights the interconnectedness of societal conceptualizations of race and disability. This is best described by Brown,⁴⁸

I often feel like a minority within a minority [...] I am frustrated and disappointed when [activists] dismiss ableism as simply non-existent or unconnected to racial oppression and white supremacy. Just as I cannot separate my *disabled* identity and experiences from my *racialized* identity and experiences, I cannot recognize racism without recognizing how it is affected by ableism.^{48(p414)}

While DisCrit explains the interdependent constructions of race and dis/ability in U.S. education and society, critics of DisCrit argue that the theory fails to account for the gendered

nature of racism (e.g., misogynoir).^{46,48} Therefore, we posit that relying on both intersectionality and DisCrit theories better guides our understanding of the scholarly neglect of Black autistic adults.

Contributors to the Scholarly Neglect of Black Autistic Adults

The way researchers approach methodology and conduct research is important, because it reflects researchers’ values and their social context (e.g., United States’ culture of white supremacy and ableism). Although this is not an exhaustive list of potential contributors of neglect, we argue that systemic disparities and methodological issues have had a cumulative impact on Black autistic individuals. Researchers have limited knowledge about the barriers that contribute to disparities in outcomes for Black autistic adults. Moreover, methodological concerns have contributed to the scholarly neglect of Black autistic adults.

Systemic Disparities for Black Autistic Adults

Implicit racial biases continue to permeate across social systems, despite explicit racial discrimination being illegal.^{49,50} Black Americans view their encounters with social institutions through a racial lens that is informed by past and current experiences of racial discrimination. Black Americans have an increased risk of experiencing racism and discrimination, increased police encounters,^{51–56} and inequitable access to health services when compared with white Americans.^{49,57–59} Despite these racialized experiences, there is little recognition of the systemic disparities that Black autistic adults and their families experience in autism research. It is critical to recognize how racial inequities contextualize outcome disparities (e.g., employment and postsecondary) for Black autistic adults.

Health care disparities for Black autistic adults

The perceived and lived experiences of Black Americans accessing services within the health care system are fraught with feelings of discrimination and mistrust as a result of distinctive socio-historical events (e.g., Tuskegee syphilis study).^{9,50} In health care, racism is perpetuated by the notion that race is biological and that the Black body is biologically and fundamentally different from the white body.⁵⁹ However, there are no data to suggest that there are fundamental racial and ethnic differences in autism incidence.⁶⁰

Therefore, we reject the notion that Black autistic adults are biologically or fundamentally different from white autistic adults. Instead, we argue that structural anti-Black racism (e.g., health care inequities) and the influences of culture create a uniquely Black autistic experience that has received little attention in adult autism research.

Research has shown that race and other intersectional identities (e.g., gender, socioeconomic status) predict health disparities for autistic youth.⁶⁰ Racial and ethnic disparities persist in the latency between diagnosis and access to services, quality of health care services, and access to services for Black autistic adults when compared with white-majority samples.^{25,60–62} White autistic adults are significantly more likely to have dual access to Medicare and Medicaid than racial and ethnic minorities.⁶³

White autistic adults are also more likely to receive benefits spending, which contributes to differences in health outcomes.^{62,63} Black autistic young adults, however, are less likely to have access to adequate mental health resources and ongoing mental health support than their white autistic peers.^{60–65} This is particularly problematic, because research shows that Black autistic youth utilize the compensatory strategies of masking⁶⁶ and code-switching⁶⁷ to assimilate to white, majority-allistic society.

Findings indicate that these strategies result in an increased risk of depressive symptoms.^{68–76} Further, some Black autistic adults were raised by families who report that health care providers were not responsive to their concerns (e.g., Black and white cultural divergence).^{9,12,14} In fact, primary care providers and education professionals demonstrate implicit bias and may not recognize the characteristics of autism in Black youth.^{9–13}

Employment and postsecondary outcomes disparities for Black autistic adults

Major reviews of employment of autistic adults often do not mention or disclose race,^{77–79} nor do they use race as a variable of analysis. However, the National Autism Indicators report²² found that twice as many white autistic young adults (66%) worked compared with Black autistic young adults (37%). Autistic young adults “fall off the services cliff” (i.e., lack of access to services following high school graduation)^{78–81} and report feeling disconnected from education (e.g., college), employment (e.g., full-time job), and social activities (e.g., access to peer groups) after high-school graduation.⁸²

Autistic young adults are also less likely to participate in transition planning meetings, enroll in postsecondary education, and live independently (i.e., based on research using majority-white samples).^{82,83} “Falling off the services cliff” may impact employment outcome disparities for Black autistic adults (e.g., unemployment and underemployment,²² but there is a lack of scholarship exploring how “falling off the services cliff” uniquely impacts Black autistic adults and their employment outcomes.

Methodological Approaches to Autism Research

Inclusive and representative methodological approaches to autism research are lacking. To better understand the disparate experiences of Black autistic adults, researchers must employ methodological approaches that highlight their voices and lived experiences. Although recruiting a diverse sample is critically important, culturally responsive scholarship requires more than the “myth of box-checking.”⁸⁴ Researchers must understand that culturally responsive research is an overarching ideology and not simply achieved by recruiting a racially diverse sample.

Researchers who “strive toward multicultural competence do not limit cultural conversations to race and ethnicity alone.”^{84(p203)} Culturally competent researchers work to include the voices of the population studied and their intersectional identities.

Exclusion of Black autistic voices within autism research

The majority of evidence-based support interventions for autistic youth were validated without diverse and represen-

tative samples (e.g., lack of equitable race and gender representation),²⁹ and only 25% of autism intervention studies for autistic youth between 1990 and 2017 reported race as a variable of analysis.²⁹ This trend is also present in the extant, although limited, adult autism research. In other words, there is a paucity of research that centers Black autistic voices in autism research. Including the voices, perspectives, and contributions of autistic individuals in autism research is essential for improving research quality.⁸⁵

Black disabled adults have been historically excluded from accessing institutions of higher education (IHEs) due to overt racism and systemic barriers (e.g., lack of access to evaluation documentation).^{83,86–88} Without the inclusion of Black autistic adults’ voices, their knowledge, lived experiences, and recommendations for the field, we continue to perpetuate Euro-centric practices, policy, and research. In the Guidelines for Moving from Neglect to Inclusion with Black Autistic Adults, we provide a set of guidelines to help researchers combat these contributors to neglect.

Guidelines for Moving from Neglect to Inclusion with Black Autistic Adults

Researchers have called for more inclusive and representative autism research—research that reflects the racial and ethnic diversity of autistic people²⁹—research that is inclusive of autistic adults^{19,23}—research that attends to participants’ intersecting identities³⁸—and research conducted by racially, ethnically, and neuro-diverse research teams.^{29,61} In addition to being more inclusive, autism research has to be culturally responsive—our work should contribute to effective, appropriately developed interventions and supports.⁸⁹

In this final section, we provide three guidelines that researchers should employ in their efforts to shift from scholarly neglect to truly inclusive autism research. First, we suggest that researchers adapt the practices of the research team. Second, we argue that researchers should construct ethnically and racially inclusive research designs. Third, we recommend that autism researchers center the voices of Black autistic adults. In the final section, we outline proposed steps toward systemic change to better support and engage Black autistic adults in research.

Adapting the Practices of the Research Team

Historically, research, practices, and policies related to the needs of autistic individuals have been centered around white American culture.^{85,87} Those practices are often implemented by white researchers and practitioners. As a result, there is a need for autism researchers who reflect the racial, ethnic, and gender diversity of autistic adults—that is, we need more scholars of color and more autistic researchers conducting autism research.^{29,61} One of the first steps that research teams can take to adapt their practices is to engage in cultural reciprocity.⁹⁰

Engage in cultural reciprocity

Researchers have a responsibility to acknowledge cultural differences between themselves and their participants, in an effort to meet the diverse needs of autistic individuals.⁹⁰ One way that researchers can do this is through cultural reciprocity. Cultural reciprocity is a fluid and intertwined component of culturally responsive research.⁹⁰ Kalyanpur and

Harry defined the cultural reciprocity as an approach that “enables professionals to develop collaborative relationships with families from culturally diverse backgrounds by becoming aware of the assumptions underlying both their and the families’ responses to the child with disabilities.”^{90(p489)}

Having an understanding of cultural reciprocity can help researchers reflect on: (1) ways their own culture and background is similar to and different from the autistic populations with whom they conduct research, and (2) ways they can apply their introspective knowledge to develop stronger research partnerships, facilitate participant empowerment, and support self-determination.⁹⁰ To engage in cultural reciprocity, researchers have to first introspectively identify how their own values and beliefs impact their interpretation of the needs of the autistic individual.

Second, researchers must identify the extent to which their values and beliefs are aligned with their participants. Third, researchers should acknowledge and respect the cultural differences between themselves and their participants. Fourth, researchers should work collaboratively with participants (or stakeholders) to engage in research efforts that align with the participant’s values.⁹⁰ Establishing cultural reciprocity facilitates empowerment among both researchers and participants, because it is an intentional effort to understand how one’s own experiences have shaped the research. This practice can support researchers in being better prepared to identify, investigate, and address autism disparities.

Construct Ethnically and Racially Inclusive Research Designs

Lack of cultural responsiveness is one factor that very likely dissuades Black communities from autism research.²⁹ Another step that researchers can take to address the disparate representation and scholarly neglect of Black autistic adults is to conduct inclusive research that reveals their nuanced perspectives, views, and needs. To that end, researchers should co-create and conduct studies with input from Black autistic adults. Researchers should also make a concerted effort to collaborate on research led by Black and autistic scholars.

Research must shift from being a practice that is done *to* autistic individuals, to research that is being conducted in collaboration *with* autistic stakeholders and participants.²⁹ We must move away from assuming the experiences of majority-white samples extend to all autistic individuals. Future research should focus on developing an understanding of the totality of unmet needs that affect autistic adults—especially vulnerable racial and ethnic minorities who are often absent from the adult autism literature. In the next section, we propose several inclusive and anti-racist methodological approaches that researchers can adopt to better meet this need.

Reject anti-Black methodological approaches to research

If researchers are to truly adopt inclusive and anti-racist methodological approaches to autism research, it will require that we dive more deeply into explorations that center the impact of racism and ableism, and disentangle the factors that contribute to disparities among Black autistic adults. It will also require that researchers reflect on our current methodo-

logical approaches and consider methodologies and outcome variables that are better aligned with the needs of Black autistic adults.

The first way that researchers can adopt an anti-racist methodological approach to autism research is by rejecting colorblind ideology. Colorblind ideology, or efforts to treat participants as equally as possible without regard to their culture, race, and ethnicity, is rooted in institutional racism and white privilege.⁹¹ Colorblind ideology often protects white researchers from the feelings of discomfort and shame that may be associated with the realities of racism.

The representation of Black autistic adults in the literature is limited. Researchers must recognize that Black autistic identities and experiences are rooted in specific racial, cultural, and ethnic practices. Researchers should reject notions of colorblindness by seeking to understand lived experiences, and recognize, honor, and celebrate the diversity of the communities with whom we work. This practice sets the foundation for more inclusive and anti-racist methodological approaches to autism research.

The second way that researchers can exercise inclusive and anti-racist methodological practices is to consider the feasibility and acceptability of the methodology for Black autistic adult participants. Although many autism researchers explore educational outcomes in children, and post-secondary outcomes in adults, a few studies explore outcomes such as eudaimonic well-being (i.e., happiness, self acceptance, purpose, quality of life).^{92,93}

For many Black participants in general, a history of unethical practices among researchers, institutions, and health care providers has led to ongoing distrust and hesitation to participate in research.⁵⁹ One way that researchers might better engage with Black autistic adults is to start by building rapport in their communities. For example, researchers can spend time volunteering in communities of color, learning about their needs, wants, and desires, before expecting Black autistic adults to actively participate in research.

One example of a methodology that can be more feasible and acceptable for Black autistic adults is community-based participatory action research.^{94,95} Action research engages “ordinary people” in reflective thoughts, discussions, decisions, and actions. Participatory research is a practice that centers the less powerful—those often marginalized—at the center of the knowledge building process. In other words, participatory research is grounded in centering the lived experiences of marginalized people.^{94,95}

Therefore, participatory action research requires that researchers develop relationships with Black autistic stakeholders to first understand their experiences and needs. Then, researchers should engage Black autistic stakeholders in the research process from study conception, to design, to data collection, to dissemination. Kurt Lewin summarized this practice as “no action without research; no research without action.”⁹⁵

Center the Voices of Black Autistic Adults

Our third guideline to better address the disparate representation of Black autistic adults in autism research is to center their voices. This means placing Black autistic adult perspectives, experiences, and input at the forefront of research. These types of intentional partnerships with Black autistic stakeholders ensure that their voices, preferences, and

contributions are reflected in the autism literature. For example, autism researchers who are conducting funded research should be intentional about creating paid opportunities for Black autistic people to serve as advisory committee members.

This helps to ensure that Black autistic voices are represented in the research development, adaptations, and dissemination efforts. For unfunded studies, centering Black autistic voices might require more creative efforts. For example, in IHEs that offer university-funded research opportunities for undergraduate and graduate students, researchers should be intentional about recruiting Black, autistic, and Black autistic student researchers to be a part of their teams.

One final way that researchers should center Black autistic voices is by citing specific recommendations from Black autistic participants and reporting findings that diverge from hypotheses and expected outcomes. For historically marginalized groups, null findings might direct researchers toward more methodologically inclusive future research. Centering Black autistic voices helps researchers better answer questions such as, “for whom are these practices evidence-based?” and it contributes to the construction of more inclusive and representative scholarship in the field. These inclusive practices and representation are key to reducing ableism and racism in our research.

Next Steps for the Field

Moving from neglect to inclusion in research with Black autistic adults requires a commitment to social justice at the researcher level, but it also requires systemic change in multiple spaces to thoroughly address the scholarly neglect of Black autistic adults. In this final section, we put forward several steps for the field to move forward toward addressing the inequities that impact the representation of Black autistic adults in autism research.

First, IHEs must work intentionally to recruit, train, and retain Black and autistic educators and autism scholars at all levels.⁶¹ The IHEs must also seek, hire, and support Black and autistic faculty. Black faculty represent ~5% of faculty in IHEs—a number that has remained nearly the same for decades.⁸ Data on the representation of autistic faculty in IHEs, however, are missing. Increasing the number of Black, autistic faculty in IHEs can also help with recruiting and retaining Black, autistic students⁶¹ who often seek mentorship from advisors who shared lived experience.

Having shared culture and experience allows Black faculty (particularly at predominately white institutions) to relate to Black students in creative and authentic ways that may not be accessible to them when working with white faculty.⁹⁶ Finally, peer-reviewed journals must also be committed to engaging in inclusive review and publication processes to overcome the scholarly neglect of Black autistic adults. These efforts should include: requiring authors to report participant demographic information, suggesting that authors report their own demographic information,²⁹ and ensuring representative racial, ethnic, and neuro-diversity among the peer reviewers.

Conclusion

Although we spend most of our lives as adults, ~2.51% of autism research funding focuses on autistic adults.^{23,64,97}

And of the research that is conducted with autistic adults, there are no data on the prevalence of Black autistic adults living in the United States. If researchers cannot measure the population of Black autistic adults, then surely we are not yet prepared to grapple with the needs of Black autistic adults who are rooted in Black culture and lived experiences—needs that are challenged by systemic injustices, and disparities upheld by white supremacy.

Autism researchers cannot be complacent about the neglect of Black autistic adults in our research. We must be intentional about adopting culturally responsive skills, strategies, and practices that will move the field forward. The strategies, recommendations, and practices presented in this article are likely just the beginning of what it will require for the field of autism research to be more racially and ethnically inclusive, but they are certainly a start. We must move away from the status quo—away from what Onaiwu calls comfortable. And familiar. And lazy. We must actively engage in shifting autism research from scholarly neglect to thoughtful and intentional inclusion.

Authorship Confirmation Statement

The authors confirm contribution to the article as follows: conception and design: K.M.M., J.N.P., K.N.P., and L.D.M.; literature search and review: A.Q.R., K.N.P.; analysis and interpretation of results: K.M.M., J.N.P., L.D.M., and K.N.P.; draft article preparation: K.M.M., J.N.P., K.N.P., L.D.M., A.Q.R., and D.L.M.M. All authors reviewed the results and approved the final version of the article.

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Address correspondence to:

Kayla M. Malone, MEd
 Applied Developmental Science and Special Education
 The University of North Carolina at Chapel Hill
 100 E. Cameron Avenue
 Chapel Hill, NC 27514
 USA

Email: kmalone@unc.edu