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**The Equity Agenda in Intellectual and Developmental Disabilities Research**

Khalilah Robinson Johnson, PhD, MS, OTR/L
The University of North Carolina at Chapel Hill
CB# 7122, Bondurant Hall
Chapel Hill, North Carolina 27599
United States of America
Khalilah\_Johnson@med.unc.edu
ORCID: 0000-0003-4774-056X

**Abstract**

This commentary on Kover and Abbeduto (2023) underscores the critical importance of naming and framing toward an equity agenda in intellectual and developmental disabilities research. More specifically, I briefly outline (1) why racialization is an important anchor in IDD discourse; (2) whiteness as a necessary point of discussion; and (3) the adoption of critical inquiry and critical praxis.

The enactment of anti-racist and anti-oppression strategies toward equity and justice have become markers of social consciousness for academic disciplines and professional organizations. As racial and social tensions heightened in the United States, scholars in the intellectual and developmental disabilities (IDD) field also “called in” researchers and service providers to address the enduring impacts of racism, ableism, and other mediators of disparities on people with IDD (Johnson et al., 2021; Scott et al., 2021). While IDD scholars can appreciate and even celebrate this collective “calling in,” the field must also recognize that few explicit calls for action address the key roles whiteness and white supremacy play in redressing these enduring issues (Johnson et al., 2021). To omit specific mentions of whiteness and white supremacy as malignancies that plague every institution, including the research enterprise, undercuts the very efforts academic and professional bodies claim to make toward reconciliation and equity.

Kover and Abbeduto, authors of the manuscript for which this commentary is written, noted that the committed actions of funders and professional organizations to rectify oppressive systems are “important, but not sufficient.” I would also argue that these actions are not transformative in that they do not dismantle the very structures (i.e., whiteness and white supremacy) that allow these systems to persist. Kover and Abbeduto go on to challenge IDD scholars to be critically reflective about methodological practices that perpetuate social inequalities and to employ research strategies from a disability justice and social justice lens. These are necessary steps for IDD scholars to consider; however, beyond incorporating intersectionality as theory and analytic method, IDD scholars must commit to research agendas and justice-oriented approaches that aim to liberate and provide a nuanced understanding of one’s multiple marginalized group memberships. Further, IDD scholars must refrain from equity tourism--capitalizing on public interest and funding opportunities for career advancement without the expertise to meaningfully address knowledge gaps (Lett et al., 2022; Neblett, 2023)--without being committed to the work that is required to transfer power and change systems.

Below, I extend Kover and Abbeduto’s discussion to address (1) why racism is important to the IDD discourse; (2) whiteness as a point of discussion in our knowledgebase; and (3) the adoption of critical inquiry and critical praxis toward equity and justice for multiply minoritized people with IDD.

**Racism and IDD: A Necessary Context**

“It is about race if it disproportionately or differently affects people of color” (Oluo, 2019, p. 16). The aforementioned statement was reaffirmed by Kover and Abbeduto who agree that people with IDD from racially minoritized backgrounds experience disparate outcomes across all life domains as discussed in IDD literature. However, they neither name nor frame racialization as the anchor through which conceptualizations of disability and IDD are inherently tied (Johnson et al., 2021). This anchoring is important to setting an equity agenda because:
 …racism also foregrounds the intersections of the physical, social, temporal, economic,
 and cultural environments with its sociopolitical histories and socioaffective components,
 grounding knowledge and actions in understanding how different forms of power
 influence social relations and knowledge generation (Johnson et al., 2021, p. 157).
This includes knowledge generation on models of disability, research design and recruitment, and who is valued and positioned as experts in the field. Failure to make these connections grossly ignores the unique concerns and experiences of multiply minoritized people with IDD.

Racism also manifests on research teams, leadership and editorial boards, and other predominately white spaces where minoritized IDD scholars and research partners are underrepresented (Johnson et al., 2021). This is briefly mentioned by Kover and Abbeduto but they do not critique the unintended consequences this can have on IDD research. Namely, the intellectual erasure of scholars of color through the politics of citation (Smith & Scott, 2021). Smith and Scott (2021) define *citational politics* as the beliefs and practices that determine how a discipline values and evaluates the work of its scholars. Scholars who speak and work from the margins have called attention to the ways mainstream (white) researchers and institutions routinely overlook their contributions. This also translates to exploitation of minoritized scholars and research partners when recruiting for research teams.

**Whiteness: A Necessary Point of Discussion**

Language codifies! What we name and how we communicate its implications generates perceptions and expectations, regardless of whether those perceptions and expectations are accurate or false. I call attention to this because of Kover and Abbeduto’s use of “dominant culture” as opposed to “white.” Whiteness is characterized by the experiences generally associated with one’s group membership to the white race and having white skin (Frankenburg, 1993; Kendi, 2019). Whiteness, as a function white group membership, relies on the “othering” of non-white people; and because of this, whiteness comes with privileges (Frankenburg, 1993). Race scholars contend that it is not possible to recognize the privileges and social dominance associated with whiteness without acknowledging that whiteness, as a racial identity, also protects and reproduces racism (Kendi, 2019; Oluo, 2019). The net effect of the fundamental disconnects between the racial self-perceptions of people who identify as white and the realities of living in a racialized society is that white IDD scholars may not (debatably will not) be able to meaningfully engage multiply marginalized people around the ideas of equity and justice (Kendi, 2019; Oluo, 2019).

**Critical Research Approaches: A Necessary Praxis**

In addition to Kover and Abbeduto’s charge to IDD scholars to adopt intersectional and participatory approaches as actional steps toward equity and inclusion, I offer that IDD scholars take up models and frameworks that are anti-racist such as the *Public Health Critical Race Praxis Model* (Ford & Airhihienbuwa, 2010) and make visible the misappropriations and misrepresentations of race and disability such as *Disability Critical Race Theory* (Annamma et al, 2013). These guideposts also account for heterogeneity, are anti-ableist and culturally affirming which are identified as limitations of categorical diagnostic labels (Fleming et al., 2022). Additionally, these frameworks emphasize how racialized group membership and other identities of difference (e.g., neurodiversity) are valued ways of being.

References

Annamma, S. A., Connor, D., & Ferri, B. (2013). Dis/ability critical race studies (DisCrit):
 Theorizing at the intersections of race and dis/ability. *Race Ethnicity and Education,
 16*(1), 1–31. https://doi.org/10.1080/13613324.2012.730511

Fleming, P. J., Stone, L. C., Creary, M. S., Greene-Moton, E., Israel, B. A., Key, K. D., Reyes,
 A. G., Wallerstein, N., & Schulz, A. J. (2023). Antiracism and community-based
 participatory research: Synergies, challenges, and opportunities. *American Journal of
 Public Health, 113*(1), 70-78.
 <https://ajph.aphapublications.org/doi/full/10.2105/AJPH.2022.307114>

Ford, C. L., & Airhihenbuwa, C. O. (2010). The public health critical race methodology: Praxis
 for antiracism research. *Social Science and Medicine, 71*(8), 1390-1398.
 https://doi.org/10.1016/j.socscimed.2010.07.030

Frankenburg, R. (1993). *White women, race matters: The social construction of whiteness*.
 University of Minnesota Press.

Johnson, K., Bogenschutz, M., & Peak, K. (2021). Propositions for race-based research in
 intellectual and developmental disabilities. *Inclusion, 9*(3), 156-169. doi: 10.1352/2326-
 6988-9.3.156

Kendi, I. X. (2019). *How to be an antiracist*. One world.

Lett, E., Adekunle, D., McMurray, P., Asabor, E. N., Irie, W., Simon, M. A., Hardeman, R., &
 McLemore, M. R. (2022). Health equity tourism: Ravaging the justice landscape. *Journal
 of Medical Systems, 46*(3), 17. https://doi.org/10.1007/s10916-022-01803-5

Neblett, E. W. (2023). Racism measurement and influences, variations on scientific racism, and a
 vision. *Social Science and Medicine, 316*, 115247.
 https://doi.org/10.1016/j.socscimed.2022.115247

Oluo, I. (2019). *So you want to talk about race*. Hachette UK.

Scott, L. A., Thoma, C. A., Gokita, T., Bruno, L., Ruiz, A. B., Brendli, K., Taylor, J. P., &
 Vitullo, V. (2021). I’m trying to make myself happy: Black students with intellectual and
 developmental disabilities and families on promoting self-determination during
 transition. *Inclusion, 9*(3), 170-188. doi:10.1352/2326-6988-9.3.170

Smith, C. A., & Garrett-Scott, D. (2021). “We are not named”: Black women and the politics of
 citation in anthropology. *Feminist Anthropology, 2*, 18-37.
 https://doi.org/10.1002/fea2.12038