1. Sara T. Kover and Leonard Abbeduto
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3. **Commentary Title:** Nothing About Us Without Us: Research Equity for Intellectual and Developmental Disabilities Research
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Abstract

Toward equity in research on intellectual and developmental disabilities (IDD) is a timely and comprehensive article highlighting gaps in the “dominant culture” approach to current research strategies designed to address IDD. Recentering systems involved in the research enterprise are recommended. The commentary provides additional guidance from a social justice, equity, and inclusion lens, including a clinical anthropology approach to research.

Kover and Abbeduto provide an overarching and comprehensive view of the opportunities and challenges for researchers dedicated to improving the health, self-efficacy, and well-being of diverse individuals with intellectual and developmental disabilities (IDD). To move to an inclusive, intersectional, and social justice research lens that reflects individuals with IDD’s priority questions and concerns, Kover and Abbeduto recommend reframing multiple systems. The authors modeled self-reflection of their status as white, non-disabled researchers with potential privileges associated with their identities; we hope other researchers will follow. Self-reflection is an integral tool that addresses racial equity in research, such as the multicultural orientation framework (MCO), and should extend to the disability field (Raque et al., 2021). An inclusion consideration for their seminal work is whether the authors collaborated with individuals with disabilities (Spanierman & Smith, 2017).

Adopting a clinical anthropological frame may assist in understanding and dismantling ableism and racism in scientific inquiry. Examining the history and cultural practices of our medical and research models and beliefs will promote the identification of implicit biases built into our medical and professional education, clinical practice, healthcare, and research systems. Education and belief systems shape and limit our concepts of disability, especially when researchers who are non-disabled work in isolation from colleagues who are neurodiverse.

The authors use the term “dominant culture” without fully explaining the term. The reader is left to surmise that the “dominant culture” is the White wealthy, able-bodied, hetero-, Christian, U.S.-born, male (American Medical Association & Association of American Medical Colleges, 2021) or the WEIRD (western, educated, industrialized, rich, and democratic) research culture described later in the article (Henrich et al., 2010). In an otherwise informative and socially progressive article, the “dominant culture” terminology is distracting without a descriptive definition and historical context. The academic and scientific communities are adopting race-conscious terminology, replacing vague non-scientific terms such as “minority” and race-based assumptions without historical context to inform evidence (Cerdena et al., 2022; Cerdena et al., 2020). “Advancing Health Equity: A Guide to Language, Narrative and Concepts,” and the CDC’S Health Equity Guiding Principles for Inclusive Communication, provide guidelines for terminology that may dismantle implicit bias in our scientific terminology (American Medical Association & Association of American Medical Colleges, 2021; Prevention, 2021). An alternate term for the “dominant culture” in research systems that dictate what science is valued, prioritized, and “resourced” might be the Resource Allocation Culture/Controller (RAC). Identifying the systems within the RAC, i.e., K-12 and college education, private and federal funding, media, political and faith communities, and healthcare systems, will assist in developing multi-sector approaches to achieve the authors’ proposed equity reframing.

The authors state that research questions, design, and metrics supported by the RAC reflect the RAC and researcher’s traditional lived experiences and “standards.” The discussion about bias in measurement instruments begins to outline challenges of current research strategies. Advancing research from a biomedical model to integrated applied clinical anthropologic approaches may expand research questions outside traditional deficit and disease models. Using a clinical anthropology approach may identify systems of oppression within research, clinical, and professional education settings that are “invisible” to the RAC. Healthcare provision increasingly acknowledges the value of cultural responsiveness and shared decision-making, so why not expect the same when developing research questions and designs (Bravo et al., 2020; Carosella et al., 2018; Krahn et al., 2015)? Clinical anthropologic strategies may encourage researchers to center IDD during hypothesis generation by obtaining oral histories of lived experiences to inform research priorities. For example, taking experience-focused oral histories from individuals with cerebral palsy who have extrapyramidal symptoms may clarify environmental and situational factors associated with fluctuation of those symptoms, leading to studies investigating neuropathophysiology and potential therapeutic approaches. Inviting partnerships with the “benefactors” of research on IDD may lead to developing investigator priorities that align with the priorities of individuals with IDD. Collaboration with the intended benefactors may lead to focused efforts to improve IDD outcomes rather than rely on investigator-initiated projects. Inclusion of qualitative data and co-constructed methodology may become a standard in research.

An often neglected area, the authors discuss intersectional aspects of IDD research for racially and ethnically diverse populations. It is imperative to understand race as a socio-political construct that, in the US, disproportionately advantages some “races” and disadvantages other “races.” When researchers include race in research analyses, they often measure the impact of racism. The authors caution about the educational disparities among Black children. Structural and institutional racism is the principal cause of educational inequality among Black children. Similarly, ableism may be one factor for the higher-than-expected suspension rates among children with IDD (Ryberg R. et al., 2021). Acknowledging the over-simplistic construct of race and disability in research designs, analyses, and interpretation of results is imperative. The history of overtly racist research practices continues to shape ethical challenges of current IRB protocols. Highlighting actionable anti-racist strategies researchers may use to address structural and institutional racism and promote equity and diversity among principal investigators may lead to structural change (Fleming et al., 2023; Ford et al., 2018; Wray-Lake et al., 2022). To increase equity in the Figure’s heuristic model, adding the clinical anthropology lens, inclusion of IDD research colleagues, and evidence-based strategies to address implicit bias (Devine et al., 2012) inherent in current research systems should be considered.

Understandably, mistrust of research and researchers continues to be present among individuals of color. Mistrust and the lack of diversity among researchers adversely impact willingness to participate in studies (Darcell et al., 2010). Education about research protocols for safety and subject rights should be prioritized as an opportunity to build trust. Universal access and community-based research locations with flexible hours may increase recruitment and engagement. Strategies for recruiting individuals whose primary language is not English should be considered beyond language and translation of assessment instruments (Gabler et al., 2021). The authors note the multiple dialects and the challenges with translating research into a single Spanish translation.

Ensuring research funding guidance, accountability metrics, and equity-informed RAC initiatives that research teams “center the experience and voices of IDD and acknowledge their identities” and lived experiences is foundational. The dissemination and uptake of findings in policy and practice are of utmost importance. Using a solely biomedical, “hard” science approach limits research. Importantly, who labeled biomedical research “hard” science versus the complexity of inclusive equity IDD-centered research that translates into informed public health policy? Maybe the bridge, translating equity-based research on intellectual and developmental disabilities to policy, is the hardest.

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