Commentary on Kover & Abbeduto for *AJIDD*

Confronting Epistemic Injustice and Inequity in IDD Research: the value of theorizing beyond dominant culture’s perspective

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Manuscript Text: 1356 words

References: 14

**Abstract**

This commentary highlights pervasive challenges related to the science of intellectual and developmental disabilities (IDD), which we often take for granted. We argue that social power asymmetry and entrenched patterns of epistemic injustices undermine our science and call attention to the need to maximize our efforts to undo these unfair practices to enhance future care and research in IDD.

Despite considerable progress in intellectual and developmental disabilities (IDD) research over the past few decades (Schalock et al., 2021; Schalock & Verdugo, 2019), social power asymmetry and entrenched patterns of epistemic injustice (Crichton et al., 2017; Fricker, 2007; Scully, 2018) still persist and drive much of the current thinking within the IDD research ecosystem (Johnson et al., 2021). Unlike the field of global health where these issues are discussed on a daily basis (Bhakuni & Abimbola, 2021), epistemic injustice and social inequities have received less attention in IDD research. The target article by Kover and Abbedutodoes an admirable job by cataloging and reflecting on many uncomfortable sources of epistemic injustice or inequity in our field.

The authors provide a thought-provoking account of the major challenges and recommend a framework to stimulate conversations and solutions to promote real social justice. The authors highlight several practices that seem to confirm the presence of epistemic injustice in our field. For example, the lack of diversity in IDD research samples and workforce has not only limited knowledge production and use, but continues to enable perpetuation of epistemic injustice within the IDD research ecosystem-*the notion that social power privileges dominant groups and ensures the exclusion of the knowledge of marginalized groups from the collective epistemic resources* (Scully, 2018). Sadly, these practices have led to the over-dependence on categorical nosologies and treatments derived from the dominant culture. According to the authors, the over-reliance on the dominant culture research paradigm, ways of viewing disability, of formulating questions, of creating and operationalizing measurement instruments or treatments/support services, and developing and implementing policies constitute major drivers of social inequities prevalent in IDD research. The authors recognize that a multicomponent strategy can disrupt historical systems of marginalization in the IDD research ecosystem, and ensure equity, diversity and inclusion at both individual and community levels.

In light of this, they propose an integrated framework highlighting the value of intersectionality and person-centered thinking, self-representation, partnerships and community engagement as well as cultural humility as active ingredients to ameliorate the negative impact of social inequities, and to subsequently maximize the impact of IDD research at all levels of care. Notably, the authors deal with potential barriers that could hinder the successful implementation of some of their excellent ideas and make recommendations regarding how those barriers could be mitigated. Indeed, if we are able to operationalize their framework genuinely, we will drastically transform the outlook of the IDD research ecosystem and create a diverse database to support policies and interventions. But will this provide the needed resources to better respond to the diverse needs of the marginalized groups everywhere? How can we do this without further entrenching epistemic injustices that we have all perpetuated in one way or another by our actions or inactions? In the next section, we provide some imperfect suggestions and hope that this commentary will generate additional solutions beyond those cited in the original paper.

1. *We need to rethink our conceptual assumptions underlying IDD and related constructs*

The field of IDD has experienced tremendous transformation in recent times (Schalock et al., 2019). However, there is increased need for greater scrutiny and accountability in both research and clinical settings. Although, our conceptions of IDD have evolved, the biomedical model has largely influenced how we theorize IDD in the US. Other models such as the social model and hybrid models including the biopsychosocial and ICF models mentioned in the paper are increasingly becoming popular and some have yielded significant results to individuals with IDD. However, the extent to which we have integrated the broader perspectives, knowledge systems or daily experiences of all people in the construction of these models remains unclear. We know that cultural factors play a central role in the understanding, social acceptance, and provision of services for individuals with IDD (Klingner et al., 2007).Additionally, certain behaviors used to characterize IDD may have differing cultural interpretations (Lord et al., 2022; Norbury & Sparks, 2013). However, most of us working with individuals with IDD often treat this condition as culturally neutral. The dominant research approach used by IDD scholars assumes that these disabilities are similar across cultures, and that diagnostic and treatment models designed for the majority group are applicable and meaningful in non-dominant contexts (Daley, 2002; Norbury & Sparks, 2013). While there are some shared similarities with IDD phenomena, significant variations abound across cultures or contexts. It is problematic to continue to relegate cultural variation to noise or nuisance in our models. Are we not missing opportunities to more precisely identify features specific to particular contexts, but do not fit predetermined, dominant-culture-based conceptualizations of difference? Absent data, presumptions of universality, most often anchored in findings from the dominant culture, may reflect entrenched, yet modern colonial expressions of power. We may have good intentions, sound methodologies and practices, but if these resources are not helping us to better address emerging social problems facing the entire IDD community, then we must alter our background assumptions so they do not become sustaining factors of social inequity.

1. *We need to adopt “Glocal” thinking in IDD research and practice*

The temptation to look within the US [or other Western/White, Educated, Industrialized, Rich, & Democratic (WEIRD; Henrich et al., 2010) societies] when conceptualizing or defining IDD-related constructs is pervasive. As the authors pointed out, our conceptions of IDD and diagnostic systems have all been based on these dominant cultures, resulting in what we call *conceptual marginalization* (i.e*., the exclusion of other people’s cultural knowledge, lived experiences and social norms in developing psychological constructs*). Since the US is a multicultural country, adopting an approach that enables us to think globally to address local problems has some merit. By doing this, we will be able to develop holistic conceptions of IDD to facilitate the development of measurement tools and care models that integrates the cultural values, knowledge resources, experiences and perspectives of all people, thus, breaking power asymmetries and injustices in our field. Another benefit of a Glocal approach is to use novel research approaches (e.g., mixed etic-emic methods) to generate data that is comparable and culturally valid both within the US and outside, and ultimately create better support services for all marginalized people. Of course, adopting this approach comes with its own challenges (e.g., language barriers, cultural variability in knowledge systems), but most of these challenges can be overcome when professionals develop cultural humility, and listen or co-create knowledge with individuals from other cultures (i*.e., holistic co-mentoring*).

1. *We must move towards community-engaged research that yields sustainable developmental outcomes*

Instead of just building partnerships to ensure representation in research samples and workforce pipelines, we could seek opportunities to develop deeper and ethical community-engaged programs ensuring that our research equitably meets the needs of the marginalized group. One that yields sustainable outcomes at both individual and community levels. For a recent example, see Randolph and colleagues (2022).

The manner in which we have historically conducted IDD research has directly marginalized people over several generations. Acknowledging the harms that our research practices have caused and expressing the urgent need for improvement is a powerful first-step toward ensuring real equity and epistemic justice. Creating an action plan for change is laudable but we need to do more so we can better serve all marginalized people around the world. We can work together with diverse people and samples to precisely characterize shared features (universals) and sources of variations (specifics) in the presentation of IDD to better inform the development of measurement tools and treatments that are meaningful and culturally valid in diverse contexts. To do this, we need to interrogate our own biases and approach our research endeavors and practices with a justice-oriented thinking thatemphasizes that all individuals, including those with a diagnosis of ID or DD, have the same human rights (Schalock et al., 2019). Every professional working in IDD research must be thoughtful about their methods of knowledge production on a daily basis, and understand their positionality and do their best to resist epistemic injustice. We applaud Kover and Abbeduto for their not so gentle nudge toward improving our science, their epistemic and cultural humility, and their call to action for people with IDD.

**Acknowledgements**: This work was supported by R01MH115046 from NIMH. The funders had no role in the production of this commentary.

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