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One world, one autism? A commentary on using an intersectionality framework to study autism in low-resourced communities

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In the short history of autism research, one of the most consistent findings across studies is that there are no differences in prevalence rates or clinical expression of autism as a function of culture, ethnicity, or geographical location (Nowell et al., 2015). On the contrary, there is increasing evidence pointing to social determinants of health (i.e., poverty, access to health care, educational level social networks, and neighborhood support) having an impact on autism symptom expression and overall quality of life of autistic individuals[1] (Magana et al., 2013).

Over the last years, there has been an increase in autism spectrum disorder (ASD) research, but the majority of studies conducted have been in high-income countries, mainly the USA, UK, and Canada (Elsabbagh et al., 2012; Sweileh et al., 2016; Zeidan et al., 2022). Furthermore, those studies conducted in low- and middle-income countries (LMIC) do not have a good representation of autistic individuals living in underserved communities. For example, one

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[1] We are aware of the diverse opinions regarding the terminology used to refer to individuals on the spectrum. We have elected to use identity-first instead of person-first language following suggestions to avoid ableist language (Bottema-Beutel et al., 2021).

of the most significant studies in Latin America was conducted by Red Espectro Autista Latinoamerica (REAL), offering caregivers' perspectives on the needs of autistic individuals in Latin American countries. Although it is a significant study for this region, its major limitation involves the utilization of a convenience sample. Such a methodological issue might have yielded a biased sample since most of the participant families came from higher educational backgrounds, had internet accessibility, and were part of a parent association, thus excluding those that did not meet these criteria (Paula et al., 2020). This case exemplifies how online research methods might widen disparities in research participation since low-resourced regions lack universal internet access and computer ownership, with many individuals having limited computer literacy. Health disparities have also been linked to health care and educational inequalities, a consistent issue in LMIC (LAMICs; Durkin et al., 2015).

Moreover, healthcare accessibility, or lack thereof, can be tied to a "global imbalance" of ASD knowledge and research (Durkin et al., 2015). ASD research not only helps widen the unbiased understanding of ASD symptomatology and the lived experiences of autistic individuals but also helps improve the quality of care (Durkin et al., 2015). In short, the current state of autism research misses a global picture of autism, including its variability that might be attributable to different social determinants of health.

Intersectionality as a research framework might aid in reducing health disparities and promoting health equity and social justice for autistic individuals living in underserved communities. Individual experiences are hardly ever shaped by only one factor but result from various factors impacting each other. When discussing autism from the intersectionality perspective, someone has different identities besides being autistic, such as race, gender, income level, and culture. In terms of the lived experiences of autistic individuals in underserved communities, another layer is added, which requires our awareness of environmental factors contributing to diagnostic or service accessibility and possible perceived stigma.

This paper discusses the intersection of poverty, culture, race/ethnicity, social status, gender, and disability, in this case, autism. Poverty is not only a measure of monetary concerns but includes an array of physical and psychosocial stressors that affects many daily domains, such as educational achievement and health outcomes. Autistic children living in poverty have higher rates of poor health outcomes (Durkin et al., 2015). Recent studies found that caregivers' concerns will vary depending on their racial and cultural background, which are thought to be related to their cultural values (Golson et al., 2021). Culture includes social norms, rites, beliefs, relationships, and other customs (Rathje, 2009). Another overlooked factor in autism is gender, as girls are identified later and less frequently than boys (Loomes et al., 2017).

Regarding race and ethnicity, recent epidemiological studies in the USA show that Black and Hispanic children are at a higher risk of a later diagnosis when compared to White children (Center for Disease Control and Prevention, 2021). In addition, compared to White parents, Black and Latino parents of autistic children report poorer quality of healthcare interactions (Magaña et al., 2015). Despite this knowledge, research continues to overlook these minority groups. For example, most prevalence studies underrepresent minority ethnic and racial participants, with samples mainly including White children (West et al., 2018). Lastly, another scarcely studied facet of intersectionality is how autistic LGBTQ+ individuals report poorer health outcomes than autistic cisgender individuals (Hall et al.,2020). This is particularly important given that autistic individuals are more likely to identify as part of this community than the general population (Hillier et al., 2020).

Other factors impacting service and educational accessibility in low-resourced settings are limited government expenditure on mental health initiatives and few available trained professionals to work with autistic individuals (Montiel-Nava et al., 2021). In addition, socio-economical factors such as insurance type, transportation, the distance of health and education institutions from home, and childcare during parent sessions have been predictive of a reduced delivery of therapeutic support services (Lindly et al., 2019).

Currently, there is not enough information on how being autistic or being the caregiver of an autistic individual might differ depending on geographical location, ethnicity, race, and educational background. The lack of ASD knowledge from LMIC results in a limited understanding of autism. This biased understanding results in subpar ASD identification and effectiveness of treatment for autistic individuals in low-resourced communities and LMIC. And thus, a call is made to reframe how we study autism in underserved communities. Data from some studies suggest that the autistic experience in low-resourced communities would vary depending on the income level, the type of health service they would have access to (public or private), and educational attainment. For example, wealthy Brazilian and Venezuelan families with private insurance and some college education might have better and faster access to information and specialists diagnosing ASD than families living in poverty with only public health insurance. In Brazil and Venezuela, parents with no private insurance experience longer wait times to access diagnostic evaluations and interventions (Montiel-Nava et al., 2022; Araripe et al., 2022).

Divan et al. (2021) emphasize that improving access to comprehensive and integrated services for autistic individuals is a world health priority, a human right, and a requirement to be included in universal health coverage. In the same document, they offer alternatives to improve the research process in underserved communities. Recommendations about increasing participants' diversity (including rural, urban, and hard-to-reach communities) and the development of adapted trials reflect the intersectionality of disability (autism), poverty, culture, and education in places where almost no autism research exists.

Suppose we used intersectionality to examine the factors mediating and moderating the access to autism services in low-resourced communities. In that case, we could address the diversity that encompasses the autism experience in terms of different income and educational levels, nationalities, ethnicities, and racial backgrounds. In doing so, we could develop a less biased body of knowledge that would allow the implementation of culturally, ethnically, and socially informed autism practices.

To summarize, the interplay of the different factors impacting autistic individuals and the diversity and heterogeneity of autistic experiences are often overlooked in most autism studies, affecting how professionals carry on diagnosis and intervention practices. Culturally, gender, racial and ethnic sensitive and informed research studies could provide more valid procedures for diverse autistic individuals. Despite not being there yet, it is our plea for the needed steps in terms of more inclusive ASD knowledge, which is the way towards better service accessibility and healthcare equity for autistic individuals living in underserved communities. However, our statement needs an action plan. Based on the literature presented and the limited effectiveness achieved by promoting inclusion and diversity, it is crucial first to operationalize ways for global researchers to sit at the table. ASD research is primarily conducted in the U.S., with limited inclusion of non-English speakers, and focused on traditional genders to mark inclusion (e.g., women) (Judd & McKinnon, 2021). Within ASD research, inclusivity and diversity usually focus on the lived experiences of U.S. autistic White individuals. At this point, if we want to bring intersectionality to the table, global ASD research needs to address what is missing to then progress from there. Such steps might start by offering translation services for non-native English speaker researchers, including members from diverse backgrounds in editorial boards, so their voices can impact global research endeavors. In addition, researchers in developed countries might start increasing the participation of historically underrepresented minorities and studying the intersection of their different identities (race, SES, gender, education, etc.). Another action is already in motion and refers to the cultural and linguistic adaptation of diagnostic and treatment instruments to be valid for the diverse autistic community (Divan et al., 2021; Hoekstra et al., 2021). These initiatives will get us closer to achieving a more global and equitable representation of the diverse expression of autism and developing the tools to offer more culturally sensitive and informed responses to the international autistic community.

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