Relevant Themes in 'Institutional Racialisation in Autism and Research Practice'

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Kwari, Tendai. (2021). Institutional Racialisation in Autism and Research Practice
https://www.researchgate.net/publication/348357073_Institutional_Racialisation_in_Autism_and_Research_Practice

Institutional racialisation exists in autism research and practice and discriminates against autistic people from the Black Asian Minority Ethnic Communities (BAME). Race bears on the way resources are made accessible, and institutions can have input determining its meaning, there is always an imbalance of power, expressed through access to resources (Garner, 2009). Ethnicity is a crucial determinant of health inequalities in the U.K., where BAME communities face more inadequate healthcare access, including autism services (Papadopulous, 2016)

Institutional racialisation in higher education and autism research
Alexander and Arday (2015) observed a lack of BAME academics in higher education with senior positions, highly selective universities disproportionately reject ethnic minority applicants, British academia remains administratively, normatively, habitually, and intellectually white. Constantine and Sue (2006) identify institutional racism in higher education as:
• biased admissions to accommodate fewer minority students
• low expectations of minority students
• exclusion of minority students from activities
• ignorant to minority students' problems and concerns
• limited courses relevant to minority students
• few minority personnel in crucial decision-making roles
• little or no funding towards minority programs.

Referenced in Tendai (2021) - To address racial disparities in autism research, we must think globally, act locally
Jones DR, Mandell DS. To address racial disparities in autism research, we must think globally, act locally. Autism. 2020;24(7):1587-1589. doi:10.1177/1362361320948313
Jones and Mandell (2020) state that a history of systemic racism has led to few BAME researchers and academics working in sciences and has likely contributed to health disparities among black autistic people and that black scientists and practitioners are more likely to study and care for disenfranchised minorities from underrepresented minority groups than white scientists.

Jones et al. (2020) indicate that **people from the BAME communities have been historically underrepresented in autism research** despite improvements in screening and diagnoses. They argue that structural racism exists in autism research and that people from the BAME communities continue to be underdiagnosed. The effects of under or misdiagnoses of autistic children result in limited access to support and services, lower rates of employment, social disengagement, and poor chances of getting a post-secondary education.

While the National Autistic Society NAS (2020) acknowledges that there are 700,000 autistic people in the U.K., there is a lack of research about people's experience from BAME communities, making it harder for them to get needed support. The BAME communities' experiences need to be heard and understood to create a society that works for autistic people. Five themes emerged when NAS (2020) asked BAME autistic people and their families to identify their needs and explain their experiences, which are:

• Challenges of getting a diagnosis due to lack of knowledge of autism and teachers' failure to identify autism, and wrongly described it as behavioural issues.
• Barriers to accessing support - including lack of knowledge about getting support, services, and information in a language they understand.
• Lack of confidence in dealing with professionals who, in some cases, lack their cultural understanding.
• Stigmatisation from within their communities.
• Denial and isolation

Institutional racialisation in autism practice and diagnoses
Ethnicity is a crucial determinant of health inequalities in the U.K., where BAME communities face more inadequate healthcare 14 access, including autism services (Papadopulous, 2016).   Broder-Fingert et al. (2020) and Dababnah (2018) point out that **multiracial children are receiving an autism diagnosis later than their white counterparts. The CDC (2019) research further noted that autistic black children with intellectual disability receive a diagnosis at older ages than their white autistic counterparts with intellectual disability.** Constantino et al. (2020b) added that black autistic children experience racial disparities due to late diagnoses, poor access to quality intervention, and more likely to be misdiagnosed and receive fewer autism services than their white counterparts. Ultimately, black autistic children experience worse health outcomes due to structural racism.

BAME communities were not born not trusting the healthcare system – but their experiences of racism led to their lack of trust (Broder-Fingert, 2020). The parents with autistic children from the BAME communities feel that their cultural, ethnic and religious sensitivities are essential but ignored by non-BAME professionals (Kandeh et al., 2020). There is a potential of confusing symptoms with cultural differences e.g. cultural differences in the use of eye contact.

Socioeconomic, racial and ethnic disparities
There is no diagnostic tool that considers the different social and cultural drives that exist in the BAME communities. While autism is diagnosed based on observing how the child talks and acts compared to other children of the same age, the goal post is the same for a refugee child whose first language is not English, and a white child born in the white and affluent communities. During diagnoses, autistic children from BAME backgrounds are challenged, at least, from four dimensions: communication, social skills, behavioural repertoires, and culture (Dyches, 2004). The dearth of bilingual or culturally competent medical and clinical autism professionals presents a challenge with autism assessment (Kapp, 2012).

Recommendations
· Society must address structural drivers of inequities, such as racism and associated barriers to equitable care in autism diagnosis and research.
· A key research priority is to include culturally diverse populations in autism research and practice.
· It is vital to carry out research focusing on the suitability of autism diagnostic tools when used in BAME communities in order to ascertain and gain correct data on autism. Inexpensive and culturally sensitive diagnostic tools are necessary to enable BAME families with autistic children to seek early support and intervention.
· Broder-Fingert (2020) advise that teaching hospitals and universities should do more to recruit and retain psychiatrists, psychologists, developmental paediatricians and neurologists from the BAME communities. However, to have a more significant multilingual workforce and capacity to diagnose autism, we must expand on who can diagnose autism.
· More so, cultural factors influencing autism diagnoses in various ethnic groups should be studied more carefully, the relationship between ethnicity and misdiagnosis needs more attention, and a provision of increased services used by BAME communities (Kawa, 2016).
· Call for more autism health workers to get drawn from teachers, social workers, and nurses from the BAME communities.
· Corbett and Corbett (2007) suggested that autism services must be accessible, raise autism awareness to families from all ethnic backgrounds and research should be needed to highlight the prevalence rates and the impact of culture on the diagnostic tools.
· Autism resources, including information packs, should be accessible in different languages other than English, and privately funded projects to raise autism awareness in BAME communities should be rolled nationally.