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Autism spectrum disorders in sub-Saharan Africa

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Autism spectrum disorder is one of the most prevalent neurodevelopmental disorders in high-income countries, but little is known about the disorder in low-income and middle-income regions, such as Africa.^{1,2} A review³ of the global prevalence of autism did not identify any data from sub-Saharan Africa, even though this region has a population of nearly 1 billion, 40% of whom are children younger than 14 years. Although public-health emphasis in sub-Saharan Africa has been on communicable conditions such as HIV, malaria, and tuberculosis,⁴ with the reduction in childhood mortality rates in the past 20 years, non-communicable diseases (particularly, neurodevelopmental disorders) are likely to become a greater health burden in these countries.⁴ Studies on autism and other neurodevelopmental disorders in Africa are urgently needed.

One major barrier to research and management of autism has been the scarcity of validated tools in Africa. Well established standardised tools for autism spectrum disorder (eg, the Autism Diagnostic Observational Schedule) have contributed to knowledge about autism in high-income countries.¹ However, use of these tools in Africa poses major challenges in terms of cultural appropriateness, cost of translations and adaptations, and copyright-related costs.² Additionally, although awareness of autism is increasing in low-income and middle-income countries,⁵ substantial challenges arising from limited awareness in many communities in sub-Saharan Africa remain, especially in families living in rural areas. Without awareness, families might not seek or be referred to appropriately skilled staff for a comprehensive assessment and diagnosis. Inadequacies in the education sector, such as poor knowledge and awareness about autism and scarcity of inclusive curricula pose similar challenges.

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Early studies suggested that autism could be a culturally bound disorder, and that autism spectrum disorder might be rare in regions such as sub-Saharan Africa. In the 1970s, Lotter⁶, a psychiatrist, identified nine children with autism in hospitals in six African countries. Subsequently case reports of autism from Kenya, Zimbabwe, Nigeria, and Ghana have been reported. Given the sheer number of African children, an estimate of the burden of neurodevelopmental disorders, including autism spectrum disorder, is needed.

Evidence from immigration studies suggests that autism could be common in Africa. Initial studies of women who migrated from Somalia to Sweden reported the frequency of autism in their children as three or four times that of children born to Swedish mothers.⁷ Various risk factors thought to be associated with immigration might predispose these children to autism spectrum disorder (eg, low vitamin D concentrations in immigrants with dark skin in places with low sun levels or perinatal infections in mothers) though the evidence for most of the hypothesised pathways is weak. Until such data are collected, factors inherent in the immigration process cannot be confirmed to contribute to increased prevalence of autism.

Autism spectrum disorder is a highly heritable neurodevelopmental disorder.⁸ More than 100 genetic polymorphisms have been associated with autism spectrum disorder,^{9,10} although many have not been replicated. Africa has greater genetic diversity than any other continent¹¹ and genetic studies of autism in Africa could provide unique insights to the pathogenesis of the disorder and into gene–environment interactions. Environmental risk factors for autism are poorly understood, but the incidence of the risk factors associated with autism in high-income countries, such as pre-eclampsia, placental insufficiency, prolonged labour, induced labour, birth asphyxia, pre-term birth, and low birthweight¹² are common in Africa.

Progress and development are needed at multiple levels and involvement from various stakeholders is required.

Awareness about autism spectrum disorder should be urgently increased, which needs partnerships between parent-support groups, not-for-profit organisations, private sector, governments, international autism organisations, media, WHO, and funders, such as National Institutes of Health and the Wellcome Trust. Programmes such as the Autism Speaks Global Autism Public Health⁵ initiative that have expanded to sub-Saharan Africa could play an important role in bridging the gap in Africa.

With awareness comes advocacy. The increasing number of parent, user, and carer groups in Africa is encouraging. However, these groups are still few and where they exist, many prioritise supporting individuals and families in local communities rather than building national and continental advocacy. Access to research and materials is being promoted through websites, but internet access is still limited in some rural areas of Africa. Harnessing more accessible technological platforms such as mobile phones could provide lasting solutions.

For examples of websites see <https://grand.tghn.org/> and <http://aut2know.co.za/>

Education and training clearly link awareness and advocacy. The goal should be to embed training in autism into health-care and social-care education to increase the knowledge and expertise across the continent. Development of appropriate educational services for children with autism in Africa is urgently needed.

Research on autism in Africa should be strengthened: development and validation of screening and diagnostic tools are key. Thereafter, epidemiological research is needed to assess the burden of autism spectrum disorder and define the clinical features of the disorder in Africa.

We have an ethical duty to develop post-diagnostic interventions—from psychoeducation, to community-based and specialist programmes. Linking educational, health-care, and social-care systems to generate coordinated knowledge, policies, and plans would ensure efficacy and cost-effectiveness of the programmes—an important consideration in resource-poor settings.

The needs of Africa are substantial, but the world has much to learn from Africa in terms of the interplay between nature and nurture in the pathway to autism spectrum disorder and neurodevelopmental disorders, and in finding creative ways to meet the needs of individuals and families in low-cost, high-impact ways.

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