



# Exploring the landscape of autism in Africa: challenges in diagnosis, support, and resources – a short communication

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## Introduction

Autism spectrum disorders (ASDs) represent enduring neurodevelopmental conditions characterized by impairments in social interaction, communication, behavior patterns, and activities. These multifaceted deficits significantly impact the quality of life for individuals with ASD and their families, necessitating lifelong support to ameliorate and manage core symptoms and concurrent disorders. Regrettably, the prevalence of ASD in Africa remains poorly documented, with a dearth of clinical symptomatology data on this continent<sup>[1]</sup>. Noteworthy research indicates an increasing incidence of ASD among immigrant populations of African descent, such as Somali children residing in Stockholm, non-Nordic-origin mothers in Sweden, and African mothers residing in the UK<sup>[2–4]</sup>. These findings underscore the urgency of epidemiological investigations in Africa, suggesting that the prevalence of ASD on the continent may exceed prior estimates. Stigmatization constitutes a formidable challenge for families with members afflicted by physical or mental disabilities. Studies conducted in the West African Coastal region have shed light on the stigma experienced by caregivers who have been prevented from attending church services due to

having a child with ASD. Caregivers in the Eastern African region have reported rejection by their communities and friends, and some have reported unwarranted accusations of spreading the condition within their neighborhoods. These manifestations of stigma stem from a pervasive lack of understanding surrounding ASD, with certain cultural beliefs attributing its occurrence to witchcraft, curses, or omens<sup>[5–7]</sup>. Children with ASD in Africa typically face delayed diagnosis and limited access to developmental support services. Many remain undetected and underserved, largely owing to their limited expressive language abilities and intellectual disabilities. This study underscores the multifaceted challenges confronting ASD children across various domains, spanning from diagnosis and support to resource availability and success stories, while also emphasizing the paramount importance of raising awareness about this critical issue with the goal of enhancing understanding and management for researchers, practitioners, and policymakers.

## Challenges in diagnosing autism in Africa

Facilitating timely diagnosis of autism is crucial to enhance the well-being of individuals with ASD, enabling prompt access to vital support and interventions. Numerous diagnostic instruments have been developed and validated within the purview of European nations and the United States<sup>[1]</sup>. These instruments are systematically employed in tandem to ensure the accurate identification of ASD and encompass the Social Communication Questionnaire (SCQ), Modified Checklist for Autism in Toddlers (M-CHAT), and Autism Diagnostic Interview-Revised (ADI-R)<sup>[8,9]</sup>. Furthermore, the Autism Diagnostic Observation Schedule-Generic (ADOS-G) stands as a recognized and high-caliber tool employed for ASD diagnosis<sup>[10]</sup>. Within the African context, diagnosing ASD presents distinct challenges arising from not only constrained diagnostic settings but also factors such as limited familiarity and adaptability with the aforementioned established diagnostic tools. A primary obstacle is the lack of awareness and knowledge regarding ASD within both the general population and healthcare professionals across Africa, partly due to limited research publications in this context. Cultural beliefs and stigma associated with autism in many African societies further hinder the identification and diagnosis of ASD, as it is often regarded as a spiritual ailment rather than a neurodevelopmental disability. Traditional healing practices are sought for quick remedies instead of recognizing the need for specialized medical care. The absence of adequately trained healthcare professionals, insufficient resources, and a dearth of diagnostic tools in low-income African countries contribute to limited

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diagnostic capabilities, ultimately restricting access to necessary services and support<sup>[11]</sup>. Addressing the challenges surrounding the diagnosis of autism is imperative to improve the quality of life and outcomes for individuals with autism, necessitating concerted efforts and interventions.

### **Support and resources for individuals with autism in Africa**

The International Child Neurology Association, on 3–5 April 2014, convened a pivotal meeting in Accra, Ghana, aimed at addressing the healthcare challenges faced by children within the ASD in Africa. The primary focus of this gathering was to foster collaboration and knowledge integration among stakeholders to advance the identification, diagnosis, and treatment of ASD across the African continent<sup>[11]</sup>. The overarching objective was to promote capacity-building and the dissemination of evidence-based management strategies for ASD within the framework of global health initiatives. Distinguished figures and authorities in the field of ASD were cordially invited from each African nation to participate in this landmark event. The conference drew participation from a diverse array of professionals, including pediatricians, pediatric neurologists, pediatric psychiatrists, psychologists, as well as speech and language therapists. Moreover, parents of children with ASD and representatives from advocacy groups were extended invitations, resulting in an assembly of over 47 attendees representing 14 African nations<sup>[11]</sup>. Key initiatives and strategies discussed at the conference: Early Intervention: Emphasis on culturally sensitive early intervention programs to identify and support children with ASD. Research Collaboration: Calls for cross-border research to understand regional trends in ASD diagnosis and management were made. Capacity Building: Implementation of training and education programs to build local expertise in ASD care was highlighted. Community Engagement: Tailored awareness campaigns to reduce stigma and increase understanding of ASD were initiated. Policy Advocacy: Advocacy for policy changes were proposed to ensure equitable access to services. Parental Support Networks: Strengthening support networks for parents of children with ASD.

### **Addressing the needs of individuals with autism in Africa**

Historically, in Africa, children were often classified based on racial and disability criteria during the era of apartheid. This classification regime was particularly influential in South Africa, giving rise to a specialized sector in education dedicated to individuals with disabilities, including those within the autism spectrum. Consequently, children with certain developmental challenges were often confined to a limited number of specialized schools tailored to their needs. Regrettably, owing to the profound communication and cognitive impairments often associated with ASD, many affected children have remained underserved, lacking access to essential interventions. These circumstances persist for various reasons, including the pervasive stigma attached to developmental disorders and the misperception that individuals with autism do not face life-threatening conditions<sup>[11]</sup>. Addressing this critical issue necessitates proactive measures, including concerted efforts by both parental and

professional advocacy groups. It is essential to garner support for initiatives aimed at fostering community awareness and dispelling the negative stereotypes and stigmatization surrounding ASDs through national-level programs.

Promoting heightened awareness and understanding of autism among medical professionals, parents, and the broader community is essential in Africa. This encompasses developing a comprehensive understanding of the clinical manifestations of autism and emphasizing the significance of timely diagnosis and the provision of accessible services. Presently, there exists the potential for early detection of autism in children, underscoring the importance of raising awareness. Adequate awareness is crucial for ensuring appropriate care, enhancing prognosis, and facilitating the integration of individuals with autism as valued and impactful members of society<sup>[12]</sup>.

Capacity building for healthcare professionals and educational initiatives play a pivotal role in promoting and advocating for autism-related matters. A key objective is to integrate the concept of autism into healthcare and community training programs, equipping individuals with the requisite knowledge and experience. Enhancing accessibility to early diagnostic services and comprehensive care for individuals with autism in Africa emerges as a matter of utmost significance. It is imperative to bolster scientific research efforts concerning autism across the continent, with the primary aim of developing and establishing widely accepted diagnostic tools. In line with the World Health Organization's guidance, facilitating timely access to evidence-based psychosocial interventions holds the potential to enhance communication skills and social behaviors in children with autism<sup>[13]</sup> (Fig. 1).

### **Success stories and best practices in Africa**

Individuals with autism have the potential to experience a significantly improved quality of life, and Ethiopia serves as a compelling example of this progress. Notably, the nation's autism-related initiatives, spearheaded by organizations such as CBM (formerly known as Christian Blind Mission) and Cheshire Services Ethiopia, exemplify transformative community interventions<sup>[14]</sup>. These programs owe their remarkable success to their community-centric, grassroots approach, extending their reach far beyond urban centers. They have effectively bridged the gap between mental health experts and the broader Ethiopian community, ensuring that their influence extends even to remote rural areas. Consequently, these organizations have adeptly identified and referred children with autism for appropriate interventions while simultaneously empowering community members through comprehensive training, enabling them to administer community-based rehabilitation initiatives.

To further advance autism care across the African continent, two strategic approaches have been proposed. The first strategy underscores the establishment of 'satellite centers' in rural towns, serving as pivotal hubs for raising awareness and delivering crucial interventions. The second strategy underscores the critical importance of directing children with autism to specialist centers rather than mainstream schools, ensuring that they receive the specialized care and support tailored to their unique needs<sup>[14]</sup>. The success stories and best practices in addressing autism in Africa, as exemplified by Ethiopia's initiatives, offer valuable insights into the potential for transformative change. While

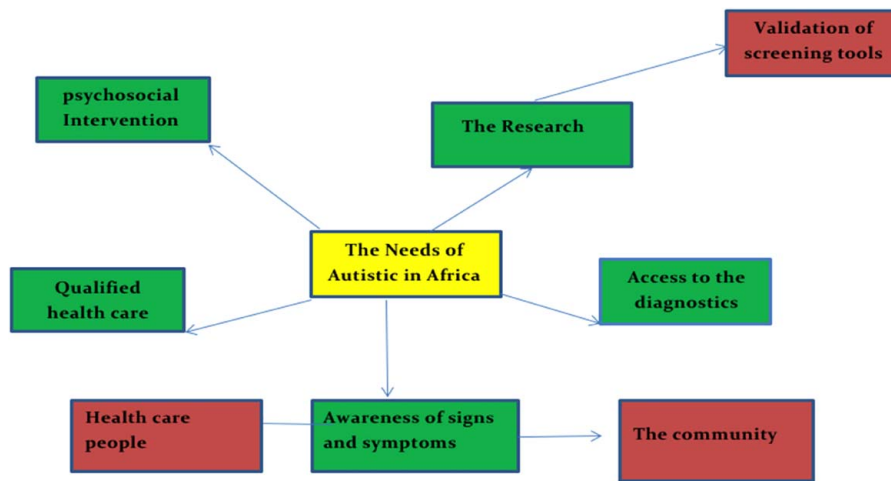


Figure 1. The needs of autistic in Africa.

progress has been made, there is a continued need for increased awareness, expanded diagnostic services, and more inclusive educational approaches to ensure that every child with autism has the opportunity to thrive (Fig. 2).

**Collaborative efforts and partnerships**

In order to enhance awareness and understanding of ASD, it is imperative for international organizations and partner agencies to actively engage in supporting national initiatives addressing ASD challenges in African countries. Notably, international organizations such as the World Health Organization (WHO), the United Nations (UN), UNICEF (United Nations Children’s Fund), and other entities collaborate closely with local autism communities. Through strategic partnerships, African nations can leverage the expertise and resources provided by these international autism agencies to advance awareness and understanding of ASD. This collaborative approach aims to improve outcomes by fostering the training of skilled healthcare professionals, supporting research endeavors related to autism, and facilitating the provision of essential treatments and services for individuals with ASD<sup>[15,16]</sup>.

**Conclusion**

Raising awareness about autism, while undoubtedly significant, represents only a preliminary step in effecting meaningful change. To achieve lasting and impactful transformation, it is imperative that policymakers, stakeholders, healthcare professionals, and society as a whole make a sustained commitment. This commitment should involve active engagement with grassroots campaigns and public health initiatives, coupled with the establishment of robust support networks and the provision of guidance to families grappling with autism. Such a comprehensive approach is designed to nurture enduring efforts aimed at generating positive outcomes for individuals with autism. In the pursuit of ensuring equitable access for individuals with autism in Africa, it is crucial to transcend the confines of mere employment and education and, instead, strive to cultivate an inclusive society. This necessitates the expansion of capacity-building endeavors beyond educational institutions, manifesting in the form of workshops and similar initiatives. By actively confronting the challenges that individuals with autism encounter, we can foster a sense of unity within African society, uniting for a common and constructive purpose.

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**Autism Initiatives in Africa**

Name of Initiative	Location	Founding Year
Orange Ribbon initiative	Nigeria	2014
Global Autism Public Health (GAPH) Initiative	Albania	2008
Christian Blind Mission (CBM)	Ethiopia	Unclear
Cheshire Services Ethiopia	Ethiopia	1962

Figure 2. Initiatives taken in various member states of Africa and their respective names and founding years.

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