

# Autism Spectrum Disorders in Africa: Current Challenges in Identification, Assessment, and Treatment: A Report on the International Child Neurology Association Meeting on ASD in Africa, Ghana, April 3-5, 2014

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## Abstract

Prevalence of autism spectrum disorders has increased over recent years, however, little is known about the identification and management of autism spectrum disorder in Africa. This report summarizes a workshop on autism spectrum disorder in Africa under the auspices of the International Child Neurology Association and the African Child Neurology Association through guided presentations and working group reports, focusing on identification, diagnosis, management, and community support. A total of 47 delegates participated from 14 African countries. Although there was a huge variability in services across the countries represented, numbers of specialists assessing and managing autism spectrum disorder was small relative to populations served. Strategies were proposed to improve identification, diagnosis, management and support delivery for individuals with autism spectrum disorder across Africa in these culturally diverse, low-resource settings. Emphasis on raising public awareness through community engagement and improving access to information and training in autism spectrum disorder. Special considerations for the cultural, linguistic, and socioeconomic factors within Africa are discussed.

## Keywords

autism spectrum disorder, autism, intellectual disability, international child neurology association, Africa, public awareness

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## Background

Autism spectrum disorders are life-long neurodevelopmental disorders characterized by impairments in social interaction and communication and restricted patterns of behavior, interests and activities, with onset in the first 3 years of life.<sup>1</sup> The global prevalence of autism spectrum disorder is reported to be increasing,<sup>2,3</sup> with the most recent estimates for the United States indicating that 1 in every 68 children who are 8 years of age have some form of autism spectrum disorder (<http://www.cdc.gov/features/dsautismdata/index.html>). However, little is known on the prevalence of autism spectrum disorder in Africa and details of clinical presentations of this disorder remain elusive for this region.<sup>2</sup>

The main goals of this workshop were to analyze the current state of autism spectrum disorder detection, diagnosis and treatment in sub-Saharan Africa. Another goal was to provide an opportunity for highly motivated professionals and lay advocacy groups to return to their countries more equipped to target key needs in the management of children with autism spectrum disorder. An ongoing priority is to collect further data to improve the identification, diagnosis and treatment of autism spectrum disorder in Africa. This is being collated by a working group of meeting participants focused on targeting health issues for children with autism spectrum disorder and the integration of research questions. An ASD Network of Africa has been established (<https://grand.tghn.org/>) since this workshop. The aims are to facilitate building capacity and the dissemination of autism spectrum disorder management recommendations within a global health framework. The network is open to all (including diaspora communities) interested in autism spectrum disorder.

## Review of Current Literature on Autism Spectrum Disorder in Africa

Autism spectrum disorder was previously perceived and documented to occur only in the well-resourced countries with high technological development. A few decades ago, some questioned the universality of autism spectrum disorder.<sup>4</sup> There has since been evidence of an increase in the prevalence of autism spectrum disorder and knowledge about the disorder in other parts of the world.<sup>5</sup> However, there remains a major gap in what is known about the global burden of autism spectrum disorder, in particular little is known about autism spectrum disorder in Africa.

Bakare and Munir<sup>6</sup> conducted a literature review of autism spectrum disorder in Africa. They found 12 relevant articles, but only 2 reviewed epidemiological data. The 12 publications were broad studies of autism spectrum disorder including reports of African immigrants in Sweden<sup>7,8</sup> and a study of 9 Arabic speaking countries, which included data from Tunisia and Egypt.<sup>9</sup> In their review, Bakare and Munir<sup>10</sup> reported that children with autism spectrum disorder in Africa were diagnosed relatively late compared to those in high-income countries. The age of diagnosis was reported to

range from 8 years through to adolescence. Moreover, 2 of these studies revealed that over half of children with autism spectrum disorder in their cohorts did not have any expressive language and/or had severe intellectual disability,<sup>11,12</sup> which may indicate that only the more impaired cases were identified. This delay in diagnosis may also contribute to the lack of appropriate language skills in many of the children with autism spectrum disorder, in part because they did not have access to early interventions. One of the major practical as well as ethical difficulties in identifying children with autism spectrum disorder in Africa lies in the general lack of appropriate services and inadequate standard of available educational and medical infrastructures.<sup>13</sup>

The lack of awareness of autism spectrum disorder was not only apparent in the general population in Africa, but also among the medical community.<sup>14</sup> In a survey by Bakare for his workshop presentation, psychiatrists and pediatricians in Nigeria were asked about the causes of Autism. Many regarded autism spectrum disorder to have supernatural causes precipitated by angered ancestral spirits, sinful wrongdoing, predominantly by the mother, or the action of the devil. They reported that it is a common pathway in Africa for a child with a neurodevelopmental disorder to be taken first to a traditional healer, before a parent seeks mainstream medical assistance. This potential delay in seeking mainstream medical assistance may contribute to a late diagnosis and could be a further exacerbating factor in the more severe cognitive and expressive language outcomes reported in children with autism spectrum disorder. These findings highlight a need for earlier recognition and diagnosis of autism spectrum disorder in Africa. Although in well-resourced countries there are many "gold-standard" tools available to screen and diagnose autism spectrum disorder, there are no available validated tools from Africa. The perception of abnormal behavior may be mediated by culture, and screening measures need to take into account contextual factors.

Although major global advances in understanding the genetic and developmental aspects of autism spectrum disorder have been made, many aspects of the condition are still poorly understood. More specifically, there is no research to date exploring risk factors for autism spectrum disorder in Africa. There are reports of increased prevalence of autism spectrum disorder in children of Somali origin living in Stockholm,<sup>8</sup> maternal birth outside the Nordic countries living in Sweden,<sup>15</sup> and mothers of African origin living in the United Kingdom.<sup>16</sup> These findings suggest that autism spectrum disorder in Africa may be more common than is recognized and emphasize the need for epidemiological research in Africa.

## Methods

Meeting participants were invited to include key leaders and experts in autism spectrum disorder in their countries. Professional participants included pediatricians, pediatric neurologists, pediatric psychiatrists, psychologists, and speech and language therapists. In addition, leaders of advocacy groups and parents of children with autism spectrum



**Figure 1.** Portrait of delegates to autism in Africa meeting, Ghana, April 3-5, 2014.

disorder were invited to participate. Over 47 participants from 14 African countries attended (Figure 1, Table 1).

### Data Collection

First, a representative from each of the countries was chosen to present information regarding infrastructure and practice (Figure 2). Each presenter was asked to include information regarding awareness, professional capacity, screening and diagnostic procedures, and clinical and educational services. Second, the participants were divided in 4 focus groups to identify areas of need for future research and development: (1) identifying children with autism spectrum disorder in Africa, (2) diagnosis of autism spectrum disorder in Africa, (3) management of autism in Africa, (4) supporting groups for families with individuals with autism spectrum disorder in Africa. Focus groups reported discussions to the entire group and set goals for next steps.

The program and lectures of the meeting can be accessed from the web: <http://icnappedia.org/ASD-in-africa>.

## Results

### Country Presentation Information

Each country representative was asked to present a summary of information relating to care services, diagnostic procedures, availability of trained personnel, and challenges faced (Table 1). Although there was a wide range in numbers of providers and services available in each of the countries represented, the numbers of pediatricians and specialists for

assessing and treating autism spectrum disorder was small compared to the population being served. Seven of the 14 country representatives reported the presence of support organizations. The representatives from most of the countries were not aware of whether there were speech and languages services or special school programs available in their countries.

The main themes which emerged from discussions related to stigma, care provision, screening and diagnostic measures. Families and individuals with autism spectrum disorder struggle with the negative stigma associated with autism spectrum disorder, and the need to address this through community engagement was frequently noted.

Pathways to care for children with autism spectrum disorder in the African setting are often different to their counterparts in well-resourced environments. The role of traditional healers was raised as they are often the first point of contact for parents of children with disabilities in many African settings. Their role in providing psychosocial support for the children and their families was discussed, and suggestions were made about including their support in the management of autism spectrum disorder.

The lack of validated screening measures, diagnostic tools, and strategies to provide clinical care which is effective but realistic within resource-limited settings in Africa was emphasized. The presentations also highlighted the lack of comprehensive services for autism spectrum disorder (or in fact any neurodisability). The ratio of specialists with expertise in



**Table 1.** Demographics and Professional Services Available by Country, Presented at the April 2014 International Child Neurology meeting.<sup>1</sup> The Information Presented in this Table is Not Based on Rigorous Epidemiological Data and Therefore may not be an Accurate Representation. Delegates Participating in the Conference Gathered the Data Informally, from Secondary Resources.

Country	Number of specialists dealing with ASD									
	Population estimate end 2012 (% under 14 years)	Support for people with ASD/diagnostic tools used	Pediatricians per 100 000 population	Pediatric neurologists (total)	Psychiatrists per 100 000 population	Clinical psychologists	Speech and language therapists	Special schools catering to ASD	Support organizations	
Benin* Democratic Republic of Congo*	10 050 702 (44%) 77 433 744 (46%)	None None	0.5 0.07	0 2	10 (total) or 0.1 ± 40 neuropsychiatrists (99% Kinshasa based) 0.05	20 NK	NK NK	NK NK	NK Some exist	
Ethiopia* Ghana*	91 728 849 (44%) 25 366 462 (38.7%)	Limited None	0.35 0.26	1 2	0.02 8 (total) or 0.06	NK 110 clinical psychologists (not all in Kenya)	NK 8	NK 4	4 types, most in Addis 4	
Kenya*	43 178 141 (42.4%)	None	0.6	5	4 pediatric 70 general 0.1	8	NK	Est 4	2	
Malawi*	15 906 483 (45%)	Limited	0.1	1	2 (total) or 0.006	1 (in private care)	1 occupational therapist 1 speech therapist (technician in private)	NK	NK	
Mozambique*	25 203 395 (45.5%)	Limited	70 (total) or 0.3	1 10 adult neurologists	13 128 psychiatric technicians 0.05	72	NK	NK	NK	
Nigeria*	168 833 766 (43.8%)	Limited	0.29	30	220 (total) or 0.09	Total unknown 3 qualified	NK	NK	NK	
Rwanda*	12 012 589 (42.3%)	Limited	26 (total) or 0.25	0	8 (total) or 0.08	NK	NK	NK	NK	
South Africa*	51 189 307 (28.3%)	Limited	1188 (total) <sup>^</sup> or 2.32	50 <sup>#</sup>	NK	7640 <sup>\$\$</sup>	2191 <sup>^</sup>	Approx 26 organizations started by parents	4 (nonprofit organizations started by parents)	
Sudan*	30 894 000 (41.4%)	Limited	0.17	None 38 adult neurologists	136 (total) or 0.4	NK	NK	8	NK	
Tanzania* Uganda*	47 783 107 (44.8%) 35 400 000 (48.9%)	Limited Limited	0.17 230 (total) or 0.45	5 3	20 (total) or 0.03 0.09	3 clinical NK	NK NK	NK NK	1 NK	
Zimbabwe*	13 061 239 (39.4%)	Limited	0.3	1	8 (total) or 0.1	7	NK	NK	2 (parent-based trusts)	

Abbreviation: NK, not known.

<sup>1</sup>Information obtained from presentations at the International Child Neurology Association meeting on autism spectrum disorder in Africa, Ghana, April 3-5, 2014.

<sup>2</sup>Information obtained from the Health Professionals Council of South Africa.

<sup>3</sup>This value includes both pediatric neurologists and developmentalists.

<sup>4</sup>This value includes all categories of psychologists.

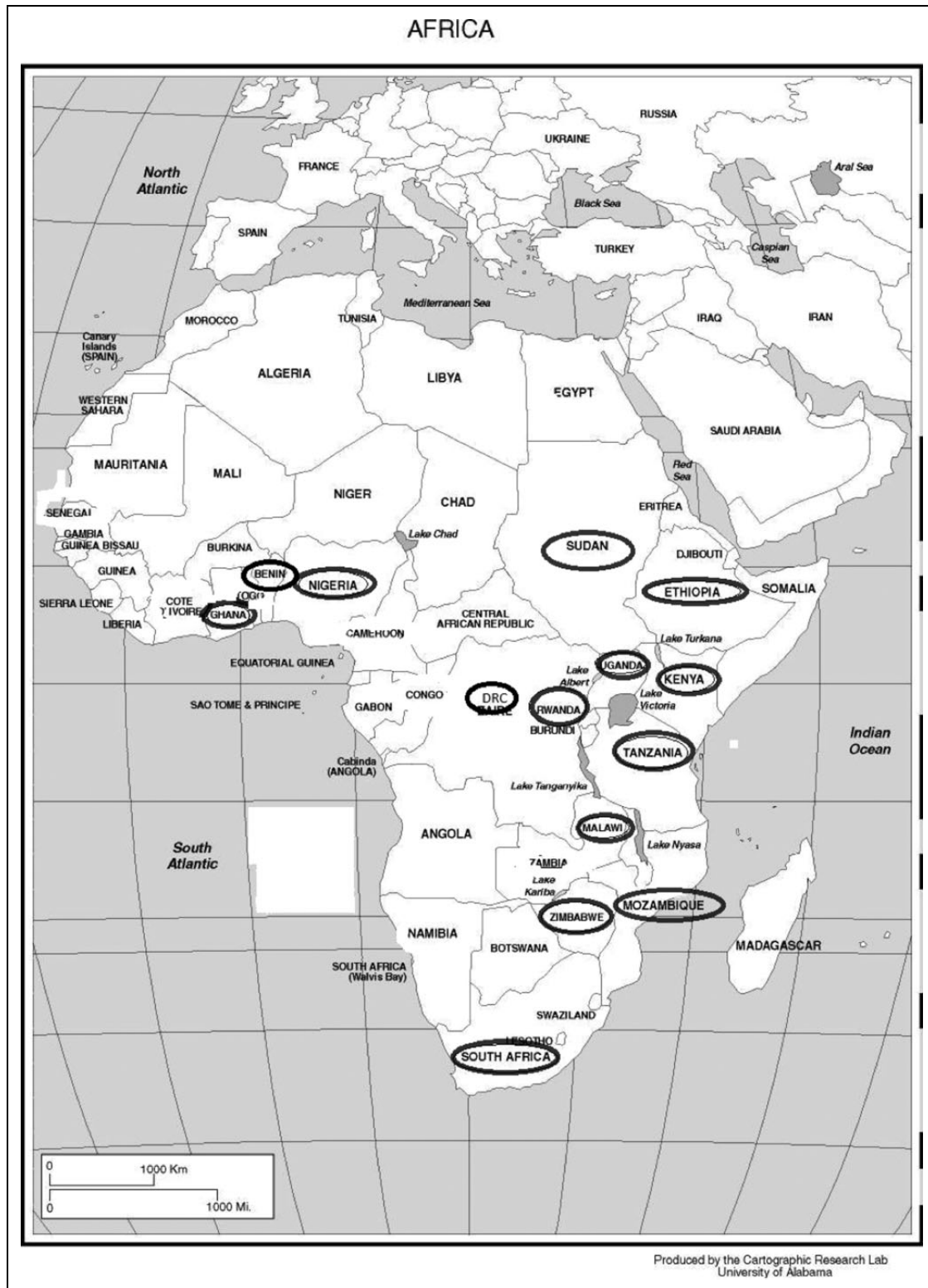


Figure 2. Map of Africa with countries represented at autism in Africa meeting circled.

autism spectrum disorder to the population is very low or nonexistent, not only for the diagnosis, but also for the management of autism spectrum disorder. There is an urgent need

for professionals and caregivers to have access to knowledge and training. Training resources in Africa are scarce and the migration of the skilled workforce is an ongoing challenge.

However training programs are becoming more established on the continent. These programs are relevant to developing the specific skills needed to practice in the African setting. The African Pediatric Fellowship Program is coordinated in such a way that staff retention is more likely since the training is undertaken as part of service development and the health practitioners return to an established, or an establishing, system. "To date most training has focused on doctors and nurses, but this training cycle is introducing skill exposure for ancillary care in the form of short courses and on-site training" (<http://www.scah.uct.ac.za/scah/apfp>).

Finally research activity is also very limited as a result of lack of funding and too few researchers. This may be the result of a focus on conditions, particularly infectious diseases that are associated with mortality, rather than noncommunicable conditions. The importance of research funding and collaborative efforts to raise awareness, training, and services across Africa was emphasized.

## Recommendations From Group Discussions

A summary of recommendations is set out below, and timelines have been established to facilitate progress toward meeting objectives in each category.

### Identifying Children With Autism Spectrum Disorder in Africa

Key points discussed were the need to ensure that the process of identification of children with autism spectrum disorder is embedded within existing services across Africa, and also within the context of other neurodevelopmental disorders, many of which are common in Africa. Identification needs to be multisectorial (including education, health, and public awareness) with screening and engagement occurring in 3 different settings: community, health care services, and schools.

**Community.** Within the community, there are notable rural and urban disparities. Recommendations for identification in a rural setting would involve a participatory approach, intensive community engagement, a basic visual developmental milestone checklist, and establishing advocacy groups to raise awareness of autism spectrum disorder. The approach for children with autism spectrum disorder in an urban setting in Africa may have to differ to rural environments, as urban families have exposure to more media, for instance, TV, radio advertisements, and billboards.

**Health Care Services.** Given the lack of awareness, baseline screening tools and referral systems in the African context, it was established that there is an immediate need for a coordinated effort to develop a concise and simple developmental and monitoring screening tool. This will be a supplement tool to be introduced alongside the existing health care services across Africa and would include key autism spectrum disorder indicators. It could be tailored to an age of convenience,

during the child's visit for immunization at 18 months. The tool would aim to screen and monitor development at that age. There was compelling evidence to suggest that the public, parents and professionals needed basic knowledge about child development and autism spectrum disorder to help identify children with autism spectrum disorder. Furthermore, it was recommended that health talks include the awareness of developmental milestones. Also it is imperative that regional databases for early childhood services be established to make appropriate referrals.

**Schools.** At school level, it was emphasized that education service providers require basic knowledge of autism spectrum disorder, not only to manage the challenging behaviors, and to identify children with autism spectrum disorder. Appropriate training would help educators to take into account the individual needs of a child with autism spectrum disorder, to address negative attitudes and bullying of those with autism spectrum disorder in the school environment. Recommendations include a brief screening tool that is general with specific autism spectrum disorder indicators to be used in schools. Parents would then have access to regional databases for early childhood services should a concern be raised. The potential for further social isolation even harm to children and families of identifying without appropriate service provision in place was highlighted.

### Diagnosis of Autism Spectrum Disorder in Africa

Key points discussed were aimed at addressing issues on how best to diagnose autism spectrum disorder in Africa, to include identifying criteria, tools for diagnosis and maintaining diagnostic standards throughout the process. These discussions were based on the foundations of health care systems across Africa, and the following points were raised: (1) criteria for diagnosis, (2) challenges with diagnosis, (3) who makes the diagnosis? (4) what tools to use for diagnosis?

**Criteria for Autism Spectrum Disorder Diagnosis.** To make a diagnosis of autism spectrum disorder, a child suspected of having autism spectrum disorder should preferably be referred to a specialist for assessment. Development of tools that can be used in busy clinics in low-resource settings is needed. These tools should be free and widely distributed. Aids to this process could include the use of drawings or videos showing autism spectrum disorder symptoms on smart phones, as well as a developmental milestone checklist to observe children suspected to have autism spectrum disorder.

**Challenges With Diagnosis.** The challenges with identifying and subsequently diagnosing a child with autism spectrum disorder include improving the awareness among the public and health care personnel, so that the pathway to diagnosis and care can be expedited. Given that the majority of the African population lives in poorly resourced settings with a significant lack of professional manpower at all levels, leading to a high patient load, lack of appointments, shorter consultations and lack of other basic

**Table 2.** Suggested Pathway to Diagnosis in Africa.

Level	Where	Who	Available tools that may potentially be useful
Primary	Home	Community health workers	MCHAT <sup>17</sup>
	Nursery	Parents	
	School Primary clinic	Teachers Nurses	
Secondary	District hospital	Medical officer	ICD 11 DSM-5 RITA_T <sup>18</sup>
	Provincial hospital	Pediatrician Psychiatrist	
Tertiary	Central hospital	Pediatric neurologist	3Di <sup>19</sup>
	Research centers	Child psychiatrist	ADOS <sup>20</sup>
		Psychologist	CARS <sup>21</sup>

Abbreviations: ADOS, Autism Diagnostic Observation Schedule; CARS, Childhood Autism Rating Scale; *DSM-5*, *Diagnostic and Statistical Manual of Mental Disorders*; ICD 11, The International Classification of Diseases 11th version; RITA\_T, Rapid Intervention Screening Test for Autism in Toddlers; 3Di, The developmental, dimensional and diagnostic interview; MCHAT, Modified Checklist for Autism in Toddlers.

resources, the role of professional training, and need for culturally and linguistically relevant tools was greatly emphasized.

**Who Makes Diagnosis?** It was recommended that **clinicians who are familiar with the diagnostic process of autism spectrum disorder would be the primary point of diagnosis**. For this to occur, however, it is essential to have professional training in place, **ideally a multidisciplinary team**. However, given the limited resources, **regional experts might be identified as a starting point toward the development of comprehensive multidisciplinary teams**. Building human resource capacity that engages the role of the teacher, nurse, medical practitioner, speech therapist, community worker, and psychologist would provide for a better service infrastructure for autism spectrum disorder within any health care system in Africa.

**Tools for Diagnosis.** Table 2 outlines a strategy designed through group discussion as a way to establish a pathway to diagnosis with potential tools that can be adapted in Africa. **Almost all the tools identified were developed and validated in the United States and Western Europe**. The challenges of transferring and adapting Western tools to diagnose autism spectrum disorder in Africa were noted. Specifically that some of these measures may be inappropriate for use in Africa due to unfamiliarity of tasks and stimuli materials for children growing up in Africa, especially those in rural settings. The authors use example of tasks from the **Autism Diagnostic Observational Schedule** as that is the tool that a few groups in Africa have started piloting to illustrate this point. The authors' experience indicates that some of the items in the scale may lead to bias during the assessment process. For instance, while possessing a bathroom sink (one of the tasks used to probe communication skills in the

Autism Diagnostic Observation Schedule evaluations) is common in many homes in Western Europe and North America, for many poor Africa families this is unlikely to exist. Children from many poor rural settings in Africa are more likely to use buckets or jugs of water for cleaning and washing purposes. Therefore children from the low SES group who are made to perform this task are likely to be doubly disadvantaged by the lack to familiarity with the stimulus materials.

Previous research in cross-cultural assessment clearly shows that stimulus unfamiliarity is likely to contribute to poor performance in tests.<sup>22</sup> Reading is yet another example of task that may lead to bias. Some cultures such as the African cultures are largely oral. **Therefore children may grow up with very limited access or familiarity to picture books;**<sup>23</sup> **if requested to participate in this task and they perform poorly, teachers may not be sure if the poor performance reflects their ability levels or their lack of familiarity with the task.**

The low literacy levels of participants and lack of adequate background training for professionals may pose additional challenges to using these measures in the African context. Further the cost of these 'gold-standard' tools are significant, and the urgent need to develop open-source tools that are readily available, sustainable and suitable for Africa was emphasized. In addition, many of the tests can take several hours to administer, further stressing limited resources. An innovative new test that takes only 10 minutes to administer was recently reported for assessment of autism spectrum disorder.<sup>18</sup> Adaptation of this open-source tool may aid in access of autism spectrum disorder diagnoses for larger numbers of children at earlier ages.

### Treatment of Autism Spectrum Disorder in Africa

Key points discussed were short- and long-term plans for training professionals and parents in evidence-based behavioral treatments for the management of autism spectrum disorder in Africa. Very limited resources are available, if any at all. There are **few therapists available. If identification and diagnostic strategies are to be refined, there is concurrent responsibility to ensure that there is adequate knowledge, capacity, and service provision for the treatment of children with autism spectrum disorder in Africa.**

Emphasis on briefing during diagnosis was discussed as a starting point leading to the need for education training for parents as the next step to management goals. In addition, applying behavioral intervention programs such as Applied Behavioral Analysis in the African context was considered. However many of these programs required intensive therapy, with frequent sessions (often many times per week), administered by specifically trained therapists on an one-to-one basis; and thus in their present format are unlikely to be practical or sustainable in Africa. Programs such Stepping-Stone Triple-P,<sup>24</sup> which are less intense yet still based on behavioral principals, may be more flexible and might be more easily scaled up were also discussed. Both these techniques emphasize the training of the parents/caregivers and families in the



management of autism spectrum disorder. It was agreed that the basic need was to establish parent support groups and initiate parent-based interventions taking into account contextual factors. Another effective intervention discussed was Motivational Interviewing used as a method of communication and counseling for families affected by autism spectrum disorder.<sup>25</sup> Training for all these interventions is essential and suggestions were made for how to best disseminate these techniques across Africa. The development of course work in existing college programs and a train the trainer model were discussed.

Recommendations were made to assess current treatment systems in place in each country/institution and to facilitate collaborative training within Africa. The importance of advocacy and buy-in of services at national government policy level were emphasized, especially for sustainability. Parent support and involvement in policy implementation is also of high importance.

### *Supporting Advocacy Groups for Families With Individuals With Autism Spectrum Disorder in Africa*

Through discussion, it was recognized that peer support and counseling for families affected by autism spectrum disorder were crucial for effective management and understanding of autism spectrum disorder. In particular, psychoeducation of parents about autism spectrum disorder and what they can expect from their children with special needs both in the short and longer terms may be most helpful. The briefing process during diagnosis was highlighted with the need for ongoing support for families, as well as practical assistance such as respite care. The training of parents as primary caregivers was considered to be of great importance as a first step to accepting the condition and understanding their short- and long-term needs. Furthermore, a recent study showed that receiving greater than 20 hours of parent-implemented intervention before age 3 years was also associated with attainment of daily living skills in young adults with autism spectrum disorder.<sup>26</sup>

It is recommended that advocacy groups of parents and professionals persuade governments and lobby for legislations to develop appropriate policies for autism spectrum disorder. Through such national strategies, support should be achieved for raising community awareness to tackle negative stigma.

### **Conclusions**

Children with autism spectrum disorder in Africa present later than in more resourced environments and have less access to appropriate developmental support services. It is likely that as most children identified with autism spectrum disorder have very little expressive language and intellectual disability, many children likely remain undiagnosed and without the necessary support. This is due to a number of factors, including perceived stigma around developmental disabilities and the fact that those affected are believed not to have a “medical” (or life-threatening) condition.

The meeting highlighted the need to improve the recognition and acceptance of autism spectrum disorder in communities across the African continent. This included addressing the potentially treatable comorbidities. Establishing services and improving awareness for families of children with autism spectrum disorder will require creative approaches to challenge stigmatization. Initiatives should have the support of national governments and their respective ministries of health and education, to include these authorities at a regional level. Developmental support services should be endorsed by policy makers and those responsible for funding allocations. These initiatives need to partner with nongovernmental organizations, parent support groups and those at home or abroad activity engaged in improving support for children with autism spectrum disorder. This will require firm commitment across many sectors.

The main outcomes of the meeting endorsed collaborative action to raise awareness, develop screening, training and service strategies for autism spectrum disorder in Africa. A virtual autism spectrum disorder Network of Africa has been established (<https://grand.tghn.org/>), to share information and offering a forum for ongoing dialogue. This network is open to all (including diaspora communities) interested in autism spectrum disorder. Further meetings sponsored by Autism Speaks and other organizations will follow. There is an urgent need to increase the awareness of autism spectrum disorder in Africa, within the context of other neurodevelopmental disorders.

### **Author Contributions**

KR drafted first draft of the manuscript. EB and JMW assisted with organization of the workshop and contributed to the manuscript. AA, MB, DCC, HTC, AS, KV, and DS assisted with data contributions, played key roles in the workshop, and critically reviewed the manuscript. KAD assisted in data collection and early and final drafting of the manuscript. CRN coordinated the workshop at the scientific and strategic levels and made critical contributions to the manuscript.

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