

Autism in Africa: The Critical Need For Life Saving Awareness

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What Is Autism?

We now recognize Autism as a complex neurobiological disorder that inhibits a person's ability to communicate and develop social relationships. It is also characterized by restricted and repetitive behavior. Parents usually notice signs in the first two or three years of a child's life. These signs often develop gradually, though some children with autism reach their developmental milestones at a normal pace and then worsen. Early speech or behavioral interventions can help children with autism gain social and communication skills. Although there is no known cure, there have been cases of children who have recovered from the condition. Not many children with autism live independently after reaching adulthood.

Autism spectrum disorder is a highly heritable neurodevelopmental disorder. More than 100 genetic polymorphisms have been associated with autism spectrum disorder, with Africa having greater genetic diversity than any other continent. Without doubt, because of this, genetic studies of autism in Africa could provide unique insights into the pathogenesis of the disorder. 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 birthweight, are also common in Africa.

Incidence and Demographics

Autism spectrum disorders are diagnosed in one in 68 children in the USA, affecting four times as many boys as girls. In the United States, Autism has been labelled a "national public health crisis, whose cause and cure remain unknown," by the CDC. Autism knows no boundaries. It cuts across every nation, every ethnic, racial and social group. Indeed, although autism spectrum disorder is one of the most prevalent neurodevelopmental disorders in high-income

countries like the United States, there is very little knowledge about the disorder in the low-income regions of the world, such as Africa. There is very little data on the prevalence of autism in Africa, even though this region has a population of nearly 1 billion, 40% of whom are children younger than 14 years. Although, in recent years, public-health emphasis in sub-Saharan Africa has been on communicable conditions such as HIV, malaria, and tuberculosis, with the reduction in childhood mortality rates in the past two decades, non-communicable diseases (especially neurodevelopmental disorders) are likely to become a greater health burden in these countries.

Some early studies have suggested that autism could be a culturally-bound disorder, and that autism spectrum disorder might be rare in regions such as Africa. However, this is proving not to be the case. In the 1970s, Lotter, a psychiatrist, identified nine children with autism in hospitals in six African countries. Shortly after this, many cases of autism have been reported from Kenya, Zimbabwe, Nigeria, and Ghana. Furthermore, emerging evidence from immigration studies now suggest that autism could be more common in Africa than initially believed. Studies of women who migrated from Somalia to Sweden gave indications that the frequency of autism in their children was three or four times that of children born to Swedish mothers. However, it was also recognized that certain risk factors thought to be associated with immigration might have predisposed those children to autism spectrum disorder. For instance, low vitamin D concentrations in dark-skinned immigrants in places with low sun levels, and perinatal infections in mothers. Yet, the evidence of such factors as being significantly inherent in the immigration process remain weak, and cannot yet be confirmed to contribute to increased prevalence of autism.

Awareness

With public awareness remaining at an appalling level, autistic individuals face major challenges associated

with stigma, adverse discrimination, abuse, severe isolation and lack of access to support. Thus a vast number of these people struggle daily with multiple barriers in their day-to-day existence. In Africa, in particular, the plight of people with autism is even worse, largely because the challenges are further exacerbated when they are combined with poverty, since there is no proper diagnosis and an abysmal lack of proper services. Worse, on the continent, there is a stigma attached to autism, and this strongly inhibits parents from seeking advice or information about the disorder, constituting a hindrance to early and correct treatment which is crucial for improving prognosis and the chance for the maximization of potential and better integration into society.

This author would like to relate the poignant story of an African living in Canada, and whose son was diagnosed with Autism at a children's hospital in Ontario. The man was shattered. His first consideration was how he could possibly break the news to his brother and other family members living at another part of Canada. "How can I tell them, they wouldn't understand," he spluttered dejectedly. What he couldn't tell them was that his son had autism. His trepidation would be surprising, and possibly confusing to the average American. His son was seven years old. Why couldn't he just tell them? To understand the man's peculiar fear, one would have to arrive at a comprehension of just how significantly and negatively African families are impacted by autism. For a start, the diagnosis is infinitely difficult to accept. For most Africans, Autism remains largely a condition that affects Caucasians, Asians and perhaps Caribbeans because of their mixed heritage. To further fuel their ignorance, even the media basically publish only stories of White, middle class autistic individuals. It is quite baffling that so many Africans subscribe to this erroneous belief. What is even more baffling is the shame, isolation and stigma that a diagnosis of Autism can wreak on an African family living in the Western world. It is surprising that they would feel that way, considering that they had done nothing wrong. After all, no one consciously solicits for infirmity of any sort. One inescapable fact, however, is that, although many Africans living in the West do try their best to fully integrate into their new societies, their values, beliefs, traditions and behaviors remain strongly sympathetic to those of their African country of origin. Their native culture forms their beliefs about all disabilities, and about autism in particular.

Surprisingly, for such a large and diverse continent of 54 countries and an estimated 3,000 languages, knowledge of autism is abysmally low across the African continent. Incredibly, this fact holds true even amongst doctors, healthcare professionals, social workers and special education teachers. Generally, Africans hold particularly strong beliefs in supernatural causes such as punishment from God, witchcraft, evil spirits and curses as causes of Autism. African cultures are collectivist in acceptance, and they are based on group values and consensus, with people being obligated to observe a myriad of traditions and customs, and failure, either wittingly or unwittingly, to observe these customs, or the breaching of local taboos, is believed to lead to consequences that could include the curse of Autism. Autism is also believed to be associated with bad omens, not only for an immediate family but also for the community in general. All these tendencies play a major role in the incipience of secrecy and isolation. They are usually the reasons given for the concealment of the diagnosis from family members and other members of the community. This should hardly surprise anyone. If a family admits to having a child with Autism, they risk being ostracized for fear that their "curse" might have adverse consequences on those close to them.

This author is in a good position to highlight the Nigerian experience as a case study, being half British, and half Nigerian herself. In Nigeria, there is increasing concern over the rise in cases of autism spectrum disorders (ASD). Yet, the level of awareness about autism in Nigeria is pathetically low. There is some awareness amongst those in the medical community, but the extent of their knowledge is often limited. Most of them only know the symptoms and manifestations of "infantile autism." The majority do not know that there are different forms of autism spectrum disorders, while some don't even believe the condition is treatable, and nearly 70 percent have no clue as to where to refer cases to, and what to do even when they are certain about the diagnosis. Many children in Nigeria with autism are either not diagnosed or misdiagnosed. They end up being hidden at home, or when they are 'lucky,' they are categorized with the deaf and mentally ill children. In the rural areas, where there are no psychiatric hospitals, the majority end up on the streets and labeled 'insane.'

There is a serious and disheartening lack of understanding about autism in Nigeria. Parents are often the most confused. Different doctors say different things, and by the time parents visit ten professionals, they come out with ten conflicting

professional explanations of the same condition. In most countries, a multidisciplinary team assesses, diagnoses and develops an individualized educational plan for each child with autism. However, what happens in Nigeria is very far from that. In Nigeria, the children are hidden at home, especially if the special schools (centers for the deaf, blind or mentally ill) reject them.

The legal framework necessary to support individuals with autism is another deficient area. The trend in most parts of the world is that 'no child should be left behind,' and that every disabled child matters, and that there should be free basic education for all. However, in Nigeria, there is no recognition of autism as a disability, and there are next to no services available to meet the needs of those with the condition, which is why it hardly comes as a surprise that many of the so-called 'mad' people on Nigerian streets are autism sufferers who were neither diagnosed nor treated. Yet they could have been treated. One significant reason for this is that, since there is no welfare program in Nigeria to offer government funding for educational and specialized services needed by these children, the entire financial burden is placed on parents. The few affluent ones prefer to send their children abroad, and if they must reside in Nigeria, they hire an expert from South Africa, the USA or the UK to work with their children on one-to-one basis. Often the cost of bringing in an expert would otherwise be more than sufficient to train 30 local therapists.

Collectivist African culture, with its clear rules of conformity, has difficulty with the strange behaviors of autistic individuals. In the West, public judgement tends to be silent and quiet, but Africans would usually openly and loudly express unsolicited opinions. Efforts to explain that a child is not just a spoilt, misbehaving brat, and to embark upon an explanation of the complexities of Autism, will almost always fail miserably. However, even though autism awareness remains low across Africa, there are some encouraging signs. The first Autism in Africa Conference that held in Accra in 2014 demonstrated a desire to learn, and to develop cohesive and inclusive strategies to increase awareness and management of Autism on the continent. Salutarly also, that conference is now an annual event, with local autism organizations being more active in different regions of the continent.

A principal impediment to awareness of Autism is inadequate research, and certainly, one significant

barrier to the research and management of autism has been the scarcity of necessary and validated tools on the African continent. One such standardized tool for autism spectrum disorder is the Autism Diagnostic Observational Schedule, which has contributed inestimable to knowledge about autism in high-income countries. Unfortunately, the use of these tools in Africa poses major challenges that border on cultural appropriateness, cost of translations and adaptations, and copyright-related issues. Admittedly, although awareness of autism appears to be on the rise in developing countries, major challenges arising from limited awareness in many communities in Africa remain, especially with rural families. Certainly, in the face of insufficient awareness, such families are not likely to seek or be referred to appropriately-skilled personnel for comprehensive assessment and diagnosis. Inadequacies in the education sectors of these developing countries, such as inadequate knowledge and awareness of autism, and the absence of scarcity of inclusive curricula tend to pose similar challenges.

The Imperative For Awareness

It is imperative to raise awareness among health care providers, therapists, parents and the general population, about the signs and symptoms of autism, and about the need to seek and provide services as soon as possible so that children with autism will be diagnosed as early as possible. Today, it is possible to diagnose autism as early as the age of one year. Awareness is also important because of the need for the right treatment, and as soon as possible, in order to improve their prognosis and allow them the chance to become independent and peak performing members of the community

There is a compelling need for greater collaboration and cooperation of the advanced countries with the developing countries, particularly African countries, in order to increase awareness, reduce negative opinions and stigmas, strengthen capacities, help with allocation of financial support to provide proper diagnosis and early intervention treatments to children with autism. There is also an equally compelling need for training centers to be established in Africa, where parents and caregivers can be educated and offered the much need support.

Awareness about autism spectrum disorder should be urgently increased, and this requires partnerships between parent-support groups, not-for-profit organizations, private sector, governments,

international autism organizations, media, WHO, and funders, such as National Institutes of Health and the Wellcome Trust. Programs such as the Autism Speaks Global Autism Public Health 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 prioritize 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.

Education and training have clear links to awareness and advocacy. The goal should be to incorporate training in autism into health-care and social-care education so as to increase 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, and the key to this are development and validation of screening and diagnostic tools. Thereafter, epidemiological research is needed to assess the burden of autism spectrum disorder and define the clinical features of the disorder in Africa.

Initiatives

On Tuesday, December 8, 2016, operating under the auspices of her global humanitarian platform, the Engineer Aja Eze Foundation, this author executed a novel initiative to generate an unprecedented level of awareness of Autism in Africa and other developing parts of the world through a high-level conference convened at the United Nations. The conference, uniquely conceptualized as a tableau of Panel Discussions, was aptly tagged: "Autism in Africa: Life Saving Awareness; Whilst Implementing The United Nations 2030 Sustainable Development Goals And Towards Agenda 2030." The conference was held in technical collaboration with the Permanent Missions to the United Nations of Zambia, Uganda, Malawi, Japan, Israel, Kenya and Angola, Nigeria and Poland. In attendance were the Their Excellencies, the Ambassadors of these countries to the United Nations, who also acted as Co-Hosts of the high-profile event that was held as a side-event under the official auspices of the 71st Session of the United Nations General

Assembly.

The Aims and Objectives of the conference were to: Raise awareness of the challenges faced by children with autism in Africa; Raise awareness about autism in Africa and to improve the lives of people living with autism in Africa; encourage collaboration and cooperation between all members states in order to share experiences and knowledge, and raise awareness of autism in Africa; and Advocate for policies which move children with autism and disabilities from exclusion to inclusion.

The principal outcome of the conference was a firm resolution to seek conveniently implementable and sustainable solutions to the lack of information on autism in Africa. It was recognized that there is a compelling need to raise awareness among health care providers, therapists, parents and the general population, about the signs and symptoms of autism, and about the need to seek and provide services as soon as possible so that children in Africa will be diagnosed as early as possible. The principal outcome of the conference was a firm resolution to seek conveniently implementable and sustainable solutions to the lack of information on autism in Africa. It was recognized that there is a compelling need to raise awareness among health care providers, therapists, parents and the general population, about the the signs and symptoms of autism, and about the need to seek and provide services as soon as possible so that children in Africa will be diagnosed as early as possible. There was also a unanimous call by the Ambassadors on the Eng. Aja Eze Foundation to immediately embark on efforts to take global autism awareness to another level, while pledging their joint full support and cooperation for any initiative that will continue to accord Autism its rightful place in global consciousness.

Significantly, it was in that regard, the Board of Trustees of the Foundation mooted an idea to publish a book that would be titled, "The Little Book of Autism." The 150-page book would be published with the primary objective of being a user-friendly manual that parents of autistic children, scholars, governments, healthcare providers, and indeed all other stakeholders in the world of Autism, can pick up and get fundamentally educated about autism in the shortest possible time, without having to labor under the burden of exposure to high-sounding academic and intellectual language that many of them may not be able to adequately grasp. The book would comprehensively cover and explain, in simple language, misconceptions, sacrosanct truths and

contemporary management options in an easily comprehensible flow and manner. The book would be published and distributed in the nations of the world Free of Charge. Country Representatives will be identified in about 20 countries, and they will be responsible for the circulation and distribution of about 250,000 copies of the book.

Conclusion

For families of African descent, social networks, including family members both abroad and back in Africa, can have a tremendous impact on how they live with autism, serving either to enhance feelings of stigma or to encourage openness and seeking support. One hopes that the World Autism Awareness Day will continue to bring more knowledge to all Africans the world over. It should be our collective hope to turn stigma, shame and isolation into awareness and acceptance. We have an ethical duty to develop post-diagnostic intervention, from neuro-psychiatric education to community-based and specialist programs. We need to link educational, health-care, and social-care systems for the generation of well-coordinated knowledge, policies, and plans that will ensure the overall efficacy and cost-effectiveness of the programs. The needs of Africa may be substantial, yet the world has much to learn from Africa in terms of the interplay between nature and neurological pathways to autism spectrum disorder and other neurodevelopmental disorders, and in finding creative ways to meet the needs of individuals and families using low-cost and high-impact methods.

Educational Leadership Implications

There is an opportunity for educational leaders throughout Africa to be at the forefront of addressing autism spectrum disorders through educational policy and educational programming across the continent. This requires transformational leadership that builds a collective vision among educators to establish educational cultures and environments that are inclusive and supportive of children with autism and their families. Working through organizations such as the United Nations and UNESCO we can transform the way we treat and educate children with autism across the African continent.

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