

The Story of Patrick's: The First Center for Children with Autism in Nigeria

Dotun Akande¹, Alissa Briggs² PhD, & Hatim Omar²

¹Patrick's Center, 13b Remi Fanikayode Street, GRA, Ikeja, Lagos.

²University of Kentucky, College of Medicine, 740 S. Limestone, Lexington, KY 40536,

Correspondence: Professor Hatim, e-mail: Hatim.omar@uky.edu

Keywords: Autism, Education, Nigeria, Treatment, Assessment,

Received: 26/5/2016; Revised: 10/6/2016; Accepted: 12/6/2016

Abstract

Autism Spectrum Disorder (ASD) is one of the most common developmental disorders. However, there are still no epidemiological studies of ASD in African countries. In Nigeria, many children are diagnosed with ASD late or only if there are symptoms that severely inhibit their ability to function. Moreover, there are limited treatment options. This paper will describe the efforts of Patrick Speech and Languages Centre (Patrick's), the first center in Nigeria specifically for children with ASD, which was set up to assess and treat autism.

Introduction

Autism Spectrum Disorder (ASD) is one of the most common developmental disorders. There is some consensus that the worldwide prevalence of ASD is near 1% (1). Knowledge and research about ASD in Africa lags behind Europe and North America (2). In fact, for several decades ASD was thought to be unique to only Western countries (2). A little less than 30 years ago, data indicated the presence of ASD in 1 out of 145 children with intellectual disabilities screened in Ghana, Nigeria, Kenya, Zimbabwe, Zambia, and South Africa (3). Recently, in a clinic population in south-eastern Nigeria, 0.8% of the children who attended the clinic over one year met the criteria for ASD (4). However, there are still no epidemiological studies of ASD in African countries.

When diagnosed with ASD, it seems that children in Africa are more likely to be predominantly non-verbal, which could relate to local diagnostic practices (5, 6). Children who are non-verbal are more likely to be referred and access medical care. Given that ASD is diverse in clinical presentation and can co-occur with intellectual disability, epilepsy, sensory difficulties, attention-deficit/hyperactivity disorder (ADHD), and other psychiatric disorders (1), medical professionals require training in order to identify ASD.

There is a low level of knowledge and awareness of ASD among the general population and healthcare workers in Nigeria (2, 7-9). A cross-sectional study of final year medical students in Nigeria indicated that less than 30 % had seen and participated in evaluating and treating a child with ASD (10). A little less than a third of nurses surveyed in Nigeria believe that ASD can be attributed to supernatural causes and about 14% attribute etiology to preternatural causes (11). Given that healthcare workers in sub-Saharan Africa live among the general population in the community and offer advice to community members on healthcare related issues, their beliefs can greatly influence help-seeking behavior (11). Parents may not take their children in for assessment and treatment if they do not attribute the origin of the disability to natural causes. Help-seeking behavior can greatly affect the

prognosis of children with ASD given that early recognition and treatment is associated with a better prognosis (12-14).

However, given the context of diagnosis and treatment in Nigeria, many children are diagnosed with ASD late or only if there are symptoms that severely inhibit their ability to function. Many children who are diagnosed with ASD are referred to a psychiatrist and end up being medicated. Mrs. Dotun Akande sought to change the treatment for children with ASD given her experience with her own son.

Patrick's

Patrick Speech and Languages Centre (Patrick's) was the first center in Nigeria to open specifically for children with ASD. Its aim is to improve the quality of life for individuals with ASD. Mrs. Akande established Patrick's in 2006 after years of frustration in trying to find an ideal environment for her son with ASD. In order to prepare to open Patrick's, she sought training from the National Autistic Society in the United Kingdom. Patrick's began its operation with three children. By May of 2007, Patrick's served 21 students. As of May 2015, Patrick's has served 160 students and has 39 students enrolled. There is a fee for enrollment and some students are supported by donations.

Patrick's aims to follow best practice. The most effective approach to treating and assessing ASD is multidisciplinary (15). Given the diverse presentations of the disability, individuals with ASD require multidisciplinary interventions tailored to their specific needs (1, 15). Children are served at Patrick's through a full school program, a part time program, or an after school program at the center depending upon the severity of the child's symptoms. An Individualized Educational Plan (IEP) is developed to address the child's specific needs. Children are placed in a group class based on age and ability. Listening and attention skills are taught first. Services provided to the children include academic instruction individualized to the child's needs, speech and language therapy, behavior modification, social skills instruction, occupational therapy, sensory integration therapy, physical therapy, music therapy, hydrotherapy, vocational therapy for adults, and work programs for adults.

Children are admitted to Patrick's if they have a diagnosis of ASD. They undergo a week long assessment to determine if they have ASD. On the first day of the assessment the child is observed in various settings (group, one on one, sensory room, and playground). On the second day, they are evaluated individually using the Assessment of Basic Language and Learning Skills (ABLLS) as a guide. At the end of the assessment, a report and recommendations is provided to the parents.

The staff at Patrick's are mostly from the College of Education Oyo (colleges of education are teacher training colleges and the degree earned is National Certificate of Education) with a background in special education. Staff also include Polytechnic graduates with basic Ordinary National Diplomas (OND) as well as individuals with masters degrees in the field of psychology. Some of the support staff are pursuing degrees in various fields (e.g., basic Ordinary National Diplomas in accounting, secretarial studies, etc), but are also trained to support our staff. The PSLC has a consulting speech and language staff who manages their speech program. All of the PSLC staff have basic Applied Behavior Analysis (ABA) training and are trained in how to use a Picture Exchange Communication System (PECS). The proprietress of PSLC is trained in ABA, PECS, sensory integration therapy, and makathon (an alternative means of communication that involves the use of signs to help our nonverbal children communicate better). Staff are provided with yearly professional development by individuals from different fields (e.g. see <http://pslcautism-ng.org/>).

Methods and Results

Data were examined for those admitted when Patrick's opened (September 2006) through to May 2015. During this time, 160 individuals attended Patrick's. The majority of students were male (114 male, 46 female). The average age at entry was 7.7 years and the average age at withdrawal was 9 years, with an average length of stay of 1.8 years. The ultimate goal is for children to leave and be reintegrated into school and society. As of May 2015, 39 individuals attended Patrick's. Of the 121 who withdrew, 34.7 percent (42 children) integrated in a regular school and accounted for the most likely reason for withdrawal from Patrick's (see Table 1). The second greatest reason for withdrawal was lack of funding (17.5%, N = 27). Patrick's is primarily funded through private donations and children are provided with financial support to attend, however, resources are not plentiful enough in order to accommodate everyone who needs services. Other reasons for withdrawal included moving (11.5%, N=14) and being unenrolled by the carer (9.9%, N=12). Reasons for withdrawal that fell under the category of "other" included moving to another specialized school, seeking specialized therapy elsewhere, or simply attending Patrick's part time or on a trial basis.

Table 1 Reasons for withdrawing from Patrick's

Reason for Withdrawal	N	Percent
Integrated into regular school	42	26.3%
Lack of Funding	27	22.3%
Moved	14	11.5%
Withdrawn	12	9.9%
Other	13	10.7%
Unknown	12	9.9%
Total	121	

Discussion

Diagnosis and treatment of ASD in Nigeria is relatively new. Patrick's was the first center in Nigeria to open specifically for children with ASD. In its nine years of operation, Patrick's has grown dramatically in terms of the number of children it serves. Patrick's engages in best practice in the assessment and treatment of ASD symptoms and aims to reintegrate children into society. Even with financial limitations, 42% of children enrolled in Patrick's were able to reenter mainstream school and society. As the recognition of ASD improves amongst healthcare professionals in Nigeria and diagnoses are made sooner, centers like Patrick's have an even greater potential to positively influence the quality of life of children with ASD through early intervention.

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