

# **Need for Effective Disability Services in Nigeria: The Case for Open Doors for Special Learners, Jos**

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## **Abstract**

In Nigeria, the majority of families who have children with intellectual and developmental disabilities do not have access to professional services. Acute shortage of special educators, coupled with social, economic and cultural problems, negatively impact the development of specialized services. In this article, the authors document the evidences and information gathered from a focus group of parents at the Open Doors for Special Learners, Jos, Nigeria. Comments and discussions revealed, among other things, superstitions participants held regarding disabilities, how families shopped for a “cure” for their children’s disabilities, and excessive caregiver burden. Recommendations are advanced to empower families and their children with disabilities.

## **Introduction**

In simple terms, disability is the limitation in performing certain tasks that society expects of an individual. Disability permeates every society, and has done so through the ages (Lambo, 1981; World Report on Disability, 2011). Today, in most parts of the world, the disabled include persons with intellectual, developmental, sensory, physical or other dysfunctions, which may be acquired, congenital, or even hereditary (Dell Orto & Power, 2007). In the absence of effective education or rehabilitation, such disabilities have the potential to impede a person’s full participation in the society and the performance of social roles.

People have reacted in different ways to disabling conditions; such reactions include: shame, prejudice, fear and exclusion from family or community life. In a developing country like Nigeria, it is evident that persons with disabilities constitute one of the poorest, socially excluded and marginalized groups within the society (Lang & Upah, 2008). Even today, Nigerians with disabilities continue to face social stigma, exploitation, and discrimination (Nigerian Institute of Legal Studies, 2010). In fact, in most communities, children with disabilities are perceived as a financial burden because they are unable to contribute to the family economy like their peers without disabilities, some of whom assist their parents by going out to the streets to sell various food items, clothing, and general merchandise (Ebigbo & Ebigbo, 1992).

According to the World Bank, Nigeria has an estimated population of over 162 million, as of July 2011 (The World Bank, 2012). The Nigerian National Assembly (2013) estimates that there are over 20 million people living with disabilities in the country today (see <http://www.nassnig.org/nass/news.php?id=420>). The Nigerian Institute of Legal Studies (2010) noted that 9 out of 10 persons with disabilities in Nigeria live below the poverty line. Overall, the citizens continue to experience great disparities in educational, economic, medical, and social opportunities, in spite of the country's abundant natural resources (Aigbokhan, 2000; Sulaiman, 2008). Against this background, it is obvious that living with a child who has a disability can have profound effects on the entire family structure.

The prevailing economic and social difficulties, and the absence of government supports as practiced in high-income countries, have resulted in the inability of most families to meet the daily needs of children with disabilities (Ajuwon, 2012). At the national level, there is a lack of political commitment commonly held by politicians and senior government officials to ascribe to disability issues a measure of importance required for practical progress in terms of disability rights (Lang & Upah, 2008). The widespread under-estimation of the abilities of persons with disabilities has created a vicious cycle of under-expectation and low priority in terms of allocating resources to improve the status quo. Consequently, many families are known to reject their children with disabilities, forcing some of these children to roam the streets begging for alms, or to die as they become exposed to the elements.

The reasons for the abandonment of the children are not implausible. Often, family members become fixated on the myths that only emphasize the embarrassment of giving birth to a child with a disability, and attributing such disability to the anger of the gods or their ancestral spirits. Because of these erroneous ideas, children with disabilities may become ostracized and denied their fundamental human rights.

In recognition of the need to enhance special education and rehabilitation services, a few church-affiliated schools and government-sponsored vocational centers were established prior to Nigeria's independence from Great Britain in 1960 (Hill, 1985; Mba, 2002; Sykes & Ozoji, 1985). In the post-1960 era, state governments and philanthropists established special schools and homes in different parts of the country, in response to the new education policy of the federal government (National Policy on Education, revised 2004). This policy, for the first time, accorded greater importance to special education in the National Policy on Education. In support of the government's desire to promote quality education for children with special needs, selected post-secondary institutions were accredited to train personnel needed to work with special learners (Ajuwon, 2011; Mba, 2002; Sykes & Ozoji, 1985). Regrettably, the few tertiary institutions that prepare special educators, rehabilitation specialists and social workers are yet to infuse into their curricula the competencies needed to assist families or caregivers in terms of how to cope effectively with disabling conditions in children, youth and adults.

Ajuwon (2011) noted that hundreds of certified special educators have been trained in Nigeria's tertiary institutions since 1974. However, there is evidence to indicate that some of these frontline workers have not been assigned to schools and agencies where their expertise can be harnessed to improve the quality of education and the living standards of children with disabilities. The Open Doors for Special Learners in Jos, Nigeria, has therefore evolved as a center of excellence to fill this vacuum, and is promoting the understanding of what it means for a child to have a disability.

### **Philosophy of the school, and study setting**

The Open Doors for Special Learners, Jos, was established in 1998, as a registered non-governmental and not-for-profit organization (<http://www.opendoorsnigeria.org>). The primary goals of the school are to: provide quality educational opportunities for children and youth with learning handicaps who have not been successful in regular schools; provide such pupils with specialized literacy skills; expand the quality of education for children with special needs; enhance the opportunities for the young learners to participate in music, arts, indigenous crafts and sports; and counsel and advise families and caregivers on how to cope with the disabilities in their children. The school has been approved as a collaborating, non-governmental organization with UNICEF/Nigeria, and is Registered with the Corporate Affairs Commission in Abuja, Nigeria, and with the Plateau State Ministry of Social Welfare,

The overarching philosophy of the school is to assist the pupils who require compensatory training because they have a learning handicap such as autism, Down syndrome, cerebral palsy, epilepsy, specific learning disabilities, or other developmental problems. The focused curriculum of the Open Doors is therefore unique given the lack of expertise of teachers in public schools, and the overwhelming prejudice and discrimination against children with intellectual disabilities in the society. These children are the least understood, and their families the most exploited. For children with intellectual disabilities who attend their neighborhood schools, it is common to see them fall behind in learning and socialization because their teachers lack the knowledge and pedagogical skills for their effective instruction.

Presently, the Open Doors for Special Learners has an enrollment of 60 pupils. These pupils receive instruction through their individual learning channels based on each child's identified needs. Professionally-trained and dedicated teachers deliver the instruction in a warm, supportive and friendly environment. There are six classes of ten pupils per class. Generally, morning sessions begin with group activities. The afternoon sessions focus on pupils who need one-on-one instruction because they cannot yet learn in a group setting.

The school places a high premium on instructing the pupils in reading, writing and numeracy skills. Children who have failed to learn these skills in their neighborhood schools are enrolled for one-on-one remediation with one of the four reading specialists. The average monthly enrollment in the Reading and Math Clinic Unit is 20 students.

It is worth mentioning that several of the students who are admitted into the school's reading program do so when they discover they cannot gain admission into regular secondary schools because of their limited entry level skills as a result of inadequate instruction they had received in the public primary schools. However, with the targeted instruction at Open Doors, some of the students are able to develop the numeracy and literacy skills required to re-enter regular secondary education, and to function within the community and/or hold a job. These students are able to excel because of Open Doors' warm and encouraging literacy-based learning environment where they learn to love books, understand numbers, and develop confidence in themselves as readers, writers and thinkers.

Some of the children at the school have conditions which need to be treated by a physical therapist; hence, the setting up of a Physical Therapy Clinic within the facility. The full-time physical therapist not only treats each child who requires therapy, but also assists parents or caregivers in implementing follow-up therapeutic activities to sustain the physical development gains of each child. Currently, 15 of the children use this specialized service. Furthermore, some therapeutic devices which have been fabricated with the ingenuity of local craftsmen are being successfully utilized within the clinic.

The curriculum of Open Doors places a high priority on vocational training. Indeed, the belief is to inculcate in the pupils useful skills that would prepare them for independent and self-reliant adulthood. At the moment, there are 15 pupils in the Vocational Training Unit where they learn how to cook, garden, and make petroleum jelly cream and candles. The plan is to expand the scope of the center's vocational training to include the manufacture of other popular products for distribution within the region.

In terms of promoting public awareness of disabilities, teachers at Open Doors frequently conduct workshops in public schools, agencies, the Ministry of Education, as well as the Ministry of Social development. These professional development activities have contributed immensely to the participants' level of awareness of cognitive disabilities, and increased their understanding of instructional methodologies.

However, activities at Open Doors are not confined to academics. On a daily basis, the children engage in learning indigenous arts and crafts, music and dance, as well as games. These extra-curricular activities aim at fostering in the learners self-discovery, communication with others, improved self-concept, skill development, community recognition and awareness, and social interaction.

Over the years, children at the school have participated in several Special Olympics events, winning medals in various categories. On the home front, the Open Doors United, the school's soccer team, periodically features in soccer competitions with other schools in the city. All these sporting events have gone a long way to promote the capabilities and interests of the pupils.

Many parents of special needs children come to Open Doors for counseling. These parents often complain about medical or counseling services they have received elsewhere. Most of them come to the school already financially exploited and emotionally traumatized by the so-called counseling and

medical “experts”. This focus group meeting, therefore, was conducted to explore the life satisfaction of parents and their insights regarding their children with disabilities.

### **Method**

The lead researcher obtained ethics clearance from his university to conduct a study on Family Quality of Life (FQOL) in Nigeria. The FQOL research was conceived as part of a larger study on families who have children with disabilities in two urban centers in Nigeria, including the city of Jos, Plateau State. The lead researcher has a close working relationship with Open Doors, and also serves as the volunteer representative of the school in the United States and Canada.

The focus group meeting at Open Doors which resulted from a larger Family Quality of Life Study also coincided with the medical and physical screenings of the children for the regional Special Olympics. The occasion afforded 30 families to visit the school and participated in the focus group meeting which lasted 2 hours. Since English is the official language of communication in Nigeria, participants did not have difficulty in following the discussions, and in writing their opinions. The third author, who serves as the coordinator of the school, acquainted the families with the purpose of the study, while the lead researcher assured the families of the confidentiality of their responses.

Essentially, participants were asked to write personal comments regarding the question: “How has raising your child with a disability affected your life satisfaction?” Participants were given ten minutes to write their feelings and opinions. The coordinator subsequently collected all written responses. Following the written answers, participants discussed in a large group session the various insights they had written down, as well as suggestions for improving services for children with learning problems.

### **Data analysis**

From the written comments, the researchers were able to identify logical clusters and then grouped the participants’ comments into seven relevant clusters. This grouping enabled the researchers to ascertain the major themes in evidence and report those themes in the order of their frequency as indicated by participants.

For the rest of this article, we thematically analyze the personalized views shared by these families at the focus group meeting. We conclude this write-up with suggestions for improving overall services for families and their children with disabilities in Nigeria.

### **Thematic experiences of participating families**

From the various comments written and discussed by participants, it is obvious that the presence of a child with a disability exerted tremendous strain on the family members’ social, psychological, and economic well-being. Overall, the participants’ concerns have been thematically categorized, thus: superstitions

surrounding the causes of disabilities, shopping for a “cure”, excessive caregiver burden, restricted social life, discomfort in religious places, deprivation of social and leisure activities, and breakdown of the family. These categories are supported with representative quotes from participants:

### **Superstitions surrounding the causes of intellectual and developmental disabilities**

One father stated that he is blessed with two male children who have autism, and lamented “... my own mother brought this misfortune on me ... In our village, newly-born children are first taken to the shrine to receive blessings from the gods.” He disclosed that while his mother presented her own sons from a previous marriage, she failed to do so with his own two children. “I’m sure this is why my two children have become retarded (sic).”

Another participant wrote how his son began to convulse after sharing food with a family friend in his village on an Easter day: “The poison in the food caused my son to convulse almost right away,” he stated. “He shook violently for a long time ... I did not know where to take him for treatment, and he continues to have this problem even at seven years of age!”

### **Shopping for a “cure”**

Parents told of how they expended large sums of money on children with intellectual disabilities. Many families regretted having spent their life’s savings in herbal centers in rural areas, with no positive outcomes. One mother said of her daughter: “At three years, our daughter was not “normal” (sic) in growing up and playing with other children. ... We followed the advice of the elders who took us to the famous village herbalist”. She noted that after 18 months of treatment with various concoctions, “There was no change in our child’s condition”.

The mother stated the daughter was kept at home for two years, until someone informed them of Open Doors where she is now enrolled. However, they have to struggle for the daughter’s school fees, with the added costs for transportation and health care.

### **Excessive caregiver burden**

A number of parents, especially mothers, cited caregiver burden as the primary stressor in their life. The daily burden is physically and financially overpowering for most of them. One mother of a child with cerebral palsy agonized thus: “There’s no safe daycare for my 9-year-old to go, I can’t go to sell foodstuffs in the market because I need to be with him at home most of the time.” She explains that employing a housemaid is not within her means. Besides, she has heard terrible things done by housemaids because they lack proper training in managing children with disabilities.

Another mother of a daughter with Down syndrome commented that she spends a lot of time looking after her child. She stated: “... I can’t do my petty trading to bring extra money that my other children need to live well”.

Several other families who commented along the same line observed that the daily burden for their child with severe disabilities resulted in the loss of other

normative activities, from social events to loss of employment and independence for mothers, in particular. A typical comment was: "... I lost my job as a typist in the government office because I needed to take care of my 7-year-old boy who has Down syndrome". The position of this mother clearly illustrates the general feeling of some other participants who shared similar frustrations. These mothers are the most restricted as they have to give up everything to look after their children, and hoping that government support would come their way some day.

### **Restricted social life**

Some parents complained that their social outlook has been severely restricted because the neighbors avoid interacting with them. One mother remarked: "When neighbors saw our baby who has Down syndrome, they did not feel comfortable talking to us ... I got the feeling these people thought the handicap would infect them!" Similarly, one dad observed that any time he goes out with his young child who has deformed legs and impaired speech, he could at times hear passers-by refer to him as "father of a mad child". According to this man, "When you hear that kind of thing, you become angry and sad and almost lose hope in your child".

Both participants, as well as a handful of others who took part in the group discussion, decried the lack of information and advice from their doctors regarding the various disabilities in their children. They shared the sentiments that the absence of timely and accurate information delayed their understanding of the disability, and increased their level of frustration in dealing with the situation.

### **Discomfort in religious places**

Many families commented that church members were sometimes uncomfortable because of the occasional disruptive behaviors of some of the children with disabilities. Two participants in particular noted that the Children's Sunday School teachers' lack the knowledge to incorporate the children with disabilities into their midst, necessitating the need for parents to have the children with them at all times. One female participant commented: "Some members of the congregation do not understand the behaviors of our child ... some even blame us (the parents), even saying to our hearing that we're unable to take care of our own children!"

Another family remarked that "Even after you explain the true situation of our child's conditions to these church members, that's when you see them avoiding you and the child".

### **Deprivation of recreation and leisure activities**

The fact that little or no time is left for leisure or recreational pursuits was a concern to some families. There was unanimous agreement by the parents that to give quality care to their child with a disability would leave no time for recreation. "The daily care means you have no time to travel even to the village to visit extended family members", a female participant noted. One male participant added: "I work long hours on the farm every day of the week, to get

enough crops to feed the seven members of the family. The extra food items I sell to earn income for other things we need”.

### **Breakdown of the family**

Two mothers reported that they found themselves in a broken home on the arrival of their child with a disability. According to one participant: “My husband showed a lot of uneasiness when our daughter with Down syndrome was born; he was abusive after we went around for two and a half years in different hospitals, with no cure”. She added that with their savings gone, life became harder, forcing the father to abandon the family.

From general accounts of abandonment as disclosed by the participants, it would seem that it is the fathers who engaged in the practice of deserting the home, leaving the mothers and siblings to fend for themselves.

### **Need for effective services in Nigeria**

From the information shared by the families with whom we interacted, it is revealing how disabilities manifest themselves in children, how parents perceive such disabilities, the way some parents seek treatment, how a disability may affect the child’s daily living and community integration, and how parents’ lives are impacted in multiple ways. These children with disabilities require appropriate services and training to reach their fullest potential.

As has been demonstrated, the impact of the disability is, however, not limited to the child. Parents of a school-age child who has a disability typically report high levels of stress and are at risk for depression (Baxter, Cummins, & Polak, 1995; Olson & Hwang, 2001). When parents learn that their child has a disability or a chronic illness, they begin a journey that takes them into a life that is often filled with deep emotions, difficult choices, visits to orthodox and unorthodox practitioners, and an ongoing need for information and services. As indicated by some families at the focus group meeting, parents may initially feel depressed, angry and isolated, and not know where to begin their search for information, assistance, or available resources. On the basis of these families’ fears and frustrations, we proffer the guidelines that follow to improve the life satisfaction of families, and to facilitate their understanding of disability issues.

### **Setting up early intervention services**

The education of the child born with a disability must begin at birth. It is often stated that education is concerned with everything that helps the child to grow. Given this realization, education must begin at birth in a situation where hereditary or congenital disability exists. The aim will be to empower the parents to assist the child to grow from helpless infancy into mature and self-reliant adulthood. The parents must be able to provide the child with love and security, new and rich experiences, and a positive self-esteem, without over-protectiveness.

### **Building effective parent/professional partnerships**

Parents and professionals must strive to form a mutually beneficial partnership that enhances the social, psychological and educational growth of the child with a disability. This is critically important in a superstitious-ridden society like Nigeria, where experienced counselors and special educators are in short supply. In the collaboration that ensues, professionals must recognize that parental influence is far more productive and long-lasting than that of medical doctors, nurses, therapists, or other helpers who may assist as the parents “shop” for a cure for their child’s condition. Observations have indicated that well-informed, optimistic and accepting parents have a most positive and significant impact on the adjustment of their child with a disability.

Once a disability has been diagnosed, the specialist responsible for further diagnosis should design clear guidelines for explaining the child’s problem to the parents. Falvey (2005) aptly noted that “Many doctors still do not talk about a child’s disability with the proper care or tact”, choosing instead to frame the information “as bad news” (p. 2). This was certainly the experience of one mother in the focus group, who believed that she did not receive sufficient information and care from her doctor during pregnancy and after the delivery of her son who has cerebral palsy.

In a large-scale study in the United States, Skotko (2005) reported that the majority of mothers in his study stated their physicians talked little about the positive aspects of Down syndrome and “rarely provided enough up-to-date printed materials or telephone numbers of other parents with children with DS” (p. 64). Skotko provides several specific recommendations, including the need for the physician to deliver the diagnosis of Down syndrome in a sensitive manner, and to link the family to advocacy and available resources within the community.

These recommendations are equally applicable to other disabilities, and physicians, counselors and social workers in Nigeria should utilize these strategies as they interact with parents.

From what some parents shared with us, it could be a majorly devastating for a parent to learn that their child has a physical or intellectual disability. Such a realization often brings with it natural feelings of fear, disappointment, guilt, and a general sense of inadequacy. Clinicians should therefore take the initiative to inform parents that their children will require a range of specialized services and that the system may be extremely difficult to navigate. Whenever possible, especially in the urban centers, these parents should be referred to advocacy groups and local schools for ongoing support and advice.

### **Understanding causation of disabilities**

Most parents in Nigeria, especially the majority who reside in rural communities, lack knowledge of the true causes of disabilities. This is exacerbated by the fact that there are few resources to aid them. Indeed, the lack of knowledge and the absence of resources can generate feelings, which freeze parents into guilt, and could well prevent them from dealing adequately and productively with the child’s disability. The critical challenge here is to increase

the number of trained medical and counseling specialists, and to enrich their curricula and field experiences so they are better trained to respond to the needs of families in terms of understanding the true causes of disabilities.

### **Mitigating social disruptions of disability**

The learning deficits and the social disruptions brought about by the child's disability can be avoided with early and timely interventions. Experts have noted that parent involvement is the indispensable ingredient for engendering optimum learning habits in children and for sustaining the accomplishments of enrichment programs (Honig, 1982). Through access to quality education, counseling and vocational services (similar to those offered at Open Doors), parents will eventually understand that whatever is positive is found not in the disability, but in the child. Their child is a unique creation, a combination of not only what there is, but also a limitless possibility of what, with their dynamic involvement, can be. It is recommended that parents be given the opportunity to discuss their concerns from the outset.

### **Developing an awareness of the variability among children with disabilities**

Special educators do agree with the assertion that the needs of children with disabilities are heterogeneous. The basic reason for this is that each child has varying levels of intellectual, physical, and emotional developments. It is essential for educators to work in concert with the parents to map out an individual program for each child with a disability. In this context, frontline personnel, including special educators, social workers and counselors must implement services in multiple settings – the home, school, and community. Furthermore, these professionals must relate activities for treatment or teaching to the needs of the family as a whole.

### **Providing respite care and financial support to families**

Participants in this forum have demanded respite care and monthly financial support. Respite care is temporary care of a child or an individual with a disability that allows the families to receive a break from caregiving. This can be justified for all those families who should be registered with the government because raising a child with a disability is challenging, particularly in a country that has no social safety nets. Not only does a family need to adjust to their child's disability, but there are additional stresses associated with raising a child with a disability, not the least of which are: the costs of appointments for medical services, costs of learning how to provide and/or modify home supports, and working with school personnel.

It can be argued that parents who provide primary care because of the absence of services, even for day care, can seldom pursue a professional career or obtain employment. Also, services such as respite care, which can release parents from daily physical care tasks, are as a rule not available in the country. Consequently, the parents perform labor-intensive chores for themselves with little opportunity to look after their own health, or engage in leisure or recreational

pursuits. In this vicious cycle, families will show a lower level of quality of life in terms of health and general well-being.

### **Implementing empirical studies on disabilities**

There is need to conduct empirical studies on a wide range of issues including: the children's physical and social development, medical practitioners' perceptions of disabilities, the perspectives of parents, teachers, and counselors, as well as the traditional beliefs that may be inhibiting the acceptance of children with disabilities. Unfortunately, the lack of sound research on disability issues, and the fragmented system of disability service continue to impede progress in the field of disability, and the recognition of the human rights of persons with disabilities. One suggestion to ameliorate this gap in research may be through a legally constituted, fully-funded National Commission on Disabilities, as is currently being debated in the Nigerian National Assembly. The agency, which should be headed by an experienced person with disability, should mobilize human and material resources to initiate research projects on disabilities, and to provide effective leadership required to substantially improve the quality of life of children, youth and adults with special needs and their families throughout the country.

### **Formulating professional code of ethics**

There is need in Nigeria to mandate and uphold professionalism in the conduct of service to children and their families. This would parallel the practice in the industrialized countries where professional organizations involved with individuals with disabilities have established standards and codes of ethical conduct (Alper, Schloss, & Schloss, 1994). These standards are generally based on the philosophical and legal principles of each professional body. These standards include, among other things, specific statements that reflect the mission of each organization, which make it imperative for all the stakeholders to understand the standards of ethical behavior advanced by their associations.

In Nigeria, it is recommended that such regulations be extended to herbal practitioners who hold sway over a large proportion of the population, in both rural and urban communities. Some families have revealed that the misdiagnosis by some herbalists and medical practitioners, or the misconduct of counselors and specialist teachers, has resulted in pervasive difficulties for their families without compensation. The professionalization of the various disciplines will curtail these malpractices, and empower the families as they seek treatment and lifelong care for their children.

### **The Future for Open Doors for Special Learners in meeting needs in Nigeria**

Children with intellectual and developmental disabilities are among the nation's most vulnerable citizens. Their needs for health care, education and social services should be recognized as worthy government investments. As has been demonstrated through the various services offered at Open Doors, families should be actively encouraged to participate in the upbringing of their children

with disabilities. Since no one setting can meet the needs of all children, families in consultation with experts, must be empowered to determine the best educational option for their children with disabilities.

Open Doors has initiated the model to engage the services of qualified personnel and provision of appropriate resources for educating children with special needs. As modeled by Open Doors, we recommend that qualified personnel be available and able to conduct appropriate assessments on children, and accurate data must be used to support the placement of these children in appropriate educational settings, including community-based schools.

Professional standards and codes should be set to guide all the stakeholders in the delivery of services. Some families have revealed that the misconduct of some professionals has become the primary obstacle to alleviating some problems that children with disabilities and their families encounter in their daily struggles to make their lives meaningful and worth living. Therefore, it is critical that legislation be enacted to guarantee appropriate education and training for all children with disabilities, and supports for their families. Such legislation would ultimately protect families who have, for so long, been exploited in their quest for appropriate treatment and services for their children with disabilities.

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