

# Challenges Faced by Nigerian Parents with Disabled Children in Caring for Them

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## Abstract

Disabilities in children pose a lot of challenges, fear and worries for the parents and careers of the disabled children. This study tried to find out those challenges faced by parents of disabled children while caring for them. Questionnaires designed to gather the needed information, were distributed to parents of children with disabilities who bring their children for treatment at a Federal government hospital in the eastern part of Nigeria. Same questionnaire was also filled online by parents with disabled children on a Facebook platform that goes by the name “Super Parent”. Our study revealed that parenting disabled children can be very stressful as there are lots of challenges faced by parents of disabled ranging from emotional and financial stress, lack of supports, discrimination, loss of social life and others which result in psychological problems, depression, physical exhaustion and reduced quality of life.

## Keywords

Disability, Parenting, Challenges, Children Disabilities

## 1. Introduction

Disability has been defined as an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while participation restriction is a problem experienced by an individual in involvement in life situations (WHO, 2020).

“Disability refers to the impact of impairment upon the performances of activities commonly accepted as the basic elements of everyday living” (Alfan,

2012). Disability is a global public health issue affecting one in seven people worldwide according to The World Health Organization (WHO, 2020). It is estimated that about one billion people or 15% of the world's population live with disability worldwide, and this includes 93 million children and 720 million adults. Disability has a higher prevalence in lower income countries and disability and poverty mutually reinforce each other (WHO, 2020). In Nigeria, the number of persons living with disabilities is estimated at 25 million in 2011, with 3.6 million people having significant difficulties in functioning (Wikipedia, 2016).

Disabilities can be congenital or acquired. Children's disability can be described as prenatal if the condition is present before the child is born, perinatal if the disability occurs during the time of birth/delivery or postnatal if the disability occurs shortly after birth. The causes of pediatric disabilities may include: diseases the mother acquired during her pregnancy, external influences such as poisoning, alcohol or drugs consumption during pregnancy or using wrong medication, mutation of genes or genetic incompatibilities between parents, premature birth, illnesses, serious infections etc.

A child's disability is a triadic experience, involving three-way inter-actions among the child who experiences the dysfunction, the family that is affected by it, and the external environment where the disability is manifested (Tali, 2002).

Parents of children with disabilities face great sadness, fear, worry and more from loved ones and even family members, regarding their little angels with eyes of spite, concern and even disbelief they are really disabled at the time. Shaw (2010) explains that whether it's Cerebral Palsy, mental retardation, amputation, traumatic brain injury, down-syndrome or learning disabilities like attention deficit hyperactivity disorder (ADHD), dealing and coping with the problems that come with children with special needs or a specific disability and those who care for them on daily basis, most certainly build up over time, often leaving the parents with a mixture of emotions they have to hide and cannot share with anyone.

Having a physically disabled child means one parent has to automatically change and adjust her cravings, hobbies and goals in life to suit the needs of their physically disabled child. Most times they have to deal with the way people look at and accept their child's condition, which most of the time, is not acceptable to these parents. Their disabled ones are sometimes discriminated against and treated without pity and love by the society. These attitudes towards disabled children could lead to the withdrawal of these children and their caregivers from taking part in activities and social events which makes these children and their caregivers depressed, weak, and excluded from the society at large to the detriment of their psychology.

Almost everyone will be temporarily or permanently impaired at some point in life (WHO, 2020), and those who survive to old age will experience increasing difficulties in functioning, but its most worrisome when manifested in children

or early adulthood when an individual is yet to live out his/her active lifetime (Abosi, 2007). Parents of disabled children are worried because such disabilities might affect the children's development, functions and activities, thereby making such children depend so much on their parents and siblings for daily functions and activities. Such children can also be stigmatized among their peers, which affect them and their parents emotionally and psychologically (Abosi, 2007; Clever & Herna, 2017).

Parenting a child with disability is quite a difficult task because it affects the child who experiences the dysfunction, the family that takes care and supports the child, and the external environment where the disability is manifested (Tali, 2002; Abosi, 2007). The carer is often deprived of living his or her own life but spends quality time caring for the disabled child. Most times, the parents miss out in social life and some could become stressed out or in some cases slip into depression.

Parenting stress is a particularly salient variable when working with families that have children with developmental disabilities (Tali, 2002; Dyson, 1997). Multiple demands on family resources are prevalent in such families, and stress levels tend to be elevated (Brett, 2002; Tunali & Power, 2002) and adversely affect perceptions of family functioning (Dyson, 1997).

Furthermore, families with children who have developmental disabilities must be considered as being at particular risk for problematic parent-child relationships that can interfere with child development and needed interventions (Brett, 2002; Falik, 1995).

Grobler (2012) provides a quick overview of some of the challenges faced by parents in looking after children with learning disabilities. She mentions constant subjection to a guilty feeling that they may be directly responsible for the disability through genetics, stressful moments while pregnant or abuse of alcohol. In addition to basic needs that must be fulfilled by their parents, children with disabilities may also need special facilities and services for their well-being. Parents of children with disabilities may therefore experience physical exhaustion and emotional stress as children with disabilities require extra attention (Grobler, 2012). Several authors (Baker, Blacher, Crnic, & Edelbrock, 2002; Baker, McIntyre, Blacher, Crnic, Edelbrock, & Low, 2003; Orsmond, Krauss, & Seltzer, 2004) have argued that it is the behavioural problems which are the most important predictors of parental stress in children with disabilities. Behavioural problems are frequently reported in young people with ASD (Gadow, DeVincent, & Azizian 2004; Tonge & Einfeld, 2003). These behavioural problems, as well as social and cognitive difficulties, may then present particular challenges for the parents (Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dunlap, Robins, & Plienis, 1992; Weiss, 1991). In a sample of parents of children with autism, Lecavalier and colleagues found parental ratings to suggest that behaviour problems and stress exacerbated each other over time (Lecavalier, Leone, & Wiltz, (2006).

In addition to these problems, parents also have to deal with many other

co-occurring difficulties, such as financial and time burden of medical treatment and other therapeutic interventions, restrictions on social activities, parental sense of loss and grief, and changes to family goals and achievements (Lecavalier, Leone, & Wiltz, 2006; McCubbin & Patterson, 1982). Furthermore, research suggests that there are insufficient support services for parents of children with autism, which might help them cope with stress (Whitaker, 2002).

Few studies have looked at the challenges faced by parents of disabled children and none of those studied what Nigerian parents face in caring for their disabled children. This study is very important considering the fact that Nigeria is one of the World's developing countries with high incidence of disabilities and with poor healthcare facilities and almost zero supports from government to parents in caring for their disabled children. This study was designed to assess the challenges faced by Nigerian parents with disabled children, in caring for them. This will help in making recommendations to government and nongovernmental bodies on ways to help alleviate the stress and challenges of parents with disabled children and also to make recommendations for practitioners from a developmental social work perspective regarding the experiences of parents who care for children with physical disabilities.

## 2. Materials and Methods

The sample for the study was drawn from the population of parents/guardians bringing their physically challenged children for Physiotherapy at the Physiotherapy treatment at the Federal Medical Centre, Owerri, Nigeria, as well as online poll from a Facebook group comprising of Nigerian parents with physically challenged children. The group that goes by the name "Super Parents" is a social media group comprising of parents of physically challenged children who come together to share ideas and draw encouragements from each other on how to cope with these children.

A questionnaire designed to gather relevant information was served to the study population. The questionnaire contained related questions to this aspect of parenting in a view to further understand challenges faced by parents/guardians in caring for their physically challenged children and how such challenges impact on these parents/guardians. Each questionnaire contained a consent form which explained the purpose of the research and reassured the participants of utmost confidentiality and participants were meant to understand that participating in the research was solely voluntarily, while seeking their consent for the information provided to be used for the research purpose.

The questionnaires were distributed physically to the parents/guardians at the Physiotherapy Department of FMC Owerri and were collected the same day after the participants filled them out. Online participants filled out the same questionnaire form through a link which was created for this research purpose and posted to the "Super Parents" platform together with the informed consent form. The data collected were analysed in terms of frequencies and percentages

using Statistical Package for Social Sciences (SPSS) [window version 15.0 Chicago IL, USA] and presented in tables in the result section.

### 3. Results

**Tables 1-10** below show the demographic characteristics of participants and their responses to the questions posed in the questionnaires which were constructed to obtain relevant information as regards the objectives of this study.

**Table 1.** Gender distribution of respondents.

Gender	Frequency	Percentage (%)
Male	6	8.3
Female	66	91.7
Total	72	100

**Table 2.** Gender distribution of disabled children.

Gender	Frequency	Percentage (%)
Male	40	55.6
Female	32	44.4
Skipped	0	0.00
Total	72	100

**Table 3.** Age distribution of disabled children when difficulty was noticed.

Age (years)	Frequency	Percentage (%)
From Birth	32	44.4%
0 - 1	20	27.8%
1 - 2	12	16.7%
2 - 3	4	5.6%
3 - 6	4	5.6%
7 - 10	0	0.00%
11 - 15	0	0.00%
Total	72	100

**Table 4.** Marital status of respondent.

Status	Frequency (no.)	Percentage (%)
Single	15	20.8
Married	57	79.2
Devoiced	0	0.00
Widowed	0	0.00
Total	72	100

**Table 5.** Respondent's perception of cause of child's disability.

Cause of disability	Frequency (no.)	Percentage (%)
Before or during Birth	24	33.3
Disease/Sickness	28	38.8
Injection	4	5.6
Curse by God	0	0
Juju/Witchcraft	3	4.2
Eating certain foods	0	0
Domestic Accident	0	0
Motor Accident	2	2.8
Don't know	3	4.2
Other (specify)	4	5.6
Sin/Disobedience	0	0
Skipped	4	5.6
Total	72	100

(In **Table 5**, comments gotten under other causes were: She was born healthy and suddenly developed traces, Trauma, Mismanagement after birth, Severe neonatal jaundice third day after birth, Noticed it when he started walking.)

**Table 6.** Parents' knowledge of the name of their child's disability.

Name of Disability	Frequency (No.)	Percentage (%)
Polio	0	0.00
Spinal Cord disorder	4	5.6
Autism	12	16.7
Cerebral Palsy	32	44.4
Club feet	0	0.00
Spina bifida	4	5.6
Down Syndrome	4	5.6
Don't Know	8	11.1
Others( specify)	4	5.6
Skipped	4	5.6
Total	72	100

The comments under others were; Erb's palsy, Hydrocephalus.

**Table 7.** Functional challenges/difficulties noticed in disabled children.

Name of functional challenge	Yes		No		Total
	(%)	(No.)	(%)	(No.)	
Visual Impairment	0.00	0	100	72	72
Hearing Impairment	22.2	16	77.8	56	72
Communication Impairment	72.2	52	27.8	20	72
Mobility Impairment	66.7	48	33.3	24	72
Daily life Activities Impairment	66.7	48	33.3	24	72
Intellectual Impairment	83.3	60	16.7	12	72
Emotional/Psychological Impairment	41.7	30	58.3	42	72

**Table 8.** Challenges experienced by parents of disabled children.

Challenges	Level of Challenges				Total
	Always	Sometimes	Never	Don't know	
Does the disability place financial pressures on your household?	61.1% (44)	33.3% (24)	5.6% (4)	0.0% (0)	72
Does family argue because of the disability?	5.6% (4)	72.2% (52)	22.2% (16)	0.0% (0)	72
Does your family have enough information to understand the disability?	27.8% (20)	27.8% (20)	33.3% (24)	11.1% (8)	72
Do you often feel guilty for your child's condition?	22.2% (16)	55.6% (40)	22.2% (16)	0.0% (0)	72
Do your family members feel fine to help your disabled child?	55.6% (40)	27.8% (20)	5.6% (4)	11.1% (8)	72
Do the thought of your child's condition often get you depressed?	33.3% (24)	61.1% (44)	5.6% (4)	0.0% (0)	72
Does your child feel isolated as a result of social perception of your child's condition?	38.9% (28)	50.0% (36)	5.6% (4)	5.6% (4)	72
Have you been discriminated by families & society?	5.6% (4)	72.2% (52)	16.7% (12)	5.6% (4)	72
Do you experience physical exhaustion?	44.4% (32)	38.9% (28)	11.1% (8)	5.6% (4)	72
Have your child ever been refused entry into school/social gathering because of his/her disability?	11.1% (8)	22.2% (16)	61.1% (44)	5.6% (4)	72

**Table 9.** Difficulties experienced by parents of disabled children in coping with daily and functional activities.

Difficulties	Level of Challenges				Total
	Always	Sometimes	Never	Don't know	
Difficulties with maintaining focus	33.3% (24)	38.9% (28)	27.8% (20)	0.0% (0)	72
Does your child's condition hinder you from learning & acquiring new skills	23.5% (16)	35.3% (24)	41.2% (28)	0.0% (0)	68
Do you experience challenges using public transportation to move around with your child as a passenger	41.2% (28)	23.5% (16)	23.5% (16)	11.8% (8)	68
Does it affect your care for your own health	22.2% (16)	22.2% (16)	55.6% (40)	0.0% (0)	72
Does it affect your domestic life (eg: taking care of your other children, preparing & cooking meals, doing housework like washing and cleaning)	33.3% (24)	33.3% (24)	33.3% (24)	0.0% (0)	72
Does it affect you in getting and keeping a job (work & employment)	27.8% (20)	22.2% (16)	44.4% (32)	5.6% (4)	72
Does it affect your social interaction with others	27.8% (20)	16.7% (12)	44.4% (32)	11.1% (8)	72
Does it affect your religious/spiritual activities	38.9% (28)	27.8% (20)	33.3% (24)	0.0% (0)	72

**Table 10.** Measures that make it easy for disabled children and their parents to cope with daily activities.

CODE	RESPONSE PERCENTAGE (%)		RESPONSE FREQUENCY (No.)	
	YES	NO	YES	NO
SS—Social Support	6.9	4.2	5	3
AD—Assistive Devices	38.9	2.8	28	2
MS—Mental Strength	6.9	1.4	5	1
FS—Family Support	29.2	0	21	0
PS— Paid Support	9.7	0	7	0
TOTAL RESPONSE	91.6	8.4	66	6

**Table 10** shows the measures adopted by parents of disabled children in order to cope with daily activities of parenting their disabled children. 38.9% of parents reported that assistive devices help them and their disabled children to cope with daily activities, 29.2% of the parents reported that family support helps them to cope with daily activities, 9.7% of parents reported that paid support helps them, 6.9% of parents reported that social support helps them and 6.9% of the parents also reported that mental strength of their children help them to cope with daily activities.

#### 4. Discussion and Conclusion

Our study revealed that parenting disabled children can be very stressful as there are lots of challenges faced by parents of disabled ranging from emotional and financial stress, lack of supports, discrimination, loss of social life and others which result in psychological problems, depression, physical exhaustion and reduced quality of life. Challenges faced by Nigerians parenting children with disabilities are not different from those of such parents from other parts of the developing world.

In this study, financial pressure appears to be the most prevailing challenge faced by parents of disabled children in Nigeria. 61% of our respondents complained of financial burden placed on the family as a result of caring for their disabled children. The fact that most of them have no support from the government and social societies makes their job of caring for their children with disabilities, a very difficult task. Previous studies (Lecavalier et al., 2006; McCubbin & Patterson, 1982; Ludlow, Skelly, & Rohleder, 2011) have supported financial pressure as one of the major challenges faced by parents of children with disabilities as there is generally, lack of resources or support from government and other external organizations. The financial constrain is reflected in the fact that only 28 of our participants which is just 38.9%, could afford to provide Assistive devices to help in caring for their disabled children and only 7 could afford the services of paid help.

Most of the mothers cannot engage in any profitable job or business as reported by 50% of our respondents and supported by Ludlow et al. who reported that most of the parents/caregivers in their study find it difficult to acquire new skills or get and keep a job and that most of the mothers quit their jobs in order to enable them to care for their special kids. This means more financial difficulties and more depression as reported by 64.5% of our respondents.

Depression in parents of disabled children could also result from discriminations meted on their disabled children by the society. Some researchers (Tali, 2002; Abosi, 2007; Clever & Herna, 2017; Boyd, 2017; Büttner & Hasselhorn, 2011; Bower & Hayes, 1998; Dumont, & Provost, 1999; Bayat, 2014) noted stigmatization on disabled children which could affect these children and their parents both emotionally and psychologically. About 94.4% of our respondents reported haven experienced discrimination at one time or the other. 41.2% of the respondents complained of difficulty with public transport, segregation and social discriminations, with 11.1% of parents claiming their children being refused entry into schools and social gatherings. Ludlow et al. (2011) recorded similar response, with 11 out of 20 parents interviewed, reporting unpleasant reactions from people against their disabled children. They reported that reactions and judgments from people were the difficult aspect of challenges they face as a result of their autistic children. As described by the social model of disability, people's attitude and behavior towards people with disability contribute immensely to disabling individuals with disability. Ludlow et al. (2011) reported that 43.24% of their responding parents described people's attitude towards them and their children as a disabling factor that makes it harder for them to participate in their community.

Lack of physical support in caring for their disabled children leaves the carers, especially the mothers, physically exhausted as reported by 85.3% of our respondents. Caring for disabled child is time consuming and the carer, who is most of the time the mother, does not have time to care for herself as she may need to also care for her other children alongside the disabled one. Most of the mothers in our study reported that they hardly have time for themselves and their social lives are halted by caring for their disabled children. There is difficulty in finding child minders and schools for children with special needs are almost non-existing in our society.

Feeling of guilt for the child's condition as reported by 77.8% of our respondents might also be one of the causes of depression in parents caring for their disabled children. Most of the parents blame themselves for their children's conditions. A good number of the respondents (77.8%) reported arguing in their families over the children's disabilities. The feeling of guilt and the blame game/argument might be as a result of lack of proper information and education on their children's conditions as 33.3% of our respondents reported that they do not have proper information on their children's conditions.

There is therefore need for healthcare givers who attend to disabled children,

to educate the parents on their children's conditions, the causes and also enlighten the masses and the parents/caregivers of physically disabled children on the social model of disability and how disability can be channeled to ability.

There is need for Nigerian government to take into consideration, the plights of the disabled in the society and make available facilities to ease the challenges faced by this population. Healthcare and educational facilities should be made available and affordable to ease the stress of parents caring for their disabled children. Healthcare providers in the country should create awareness among women attending antenatal clinic in their facilities on complications that could arise from pregnancy and could lead to disabilities in their babies, and ways to identify and avoid these complications. Pregnant women should also be educated on early signs of jaundice and other infant diseases that could lead to disabilities.

Awareness should be created in our schools and social places on the dangers of discriminating against children living with disabilities as it affects both the children and their parents adversely. Schools should be taxed with the duty of making children with disabilities comfortable by providing accessible amenities and ensuring that other children do not discriminate against them. Religious leaders should be enlightened and mandated to encourage their members not to discriminate against people with disabilities but rather to encourage such parents as their supports go a long way to alleviate the stress of caring for their children with disabilities.

Public transports should be mandated, by law, to have seat reservations for people with disabilities or parents carrying children with disabilities.

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## **Conflicts of Interest**

The authors declare no conflicts of interest regarding the publication of this paper.

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