

# **CHALLENGES FACED BY CHILDREN WITH SPECIAL NEEDS IN GHANA AND THE SUPPORT SYSTEMS AVAILABLE TO THEM AND THEIR FAMILIES**

## **Abstract**

### **Background**

Children with special needs have longstanding physical, developmental, emotional, and behavioural problems that require attention. Caring for these children can be overwhelming, thus, support systems are needed to ease the burden and improve the quality of life of the children and their caregivers.

### **Aim**

To examine the problems of children with special needs and identify the support systems available to them through their families, friends, governmental and non-governmental institutions.

**Study Design:** Cross-sectional study

**Place of study:** Korle-Bu Teaching Hospital, the Special Mothers Project Group and With God Physiotherapy and Care Center, Accra, Ghana from May-June 2018

### **Methodology:**

The study was conducted in 2019 among 64 caregivers of children with special needs at the three sites using purposive sampling. A questionnaire was designed for data collection. The data were summarized using descriptive statistics.

### **Results**

Developmental conditions encountered were cerebral palsy 24(38%), seizure disorder 15(23%), speech delay 5(8%), Down's syndrome 3(5%), ADHD 2(3%), autism spectrum disorder 1(2%), 4(6.3%) unspecified and 10(16%) others. Caregivers reported problems with delayed development, feeding, health, speech, intellectual capacity, and behavior including social

interaction. About half, (52%), had assistance in caring for their child at home mainly through family, 22% received financial assistance, while 10.9% had access to specialized care. More than half, 33 (52 %) were reported to have some form of nursery or mainstream school placement and one was in a special school. Speech and Language therapy and physiotherapy were the most used forms of rehabilitation. Financial support from government and other institutions was limited but 42.2% had access to support groups.

## **Conclusions**

The most significant problem for caregivers was their child's developmental problem. While the family remained the most dependable source of support, support groups, therapy services and school placements were also available but uptake was sub-optimal and external financial support was limited.

**Keyword:** caregivers, developmental disorders, delay, support, challenges, special needs,

## **INTRODUCTION**

Children with special needs are vulnerable children who require special care and attention. They include children who have special educational needs, that is, learning difficulties or disabilities that make it harder for them to learn than most children of the same age; or disabilities which prevent or hinder them from making use of educational facilities generally provided for their age mates [1]. McPherson et al. also, defined children with special health care needs as those who have or are at increased risk for chronic physical, developmental, behavioural, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally [2]. Developmental conditions associated with special needs include cerebral palsy, Trisomy 21(Down's syndrome), seizure disorders, attention deficit hyperactive disorder (ADHD), autism, and others. The Organization for Economic Cooperation and Development further categorizes children with disabilities into three distinct groups which include disabilities for which there is substantive normative agreement such as blindness, deafness and severe intellectual impairment; disabilities that are manifested as difficulties in

learning and disabilities that are as a result of socio-economic, cultural, and linguistic disadvantages [3].

Global estimates suggest that over a billion people representing approximately 15% of the world's population are living with moderate to severe disability out of which 93 million (5.1%) occur in children 0-14 years, with 13 million (0.7%) having severe disease [4]. In addition, an estimated 1.2% of the global burden occurs in persons 0-14 years old living in Africa. The prevalence rates of all forms of developmental disabilities in sub-Saharan Africa are reported to range between 11 to 60 per 1,000 children [5]. According to the United States (U.S) national survey on children with special health needs in 2013, 23 percent of all households in the U.S. who have children will have at least one child with special health care needs [6]. The survey also revealed that the children aged five years and below had the lowest prevalence of special health care needs, (9.3 percent) and this was followed by children aged between 6 and 11 years (17.7 %). The highest prevalence was among those aged 12-17 years (18.4%). Furthermore, more boys (17.4 percent) than girls (12.4%) were affected [6].

The needs of children with special needs cut across Maslow's hierarchy of needs and are stratified as physiological, safety, love and belonging, esteem and self-actualization. This is represented in a pyramid, at the base of which are the physiological needs [7]. Furthermore, the reason for their being special is because of some extra needs they have that require special attention. These can be classified into broad categories such as care needs, educational needs, and emotional and social needs. Developing support systems for children with special needs often poses a challenge to the government, families, and various institutions as every child has their own peculiar needs, moreover, these needs are shared by the family [2]. Over the years, studies have been conducted on the challenges and difficulties faced by caregivers of children with developmental conditions in Africa. This includes studies from Kenya, [8,9,10], Swaziland [11], Namibia [12], Nigeria [13] Ghana [14,15,16] and other parts of Africa [17]. The majority of these studies were qualitative and used sample sizes of 30 or less. They showed that caregivers faced challenges of social exclusion from stigma, difficulties with accessing care, financial problems, and stress, among others.

According to the Lein foundation's inclusive survey in Singapore, majority of the care burden falls on the mothers of children with special needs who are mostly the primary caregivers [18]. Most of them struggled to find information on what to do next or who to contact after their child's diagnosis. One in two parents was able to find and use available services and programs. Beyond the burden of caring for their children, families sometimes had limited capacities and resources to handle the care needs of their children with special needs. Other prominent concerns were financial needs, social acceptance and combining the care of other children in the family [18,19]. Thus, the impact of the needs of these children extends beyond themselves to their families and society at large [19]. Though there are several support systems in Ghana for children with special needs, it is not clear whether they access these services as literature on the subject is limited information. Therefore, this study sought to assess the challenges faced by children with developmental conditions as reported by their caregivers and explore the support systems available to them and their families.

## **METHODS**

### **Study Design**

The study was a descriptive cross-sectional study conducted at the Korle-Bu Teaching Hospital, the Special Mothers project group, and the With God Physiotherapy and Care Center in Accra. It was conducted from the 7<sup>th</sup> of May 2018 to the 7<sup>th</sup> of June 2018 using questionnaires.

### **Study site**

Korle Bu Teaching Hospital is the third largest hospital in Africa. It was established on October 8, 1923, and is located in Accra, Ghana. From an initial bed capacity of 200 beds, it currently has 2000 beds, 21 departments and three centres of excellence. The average daily attendance to the hospital is 1500 patients and around 250 patients are admitted in a day [20]. The Department of Child Health (DCH), is one of the clinical departments at the hospital. It is a tertiary referral center for children with medical problems. It runs 6 specialty clinics including a neuro-developmental clinic which runs on Mondays from 9 am to 1 pm. About 31 patients are seen at each clinic per an appointment system as well as occasional walk-ins. At the time of the study, it mainly attended to children aged 0-12 years old.

The Special Mothers Project is a support group as well as an advocacy and awareness creation group on cerebral palsy based in Accra. It was founded by Mrs. Hannah Awadzi and had up to 120 mothers enrolled at the time of the study. The group has quarterly meetings and handles issues affecting these mothers and the care of their children. They also receive training from professionals on the care of their children at home. The With God Physiotherapy and Care Center was established in May 2017 and is managed by a member of the Special Mothers Project. It catered for 10-15 children at the time of the study and is a private facility, providing care and rehabilitative services for children with cerebral palsy.

### **Sampling strategy**

Purposive sampling was used in this study. This sampling method was adopted because of the difficulties anticipated in obtaining adequate numbers of study participants due to a general reluctance of families of children with disability to participate in research.

### **Study Population**

The study included primary caregivers of children aged 0-17 years with Down syndrome, Autism Spectrum Disorder (ASD), Attention Deficit Hyperactive Disorder (ADHD) and Cerebral Palsy present at the three (3) study sites at the time of the interviews who expressed their willingness to take part in the study. This age range was selected based on the legal definition of a child according to the Children's Act 1998 in Ghana which defines a child as anyone below the age of 18 years [21]. For this study, primary caregivers were mothers, fathers, grandparents, other relatives, foster parents, and guardians who had the main responsibility of caring for the well-being of a child with special needs. They also had to be attendants at either, the neuro-developmental clinic of the Korle-Bu Teaching Hospital, the Special Mothers Project meeting or mothers who had their children at the With God Physiotherapy and Care Center.

Primary caregivers who were not present at the time of the interviews were excluded from the study. Only one caregiver was allowed to be a respondent for each child after which informed consent was obtained. Caregivers who declined were not part of the study. Though the interviews focused mainly on the caregivers of children with the selected neuro-developmental conditions, due to difficulties obtaining adequate numbers of participants, some caregivers of children with neurodevelopmental conditions with unknown diagnoses and neurological conditions other than

the ones mentioned above such as seizure disorder, stroke from sickle cell disease and others who were willing to participate, were included.

### **Data Collection Instrument and Methods**

The data was collected with a questionnaire that had 30 questions grouped in sections. The questions included questions on demographic information such as age, sex, and marital status of caregivers. Information was also sought on the child's health problems such as feeding problems and other medical problems. The various support systems including support from family, governmental and non-governmental institutions, therapy services and educational placement that were available and accessed by the caregivers were also interrogated.

The interviews were carried out throughout the study period by the principal investigator and her trained assistant after recruiting primary caregivers of children from the Paediatric Neurodevelopmental Clinic at the Department of Child Health, Korle-Bu Teaching Hospital. Members of the Special Mothers Project were interviewed during one of their meetings. Caregivers attending the With God Physiotherapy and Care Center at Teshie in Accra were also interviewed around the same time.

### **Data handling, Analysis and Presentation**

Questionnaires were checked to ensure that they were fully completed. The data collected were entered into a database and analyzed using the Statistical Package for Social Sciences (SPSS) application version 21.0. The data were presented in frequency tables, and charts using Microsoft Excel software version 2010.

### **Ethical Consideration**

The protocol was designed and approved by the Department of Community Health, School of Public Health (now part of the University of Ghana Medical School). It then went through an approval procedure for student projects laid down by, Korle Bu Teaching Hospital. As part of this process, the proposal was sent to the Central Administration of the hospital. From there, it was sent to the Department of Child Health to be reviewed. After obtaining approval from the Department of Child Health, the hospital administration granted approval and a fee was paid to the hospital. Permission was also obtained from the founder of the Special Mothers project, and the owner of the With God Physiotherapy and Care Center. Written consent was obtained from

all the caregivers before they were recruited, and confidentiality was ensured. The research topic, aims and benefits were explained to caregivers. They were informed that their participation was entirely voluntary and that they could stop at any time without any consequences on their child's healthcare.

## RESULTS

### Socio-demographic characteristics of the respondent

Altogether a total of 64 caregivers were interviewed. This included 48 (75%) from the pediatric neurology clinic at the Korle-Bu Teaching Hospital, 14(22%) from Special Mothers' project and 2(3%) from the With God Physiotherapy and Care Center in Accra. The majority, 57(89%) of the caregivers were between the ages of 25-45 as shown in Table 1. A similar proportion of caregivers (85.9%) were married (Table 1). About half, 34(53.1%) of the children of the caregivers interviewed were five years or younger, while 15(23.4%) were between 6 and 10 years. The socio-demographic characteristics of the caregivers and their children are reported below (Table 1).

**Table 1: Socio-demographic characteristics of respondents and their children**

CHARACTERISTIC	FREQUENCY	PERCENTAGE (%)
<b>Gender of Caregivers</b>	<b>N=64</b>	
Male	14	21.9
Female	50	78.1
<b>Age of caregivers (years)</b>		
<15	0	0
15-24	1	1.6
25-35	18	28.1
36-45	39	60.9

> 45	6	9.4
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### **Marital Status of Caregivers**

Single	4	6.3
Married	55	85.9
Divorced	5	7.8

### **Occupation of caregivers**

Traders/Business Men And Women	23	35.9
Teachers	5	7.8
Seamstress	4	6.3
Health Workers	4	6.3
Banker/Accountant	3	4.7
Others	18	28.1
Unemployed	7	10.9

### **Age of children (years)**

>13	5	7.8
11-13	10	15.6
6-10	15	23.4
≤ 5	34	53.1

### **Developmental Conditions of the Children**

Cerebral Palsy	24	37.5
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Seizure Disorder	15	23.4
Speech and Language Delay	5	7.8
Down's Syndrome	3	4.7
Attention Deficit Hyperactivity Disorder (ADHD)	2	3.1
Autistic Spectrum Disorder	1	1.6
Unknown Diagnosis	4	6.3
Others	10	15.6

### **Developmental conditions**

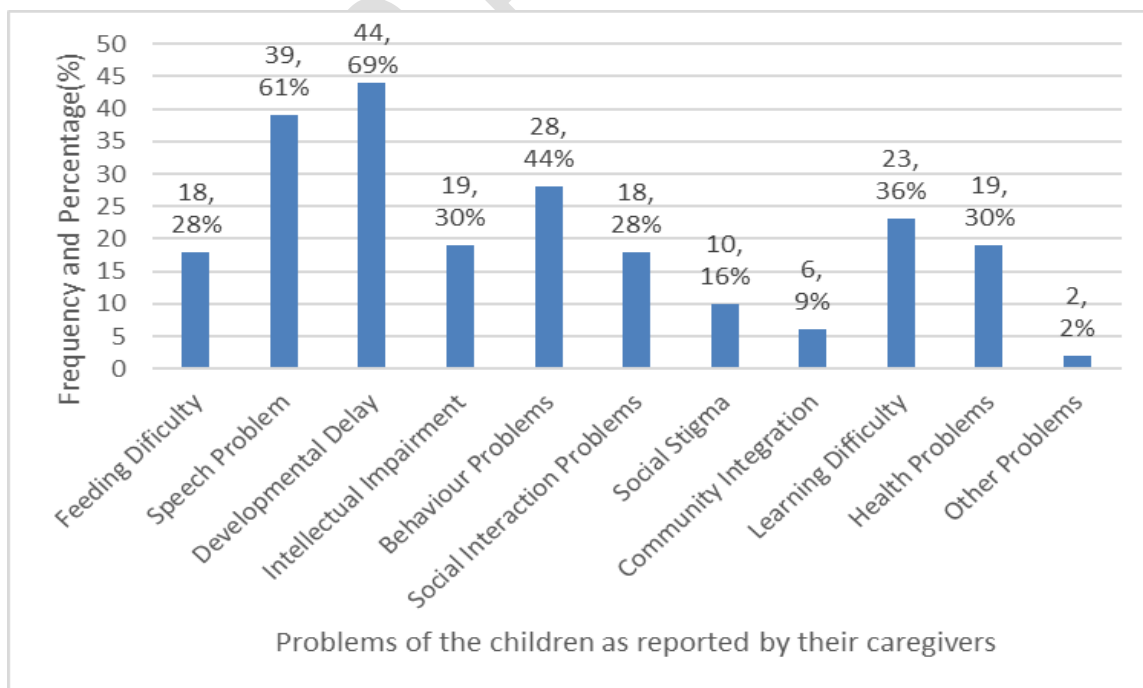
The developmental conditions of the children of the respondents as shown in Table 1 include cerebral palsy 24(37.5%), seizure disorder (main diagnosis) 15(23.4%), speech and language delay 5(7.8%), Down's syndrome 3(4.7%), ADHD 2(3.1%), autism spectrum disorder 1(1.6%), and others 10(15.6%). Four (6%) of the caregivers did not know the diagnosis of their child's condition. Among the diagnoses given for the group labeled as others were cases of perinatal asphyxia (possibly with an evolving motor disorder), microcephaly, muscular dystrophy, stroke from sickle cell disease and learning difficulty.

### **Problems and challenges faced by children with special needs.**

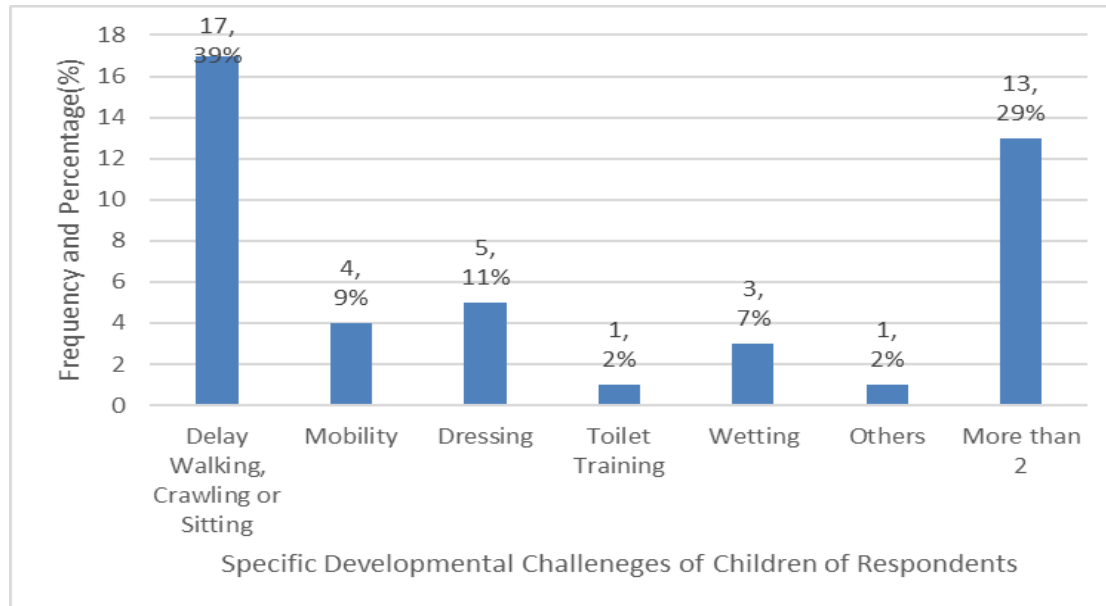
The problems reported by the caregivers of the children are presented in Figure 1 (multiple responses were applied). Many of the caregivers, 44 (69%), reported delayed development as a major problem. In addition, 39 (61%) of respondents reported speech problems, while 18 (28%) of the children were reported to have feeding problems and a similar proportion, 18 (28%) had social interaction difficulties. Twenty-three (36%) caregivers reported that children experienced learning difficulties i.e., specific problems related to learning at school such as reading and writing while intellectual impairment (perceived problems with intelligence in children) was reported as a problem by 19 (30%) caregivers; even though both terms are sometimes used interchangeably. Ten (16%) out of the 64 caregivers reported social stigma as a major problem

and 2 respondents had other problems. Altogether, 28(44%) of the children had behavior problems out of which the majority were reported to be aggressive, 15(54%), while 7(25%) were hyperactive and 3(11%) of them had repetitive behaviours. Four of these children were reported to have two or more behavior problems and with some patients, the delay reported occurred in more than one area of development.

Other specific developmental challenges reported by caregivers were delays in walking and sitting (39), mobility problems (9), dressing (11), toilet training (2), bed wetting (7) and others (2) as summarized (Figure 2). In all, 19 of the children participating in this study also experienced various co-morbid conditions or health problems. Five (5) of them (26%) were reported mostly to have had infections, 3(16%) had problems associated with congenital anomalies and two (11%) had nutritional deficiencies. Among the 9 (47%) children with other health problems, one (1) had asthma, two (2) had a seizure disorder, one (1) had a recurrent ear problem and one (1) child with cerebral palsy had jaundice, however details of the cause of the jaundice was not provided, whilst four (4) of these respondents (21%) did not specify the co-morbid health problem their children had. The school placement, rehabilitative services and other forms of support reported by respondents are summarized in Table 2.



**Figure 1: Problems of the children as reported by their caregivers (n=64).**



**Figure 2: Specific developmental challenges of the children of respondents**

**Table 2: School placement, rehabilitative services and support reported by respondents.**

Category	Frequency	Percentage
<b>School Placement</b>	<b>N=57</b>	
Not in any school Placement	24	42.1
Creche	4	7.0
Nursery	4	7.0
Mainstream school	24	42.1
Special school	1	1.8

<b>Rehabilitation services</b>	<b>N=64</b>	
No service	23	36.0
Physiotherapy	16	25.0
Speech and language therapy	18	28.1
Occupational Therapy	-	
Other	7	10.9
<b>*Support systems</b>	<b>N=64</b>	
Support with home care	33	51.6
Access to specialized care	7	10.9
Financial assistance	14	21.9
Support groups	27	42.2
Awareness of supportive policies	47	73.4
<b>Individuals/organizations who provided the most support.</b>	<b>N=56</b>	
No support	5	8.9
Husband	22	39.3
Wife	6	10.7
Parents	8	14.3
Siblings	4	7.1
Aunties	2	3.6
In-laws	1	1.8

Other Family	<b>4</b>	<b>7.1</b>
Friends	<b>2</b>	<b>3.6</b>
Church	<b>2</b>	<b>3.6</b>

N refers to the number of caregivers who responded to the question

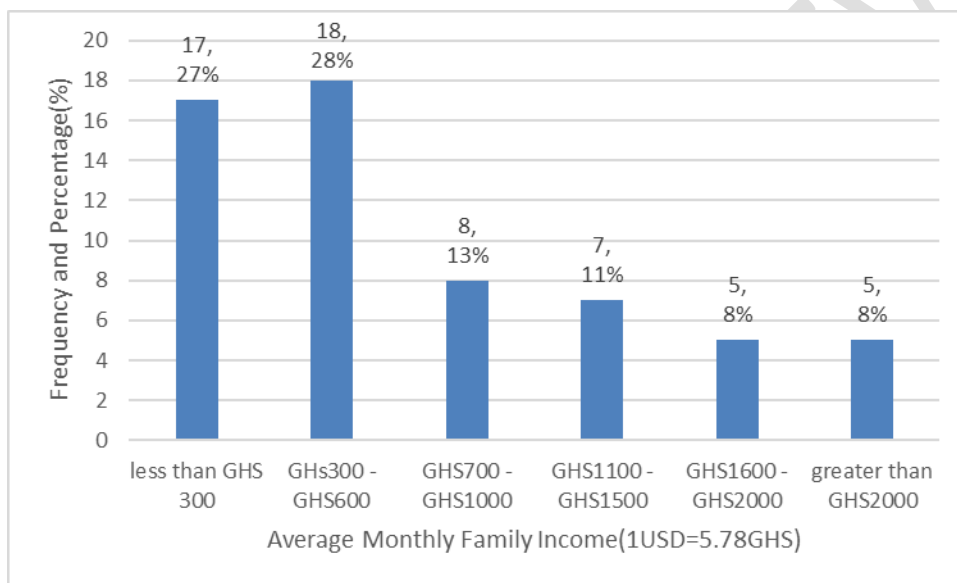
\*Multiple responses apply

Of the majority of children in a school placement in this study, 24(42.1%) were in mainstream schools. A similar proportion of children 24(42.1%) were not in any school placement at all. Those not in a crèche, nursery, or school included fourteen (14) preschool children under the age of 5 years and ten (10) school-aged children (5 years and above). Over a third, 36% (23) did not use any rehabilitative services. For those who used these services, speech and language therapy (28.1%), and physiotherapy (25.0%) were the most used forms of rehabilitation. Occupational therapy was not readily available and thus was not used by any of the participants. Clinical services such as ophthalmology clinics, neurology clinics, orthopedic services, and psychology services were available and used by participants. Few children had access to financial support (14) or specialised care (7) such as special schools, individualized care from social welfare services, and counseling services.

Table 2 also shows the individuals and organisations who provided the caregivers with the most support. About half of the 33 respondents had some form of assistance at home, and out of these, the majority of the help, 45%, representing 15 caregivers, came from the nuclear family; twelve (36%) others were assisted by extended family, 3 (9%) were assisted by house helps, 2(6%) had assistance from a nanny, while 1(3%) had other forms of help. The majority of the respondents, 35(55%), reported that their family members were their first point of call in crises. The rest reported that they will call on friends, the church, a doctor or family physician, their support groups or report to the hospital in crises. Some did not have any immediate point of call in crises. The most supportive individuals were reported to be the husbands of caregivers.

As shown below (Figure 3), only five (8%) out of the 64 respondents, had an average monthly family income of more than GHC 2000, similarly, only 5 (8%) had an income between GHC

1600 and GHC 2000 (1USD = 5.78GHC). More than half of the respondents 35 (55%) were in the lower bracket of 600 GHC or less. Four (6%) of them could not estimate how much the family generates within a month. In addition, only 28% of the respondents reported that their average monthly family income was sufficient while 72% of them said the monthly income was insufficient. The number of caregivers who did not have sufficient income but had access to some additional forms of financial assistance was 10 (24%) while the majority, 31 (76%) of respondents had no access to additional financial assistance. Those with some form of assistance mostly received it from family, reported by 10 (71%), respondents, financial institutions reported by 2 (14%), with support from friends and non-governmental Organisations (NGOs) reported by only one respondent each.



**Figure 3: Average income of families with children with special needs.**

A total of 47 respondents, (73.4%), were aware of one or more of the government policies relating to special needs while 15 of them (23%) had no idea about the policies and two were unsure whether they knew about them or not. In all, 53 (85%) of the caregivers knew about the Disability Act 715, Ghana, 8(13%) of respondents knew about the UN Convention on the Rights of people with disability, and knowledge about the Inclusive Education Policy was reported by 18% (11).

## **DISCUSSION**

The majority of the children whose parents were interviewed were under the age of 5 years which is a very sensitive period of child development, requiring a lot of attention and care. An article by Sylva, referring to Piaget's study of mental development in children, noted that between the ages of 0-6, several factors are present that affect the development of a child [22]. Care needs which include the health and self-care needs of these children are multiple. In this study, caregivers reported challenges with their children's problems including delayed development, feeding, health, speech, intellectual capacity, and behaviour, such as social interaction. This is in consonance with Fernald et al.'s, report that the development of a child with special needs may be delayed as compared to other children their age and are affected by positive and negative factors in the environment such as maternal education, household wealth and parental support [23]. The results from this study showed that developmental delay in general was the most disturbing challenge for parents, followed by speech problems. For as long as they remain delayed and are growing to catch up, the children require support to care for themselves, move about, dress, learn how to talk and communicate effectively making them dependent on the parents for a greater than-expected time of their lives. Furthermore, not having the knowledge to deal with the problem or make appropriate educational decisions adds to parental stress [11]. Even though several co-morbid conditions existed with these conditions, the major health concerns identified were infections, similar to what most children in the tropics experience.

According to WHO, the emotional and social needs of a child with special needs consist of communication problems, self-esteem, social stigma, and societal neglect and children may have a mixture of these problems [24]. More than a fourth (28%) of the children demonstrated challenges with social interaction which generally affects their ability to play, make and build friendships and communicate with others. Pijl et al. in a paper on the social position of pupils with special needs in regular schools reported that children with special needs do not have many friends, they are less often seen engaging in sub-group activities and are likely to be found isolated in groups [25]. Some caregivers in this study (16%) reported that they had experienced some form of social stigma.

The family (both nuclear and extended) remains the backbone of support for parents and caregivers of children with special needs. This strong support system helps to minimize the impact of the condition and the burden of care is shared. There was very limited external support for families in this study similar to reports from Kenya and Namibia [8,12]. Additionally, less than half of the caregivers received support from support groups as this concept is new in Ghana. Many of the respondents did not know other families with children with special needs and only 27(42.2%) knew and belonged to a support group limiting access to parent-to-parent support. According to Damanyanti and Pankaj, studies have demonstrated the effectiveness of parent-to-parent support in helping families raise their children with special needs [26]. A study of support groups for children with cerebral palsy in Ghana reported that these groups could provide an alternate form of social network for caregivers no matter how complex their situation is [15].

Finances are a major requirement and essential for meeting the care needs of children with special needs. [10,13,27]. When the Ghana Persons with Disability Act (Act 715) was introduced in 2006, it was expected that the Act would provide a legal framework to meet the needs of people with disabilities, and partly fulfil Ghana's constitutional and international obligations to protect people with disabilities [28]. However, the study found that the majority of the respondents had insufficient funds to take care of the needs of the child and yet, most parents did not have access to any kind of additional financial support. For the few that had, they depended mainly on their families for support. The government of Ghana has introduced a support system for needy children and children with cerebral palsy through the Livelihood Empowerment Against Poverty (LEAP) Programme [29]. In addition, 3% of the district assembly common fund is set aside for persons with disability but caregivers have to put in an application to get it. These forms of support are available at the local government level through social welfare services. Unfortunately, it appears that these caregivers were either not aware of the role of social services and these provisions or did not have access as has previously been reported [30]. A lack of awareness of services and policies was also found in the Namibian study emphasizing the need to empower caregivers with knowledge [12].

The country has an inclusive education policy which was developed by the Ministry of education in partnership with other agencies to guide the government's provision of education for all children with special educational needs [31]. The policy was fully adopted in 2012 [32] and was

reinforced by the ratification of the UN Convention on the Rights of Persons with Disabilities in 2012 [28]. Altogether, 42% of the children were not attending any crèche, nursery or mainstream or special school. School or nursery placement and playgroups are important for the education and socialization of children with special needs as well as providing respite for caregivers. Schools can also provide stimulation for development, particularly speech and language skills especially when special services are offered [33].

Nursery placement in Ghana is provided by private operators and is expensive for some families. Furthermore, not all nurseries are prepared to take children with special needs. Those with facilities for providing special education come with additional costs. For those who start mainstream school, some drop out on the way [16]. This is possibly why some of the children were not in any form of educational placement. A multi-country study in 30 countries worldwide, found that children above 5 years with disabilities were less likely to attend school [17]. A study in Kenya also found that access to schools for children with disabilities was lower than for those without disabilities and a greater proportion of school-aged children with various disabilities did not attend school [33]. Therefore, additional effort must be made to ensure that children with special needs are supported and able to access nursery or school. There was also minimal access to special care services for children with special needs in the study.

This study, like others, was limited by the general reluctance to participate in research possibly due to social stigma [27]. For this reason, we included some caregivers who were willing to participate but were uncertain about their child's diagnosis. Another limitation was, the non-probability sampling method used which makes the findings mainly relevant to children with special needs within this context, limiting the ability to generalize the findings. However, our findings were similar to the findings from other reports. The study also relied solely on the report of caregivers.

## **CONCLUSION**

The challenges of children with special needs in this study were varied but similar to other reports. They ranged from problems with delayed development and intellectual function to health needs, finance and behavioural problems but the most significant for caregivers was their child's developmental delay and speech problems. Not all children had access to rehabilitative services,

nursery or school placement and external financial support. More than half of the caregivers were in the low-income bracket and almost three-quarters reported insufficient income with only about a quarter receiving financial support. For most caregivers, the family remained their single and most dependable source of support. More effort must be made to link caregivers to social services, strengthen family support, create awareness of support groups, systems and policies, as well as external support, especially financial through government and educational placements. The forms of support available should be compiled and communicated to caregivers in a way that enables easy access.

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