ACCESS TO HEALTHCARE FOR CHILDREN WITH DISABILITIES IN THE
GREATER ACCRA REGION

BY

OPEYEMI RASHIDAT LASISI

(10601135)

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AWARD OF A MASTERS IN PUBLIC HEALTH (MPH) DEGREE

JULY 2017
DECLARATION

I Opeyemi Rashidat Lasisi declare that every content of this research except as appropriately cited is a result of my own original research and have not been presented either in whole or in part for any other degree elsewhere or in this school.

11th October, 2017

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Opeyemi Rashidat Lasisi      Date
(Student)

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11th October, 2017

Dr. Deda Ogum Alangea      Date
(Supervisor)
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I would like to thank God for everything: I am only a product of his grace.

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My love goes out to my fiancé Oluwaseun Kolade. I can only say God bless you.
ABSTRACT

Background and Objectives: People with disabilities have special healthcare needs that usually remain unmet. Studies have identified barriers encountered by people with disabilities in accessing healthcare. This study was aimed at identifying factors that both facilitate and hinder access to healthcare for children with disabilities [with focus on Autism, cerebral palsy (CP) and Down syndrome (DS)] in the Greater Accra region of Ghana.

Method: The study employed a cross sectional study design and it used a mixed method approach; involving quantitative and qualitative methods. The quantitative component involved administration of semi-structured questionnaires to parents/caregivers of children with Autism, CP and DS in seven (7) special schools in the Greater Accra Region. The qualitative component involved the use of in-depth interviews with parents/caregivers of children with Autism, CP and DS and key informant interviews with specialist healthcare providers.

Results: Results of a one-way analysis of variance showed that mean access score was significantly different for categories of educational level \([F (2, 35) =5.79, p=0.0067]\) and household income range \([F (2, 35) = 5.94, p=0.0060]\). Children who attended private schools had a higher mean access score [difference (S.E) = 14.03% (4.62)] compared to those who attended public school, Welch’s t-test, \(t (16.7) = 3.0372, p=0.0075\). Qualitative results identified influential health service factors as: availability of specialist healthcare provider; availability of disability friendly structures; attitude of healthcare providers; lack of coordination of care; and inappropriate service delivery processes. Individual factors influencing access were found to be cost of affording services/medications, and
perception of child’s condition. Other factors identified qualitatively were; social factors such as stigmatization and factors related to the child’s condition.

**Conclusion:** Findings from this study highlights challenges related to both access and utilization of needed healthcare services for children with disabilities. Improving access to healthcare services would thus involve a coordinated, concerted and deliberate effort on the part of the government, parents and all stakeholders involved in care for children with autism, cerebral palsy, and Down syndrome.
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<table>
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<th>Description</th>
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<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
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<tr>
<td>CP</td>
<td>Cerebral palsy</td>
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<td>CHPS</td>
<td>Community-based Health Planning and Services</td>
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<td>CRC</td>
<td>Convention on the Rights of Children</td>
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<tr>
<td>DS</td>
<td>Down Syndrome</td>
</tr>
<tr>
<td>ENT</td>
<td>Ear Nose and Throat</td>
</tr>
<tr>
<td>GAR</td>
<td>Greater Accra Region</td>
</tr>
<tr>
<td>GFD</td>
<td>Ghana Federation of Disability Organizations (GFD)</td>
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<td>GIT</td>
<td>Gastrointestinal tract</td>
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<tr>
<td>GNAD</td>
<td>Ghana National Association for the Deaf</td>
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<tr>
<td>GSS</td>
<td>Ghana Statistical Service</td>
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<tr>
<td>GSPD</td>
<td>Ghana Society of the Physically Disabled</td>
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<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<tr>
<td>IDI</td>
<td>In-depth Interview</td>
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<tr>
<td>KII</td>
<td>Key Informant Interview</td>
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<tr>
<td>MOH</td>
<td>Ministry of Health</td>
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<tr>
<td>NHIS</td>
<td>National Health Insurance Scheme</td>
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<tr>
<td>UNCRPD</td>
<td>United Nations Convention on the Rights of Persons with Disabilities</td>
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CHAPTER ONE

1.0. INTRODUCTION

1.1. Background

Disability is defined by the international classification of functioning disability and health (ICF) as an overall term for impairments that limit activity and restrict participation. It is the interplay between an individual with a health condition and his/her personal/environmental factors (WHO, 2015). It is a state of decreased functioning that is associated with disorder, injury, disease or other health conditions, which in the context of one’s environment is experienced as an impairment, activity limitation, or participation restriction (Leonardi et al., 2006). The term disability is used to characterize individual functioning and activity limitation that usually restricts the participation of disabled people in areas of physical, cognitive, sensory, and intellectual activities. A child is said to have a disabling condition if he or she has a health condition or impairment that restricts functioning in one or more areas. These areas can be in the child’s physical movement, cognitive and sensory functions, self-care, memory, self-control, learning, etc. (Vargas-Barón et al., 2009).

Over time, children living with disabilities have remained a neglected population exposed to social stigma and neglect, and other challenges such as inadequate access to health care (UNICEF, 2013). Despite the need for specialty services, children with disabilities usually encounter financial, structural and social challenges in assessing health care services. People with disabilities do not usually benefit from health promotion and prevention activities because they are scarcely targeted. For example, they are less likely to have their weights checked (WHO, 2015). Generally, young children with disabilities encounter barriers, they do not receive adequate care with regard to mainstream programs.
and services required for their development (Johnson et al., 2012). They are vulnerable to inadequate healthcare service and hence usually have unmet healthcare need. Several factors may facilitate or act as barriers in accessing mainstream and specialty health care services for children with disabilities. Some of the barriers encountered by children with disabilities and their families include inadequate policies, discriminatory attitudes, inadequate services, and inaccessible environments (WHO, 2011). Children with disabilities face challenges in accessing available, appropriate and affordable health care, and often lack health insurance for specialty care and assistive devices. Shortage of healthcare personnel in certain settings of developing countries will also influence access. If they remain unable to access timely and appropriate health care as well as early intervention, their impairment could get more severe, leading to lifetime consequences, increased poverty and a poor quality of life (Johnson et al., 2012).

The prevalence of disabilities in children is likely to be higher in poor regions and in regions of deprivation. Depending on the study and assessment tool, prevalence of child disabilities may vary from 0.4% to 12.7% in developing countries (Bornstein & Hendricks, 2013). Identifying and characterizing disability in most developing countries is challenging due to the lack of cultural and language-specific tools for assessment and also the lack of accurate data on disability. House hold surveys and censuses also do not effectively capture childhood disability. The absence of registries in most developing countries, and poor access to culturally suitable clinical and diagnostic services also contribute to lower estimates (WHO, 2011). Owing to these limitations, many children with disabilities may not be identified and may not receive the needed health care services.
Globally, over a billion people have been reported to have one form of disability or another (WHO, 2011). This accounts for about 15% of the world population. Among this population, it is estimated that 93 million children (5.1%) aged 0–14 years live with moderate or severe disabilities, with 13 million children (0.7%) aged 0-14 years experiencing severe difficulties. Among those 15 years and older, the figures were 19.4% (892 million) for those with moderate or severe disabilities and 3.8% (175 million) for those with severe difficulties (WHO, 2011). Generally, people with disabilities have lesser access to healthcare services, and because of their special and unique health care needs, they report seeking more health care and also report unmet needs than those without disabilities (WHO, 2015).

1.2. Problem Statement

In Ghana, the national population and housing census 2010, statistics show that 737,743 live with some form of disabilities thus representing 3% of the population. The data shows that there are more females (52.5%) than males (47.5%) living with some form of disability. The regional distribution show that the Volta region has the highest prevalence of disability (4.3%) while the lowest proportions were recorded in the Brong-Ahafo region (2.3%). Greater Accra and Ashanti regions both report prevalence rates of 2.6% while upper East and Eastern region are 3.8% and 3.6% respectively (GSS, 2012). Greater Accra is the country’s capital and it houses the greatest percentage of human resources for health (GHS, 2015) and also known to have the highest proportion of medical officers and nurses, yet we do not know the factors that both facilitate and hinder access to healthcare for children with disabilities.

In Ghana some studies on disabilities have been carried out. For example, Ganle and colleagues explored challenges women with disability face in accessing and using
institutional maternal health services in Ghana (Ganle et al., 2016). Also, Agbenyega, (2003) explored the power of labelling (persons with disability) and its effect on access to education, treatment, and management of persons with disability. Furthermore, (Badu et al., 2016) examined the attitudes of health service providers from the perspective of PWD in Kumasi, Ghana. Badu and colleagues also considered financial access to healthcare services among persons with disabilities in Kumasi, Ghana (Badu, et al., 2015)

The need to identify barriers encountered in accessing health care services by children with disabilities is an important issue and is relevant to article 7, 25 and 26 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) adopted in 2006 (United Nations, 2006). Given these circumstances, the need for a research on factors influencing access to healthcare for children with disabilities (Autism, CP, and DS) in the Greater Accra region cannot be overemphasized. Hence, this study seeks to add to the existing body of knowledge regarding access to healthcare among children with Autism, CP, and DS. Findings from this study is expected to inform policy and programmes aimed at addressing issues of health care access for children with disabilities.

1.3. Justification

People with disabilities have a wide range of health care access issues. They report more problems accessing healthcare services than those without disabilities. This problem of access tends to be higher among those with the poorest health and most severe disabilities (Drainoni et al., 2006).

Also, neurological conditions have been identified by the World Health Organization as a great threat to global public health (World Health Organization, 2006). It is also believed
that these conditions are more prevalent in the developing world but unfortunately the establishment of neurological services remains a significant challenge in many of these countries (Idro et al., 2010). Although early childhood is a crucial phase of life, child neurological services have not received appropriate attention at policy levels in the Ghanaian context (Wilmshurst et al., 2013). In Ghana, not all regional hospitals have access to a qualified pediatrician and child neurology services are not provided (Wilmshurst et al., 2013).

There is therefore the need to identify the individual and health service factors that both facilitate and hinder access to healthcare for children with Autism, Cerebral palsy and Down syndrome. Findings from this study is expected to inform policy makers and stakeholders in their decisions regarding programmes aimed at improving access to healthcare for children with disabilities (Autism, CP, and DS) as well as facilitating health care access plans and strategies in order to meet their overall health care needs and ensure access to available and affordable health care.

The conceptual framework adopted for this study is an adaptation of the International Classification of Functioning, Disability and Health (ICF) (Functioning and Disability Reference Group, 2010, Amin et al., 2011). The framework suggests that the relationship between activity limitations and access to health services is influenced by factors such as; the context that people live in and the existing health system (World Health Organization, 2002).
The conceptual framework shows the relationship between the dependent variable (access to health care) and the independent variables (individual and health service factors influencing access to health care). Individual factors such as highest level of education of parent/caregiver, household income range, and perception of child’s disability may directly influence access to healthcare for child. Also, health service factors which include availability of health care providers, proximity to health facilities, availability of disability friendly equipment, accessibility of national health coverage, convenience of appointment times, proximity to health facility, and communication barriers may influence access to healthcare. Parents/caregivers with lower income and lower education level may tend to have lesser access to healthcare as compared to parents with higher income and education level. Parent/caregivers” perception may also directly influence access to healthcare for child/ward.

1.5. Aims and Objectives.

General Objective

1. To identify factors that influence access to healthcare for children with autism, cerebral palsy, and Down syndrome

Specific objectives

1. To identify healthcare services available for children with Autism, Cerebral palsy, and Down syndrome

2. To identify individual (parental) factors that influence access to healthcare

3. To identify health service factors that influence access to healthcare
CHAPTER TWO

2.0. LITERATURE REVIEW

2.1. Introduction

Data on prevalence of children with disabilities are scarce. In this chapter, we therefore extrapolate information from the body of literature on population other than children and also on other disabilities other than autism, cerebral palsy, and Down syndrome. The chapter is divided into three sections: the concept of disability in children, access to healthcare and factors influencing access to healthcare.

2.2. The Concept of Disability

In the past, individuals and societies had different understandings and conceptualizations of the term disability for example; religious, supernatural, or spiritual beliefs (Goodley, 2014) were the basis for understanding the concept of disability.

In Ghana, perceptions, traditions, and cultures are the basis on which people construct disability (Agbenyega, 2003, Kwadwo et al., 2014). The construction of disability in the Ghanaian society is such that children born with disabilities as well as families of children with disabilities are regarded as cursed or possessed and this of course affects the way persons especially children with disabilities access education, treatments, and other basic needs (Agbenyega, 2003).

Recently, several models of disabilities such as; the individual model (medical model and psychological model), social model, biopsychosocial model, capability model, the human rights model, the nagi model have emerged, and of these models, the two most prominent
and most widely discussed are the medical and social models of disability (Mitra, 2006, Harpur, 2012).

The medical model of disability presents disability as an individual’s feature caused by any health conditions, diseases, or trauma. This model of disability attributes the problem/impairment to the individual and considers a medical approach as the solution/treatment/intervention (Mitra, 2006, Burger & Burger, 2010).

In the early 1980s, Oliver introduced the social model of disability. This resulted in a shift in the conceptualization of disability from individual impairment to social inclusion (Mike Oliver, 2013, Oliver & Bochel, 1991). The social model of disability considers disability not as a medical condition but as a limitations that results from an individual’s inability to participate in activities. This model consider disability as a social construct. In this model, the focus is moved from the individual to the society (Mitra, 2006). Contrary to the medical model, the social model of disability considers a change in the interaction between the individual and the society as the solution/intervention (Burger & Burger, 2010).

More recently, a more useful model of disability emerged—the biopsychosocial model. It is on this model that the International Classification of Functioning, Disability and Health (ICF) is based. This model is an integration of the two main models of disability; the medical and social models of disability (World Health Organization, 2002, Functioning and Disability Reference Group, 2010). The International Classification of Functioning, Disability and Health (ICF) is a multipurpose classification framework that describes and organizes information on functioning and disability. It is WHO’s framework for health and disability. The ICF model which has become a widely acceptable model of disability was approved by the World Health Assembly in 2001 (Functioning and Disability
Reference Group, 2010). It classifies problems with functioning into three areas: impairments, activity limitation and participation restriction. Disability is thus a term that is used to refer to impairments that results in activity limitation and restricts individual’s participation (WHO, 2015).

Variations in reported prevalence rates of disabilities across countries can be attributed to differences in defining and measuring disabilities. It is more difficult to identify disabilities in children as they develop than it is in adults hence data on prevalence of disabilities in children tend to be even scarcer. Few countries have reliable data on the statistics of children with disabilities. Thus persons with disabilities are excluded from benefiting from services they qualify for (UNICEF, 2013).

The human rights approach to disability and the social model of disability emphasizes that much beyond the impact of the child”s impairment, there exists environmental barriers in accessing basic health and social services Although the social model highlights environmental factors as influencing general health of children with disabilities, it also incorporates the component of the health system, doctors and health care professional factors. Some of the factors include the structure of health systems, prevailing attitudes and conceptions, and lack of access to buildings and transport (UNICEF, 2007).

Autism is a neurological condition that is usually diagnosed in childhood and persists through the life span of the individual. It presents as an impairment that results in difficulties in social interaction and communication (Tekinarslan, 2013, Seltzer et al., 2004).

Cerebral palsy is a neurological condition that affects the muscles of the brain and it manifests in difficulties affecting movement and muscle coordination of the body (Tekinarslan, 2013).
Down syndrome (DS) is a condition arising from an extra chromosome 21, which involves multiple congenital abnormalities. DS just like autism and Cerebral palsy continues through the life of the individual (Gawali et al., 2017).

2.3. Access to Health Care

Access to healthcare is key in healthcare systems performance. The concept of access has been used and defined by many authors and in many discussions, yet there seem not to be a universally accepted definition and measurement for access. In healthcare, access is usually defined as access to a healthcare provider or access to services (Levesque et al., 2013). Some researchers have presented access as an interrelationship between characteristics of the individual or population and health service delivery while others have argued that access can best be measured as consumer’s satisfaction. Aday & Andersen (1974) conceptualized access as an interrelationship between variables (health policy objectives, health system characteristics, population characteristics, utilization of health service, and consumer satisfaction). They considered health policy as directly influencing delivery system.

According to Penchansky & Thomas, (1981), “Access is viewed as the general concept which summarizes a set of more specific areas of fit between patient and the health care system” (P. 128). These dimensions of fit are availability, accessibility, accommodation, affordability and accessibility. Khan & Bhardwaj, (1994) presents access as the result of a relationship/an interplay between individual factors and health system factors. Access to health care is defined here as the opportunity to have health care need met. Hence access to health care results from the interconnection between health systems, environmental factors and individual characteristics. The availability component of the
definition of access examines the association between availability of health care providers and patients in need of health care services. Accessibility is an indicator of proximity to available health care services. For example distance between health consumer and available health facilities. Accommodation considers patient’s perception of appropriateness of service delivery processes (For example hours of operation). Affordability measures the financial cost of health care services relative to the consumer’s income status. Acceptability measures consumer’s reaction to health care provider’s attributes (For example ethnicity, religion) (Penchansky & Thomas, 1981) The concepts and definitions of the five dimensions of access is as shown below.

Kalkreneer et al (2010) used a population based design to evaluate the associations between geographic access to health services and the timing of autism diagnoses among children with surveillance-identified autism. They hypothesized that closer proximity to autism-specific agencies and higher density of healthcare providers will be associated with earlier diagnosis. Findings from the study revealed that there is indeed a positive association between geographic access to health services and early diagnosis.
### 2.4. Concepts and Definitions of the Dimensions of Access

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<th>Definition</th>
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<tr>
<td>Availability</td>
<td>The relationship between volume and type of existing and the clients’ volume and types of needs. It is the adequacy of required healthcare providers; of facilities, of specialist healthcare and services.</td>
</tr>
<tr>
<td>Accessibility</td>
<td>The relationship between the location of supply and the location of clients, nearness of health facility to clients, taking account of client transportation resources and travel time, distance and cost.</td>
</tr>
<tr>
<td>Accommodation</td>
<td>This refers to clients’ convenience and satisfaction with service delivery processes (including appointment systems, hours of operation), the clients’ ability to use these processes perception of their appropriateness.</td>
</tr>
<tr>
<td>Affordability</td>
<td>The relationship of prices of services and providers' insurance or deposit requirements to the clients' income, ability to pay and existing health insurance.</td>
</tr>
<tr>
<td>Appropriateness</td>
<td>The relationship of clients' attitudes about personal and practice characteristics of providers to the actual characteristics of existing providers, as well as to provider attitudes about acceptable personal characteristics of clients. Providers either may be unwilling to serve certain types of clients (e.g. welfare patients) or, through accommodation, may make themselves more or less available.</td>
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Source: (Penchansky & Thomas, 1981)

There are other documents in international law and from international meetings that address rights of people with disabilities and the human rights of children. The African decade of disabled persons (2001-2009), The United Nations General Assembly Resolution on The Rights of the Child (2002), and A World Fit for Children (2002), a document in which special reference to the rights of children with disabilities was made regarding full access to services including proper treatment and care (UNICEF, 2007).

The Ghana Federation of Disability Organizations (GFD) is the nation’s umbrella disability organization and was established in 1987. One of the core activities of the GFD is to advocate for policy formulations as well as protect the rights of persons with disabilities. The GFD is made up of other disability organizations such as Ghana Society of the Physically Disabled (GSPD), and Ghana National Association of the Deaf (GNAD). The campaigns and advocacies of these organizations led to the passage of The Persons with Disability Act, 2006 (ACT 715) by the Ghanaian parliament in 2006. The Act has been considered a notable achievement as it is a step further in ensuring inclusion of people with disabilities. Sections under the Disability Act that caters for healthcare, access, and facilities are as follows: Section 31- Medical Treatment, Section 32-Training of Health Professionals, Section 33-Health Programs, Section 35-Establishment of Assessment Centers. According to section 34 which addresses the issue of Periodic
Screening of Children, services should be provided for children with disabilities in order to detect, prevent and manage disabilities. Section 7-Access to Public Services states that a person who provides service to the public shall put in place the necessary facilities that make the service available and accessible to a person with disability. Although the Disability Act covers areas such as rights to education, healthcare facilities and so on, it has been criticized on the basis that it has no specific provisions for children and women with a disability, (Asante & Sasu, 2015, ACT, 2006).

2.5. Factors Influencing Access to Healthcare

Data on disability are usually unavailable and this might pose a challenge in healthcare access as children with disabilities will remain unidentified and hence excluded from health prevention and promotion services. Available data on their disability type and how their lives are affected by the disabilities will permit inclusion into public services and hence they can enjoy their rights. (UNICEF, 2007, UNICEF, 2013).

A qualitative study conducted to understand the experiences of immigrants with intellectual and developmental disabilities in accessing healthcare in America identified factors limiting access to healthcare as well as factors that facilitates healthcare access (Bogenschutz, 2014). Factors limiting access were identified as lack of cultural competence in all levels of health service provision, unavailability of accurate and adequate information about service providers and insurance, and troubles with coordinating multiple specialist services. Factors that facilitates healthcare were identified as cultural and language sensitivity of healthcare providers and school systems that help coordinate.

Similarly, a qualitative study was conducted among parents of Latino children with autism with the purpose of understanding as well as describing community, family, and
health care system barriers to Autism Spectrum Disorder (ASD) diagnosis (Zuckerman et al., 2014). The authors identified factors limiting access to healthcare services as low levels of information about ASD, high levels of stigmatization, poverty, limited English competency, lack of empowerment to harness available services. Other factors identified were negative attitudes of healthcare providers, inconvenient, uncomfortable and complex diagnostic processes.

Porterfield & McBride (2007) conducted a study to assess the effect of poverty and education on perceived need and access to health care services among children with special health needs. They examined perceived need for and access to specialist physician services, therapy services, and prescription medications. Parent/caregiver’s education level and family income were the major independent variables. Findings from this study showed that income and education both affect access, because less-educated and lower-income parents had a lower perceived need for specialized health care services as compared to more educated and higher-income parents.

A qualitative research was conducted in Nicaragua to explore caregiver’s perception about child’s disability and it’s implication on health care access. Findings from the study shows that parents who receive education about disability have better understanding about their child’s disability and this will influence access to care (Matt, 2014).

In Ghana, the mission of the Ministry of health (MOH), is to improve the health status of all individuals as well as provision of universal access to affordable and quality health services. Despite the introduction of the National Health Insurance Scheme (NHIS), in 2005, people who live with disabilities still continue to encounter financial barriers in accessing both mainstream and special health care services (Badu et al., 2015). (Odoom, Tauro, Williamson, Yeboah, & Laird, 2013) Odoom et al.(2013) also reported that people
with intellectual disabilities have poorer health, lower life expectancy, many unmet health need compared to persons without disabilities. They also experience stigmatization and discrimination and are faced with barriers in accessing health care services. Some of these barriers include; communication barriers, physical inaccessibility, lack of training of healthcare providers, lack of coordinated care, lack of appropriate policies among others (Odoom et al., 2013).

McGrath and colleagues (2011) reported that children with Down syndrome in the United States disproportionately face greater disease burden and have many unmet healthcare need. Similarly, in the United States, Austin and his colleagues (2016) also stated that children with disabilities especially those with autism usually encounter difficulty accessing specialty care. Some of these difficulties were identified as limited clinician resources, geographic distribution of specialists, and insurance obstacles leading to long wait times. They sought to improve access to care at autism centres using a system analysis approach. At the end of their study, both sites achieved improvements in their complex health systems, recording a 94% reduction in the number of persons on the waiting list (Austin et al., 2016, McGrath, et al., 2011).

In a longitudinal study in 2003, Scheer and his colleagues examined people with cerebral palsy, multiple sclerosis and spinal cord injury regarding access to, utilization of and satisfaction with health care services. In their analysis. They examined access barriers to specialist, primary and rehabilitative care and their consequences for health functioning and general wellbeing. Barriers identified were classified as structural, environmental and process barriers. Structural barriers included limited health plan benefits and access to durable medical equipment. Environmental barriers included transportation barriers and access to durable equipment. Health service delivery process barriers were identified as
lack of provider knowledge and difficulty with scheduling appointments (Scheer et al., 2003).

Similarly, Kuwana (2014) reviewed literature on the health situation of children with disabilities in South Africa and Namibia particularly with the aim of exploring the barriers to accessing government supported health care services for children with disabilities. Barriers identified were broadly classified into structural, environmental and process barriers. Poverty was highlighted as one of the structural barriers. It covered the financial incapability of people with disabilities in accessing available health care services. Environmental barriers included inadequate government specialist services, high cost of transportation, and inaccessibility of health facility structures by people with disabilities. Process barriers are the difficulties experienced in any of the series of events involved in service delivery. According to the review, they included negative attitude of health care provider, communication barriers between patient and health provider, and poor quality of service delivery.

An expert opinion exercise conducted to identify research priorities for health of people with disabilities (PWD) as an essential step to include the needs of people with disabilities into the growing health agenda, Tomlinson et al. (2009) pointed at the need to identify barriers encountered by PWD in accessing mainstream health care. In their work, they stated that people with disabilities have special health care needs peculiar to their health conditions that are usually unmet. Barriers in accessing health care identified from this study ranged from screening, diagnosis, accessing treatments, and receiving continuing support.

In a qualitative study in Southeastern Brazil involving people with physical, hearing, and vision disabilities, the author’s found out that one third of their 25 study participants
encountered transportation barriers in accessing health care services (Castro et al., 2011). The analysis of the result showed varying patterns in the barriers they experienced. Other access barriers reported by the study include delayed services due to long waiting time and communication barriers as a result of lack of signs for study participants with hearing disabilities. Furthermore, the lack of ramps and disability friendly structures such as wheel chairs and elevators were reported among environmental barriers to health care.

Scurlock et al. (2008) conducted a study with the objective of comparing financial barriers to care experienced by United States school children (5-17 years) with and without disabilities. Financial barriers to care was defined as; inability to afford prescriptions, delayed medical care, and forgone medical care due to cost. Children were classified into four categories according to health conditions; activity limitation, disabling condition, chronic asthma, and no health condition. The authors found from their analysis that uninsured children and children with activity limitation were more likely to experience financial barriers to care.

A study conducted in Windhoek, Namibia among parents of children with mental disabilities with the aim of describing the experiences of parents/caregivers of children with disabilities as they accessed health care for their children. Findings from the study indicated that similar to neighbouring South African countries, there is a high level of unmet health care need in Namibia. Findings also identified poor service provision with regards to language barriers and need for therapeutic services, transportation barriers, and financial barriers. They also found from the key informant interviews that access to education is a factor that influences access to health care services. The authors noted that most of the barriers associated with healthcare access were due to the health system of
Namibia, and hence recommended that the issue of healthcare provision be addressed (Coomer, 2013).

Personal factors such as educational status of the parents of children with disabilities, health status and also their knowledge about disabilities in children can influence access to care. Other factors such as availability of assistive devices, attitude and willingness of health care providers to provide needed care can also influence access to health care for children with disabilities. Cultural factors can also influence access to health care. Poverty has also been identified as influencing access to health care (Porterfield & McBride, 2007).
CHAPTER THREE

3.0. METHODOLOGY

This section gives a detailed description of the method employed in answering the question of what factors influence access to healthcare for children with disabilities (Autism, CP, and DS) in the Greater Accra region of Ghana.

3.1. Study Design

This is a mixed method cross-sectional study. This approach was employed in order to unearth and explore factors influencing access to healthcare from the parent/caregivers perspective, health care provider’s perspective, and also to understand the healthcare services available for children with Autism, CP and DS. Quantitative method involved the use of semi-structured questionnaires to obtain information from parents/caregivers of children with Autism, Cerebral palsy and Down syndrome about individual and health service factors that both facilitate and hinder access. Qualitative method involved the use of key informant interviews and in-depth interviews. Key informant interviews were conducted with healthcare providers offering services to children with disabilities in private and public health facilities. In-depth interviews were conducted with parents/caregivers of children with disabilities in six (6) special education schools in the Greater Accra region. The duration for data collection for this study spanned six weeks (May, 22\textsuperscript{nd} to June 30\textsuperscript{th}).

3.2. Study Location

The study was carried out in the Greater Accra region (GAR) of Ghana. GAR is one of the 10 administrative regions in Ghana. It lies in the SouthEast of the country and is
bordered by the Gulf of Guinea on the south. It is bordered on the north by the eastern region, on the east by Lake Volta. The region is administered at two different but complementary levels; the traditional and political levels. The traditional level of administration operates through a network of local governance that involves purely traditional affairs concerning customs and land administration. The political administration of GAR is through the local government system. The region is divided into sixteen (16) administrative areas which is administered by a Chief Executive. The population structure of the GAR has a broad base with a higher population of children and a thin peak with very few elderly persons.

Demography

GAR is the second most populated region, with a population of 4,010,054 as at 2010 population and housing census representing a 38% increase in population over 2000. The population density of Greater Accra is 1,236 persons per square kilometre. Greater Accra had a sex ratio of 93.6 in 2010, which means there are about 94 males to every 100 females in the region (GSS, 2012).

Accra is divided into 10 administrative health sub-districts, which include: Accra Metro, Ledokuku-Krowor Municipality, Tema Municipality, Ashiaman Municipality, Adenta Municipality, Ga West District, Ga South District, Ga East District, Dangme West District and Dangme East District.

This study was carried out in seven (7) special schools in the Greater Accra region. The facilities include; Multi kids academy, New Horison International, Dzorwulu Special School, Autism Awareness Care and Training Centre, Woodfield Manor Special Schools, Awaawaa 2 Foundation, and Echoing Hills Village.
Health Facilities

The city of Accra has approximately 20 government-run health facilities, which include: four Hospitals (Achimota Hospital; Princess Marie Louise Children’s Hospital; La General hospital, and Ridge hospital); in addition, there are a number of polyclinics and quasi-governmental facilities, smaller Community-based Health Planning and Services (CHPS) Compounds, and more than 800 private health facilities.

Figure 1: Map of Greater Accra Showing Districts.
Source: Google Maps (2016).

3.3. Study Variables

The outcome variable is access to healthcare. We defined access to healthcare as access to a healthcare provider or access to services. According to Penchansky & Thomas (1981), there are five dimensions of access, this outcome variable was measured as a
composite variable comprising of five dimensions: availability; accessibility; affordability; appropriateness and accommodation. Considered with the „availability” sub-component were questions related to: availability of a personal primary healthcare provider; availability of a personal specialist healthcare provider (physiotherapist and speech and language therapist) and access to medicines. Accessibility as a sub-component had questions on: distance to healthcare facility; proximity to healthcare facility; convenience of opening hours and access to medical equipment. Affordability comprised of questions on: availability of health insurance; type of health insurance; awareness of sponsorships from NGO and ability to afford care and need to postpone and/or forgo care. The Appropriateness sub-component of access included questions on: attitude of healthcare provider; satisfaction with questions answered and ease of communicating with healthcare provider. The sub-group accommodation consisted of convenience of appointment, ability to access toilet facilities and waiting time.

Independent variables considered in this study are the individual and health service factors that influence access to healthcare. The individual (parental/caregiver) factors are: perception of child’s disability; household income range per month and highest level of education attained. Health service factors included: availability of specialist healthcare providers; convenience of appointment times; proximity to source of care; communication barriers between healthcare provider and parent of child; availability of disability-friendly equipment in health facilities; accessibility of National Health Coverage and attitude of healthcare provider.
3.4. Sample Size Determination

The minimum sample size for this study was estimated using the $N = \frac{z^2pq}{e^2}$ formula for estimating sample size for a cross sectional study (Charan & Biswas, 2013).

$N = \frac{z^2pq}{e^2}$

Where $z = 1.96$ at 95% confidence interval

$p = 98.2\%$ = proportion of children with perceived special healthcare needs who had access to prescriptions and medications (Porterfield & McBride, 2007),

$q = (1-p) = 0.018$

$e$ = margin of error =5% =0.05

Sample size $N = 27$

Assuming a non-consent rate of 50% (based on inquiries from key informants),

Sample size $= 27 + 10 = 37$ (minimum sample size)

3.5. Sampling Method

The study employed three sampling techniques to achieve its objectives: total population census of parents/caregivers; snowballing technique for healthcare workers and social worker; and purposive sampling for a sub-population of survey participants. Total population sampling was used to select all eligible participants who consented to participate due to the relatively small size of the target population.

The qualitative aspect employed the snowballing sampling technique to identify healthcare providers who render services to children with disabilities while purposive sampling was used to select participants (parents/caregivers) for the in-depth interviews. Participants were selected for the in-depth interview based on background characteristics such as highest level of education, household income range and disability type of child.
Nine special education facilities in the Greater Accra region were identified. Permission was sought from the school heads to use their facilities as study sites. Permission was received from 7 out of the 9 educational facilities. One of these 7 schools doubles as a foster home for children with disabilities thus parents could not be reached. Of the remaining six schools, the total eligible participants summed up to 179. A total of 73 informed consent forms were sent to eligible parents/caregivers who were successfully contacted (both through phone and physical contact) within the period of the study. Only 47 participants consented to participate in the study. A total of 38 thirty eight (38) parents/caregivers of children with Autism, cerebral palsy and Down syndrome (aged 5-17) in the selected special needs schools were successfully surveyed. Hence a response rate of 52% (i.e. proportion of participants who consented out of the total number successfully reached).

Inclusion and Exclusion Criteria
Parents/caregivers of children with any disabilities other than Autism, CP, and DS were excluded from the study. Only parents of children with autism, CP, and DS within the ages 5 and 17 who consented (written/verbal) were included in the study. Healthcare providers offering services to children with autism, cerebral palsy, and Down syndrome who were identified through snowballing sampling technique were recruited and interviewed.
3.6 Data Collection Method

Permission letters signed by the head of department were together with the ethical approval letter obtained from the Ghana Health Service Ethics Review Committee and the permission letter obtained from the Ghana Education Service were presented to the head/school administrator/program coordinator of the special education facilities. Permission was therefore first obtained from selected schools before the commencement of data collection. All sampled parents/caregivers of children with Autism, Cerebral palsy and Down syndrome whose children are within the ages of 5 and 17 were given consent forms with duplicated signature pages. Parents/caregivers were asked to indicate interest by appending their signatures on the signature pages of the consent form. They were also asked to return the duplicated copy of the signature page with the following information for follow up; participant’s name, relationship with child/ward, child/ward’s name, and interview type preferred. Options for interview format included; phone interview or face-to-face interview. Parents who indicated interest returned their filled forms and were recruited for the study. Parents/caregivers who indicated interest were contacted. Time and venue (for face to face) was scheduled based on participant’s convenience. Questionnaires were interviewer administered to parent/caregivers of children with Autism, Cerebral palsy and Down syndrome. Of the total number of parents/caregivers who consented, eight (8) were purposefully selected across all three condition types (Autism, CP, DS) based on their income and education level to be involved in in-depth interviews. In-depth interviews lasted for an average of 45 minutes. Issues such as healthcare needs of child/ward, challenges encountered in accessing mainstream and special health care services for ward/child, and facilitating factors for healthcare access were discussed. In-depth interviews with sub-population of
parents/caregivers was purposefully to document lived experience of accessing health for a child with disability, and also to unearth certain factors that influence access to healthcare that may have remained uncaptured by the survey.

Specialist healthcare providers offering services to children with disabilities were identified through snowballing technique. All key informant interviews were conducted within the work premises of identified healthcare provider upon appointment. All KII was conducted in English, and were all face-to-face interviews. Some in-depth interviews were conducted in English and others in the local dialect (Twi). All in-depth interviews and key informant interviews were tape recorded for transcription.

In all, eight (8) IDIs were conducted with parents/caregivers selected based on background characteristics (income and education). All identified healthcare providers (n=4) rendering services to children with autism, cerebral palsy, and Down syndrome were interviewed; 2 from private health facilities and 2 from public health facilities. Another KII was conducted with a social worker in charge of the foster home for children with disabilities.

3.7. Data Collection Tools

Quantitative method

Semi-structured questionnaires were used to collect data from study participants. Semi structured questionnaires were used for the survey. Questionnaires consisted of four (4) sections which included; socio-demographic variables, individual factors influencing access to health care, measures of access to healthcare, and a fourth section on special services. The entire questionnaire had a total of fifty eight (58) items; ten (10) in section
1 (background information), four (4) in section 2 (individual factors), thirty (30) in section 3 (measures of access to healthcare), and fourteen (14) in section 4 (specialist care). Questions in the questionnaire were adapted from Eide et al. (2015), Porterfield & McBride, (2007), and Vergunst (2016).an unpublished PHD thesis

Qualitative method

Interview guides were used for the qualitative aspect of this study. Interview guide for in-depth interview contained questions and probes on: the nature of child’s condition; parent/caregiver’s perception of cause of child’s condition, and challenges encountered in accessing care. Key informant interview guides contained questions and probes on: mainstream and special healthcare services available for children with autism, cerebral palsy, and Down syndrome; healthcare provider’s perception of challenges parents encounter in accessing health care services for their children with disabilities; health system factors that may influence access to healthcare for the population group in question, and their overall feeling about access to healthcare for children with disabilities in the Ghanaian context. At the end of the key informant interviews and the in-depth interviews, additional comments were also entertained (comments on factors facilitating or hindering access to healthcare).
3.8. Data Processing and Analysis

Quantitative Data Analysis

Quantitative data were entered into Microsoft Excel 2013, cleaned and exported into STATA SE Version 14, a software for quantitative data analysis. Participants’ characteristics were summarized using descriptive analysis (i.e. frequencies and percentages) and presented in a table. Participant responses were scored for all five aspects of healthcare. The outcome variable (overall access) was a composite variable generated by a summation of scores accrued on its five sub-components; availability, affordability, accessibility, appropriateness, and accommodation. Assigned scores ranged from 0 to 8 for availability; 0-10 for accessibility; 0-27 for affordability; 0-20 for appropriateness, and 0-6 for accommodation, and 0-71 for overall access. Each of these scores for all five sub-components and for overall access were converted into percentage scales.

The higher the score in a particular domain, the higher the access. For example, availability was measured using the following variables: access to a personal healthcare provider; access to medicines; access to a personal physiotherapist, and access to a personal speech and language therapist. Negative responses (No) for the four questions were given a score of 0 and the positive responses (Yes) were given scores ranging between 1 and 3.

A one-way analysis of variance was conducted to determine if the mean access score was significantly different within groups of categorical independent variables. These categorical independent variable are; age of respondent, highest level of education completed, disability type, income, and time of observation of condition. The ANOVA
was followed with a planned post-hoc test based on Bonferroni test statistic and the corresponding p-value

Welch’s t-test was also conducted to compare mean access scores for categorical variables with only two levels.

Cronbach’s alpha was used in measuring the reliability of the scale used in assessing overall access to healthcare as well as its five sub-components (availability, accessibility, affordability, appropriateness, and accommodation).

**Qualitative Data Processing and Analysis**

All IDIs and KIIs were digitally recorded with participant’s consent. Digitally recorded interviews (key informant and in-depth interviews) were transcribed. Interviews conducted in the local dialect were transcribed verbatim in English by the research assistant familiar with the language. All transcriptions were verified and were transported into NVIVO version 10. Coding schemes were then thematically developed based on research objectives and emerging themes and all files coded. Queries were run to summarize themes under appropriate sub-headings. A codebook was developed for the themes which was augmented with field notes of the interviews. Appropriate quotations were selected to support the themes.
3.9. Quality Control

A reliable and experienced research assistant who is familiar with the local dialects was trained for the purpose of this research. Objectives of the study were thoroughly explained to the research assistant. During the training and prior to pretesting of data collection tools, the data collection tools were translated to the local dialect and back to English by another researcher familiar with the local languages in order to improve the trustworthiness of the tools. Interviews were conducted by researcher and research assistant.

Transcriptions were verified before transporting into NVIVO version 10 for analysis.

3.10. Ethical Consideration

Ethical approval was obtained from the Ghana Health Service Ethical Review Committee (GHS-ERC: 28/12/2016). Permission was obtained from the Director General of the Ghana Education Service (Appendix VII). Permission was also sought from the Heads of the special needs schools prior to data collection. Informed consent forms (Appendix I) were administered to eligible study participants and only interested participants who signed the consent forms were invited for interview. Informed consent forms (Appendix II) were also administered to identified healthcare providers prior to data collection. Study participants were assured of confidentiality and anonymity. Transcripts were anonymized and records identifying participants was kept confidential. Participants were duly informed about voluntary participation and withdrawal from the study; of their right to choose whether or not to participate in the study and to withdraw from the study if and when they so choose.
CHAPTER FOUR

4.0. RESULTS

4.1. Characteristics of Participants

A total of 38 participants (parents/caregivers) were successfully interviewed. A greater percentage of respondents were parents (79%) and others were caregivers (21%). Out of the 38 respondents, 47.4% had children/wards who were autistic, 21% had cerebral palsy, and 32% had Down syndrome. Autism was the most prevalent condition in private schools while Down syndrome was the most prevalent in the public school. Table 1 shows characteristics of the parents/caregivers and their children/wards.
### Table 1: Characteristics of Study Participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency</th>
<th>Percentage %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of respondent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 40</td>
<td>13</td>
<td>34.2</td>
</tr>
<tr>
<td>40-49</td>
<td>15</td>
<td>39.5</td>
</tr>
<tr>
<td>50+</td>
<td>10</td>
<td>26.3</td>
</tr>
<tr>
<td>Sex of respondent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11</td>
<td>29</td>
</tr>
<tr>
<td>Female</td>
<td>27</td>
<td>71</td>
</tr>
<tr>
<td>Sex of child/ward</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>26</td>
<td>33.3</td>
</tr>
<tr>
<td>Female</td>
<td>12</td>
<td>66.7</td>
</tr>
<tr>
<td>Highest educational level completed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None/Primary</td>
<td>4</td>
<td>10.5</td>
</tr>
<tr>
<td>Secondary</td>
<td>16</td>
<td>42.1</td>
</tr>
<tr>
<td>College graduate</td>
<td>18</td>
<td>47.4</td>
</tr>
<tr>
<td>Household income range per month (GHC)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-500</td>
<td>17</td>
<td>44.7</td>
</tr>
<tr>
<td>501-1000</td>
<td>8</td>
<td>21.1</td>
</tr>
<tr>
<td>&gt;1000</td>
<td>13</td>
<td>34.2</td>
</tr>
<tr>
<td>Relationship with child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>30</td>
<td>79</td>
</tr>
<tr>
<td>Caregiver</td>
<td>8</td>
<td>21</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>27</td>
<td>71</td>
</tr>
<tr>
<td>Unmarried</td>
<td>11</td>
<td>29</td>
</tr>
<tr>
<td>Employment status&lt;sup&gt;1&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>34</td>
<td>89.5</td>
</tr>
<tr>
<td>Unemployed</td>
<td>4</td>
<td>10.5</td>
</tr>
<tr>
<td>Relationship with child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>30</td>
<td>79.0</td>
</tr>
<tr>
<td>Caregiver</td>
<td>8</td>
<td>21.0</td>
</tr>
<tr>
<td>School type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>29</td>
<td>76.3</td>
</tr>
<tr>
<td>Public</td>
<td>9</td>
<td>23.7</td>
</tr>
<tr>
<td>Disability type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>18</td>
<td>47.4</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>8</td>
<td>21.1</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>12</td>
<td>31.6</td>
</tr>
<tr>
<td>Time of observation of signs of condition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 6 months</td>
<td>16</td>
<td>42.1</td>
</tr>
<tr>
<td>6 months-1 year</td>
<td>3</td>
<td>7.9</td>
</tr>
<tr>
<td>&gt; 1 year</td>
<td>19</td>
<td>50.0</td>
</tr>
<tr>
<td>Perception of cause of condition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>29</td>
<td>76.3</td>
</tr>
<tr>
<td>Non-medical/Spiritual</td>
<td>9</td>
<td>23.7</td>
</tr>
</tbody>
</table>

<sup>1</sup> Employment status: Employed included parents/caregivers who were either self-employed or employed part time or full time. Unemployed included those who were either students, homemakers, or retired.
Tables 2 and 3 represent characteristic of study participants involved in the in-depth interviews (8 purposefully selected from survey) and key informant interviews (4 health practitioners and a social worker) respectively.

### Table 2: Summary Characteristics of In-depth Interview (IDI) Participants (N=8)

<table>
<thead>
<tr>
<th>Disability type</th>
<th>School type</th>
<th>Autism</th>
<th>Cerebral palsy</th>
<th>Down syndrome</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Private</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Public</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Relationship with child</td>
<td>Parent</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Caregiver</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Highest education completed</td>
<td>None/Primary</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Secondary</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>College Graduate</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Household income range per month (GHC)</td>
<td>0-500</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>501-1000</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>&gt;1000</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

### Table 3: Summary of Key Informant Interview (KII) Participants (N=5)

<table>
<thead>
<tr>
<th>Professional background</th>
<th>Type of health facility</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Private</td>
</tr>
<tr>
<td>Pediatrician</td>
<td>2</td>
</tr>
<tr>
<td>Neurologist</td>
<td>0</td>
</tr>
<tr>
<td>Social Worker</td>
<td>1</td>
</tr>
</tbody>
</table>
4.2. Statistics of Measures of Access to Healthcare and Overall Access

Table 4 shows mean and median scores for overall access, and the five sub-measures of overall access (availability, accessibility, affordability, appropriateness, and accommodation). The mean percentage score for overall access was 58.7% with minimum and maximum percentage scores of 29.6% and 81.7% respectively. These percentage points signify level of overall access used in further analysis.

<table>
<thead>
<tr>
<th>Statistics</th>
<th>Mean (%)</th>
<th>SD</th>
<th>Median (%)</th>
<th>Min (%)</th>
<th>Max (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Availability</td>
<td>23.7</td>
<td>18.1</td>
<td>12.5</td>
<td>0.0</td>
<td>50.0</td>
</tr>
<tr>
<td>Accessibility</td>
<td>60.0</td>
<td>22.4</td>
<td>60.0</td>
<td>20</td>
<td>100.0</td>
</tr>
<tr>
<td>Affordability</td>
<td>57.6</td>
<td>23.2</td>
<td>61.1</td>
<td>0.0</td>
<td>92.6</td>
</tr>
<tr>
<td>Appropriateness</td>
<td>73.8</td>
<td>21.7</td>
<td>80.0</td>
<td>20.0</td>
<td>100.0</td>
</tr>
<tr>
<td>Accommodation</td>
<td>58.3</td>
<td>21.5</td>
<td>50.0</td>
<td>16.7</td>
<td>100.0</td>
</tr>
<tr>
<td>Overall Access</td>
<td>58.7</td>
<td>14.2</td>
<td>61.3</td>
<td>29.6</td>
<td>81.7</td>
</tr>
</tbody>
</table>

4.3. Factors Influencing Access to Healthcare.

A one-way analysis of variance was conducted to determine if the mean access score was significantly different for groups of categorical independent variables (age of respondent, highest level of education completed, disability type, income, and time of observation of condition). An analysis of variance showed that the effect of highest level of education on access was significant, F (2, 35) = 5.79, p=0.0067. Also, that the effect of household income range was significant, F (2, 35) = 5.94, p=0.0060. Age of respondent, child’s disability type, and time of observation of condition were not significantly associated (p>0.05) with mean access to healthcare. (See table 4 below).
Welch’s t-test was also conducted to compare mean overall access scores between categorical variables with only two levels (sex of respondent, sex of child, marital status, employment status, school type, relationship with child, and perception of condition). Welch’s t-test showed that school type was significantly associated with overall access [(t=3.0372), Welch’s $df = 16.7$, $p=0.0075$], with private school children having 14.03% (S.E = 4.62) higher access to healthcare (see table 4 below). Sex of child, marital status, employment status, school type, relationship with child, and perception of condition were not significantly associated ($p>0.05$) with mean access to healthcare.

A planned post-hoc test (Bonferroni) was conducted with variables which were statistically significant from the ANOVA: The variables are; highest level of education obtained; household income range, and school type. Bonferroni post-hoc test revealed significant differences in the mean access score between college graduates and those with no education [$F (2, 35) = 5.79$, $p=0.012$]. Participants with tertiary education had mean access score 21.5% higher than those with no/primary education. No statistically significant difference was observed between: college graduates and those with secondary education; and between those with secondary education and no/primary education ($p>0.05$).

Similarly, post-hoc test using Bonferroni indicated that the mean access scores for participants with income range of GHC 0-500 was significantly different [$F (2, 35) = 5.94$, $p=0.005$] from those of income range GHC >1000. Participants with income range of GHC >1000 had mean access score 15.8% higher than those with income range of GHC 0-500. However, the GHC 500-1000 income range did not significantly differ from the GHC 0-500 and GHC > 1000 income ranges ($p>0.05$).
Table 5: Assessing Factors Influencing Access to Healthcare

<table>
<thead>
<tr>
<th>Covariates</th>
<th>Overall Access Scores (%)</th>
<th>Test statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean ±S.D</td>
<td>F</td>
</tr>
<tr>
<td>Age of respondent (years)</td>
<td></td>
<td>0.89</td>
</tr>
<tr>
<td>&lt;40</td>
<td>59.91 ±14.31</td>
<td></td>
</tr>
<tr>
<td>40-49</td>
<td>61.13 ±13.8</td>
<td></td>
</tr>
<tr>
<td>50+</td>
<td>53.66 ±14.72</td>
<td></td>
</tr>
<tr>
<td>Sex of respondent</td>
<td></td>
<td>0.57*</td>
</tr>
<tr>
<td>Male</td>
<td>60.69±12.82</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>57.96±14.85</td>
<td></td>
</tr>
<tr>
<td>Sex of child</td>
<td></td>
<td>0.72*</td>
</tr>
<tr>
<td>Male</td>
<td>59.9±13.30</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>56.10±16.21</td>
<td></td>
</tr>
<tr>
<td>Highest education completed</td>
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<td>5.79</td>
</tr>
<tr>
<td>None/Primary</td>
<td>43.66±4.15</td>
<td></td>
</tr>
<tr>
<td>Secondary</td>
<td>55.28±12.22</td>
<td></td>
</tr>
<tr>
<td>College graduate</td>
<td>65.18±13.92</td>
<td></td>
</tr>
<tr>
<td>Household income range per month (GHC)</td>
<td></td>
<td>5.94</td>
</tr>
<tr>
<td>0-500</td>
<td>52.44±11.72</td>
<td></td>
</tr>
<tr>
<td>501-1000</td>
<td>56.69±16.98</td>
<td></td>
</tr>
<tr>
<td>&gt;1000</td>
<td>68.26±10.55</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
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</tr>
<tr>
<td>Married</td>
<td>60.15±14.85</td>
<td></td>
</tr>
<tr>
<td>Not married</td>
<td>55.31±12.31</td>
<td></td>
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<tr>
<td>Employment status</td>
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</tr>
<tr>
<td>Employed</td>
<td>59.24±14.30</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>54.58±14.29</td>
<td></td>
</tr>
<tr>
<td>Relationship with child</td>
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<td>3.04*</td>
</tr>
<tr>
<td>Parent</td>
<td>60.38±13.62</td>
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</tr>
<tr>
<td>Caregiver</td>
<td>50.64±15.48</td>
<td></td>
</tr>
<tr>
<td>School type</td>
<td></td>
<td>2.33</td>
</tr>
<tr>
<td>Private</td>
<td>62.07±13.35</td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td>48.04±11.69</td>
<td></td>
</tr>
<tr>
<td>Disability type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>62.22±12.51</td>
<td></td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>60.21±13.16</td>
<td></td>
</tr>
<tr>
<td>Down syndrome</td>
<td>51.41±15.22</td>
<td></td>
</tr>
<tr>
<td>Time of observation of signs of condition</td>
<td></td>
<td>0.65</td>
</tr>
<tr>
<td>&lt;6months</td>
<td>55.96±15.97</td>
<td></td>
</tr>
<tr>
<td>6months-1year</td>
<td>63.85±14.11</td>
<td></td>
</tr>
<tr>
<td>&gt;1year</td>
<td>60.79±13.00</td>
<td></td>
</tr>
<tr>
<td>Perception of cause of condition</td>
<td></td>
<td>1.02*</td>
</tr>
<tr>
<td>Medical</td>
<td>59.93±14.73</td>
<td></td>
</tr>
<tr>
<td>Non-medical/Spiritual</td>
<td>54.93±12.18</td>
<td></td>
</tr>
</tbody>
</table>

*#- P-value estimates from the welch t-test
F-F test statistics from one-way analysis of variance
*p<0.05, ** p<0.01 ***p<0.001
4.4. Reliability Statistics

Table 6 shows the scales of reliability coefficient for the items used in measuring the five sub-components of overall access (availability, accessibility, affordability, appropriateness and accommodation). Affordability, appropriateness and accommodation were found to be reliable while availability and accessibility were not as reliable in measuring access to healthcare. However, overall access was found to be reliable; scale reliability coefficient for the items used in measuring overall access was 0.79, which indicates a greater internal consistency of the items in the scale (Gliem & Gliem, 2003, Nunnally, 1978) (table 5).

<table>
<thead>
<tr>
<th>Item</th>
<th>Scale</th>
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</thead>
<tbody>
<tr>
<td>Availability</td>
<td>0.1215</td>
</tr>
<tr>
<td>Accessibility</td>
<td>0.2065</td>
</tr>
<tr>
<td>Affordability</td>
<td>0.7583</td>
</tr>
<tr>
<td>Appropriateness</td>
<td>0.6913</td>
</tr>
<tr>
<td>Accommodation</td>
<td>0.583</td>
</tr>
<tr>
<td>Overall access</td>
<td>0.7943</td>
</tr>
</tbody>
</table>

Participants with household income range greater than 1000 GHC had highest access scores compared to participants with household income range of 501-100 GHC, and 0-500 GHC. The figure below (Figure 2) shows a boxplot of overall access on a percentage scale (0-100) for the different household income range (GHC) categories.
Figure 2: Box and Whisker Plot Showing Overall Access for Household Income Ranges.

The figure below shows overall access on a percentage scale (0-100) for the different education levels. Participants who had tertiary education had highest access scores compared to participants with secondary and no/primary education.

Figure 3: Box and Whisker Plot Showing Overall Access for the Different Levels of Education Attained.
4.5. Health care Services Available for Children with Autism, Cerebral Palsy, and Down syndrome

Findings from the qualitative aspect of the study revealed that general/mainstream healthcare services such as dentistry, audiology, ophthalmology, etc. required for the optimum growth and development of children with autism, cerebral palsy, and Down syndrome are available. However, these services are not easily accessible by the children due to certain factors such as shortage of healthcare personnel/challenge of availability of healthcare providers. This barrier to access was echoed by both parents/caregivers, and healthcare providers.

“In an ideal situation, we also need a gastroenterologist specifically for children with autism because the research is showing that they have lots of Gastrointestinal tract (GIT) issues and in Ghana we do not have gastroenterologists specifically for children with autism, even for regular children I think we have only one or two gastroenterologists so that’s a big challenge for them” (Healthcare Provider Private Facility).

While the limited number of specialists affects all children, specific disability types imposes further challenges to utilization of specialist services. A parent whose child has Down syndrome recounts her inability to access dental care for her child

“...like with my son’s teeth there should be a way you can handle a child with challenges. Maybe they should specialize in knowing how to... I mean they go to their medical school you want to handle a child with these challenges you have to specialize on that...” (Parent of child with Down syndrome-Private school).

“The other time, the tonsils was so swollen we went to the Ear Nose and Throat (ENT) at a hospital and we went there... It didn’t come on, the doctor did everything that he could and the test didn’t come on so I always pray he doesn’t get sick because taking care of him is very difficult.” (Parent of child with Down syndrome-Private school).

Furthermore, other specialized healthcare services needed by children with autism, cerebral palsy, and Down syndrome services such as speech and language therapy,
occupational therapy, etc. are also not readily available for them. Hence there are challenges encountered in accessing the available services.

“...there’s no access to a speech therapist. Physiotherapy are also not many. I think they’re more than the speech therapists though but they’re not enough. And it’s also expensive. And physiotherapy is such that you need it continuously, but because of poor access, you have clients who have to go once a week or once in 2 months, to do it and so they don’t get optimum care. The same goes with the occupational therapist...” (Healthcare provider Private Facility 1).

4.5. Factors Influencing Access to Healthcare-Qualitative

The study generally revealed a number of factors relating to the healthcare system (also referred to as health service related factors) which could either facilitate access or serve as a barrier in accessing healthcare services. The study also revealed parental/caregiver factors, social factors, and condition-related factors which influence access to healthcare for children with autism, cerebral palsy, and Down syndrome.

Health Service Barriers and Facilitators of Access to Healthcare

Participants recounted some of the challenges usually encountered in a bid to access mainstream and special services for children with disabilities. These challenges were centered on; availability of specialist healthcare providers, inadequate disability friendly structures, knowledge and attitude of healthcare providers, fragmentation of available services, and inappropriate service delivery processes. These findings pervaded across parents/caregivers and across healthcare providers from private and public health facilities. There are thus expounded below.

Autism, Cerebral palsy, and Down syndrome are neurological conditions that require knowledge and expertise of both general practitioners and specialist healthcare providers. In-depth interviews with healthcare providers revealed the challenge of inadequate
specialist healthcare providers required for the effective management of these conditions.

An interview with a healthcare provider rendering services to children with disabilities confirms this assertion

“We have this challenge where the patient comes in and the nurse would have to say...
“Or sorry but today there’s no clinic for patients like this, go and come on Monday”; now she even tells you, ‘even this coming Monday is fully booked. In fact, it is booked all the time for the next three months so come back in four months’ time’. It’s a big challenge and that’s what is happening because the fact is I can’t see more than a certain number of children in a day” (Healthcare Provider Private Facility2).

“For the health facilities, we don’t have the appropriate facilities, we don’t have enough staff specialized and when it comes to these conditions we need more specialized people to handle them”. (Healthcare Provider Public Facility 2).

Findings from the study revealed also that availability of health service providers would facilitate access to healthcare services

“I don’t think they have adequate access the queues are usually too long, we do not have enough health care personnel handling children with special needs, so until we get enough healthcare providers at every facility, we can’t say they are getting adequate care” (Healthcare Provider Private Facility2).

The study also revealed a lack of specific medical services for children with disabilities as indicated by the following responses:

“Ghana has a population of twenty five million and yet there are probably just eight speech therapist in the whole country” (Healthcare Provider Public Facility1).

“...So sometimes you’ll be told that there’s a specialist here then you’ll have to go and check on that specialist. The main problem is that for autism, you don’t have a place where you can go and say these are the specialists you need and have them” (Parent of child with autism-Private School).

Another important factor revealed in this study is centered on the knowledge and attitude of healthcare providers regarding the conditions. This challenge results in a lack of trust in the healthcare system thereby causing parents to become reluctant to use health
services provided. A healthcare provider recounted her interaction with a parent on this subject as reported below;

“...I’ve had parents who have told me they saw a doctor or a nurse who has said; this child is not going to be proper/amount to anything so forget about him...” (Healthcare provider Private Facility 1)

“This issue of access to healthcare is a very challenging one, now as soon as you get to the OPD, the way they are being received, is like “who is this child”, you don’t receive any special treatments whatsoever” (Social worker Special Education facility).

“The doctors have no problem at all with attending to my child but the nurses do. Some of the nurses withdraw when they see the child. I don’t know if they are afraid. I assume that some of them are scared and so wouldn’t want to come close to him. Some withdraw from him completely while others just goes back” (Caregiver of child with cerebral palsy-Private School).

“...Even after seeing a specialist, I feel that nothing has been done. You go through a very difficult time trying to see one and you don’t feel a sense of closure, you don’t think you have dealt with the situation, sometimes you even have more questions than answers...” (Parent of child with autism-Private School).

While some parents recounted negative experiences with regard to the attitude of healthcare workers, some healthcare providers argued that they (healthcare providers) are doing their best and are being as collaborative and courteous as they should be

“Oh yes, in the mainstream hospitals, I think that children are treated the same. Now remember that because of the HIV training everybody has had now, people have learnt, health workers have learnt not to discriminate among patients. So I think that has sort of canceled the issue of stigma in the hospital” (Healthcare Provider Private Facility 2)

“Well we as health workers don’t discriminate. When it comes to hospital we don’t discriminate we treat everyone equally”. (Healthcare Provider Public Facility 2).

Another finding from the study revealed the impact of access to information and education for parents/caregivers as hindering access to healthcare. Parents/caregivers do not have adequate knowledge about their children/wards health condition. Providing access to relevant and appropriate information about autism, cerebral palsy, Down syndrome would facilitate healthcare access.
“...you tell a patient your child has autism, cerebral palsy, Autism...what does it mean? Does the patient really understand when you say you have autism? All she knows is...oh my child would not talk and there”s no cure. Can”t she come to a place where she receives adequate information about the condition and how it can be managed? It”s quite appalling. You tell them, a lot of them just go home and go and fight. „Oh, father is the cause of this”, „mother is the cause of this”...” (Healthcare Provider Public Facility 1).

“...every time something you”re not comfortable with is happening, there should be a doctor you can see who can guide you, she doesn”t have the words to describe what is happening to her, so we need people who would understand these things and help us. I feel that on the side of the healthcare system, education is key, because some of these things, if people knew, they would maybe know what to expect and then you should come to the hospital if you should see something like this and it would help people” (Parent of child with autism-Private school).

“For parents, you see, I guess information would facilitate access to healthcare. So if there was a way that they would all know that, okay, these hospitals are places that are very disability friendly or where you can have access to services, a specialized... somebody with specialty in that field, okay, and then it would be very good”. (Healthcare Provider Private Facility 1)

The lack of a coordinated system of care for children with autism, cerebral palsy, and Down syndrome is another factor revealed by the study as hindering access to healthcare. This situation as reported by both parents and healthcare providers negatively influences parents/caregiver”s access to adequate and appropriate care for their children/ward. Respondents described the nature of care received as “fragmented” and “uncoordinated” as evident from their responses.

“...we do not also have the resources to actually screen them in every centre. So a mother would have to go to one place to get screened, and then come to another place to get treatment...we do not want to send patients from hospital to hospital looking for eye care, hearing care, we would want all those things in a centre, so that the child can have access to all of that...” (Healthcare Provider Private Facility2).

“...So our needs shouldn”t be isolated it should be together, because we need so many things...” (Parent of child with autism-Private School).

The process of service delivery and the waiting time are other health service related factors influencing access to healthcare as revealed by the study.
“…Sometimes you arrive at the hospital early in the morning and leave around 4pm because the patients there are many and this delays us. Anytime I take my son to the hospital, I consider it a full day’s affair” (Caregiver of child with autism-Private School).

“I had an experience at one of the facilities’ pediatric. My son drank kerosene so he had to be rushed there. I could see that my son was weak. After telling the nurse about the issue, she told me that they were attending to other kids…” (Parent of child with cerebral palsy-Private School).

Finally the children with autism, cerebral palsy, and Down syndrome are usually unable to access disability friendly facilities and structures. This acts as a barrier in receiving appropriate access to healthcare. Responses from respondents confirm that the structures and equipment at the facilities are not accommodating and appropriate for children with disabilities. This is evident in participants’ responses.

“I’ve seen mothers who have to carry children on their back. A 14 year old who doesn’t have a wheel chair. If she has a wheel chair they can’t put the wheel chair in the trotro. So, even our transportation system is a barrier to getting them to the hospital…. So the logistics into even hospital is even a big deal for them”. (Healthcare Provider Private Facility1)

“If you go to the physiotherapy unit, what equipment is available for children with Cerebral palsy? It’s nil, it’s the physiotherapists who are improvising or the parents have to buy it; like the specialized chairs, the wheel chairs, the parents have to buy it themselves. So if the mother can’t afford it then it means the child cannot access adequate care” (Healthcare Provider Private Facility2).

“…A child reaches a stage, he needs a wheel chair, who assesses it? Do we have a wheel chair service for instance in this hospital? No. All you know is that every time the mothers are carrying them. Maybe the child has now become heavy, child has graduated, and he needs a wheelchair. But you see because the integrated service is not there, we are missing out in the total care of these children”. (Healthcare Provider Public Facility1).

“A child with cerebral palsy for instance would struggle because our pavement…..nothing here is friendly. Everywhere in Ghana is not friendly how much more hospital. …if it’s a door, it’s just a knob that you have to press on to, you don’t need to pull on a handle but here we have handles that you have to pull on. So we don’t have everything in place for those with disabilities especially with cerebral palsy”. (Healthcare Provider Public Facility2).
Individual (Parental) Factors Influencing Access to Healthcare

The study generally revealed costs of affording services and knowledge and perception of child’s condition as factors influencing health. These factors are classified under parental factors. These findings permeate through the responses of parents/caregivers as well as healthcare providers.

“…our society is such that a lot of the times, they may not immediately bring children to the hospital who have these conditions. They’ll have the myths and say that this is not a hospital disease; this is a witch who is doing it, this is spiritual”. So a lot of children may be kept in the house and may not even access medical care (Healthcare Provider Private Facility1).

“…sometimes they’ll be forced to seek healthcare when it’s getting dangerous but whatever you tell them to do they do not do because they believe it’s something spiritual” (Healthcare Provider Private Facility1).

This also explains the reason why some parents resort to other sources of care asides medical care as indicated by a respondent

“We used to go to the children’s hospital until we were referred to a tertiary hospital. When they referred us, we did not go. We rather resorted to traditional methods until we realized no improvement... We used both traditional and conventional medicines” (Caregiver of child with autism-Private School).

“Frankly, after taking him to the hospital several times without improvement, I considered it spiritual. That’s how I see it” (Parent of child with Down syndrome-Public School).

“I told his dad the medications given at the hospital were useful but he stated that the spiritualists' efforts and medications are rather useful” (Caregiver of child with autism-Private school).

Cost of affording services and medications is another important factor that influences access to healthcare for children with disabilities. Parents/caregivers and healthcare workers alike reported on the cost of medications needed by children with autism, cerebral palsy and Down syndrome. Some parents recounted how they have had to postpone and sometimes forgo medical care due to cost.
“Because of cost, we had to postpone one of his surgery because of the bill involved. We had to go and prepare ourselves before doing the surgery” (Parent of child with cerebral palsy-Private School).

“...a lot of the kind of care and medications these children would need is not on the national health insurance so parents would have to pay out of pocket and if you can’t pay you can’t access the care” (Healthcare Provider Private 1)

“His medications are also very expensive. If you will pay GHC 50 for a normal drug, you will end up paying GHC 100.00 for his medications. There is no medications we have bought that is less expensive” (Caregiver of child with cerebral palsy-Private School)

Other parents/caregivers have been unable to afford some of the necessary special services required for their children’s optimum development. Services such as speech therapy, occupational therapy etc. Respondents recounted it was more difficult to afford services and medications because most of their medications are not covered by the national health insurance and are therefore not easily affordable.

“He doesn't have access to a specialist because of the cost involved; if you don’t have a lot of money, you can’t afford them” (Caregiver of child with cerebral palsy-Private school).

“Right now, I don’t not have a personal speech therapist for my child because it was expensive. We used to pay a huge sum to have the specialist come to the house “(Parent of child with autism-Private school).

“...in the early stages it was so bad and if I had not had the money to do it he would have died. In fact if you don’t have money and you have a child with challenges it’s very difficult...” (Parent of child with Down syndrome-Private school).

“...even the medicine that the doctor prescribed, hundred Ghana, I bought it three times and that”’s all I couldn’t even continue. It’s not easy my sister, it’s not easy at all... ” (Parent of child with cerebral palsy-Private school)

“We have quite a number of the new anti-seizure medications and they’re not on the national health and so they are expensive” (Healthcare Provider Private Facility1).

**Emerging Themes**

The emerging themes from the interviews were classified under social factors influencing access to healthcare and condition related factors influencing access to healthcare
Social Factors Influencing Access to Healthcare

The recurring theme under social factors influencing access to healthcare is on social stigmatization. It is interesting to find that besides the stigmatization and discrimination from the general public towards children with autism, cerebral palsy, and Down syndrome, healthcare providers especially nurses and general practitioners as well are implicated in this. Parents/caregivers and healthcare providers expressed their displeasure with this situation as well as how it influences access to appropriate medical services.

“Sometimes on our way to the hospital, the drivers are unwilling to pick us. They pretend they have other customers to attend to but I know it is because of the child I have with me. People act that way often so we are used to it” (Caregiver of child with cerebral palsy-Private school).

“... The stigmatization, when they go to the hospital, the way they are treated... “Ask your child to sit, she’s disturbing!” you know instead of that care and affection that they expect from the health professional but it doesn’t come that way...” (Social Worker Special Educational Facility).

Condition-Related Factors Influencing Access to Healthcare

Inability to receive adequate healthcare services may be as a result of the conditions themselves. Findings from this study revealed that due to the hypersensitivity and sensory issues associated with these conditions; especially autism and Down syndrome, Parents find it frustrating taking their children to the health facility for care. The study also revealed that healthcare providers, especially general practitioners do not seem to be adequately prepared for their clients.

“...Going to a regular doctor, sitting in line in a queue, to see the doctor is also a very big issue. So if they go and they’re so many people around, if the place is busy, bustling, there’s noise, they may have more tantrums, anxiety. So a lot of parents would tell you that just taking them to the hospital, is even challenging for them” (Healthcare Provider Private Facility1).

“When we took one of our residents to the hospital, he didn’t allow them to take the scan, he wouldn’t allow them they had to tie him to the bed to treat him” (Social Worker Special Educational Facility).
“They’ve given us a list for tests, but that can’t come on. The doctor herself even knows because my son wouldn’t sit down for you to put this thing on his forehead or ECG on his chest” (Parent of child with Down syndrome-Private School).
“...and I remember we took him to an optician. I mean the understanding wasn’t there so he couldn’t...I mean like putting his eyes through the thing...” (Parent of child with Down syndrome-Private School).
“Well one aspect that I think we need to focus on is behavior therapist. We don’t have people who manage behavior in this country. When you look at the children lots of them have behavioral problems. It’s a very common problem” (Healthcare Provider Public Health Facility 1)
“It’s so difficult to be able to take a child to maybe a polyclinic with all these noise and the queuing. Nobody is going to give you preferential treatment if you go and say that my child has autism so let me jump the queue or give me a specific time so I know if I come at 10 o clock you see me and I’m gone. So, a lot of parents would just shy from taking their children” (Healthcare Provider Private Health Facility 1)
“...So access to a medical professional who is comfortable enough to see them is a challenge” (Healthcare Provider Private Facility 1).
“...and because a lot of them may not be able to communicate adequately, they may have other gut issues that you can’t really pinpoint. If they’re nonverbal, then it becomes even a bit more challenging because even with their regular healthcare needs; if they have an otitis media; ear infection, if they have some kind of joint pain, if they have constipation, they’ll not be able to tell you...” (Healthcare Provider Private Facility 1).
CHAPTER FIVE

5.0. DISCUSSION

This study found that general healthcare services are available for children with autism, cerebral palsy and Down syndrome but there are challenges in accessibility, appropriateness and accommodation of these services. The study also found that special services required by these children such as physiotherapy, occupational therapy, speech and language therapy, and a whole range of other services are not readily available for them.

Furthermore, the study also quantitatively identified individual (parental) factors influencing access to healthcare as; parent/caregiver’s highest level of education, parent/caregiver’s income range per month, and child’s school type.

Findings from this study are discussed in light of other existing literature.

5.1. Individual Factors Influencing Access to Healthcare

Demographic characteristics of study participants in this study are similar to those of the general population as reported by the 2014 Ghana Demographic and Health Survey (GDHS) (GSS, GHS, 2014). However, a greater percentage of our study population (47.4%) had acquired up to tertiary education. Parents/caregivers with higher education levels had better access to care for their children with disabilities compared to those of lower education levels. The impact of parent education on access to care has also been documented by Porterfield & McBride, (2007) among children with special healthcare needs in the United States. Evidence from this work is similar to the findings of Thomas et al. (2007) who assessed access to care for autism-related services and found that access to care was limited by low levels of education. Education generally improves access to
healthcare services. Higher levels of education is a predictor for increased access to information hence parents/caregivers with higher education have better access to healthcare services (Tek & Landa, 2012).

Generally, poor people have less access to healthcare services (Peters et al., 2008). Children in poverty (< 100% poverty level) do worse in terms of access compared to children from wealthy families (Liptak et al., 2008). This study found that participants with higher household income range per month (GHC > 1000) were found to have better overall access as compared to those with household income range of GHC 501-1000 or lower. Higher income increases the odds of service use (Thomas et al., 2007). Poor access to healthcare for children with Autism Spectrum Disorder (ASD) is due to poverty. Poverty also influences families” access to healthcare services (Zuckerman et al., 2014, Kuwana, 2014). Findings from this present study also supports evidence from the United States which identified poverty and lack of information as barriers to accessing required health services (Porterfield & McBride, 2007).

Although there is evidence from Danseco (1997) on the influence of parental beliefs/perceptions on child’s disability, this study did not find significant association between parent/caregiver perception and access to healthcare. This lack of association between parents”/caregivers perception and access was also reported by Matt (2014), in Nicaragua.

5.2. Health Service-Related Factors Influencing Access to Healthcare

This study found availability of trained specialist healthcare providers, availability of disability friendly structures, knowledge and attitude of healthcare providers and access
to information as factors influencing access to healthcare among others. These findings are similar to findings by Eide et al. (2015) who found that lack of transport, availability of services, inadequate drugs or equipment, and costs, are the four major barriers for access among individuals with disabilities in South Africa, Namibia, Malawi, and Sudan. In contrast to the findings from this study, Reichard et al. (2004) reported ease of access to disability friendly equipment and structures by families of individuals with developmental disability in Kansas, U.S.A.

This current research work also found that attitudes of healthcare provider would facilitate and/or hinder access to healthcare. Reichard et al. (2004) also reported attitudinal barriers due to lack of training of healthcare providers in the care of individuals with developmental disabilities thus supporting findings from this study. Negative views and attitudes of healthcare providers expressed towards persons with intellectual disabilities have been reported by Hemm et al. (2015). Furthermore, this study found that low knowledge levels and negative attitudes of healthcare providers reduces parents/caregivers’ trust in the healthcare system. This highlights the need for training of specialist healthcare providers as recommended by Hemm et al. (2015).

In a mixed methods study conducted by Stein et al. (2016), to understand oral care challenges among children with Autism Spectrum Disorder (ASD), fifty percent (50%) of parents reported difficulty accessing dental care due to sensory sensitivities related to the condition. Fifty three percent (53%) also reported that their child’s uncooperative behavior negatively influenced access to dental care. These findings resonate with evidence from the qualitative aspect of this present study regarding condition related factors influencing access to healthcare.
Similar to our findings on cost of affording services as a factor influencing access to healthcare, Stein et al. (2016) also reported cost of affording services as one of the main challenges with assessing services.

Vohra et al., (2014), found that caregivers of children with autism spectrum disorders (ASD) were significantly more likely to report difficulty using services, lack of source of care, inadequate insurance coverage, lack of shared decision making and care coordination, and adverse family impact as compared to caregivers of children with developmental disabilities, mental health conditions, or both.

In conclusion, this study identified both individual and health service-related factors that influence access to healthcare for children with autism, CP and DS. The challenges identified require concerted efforts in the area of health professional training and acquisition of disability-friendly equipment to ensure that children with disability can utilize available healthcare.

5.3. Limitations and Strengths of the Study

The key strength of this study was the use of mixed methods to explore both healthcare provider and parent/caregiver perspectives on factors influencing access to healthcare.

The primary limitation of this study is with the generalizability of the results due to the small number successfully reached, which is accounted for by the limited proportion of consenting participants.

One key limitation of this study is with the relatively low reliability (ranging between poor and acceptable) of the scales measuring sub-dimensions of access except for affordability which had an “acceptable” reliability. Nevertheless, the scale measuring
overall access had high internal consistency Chronbach’s alpha =0.79). The concepts of availability and accessibility need further exploration in this setting in order to improve measures of access to healthcare.

Also, the recruitment of respondents through special education facilities may have introduced selection bias against parents whose wards are not in school due to extreme poverty or other factors related to their ward’s condition.

Lastly, the inaccessibility to a significant proportion of parents as well as the low response and consent rate recorded may further heighten the effects of selection bias on the external validity of study findings.
CHAPTER SIX

6.0. CONCLUSIONS AND RECOMMENDATIONS

6.1. Conclusions

Findings from this study highlights challenges related to both access and utilization of needed healthcare services. Healthcare services available to children without disabilities may not be easily accessible by children with disabilities due to some of the identified factors. There is therefore, a need for a more coordinated, collaborative and multidisciplinary approach towards improving access to healthcare for children with disabilities. More patient-centered training for healthcare providers as well as the provision of disability-friendly structures, equipment, and healthcare facilities and services is needed.

6.2. Recommendations

Improving access to healthcare services would involve a coordinated, concerted and deliberate effort on the part of the government, parents and all stakeholders involved in care for children with disabilities. Recommendations for addressing the challenge of access to healthcare for children with disabilities are outlined below.

- The Ghana Health Service should engage relevant stakeholders (Ministry of Gender, Children and Social Protection, professional health worker groups, experts on disability and media organizations) in the development and implementation of educational programmes aimed at improving inclusion of
persons with disabilities especially in the area of healthcare in order to address the challenge of social stigmatization.

- The Ministry of health should develop and implement policies towards the training and recruitment of specialist healthcare providers for the management of conditions of persons with disabilities in order to make them more responsive to the needs of persons with disabilities.

- The Ghana Health Service should increase efforts at providing disability friendly equipment and environment such as hearing aids, wheelchairs, ramps, etc. especially for children with disabilities in health facilities more (Not just for physically disabled).

- The national health insurance scheme should increase the range of services and medications available for insured children with disabilities.

- Relevant stakeholders (Ghana Medical Association (GMA), Ghana Health Service (GHS), Ministry of Gender and Social Protection) should consider providing guidelines on case management for persons (especially children) with disabilities to ensure improved coordination of care for them.
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Appendix I-Parent Consent Form

PARENT CONSENT FORM

Study Title: Access to Healthcare for Children with Autism, Cerebral palsy, and Down syndrome.

Principal Investigator: Lasisi, Opeyemi Rashidat. Graduate student, School of Public Health, University of Ghana.

You are invited to participate in this research study on identifying factors that influence access to healthcare for children with Autism, Cerebral palsy, and Down syndrome. The form will be read and explained to you. Please do not hesitate to ask any questions that you have.

Background: Children with disabilities (for the purpose of this study: Autism, Cerebral palsy, and Down syndrome) have mainstream and special healthcare needs that are usually unmet. Parents/caregivers usually experience difficulties accessing healthcare for their wards. The purpose of this study is to identify the factors that both facilitate and hinder access to healthcare.

Description of Procedure: If you agree to participate in this study, you will be asked to complete a short questionnaire about yourself. You will also be required to give responses to certain questions about your experiences with accessing mainstream and special healthcare for your child.

Potential Benefits and Risks: The risks attached to participating in this study are discomfort in answering questions as well as the possibility of psychological trauma. If you feel uncomfortable answering some questions, you will be advised to withdraw from the study if you so wish. In the case of psychological trauma you would be referred to a social welfare worker.

There are no direct benefits to participating in this survey. However, findings from the study is expected to inform policy makers on decisions about healthcare access for children with disabilities which will in turn impact on your ease of access to health services.

Costs and Compensations: For participating in this study, your child will receive a small gift (an exercise book, a pen, crayons, and a pencil).

Participation Rights: Your participation is completely voluntary. You may refuse to participate or leave the study at any time. If you decide not to participate in the study, it will not result in any penalty or loss of benefits to which you are otherwise entitled.

Confidentiality: Records identifying participants will be kept confidential to the extent permitted by applicable laws and regulations and will not be made publicly available. However, the Ethical Review Committee (a committee that reviews and approves human subject research studies) may inspect and/or copy your records for quality assurance and data analysis.

Questions: if you have any questions concerning the study, please feel free to ask at any point. For further information about the study contact: Opeyemi Rashidat Lasisi at 0553598835, orlasisi@st.ug.edu.gh (Legon, Ghana) OR Hannah Frimpong 233 (0) 243235225 or 0507041223 Hannah.Frimpong@ghsmaill.org

University of Ghana  http://ugspace.ug.edu.gh
PARTICIPANT STATEMENT AND SIGNATURE-PARENT’S COPY

Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, and that all your questions have been satisfactorily answered.

**Participant’s Statement**

I certify that I voluntarily agree to answer the survey questions that the survey has been explained to me and all my questions have been answered satisfactorily. I understand I am free to discontinue participation at any time if I so choose.

Parent/caregiver’s name  ……………

Signature/thumbprint of parent/caregiver  …………………………………………………

Date  …………………………………

**If parent/caregiver is unable to read the form for themselves, a witness must sign here:**

I was present while the benefits, risks, and procedures were read to the subject. All questions were answered and the subject has agreed to take part in the research.

Signature of witness  …………………………………………………

Date  …………………………………

**Investigator’s Statement**

I certify that the participant has been given ample time to read and learn about the study. All questions and clarifications raised by the participant have been addressed. It is my opinion that the participant understands the purpose, risks, benefits and procedures that will be followed in this study and has voluntarily agreed to participate.

Signature of principal investigator  ………………………………………………………

Date  ……………………………… ID NUMBER …………… (To be assigned by research team)

As an indication of your willingness to participate in this study, please kindly fill the form below. The duplicate copy is to be retained by you.

**CHOICE OF INTERVIEW FORMAT**

As an indication of your willingness to participate in this study please kindly fill the form below returning a copy and leaving a copy for your reference purpose.

Name  ………………………………………………………

Name of Child/ward  …………………………………………………

Relationship with child  ………………………………………

Phone number  ………………………………………

Interview format preferred on scheduled dates (please tick most convenient for you)

Face to face  ☐

Phone interview  ☐
PARTICIPANT STATEMENT AND SIGNATURE-RESEARCHER’S COPY
Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, and that all your questions have been satisfactorily answered.

Participant’s Statement
I certify that I voluntarily agree to answer the survey questions that the survey has been explained to me and all my questions have been answered satisfactorily. I understand I am free to discontinue participation at any time if I so choose.

Parent/caregiver’s name  ........................................................................................................
Signature/thumbprint of parent/caregiver  ...........................................................................
Date ..........................................................................................................................

If parent/caregiver is unable to read the form for themselves, a witness must sign here:
I was present while the benefits, risks, and procedures were read to the subject. All questions were answered and the subject has agreed to take part in the research

Signature of witness  ............................................................................................................
Date ..........................................................................................................................

Investigator’s Statement
I certify that the participant has been given ample time to read and learn about the study. All questions and clarifications raised by the participant have been addressed. It is my opinion that the participant understands the purpose, risks, benefits and procedures that will be followed in this study and has voluntarily agreed to participate

Signature of principal investigator ..................................................................................
Date ...................................... ID NUMBER ..................... (To be assigned by research team)

As an indication of your willingness to participate in this study, please kindly fill the form below. The duplicate copy is to be retained by you.

CHOICE OF INTERVIEW FORMAT
As an indication of your willingness to participate in this study please kindly fill the form below returning a copy and leaving a copy for your reference purpose.

Name  ..........................................................................................................................
Name of Child/ward  ...........................................................................................................
Relationship with child  ..................................................................................................
Phone number  ..............................................................................................................

Interview format preferred on scheduled dates (please tick most convenient for you)
Face to face  ☐
Phone interview  ☐
Appendix 11-Healthcare Provider Consent Form

Healthcare Provider Consent Form

**Study Title:** Access to Healthcare for Children with Autism, Cerebral palsy, and Down syndrome

**Principal Investigator:** Lasisi, Opeyemi Rashidat. Graduate student, School of Public Health, University of Ghana.

You are invited to participate in this research study on identifying factors that influence access to healthcare for children with Autism, Cerebral palsy, and Down syndrome. The form will be read and explained to you. Please do not hesitate to ask any questions that you have.

**Background:** Children with disabilities (for the purpose of this study: Autism, Cerebral palsy, and Down syndrome) have mainstream and special healthcare needs. Parents/caregivers usually experience difficulties accessing healthcare for their wards. The purpose of this study is to identify the factors that both facilitate and hinder access to healthcare.

**Description of Procedure:** If you agree to participate in this study, you will also be required to give responses to certain questions about your opinion on health service factors influencing access to healthcare.

**Potential Benefits and Risks:** There are no risks or direct benefits to participating in this survey. However, findings from the study is expected to inform policy makers on decisions about healthcare access for children with disabilities as well as health service delivery for children with disability.

**Costs and Compensations:** For participating in this study, you will be compensated with a ball-point pen and a note book.

**Participation Rights:** Your participation is totally voluntary. You may refuse to participate or leave the study at any time. If you decide not to participate in the study, it will not result in any penalty or loss of benefits to which you are otherwise entitled.

**Confidentiality:** Records identifying participants will be kept confidential to the extent permitted by applicable laws and regulations and will not be made publicly available. However, the Ethical Review Committee (a committee that reviews and approves human subject research studies) may inspect and/or copy your records for quality assurance and data analysis.

**Questions:** if you have any questions concerning the study, please feel free to ask at any point. For further information about the study contact: Opeyemi Rashidat Lasisi at 0553598835, orlasisi@st.ug.edu.gh (Legon, Ghana) OR Hannah Frimpong 233 (0) 243235225 or 0507041223 Hannah.Frimpong@ghsmail.org
Participant Statement and Signature-Participant’s Copy
Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, and that all your questions have been satisfactorily answered.

Participant’s Statement
I certify that I voluntarily agree to answer the survey questions, that the survey has been explained to me. All my questions have been answered satisfactorily. I understand I am free to discontinue participation at any time if I so choose.

Healthcare provider’s Name -----------------------------------------------
Signature/thumbprint of healthcare provider----------------------------------
Date --------------------------

Investigator Statement
I certify that the participant has been given ample time to read and learn about the study. All questions and clarifications raised by the participant have been addressed. It is my opinion that the participant understands the purpose, risks, benefits and procedures that will be followed in this study and has voluntarily agreed to participate

Signature of principal investigator----------------------------------------
Date -------------------------- ID NUMBER---------------------- (To be assigned by research team)
Participant Statement and Signature-Researcher’s Copy
Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, and that all your questions have been satisfactorily answered.

Participant’s Statement
I certify that I voluntarily agree to answer the survey questions, that the survey has been explained to me. All my questions have been answered satisfactorily. I understand I am free to discontinue participation at any time if I so choose.

Healthcare provider’s Name --------------------------------------------------------------
Signature/thumbprint of healthcare provider-----------------------------------------------
Date ---------------------------

Investigator Statement
I certify that the participant has been given ample time to read and learn about the study. All questions and clarifications raised by the participant have been addressed. It is my opinion that the participant understands the purpose, risks, benefits and procedures that will be followed in this study and has voluntarily agreed to participate

Signature of principal investigator------------------------------------------------------
Date --------------------------- ID NUMBER------------------------ (To be assigned by research team)
Appendix III-Questionnaire on Access to Healthcare for Children with Disability

This school based survey is targeted at parents of children with autism, cerebral palsy, and Down syndrome whose children attend the special schools in the Greater Accra region of Ghana. It seeks to collect background information of parents and child, and information on healthcare access. Findings from this study will help in developing programmes and policies that would improve access to healthcare. Please tick as appropriate.

SECTION A: BACKGROUND INFORMATION
1. What was your age at last birthday? ...........
2. What is your relationship status with child?
   Parent ☐ Caregiver ☐
3. What was your child’s age at last birthday? ........
4. What class is your child? ...........
5. What is the gender of your child?
   Male ☐ Female ☐
6. What is the nature of child’s condition
   Autism ☐ Cerebral palsy ☐ Down syndrome ☐
7. What is your employment status?
   Self-employed ☐ Employed (part time or full time) ☐
   Student ☐ Home maker ☐ Unemployed ☐ Retired ☐
8. What is the highest level of education you have completed?
   None ☐ Primary ☐ Junior High School (JHS) ☐ Senior High School ☐
   College Graduate ☐
9. Marital status
   Single ☐ Married ☐ Divorced ☐ Widow ☐
10. What is your household income range per month?
    0 – GHC500 ☐ GHC 501 - GHC1000 ☐ GHC1001 – GHC2000 ☐
    GHC 2001 – GHC5000 ☐ GHC 5000 or more ☐

SECTION B: INDIVIDUAL FACTORS
11. What age was child when you began observing signs of condition?
    Less than 6 months ☐ 6months -1 year ☐ Greater than 1 year ☐
12. Were your suspicions confirmed by a health provider?
    Yes ☐ No ☐
13. If NO please state who confirmed it? ..........................................
14. What do you consider the cause of child’s condition?
    Medical ☐ Spiritual ☐ Judgement for a wrong doing ☐
    Spiritual possession/attack ☐ A test from God ☐

SECTION C: MEASURES OF ACCESS TO HEALTH CARE AVAILABILITY
15. Does your child have access to a personal primary healthcare provider?
    Yes ☐ No ☐
16. Does your child receive adequate medicines as and when needed?
    Yes ☐ No ☐
17. Does your child have a personal physiotherapist?
18. Does your child have a personal speech and language therapist?
   Yes □  No □

ACCESSIBILITY
19. On the average how long does it take to get to the health facility using the usual means of transportation?
   Less than 30 minutes □  30 minutes – 1 hour □  I hour and above □
20. Is there a children’s hospital/ special service provider within your vicinity? (i.e. about 30 minutes” drive away)
   Yes □  No □
21. Does the healthcare facility have convenient opening hours?
   Yes □  No □
22. Has it been easy finding where to seek healthcare?
   Yes □  No □
23. Do you find it difficult moving your child around the healthcare facility (e.g. to the toilet, to take temperature readings of child, etc.)
   Yes □  No □

AFFORDABILITY

General Health
24. Are you aware about any health insurance plans that covers your child’s general health?
   Yes □
   No □  (please move to question 21)
25. Which health insurance plan(s) covers your child?
   National Health Insurance □  Private health insurance □  None □
   Others please specify …………………………………………………
26. Has there been any point in the last 12 months when you were unable to afford prescriptions/supplements?
   Yes □  No □
27. Have you had to postpone medical care due to cost?
   Yes □  No □
28. Have you had to forgo medical care due to cost?
   Yes □  No □

Special Services
29. Has there been any point in the last 12 months when you were unable to afford prescriptions/supplements due to cost?
30. Are you aware about any financial sponsorship from any NGO for your child’s condition?
   Yes □  No □
31. If yes please list below
   ………………………………………………………………………………………
32. Has your child enjoy any of such benefits?
   Yes □  No □
33. Have you had to postpone special care due to cost?
   Yes □  No □
34. Have you had to forgo special care due to cost?
   Yes ☐  No ☐

35. Does insurance cover for special healthcare services? (E.g. physiotherapy, chiropractic, speech and language therapy, etc.)
   Yes ☐  No ☐

APPROPRIATENESS
General and Special Care
36. Are the healthcare providers usually courteous/polite/respectful?
   Yes ☐  No ☐  Sometimes ☐
37. Do the healthcare providers who treat your child answer all questions about your child’s health?
   Yes ☐  No ☐  Sometimes ☐
38. Do healthcare providers seek your consent when making decisions about your child’s health?
   Yes ☐  No ☐  Sometimes ☐
39. Do the healthcare providers make explanations in understandable terms?
   Yes ☐  No ☐  Sometimes ☐
40. Do you find it easy to communicate your child’s health challenges to the provider?
   Yes ☐  No ☐  Sometimes ☐
41. Overall, how would you rate the care your child received in the last 12 months?
   Excellent ☐  Good ☐  Fair ☐  Poor ☐  Very poor ☐

ACCOMMODATION
42. Do you get an appointment to suit you/ or child?
   Yes ☐  No ☐  Sometimes ☐
43. Are toilet facilities appropriate for your child?
   Yes ☐  No ☐
44. Do you consider the waiting time in the waiting room too long?
   Yes ☐  No ☐  Sometimes ☐

SECTION D: SPECIALIST CARE (PHYSIOTHERAPY, SPEECH AND LANGUAGE THERAPY, ANY OTHERS)
45. Do you incur any extra costs seeking care for child? (E.g. hiring a facilitator, recruiting extra helps etc.)
   Yes ☐  No ☐
46. What aspects of healthcare does your health insurance cover?
   Consultation ☐  Medications ☐  Laboratory tests ☐  Other ☐
47. Have you ever considered quitting your job because of child’s condition?
   Yes ☐  No ☐
48. Have you actually quit your job because of child’s condition?
   Yes ☐  No ☐
49. How often do you take child for routine care?
   Never ☐  Monthly ☐  Bimonthly ☐  Every 3months ☐
   Every 6months ☐  Yearly ☐  By appointment ☐
   When I feel a need to ☐
50. Are you aware about any health insurance plans that cover child’s condition?
51. Which health insurance plan(s) covers your child?
   - National Health Insurance □
   - Private health insurance □
   - None □
   - Others please specify ...........................................

52. What is your usual means of transportation to the healthcare facility?
   - Walking □
   - Trotro □
   - Taxi □
   - Personal car □

53. During the past 12 months, was there any time when your child needed care from a specialty doctor?
   - Yes □
   - No □

54. Have you sought for care from other sources apart from a healthcare facility?
   - Yes □ (please move to question 37)
   - No □ (please move to question 38)

55. Please state other sources of care used
   - Social support groups □
   - Traditional sources of health care □
   - Child’s school □

56. If your child has no personal physiotherapist and/or speech and language therapist, please tick all possible reasons
   - No available information on specialists □
   - Cost of a specialist is unbearable □
   - No specialty doctor identified yet □
   - Difficulty getting referrals □
   - Difficulty using service □
   - Other (please specify) ...........................................

57. If yes please state the special healthcare services received by child?
   ........................................................................................................................

58. Apart from a physiotherapist and a speech and language therapist, do you have access to any other specialist healthcare provider(s) and/or service(s)?
   - Yes □
   - No □

THANK YOU FOR YOUR TIME
Appendix IV-Interview Guide 1-In-Depth Interview

PURPOSE OF INTERVIEW: The purpose of this interview is to better understand the healthcare services required by children with intellectual disabilities (Autism, Cerebral palsy, and Down syndrome) and also to understand the factors that both facilitate and hinder access to healthcare.

DEFINITION OF TERMS:
Access: Access is defined as the opportunity to have healthcare needs met. For the purpose of this interview we will consider access in five dimensions. They are: availability, accessibility, affordability, accommodation, and appropriateness.
Healthcare: Healthcare is defined as the act of taking preventative or necessary medical procedures to improve one’s wellbeing.

Factors influencing healthcare access are classified under individual factors and health system related factors.

INDIVIDUAL FACTORS
1. Tell me about the nature of your child’s health condition?
   - Autism
   - Cerebral palsy
   - Down syndrome

2. What is the major source of your knowledge on child’s condition?
   - Probe 1: How did you find about child’s condition?
   - Probe 2: How long ago have you known about your child’s health condition?
   - Probe 3: What is your perception about child’s condition?
   - Probe 4: Do you think there are any spiritual or cultural factors related to the condition?

3. Tell me about your child’s healthcare needs (primary and special)

4. Are there any peculiarities in healthcare needs (of specified condition) as compared with children without Autism, Cerebral palsy and Down syndrome?

5. If yes, what are they?
   - Probe 1: How do the health care needs differ?
   - Probe 2: What special services are needed by child?

6. What are the challenges experienced in accessing healthcare services for the already identified healthcare needs?
   - Probe 1: What do you think about the cost of specialist service?
   - Probe 2: How well do you understand what the doctor says about your child’s condition?
   - Probe 3: What do you think about waiting time to get treatment?
   - Probe 4: Any other challenges?

7. On the average, what percentage of your income goes into this child’s health?
   - Probe 1: Have you had to delay care due to cost?
   - Probe 2: Is your child covered by any health insurance (private, government or any other?)
   - Probe 3: What part of healthcare (mainstream or special) does existing insurance cover?

8. What sources of healthcare do you seek for child?
   Do you seek spiritual or traditional sources of healthcare for your child?
HEALTH SERVICE FACTORS

9. Does child have a specialist healthcare provider?

10. If yes what is the nature of service available or rendered by specialist healthcare provider?
   - Physiotherapy
   - Speech and language therapy
   - Others

11. If no why?
   - Probe 1: Don’t know about any available special care provider?
   - Probe 2: Have you experienced difficulties locating specialist healthcare providers?
   - Probe 3: Cost or affordability of a specialist healthcare provider?
   - Probe 4: Proximity to healthcare service?

12. What issues if any have you faced in accessing care for your child?
   - Probe 1: What is your overall feeling about access to care for children with Autism cerebral palsy and Down syndrome?
   - Probe 2: What issues, if any, have you faced with regards to accessing affordable mainstream and specialist healthcare?
   - Probe 3: What factors facilitate your access to care (e.g. knowledge about health provider, your level of education, knowledge about child’s condition, etc.)?

13. If yes how often do you have appointments with him/her (specialist healthcare provider)?
   - Probe 1: How convenient are the appointment times for you?

14. Please share your experiences with the health service provider (s) (primary and specialist)
   - Probe 1: Describe the healthcare provider’s attitude towards child during treatments and appointments?
   - Probe 2: Do the health providers refrain (are unwilling, make themselves unavailable) from attending to child?
   - Probe 3: Please share your experience(s) (if any) of discrimination at health facility against child due to his/her health condition
   - Probe 4: Does healthcare provider consider your perceptions about child’s health in decision making?

15. Are they any existing communication barriers between you/child and healthcare providers?
   - Probe 1: Do you completely understand the doctor when he/she reports about your child’s condition?
   - Probe 2: Do you find it difficult explaining your ordeals to the doctor?
   - Probe 3: Are you involved in decisions that relate to child”s health?

16. Are disability-friendly equipment available at healthcare facilities?
   - Probe 1: Does child find it difficult accessing the health facility environment?
   - Probe 2: Please tell me about the accessibility of healthcare provider’s office?
   - Probe 3: Do you have access to wheel chairs and mobility aids at health facility? In closing, is there anything you would like to tell us?
Appendix V-Interview Guide 2-Key Informant Interview

PURPOSE OF INTERVIEW: The purpose of this interview is to better understand the healthcare services required by children with disabilities (Autism, Cerebral palsy, and Down syndrome) and also to understand the factors that both facilitate and hinder access to healthcare.

DEFINITION OF TERMS: I will define the following terms to my interviewee

Access: Access is defined as the opportunity to have healthcare needs met. For the purpose of this interview we will consider access in five dimensions. They are: availability, accessibility, affordability, accommodation, and appropriateness.

Healthcare: Healthcare is defined as the act of taking preventative or necessary medical procedures to improve one’s wellbeing.

Factors influencing healthcare access are classified under individual factors and health service factors.

1. For each population group of children with:
   - Autism
   - Cerebral palsy
   - Down syndrome
     a. From your experience(s) working with children with disabilities, what are the major healthcare needs of each group:
     b. What barriers keep parents/caregivers of children in the population group from using healthcare service exists (e.g., cost, transportation, language, quality)
     c. Are they any areas of weakness in the current health services (mainstream and special) for children with disabilities?
     d. What services are currently provided for them
     e. What services need improvement in the way they are delivered?

2. What health services are needed but not available for this population group?

3. What challenges if any are there in recruiting, training, and maintaining specialist healthcare providers (physiotherapists, speech and language therapists, and others)?
   - Probe 1: Why a, b, c is a challenge?
   - Probe 2: How can the challenge(s) be overcome

4. In your opinion, do specialist healthcare providers have adequate about;
   - Autism
   - Cerebral palsy and
   - Down syndrome

5. What is the nature of communication barriers experienced between provider and parent/caregiver of child with Autism, cerebral palsy and Down syndrome

6. What do you think about the subject of discrimination and/or stigmatization from healthcare workers towards the children

7. How well are clients able to utilize existing medical equipment, structures or processes?
   - Probe 1: How well do clients access disability friendly equipment in health facility if available?
   - Probe 2: What ideas do you have for addressing these barriers?

8. How do you perceive cost of insurance for special services if any?
9. What role do you think parent/caregiver’s health illiteracy play in access to healthcare?
10. Tell me about waiting time for appointments
11. How best do you think access to healthcare can be facilitated?
12. What issues if any have you faced when dealing with access to care for children in the above population group?
   
   **Probe 1**: What is your overall feeling about access to healthcare for the population group?
   
   **Probe 2**: What factors facilitates access to healthcare in your own opinion?

In closing, is there anything else that you would like to tell us?

**THANK YOU FOR YOUR TIME.**
The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol.

<table>
<thead>
<tr>
<th>GHS-ERC Number</th>
<th>GHS-ERC:28/12/2016</th>
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<tbody>
<tr>
<td>Project Title</td>
<td>“Access to Healthcare for Children with Disabilities in the Greater Accra Region”</td>
</tr>
<tr>
<td>Approval Date</td>
<td>14th March, 2017</td>
</tr>
<tr>
<td>Expiry Date</td>
<td>13th March, 2018</td>
</tr>
<tr>
<td>GHS-ERC Decision</td>
<td>Approved</td>
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</tbody>
</table>

This approval requires the following from the Principal Investigator:

- Submission of yearly progress report of the study to the Ethics Review Committee (ERC)
- Renewal of ethical approval if the study lasts for more than 12 months,
- Reporting of all serious adverse events related to this study to the ERC within three days verbally and seven days in writing.
- Submission of a final report after completion of the study
- Informing ERC if study cannot be implemented or is discontinued and reasons why
- Informing the ERC and your sponsor (where applicable) before any publication of the research findings.

Please note that any modification of the study without ERC approval of the amendment is invalid.

The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Kindly quote the protocol identification number in all future correspondence in relation to this approved protocol.

SIGNED......................................................

DR. CYNTHIA BANNERMAN
(GHS-ERC CHAIRPERSON)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra
IN HER NAME, 
the number and date of the letter should be quoted.

My Ref. No. EP 3012/VOL.III/75

Your Ref. No. 

PERMISSION TO CARRY OUT A STUDY TO IDENTIFY FACTORS INFLUENCING ACCESS TO HEALTHCARE FOR CHILDREN WITH DISABILITIES IN THE GREATER ACCRA REGION

Permission is being granted Ms. Opeyemi Rashidat Lasisi, a Graduate student (Department of Population, Family and Reproductive Health of the University of Ghana School of Public Health) to conduct the above mentioned study.

The study seeks to identify factors that both hinder and facilitate access to health care for children with autism, cerebral palsy and Down syndrome of ages between 5 – 17 years in both public and private Special Schools.

The survey will involve parents of children with the above mentioned conditions. Consenting parents will be interviewed in order to better understand their experiences with health care system.

Ethical approval has been received from the Ethical Review Committee (ERC) of the Ghana Health Service. All information obtained would be kept confidential and use for the research purpose only. It is hoped the outcome of the study will help inform policy making and programme development that will enhance access to health care. The results will be shared with the Ghana Education Service for the purposes it may be determined as needful.

Participation in this study is completely voluntary and parents are free to withdraw from it without giving any reason for doing so.

By this letter, Ms. Opeyemi Rashidat Lasisi is being permitted to contact the parents of the selected children of the special schools through their respective Metropolitan/Municipal/District Directors of Education for further discussions on arrangements for their participation. Heads of special schools are to encourage parents of the selected children to participate in the study.

Please, find attached a copy of the Ethical approval for the research.

Thank you.
CYNTHIA BOSUMTWI-SAM (MRS.)
DIRECTOR
BASIC EDUCATION DIVISION
for: DIRECTOR GENERAL

METRO/MUNICIPAL/DISTRICT DIRECTORS OF EDUCATION, GAR

cc: Regional Director of Education, GAR, Accra

The Ag. Head of Department
Department of Population, Family
and Reproductive Health
School of Public Health
University of Ghana, Legon