

KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY,

KUMASI

COLLEGE OF HEALTH SCIENCES

SCHOOL OF PUBLIC HEALTH

DEPARTMENT OF HEALTH PROMOTION AND DISABILITY STUDIES



**BARRIERS AND FACILITATORS TO HEALTHCARE ACCESS FOR
PEOPLE**

**WITH INTELLECTUAL DISABILITY (PWIDs) IN THE ASHANTI
REGION OF
GHANA**

BY

ADDO DORCAS

NOVEMBER, 2019.

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**A THESIS SUBMITTED TO THE DEPARTMENT OF HEALTH
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IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE

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DISABILITY, REHABILITATION AND DEVELOPMENT

NOVEMBER, 2019

DECLARATION

I hereby declare that, except for the references, which I have duly acknowledged, this thesis is the result of my own research and that it has neither in part nor whole been presented elsewhere for the award of another degree.

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Date

DEDICATION

This work is dedicated to my lovely husband, Jeremiah Ewudzie-Sampson and my children, Barima Kwesi Antobra Ewudzie-Sampson, Owura Kofi Kesse EwudzieSampson and Nsorama Odi Ewudzie-Sampson. And to a special Mom in the entire world, Madam Ernestina Offei



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LIST OF ABBREVIATION

ASD	Autism Syndrome Disorder
CBR	Community-Based Rehabilitation
CHRPE	Committee on Human Research and Publication Ethics
CRPD	Convention on the Rights of Persons with Disabilities
DPOs	Disabled Persons Organizations
GES	Ghana Education Service
GPs	General Practitioners
ICF	international classification of functioning disability and health
ICT	Information Communication Technology
ID	Intellectual disability
IDD	Intellectual and Development Disability
IOM	Institute of Medicine
KATH	Komfo Anokye Teaching Hospital
NGOs	Non-Governmental Organizations
NHIS	National Health Insurance Scheme
PWIDs	People with Intellectual Disability
SDGs	Sustainable Development Goals
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization

ABSTRACT

People with intellectual disabilities are at higher risk of developing preventable diseases due to challenges they encounter in accessing healthcare. Such challenges have led to shorter life expectancy than the general public. The aim of this study was to assess the barriers and facilitators that influence access to healthcare services for People with Intellectual Disability (PWIDs) in the Ashanti Region of Ghana.

This study was qualitative and used purposive sampling to select participants from two Intellectually Disabled Schools namely, Garden City and Life Community and Vocational School in the Asokore Mampong and Oforikrom Districts respectively. Data was collected by means of semi-structured interviews, focus group discussions and unstructured observation.

Findings showed that specific health needs of PWIDs included chest infections, common cold, sensory challenges and stomach infections among others. Challenges they encountered in accessing health included, among others, high cost of medication and the inability of healthcare providers to communicate effectively with PWIDs. It however emerged that the introduction of sign language in various health training institutions has contributed to positively shaping the attitude of some healthcare providers towards issues of disability and has served as a major factor that has enhanced access to health for PWIDs.

The study recommends the need for some of the medications prescribed for PWIDs to be covered by the National Health Insurance Scheme. It also recommends continuous

training of healthcare providers about issues of disability, especially those with intellectual disability as this has the potential to promote the socio-environmental understanding of disability and health care.

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CHAPTER ONE

INTRODUCTION

1.0 Introduction

This chapter gives an overview of the issue under investigation. It covers the background of the study; statement of the problem, research questions, the main and specific objectives, justification of the study, scope, organization and limitations of the study as well as the conceptual framework and definition of terms.

1.1 Background to the study

The health of individuals plays a significant role in the socio-economic development of a nation. When the health needs of individuals are met, they become free to focus on other aspirations of life such as work, education among others which go a long way in ensuring the overall development of the nation (Nordhaus, 2002). Life expectancy will improve as individuals' experience quality and accessible healthcare (Mugilwa *et al.*, 2005, Marmot *et al.*, 2008). These invariably affect work productivity leading to sustainable growth in the long-run.

A robust healthcare delivery system responds effectively to the needs of their consumers not just in terms of treatment of health-related problems but also by addressing overall well-being of the person through collaborative efforts of counseling and respecting the health rights of the individual (Lindsey, 2002). In as much as healthcare is paramount, its utilization among persons with disabilities

(PWDs) differs dramatically across countries and communities. In every society, PWDs lag behind other citizens in accessing healthcare (Rimmer *et al.*, 2004). This is more pronounced in persons with intellectual disability.

Intellectual disability (ID) is a generalized disorder characterized by significantly impaired cognitive functioning and deficits in two or more adaptive behaviors. (OtiBoadi, 2015). In this instance ID will experience problems with recalling information, telling the time, conceptualizing time, maintaining self-care and accompanying activities needed to maintain daily life skills. The signs and symptoms of intellectual disability are all behavioral and have its onset before the age of 18 years. (Oti-Boadi, 2015). It is associated with lifetime limitations of adaptive functioning and low intelligent quo-efficient IQ (70 or less).

It is estimated that, 1% to 3% of the world's population has an intellectual disability as at 2008. (Balogh *et. al*, 2008). There is lack of information about the number of persons with ID in Africa but Ghana has some scanty available data from which cues can be revealed. For example, the 2010 Population and housing census has a crude total number of IDs in Ghana as 15.2% of the total Disability figure of 737,743. (Ghana Statistical Service, 2014)

People with intellectual disabilities have many special health care needs that have to be addressed. Therefore, person-centered services must be aware of the wide range of needs to which they must be able to respond while treating each person as an individual (Population and Housing Census, 2010). Goal 3 of the Sustainable Development Goals

(SDGs) emphasizes healthy lives and the promotion of wellbeing for all. This can only be achieved if all persons, including Persons with Intellectual Disabilities (PWIDs) have access to quality healthcare that meets their needs.

The U.S. Surgeon General's Report on Health Disparities and Mental Retardation (2001) states that people with intellectual disabilities of all ages experience poorer health outcomes and has more difficulty accessing health care. They are seven times less likely to receive emotional support than people with other disabilities and combined with poorer social networks, they are less likely to be able to use these resources to get well and experience a good quality of life (Havercamp, 2004; Ormel, 1996). Even though Ghana's Disability Act 2006 (Act 715, section 31) clearly emphasizes the right of persons with disabilities to healthcare and the responsibility of the state to eliminate all barriers to health access. Nonetheless, there exist health care challenges for PWIDs.

A research conducted by Hosking *et al* (2016) established that thirty-seven (37%) of the deaths of people with intellectual disabilities were classified as being caused by lack of healthcare interventions compared with 22.5% of deaths amongst the general population. It has also been established that, individual with intellectual disabilities are four times more likely to die of preventable causes of diseases such as malaria than the general population (Horwitz, 2000). Alborz *et al* (2005) identified significant factors which may affect access to a comprehensive healthcare delivery by people with intellectual disabilities. Amongst the factors identified were: difficulty in recognizing the particular health problem and communicating with others. PWIDs usually rely on a third party judgment to ascertain their health status, and to recognize signs of ill health in order to take appropriate action (Alborz *et al*, 2005; Krahn *et al*, 2006). When a

problem is identified and support is minimal, key challenges arise in term of organizational barriers within the healthcare delivery system. Challenges include scarcity of services, difficulties with physical access, a failure to make ‘reasonable adjustments’ to meet need (for example the production of easy-read materials or offering a longer appointment), ‘diagnostic overshadowing’ (whereby physical health problems are viewed as being part of the person’s intellectual disability) and negative attitudes amongst healthcare staff (Emerson *et al*, 2012). Additionally, PWIDs are faced with stigmatization arising from healthcare professionals with bad interpersonal skills (Alborz *et al*, 2005).

To promote access to healthcare for persons with intellectual disabilities, these identified gaps need to be properly addressed. The Royal College of Psychiatrists (2012) highlighted on collaboration as a key element of facilitating access to healthcare access among persons with intellectual and mental disabilities. In their report, they stressed that engagement with key stakeholders such as ministries responsible for disability issues would contribute to eliminating access barriers. The report further stressed that established protocols to address the specific needs of the PWIDs’ population with adequate training and sensitization workshops among caregivers and healthcare professionals would help ensure quality of services (Royal College of Psychiatrists, 2012).

The 1946 Constitution of the World Health Organization (WHO) states among others that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being”. To this effect, the Community-Based Rehabilitation

(CBR) programme developed by the WHO highlights five important components of health services for PWDs. These services are health promotion, health prevention, medical care, rehabilitation and assistive devices. These components can improve healthcare for PWIDs to ensure sustainable development through accessible and proper linkages between PWDs and the health systems (WHO, CBR Guidelines, 2010).

This research adopted a qualitative but participatory approach to investigate barriers to healthcare access among PWIDs in the Ashanti Region of Ghana.

1.2 Problem statement

The problem is that according to the WHO (2015), PWDs 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. Also, the World Disability Report (WHO, 2011) revealed that PWDs suffer minor to complex medical conditions which require swift medical attention.

Though PWIDs make up 15% of the world's population, little or less attention is paid to their medical needs (United Nations, 2006). The challenges are more profound for people with intellectual disabilities (Krahn & Drum 2007).

The health needs of PWIDs range from referral services, rehabilitation, financial aid, transportation need, and assistive devices among others. Empirical evidence reveals that these needs which are coupled with a plethora of barriers such as financial, sociocultural and transportation among others could further impair and deprive PWIDs (Badu, 2014).

Therefore, the need to identify barriers encountered in accessing health care services among PWIDs 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) (United Nations, 2006). With a paucity of research done in the area of healthcare access among PWIDs in developing countries such as Ghana (Oti-Boadi, 2015), this study becomes more imperative.

1.3 Research questions

Every research is important for the reason that it answers a particular problem.

Following the above problem statement, the research sought to answer the following:

1. What are the health needs of PWIDs?
2. What are the social barriers of the PWIDs?
3. What are the experiences healthcare professionals in providing services to PWIDs?
4. What are the enablers to accessing healthcare service for PWIDs?

1.4 Research objectives

1.4.1 Main objective

The main objective of the study was to assess the factors that influence access to healthcare services for People with Intellectual Disability (PWIDs) in Ashanti Region of Ghana.

1.4.2 Specific objectives

Specific objectives of the study are;

1. To explore the healthcare needs of PWIDs in Ashanti Region.
2. To identify the challenges PWIDs encounter in accessing healthcare in Ashanti

Region.

3. To ascertain the experiences of healthcare professionals in providing healthcare services to PWIDs in Ashanti Region.
4. To explore the enablers to healthcare services for People with Intellectual Disabilities PWIDs in Ashanti Region.

1.5 Conceptual framework

Conceptual framework refers to the building blocks which provide the pillars upon which research is conceptualized. The research therefore draws on these variables to review and synthesize ideas from literature in health research, education, social sciences and other fields. *Figure 1.1* is the conceptual framework for the study. The conceptual framework for the study therefore shows the relationship between the dependent variable (access to health care) and the independent variables (barriers, enablers, health needs, experiences influencing access to health care).

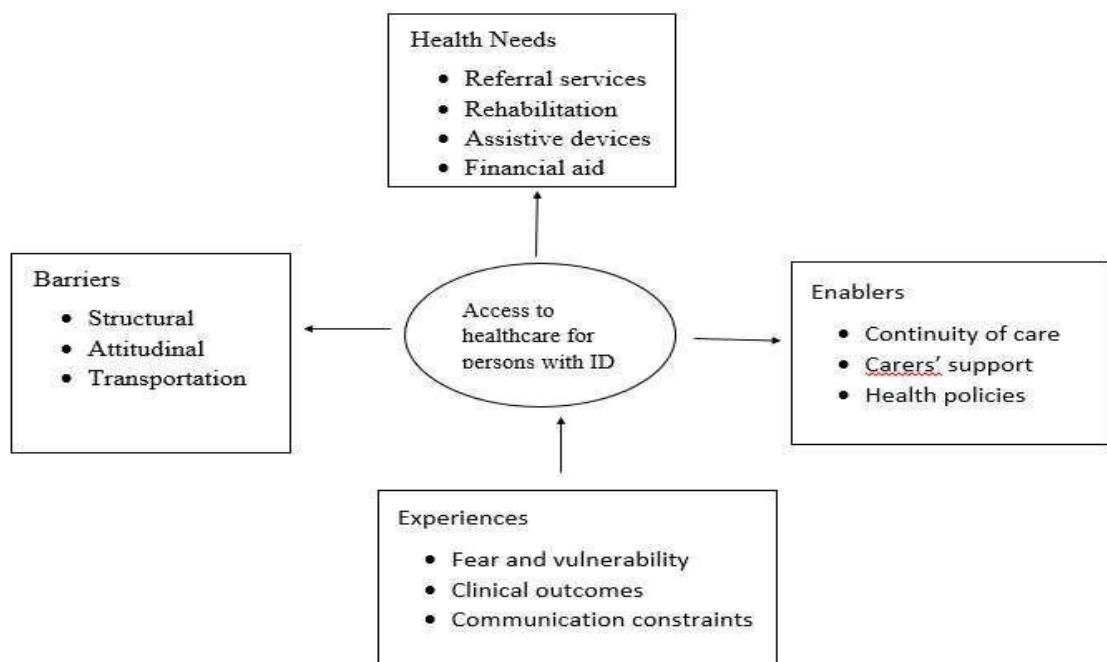


Figure 1.1 Conceptual framework of the study

Source: Authors construct 2019

1.6 Justification of the study

Identification of the barriers within the healthcare delivery for people with intellectual disability and the necessary mediations to mitigate the barriers have been identified as the top research priority globally by the World Disability Report (WHO, 2011). Goal 3 of the Sustainable Development Goals (SDGs) emphasizes healthy lives and the promotion of wellbeing for all. This can only be achieved if all persons, including persons with intellectual disabilities have access to quality healthcare that meets their needs.

It is envisaged that the findings of the study would contribute to enhancing the knowledge about health care needs of PWIDs at the special schools in Ashanti region. This could positively influence the health outcomes for people with intellectual disabilities, and lead to the attainment of inclusive healthcare provider in Ashanti Region. Such research-based evidence would also help to develop intervention and training models that could improve access to health for PWIDs.

Also, results of the study would inform policy action and serve as a stepping stone for the formulation of inclusive healthcare policies for persons with disability in general. This would invariably help in the attainment of SDG 3 and also help improve the quality of life of PWIDs.

It is envisaged that findings of this study would add to the existing body of knowledge regarding access to healthcare among children with Autism, Cerebral Palsy, and Down syndrome. Also, the findings from this study is expected to inform policy and programmes aimed at addressing issues of health care access for persons with intellectual disabilities.

1.7 Scope of the study

The study was conducted in two special schools within Ashanti Region of Ghana. The schools were Garden City Special School and Life Community Vocational School. These schools were chosen because of the availability of Persons with Intellectual Disability (PWIDs). PWIDs, teachers and caregivers within the schools were included in the study. To acquire a spectrum of information on barriers and facilitators to healthcare, health professionals from Kwadaso SDA hospital, Garden City Clinic and Faustina's Chemical Shop were also included in the study. These were institutions that PWIDs in the various schools utilize for healthcare.

1.8 Organisation of the study

The study is divided into six chapters. Chapter one covers the background of the study, problem statement, justification, objectives, research questions, scope, and organisation of the study. Chapter two presents empirical studies, review of concepts and theories that are related to the study. Chapter three focuses on the research methodology which consist of the profile of the study area, study population, sampling procedure and sample size, research design, research instrument, administration of research instrument as well as data handling and analysis. Chapter four presents an analysis the results of

the findings of the study. Chapter five discusses the findings of the study and chapter six gives the summary of the major findings, conclusions and recommendations.

1.9 Limitation of the study

The major limitation of the study was the limited number of healthcare professionals available. This could affect the generalization of findings with respect to the views of healthcare professionals as fewer sample participated in the study.



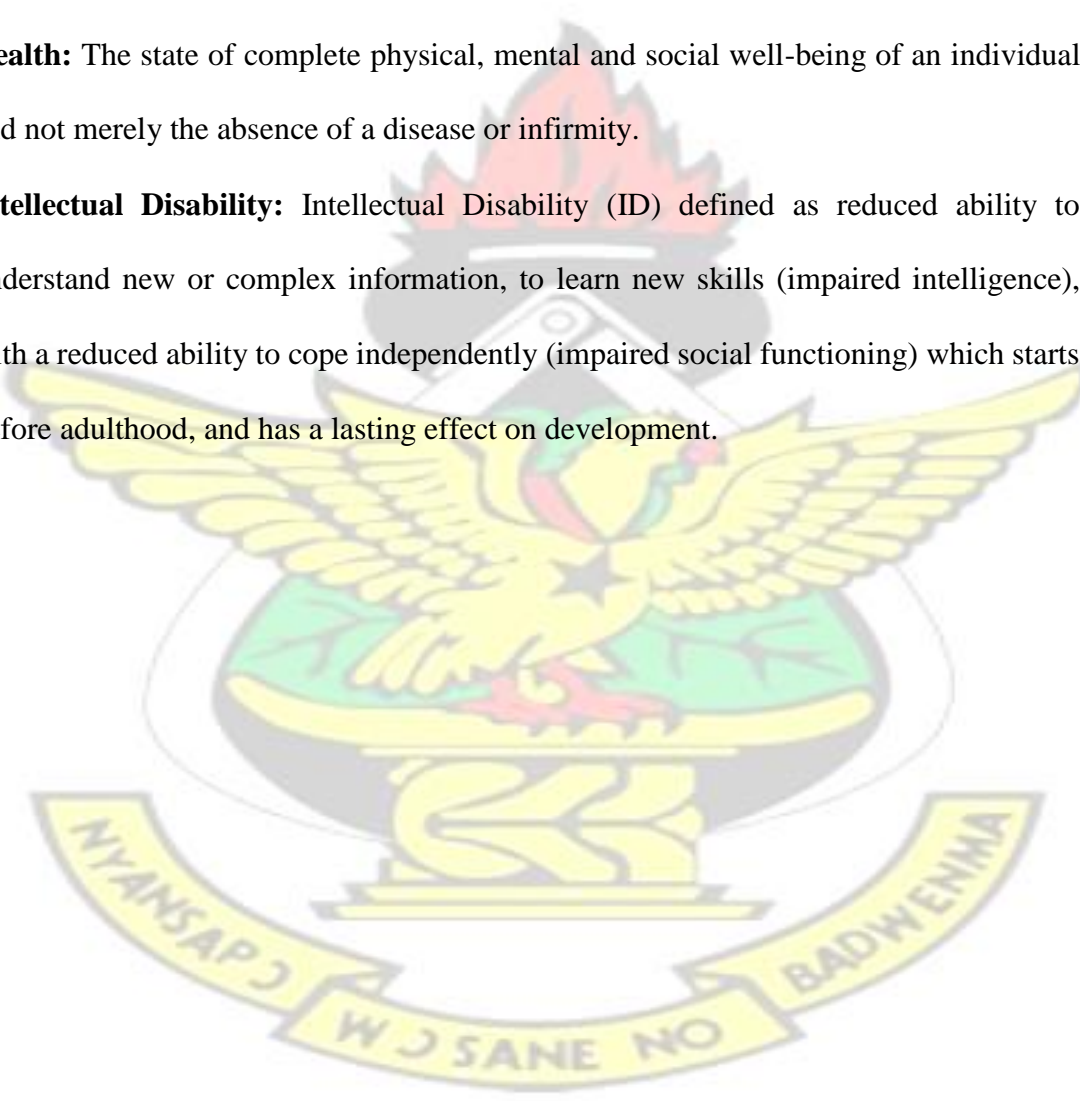
1.10 Definition of terms

Barriers: Factors in a person's environment that, through their absence or presence, limit functioning and create disability.

Facilitators: Factors that help or assist persons with disabilities to actively engage in societal activities e.g. policies.

Health: The state of complete physical, mental and social well-being of an individual and not merely the absence of a disease or infirmity.

Intellectual Disability: Intellectual Disability (ID) defined as reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which starts before adulthood, and has a lasting effect on development.



CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter explores literature on factors influencing healthcare access for persons with intellectual disability. Information from the body of literature is extrapolated on the population other persons with intellectual disability. The chapter is divided into five sections; concept of intellectual disability, access to healthcare, barriers faced by persons with intellectual disability in accessing healthcare services, enablers of healthcare access and experiences of persons with intellectual disability and healthcare professionals in attaining quality healthcare.

2.1 Disability

The understandings of disability have shifted considerably over time (Graham et al., 2014). According to Shildrick (2012) disability remains very complex and uneasy to define. The international classification of functioning disability and health (ICF) defines disability as an overall term for impairments that limit activity and restrict participation. In other words, it is the communication between individuals with a health condition (e.g. cerebral palsy, Down syndrome and depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports (WHO, 2018). Also 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 (Vargas-Barón et al., 2009). Disability is part of the human condition and life cycle which will be experienced by almost everyone, either temporarily or permanently

and those who survive to old age will encounter increasing difficulties in functioning. (WHO, 2011). Despite disability being around for centuries, it is only since the 1950s and 1960s that disability studies has become a distinct discipline. It hence has a relatively short history (Goodley, 2011). Disability studies is thus a relatively new enterprise (Gleeson, 1997) emerging as a systematic discourse in the 1950s but gaining momentum since the 1970s. Despite disability issues (with their concerns of medical, health and rehabilitation) within the academic sphere not being new (Hemingway, 2008), disability studies in recent years has become a distinct international academic discipline with much energy and vibrancy (Shildrick, 2012). According to Gleeson (1997), the disability debate still suffers the “legacy of theoretical deprivation” or “theoretical underdevelopment”. Given that most persons with disabilities live in low- and middle-income countries in which Ghana is included, there are needs for empirical disability research in these contexts and to strengthen and support research on disability (Graham et al., 2014).

2.1.1 Concept of Intellectual Disability (ID)

Intellectual Disability (ID) defined as reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which starts before adulthood, and has a lasting effect on development (Black, 2013). Intellectual disability is also known as mental retardation (MR), although this older term is being used less frequently (Daily, Ardinger & Holmes, 2000). From a clinical perspective ID involves impairments of general mental abilities (generally recognized as an IQ below 70) that impact adaptive functioning in three areas: thus the conceptual area, which includes skills in language,

reading, writing, math, reasoning, knowledge, and memory; the social area, which refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities and also the practical area, which centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks (The American Psychiatric Association, 2013). It can be deduced from the various definitions that people with intellectual disability (PWID) can go through difficulties in intellectual functioning, communication, self-care, home living, social skills, self-direction, health and safety, leisure, and work. It is argued that children with an intellectual disability (ID) have significant deficiencies in intellectual and adaptive functioning. Such children can show an increase incidence of several other disorders or impairments compared with children without ID (Allerton, Welch, and Emerson 2011). The signs and symptoms of intellectual disability are all behavioral which include every day social and practical skills and has its onset before the age of 18 years however the age at which the individual displays symptoms can vary. It is connected with lifetime limitations of adaptive functioning and low intelligent quo-efficient IQ (70 or less). Schalock *et al*, (2007) proposed that every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of ID.

According to Gluck (2014), ID can be mild, moderate or profound. Individuals that are mildly ((IQ of 50–70) affected has the ability to communicate effectively and live relatively independently with minimal support within the community. For individuals that are moderately (IQ of 35–49) affected, with the aid of lifelong support, they can have significant relationships, can communicate, understand daily schedules and make

choices for themselves. However, individuals with severe or profound (IQ <34) are totally dependent on those around them and will require lifelong help with personal care tasks, communication, and accessing and participating in community facilities, services and activities. An ID can be caused by any condition that impairs development of the brain before birth, during birth or in the childhood years (Arch, 2011).

It is estimated that about 1- 3% of the world's population has an ID. Some studies also maintain that a greater part of persons with ID lives in the less developed countries. (WHO, 2001; Balogh et. al, 2008). Coppus (2013) established that life expectancy of PWID is lower than that of their non-disabled peers. In the study undertaken by Hosking *et al* (2016) 37% of the deaths of people with intellectual disabilities were classified as being amenable to healthcare intervention compared with 22.5% of deaths amongst the general population.

It is believed that a range of internal and external factors give rise to such a situation. Nonetheless, one key influence is their access to appropriate and timely healthcare and the quality of the healthcare received (Emerson *et al*, 2012).

2.2 Access to Health Care for Persons with Disability

The concept of healthcare access has been widely used and defined by many authors. Access is related to allowing individuals with health problems or difficulties to seek health care resources in order to promote or preserve their health (Guilford et al. 2002). Some researchers conceptualized access as a mutual relationship between the health

service delivery and the characteristics of individuals or populations others also viewed it as the consumer's experience with the health care system, which included utilization of services, and satisfaction with the organization and delivery of health care. Scheer also defined access as the use of services relative to the actual need for care; lack of access occurs when there is a need for services and those services are not utilized (Scheer et al. 2003).

Penchasky and Thomas (1981) cited in Wyszewiansk (2002) viewed access as a broad concept that describes a fit between the service users and providers characteristics and expectations. This fit has five dimensions which are availability, accessibility, accommodation, acceptability and affordability. Guilford and colleagues (2002), further used the term utilization as a procurator to access, which is dependent on affordability, physical accessibility and acceptability of the services. The availability dimension of the definition of access examines the existence of a specific service within reach of the consumer.

Accessibility signals the location of the available health services and the consumer nearness to health facility taking into account transportation and time.

Accommodation takes into consideration the consumer's convenience and satisfaction with service. Also patient's perception of appropriateness of service delivery processes (including appointment systems, hours of operation). Affordability also measures the

relationship the cost of health care services relative to the consumer's ability to pay.

Acceptability measures the reactions of consumers to the attributes of health care providers (Penchansky & Thomas, 1981).

Health is important in itself, because it enables a person to have a good life however, poor health or lack of access to needed healthcare also makes it more difficult for other rights to be realized. As a result, individuals' healthcare needs are addressed through health promotions, preventative care such as immunization, treatment of illnesses and referral to specialized services where needed (World Bank & WHO 2011). However, there are many people that are not beneficiaries of these programs, many of them are PWD. Although they have the same health needs as every other member of the population, including immunization, screening, sexual and reproductive health, and all other aspects of regular healthcare they have a wide range issues with regards to health care access. This problem of access tends to be higher among those with the poorest health and most severe disabilities (Drainoni *et al.*, 2006).

Healthcare access among persons with disabilities varies across countries and communities worldwide, however as compared to non-disabled, persons with disabilities have limited healthcare access. (Rimmer *et al.*, 2004). They are less likely to access general health care as compared to the general population even though they experience a number of health problems through their life (Lehmann *et al.*, 2013). They are often described as having a "thinner margin of health" (WHO, 2011). The situation faced by PWID is grimmer. According to Horwitz, (2000) persons with intellectual disabilities are four times more likely to die of preventable causes than the general population. Although they make 2% of the population, it is argued that in low and middle income countries persons with intellectual disabilities are poorly

represented at all forums (Maulik, 2011). According to Havercamp, (2004) among the various disabilities, PWID are seven times less likely to receive emotional support than the others. And also less likely to utilize resources to get well and experience a good quality of life. The U.S. Surgeon General's Report on Health Disparities and Mental Retardation (2001) states that persons with intellectual disabilities of all ages experience poorer health outcomes and have more difficulty accessing health care.

A number of authors have considered the importance of having access to quality healthcare.

As individuals experience accessible and quality healthcare life expectancy is likely to improve. Also social and economic burden associated with health problems can minimize (Mugilwa et al., 2005, Angus et al., 2012). As a universal human right, the right to health which is applicable to every individual equally has received an appreciable recognition in relation to persons with disabilities in the Convention on the Rights of Persons with Disabilities (CRPD) which states in Article 25 that "People with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disabilities" (kanter, 2006). Badu et al., (2016) put forward that supporting this right is the Sustainable Development Goals (SDGs) where universal access to healthcare has become paramount to ensure inclusive development.

2.3 Frameworks of Healthcare Access

Definitions of access that are driven by frameworks are designed to guide research by providing a logical structure of understanding and allows researchers to link study findings to the science. Models of access to healthcare focus on the interplay between individual and environmental factors. These models have exclusive outcomes that focused on different areas of policy interest, such health status, satisfaction, and use of health services (Burns & Grove, 2005).

2.3.1 Aday and Anderson Model of Access

Aday and Andersen model of access to care as widely used has progressed over time to better capture the factors that influence the use of healthcare systems. This model recognizes the use of medical services as a function of predisposing, enabling, and need-related factors. Within this model, health policy is a factor that alters both the characteristics of the health delivery system and characteristics of populations at risk. Organization of health delivery systems and resources are also affected by health policies which either assist or avoid issues such as health insurance, education of healthcare professionals, patients' bill of rights and support for healthcare services in underserved areas. This influence is believed to be one way. Although advocacy on behalf or by these populations can lead to changes, individual characteristics of patients are seen as having little direct influence on the delivery system. Within this model, the availability of perceived and evaluated needs and services of the consumer is connected to health service utilization. According to Aday and Anderson Consumer satisfaction with services is a factor of how well the system fits with consumer needs, resources and concerns and this is only significant to the extent that there is interaction with utilization of those services. Despite this model being widely used it is noted that

emphasis was on need factors and individual characteristics other than cultural and contextual factors, also it's failed to address differences in healthcare quality (Portes, 1992; Millman 1993; Gold, 1998; cited in Michelle et al., 2015).

2.3.2 Institute of Medicine (IOM) Model of Access

The institute of medicine (IOM) Model of Access to Healthcare Services was developed in the 1990 with the aim of providing a structure that links personal receipt of care to achievement of optimal health outcomes (Institute of Medicine, 1993). This model precisely address the issue of equity and disparate healthcare. In the IOM model, aspects of access include barriers to access, use of services, and mediators that have a unidirectional linear relationship with each other. Health outcomes are mediated by the quality of providers, the appropriateness of the care, the efficacy of a treatment, and an individual's adherence to that treatment once individual interact with healthcare systems (Institute of Medicine, 1993). The IOM model lay out how individual and system determinants can hinder or support healthcare utilization and how individual's own life style, culture, health behavior and healthcare systems influence both health and access to healthcare. Barriers to access are described as personal, structural, and financial factors that may inhibit use of services. Using mortality, morbidity, wellbeing, and functional ability plus equity of services the IOM model measures access outcome (i.e., health status) objectively. This model identifies barriers and/or mediators that alters outcome, and these may be used when formulating health policy (Kakari-Martin, 2010).

2.3.3 Andersen's Behavioral Model of Health Services Use

The Behavioral Model of Health Services Use (Behavioral Model) was primarily developed to determine why families use health services and to inform health policy in the 1960s (Andersen, 1995). The Behavioral Model has been used by a large number of studies worldwide to influence health policy decisions. However due to emanating issues in health policies there have been several revisions with the most contemporary revision measuring how individual level and community level characteristics influence access (Davidson et al., 2004). This Outcome comprises of the sub concepts potential access, realized access, and access outcomes. Potential access is defined as the enabling resources that will increase the probability that people will use services (Andersen & Davidson, 2001). Realized access is the actual use of services (Davidson et al., 2004), whereas access outcomes is the degree to which effective and efficient access is achieved once the person enters the system (Davidson et al., 2004). Over time these outcome measures that have evolved no longer focus on consumer satisfaction.

Preferably it now incorporates an all-inclusive and wide array of determinants (Davidson et al., 2004). Determinants include demographic factors (age and gender), social structure (education, occupation, ethnicity, and other factors measuring status in the community, as well as coping and the health of the physical environment), and health beliefs (attitudes, values, and knowledge that might influence perceptions of need and use of health services) (Goldsmith, 2002).

2.4 Health Needs of Persons with Intellectual Disabilities (PWIDS)

Health needs differ from one person to the other. Each person has unique and individual needs therefore health needs should be assessed at all levels (Marmot et al., 2008). Persons with intellectual disabilities have a different pattern of illness and mortality from the general population. They have a greater prevalence of significant medical and mental health problems compared to the general population. Health care for people with ID has been characterized by a lack of communication, poor understanding of their everyday and special health needs and poor procedures for the delivery of services. It has been well established that people with ID do not access preventative health care and health promotion programs to the same degree as others in the community. Also health promotion material available are in formats that are not accessible to people with an intellectual disability inequality in health for people with ID are evidenced by high mortality including premature death from preventable causes, with health conditions often unrecognized or not treated properly (Heslop et al., 2014).

Current research shows that people with intellectual disability go on to experience poorer health outcomes and have more difficulty in obtaining the necessary health services than other populations (Krahn & Drum 2007). Reiterating this, Brown and colleagues (2010), stated that there is evidence that these patients' needs are often poorly met by health services, with many experiencing significant barriers to accessing health care appropriate for their individual requirements. Campbell (2007), asserted that patients with intellectual developmental disorder (IDD) have more complex health needs than the general population but face much greater difficulty in getting good and adequate health care. A study conducted by McColl *et al.*,(2010) found that adults

with disabilities aged 20-64 had three times the level of unmet healthcare needs as compared with adults without disabilities. Likewise World Health Surveys in the *World Report on Disability* showed that both men and women with disabilities were significantly more likely to report needing healthcare services but not receiving them, than people without disabilities (women: 5.8% versus 3.7%; men: 5.8% versus 4.1%). Furthermore, in Malaysia it was reported that persons with disability were having low health outcomes. This was as a result of health facilities not being able to meet their needs, but after effective initiative and policy implementation their health outcomes increased about 60% (Dainly, 2014).

Badu (2014) indicated that health needs of persons with disability includes referral services, rehabilitation, financial aid, transportation need, and assistive device among others. A survey by Lewis & Stenfert Kroese, (2010) indicated that nurses were less likely to attend to the patient with intellectual disabilities and less likely to explain treatments or perform invasive treatments. These patients were also more likely to be placed in a side room away from the rest of the patients. Also families reported that persons with Autism Syndrome Disorder (ASD) were often heavily medicated or put in physical restraints due to the emergency room staff not having knowledge of the communication and behavioral challenges (McGonigle et al., 2014).

In addition Iacono & Davis, (2003), reported on 119 adults with intellectual disabilities who were hospitalized. The study found numerous medication errors including missed medications with only 12% receiving the correct medications and 22% receiving their medications late. Patients were also described as receiving poor care with 18% not being

well hydrated, 39% not being brought to the bathroom when they needed it, and 11% not being assisted out of bed when they needed to get out of bed

2.5 Barriers Faced by Persons with Intellectual Disability (ID) in Accessing Healthcare services.

Scheer et al., (2003) defined barriers to access as factors that contribute to preventing a person from utilizing the available services when needed. These barriers can be generally classified under environmental, structural and process barriers. Environmental barriers includes social attitudes, architectural design, climate and terrain (WHO and WB 2011). Transportation barriers, such as access to public transportation, publicly funded ambulance system, and private transport are also included under environmental barriers (Smith 2008). Structural barriers are barriers due to financial limitations and they denote the ability to pay for services such as medical rehabilitation services; high-quality, well-fitted, and functional durable medical equipment and repair of these (Smith 2008). Process barriers are difficulties inherent in the delivery of service. It includes provider knowledge, timeliness of service, communication between the provider and the user, receipt of preventative care and scheduling of appointments (Scheer 2003, Drainoni *et al.*, 2006).

A study done by Bogenschutz, (2014) to understand the experiences of immigrants with intellectual and developmental disabilities in accessing healthcare in America identified factors limiting healthcare access. 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

were identified as factors limiting healthcare access. Likewise, a study 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) revealed low levels of information about ASD, high levels of stigmatization, poverty, limited English competency, lack of empowerment to harness available services were limited factors identified. Other factors identified were negative attitudes of healthcare providers, inconvenient, uncomfortable and complex diagnostic processes. A number of studies which have explored the experiences of individuals with intellectual disability, and their care givers, in accessing mainstream health services for physical health problems, highlighted communication difficulties, resulting from individuals with intellectual disability being excluded from consultations, failure of General Practitioners (GPs) to conduct health reviews, review medication and conduct blood tests and investigations lack of health promotion and screening and inadequate knowledge of doctors about the health needs of people with intellectual disability as barriers to healthcare. This has contributed to diagnostic overshadowing, where physical or mental health problems are misattributed to the individual's intellectual disability, leading to delayed diagnosis and treatment (Ziviani 2004; Ward et al., 2010). In addition, studies have also reported a lack of support offered to care givers, disregard for information provided by care givers and unrealistic expectations of caregivers to take on care giving responsibilities on the ward (Dinsmore, 2012).

Several studies concluded that patients with intellectual disability received suboptimal care, and were denied appropriate treatment (Ziviani 2004; Gibbs, 2009; Ward *et*

al.,2010) Moreover Stigmatization and marginalization are seen as significant barriers in accessing healthcare services. These are particularly engrafted in the negative community and family attitudes towards persons with disability leading to feelings of rejection, shyness and lack of confidence (UPHLS 2015). Many times Health professionals show negative attitudes and behavior towards individuals with intellectual disability including questioning whether the person was worthy of surgical treatment, due to discriminatory judgements about the person's quality of life. Recent studies also reported that adults with Intellectual and Disability Development (IDD) experienced both expressive and receptive communication challenges and this was a barrier to accessing health care. Adults with IDD either had difficulty understanding the information from their provider or were not able to effectively communicate their thoughts, wants, or needs regarding their health or need for health services (Greenwood et al, 2014; Nicolaidis et al., 2015; Zerbo, et al., 2015). Carroll (2015) found that adults with cerebral palsy (CP) had difficulty with insurance companies approving needed services like physical therapy to maintain function. Kurre (2014) noted the complexities of providers staying up to date with Medicaid and Medicare regulations which affected care access.

Thomas *et al.*, (2007) findings also showed that access to care for autism-related services was restricted by low levels of education. Income levels of family members/parents influences their perceived need for specialized health care services for a disabled person. 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, 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. (Austin et al., 2016, McGrath, et al., 2011).

2.6 Enablers to Healthcare Services for people with Intellectual Disabilities

To promote healthcare access and address healthcare needs among persons with disability, knowledge about the enablers and barriers in access to healthcare is imperative (Drainoni et al., 2006). Whittle *et al.*, (2018) defined enablers as interventions or processes by which access to health services and healthcare is facilitated. A study by Smith (2009), showed that Persons with disabilities, as well as rural residents, were more often found to have a regular source of care. This continuity of care was an important facilitator for access to care. Also, findings of Bogenschutz et al.,(2014) indicated that, access to healthcare services among immigrants and refugees with intellectual and developmental disability was facilitated by linguistically and culturally sensitive practitioners, favorable comparisons to the country or origin and systems such as schools that helped to coordinate care.

A scoping review on barriers and enablers to Accessing Mental Health Services for People with Intellectual Disability identified adoption of innovative methods of service delivery particularly those that take into consideration the logistical issues as enabler to availability of service. Some alternative models, including stepped-care models and tele-psychiatry were described (Whittle et al. (2018). For instance, the Cedars-Sinai Tele psychiatry Clinic treats clients with intellectual disability by using a collaborative

care model using tele-psychiatry methods (including telephone, email, and remote videoconferencing). Many of the participants in the study had very limited communication (50 words or less) and 84% had mild to profound intellectual disability. The study found that clients showed improvement over time, requiring fewer visits and fewer medication changes. Psychiatrists also identified internalizing disorders in clients where previously none had been identified, indicating that specialist psychiatrists were able to communicate more effectively with clients with communication difficulties (Szeftel et al., 2012). According to Whittle et al., 2018, the supposed effectiveness of this type of model indicates alternative service models that are advantageous among people with intellectual disability. Comparably Jackson (2009) proposed that a stepped-care model which involves the intentional delivery of effective treatments using minimal resources according to the intensity of need is highly effective care for people with an intellectual disability.

Furthermore, The Royal College of Psychiatrists highlights interagency collaboration as a key element of facilitating access to mental health services. It's Enabling People with Mild Intellectual Disability and Mental Health Problems report recommends that each organization providing mental health and intellectual disability services should have established protocols to address the specific needs of the population, and that these protocols should be jointly instituted with all services and local authorities (Royal College of Psychiatrists, 2012). The Department of Developmental Disability Neuropsychiatry, (2014) accentuate the importance of interagency collaboration, and offers practical strategies as to how to achieve effective collaboration and communication between services, including information-sharing agreements and

protocols, formal strategies, and memorandums of understanding between agencies to enhance cross-sector collaboration and the development of joint assessment protocols (Department of Developmental Disability Neuropsychiatry, 2014).

Across literature, Clear referral pathways and system guidelines were identified an enabler to access (Whittle et al., 2018). Jackson's (2009) report on a successful psychology service for adults with intellectual disability underscore the importance of a single point of access for entry to the service, which streamlines the referral pathways into that service. As a way to minimize diagnostic overshadowing. Contemporary research emphasized on collaborative approaches, such as capacity building and training (Burke, 2014).

In Mastebroek et al., (2016) study, Facilitating factors were mainly related to carer interventions, personal connections with patients and GP communication with patients and carers outside the consultation. A study conducted by Wijne et al, (2013) to identify the factors that promote and compromise the implementation of reasonably adjusted healthcare services for patients with intellectual disabilities in acute National Health Service (NHS) hospitals revealed Intellectual Disability Liaison Nurse and the ward manager as key enablers. The evidence suggests that ward culture, staff attitudes and staff knowledge are crucial in ensuring that hospital services are accessible to vulnerable patients.

2.6 Experiences of Healthcare Professional in Providing Healthcare Services to People with Intellectual Disabilities PWIDS.

A comprehensive care for People with intellectual disability calls for team of healthcare professionals with a broad range of specified skills, in order to meet the different health, behavioral, advocacy, and societal needs of persons with ID (Aubery, 2018). Health professionals have a unique and vital role in meeting care needs of people with intellectual disability. Within this crucial role, direct care, care management and administration, liaison work and educational activity are underpinned by the promotion of client autonomy (Long & Kavarian 2008). Existing literature indicates that as they work out to develop services for PWID they can become prospective agents of inclusion (Alaszewski et al. 2001; Gates 2006)..

According to Aubery (2018), varied needs of people with intellectual disability and diverse practice settings creates a fragmented system that makes it difficult for health professionals to sail. Findings from her study revealed lack of education regarding this population, healthcare complexity of this population, role ambiguity, varied practice settings, nursing model of care controversy, and caseload distribution and acuity as varied challenges nurses encounter in the field of intellectual developmental disorder (IDD). Access to Acute Network (Secondary Care) (2002), reports challenges general hospital staff in providing care. This includes receiving poor information on admission; concerns about communication difficulties and consent; perceived risks to other patients from people with challenging behavior and limited staff training and understanding of the needs of people with intellectual disabilities.. From service providers perspective, communication barriers include difficulty with calming patients,

explaining hospital procedures, assessing pain levels, and preparing clients for discharge (Tyler et al, 2010). Communication in nursing patients with IDD clearly demands skills and competences in communication strategies above and beyond the spoken word. A systematic review on nurses' experiences of caring for patients with intellectual developmental disorders revealed communication as a barrier that affects the assessment of care needs and the quality of care provided resulting in insufficient and unsafe care Appelgren et al., (2018). Muskat et al., 2015 stated that health professional's inability to comprehend what IDD patients and thus resulting in difficulty assessing their needs is not rare. Such difficulties can be aggravated by health care professionals being prone to using jargon.

A study was conducted by Campbell (2011) to explore Nurses' Experiences of Working with Adults Who Have an Intellectual Disability and Challenging Behavior showed that participants experienced violent incidents, with emotional reactions been described as; anxious, fearful, vulnerable, stressed, scared, nervous, worried, concerned and being angry, the majority of which relate overall to anxiety. Similarly In Howard and Hegarty's (2003) study, the participants described their emotions as: scared, sad/upset, angry/frustrated, apathetic, and tense/ wound up, in an adrenaline reaction/ shock and suppression of natural reactions. McConkey & Truesdale (2000) opined that the development of therapeutic relationships are known to be affected by Insecurity felt by professionals in the provision of care to people with intellectual disabilities. In addition, findings of Sowney *et al*, (2006) indicated nurses caring for adult with intellectual disability experienced fear and vulnerability and an inability to cope without support of patient carers. The experience of fear and vulnerability was

considered by participants to be a consequence of their lack of knowledge. The lack of a basic understanding of the nature of intellectual disability was also reported to reduce the ability to ‘pick up’ on cues that might be demonstrated by an individual’s behavior. Ailey and Hart (2010), Friese and Ailey (2015), and Hsieh and colleagues (2014) among others, asserts that nurses and providers want to be educated in the care of the intellectually disabled and through education the quality of care can be improved. Appelgren et al., (2018) review also reflected how unpredictable situations could lead to registered nurses experiencing moral distress (i.e. anger and negative thoughts about patients), resulting in guilt and a need to distance themselves from the situation and the patient. This experience was related to being able to deliver safe care in all types of environments, whether high risk or low risk. Studies have found staff working with both learning disability and personality disorder diagnosis as both positive and negative experiences. Familiar themes include responsibility for clients, the complexity of clients leading to negative staff feelings, a need to enforce boundaries, the emotional impact of work, a need to make sense of the presentation and difficulties with the relationship (Cotes 2004; Thompson et al. 2008 & Crawford et al. 2010). Thompson et al. (2008) reported a duality between clinicians feeling responsible for clients and putting the responsibility for behavior onto them. Despite the struggles and difficulties nurses encounter caring for PWID that positive experiences such as job satisfaction acted as a buffer. In Lee and Kiemle (2014) findings nurses reported that looking beyond negative assumptions resulted in the breakdown of some of the relational barriers between ‘client’ and ‘nurse’

CHAPTER THREE

METHODOLOGY

3.0 Introduction

Hussey and Hussey (1997) defined research methodology as the overall approach to the research process, from the theoretical underpinning to the collection and analysis of data. In their view, it is concerned with why certain data is collected, what data is collected, from where is data collected, when is it collected , how data is collected and analyzed

This chapter provides a description of the methods used, steps that were taken and tools that were employed for data generation and analysis in order to address the research problem. It focused on the research setting, research design and approach, study population, sample size, sampling technique, data generation tool, data analysis procedure and ethical considerations.

3.1 Study setting

The study was conducted in two special schools for persons with ID; specifically, Garden City Special School and Community Special Vocational School-Deduako in the Asokore Mampong and Oforikrom municipality both in the Ashanti Region of Ghana. Ashanti region is located in the south of Ghana and is the third largest of sixteen administrative regions.

3.1.1 Garden City Special School

Garden City Special school is a school for the intellectually disabled. The school was started precisely on 4th April 1997 by one Mr Boakye at Dichemso in Kumasi. It was started as a home care with four (4) children. Nana Opoku Agyemang the proprietor of Texas Hotel at Asokwa in Kumasi later brought his daughter to add up to five children. Nana Opoku Agyeman and some concerned persons such as the Late Mrs.

Peggy Appiah, Mr. Aklolatse, Mr. Brown, Mrs. Amonoo Neizer and Mrs. Hayford Benjamin formed friends of the mentally handicapped to assist the children. In 1985, when the student population increased to eighty (80), the government took over the school and staffed it with trained teachers. In 1996, the school was moved to Asokore Mampong; its present location by the help of a young German volunteer, Mr. Klaus Jahn. The school currently operate under the special education division of the Ghana Education Service (GES).

3.1.2 Community Special Vocational School

Life Community Special Vocational School is a school for intellectually disabled individuals. The school is located at Deduako - Kumasi near KNUST. Life Community Special Vocational School was in the year 2000 a hospital but was later converted into a community school in 2002. The vision of the school was to give knowledge and skills to intellectually disabled students. Students enrolled were expected to have basic education in other specials schools. Students are practically taken through handiworks and vocational skills such as candle making, tie and dye batik making, beads, necklace and handbags among others.

Initially, the German Volunteer Corpse was solely responsible for the running of the school, however, they requested for the intervention of the government due to financial and structural challenges. Currently all workers are on government payroll, government provides subventions and supervises teaching and learning at the facility.

Maintenance of structures at the school is carried out by the German Volunteers Corpse. The Community Special Vocational School, Deduako is an institution fully supervised by the Ghana Education Service (GES) under the Special Education Division. The staff is made up of twenty (23) teaching and non-teaching staff and 74 students. The Headmaster indicated that due to the hard work of staff, the 2015 National Best Teacher was selected from the school.

The school is challenged financially due to late disbursement of scanty funds and unavailability of needed resources to facilitate teaching and learning. The teacher to student population ratio is high, requiring more skilled teachers. There are fewer dormitories in relation to the student population. Although students produce various wares and products, there is no ready market for their products.

3.2 Research design and approach

Research design refers to the actual plan or strategy the researcher chooses to put together the various components of the study in a coherent manner. It is a pattern for collection, measurement and analysis of data (Creswell, 2013). It is also the blueprint for conducting the study that maximizes control over factors that could interfere with the validity of the findings (Burns & Grove, 2001). Thus, it helps the researcher to plan and implement the study in a way that will help the researcher to obtain intended results,

thus increasing the chances of obtaining information that could be associated with the real situation. An exploratory design was employed for the study. Brown (2006) described exploratory design as a type of design that is used when little or no previous research has been done regarding a phenomenon under investigation. Thus, the researcher selected the design due to the paucity of studies done in the area of barriers and facilitators to healthcare access among persons with intellectual disability upon perusal of literature.

A qualitative approach was also adopted for in this study. Qualitative research with its roots in the humanities aims at understanding social phenomena in a naturalistic setting emphasizing the attitudes, views and experiences of participants other than providing quantified answers to questions (Nieswiadomy, 2008). It brings out the details of realities by focusing on obtaining deep and meaningful information (Nieswiadomy, 2008). This approach enabled the study to identify important information through in-depth interviews on the health needs of the IDs in the study setting and the presentation of findings through themes to make results and analysis more meaningful.

3.3 Study population and sample size

Babbie (2004) described the population of a study as a particular group of individuals that the researcher considers for the study. In other words, sample population is made up of all the participants or respondents of the study or a group of people who share common characteristics like, age, gender, health condition among others. The population for the study consisted of caregivers/parents of PWIDs, teachers of PWIDs, Healthcare providers of PWIDs (Doctors, Nurses, Allied Health Professionals) and

selected stakeholders who the researcher believe have interest in the well-being of PWIDS. These stakeholders' included leaders of Disabled Persons Organizations (DPOs) and managers of Non-Governmental Organizations (NGOs).

In numerical terms, the study population consisted of 169 student population, 62 teaching and non-teaching staff at Garden City School. Community Special and Vocational School had (23) teaching and non-teaching with 74 students. These together culminated into a total of 243 students with IDs in these schools and 85 teaching and non-teaching staff. This also culminates into approximately 243 parents and guardians of these students. Other stakeholders including Doctors, nurses and social workers who had close contact and interest in the welfare of these children were considered.

3.4 Sampling technique

Sampling technique is an identification of the specific process by which the entities of the sample are chosen or selected for the study (Marshall, 1996). It is the technique employed by the researcher in the selection of the sample for the study. For this study, purposive sampling technique was used for the selection of the participants. Purposive sampling technique is used when a researcher selects particular individuals within the sample to be used for a specific study (Crossman, 2014). This was used in the selection of the participants because of the desired characteristics needed for the study. These characteristics were the type of disability chosen for the study and the healthcare professionals who provided the requisite healthcare for PWIDs. Also, caregivers, parents and stakeholders are included as they could provide information on the enablers to facilitate healthcare access among PWIDs.

On the part of the students with ID, the following inclusion criteria was set.

- Studies must have mild to moderate intellectual disability.
- He/she should have the ability to understand and express himself/ herself
- The student must have assessed health care services at least ones.
- The person was willing to participate in the study.

Based on this criterion, two groups of twelve each were picked purposively with the assistance of staff of the school to participate in the discussions. This number was based on the maximum number needed to make focus group discussions more effective while the two sets were convenient based on the time frame and resources available for the study.

On the part of parents, twelve were available during their weekly meetings to discuss the welfare of their children. Permission was sought from these individuals to participate in the study of which they obliged. These twelve were purposively selected to be part of the discussions of the day. Six school mothers from Garden city and Community special and vocational school were also put together into a focus discussion group as they were conveniently chosen from the number of school mothers who were available and willing to participate in the study.

Through snow balling, the other stakeholders including four health workers and five institutional stakeholders such as social workers and community leaders were also selected to be part of the study. Snow balling was done as school management directed the investigator to health workers who have taken care of some of these children when they were sick. The same applies to the community leaders as school management made

mention, these individuals who mattered in the process. In all 51 respondents participated in the study.

3.5 Data collection instrument

Key informant interviews (interview guide) and focus group interviews were the instruments employed for data collection. The process of the interview followed the following pattern – an opening introduction, guiding questions, and a final closing statement. This process was repeated for each interview, to ensure consistency. The interviews were conducted in Twi and English, and they lasted about 45 minutes to 1 hour. An audiotape was used to collect and capture data. The interviews were recorded with the consent of the participants, and they were later transcribed verbatim.

3.5.1 Key informant interviews

Key informant interviews are qualitative in-depth interviews with people who know what is going on within a specified community the purpose of which is to collect data from a wide range of people-including community leaders, professionals or residents (Carter & Beaulieu, 1992). Key informant interviews have been found to have greater advantages due to the fact that the interviewer can adapt the questions as necessary; clarify doubts, and ensure that the responses are properly understood by repeating or rephrasing the question, and could establish friendly relationships and motivate respondents (Kripanont, 2007). Rich data are usually obtained by using interviews, because unconscious exhibition of body language by respondents are easily detected.

Key informant interviews were conducted with the assistance of an interview guide for health professionals and stakeholders. Due to the fact that, not all health professionals

had come into contact with treating children with IDs in the discharge of their health care services, the study sought information from school management about some of the health workers they usually visit. The two schools indicated that they had resident nurses who took care of the immediate health needs of the children. These nurses were contacted for in-depth face-to-face interviews. The schools further identified two medical doctors who usually came on medical outreach to take care of the health needs of children at specific periods and thus, any medical complications were referred to their health facilities. These health professionals were also contacted via phone conversation to seek their consent to be part of the study. The interview was conducted in the comfort of their work places at a time convenient for them. The only major challenge was due to the tight schedule of the medical doctors, it took some time for them to have a schedule for this interview.

Two social workers at the Ejisu Municipal Assembly were also contacted through a face-to-face interaction as the researcher visited the premises of the assembly to seek for permission to conduct the interviews. Interview was conducted for them on a mutually appropriate date that was fixed and discussions were made on the social implications of the health needs of PWIDs' access to health care.

Two heads of Disabled Persons Organizations (DPOs), two social workers and one other institutional stakeholder from a non-governmental organization (NGO) were also contacted for key informant interviews. Issues such as the community's role in ensuring the access to health care for PWIDs were discussed based on preset interview guides.

3.5.2 Focus group discussions

Focus group discussions are used to understand people's views as well as behaviours. Where number of people involved which ranges from six to twelve are interviewed concurrently, with a moderator who leads the respondents in a fairly unstructured discussion about the phenomenon under investigation (Carter & Beaulieu, 1992).

Focus group discussions were used to explore the caregivers' (house mothers) and PWIDs' views on the barriers and facilitators to health care among PWIDs.

Two groups of twelve each of PWIDs were put together for focus group discussion for, one from each school which was part of the study. Under normal circumstances, a leader and a secretary are chosen from among the participants to moderate the discussions in any focus group. However due to the special nature of participants, it was difficult to have a leader who could independently moderate the discussion leaving the responsibility on the shoulders of the principal investigator. School mothers and teachers were also available to offer valuable assistance. Children were asked of their health needs and challenges they face in assessing health care services.

3.5.3 Observations

Data were also taken through observation. The researcher observed participants in the study area with regards to the study theme so as to have the real feel of how they access and health. The researcher observed how PWIDs interacted with caregivers and health professionals whenever they needed health services.

3.6 Data management and analysis

Data analysis involves critically examining, categorizing and summarizing data generated to make meaning for interpretation and drawing conclusions (Weber, 1990). Thematic content analysis was used in analyzing the data. This involved a procedure of transcribing data, coding the data, organizing the data, generating themes, and describing them. The data collected through the interview by audio recording were transcribed into written notes to include notes already taken from the field. Responses were coded by assigning the same code to the same responses on an issue and different codes on diverging views. The data were then categorized by grouping extracts with the same code while taking note of other codes. Themes were then generated to make meaningful interpretations and to highlight important findings. For instance, the data was coded similar to this format for analysis and interpretation.

In terms of management, field data were first entered into a computer, identified with a unique code assigned by the researcher. The transcripts in a word document form was then saved on the researcher's personal computer in identifiable folders using a password to make them inaccessible to a third party. A copy of the transcripts' folder was also saved in the researcher's email inbox. The printed-out transcripts, the field notes and audio records were labeled and then stored in the researcher personal drawer under lock and key.

3.7 Methodological rigour

In qualitative research, rigour refers to the trustworthiness of the research findings. According to Parahoo (2006), determining rigour in qualitative research is not an easy

task; however, researchers want their findings to reflect truthfully the phenomenon they are studying and to contribute to knowledge that is beneficial to others. The framework includes the following four criteria for developing trustworthiness of a qualitative study: credibility, dependability, conformability and transferability.

In this study, the researcher, through the use of semi-structured interviewing techniques, tape recordings of the interviews and transcriptions of verbatim quotes, increased the accuracy of the descriptions of participants' experiences and therefore increased the credibility of the findings. All potential and inherent biases, feelings, personal beliefs and values about the researcher were minimized.

Dependability is concerned with the ability of the data to remain stable over time. Would the study findings be replicated if undertaken with similar participants in a similar context? Credibility cannot be attained in the absence of dependability. The researcher used an audit trail to enhance the dependability of the study. Audit trail involved tracking and recording all decisions which could influence the study so an independent auditor can examine the data (Streubert *et al.*, 2010).

Conformability refers to the objectivity of the data, such that there are no biases, the findings represents the information participants provided (Polit & Beck 2010). Strategies that were used to facilitate the conformability of the study included a well documented audit trail in addition to the procedures outlined.

Transferability in qualitative research refers to the extent to which the reader is able to transfer the findings of the study situations to other similar settings (Parahoo, 2006).

In this study, direct quotes from participants and description of the setting in which the phenomenon was described was used to determine if it would fit into similar contexts.

Accurate records were kept of all interviews and interactions with participants, as the careful recording of data was crucial to the study. The researcher considered at all times, strict attention to details, adhering to procedures and through consistency and accuracy throughout the research process.

3.9 Ethical considerations

The study was approved by the Committee on Human Research and Publication Ethics (CHRPE) at the Kwame Nkrumah University of Science and Technology. Also, the participants' consent were sought before they participated in the study. The objectives of the study and the potential risks and benefits to the participants were explained clearly to participants. In addition, participants were assured that any information provided would remain secret. Names and identity of participants were not revealed in this study and they were not obliged to answer all questions. Lastly, participation was voluntary and participants were informed that they could withdraw from the study as they wish. Participants either orally consented or signed a consent form before participating in the study.

CHAPTER FOUR

RESULTS

4.0 Introduction

This chapter presents findings on barriers and facilitators to healthcare access for persons with intellectual disability. The study used two focus group discussions which constituted PWIDs and parents/ caregivers and key informant interviews which also constituted health professionals and institutional stake holders to explore the barriers and facilitators of access to healthcare for persons with intellectual disability. Themes identified during analysis of the interview were arranged into categories with relating subthemes. These were presented using participants own verbal accounts and done in accordance with the objectives of the study.

4.1 Demographic Characteristics of Participants

The demography of participants helps in understanding the characteristics of the various participants involved in the study. Out of the 51 participants, majority of them 33 (64.70%) were females with the remaining 11 (35.28%) being males. 24 (47.06%) were PWIDs, 12 (23.53%) were parents, 6 (11.76%) were caregivers, 5 (9.80%) were institutional stake holders and 4 (7.84%) were health professionals. Out of 24 PWIDs interviewed, 13 (54.17%) were between the ages of 15-25 years while 7 (29.17%) were between 26-36 years and 4 (16.67%) were between 37 years and above. Also, 11 were males and 13 were females. Of the disability type presented, majority had autism 8 (33.33%), followed by Down syndrome 7 (29.17%) with cerebral palsy and other conditions having 5 (20.83%) respectively .

The background of the health professionals showed that 2 were males (doctors) and 2 were females (nurses)

Table 4.1: Demographic characteristics of participants

VARIABLE	GARDEN CITY		L.C. DEDUAKO		TOTAL	
	Freq	%	Freq	%	Freq	%
PWIDs						
Age (y)						
15- 25	6	50	7	58.33	13	54.17
26- 36	5	41.67	2	16.67	7	29.17
37- 47	1	8.33	3	25	4	16.67
Gender						
Male	5	41.67	6	50	11	45.83
Female	7	58.33	6	50	13	54.17
Disability Type						
Autism	4	33.33	4	33.33	8	33.33
Cerebral palsy	3	25	2	16.67	5	20.83
Down syndrome Other	4	33.33	3	25	7	29.17
	2	16.67	3	25	5	20.83
Relationship with PWIDs						
Parents	6	60	6	75	12	66.67
Caregiver	4	40	2	25	6	33.37
Gender						
Male	2	20	1	12.5	3	16.67
Female	8	80	7	87.5	15	83.33
Health Professionals						
Sex						
Male	1	50	1	50	2	50
Female	1	50	1	50	2	50
Background						
Doctor	1	50	1	50	2	50
Nurse	1	50	1	50	2	50

Field work 2019

For the institutional stakeholders, 3 were males (60%) and 2 were females (40%). 2 were heads of Disabled Persons Organizations (DPOs), 2 social workers and 1 other institutional stakeholder from a non-governmental organization (NGO) (see table 4.2).

Table 4.2 Demographic characteristics of institutional stakeholders

VARIABLE	FREQUENCY	PERCENTAGE (%)
Position		
Head of DPO	2	40
Social worker	2	40
Head of NGO	1	20

Field work 2019

4.2 Healthcare needs of Persons with Disability

4.2.1 General health care needs

General health care needs of PWIDs include treatment of acute and chronic illness, health promotion and preventive care (immunization, health screening). Conditions PWIDs mostly present for primary healthcare are malaria, headache and diarrhea. Common cold and cough were the underlying cause for the conditions PWIDs mostly presented for treatment. These were related in the following;

“I go to the hospital when I have headache. I always go there with my mother” (PWID). “Sometimes I suddenly cough and bleed through the coughing and they had to rush me to the hospital” (PWID).

‘I sometimes become very weak which is a sign of becoming sick but my visit to the hospital with the help of my Grandma, helps me get well after I go to the laboratory and later given medicine as prescribed by the Doctor’ (PWID).

Reiterating this, other participants also stated that; “Conditions we mostly take to the doctor is malaria, headache” (caregiver). “I send my child to the hospital if my child is not fine or suffering from malaria or any other sickness” (Parent)

Specific conditions they bring here for treatment is malaria. We treat the underlying cause, because their symptoms differ. Some also come with diarrhea, cough and sneezing. For this week, we have had two children here (Doctor)

In relation to this, most of the caregivers reiterated that they acted as mediators in communicating health needs, even though most PWIDs actually knew what was wrong with them. In other instances, the presence of a sign language interpreter facilitated communication of health needs. “Hmm... it’s not easy sometimes we go to the hospital and the doctors find difficulties understanding these children. I always speak for them” (Caregiver)

I have been taking care of them for a while and I actually understand when they are not feeling well. In the hospital, the doctor always allows me to speak as most of the children I take care of have communication difficulties (Caregiver)

It was further noted that, PWIDs hardly receive health promotion and preventive health practices such as immunization and general health screening that are offered to the general population. They do not fully engage health promotion programs, such as those for healthy eating, physical activity, and health screening programs. Participants commented on this as follows;

Persons with disability do not often benefit from health promotions programs or campaigns. And people with ID are no exception. Content of the education are mostly in formats that are hard for them to understand. They have other health risk, so supporting them with a healthy lifestyle can help combat some of their unmet health needs. (Doctor).

There should be regular health checks for them. There should be appropriate screening protocols and immunization for them. You know some of them are obese, they need to exercise and have a good body composition and also provide nutrition information for caregivers and parents (Nurse)

Emphasizing the need for health education, some mothers expressed their concerns;

Health awareness is very important. I think health education should target the caregivers too regarding living practices in areas such safety practices, oral hygiene nutrition and others. When they have more knowledge in these areas as they do it with our children they also learn from them. They will be educators to our children. (Parent)

Yes even though we teach them. They can also benefit from health education. Videos are mediums that could help them understand. They will watch it and next time you will see them doing. We mothers and care givers should also be targeted in oral care, nutrition, exercise so that they can be fit. (Parent)

4.2.2 Specialized Needs

Specialist health care needs may be associated with primary, secondary, and comorbid health conditions. Some people with disabilities may have multiple health conditions where assessment and treatment may necessitate the knowledge and skills of specialists. It was noted that aside general health needed they also need specialized care in health services that are specific to their disability. Services that will help in early identification, interventions designed to minimize or prevent further disability manifesting. Participants expressed this in the following quotes;

People with ID require access to specialist health services in addition to primary care and secondary care health services. They will need psychological support, physical therapy, and others. (Doctor).

My child cannot speak too, so is not so long that they advised me that now he has come down a bit but I must go and see the speech therapist, so I just went there last Tuesday and they referred me. So they need special care' (mother).

Looking at their behavior, they will need behavioral therapies that can calm them. Not only behavior but other special care. I sent my child to the hospital some time ago because there was certain flow of liquid from her ears (Parent).

Expressing concerns on the need for special health services for PWIDs, some participants highlighted that;

I think there should be a permanent healthcare staff, a nurse, a doctor who are knowledgeable in the field of developmental disability, who will be working with them, learn their behavior and understand them'(Doctor).

Using health services can be challenging for people with ID and their family.

There should be specialist available to take care of them because they have difficulty communicating their needs in an easily understood manner.

(Doctor)

I want the hospital to make permanent Doctors for about few parents so that always go on review the same Doctor will care for you to ensure your Doctor checks on the child condition improving or not and also to avoid waste of time and complications because they do not get uniform information about the child condition to the varied Doctors (mother).

Supporting this, another participant said that; “As for me I wish we will get special nurses and special Doctors who will understand our conditions and treat us well without shouting at us” (PWID)

As regards to interventions to minimize or prevent further disability, some participants emphasized the need for assistive products such as hearing aids, eye glasses and others. They expressed that these products can benefit PWIDs by improving their functional capabilities. Participants expressed this as follows; “My child speech is not clear, so if there is something like an aid that can help, I think it will improve my child’s communication and even lessen my work” (Parent). People with ID can have problems with vision and hearing, so I think when they are assessed and given products that will assist them like spectacles or something; I think it will benefit them a lot. We once had a child with ID who had problems with vision. Yeah she could see but it was partial. So when they are going to eat or go to class her mates will help her (caregiver).

Another participant attributed some of the communication problems to hearing loss;

Some of them have low frequency hearing loss, others high frequency loss. But we put them together that they all cannot hear. Because of that they don’t hear, you talk to them they don’t understand. Talk to them softly, they will listen; some will look at you and make actions to you. Those who need hearing aids should we provide be given (Doctor).

Reiterating this one participant commented on the importance of assistive products; I know assistive products basically promote well-being and improve functional

capability. That is why those who cannot see properly have eye glasses. Those who have dental problems also have theirs. Therefore, if people with Id also have aids let's say to help like improve their speech, I think daily functioning will be improved and I believe will have a positive impact on their quality of life. (Parent)

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4.2.3 Triggers of these health needs

As it is common knowledge on the health needs of PWIDs, the triggers of these health needs are mostly ignored. These range from social factors in the home, lack of proper nutrition, inactivity and lack of attention from caregivers on the early onset of health problems.

The study identified that, some of the PWIDs were left out of immunization programmes especially when they were out of school. Without these immunization programmes, PWIDs are prone to diseases that are preventable. Staff of the schools had this to say on immunization;

When there is general immunization programmes, health workers will visit the school to organize some for them when they are in school. I remember they have had polio vaccination, Hepatitis B screening and vaccination. The problem is that, with the Hepatitis B vaccination, some parents couldn't afford. When they are in school, we are able to help them get involved in immunization programmes but they are out of our hands when they go home. (Staff)

Parents said, they sometimes feel embarrassed when they are to present their wards for immunization programmes. One parent said,

It becomes embarrassing when you present your child for immunization especially at the hospital. I only presented my child for postnatal services during the first three months of the child's life. When I realized what was wrong with my child, I was embarrassed to send him again.

Another parent added that,

I remember the first time I sent my child with cerebral palsy for weighing, all the mothers around looked at the child with embarrassing eyes. Some of the health workers were even hesitant to hold the child let alone take care of her. The same thing applies to health workers who come into the community to conduct immunization programmes and so I don't even bother to send the child.

Parents were also asked about nutrition, exercises that will prevent obesity and protection from mosquitoes to prevent malaria.

I must confess my child get the best of care in the school than when he comes home. I know that, they exercise and eat proper foods in the school but before I sent him to the school, I didn't feed him well. Sometimes, I was just tired of the excessive eating of the child and just give him sleeping pills for him to sleep most of the time. He was not going anywhere and led to him becoming obese.

Another parent added,

My child is a day student and she doesn't sleep in mosquito net as we live in a single room with my husband. There is no way we can hung a net in the middle of the room and we can't sleep with her on the bed where we have the net. Mostly, we apply insecticide sprays in the room but that is ones in a while. I

believe that may be the cause of the frequent malaria cases I present to the hospital.

One of the Doctors also identified the delay of parents to present their children to the health facility resulting in complications of simple cases.

Sometimes, the parents will delay in bringing the children to the hospital and by the time they come, the disease would have progressed into complications. I believe it is as a result of the communication challenge most parents have with the child. Some of the children are not able to talk to the parents when they are feeling unwell and it will only take advanced symptoms for them to notice.

4.2.3 Impact of health needs

PWIDs expressed that most of the health needs they presented to the hospital for treatment had invariably affected their health and social life as a whole. Participants recounted this as follows: “If I get malaria, I can’t play and this makes me feel weak” (PWID). “I like playing with my friends but as soon as I get sick, I can’t play with them again” (PWID). “When the mosquitoes bite me, they give me malaria. For some days, I can’t eat well and madam will take me to the hospital. After taking the medicines, I feel good” (PWID).

Similarly, the caregivers and parents also recounted the fact that whenever a PWID is presented to the hospital for treatment of an ailment, it poses significant negative impact on their life. Below are some narrations:

For my ward, his condition is mild. He plays with other children and often runs errands for me. Anytime he is sick, you can feel it. He is not active anymore. It

gets me worried because aside the medications which are expensive.... treating him of malaria becomes a headache. I stopped working to take care of him.

(Parent)

I have been taking care of them for a number of years now. I am passionate about their well-being. There was onetime a girl was sick and for days she was eating well. While waiting for the doctor to come and assess the situation, her condition became worse. It kept me worried, but I was praying for her to get better. (Caregiver)

4.2.4 How IDs expressed themselves to healthcare provider in the consulting room.

Healthcare providers based their treatment on what parents say. With mild to moderate IDs, they are in some cases able to express what is wrong with them just that, they do them in an diverting way.

For example, during the focus group discussion, one PWID was asked, “What type of sickness usually troubles you? He just responded “ebola”. Another said “AIDS”. These just names of sicknesses they have heard and were mentioning them without actually knowing what they were. It then becomes difficult to understand their health needs let alone presenting them to the health care provider.

With this impediment, the study turned attention to the parents, to try find out from them how they detect and interpret the sickness of their children, and how they presented the issue to the doctor. One parent said,

Usually, when the child has stomach pains, he is able to point to the stomach for me to understand. Sometimes, he will have diarrhea and based on that, I am able to know what is wrong. When he has malaria, I see the signs of malaria such as

fever and based on that, I know. When you asked him, he will not be able to tell you specifically what is wrong with him.

Another parent who has a child with moderate to profound ID said,

“My child is not able to talk at all. However, I have been trained by the school to use picture communication to understand her. Apart from identifying the signs of impending sickness, I have pictures of someone holding the head with headache and stomach pains because these are areas of the body that usually present no symptoms for you to see. She is able to point to the picture of what is wrong with her. The rest of sicknesses, I identify them through symptoms.

The issue of presentation to healthcare providers was asked from the medical practitioner and this was what he had to say:

In most cases, it is the caregiver who presents the child’s case to us based on the symptoms they have. The mistake of some of the medical practitioners is that, they just take what the caregiver says and prescribe medications based on that. I go further to ask the caregiver additional symptoms they may not have noticed. If I suspect malaria, I recommend malaria testing and sometimes to the laboratory based on what I suspect to be the problem. In some cases, I have a way of communicating with those who can speak to tease out their problems. One hospital nurse continued, “The problem is not with those who can speak, but with those who cannot. In that case, we take vital signs of the child and the results will indicate a lot such as the presence of fever, high blood pressure

among others. Based on these signs, further investigations are conducted based on the prescription by the doctor such as malaria testing etc.

A teaching staff added to the conversation; I think those nurses and Doctors who have been treating ID children know their condition and thus have time for them. However, if the parents take them to the general hospitals during vacations, the issue becomes different. Parents complain that, some of the nurses don't even want to touch them especially when it comes to taking vitals. The doctors also don't have time due to long queues they are looking taking care of. They just listen to the parent and prescribe medications. Now most of the parents prefer to send the children to the hospitals the school management usually send the children to when they are sick.

4.3 Challenges Encountered by PWIDs in Accessing Health Care

Analysis of the interview highlighted the following as challenges or barriers to accessing Health Care. They are: Attitudinal Barriers, Financial Barriers, and Structural (Health policies) barriers and Communication barriers.

4.3.1 Attitudinal Barriers

The study revealed that participants suffered negative attitude from health professionals in accessing health care. This negative experience of PWIDs is exemplified in the following quotes: “The health workers who are supposed to know better sometimes even yell at the children, which is very bad and makes us feel sad as mothers of these children. (Parent) sometimes you will really keep long at the hospital, the treatment session is very slow and the health workers

do not also pay full attention to the work, they will be doing their own thing like being on phone for a long time while patient are in cue to the consulting room.

(Parent)

Health workers should be educated on how to do their work well because their attitudes do not help us at all, they think that we have our children and if you even go the hospital, they do not give you any support.(Parent)

Some other participants also narrated the negative attitudes in the following;

“Some health workers do not have patience for us at all. Sometimes I get angry but my mother tells me to calm down and wait” (PWID)

Sometimes when am going for my card, I was not able to walk hurriedly and my mum was helping me and the nurse shouted at my mum to hurry up and someone said have patience because her daughter is sick.(PWID)

4.3.2 Financial Barriers

On Barriers to health care by the PWIDs, analysis of the data revealed that participants faced financial barriers when it comes to them accessing health care, these financial barriers revealed by participants included inaccessibility to the use of health insurance and high cost of medication. Below are direct quotes of participants to support these findings.

As for me the cost of the medicine for my child is very expensive and in raising such amounts, is not easy at all, especially if you are not working and sometimes you can roam the whole of Kumasi and you will not get the medicine’(Parent).

Health Insurance is an important policy to promote health care of all especially the low income citizens, however, on the access to health insurance for health care, participants revealed the following as barriers to them using such service.

As for the health insurance, it covers nothing this is because if even your card is active and has not expired, they will tell you that the health insurance card does not cover the cost of medication so you have to buy the medicine and these medicines are very expensive. (Caregiver)

Another explained that: The health insurance can only covers for your folder, you have to pay for all other cost incurred because they say the health insurance does not cover at all. (Parent)

I think the health insurance has served no service to us because you have it but you cannot access free or part payment health care service with it, then what was it purpose in the first place, if they don't extend it then they should cancel it, because it is giving us false hope. (Caregiver)

4.3.3 Structural Barriers

Participants revealed that in seeking for health care, the time spent at the hospital waiting for their turn was too long. One participant explained that “Sometimes is annoying, you can come here at dawn and go back home very late because we normally keep very long a time at the hospital waiting for our turn” (Parent). Two others added:

Hmm, here in KATH, their services are very poor, because sometimes you will just be sitting there no one will even direct you as where to go and where not to go as part of the processes and you can spend like a whole day there and

sometimes you will not see the Doctor and they will ask you to come the following week, which is very bad (Caregiver).

‘The time we waste here at the hospital is very bad and this has been consistent, not that today you keep long and tomorrow it changes, no always the same, I think the Doctors are few which makes one Doctor attend to many patient, thereby resulting in us wasting too much a time. (Parent)

4.3.4 Communication Barriers

Analysis of the findings indicated that inability to express condition to health professionals and caregivers of PWIDs especially in seeking primary health care is a big barrier. Although the PWIDs themselves said, they seem to be communicating as effectively as they can, health care providers and parents usually do not understand.

For example, one PWID said, “when am not feeling well and I tell my mother, she will not mind me.” Another said, “the doctor does not understand when I say am sick

Parents however said their frustrations about the communication difficulties they encounter when it comes to identifying health challenges in their wards.

“It is true that they will tell you they are sick but sometimes will not be able to tell you exactly what is wrong with them. My child for example will keep on saying I am sick but when he is asked which part of the body, he will keep on repeating the I am sick.”(parent)

“My child has Moderate down syndrome and is unable to tell you exactly where he is sick. I only look out for signs and symptoms such as fever, frequent visitation to the gents and rushes. Sometimes he will have sores and rushes in

the mouth and on the lips and I will realize he not feeling well.” Another parent added.

Health care providers also shared their experiences with communicating with PWIDs

‘Sometimes is not easy when diagnosing a particular condition. This is because they cannot explain their condition vividly, they are not specific, and they mostly generalize so it makes diagnoses and treatment a bit complicated sometimes’ (Nurse).

‘Because they mostly come here with wounds and malaria, I use my past experience to always give them malaria treatment first because they can’t explain what is wrong with them and if you ask their care givers they mostly know nothing about their condition’ (Nurse)

‘Hmm working with this people is not easy, sometimes at dawn, when they are not well, they can’t explain well to you what is wrong except maybe stomach ache and headache that their signs will give you a clue so you give them first aid’ (Caregiver).

‘Sometimes you ask these people questions in your quest to arrive at what is wrong with them and the responses they give you is so far contradictory from your expected response, making it very difficult to offer any help, and is because of their disability so we sometimes understand’ (Nurse).

4.3.5 Environmental barriers

PWIDs also face environmental challenges when it comes to their access to health care. These challenges range from lack of ramps at health facilities, elevators and difficulties in assessing various facilities at the health centers.

Since most of the PWID participants were resident in the schools, their health accesses were facilitated by staff of the school. The schools have resident nurses who provide nursing services to those who fall sick. Medical Doctors also come on routine visits to treat these children with health conditions. That is, PWIDs who are resident in the schools usually have little environmental challenges in accessing health care. The challenge however arises when they are on vacation and those who are not resident in the school.

One PWID indicated during the discussion that; “I can’t climb the stairs when I go to the hospital. I become tired”.

Another PWID with hemiplegia CP said; “when my mother takes me to the hospital, she sometimes carry me at her back to climb the stairs. Sometimes I sit in the wheelchair for her to push me.

Parents were those who felt the direct consequences of these barriers and they had these to say.

“I took my child to KATH when he was about 14 years old and it was very difficult. Because I took trotro to Komfo Anokye, I had to carry him at my back from the ‘Gyee’ roundabout to the OPD center of the hospital as I had no wheelchair. When I was asked to see the E and T people, no nurse bothered to

get me a wheel chair. I carried him around the hospital, climbing up and down stairs for medications etc.”

“I mostly go to the health centers and the district government hospital and sometimes to private hospitals when my child is sick. With the private hospitals, there are ramps and even elevators when you have to climb a storey building. They also quickly provide you with wheelchairs when they notice the need for it. But the government one, the roads to the hospitals are sometimes bad for wheelchairs and few ramps at the hospital.” Another parent added.

The social workers and the representative from the NGO also added to the conversation in these words:

“I know all public places are to make their environment disability friendly. Some of the health facilities are complying especially when it comes to ramps but their road are sometimes poor. Storey buildings in some of these hospitals lack elevators and disabled people made to climb. Some parents have been complaining about these issues and we have been visiting some of these facilities too but they always complain about financial impediments to building a disability friendly environment. But I believe things are gradually getting better and we will get there”.

4.3.6 How the barriers influence access to health care

The barriers mentioned above have major influences on access of PWIDs to health care in the study setting. On the attitudinal front, lack of patience for PWIDs and comments that emanate from health workers and other health care seekers at the various health

centers deter parents from sending their children to the hospital when they are sick. Financially, with high cost of medications and lack of coverage for various medications covered by the National Health Insurance Scheme, it becomes very difficult for parents of PWIDs to access health care services. Though this may be a general problem among the Ghanaian population, these parents face peculiar challenges as the conditions of their children sometimes prevent them from working thereby depleting their present account.

On the structural barriers, most hospitals around the country have little or no structures in place to enable PWIDs have easy access to health care services. There are no or few professionally trained health workers who are able to specifically deal with persons with disability. Specialized services are lacking, and so are specialized communication tools to truly understand the problems presented by PWIDs to the health facilities. These and many others cause parents and caregivers to stay away even when their children are sick and thus resort to self-medications. As one parent puts it;

Mostly, I go to the drug store to buy medication for my child when he is sick. Sometimes is financial problem, other times I can't bear the attitude of health worker and the public towards my child and other times is because some of the doctors will prescribe the same medication for you over and over as they don't do any proper assessment of the child's illness. So I just buy medicines from the store based on the symptoms of the child.

4.3.7 Coping mechanisms employed

Analysis of the findings revealed that caregivers and parents employed emotional resilience and intrinsic motivation as possible coping mechanisms employed.

4.3.7.1 Emotional resilience

Emotional resilience refers to the ability to adapt to stressful situations without lasting difficulties. Analysis of the study revealed that caregivers and parents of PWIDs employed emotional resilience as the most possible coping mechanism in addressing the challenges encountered.

They do so by suppressing their emotions. A participant reiterated:

I psych myself whenever I come to the hospital. There are times the nurses are receptive to us but there are times they are not. Joining long queues and sometimes you receive harsh comments from other patients and even the nurses get me frustrated. But I keep my temper down so that I could be served.

(Parent).

A caregiver added that

The challenges we encounter in accessing health facilities for their PWIDs are enormous, but we try to calm down in stressful situations. I remember a time when one PWID I sent to KATH was moving up and down because of a long queue. One comment from a nurse really angered me, but I never reacted. I just stayed cool and waited patiently for them to call us.

A participant also communicated that when they are knocked off by their emotions, they 'remember the power of time'. "Yes, sometimes you get stuck in your emotions. But I believe time heals all wounds and in no time, I recover from the frustrations" (Parent).

4.4 Enablers to Health Care

As already indicated in the literature review, enablers are measures and things put in place to facilitate access of PWIDs to health care. Though these individuals face numerous challenges, various attempts ranging from schools and health facilities are being made to facilitate their access. These enablers have been analyzed at various levels such as, educational level, communication level, structural and parental level.

4.4.1 Educational or school level

As majority of the PWIDs spend most of their time in school, school authorities have put in place various measures to facilitate the health needs of their students. They have a sick bay with resident nurses living in the school to take care of the urgent and sudden health care needs of the children. They also have visiting medical experts who come regularly to take care of the health needs of the children.

A staff of Garden City had this to say: usually, we have a nurse in the school who takes care of the urgent needs of the children. As she has been living with them for some time, she understands and knows their challenges so it makes her work less difficult. Medical officers also come every month for routine checkups to identify and treat diseases among these children. The problem arises when we are on vacation. When they fall sick at home, some of the parents will even wait until school resumes for them to come back for treatment.

4.4.2 Communicational level

Communication with PWIDs to truly understand their health needs was one major challenge identified. Although this problem was widespread in various hospitals, some

few ones have started putting in place measures to facilitate communication. One of the medical officers said;

Now, my hospital has employed a disability expert with understanding in sign language interpretation. Not only does he communicate effectively with the hearing impaired, he also knows how to communicate with PWIDs even the severe and profound ones. This makes our work easier and so, they are always around to assist. Apart from that, hospital staffs have been trained on how to show empathy and communicate effectively with caregivers and parents of Persons with disability in general. This makes our hospital the preferred place for most of the Persons with disability.

Generally speaking, the representatives of the NGO and the social welfare drew attention to the fact that, the Ghana Health Service has started introducing training in sign language for health workers to enable them communicate effectively with PWIDs.

“I believe a time will come when all health workers will have in-depth knowledge on the peculiar nature of the challenges facing persons with disability. They will be better equipped to deal with them through training as they have started introducing sign language in the curriculum of the nurses and other health workers.”

4.4.3 Structural level

As various structures within the health facilities deterred some Persons with disability from accessing health care, few hospitals have started putting in place measures to reduce their difficulties. For example, the visiting medical expert from Komfo Anokye Hospital to the school had this to say:

“Currently, KATH has a dedicated consultation room solely for persons with disability called room 10 and so any disabled person who comes to the hospital is sent there. At this consulting room, there is a General Medical practitioner who also has broad knowledge in dealing with PWDs. There is also a disability expert, with sign language interpretation competence and nurses with same. So it makes their ability to diagnose and understand PWIDs easier as well.”

The other medical expert also added that,

“wheelchairs are readily made available to PWDs who are unable to walk especially the obese PWIDs. Nurses immediately sit them in the wheelchair and push them around of which majority of them enjoy. We have also made our environment, disability friendly through the construction of ramps all around the premises to make movement with the wheelchair very easy.”

4.4.4 Parental level

Parents of PWIDs in the various schools where this study was conducted have come together to meet every two weeks to discuss challenges and find practical solutions to them. During such meetings, parents and caregivers are trained on how to communicate effectively with their children and to understand what is wrong with their children. They are also trained on how to handle the children at home so as to reduce the health complications these children encounter.

One parent said that;

“School authorities teach us how to communicate with our children more effectively and also how to handle them. Before I came here, I didn’t know how to interact and understand my child when he was sick but now, I do.”

Another parent added;

“We coming together has really helped us to have a united front. We are able to discuss challenges facing us and the children and also know various hospitals that sensitive to our plight. It is here that I have been able to get the phone number of doctors who really understand my child and so whenever she is sick, I just call him and makes things easier.”

A staff of the school also reiterated the kind of health talks and advice given to parents;

“The medical doctors usually interact with parents and give them advice on how to take care of the health needs of the children. Advice on nutrition, early signs and symptoms to look out for when the children are having health difficulties are given them. Apart from that, teachers also give them advice on how to handle the children especially CP children so as not to complicate their health.”

4.5 Experiences of Healthcare Professional Caring for Persons with Intellectual Disability

4.5.1 Nature of health services

Healthcare professionals expressed the view that the nature of health services provided had shaped their life experiences in dealing with PWIDs. They expressed that the kinds of services are not always in line with their health needs but they try to meet their needs.

Participants expressed this as follows:

Here in this special school as the only nurse, I am limited in the provision of services for the PWIDs. I mostly provide triage nursing care for them- wound dressing. Their health needs are diverse (Nurse).

In my years of professional studies as a doctor, I was not adequately exposed to intellectual disability and healthcare. Generally, the nature of services I mostly

provide the PWIDs include respite care- providing a care in line with the disability, especially those with autism, down syndrome and cerebral palsy. Sometimes, the nature of services is for secondary conditions such as malaria therapy, cold, diarrhea among others (Doctor).

Sometimes you are stacked with treatment protocols as the prognosis must corroborate with the condition. Since they present special cases of intellectual disability with varying degrees- mild and profound, the nature of services given becomes a bit problematic. Anyway, I try to meet the needs through my understanding of intellectual and psychiatric care. Thus, the services provided are in line with the child's disability" (Doctor).

4.5.2 Negative experiences of healthcare professionals

The experiences of healthcare professionals were found to be negative. Participants expressed non-adherence to treatment, behavioral issues and fear as the negative experiences in dealing with PWIDs.

4.5.2.1 Non adherence to treatment

Participant's related non adherence to treatment was due to communication problems. They believed that Caring for PWIDs demands skills in communication strategies. PWIDs inability to present their health concerns and also understanding how complex the health delivery system works makes it difficult for health professionals to assess their needs and PWIDs to also comply to treatment. They also explained that accurate medical evaluation and medical history is derived from parents or caregiver's observations and verbal account. Participants expressed these as follows;

“Their speech is not clear. Some cannot talk at all; hardly will you understand what they say. So the teachers or caregivers who bring them here are the ones who describe the situation, then I also examine them and then come to the diagnosis to give them drugs” (Doctor).

‘Mostly it is the caregiver’s observations that we use. However, some are able to tell how they are feeling, some are not able say. There was a time one was able to tell me that his head aches. Because we too we can’t explain the treatment procedures well for them to understand getting them to adhere becomes difficult’ (Nurse).

‘Yes, we look at their mannerism, even though we take caregivers verbal account, because some can’t explain what the pain they are going through. We look at their gestures and pick up certain cues. Sometimes assessing their pain level is difficult’ (Nurse).

4.5.2.2 Behavioral issues

Participants explained that PWIDs behavioral issues hinders their delivery of care. Providing quality care for PWIDs was described as stressful. Managing aggressive behavior of PWIDs in order to cooperate with examinations and treatment procedures was described as stressful. This was related in the following quotes;

Because of their condition, for instance, with wound dressing, I would have done it every three days but here sometimes after the dressing, they remove the dressing and you have to do it again, so it stresses you. (Nurse)

We treat them nicely but sometimes, their behavior, they are aggressive so to get the person to follow what you are doing is not easy. That will even make

you react in a particular manner for instance when you talk to a patient and does not speak to you right or with a frowned face you. (Nurse)

But sometimes the patients do not help. You want to deliver quality care but it doesn't go your way. I remember one instance when a man had nothing and I had to try and give him other healthcare. It wasn't easy. For some if you want to check temperature they will not allow you. (Nurse)

4.5.2.3 Fear

Participants indicated that being able to provide care in a safe and conducive environment was related with fear. Participants noted that they sometimes felt unsafe working with PWIDs due to their unpredictable nature. This was explained in the following quotes. "There are some who don't like the hospital environment, some can even pretend, and you know some of their actions are unusual. Dealing with such a person can even put you at risk" (Nurse). "Working with people with ID sometimes there is this fear of not knowing what will happen. Because there are times they can be very aggressive, they will not allow you to render your service" (Nurse).

There are times they are hyperactive full of energy. Let's say you are to give this person injection; you would have to develop a strategy that will help you. If not, struggling with them, where lays your strength. Sometimes the environment we deliver the care is not safe and it affect the quality of care given (Nurse).

4.5.3 How health professionals cope with these challenges

These challenges one health worker indicated are the main deterrents of some health professionals failing to take care of the health needs of PWIDs. Even if they do take care of them, thorough assessment is not done thereby reducing the chances of PWIDs receiving proper treatment. However, the health's professional who were interviewed for this study shared measures they have adopted in dealing with such issues.

On the issue of non-adherence to medications, one doctor said;

Though the responsibility lies on parents and caregivers to help them in taking their medications, I also try to help by recommending injections at the health facility if the need be. I also try to add medications that have sweet taste. With those ones, they take them without complaining. I also advise them to put the medications into foods they can swallow such as fufu and banku without them knowing.

On the issue of aggression health professionals have these to say

Mostly, they become aggressive when they feel threatened so when it comes to that, you have to allow them to calm down before you continue with the treatment. Sometimes, you have to hold them especially when you want to give them injections especially with autistic children. Sometimes, you give them distractors such as toys, video games for their attention to be drawn to these things before you can treat them.

Lastly on fear, health professionals concluded that, even though they sometimes fear for their safety when dealing with PWIDs due to their aggressiveness, they must understand that, they are different and it their job to treat them when they are sick.

CHAPTER FIVE DISCUSSIONS

5.0 Introduction

Health is an essential ingredient of well-being. But for persons with intellectual disability, access to healthcare is fraught with a myriad of barriers. This study therefore focused on the barriers and facilitators to healthcare among persons with intellectual disability within the Ashanti region.

This chapter presents the discussion of results from the study. It delves deeper into the findings to make meaning about the barriers and facilitators to healthcare among persons with intellectual disability with reference to previous and relevant works done by other researchers.

5.1 Health needs of persons with intellectual disability

The findings of the study revealed the pattern of the health needs of PWIDs and consisted of their utilization of health services within facilities, specialized care, health promotion programmes and assistive products.

The utilization of health services was mostly found on the health conditions that PWIDs mostly presented at health facilities. The findings reported that malaria was the most

common health condition reported at the healthcare facility. According to the findings of the study, PWIDs did not fully engage in health promotion programmes, such as healthy eating, physical activity, and health screening programmes. This infers that majority PWIDs are left out of health education programmes which could invariably have adverse effect on their health. This corroborates with a study conducted by Robertson et al. (2015) who established that people with ID do not access preventative health care and health promotion programs to the same degree as others in the community. The study further reported that health promotion materials available are in formats that are not accessible to PWIDs. Such inequalities in health for people with ID are evidenced by high mortality including premature death from preventable causes. Therefore, it can be concluded on the basis of the findings that health education and screening programmes would help in early identification and prevention of diseases among PWIDs.

Findings of the study revealed that that aside the general healthcare received, PWIDs also need specialized care in health services that are specific to their disability. Services that will help in early identification, interventions designed to minimize or prevent further disability were reported by participants in the study. Such services included physical therapy, psychotherapy and speech therapy. This is consistent with a study by Dainly (2014) in Malaysia which reported that persons with intellectual disability experienced low health outcomes as a result of health facilities not being able to meet their special health needs.

Analysis of the interview revealed that people with intellectual disability can benefit from assistive products. Participants indicated that assistive products such as hearing aids, eye glasses among others can improve functional capabilities of PWIDs. This supports the findings of a quantitative study on access to healthcare among persons with disability which found that assistive devices contributed to functional independence and helped persons with disability to integrate fully into mainstream society (Badu, 2014). From this, the call for achieving sustainable development goal of inclusion and well-being needs to be properly looked at in an attempt to meeting the health needs of PWIDs.

5.2 Barriers/Challenges faced by PIWDs in accessing Health Care

The findings of the study revealed that a myriad of challenges confront access to health care among persons with intellectual disability in the Ashanti region of Ghana. These challenges reported were attitudinal, financial, structural and communication in which findings of a study on healthcare access places emphasizes on equity for all (Oliver and Mossialos, 2004).

In the study of Oliver, A. and Mossialos, E., 2004, attitudes of healthcare professionals were reported as negative. Bogenschutz (2014) also reported attitudinal barriers due to lack of training of healthcare providers in the care of individuals with developmental disabilities and 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 health workers have low knowledge levels of how to engage with IDs found by Powrie and Melville

et. al, that health professionals have significant unmet training needs relevant to their work with people with Intellectual disabilities (Powrie 2003; Melville et. al, 2005) and negative attitudes of healthcare providers reduces parents/caregivers' trust in the healthcare system. This therefore implies the quality of services being rendered to persons with intellectual disability would be affected and this can impose serious implications in health care delivery.

Zuckerman *et al.* (2014) in a qualitative study conducted among Latino parents of children with autism spectrum disorders revealed that the negative attitudes of healthcare providers coupled with inconvenient, uncomfortable and complex diagnostic processes hindered access to healthcare for their children with autism. This resonates with the findings of this study and places much emphasis on the importance of training for healthcare professionals on ID.

In the context of healthcare access, cost is critical in ensuring quality and effectiveness of services. This relates to the Penchansky's model of healthcare access which stages that affordability measures the relationship the cost of health care services relative to the consumer's ability to pay (Karikari-Martin P., 2010). Findings of the current study revealed that carers and parents of persons with intellectual disability experience inaccessibility to health insurance as well as high cost of medications. These therefore place a huge burden on their income. Therefore, these findings are in conformity to a study by Krahn et al., which emphasizes that financial disparities with access to healthcare by people with intellectual disabilities (Krahn et al., 2006). From the findings, it is evident that though persons with ID have access to universal health coverage through the health insurance, they are limited to its usage since it covers basic

OPD charges of the entire hospital charges so this reduces their full access to healthcare. This could imply that there are issues in the healthcare sector of persons with intellectual disability that needs to be addressed; most especially in the line of affordability of health care.

Healthcare usage depends largely on the effectiveness of structures; including policies, infrastructure as well as healthcare systems. Smith (2008) argued that persons with intellectual disability are faced with structural barriers to healthcare access. According to the researcher, structural barriers denote those barriers that arise from health systems policies and mostly manifests in health insurance, medical equipment as well as rehabilitation services. The study reported that participants experienced poor services within the health facilities that they sought healthcare. This finding could mean that not much has been done in ensuring the structural access to healthcare by all as some previous studies emphasized on strengthening health systems to promote universal access to healthcare for all and sundry (Portes, 1992; Millman 1993; Gold, 1998; cited in Michelle et al., 2015).

Communication is effective in healthcare delivery. Research suggests that effective communication helps improving patient's health outcomes. The study revealed that PWID experience communication barrier in their quest to access healthcare and this is evidence in a study that propounded that: Adults with ID either had difficulty understanding the information from their provider or were not able to effectively communicate their thoughts, wants, or needs regarding their health or need for health services (Greenwood et al, 2014; Nicolaidis et al., 2015; Zerbo, et al., 2015). This could

mean that, access to effective means of communication with regards to one's background is very essential in healthcare delivery and for that matter the healthcare needs of individuals with intellectual disability.

5.3 Coping Mechanisms among Caregivers of Persons with intellectual disability

Analysis of the findings revealed that caregivers and parents of PWID employed emotional resilience and intrinsic motivation as possible coping mechanisms. This is consistent with a study by Hastings *et al.* which focused on positivity in parents and caregivers of children with ID (Hastings *et al.* 2005; Bayat 2007; Blacher and Baker 2007) this same study is in line with a growing trend within psychology towards positive psychology, which is a focus on adaptive, rather than maladaptive functioning, and on strengths and abilities, rather than weaknesses (Seligman and Csikszentmihalyi 2000). Thus, the orientation of positive psychology is towards identifying resilience as opposed to risk.

5.4 Enablers to Health Care among PWIDs

The enablers to healthcare refer to the various interventions or processes by which access to health services and healthcare is facilitated (Whittle *et al.*, 2018). Therefore, enablers act as cushions for promoting the health of persons with intellectual disability. Findings of the study revealed enablers at four major levels and these are: the school level, structural level, communication level and at the parental level.

At the school level, it was realized that, school management are putting in place measures such as establishing sick bays with resident nurses at the school to cater for

the health needs of the children. They also requested for the services of medical experts on monthly basis to perform general checkups and assessment of the health conditions of these children.

At the structural level, hospitals were putting in place dedicated consulting room for PWDs to cater for their specific needs. The environment in most health facilities were also being maintained and restructured to be disability friendly through the construction of ramps and wheel chairs for PWDs.

At the communication level, disability experts are now being employed at some health facilities that had profound knowledge in how to communicate effectively with PWDs in general. Sign language studies were also being introduced into the curriculum of training health professionals.

At the parental level, parents are forming associations to fight for the rights of their children with a common voice. These associations also serve as platforms for receiving education and information on how best they can meet the health needs of their children.

5.5 Experiences of healthcare professional caring for persons with intellectual disability

Healthcare professionals are faced with both positive and negative experiences in caring for persons with intellectual disability. According to Aubery (2018), the varied health needs of PWID and diverse practice settings create a fragmented system that makes it difficult for health professionals to execute their duties. Findings of the study reported non-adherence to treatment, fear and behavioral issues as the experiences health

professionals working with PWIDs face in relation to non-adherence to treatment procedures. Participants recounted non-adherence to treatment to communication problems. The healthcare providers believed that caring for PWIDs demands skills in communication strategies. People with IDs inability to represent their health concerns and to understanding how complex the health delivery system works, makes it difficult for health professionals to assess their needs for PWIDs to also comply with treatment. They also explained that accurate medical evaluation and medical history is derived from parents or caregiver's observations and verbal account. This finding is in agreement with a study conducted by Appelgren et al., (2018) who concluded that communication in nursing patients with ID clearly demands skills and competences in communication strategies above and beyond the spoken word. Thus, healthcare professionals need training in effective communication to properly address the communication constraints.

Results of the study also revealed that health professional's encountered communication difficulties in diagnosing health conditions of persons with intellectual disability. The health professionals further stressed that they resorted to their past experiences in drawing up treatment plans for their health concerns. This finding supports a research conducted by Ward *et al* (2010) who explored the experiences of individuals with intellectual disability, and their care givers, in accessing mainstream health services for physical health problems. The results of the study highlighted communication difficulties, resulting from individuals with intellectual disability being excluded from consultations. This caused the failure of General Practitioners (GPs) to conduct health reviews, review medication and conduct blood tests and investigations. This therefore

results to diagnostic overshadowing, where physical or mental health problems are misattributed to the individual's intellectual disability, leading to delayed diagnosis and treatment.

Again, participants explained that behavioral issues of PWIDs hinder their delivery of care. Providing quality care for PWIDs was described as stressful. This was revealed in the managing of aggressive behaviours of PWIDs in order to cooperate with examinations and treatment procedures. In a study conducted by Campbell (2011) to explore Nurses' Experiences of Working with Adults Who Have an Intellectual Disability and Challenging Behavior, results of the study showed that participants experienced violent incidents, with emotional reactions been described as; anxious, fearful, vulnerable, stressed, scared, nervous, worried, concerned and being angry, the majority of which relate overall to anxiety. These reactions were triggered by maladaptive behaviours of persons with ID. This finding is consistent with the current study. Addressing the behavioural impulses would help ensure optimal care being given to persons with ID and would invariably enhance their quality of life.

The study also revealed that being able to provide care for PWIDs in a safe and conducive environment was related with fear. Participants noted that they sometimes felt unsafe working with PWIDs due to their unpredictable nature. This confirms a research conducted by Sowney *et al*, (2006). From the study, it was found that nurses caring for adults with intellectual disability experienced fear and vulnerability and an inability to cope without support of the caregivers. The experience of fear and vulnerability was considered by participants to be a consequence of their lack of

knowledge. The lack of a basic understanding of the nature of intellectual disability was also reported to reduce the ability to ‘pick up’ on cues that might be demonstrated by an individual’s behavior. Understanding the etiology of persons with intellectual disability would address phobias among healthcare providers and hence contribute to the provision of better care services.

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CHAPTER SIX

SUMMARY, CONCLUSION AND RECOMMENDATIONS

6.0 Introduction

This study sought to explore the barriers as well as the facilitators to healthcare access among PWIDs within the Garden City Special School and Life Community Vocational School in the Kumasi Metropolis.

6.1 Summary of the major findings

Health needs of PWIDs identified were specialized care, utilization of health services, health promotion programs and assistive products. However, in trying to access health services to take care of these needs, PWIDs faced numerous barriers. These barriers identified were attitudinal (negative attitudes among health care providers), financial (inaccessible health insurance and high cost of medications), structural (inflexible health policies and communication constraints) and environmental barriers (inaccessible environment at health facilities). The healthcare providers’ experiences in providing care included non-adherence to treatment, fear and improper behaviour exhibited by PWIDs.

The study also investigated the enablers in increasing health care access among PWIDs. Various interventions were being put in place at all levels to facilitate the easy access of PWIDs to health services. These included the employment of specialized disability experts at some health facilities who would be able to communicate with PWDs and the establishment of special departments to deal with the PWDs (Structural enablers). At the school level, school authorities have built sick bays with resident nurses who take care of the health needs of children as well as invitation of medical experts on routine basis to cater for the needs of PWIDs. On communication level, parents were being trained to better understand and communicate with their children while the Ghana Health services is introducing Sign Language into the curriculum and training of health personnel to be responsive to the plight of PWDs.

6.2 Conclusion

Based on the findings, it can be concluded that:

Access to healthcare among PWIDs is fraught with a myriad of barriers. In addressing these barriers, the enablers or facilitators to healthcare need to be properly adhered to; more especially educational interventions for increasing knowledge base of health professionals as well as the integration of caregiving in health care systems. The experiences of health care providers, attending to the health needs of PWIDs were found to be negative and this has serious implications in healthcare delivery for PWIDs.

6.3 Recommendations

Based on findings of this study, the following recommendations are made:

1. With one major finding of this study being the inability of some health care providers to fully understand the needs of PWIDs especially in the area of communication, it is recommended that, the Ghana health service in conjunction with 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 PWIDs. Also, continuous training of healthcare providers within the hospitals across the nation about issues of disability and how to provide PWIDs with holistic healthcare must be taking into account by Ghana Health Service and the various health facilities through internal training and workshops.
2. Another important finding was the difficulties parents had in accessing the National Health Insurance as many medications and treatments were not catered for by the scheme. Based on this, it is recommended that, the Ministry of Health in collaboration with the National Health Insurance Authority under the auspices of the Ghana Health Service should expand coverage of the National Health Insurance Scheme to include medications prescribed for PWIDs as well as the availability of drugs prescribed for them.
3. With the problem of stigmatization of patient (PWID) by people without Intellectual Disability at the various health facilities, it is recommended that, 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. Thus, various seminars and sensitization programmes could be organized to educate the public on matters relating to intellectual disability.

4. With environmental and communication barriers being a major impediment in the access of PWIDs to health services, it is recommended that, the Ghana Health Service increases efforts at providing disability-friendly equipment and environment such as hearing aids and communication devices among others for persons with intellectual disability to help ensure continual access to healthcare.
5. Professional competencies and empathy of health care providers can be improved through the Ministry of Health in collaboration with the Ghana Medical Association, Nursing and Midwifery Council, Pharmaceutical Society and the Allied Health Professions Council introducing disability courses in the health training schools. This will help increase knowledge on issues of disability which would invariably improve professional practice.
6. The Ghana health service in collaboration with the Ghana Education Service should introduce health screening programmes for PWIDs in the special schools for early identifications of preventable diseases as most PWIDs are left out

various immunization programmes and education aimed at reducing morbidity and prevention of diseases.

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REFERENCES

- Ailey, S.H. and Hart, R. (2010). Hospital program for working with adult clients with intellectual and developmental disabilities. *Intellectual and developmental disabilities*, 48(2), pp.145-147.
- Alborz, A., McNally, R., Glendinning, C. (2005) Access to healthcare for people with learning disabilities: Mapping the issues and reviewing the evidence, *Journal of Health Services Research Policy*, 10 (3) 173 – 182
- Allerton, L.A., Welch, V. and Emerson ,E. (2011).Health inequalities experienced by children and young people with intellectual disabilities: a review of literature from the United Kingdom. *Journal of Intellectual disabilities*, 15(4), pp269-278
- American Psychiatric Association (2013), Diagnostic and Statistical Manual of Mental Disorders (DSM-5).
- Andersen, R.M., Davidson, P.L. and Baumeister, S.E.(2007). Improving access to care in America. *Changing the US health care system: key issues in health services policy and management. 3a. edición. San Francisco: Jossey-Bass*, pp.3-31.

- Anderson, R.M. (1995). Revisiting the behavioural model and access to medical care: does it matter? *Journal of health and social behaviour*.pp.1-10
- Angus, J. E., Lombardo, A. P., Lowndes, R. H., Cechetto, N., Ahmad, F., and Bierman, A. S. (2008) Australian Institute of Health and Welfare “Disability in Australia: intellectual disability”
- Appelgren, M., Bahtsevani, C., Persson, K., and Borglin, G. (2018) Nurses’ experiences of caring for patients with intellectual developmental disorders: a systematic review using a meta-ethnographic approach, *BMC Nursing* 17:51 <https://doi.org/10.1186/s12912-018-0316-9>
- Arc (2011), Causes and Prevention of Intellectual Disability.
- Auberry, K. (2018). Intellectual and Developmental Disability Nursing: current challenges in USA, *Dove press journal: Nursing research and Reviews*. 8, 23-28 <https://doi.org/10.2147/NRR.S154511>
- Baart, J. and Taaka, F. (2017). Barriers to healthcare services for people with disabilities in developing countries: A literature review. *Disability, CBR & Inclusive Development*, 28(4), pp.26-40.
- United Nations. (2006). United Nations Web Services Section, Department of Public Information. Convention on the Rights for Persons with Disabilities: Some facts about persons with disabilities. Retrieved from <http://www.un.org/disabilities/convention/facts.shtml> [Accessed on 6/10/2019]
- Babbie, E. (2004). *The practice of social research* 217.
- Badu, E. (2014) *Healthcare accessibility barriers confronting persons with disabilities in the Kumasi metropolis*. Kumasi: Kwame Nkrumah University of Science and Technology.

- Balogh, R., Brownell.M., Ouellette-Kuntz, H. and Calantonio,A., (2010). Hospitalization rate for ambulatory care sensitive condition for persons with and without an intellectual disability- a population perspective. *Journal of Intellectual Disability research*, 54(9). pp. 820-832
- Balogh, R.; Ouellette-Kintz, H.; Bourne, L.; Lunskey, Y.; Colantonio, A. Organising health care services for persons with an intellectual disability. *Cochrane Database Syst. Rev.* 2008.
- Bogenschutz, M. (2014). "We find a way": challenges and facilitators for healthcare access among immigrants and refugees with intellectual and developmental disabilities. *Medical care*, 52, pp.S64-S70
- Brown M, MacArthur J, McKechnie A, Hayes M, Fletcher J. Equality and access to general health care for people with learning disabilities: reality or rhetoric? *J Res Nurs.* 2010;15(4):351–61.
- Brown, R. (2004). A framework for evaluating safety-net and other community-level factors on access for low-income populations. *Inquiry*, 41, 21-38. emy Press.
- Brown, R.B. (2006) "Doing Your Dissertation in Business and Management: The Reality of Research and Writing" Sage Publications, p.43
- Burke, C.-K. (2014). *Feeling down: Improving the mental health of people with learning disabilities*. London: London Foundation for People with Learning Disabilities.
- Burns, N., & Grove, S. (2005). *The practice of nursing research: Conduct, critique and utilization*. St. Louis, MO: Elsevier.
- Burns, N., & Grove, S. K. (2001). *The practice of nursing research: Conduct, critique & utilization*, 5th Edition (p.33). Missouri: Elsevier Saunders

- Campbell M. The importance of good quality services for people with complex health needs. *Br J Learn Disabil.* 2007;36(1):32–7.
- Campbell, K, A (2011) Nurses' Experiences of Working with Adults Who Have an Intellectual Disability and Challenging Behaviour, *The British Journal of Development Disabilities*, 57:112, 41-51
- Carrillo, J. E., Carrillo, V. A., Perez, H. R., Salas-Lopez, D., Natale-Pereira, A., & Carroll, E. M. (2015). Healthcare transition experiences of young adults with cerebral palsy. *Journal of Pediatric Nursing*, 30, 157-164. Comprehensive health care services for people with learning disabilities
- Carter, K.A. & Beaulieu, L.J. (1992). *Conducting A Community Needs Assessment: Primary Data Collection Techniques*. Gainesville, FL: University of Florida—Institute of Food and Agricultural Sciences
- Chen , B.K., Blankenship, C.J., Austin, B.S., Cantu, V.C. and Kotbungkair .W.(2016). Hiring of people with disabilities : perception of Hispanic small business owner. *Journal of Vocational Rehabilitation*, 45(2),pp.185-196
- Coppus. A.M.W. (2013). People with intellectual disability: What do we know about adulthood and life expectancy? *Developmental Disabilities research reviews*. 18 (1), pp. 6-16
- Cotes E. J. (2004) Stress, burnout and the attitudes and experiences of mental health professionals working with clients who meet the criteria for a diagnosis of personality disorder (Doctoral dissertation, University of Warwick). Available at: <http://go.warwick.ac.uk/wrap/1208> (accessed on 29 April 2019).
- Crawford M. J., Adedeji T., Price P. & Rutter D. (2010) Job satisfaction and burnout among staff working in communitybased personality disorder services.

International Journal of Social Psychiatry 56, 196–206. CrossRefView Record
in ScopusGoogle Scholar

Creswell, J. W. (2013). *Research design: qualitative, quantitative and mixed methods approaches*.

Crossman, B. (2014). A blueprint for mapping and modelling ecosystem services. *Ecosystem services*, 4, pp. 4-14.

Crotty, M (1998) “*The foundations of social research: meaning and perspective in the research process*”, Sage London.

Dainly, J (2014)'*Health needs of the physically disabled*', in Verony.C.H (2014)State of Health InMalaysia.Penang:Southbound,pp56.

Davidson, P., Andersen, R., Wyne, R., & Brown, R. (2004). A framework for evaluating safety-net and other community-level factors on access for lowincome populations. *Inquiry*, 41, 21-38.

Department of Developmental Disability Neuropsychiatry. (2014). the guide: Accessible mental health services for people with an intellectual disability. In 3DN (Ed.). Sydney, Australia: UNSW.

Dinsmore AP (2012) a small-scale investigation of hospital experiences among people with a learning disability on Merseyside: speaking with patients and their carers. *British Journal of Learning Disabilities* 40: 201–212.

Discussion Paper Series: Social Protection Unit, Human Development Network, The World Bank.

Drainoni, M.L., Lee-Hood, E., Tobias, C., Bachman, S.S., Andrew, J. and Maisels, L. (2006).*Cross-disability experiences of barriers to health-care access: consumer perspectives. Journal of Disability Policy Studies*, 17(2), pp.101115.

- Ekman, B. (2004). Community-based health insurance in low-income countries: a systematic
- Elaine, P., (2003). Primary health care provision for adults with a learning disability. *Journal of advanced nursing*, 42(4), pp.413-423.
- Elwan, A. (1999a). Poverty and Disability A Survey of the Literature Social Protection
- Elwan, A. (1999b). Poverty and disability: A survey of the literature: Social Protection Advisory Service.
- Emanuel, E.J., Fairclough, D.L., Slutsman, J., Alpert, H., Baldwin, D. and Emanuel, L.L., 1999. Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *New England Journal of Medicine*, 341(13)
- Emerson E, Baines S, Allerton L, Welch V. (2012) Health inequalities and people with learning disabilities in the UK. Durham: Improving Health and Lives Learning Disability Observatory
- Friese T and Ailey S (2015) Specific standards of care for adults with intellectual disabilities. *Nursing Management* 22,32–37
- Gates, B (2006) Care Planning and care delivery in intellectual disability nursing. Blackwell Science. London. ISBN. 1-4051-3122-5
- Ghana. statistical service, 2014. 2010 population and housing census report. Ghana statistical service
- Gibbs, S.M., Brown, M.J. and Muir, W.J.,(2008). The experiences of adults with intellectual disabilities and their carers in general hospitals: a focus group study. *Journal of Intellectual Disability Research*, 52(12), pp.1061-1077.
- Gillespie,A. and Graham, s., 2014. Meta analysis of writing interventions for student

Gleeson, B.,1997. Community care and disability: the limits to justice. *Progress in Human Geography*, 21(2), pp. 199-224

Gluck.S.2014. Intellectual disability Article. Helthy place.retrieved on 2019 october 27 from <https://www.healthyplace.com/neurodevelopmental-disorder/intellectual-disability-intellectual-disability-article>.

Goldsmith L. (2002). *A critical history of Andersen's Behavioral Model of health services use: reflection of how we study access to health care*. Presented at: Academy for Health Services Research and Health Policy Meeting. Washington (DC).

Goodley, D.(2011). *Disability studies: an interdisciplinary introduction*. Sage .

Gulliford, M., Figueroa-Munoz, J., Morgan, M., Hughes, D., Gibson, B., & Beech, R.

H. (2002). What does 'access to health care' mean? *Journal of Health Services Research & Policy*, 7(3), 186-188.

Hargate, A., Hemingway, S., Plummer, S. and Padgett, K., 2008. A systems approach to improve the physical healthcare interventions available to service user. *Mental Health Nursing* (online),28(3),p.6

Hastings R. P. & Brown T. (2002) Coping strategies and the impact of challenging behaviors on special educators' burnout. *Mental Retardation* 40, 148–56.

Havercamp, S. M., Scandlin, D., & Roth, M. (2004). Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. *Public Health Reports*, 119(4), 418-426. Hemingway,

L.2011. *Disabled people and housing choices, opportunity and barriers* policy press.

Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. (2014) .The confidential inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *Lancet*. 383:889–95.

Heslop, P. Blair, P. Fleming, P., Hoghton, M., Marriott, A., Russ, L. (2013) *Confidential Inquiry into Premature Deaths of People with Learning Disabilities*, Bristol: Norah Fry Research Centre, University of Bristol

Horwitz, S. M., Kerker, B. D., Owens, P. L., & Zigler, E. (2000). The health status and needs of individuals with mental retardation. Washington, D.C., Special

Olympics, Inc.: Yale University

Hosking, F.J., Carey, I.M., Shah, S., Harris, T., DeWilde, S., Beighton, C., Cook, D.G.

(2016). Mortality among adults with intellectual disability in England: comparisons with the general population, *American Journal of Public Health*, d.o.i. 10.2105/AJPH.2016.303240

Howard, R. and Hegarty, J.R. (2003). Violent incidents and staff stress. *The British Journal of Developmental Disabilities*, 49, 3- 21.

Howard, R. and Hegarty, J.R., 2003. “ VOILENT incidents and staff stress.” *The British Journal of Development Disability* 49(96)pp.3-21

- Hsieh, K., Rimmer, J. and Heller, T., 2012. Prevalence of falls and risk factors in adults with intellectual disability. *American journal on intellectual and developmental disabilities*, 117(6), pp.442-454.
- Hussey, J & Hussey, R. (1997) “*Business research: a practical guide for undergraduate and postgraduate students*”. Macmillan Press LTD, Basingstoke, Hampshire.
- Iacono T. & Davis R. (2003). The experiences of people with developmental disability in Emergency Departments and Hospital Wards. *Research in Developmental Disabilities* 24, 247–264. *Incarceration*. Washington D.C: Institute Justice Policy Canter.
- Institute of Medicine. (1993). Access to health care in America. In M. Milliman (Ed.), Committee on monitoring access to personal health care. Washington, DC: National Academy Press.
- Jackson, T. (2009). Accessibility, efficiency and effectiveness in psychological services for adults with learning disabilities. *Advances in Mental Health and Learning Disabilities*, 3(4), 13–18.
- Johnson, J. L., Woll, J. (2003): A national disgrace: health disparities encountered by persons with disabilities; *Disability Studies Quarterly*, 23, 1, 61-74
- Kanter, A.S., 2006. The promise and challenge of United Nations Convention on the Right of Persons with Disabilities. *Syracus J. Int'l L. & com.* 34 (2006): 287
- Karikari-Martin, P., (2010). Use of healthcare access models to inform the patient protection and affordable care act. *Policy, Politics, & Nursing Practice*, 11(4)
- Karikari-Martin, P., (2010). Use of healthcare access models to inform the patient protection and affordable care act. *Policy, Politics, & Nursing Practice*.

- King matthew, Nora Shields. Imms, C, Black,M.and Ardern, C, (2013). Participation of children with intellectual disability compared with typical developing children. *Research in developmental disabilities*, 34(5), pp.1854-1862.
- Krahn, G.L., and Drum, C.E., 2007. Translating policy principles into practice to improve health care access for adult intellectual disabilities: a research review of the past decade. *Mental retardation and developmental disabilities research reviews*, 13(2), pp.160-168.
- Krahn, G.L., Hammond, L. and Turner, A. (2006). A cascade of disparities: health and health care access for people with intellectual disabilities. *Mental retardation and developmental disabilities research reviews*.
- Krahn, G.L., Hammond, L., Turner, A. (2006) A cascade of disparities: health and health care access for people with intellectual disabilities, *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 70 – 82
- Kripanont, N. (2007). *Examining a technology acceptance model of internet usage by academics within Thai business schools* (Doctoral dissertation, Victoria University).
- Kumasi Metropolitan Assembly. (2013). Medium Term Development Plan of Kumasi Metropolitan Assembly, 2010-2013 Kumasi, Ghana: Ministry of Local Government & Rural Development, Accra.
- Kurre, P. A. (2014). Orthopaedic care coordination for the intellectually and developmentally disabled adult in the resident care setting: A perfect storm. *Orthopaedic Nursing*, 33, 251-254
- Lee, A. and Kiemle, G., (2015). ‘It's One of the Hardest Jobs in the World’: The experience and understanding of qualified nurses who work with individuals

diagnosed with both learning disability and personality disorder. *Journal of Applied Research in Intellectual Disabilities*, 28(3), pp.238-248.

Lehmann, B. A., Bos, A. E., Rijken, M., Cardol, M., Peters, G. J. Y., Kok, G., & Curfs, L. G. (2013). Ageing with an intellectual disability: the impact of personal resources on well-being. *Journal of Intellectual Disability Research*, 57(11), 1068-1078.

Lewis, S., & Stenfert-Kroese, B. (2010). An investigation of nursing staff attitudes and emotional reactions towards patients with intellectual disability in a general hospital setting. *Journal of Applied Research in Intellectual Disabilities*, 23, 355-365.

Lindsey, L.M (2002), *Advances in Psychiatric Treatment: Comprehensive health care services for people with learning disabilities*, vol. 8, pp. 138–148.

Long T & Kavarian S (2008) Aging with developmental disabilities: an overview. *Topics in Geriatric Rehabilitation* 24, 2–11.

Marmot, M., Friel, S., Bell, R., Houweling, T. A., & Taylor, S. (2008). *Closing the gap in a generation: health equity through action on the social determinants of health. The Lancet*, 372(9650), 1661-1669.

Marshall, N. M. (1996). *Sampling for qualitative research: family practice*, 13 (6), 522-526.

Mastebroek, M., Naaldenberg, N., A van den Driessen Mareeuw, F., LagroJanssen, A.L.M., and Schrojenstein Lantman-de Valk, H.M.J. (2016). Experiences of patients with intellectual disabilities and carers in GP health information exchanges: a qualitative study. *Family Practice*, 2016, Vol. 33, No. 5, 543–550

- Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: A meta-analysis of population-based studies. *Research in Developmental Disabilities*, 32(2), 419-436.
- McColl, M.A., Jarzynowska, A. and Shortt ,S.E.D. 2010. Unmet healthcare needs of people with disabilities: population level evidence. *Disability & society*, 25(2).pp.205-218
- McConkey R, Trusedale M. (2000) Reactions of nurses and therapists in mainstream health services to contact with people who have learning disabilities. *J Adv Nurs*. 32(1):158–63.
- McGonigle, J.J., Venkat, A., Beresford.C., Campbell, T.P and Gabriels, R.L. (2014). Management of agitation in individual with autism spectrum disorders in the emergency department. *Child and Adolescent Psychiatric Clinic*, 23(1), pp.83-95
- McGrath, L.M., Pennington , B.F., Shanahan, M.A.,Santerre-Lemmon,L.E., Barnard, E.G./Defries,J.C. and Olson, R.K. (2011). A multiple deficit model of reading disability and attention- deficit/hyperactivity disorder : searching for shared cognitive deficits. *Journal of child psychology and psychiatry*, 52(5), pp, 547-557.
- Melville, C.A., Finlayson, J., Cooper, S.A., Allan, L., Robinson, N., Burns, E., Martin, G. and Morrison, J.,(2005). Enhancing primary health care services for adults with intellectual disabilities. *Journal of intellectual disability research*.
- Michelle ,A. M, Elham, M., and Shoou-Yih,L., (2015). The intersection of disability and healthcare disparities: a conceptual framework. *Disabil Rehabil*, 2015; 37(7): 632–641 ! 2014 Informa UK Ltd. DOI: 10.3109/09638288.2014.9 38176

- Mugilwa, L. O., Wasala, W. O., & Oyugi, L. N. (2005). Health care service utilization in Kenya. Colombo, Sri Lank: Poverty and Economic Policy (PEP) Research Network's Poverty Monitoring, Measurement and Analysis (PMMA). Muskat, B., Burnham Riosa, P., Nicholas ,D.B., Roberts W. (2015) ; Autism comes to the hospital: The experiences of patients with autism spectrum disorder, their parents and health-care providers at two Canadian paediatric hospitals. *Autism*19(4):482–490. doi: 10.1177/1362361314531341. [[PubMed](#)] [[CrossRef](#)] [[Google Scholar](#)]
- Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., Boisclair, W. C. (2015). “Respect the way I need to communicate with you”: Healthcare experiences of adults on the autism spectrum. *Autism*, 19, 824-831.
- Nieswiadomy, R.M. (2008). *Foundations of Nursing Research*. Upper Saddle River, NJ: Pearson Education, Inc..
- Nordhaus, W. D. (2002). *The health of nations: the contribution of improved health to living standards*: National Bureau of Economic Research.
- Ormel, J., Lindenberg, S., Steverink, N., & Verbrugge, L. (1996). Subjective wellbeing and social production functions. *Social Indicators Research*, 46, 61-90. Oti boadi mabel. (2015). *Africentric wourld view and psychological health among primary caregivers and children with intellectual disability in Ghana*(Doctoral dissertation, university of ghana)
- Parahoo K. (2006) *Nursing Research Principles, Process and Issues*, 2nd edn. Palgrave Macmillan, Hampshire
- Penchansky R, Thomas JW. (1981). The concept of access: definition and relationship to consumer satisfaction. *Med Care*19: 127–40

- Polit D.F. & Beck C.T. (2010). *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*, (7th Ed). Wolters Kluwer Health | Lippincott Williams & Wilkins,
- Polit, D. & Hungler, B. (1999). Nursing Research. *Dimensions Of Critical Care Nursing*, 11(1), 63.
- Powell, H. and Kwiatek, E., (2006). Integrated care pathways in intellectual disability nursing. *Care Planning and Delivery in Intellectual Disability Nursing*. Blackwell Publishing, Oxford, pp.21-52.
- Rimmer, J. H., Riley, B., Wang, E., Rauworth, A., & Jurkowski, J. (2004). *Physical activity participation among persons with disabilities: barriers and facilitators*. *American journal of preventive medicine*, 26(5), 419-425.
- Rimmer, J.H., (1999). Health promotion for people with disabilities: the emerging paradigm shift from disability prevention to prevention of secondary conditions. *Physical therapy*, 79(5), pp.495-502.
- Robertson, J., Hatton, C., Baines, S. and Emerson, E., (2015). Systematic reviews of the health or health care of people with intellectual disabilities: a systematic review to identify gaps in the evidence base. *Journal of Applied Research in Intellectual Disabilities*, 28(6), pp.455-523.
- Royal College of Psychiatrists. (2012). Enabling people with mild intellectual disability and mental health problems to access healthcare services: College report. London: Author
- Schalock, R.L., Bonham, G.S. and Verdugo, M.A.(2008). The conceptualization and measurement of quality of life: Implication for program planning and evaluation

in the field of intellectual disabilities. *Evaluation and program planning*, 31(2), pp. 181-190

Scheer J., T. Kroll, M. T. Neri, P. Beatty. (2003). "Access barriers for persons with disabilities: the consumer's perspective". *Journal of Disability Policy Studies*, 13:221–230

Seligman M. E. P. & Csikszentmihalyi M. (2000) Positive psychology: an introduction. *American Psychologist* 55, 5–14.

Sheldrick , R.C., Neger,E.N., Shipman,D. and Perrin,E.C. (2012). Quality of life of adolescents with autism spectrum disorders: Concordance among adolescents 'self-reports, parents' reports, and parents' proxy report," *Quality of life research*, 21(1), pp. 53.57

Smith Diane L. (2008). "Disparities in health care access for women with disabilities in the United States from the 2006 National Health Interview Survey". *Disability and Health Journal* 1 :79-88

Sowney M, Barr OG.(2006) Caring for adults with intellectual disabilities: perceived challenges for nurses in accident and emergency units. *J Adv Nurs*. 55(1):36–45

Streubert H. J. & Carpenter D. R. (2010) *Qualitative Research in Nursing: Advancing the Humanistic Imperative*, 5th edn. Lippincott Williams & Wilkins, Philadelphia.

Szeftel, R., Federico, C., Hakak, R., Szeftel, Z., & Jacobson, M. (2012). Improved access to mental health evaluation for patients with developmental disabilities using telepsychiatry. *Journal of Telemedicine & Telecare*, 18(6), 317–321.

Thomas, C., (2007). Sociologies of disability and illness: Contested ideas in disability studies and medical sociology. Macmillan International Higher Education.

Thomas, R., & Barnes, M. (2010). Life expectancy for people with disabilities. *NeuroRehabilitation*, 27, 201-209.

Thompson A. R., Powis J. and Carradice A. (2008) Community mental health nurses' experiences of working with people who engage in deliberate self-harm: an interpretative phenomenological analysis. *International Journal of Mental Health Nursing* 17, 151–159

Tuffrey – Wijne, I./ Goulding, L., Giatras, N., Abraham, E., Gillard, S., White, S., Edwards, C and Hollins, S. (2014). The barriers to and enablers of providing reasonably adjusted health services to people with intellectual disabilities in acute hospitals: evidence from a mixed- methods study. *BMJ open*, 4(4), p.e004606.

Tuffrey-Wijne I, Goulding L, Giatras N, et al. (2014). The barriers to and enablers of providing reasonably adjusted health services to people with intellectual disabilities in acute hospitals: evidence from a mixed methods study. *BMJ Open* 2014

Tyler, C. V., Jr., Schramm, S., Karafa, M., Tang, A. S., & Jain, A. (2010). Electronic health record analysis of the primary care of adults with intellectual and other developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 7, 204-210.

Varas-Barlon, E., Janson, U. and Mufel, N. (2009) . Early childhood intervention , Special Education, and Inclusion: a focus on Belarus. UNICEF regional office for CEE/CIS.

- Ward,R.L., and Freedman, R.L., 2010. Uncovering healthcare inequalities among adult with intellectual and developmental disabilities. *Health and Social Work*, 35(4). pp.280-290.
- Weber (1990). 'An overview of content analysis.' *Practical Assessment, Research & Evaluation*. [Online] 7(17). Available from: <http://PAREonline.net/getvn.asp?v=7&n=17> [Accessed 14th December, 2018].
- Whittle,L,E., Fisher,R,K., Reppermund,S., Lenroot ,R., and Trollor,J (2018). Barriers and Enablers to Accessing Mental Health Services for People With Intellectual Disability: A Scoping Review, *Journal of Mental Health Research in Intellectual Disabilities*, 11:1, 69-102
- World Health Organization 2001, Mental and Neurological Disorders Fact Sheet, 2001, available at: http://www.who.int/whr/2001/media_centre/en/whr01_fact_sheet1_en.pdf. [Accessed on 18 April, 2019]
- World Health Organization (2011). World Report on disability Main Report (Malta ed., Vol. 1 of 2): World
- World Bank & WHO, 2011. World Report on Disability, Washington, DC. Available at:http://www.who.int/disabilities/world_report/2011/report.pdf.
- World healthorganisation 2011. Chapter 1. Understanding disability WHO. World report on disability. Malta : WHO, pp.3-17
- Wuang, Y.P. and Su, C.Y.,2009. Rash analysis of the Developmental Test of Visuomotor integration in children with intellectual disabilities. *Research in Developmental Disabilities*, pp. 1044-1053
- Wyszewiansk Leon. 2002. Access to care: Remembering old lessons. *Health Services Reseach* 37:6 1441-1443

Ziviani J (2004). Meeting in the middle: improving communication in primary health care consultations with people with intellectual disability. *J Intellect Dev Disabil* 29: 211–225.

Zukerman, K.E., Lindly, O.J., Bethell, C.D. and Kuhithau, K., 2014. Family impact among children with autism spectrum disorder: the role of health care quality. *Academic paediatrics*, 14(4), pp.398-407.



APPENDICES

Appendix 1: Interview guide

I am Dorcas Addo, an MPHIL. Student of Disability, Rehabilitation and Development

I am conducting a study on Barriers and Facilitators to Healthcare Access for People with intellectual disability (PWIDS) in the Ashanti Region of Ghana and your participation in this study is highly appreciated. Your participation in the study is purely voluntary and information given will be used solely for academic purposes and your identity is protected in reporting the results.

SO1: To explore the health needs of persons with intellectual disability in the Kumasi Metropolis

What general health needs do you present to health centres for treatment?

What specific health needs do you seek treatment for?

What would trigger these needs?

How do you present these health needs to healthcare providers?

How effectively or adequately are these health needs taken care of by health personnel?

In what ways do these health needs impact on your life as a person with intellectual disability?

SO2: To identify the challenges Persons with Intellectual Disability encounter in accessing health care in the Kumasi Metropolis

What barriers do persons with intellectual disability encounter in accessing health?

In what ways do these barriers influence access health?

How often are these barriers encountered?

In which units of health centres are these barriers mostly encountered?

In what ways do PWIDs cope with these barriers?

How effective have the coping mechanisms been for PWIDS?

What could be done address these challenges?

SO3: To ascertain the experiences of health care professionals in providing health care for persons with intellectual disability in the Kumasi Metro

How often do you provide health services for PWIDS?

What is the nature of health services you usually provide for PWIDS?

What challenges do you encounter in the provision of services for PWIDS?

In what ways do these challenges influence the services you provide for them?

What coping mechanisms do you employ to deal with these challenges?

What can be done to effectively address the challenges encountered?

SO4: To explore enablers to health care for persons with intellectual disability in the Kumasi metro.

What services are provided at health centres to facilitate PWIDs access to health?

Which of these services mostly facilitates health access for PWIDs?

In what ways do these services promote access to health for PWIDs?

In which units of health service provision are access to health mostly facilitated for PWIDs?