

**ENSIGN COLLEGE OF PUBLIC HEALTH, KPONG,
EASTERN REGION, GHANA**

**PARENTS' PERCEPTION ON THE QUALITY OF CARE FOR
CHILDREN WITH INTELLECTUAL DISABILITY BY
HEALTHCARE PROFESSIONALS IN THE ADENTA
MUNICIPALITY, GHANA**

by

DEBBIE MANGORTEY

177100115

**A thesis submitted to the Department of Community Health in
the Faculty of Public Health in the partial fulfilment of the
requirement of the degree**

MASTER OF PUBLIC HEALTH

JUNE, 2019

DEDICATION

This is dedicated to the Almighty God, who granted me the knowledge, strength, courage and endurance to go through this program.

I also dedicate this thesis work to my children, Michelle Miller and Kofi Entsi Yankson, for sacrificing family time with me to enable me to go through this program. This is also dedicated to these individuals because, our peculiar situation as a family, provide some input into the knowledge I gained throughout this program.

This is also dedicated to the nannies I had within the period who helped with the care of Kofi whiles I was away in school – Joyce Tetebea, Mary Libowl and Victoria Amoah. And to every individual who contributed to this achievement, I am grateful.

ACKNOWLEDGEMENT

I am grateful to God for the strength, knowledge, courage, and endurance to undertake this study. My sincerest thanks go to my academic supervisor; Dr. Reuben Esena for his invaluable guidance, patience, and supervision during the study. I will also like to thank my family, my children, Michelle Miller, and Kofi Entsi Yankson for their support and understanding to enable me to go through this program.

My sincere thanks further go to Dr. Dadebo, the Municipal Health Director of Adentan and all the staff of the Amanfro and Nii Ashale Health Centres who contributed to my data collection, especially Ophelia. Special appreciation to Dr. Sharon Talboys, Dr. Edith Tetteh, Emmanuel Kofi Bondah, Emmanuel Brimpong and all my classmates, friends and relatives for their individual support all throughout this study.

I will also like to thank the families that shared their experience of the health system with me as well as the health workers who shared their experience and knowledge on the care of children with intellectual disabilities with me. Thank you and God bless you all.

DEFINITION OF TERMS

- Autism Spectrum Disorders:** A condition related to brain development that impacts how a person perceives and socializes with others, causing problems in social interaction and communication. The disorder also includes limited and repetitive patterns of behaviour.
- Activities of Daily Living:** Routine activities people do every day without assistance. There are six basic ADLs: eating, bathing, getting dressed, toileting, transferring and continence.
- Attention Deficit and Hyperactive Disorders:** A chronic condition including attention difficulty, hyperactivity and impulsiveness.
- Community-Based Rehabilitation program:** A community development strategy that aims at enhancing the lives of persons with disabilities (PWDs) within their community.
- Cerebral palsy:** A problem that affects muscle tone, movement, and motor skills. Often is caused by brain damage that happens before or during a baby's birth, or during the first 3-to-5 years of a child's life.
- Down syndrome:** A genetic disorder caused when abnormal cell division results in extra genetic material from chromosome 21 which causes a distinct facial appearance, intellectual disability, and developmental delays. It may be associated with thyroid or heart disease.
- Early intervention services:** Early intervention services are a range of targeted **services** to help young children who have developmental delays or specific health conditions.
- Intelligent Quotient:** An IQ of 100 means that the child's chronological and mental ages match. Traditionally, IQ scores of 90–109 are considered average; scores below 70 indicate mental retardation.

Intermediate Care Facility: A health-related facility designed to provide custodial care for individuals unable to care for themselves because of mental or physical infirmity.

West Syndrome: A severe epilepsy syndrome composed of the triad of infantile spasms, an interictal electroencephalogram (EEG) pattern termed hypsarrhythmia, and mental retardation.

LIST OF ACRONYMS

AAMR	American Association on Mental Retardation
ADD	Action on Disability and Development
ADHD	Attention Deficit and Hyperactive Disorders
ADL	Activities of Daily Living
AIDS	Acquired Immune Deficiency Syndrome
ASD	Autism Spectrum Disorders
CBR	Community-Based Rehabilitation program
CHRI	Commonwealth Human Rights Initiative
CP	Cerebral palsy
CRPD	Convention on the Rights of Persons with Disabilities
DACF	District Assembly Common Fund
DS	Down syndrome
GFD	Ghana Federation of Disability Organizations
GP	General Practitioner
GSGDA	Ghana Shared Growth and Developmental Agenda
HIV	Human Immunodeficiency Virus
ICF	Intermediate Care Facility
ICS	Individualized Care Scale
IDD	Intellectual and Developmental Delays/Disabilities

IQ	Intelligent Quotient
NGO	Non-Governmental Organizations
PWD	Persons with Disabilities
PWID	Persons with Intellectual Disabilities
QOCS	Quality of Care and Support
UN	United Nations
WD	West Syndrome
WHO	World Health Organization

ABSTRACT

Persons born with intellectual and developmental delays tend to have additional health needs that are not met at the primary health level because of lack of facilities, limited knowledge and skills of the health personnel at that level to be able to support such families adequately. This puts barriers of access to health care in the ways of such families. This study seeks to suggest ways of addressing these barriers to make the 'health for all' meaningful to such families.

The study design was a qualitative cross-sectional one. Sixteen (16) participants were interviewed for this study using a self-structured in-depth interview guide to get their perception of the quality of health care delivery for children with intellectual disabilities. The participants were made up of nine (9) health and allied health workers and seven (7) parents of children with different types of intellectual and developmental delays. The analysis was conducted using the Dedoose online analysis software to code the themes that are discussed in the results section of this study.

The results of the study showed that the health needs of children with intellectual and developmental delays are multifaceted and requires a multi-disciplinary team to address these. We also found out that there is a knowledge gap for the health care professionals at the primary health level when it comes to the care of children with intellectual disabilities. This study also brought to the fore that when parents/carers of these children don't get the needed care/support from the health system, they resort to traditional and religious sources of care.

The study concludes that the Ghana Health Service works through the District and Municipal Directors of Health Services to begin to build the capacities of the health personnel at the CHPS and health centre levels to be able to achieve the universal access to health for all through the primary health care system, by providing the targeted care for these children and their families.

Table of Contents

Chapter 1	1
Introduction.....	1
1.1 Background of Study	1
1.2 Problem Statement.....	2
1.3 Relevance of the Study	3
1.4 Research Questions.....	4
1.5 General Objectives.....	5
1.6 Specific objectives	5
1.7 Profile of Study Area	6
1.8 Scope of Study	7
1.9 Organization of Report	7
Chapter 2.....	8
Literature review.....	8
2.1 Introduction.....	8
2.2 International Conventions of Disability.....	8
2.3 Challenges faced with people with physical disabilities in their working life.....	8
2.4 Mental retardation (Intellectual Disability).....	9
2.4.1 Classification of Intellectual Disability.....	10
2.5 Early Signs and symptoms of intellectual disability.....	15
2.5.1 Causes of ID.....	16
2.5.1 Environmental Factors	17
2.6 Intelligence quotient.....	20
2.7 Adaptive behaviour.....	20
2.8 Health Care and Disability.....	23
2.9 Barriers to health-care services for people with disabilities	24
2.9.1 Physical and geographical barriers.....	24
2.9.2 Communication and information barriers	24
2.10 Inclusive health	25
2.11 CBR and the health sector.....	26
2.11.1 Health promotion	26
2.11.2 Prevention	26
2.11.3 Medical care.....	27
2.11.4 Rehabilitation.....	27
2.11.5 Assistive devices	27
2.12 Attitudes Towards Persons with Disability in Ghana	27
2.12.1 Policies supporting disability in Ghana.....	28
2.13 Prevalence of intellectual disability in Ghana.....	32

2.13.1 Intellectual Disability and Age in Ghana	33
2.13.2 Intellectual Disability and Marital Status in Ghana	33
2.13.3 Intellectual Disability and Educational Characteristics In Ghana.....	33
2.13.4 Intellectual Disability and Region of Residence	33
2.13.5 Intellectual Disability and Ethnicity.....	34
Chapter 3.....	37
Methodology	37
3.1 Introduction.....	37
3.2 Data Collection Techniques and Tools	37
3.3 Study Population.....	38
3.4 Study Variable	38
3.5 Sampling techniques	39
3.6 Pre-testing	39
3.7 Data Analysis	39
3.8 Ethical Consideration.....	40
3.9 Limitations of Study	40
Chapter 4.....	41
Results.....	42
4.1 Introduction.....	42
4.2 Demographic characteristics of participants	42
4.3. Objective 1: Healthcare needs of children with intellectual and developmental delays	43
4.3.1 Physical health needs	43
4.3.2 Clinical health needs	44
4.3.3 Psychosocial health needs.....	45
4.4 Objective 2: Health workers' knowledge and perception of the processes of management of the health needs of children with intellectual disabilities	45
4.4.1 Types and frequently seen disabilities	45
4.3.2 Health worker assessment of children with disabilities	47
4.3.3 Types of services offered and perception of quality of care	47
4.4 Objective 3: Healthcare barriers confronting quality of care for children with intellectual and developmental disabilities.....	49
4.4.1 Cost of care	49
4.4.2 Perceptions and attitudes to disability.....	49
4.5. Objective 4: Alternative forms of care for children with Intellectual and developmental disabilities	50
Chapter 5.....	52
Discussion	52
5.1 Introduction.....	52
5.2 Health Needs of children with Intellectual and Developmental Delays	52

5.3 Perception of the quality of care	53
5.4 Healthcare barriers	54
Chapter 6.....	57
Conclusion and recommendations	57
6.1 Introduction.....	57
6.2 Conclusion	57
6.3 Recommendations.....	58
References.....	60
Appendices.....	67

LIST OF TABLES

Table 1	Characteristics of study participants – health workers	-	43
Table 2	characteristics of study participants – parents	-	44
Table 3	Description of disabilities by health workers	-	47

LIST OF APENDICES

Participant Consent form	-	67
Interview guide	-	68-69
Ethical Board approval	-	70

CHAPTER 1

INTRODUCTION

1.1 Background of Study

Healthcare access is important for every individual both abled and disabled because a healthy person can work effectively to contribute to the development of his nation. When an individual's health needs are met, there is a positive thinking about their future and attainment of proper welfare (Nordhaus, 2012). Life expectancy will improve as individuals experience quality and accessible healthcare (Mugilwa *et al.*, 2015, Marmot *et al.*, 2008). To achieve this, policy makers and stakeholders will have to put in place policies that will meet international regulations for quality healthcare. This is captured in the 1948 Constitution of the World Health Organization (WHO) that, "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being" (WHO, 1948)

To this effect, the Community-Based Rehabilitation (CBR) programme developed by the WHO highlights five important components of health services for Persons with Intellectual Disability (PWIDs). These services are health promotion, prevention, equal medical care, rehabilitation, and assistive devices. These components can improve healthcare for Persons with Intellectual Disability (PWIDs) to ensure sustainable development through accessible and proper linkages between PWIDs and the health systems (WHO, CBR 2010).

However, healthcare utilization among PWIDs differs dramatically across countries and communities. In every society, PWIDs lag other citizens in accessing quality healthcare (Rimmer *et al.*, 2014). This problem is common to the intellectually disabled children in Africa and most developing countries and widens the access gap between themselves and their counterparts in the developed world (ADD, 2015). Many explanations that support these problems point out that disabled persons are classified as being among the poorest of the poor

and seen as unproductive and a burden to society. They, therefore, lack access to public health and other social services that will improve their wellbeing. Specialists with knowledge on disability-related issues are also lacking and hence special needs pertaining to their health are not seriously addressed (Elwan, 1999). More importantly, physical proximity like transportation and patient's ability to afford health services constitute the two major reasons why PWIDs around developing countries do not obtain quality healthcare from healthcare providers (WHO, 2013, Peters *et al.*, 2008).

Families of Persons with Intellectual Disability (PWIDs) face numerous physical, communication, attitudinal, financial, administrative, and organizational barriers within health care settings (Lawthers *et al.*, 2003; Lin, Lin, & Lin, 2010). Compared to those without disabilities, disabled people are more likely to report inadequate care, incomplete understanding of their conditions, poor communication, and lack of confidence in their physicians as well as less use of preventive services (Chan *et al.*, 2008; Iezzoni *et al.*, 2003). Overall, people with disabilities are less satisfied with their health care than others (Harris Interactive Inc., 2010; Shin & Moon, 2008). These disparities exist despite a consensus that full and equal treatment based on need should not be merely an aspiration: it is a right (Nocon & Sayce, 2008).

1.2 Problem Statement

In residential areas as an example, important stakeholders in service quality are service users (PWIDs), their parents and families, the professionals who provide the care service and the managers of centres where the care is given. Registered Mental Handicap Nurses (RMHN), are one group of professionals trained to provide frontline care for people with intellectual disabilities across their lifespan. Most nurses who work in these residential centres provide hands-on care to clients with wide-ranging needs twenty-four hours a day. While they work as

part of a multidisciplinary team, they are responsible for the care they provide as well as for the quality of that care. Although they collaborate with other professionals and liaise with the families of clients, nurses are the professionals who provide the continuous day-to-day care for clients. In addition to their responsibility for nursing care, nurses are also likely to be important mediators of the interventions other professionals provide for clients since in many cases it is the nurse that will implement and help evaluate many of these.

Despite these considerations, there is a lack of information on what nurses do for clients, if their care is guided or influenced by any ideology or model, or of how they perceive their level of participation in overall service quality. Little information exists on the dimensions of care they see as important or the approach they adopt to evaluating their care of clients. For example, various dimensions and attributes of quality have been identified in the literature (Felce & Perry 2015, Maes *et al.*, 2010, Alaszewski *et al.*, 2011), but whether nurses recognize these or see them as important is not known especially within the Ghanaian context, as very few studies on nursing quality for PWIDS has far been published.

It is obvious to note that vulnerable groups including PWIDs have differential needs in accessing healthcare. Yet, there is lack of recognition by stakeholders to specifically identify the differences in need. This implies that policy makers find it difficult to incorporate the needs of a person's disability into policy documents and integrate them into the implementation process. This study is thus being conducted to address this gap.

1.3 Relevance of the Study

The rationale and justification for this study is grounded in the foregoing discussion, the expanding role of healthcare professionals' care for people with intellectual disabilities, and the involvement of the nurse and care givers as the frontline provider of care. The researcher acknowledges that families, other professional groups and service managers all share an

involvement in service quality. However, because the healthcare professionals provide the frontline personal and continuous care for clients, this study is focused on them. Issues and influences that affect care givers providing quality of care for clients.

Findings from this study would promote inclusive healthcare policies that will reveal critical supports pertaining to healthcare of PWIDs. It will inform policy planners to jointly factor disable and non-disables into healthcare policy rather than competing for limited funds.

It will also fill knowledge and literature gap on healthcare accessibility barriers confronting PWIDs for students, researchers, academicians and all other stakeholders in Ghana, Africa and the world at large.

Furthermore, findings from this study will aid families in which there is a person with intellectual disability to understand the ways they can cope with their affected relatives and to strengthen positive attitudes towards relatives with such impairment.

1.4 Research Questions

The objectives raised above under the research study will be guided by the following research questions;

1. What are the healthcare needs of persons with intellectual disabilities?
2. What are primary health workers' knowledge and experience on the care for persons with intellectual disabilities?
3. What are the barriers of care for persons with intellectual disabilities?
4. Which alternative forms of care are available to children with intellectual disabilities other than the public health systems?

1.5 General Objectives

To assess the perception of quality of care by parents of children with intellectual disabilities by health professionals, especially at the primary healthcare levels.

1.6 Specific objectives

The specific objectives are to:

- i. identify the healthcare needs of persons with intellectual disabilities.
- ii. describe nurses' perceptions of the process of healthcare management of children with intellectual disabilities.
- iii. explore the healthcare barriers confronting quality of care for children with intellectual disabilities.
- iv. identify alternative forms of care available other than the public health systems on the quality of care of children with intellectual disabilities.

1.7 Profile of Study Area

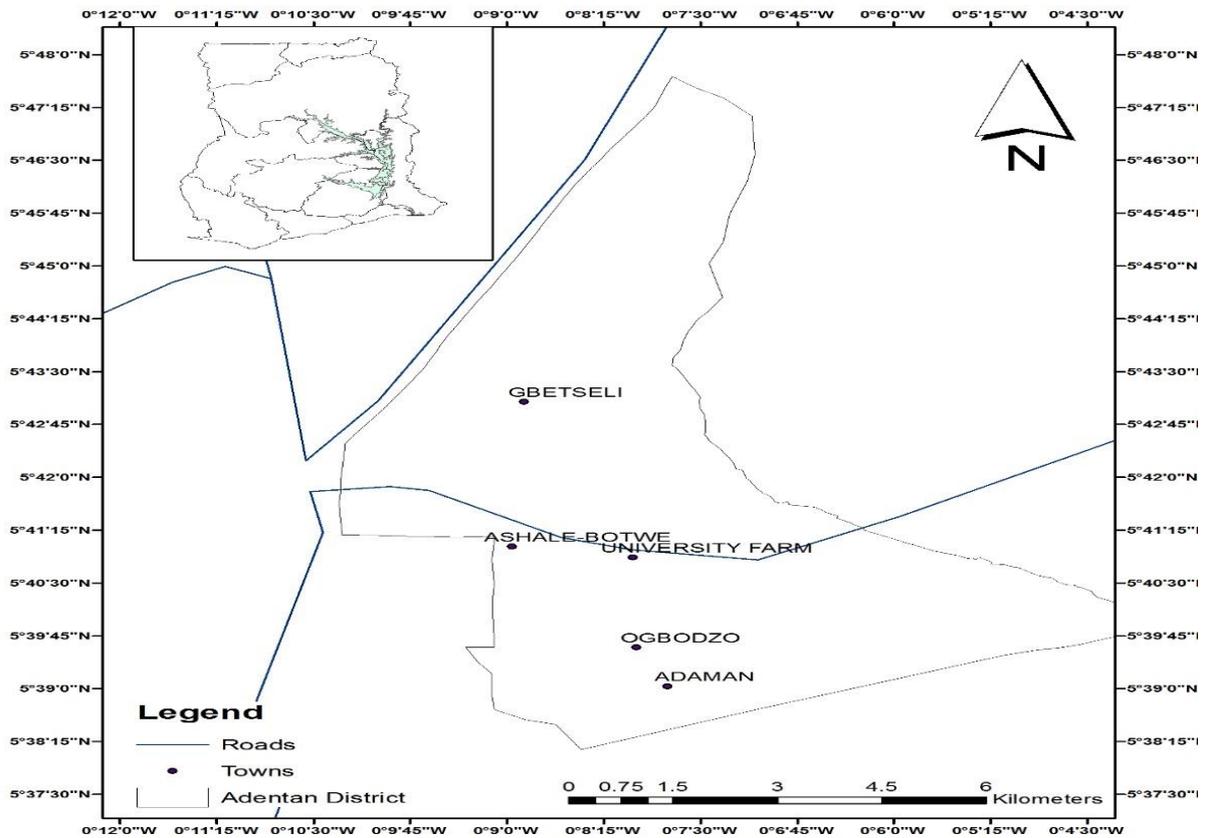


Fig. 1 Map of the Adentan Municipality

The Adentan Municipal is in the Greater Accra Region of Ghana (Fig. 1). Its capital is Adentan East. It is situated close to La Nkwantanang Madina Municipal District, Kpone Katamanso District, Tema Metropolis District, and Krowor Municipal. Report from the 2010 National Population and Household Census indicated the total area is about 92.84 square kilometres and the population of the district is 78,215 with 39,366 males and 38,849 females (Ghana Statistical Service, 2012)

The Municipal Assembly is currently divided into four Zonal Councils namely: Gbentaana, Koose, Sutranaa, and Nii Ashale.

1.8 Scope of Study

The study was conducted in the Adentan Municipality of the Greater Accra Region of Ghana. The municipality is divided into four sub-municipalities for effective health planning and service delivery. The study focused on the knowledge of and perception of disability by health workers and whether these affect the quality of care delivered to families caring for children with intellectual and developmental delays. The study also sought to understand parents and caregivers' knowledge and understanding of the various disabilities their children are living with and whether they understand what to expect from the health systems and their perception of the quality of service delivery for them.

1.9 Organization of Report

The study is divided into six main chapters. The first chapter describes the background, problem statement, rationale, conceptual framework as well as the research questions and objectives of the study. It also includes the profile of the study site, the scope of the study as well as the organisation of the study. The second chapter focuses on the literature review related to studies/work or reports that had been done by other people in this study area. The third chapter looks at the methodology employed, the study population and the data collection tools used. The fourth chapter is for the reporting of the findings revealed from the study. Chapter five discusses the findings in chapter four in relation to the research questions, objectives and literature review. Chapter six will be used to draw the conclusions of the study and give recommendations for stakeholders of the study area.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter presents an overview of available literature on intellectual disability and addresses studies on intellectual disability. Furthermore, it reviews literature on the perception of people on individuals with intellectual disability and how health professionals care for such individual. These are presented as follows:

2.2 International Conventions of Disability

Article 1 of the UN Convention on the Rights of Persons with Disabilities and Optional Protocol states that “The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”. This Convention was formulated on the 13 December 2006. On the other hand, the Commonwealth Human Rights initiative also stated firmly that each member states and parties are to ensure that they follow the slated down conventions (Liker, 2009).

2.3 Challenges faced with people with physical disabilities in their working life

Research work by Yvonne Zimba (2015) makes it evident that people with disabilities have the same health needs as non-disabled people especially for immunization, cancer screening among others. People with disabilities have the same health needs as non-disabled people – for immunization, cancer screening, etc. They also may experience a narrower margin of health,

both because of poverty and social exclusion, and because they may be vulnerable to secondary conditions, such as pressure sores or urinary tract infections. Evidence suggests that people with disabilities face barriers in accessing the health and rehabilitation services they need in many settings.

Disability is the loss of the ability to partake equally in societal and environmental activities due to social and environmental barriers. This condition is significantly impaired relative to the usual standard of individuals or groups. This condition cuts across individual functioning, including physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness, and various types of chronic disease.

Other definitions have it that disability is conceptualized as being a multidimensional experience for the person involved. There may be effects on organs or body parts and there may be effects on a person's participation in areas of life. Congruently, three main dimensions of disability are known in ICF: body structure and function (and impairment thereof), activity (and activity restrictions) and participation (and participation restrictions).

The classification also recognizes the role of physical and social environmental factors in affecting disability outcomes.

2.4 Mental retardation (Intellectual Disability)

The American Association on Mental Retardation (AAMR) defines mental retardation (MR) as a disability characterized by major limitation to intellectual functioning and adaptive behaviour. This is usually seen in the conceptual, social, adaptive skills of an individual. This is seen most often in children below the ages of 18 years and exhibits severe problems in the individual's capacity and ability to perform functions that affect participation in activities of the child (Esmaceli-Nieh and Sherr, 2014). Intellectual disability can also be referred to as mental retardation. This condition impairs the skills of an individual during the development

period. Due to arrest or incomplete development of the mind, cognitive, language, motor, and social abilities are malfunctioned.

Disability can occur with or without any other mental or physical disorder. On the other hand, individuals that are intellectually retarded can experience the full range of mental disorders, and the prevalence of other mental disorders is at least three to four times greater in this population than in the general population. However, individuals that are intellectually disabled are at a greater risk of physical and sexual abuse. Adaptive behaviour is always impaired, but in protected social environments where support is available, this impairment may not be at all obvious in subjects with mild mental retardation.

Intellectual disability can be broken down into two main categories. These are syndromic intellectual disability, in which intellectual deficits associated with other medical and behavioural signs and symptoms are present. The other condition is the non-syndromic intellectual disability, in which intellectual deficits appear without other abnormalities. Examples include down syndrome and fragile X syndrome are examples of syndromic intellectual disabilities.

Research has shown that Intellectual disability affects about 2–3% of the general population. (Vasconcelos, 2004). Seventy-five to ninety percent of the affected people have mild intellectual disability on-syndromic or idiopathic cases account for 30–50% of cases. About a quarter of cases are caused by a genetic disorder, and about 5% of cases are inherited from a person's parents. Cases of unknown cause affect about 95 million people as of 2013 (Ardinger *et al.*, 2000).

2.4.1 Classification of Intellectual Disability

Individuals suffering from intellectual disability usually have several problems. In order to adequately address these issues, several diagnoses have been used to classify these problems. This is done by addressing the mental degree of mental retardation by recording the presence

of associated physical and mental disorder, to record the degree of psychosocial disability, and to note the psychosocial situations. According to the International Classification of Disease (ICD)-10 guide for mental retardation (World Health Organisation, 1996) the factors were recorded in a systematic and orderly way using a multiaxial system. The axes in a multiaxial system are means of recording different kinds of features of the case, the following axes form the structure of the ICD scheme of classification for the mentally retarded.

Axis I: Severity of retardation and problem behaviours

Axis II: Associated medical conditions

Axis III: Associated psychiatric disorders

Axis IV: Global assessment of psychosocial disability

Axis V: Associated abnormal psychosocial situations

2.4.1.1 Axis I: - Severity of Retardation and Problem Behaviours

This axis is used to record codes from Section F7 of the classification. The severity of retardation is recorded with a second digit code (F70 to F79).

It is possible to record problem behaviours by using a decimal place code. In ICD-10 abnormal behaviour associated with mental retardation can be specified in only three ways as none or minimal (x.0); significant, requiring attention or treatment (x.1); or 'other' (x.8). In this guide, 6 additional second decimal codes have been provided to record the type of behaviour when x.1 (significant) is employed. These additional codes are described at the end of this section.

The coding for the degree of mental retardation are:

- **F70** - Mild Mental Retardation
- **F71** - Moderate Mental Retardation
- **F72** - Severe Mental Retardation
- **F73** - Profound Mental Retardation
- **F78** - Other Mental Retardation

- **F79** - Unspecified Mental Retardation.

2.4.1.2 Mildly retarded

These individuals learn languages with some delay, but most achieve the ability to use speech for everyday purposes, to hold conversations, and to engage in the clinical interview.

Most of them are dominant in the self-care such as eating, washing, dressing, bowel and bladder control. Their main challenge with their academic work in school particularly reading and writing. Nevertheless, they can be helped by education intended to develop their skills and compensate for their handicaps.

Most of those in the higher ranges of mental retardation are potentially capable of work demanding practical rather than academic abilities, including unskilled or semi-skilled manual labour. However, if there is also a noticeable emotional and social immaturity, the consequences of the handicap, e.g. inability to cope with the demands of marriage or child-rearing, or difficulty fitting in with cultural traditions and expectations, will be apparent.

In general, the behavioural, emotional, and social difficulties of the mildly mentally retarded, and the needs for treatment are more closely akin to those found in people of normal intelligence than to the specific problems of the moderately and severely retarded.

2.4.1.3 Moderate mental retardation

Clinical Description

These individuals are slow in the use of language and comprehension development. They need a lot of supervision since self-care and motor skills are also delayed thereby affecting their achievements. Progress in school work is limited, but a proportion of these individuals learn the basic skills needed for reading, writing, and counting. In order to help this group of people, educational platforms can be made available for them to develop their limited potential and to acquire some basic skills; such programmes are appropriate for slow learners with a low ceiling

of achievement. As adults, moderately retarded people are usually able to do simple practical work, if the tasks are carefully structured and skilled supervision is provided. Completely independent living in adult life is rarely achieved. Generally, however, such people are fully mobile and physically active and the majority show evidence of social development in their ability to establish contact, to communicate with others, and, to engage in simple social activities.

Diagnoses of such people have indicated that the IQ is usually in the range 35 to 49. Discrepant profiles of abilities are common in this group, with some individuals achieving higher levels in visuospatial skills than in tasks dependant on language, while others are markedly clumsy but enjoy social interaction and simple conversation. The level of development of language is variable: some of those affected can take part in simple conversations while others have only enough language to communicate their basic needs. Some never learn language, though they may understand simple instructions and may learn to use manual signs to compensate to some extent for their speech disabilities.

Disabilities such as childhood autism or other pervasive developmental disorders are present in small percentages and have a major effect upon the clinical picture and the type of management needed. Aside that Epilepsy and neurological and physical disabilities are also common, although most moderately retarded people can walk without assistance. It is sometimes possible to identify other psychiatric conditions, but the limited level of language development may make diagnosis difficult and is dependent upon information obtained from others who are familiar with the individual.

2.4.1.4 Severe mental retardation

This category is broadly like that of moderate mental retardation in terms of the clinical picture, the presence of an organic aetiology, and the associated conditions. The lower levels of achievement mentioned under F71 are also the most common in this group. Most people in this

category suffer from a marked degree of motor impairment or other associated deficits, indicating the presence of clinically significant damage to or maldevelopment of the central nervous system.

2.4.1.5 Profound mental retardation

Indicates that the IQ in this category is estimated to be under 20, which means in practice that affected individuals are severely limited in their ability to understand or comply with requests or instructions. Most such individuals are immobile or severely restricted in mobility, incontinent, and capable at most of only very rudimentary forms of nonverbal communication. They possess little or no ability to care for their own basic needs and require constant help and supervision.

Diagnostic studies have shown that IQ is under 20. Comprehension and use of language is limited to, at best, understanding basic commands and making simple requests. The most basic and simple Visio spatial skills of sorting and matching may be acquired, and the affected person may be able with appropriate supervision and guidance to take a small part in domestic and practical tasks. Pervasive developmental disorders in their most severe form, especially atypical autism, are particularly frequent, especially in those who are mobile.

2.4.1.6 Other mental retardation

This category should be used only when assessment of the degree of intellectual retardation by means of the usual procedures is rendered particularly difficult or impossible by associated sensory or physical impairments, as in blind, deaf-mute, and severely behaviourally disturbed or physically disabled people.

2.4.1.7 Unspecified mental retardation

There is evidence of mental retardation, but insufficient information is available to assign the patient to one of the above categories.

Diagnostic Intellectual disability (ID) begins during childhood and involves deficits in mental abilities, social skills, and core activities of daily living (ADLs) when compared to same-aged peers. There often are no physical signs of mild forms of ID, although there may be characteristic physical traits when it is associated with a genetic disorder (e.g., Down syndrome). The level of impairment ranges in severity for each person.

2.5 Early Signs and symptoms of intellectual disability

1. Delays in reaching or failure to achieve milestones in motor skills development this includes sitting, crawling, walking,
2. Slowness learning to talk or continued difficulties with speech and language skills after starting to talk,
3. Difficulty with self-help and self-care skills (e.g., getting dressed, washing, and feeding themselves),
4. Poor planning or problem-solving abilities, Behavioural and social problems,
5. Failure to grow intellectually or continued infant-like behaviour,
6. Problems keeping up in school, Failure to adapt or adjust to new situations
7. Difficulty understanding and following social rules

Mild ID (IQ 50–69) may not be very evident in childhood until children begin school (Even when poor academic performance is recognized, it may take an expert assessment to distinguish mild intellectual disability from a specific learning disability or emotional/behavioural disorders. People with mild ID are capable of learning reading and mathematics skills to approximately the level of a typical child aged nine to twelve. Self-care and practical skills, such as cooking or using the local mass transit system can easily be learnt. As individuals with

intellectual disability reach adulthood, many learn to live independently and maintain gainful employment

Moderate ID (IQ 35–49) is approximately always obvious within the first years of life. Speech delays are particularly common signs of moderate ID. People with moderate intellectual disability need considerable supports in school, at home, and in the community in order to fully participate. While their academic potential is limited, they can learn simple health and safety skills and to participate in simple activities. As adults, they may live with their parents, in a supportive group home, or even semi-independently with significant supportive services to help. As adults, they may work in a sheltered workshop

2.5.1 Causes of Intellectual Disability

Research has it that approximately 3% of the whole population of the world has IQ level less than 70 (23). Although many genes that are involved in MR have been mapped yet the causes of MR in almost 50 % of MR cases are unknown. 5.1% of the MR patients are affected with fragile X syndrome. There are many factors which are responsible for MR. These factors include environmental factors, genetic factors, malnutrition, maternal use of alcohol during pregnancy, drug, and poverty. These factors are categorized under the heading of behavioural or social factors. (Muhammad Iqbal *et al*, 2016)

Congenital dysfunction of the brain, injury of the brain during the critical period of prenatal or postnatal development may also be responsible for MR. MR may also be the result of near drowning, traumatic brain injury and central nervous system malignancy. In industrial nations 1 to 7 in 1000 MR births is because of Foetal Alcohol Syndrome. It is the most common cause of MR in these nations. The second leading reason of MR is Down's syndrome. It is also termed as trisomy of chromosome number 21. The incident rate of Down's Syndrome is 1 in 700 births. One of the important factors responsible for genetic disorders is consanguineous marriages.

The study of genetic disorders like MR becomes very easy in the regions where the rate of cousin marriages is very high.

2.5.1 Environmental Factors

2.5.1.1 Prenatal Problems

The Stage of foetus development is a critical stage during pregnancy this occurs in the first trimester of the pregnancy. Mothers with fever for a long period during this stage may have their babies affected. Infectious agents such as human immunodeficiency virus, Rubella, herpes, syphilis, and cytomegalovirus may also cause MR if the mother is infected with any of these infectious agents during pregnancy. Abnormal developmental of the foetus may cause MR in the foetus. Subsequently, postnatal exposure of infant to heavy metals such as lead can cause MR in infant. This postnatal exposure is very critical in infants who have low birth weight. Phenylketonuria (PKU) which itself is a genetic disorder but if it is untreated in infectious mothers it may also result in MR in the foetus. Drugs such as alcohol by the pregnant mother may also cause MR in the baby.

2.5.1.2 Neonatal Problems

Neonatal periods include late pregnancy, during delivery and first four weeks of life. Any problem during these processes may result in MR. Complications of pregnancy, kidney disease, heart disease and diabetes in mother may result in MR in children.

Birth asphyxia, birth trauma, complicated delivery, severe prematurity, and very low birth weight are delivery perinatal problems, which may result in MR. Problems such as severe jaundice, hypoglycemia, and septicaemia during this neonatal period may result in MR.

2.5.1.3 Postnatal Problems

This period involves infants and childhood. Problems such as Japanese encephalitis, Bacterial meningitis, Tuberculosis, head injury, prolonged malnutrition and chronic lead exposure during this period may result in MR.

2.5.1.4 Exposure to Certain Types of Toxins or Diseases

Exposure to heavy metals like mercury and lead may also responsible for MR. On the other hand, some infectious diseases such as meningitis, whooping cough, measles, etc. if not treated properly may result in MR. Iodine Deficiency is affecting approximately two billion people in the world. Iodine deficiency in mother during pregnancy restricts the growth of brain of the fetus which leads to hypothyroidism and because of this deficiency, the affected fetus will be mentally retarded because of the restricted brain growth.

2.5.1.5 Malnutrition

Malnutrition is also a very important cause of MR. This affects the child's mental ability especially for people in deprived areas. Because of famines, people face the problem of nutritional deficiency which ultimately results in mental retardation.

2.5.1.6 Metabolic Disorders

Metabolic disorders are arisen because of the missing of one or more key enzymes in the metabolism of different substances. These metabolic disorders along with other problems may also cause MR. For example, PKU is a metabolic disorder which is the result of point mutation. With the advancements in the field of molecular medicine metabolic disabilities can be prevented with early treatment.

2.5.1.7 Down syndrome

Down syndrome, or trisomy, is the most frequent cause of MR, with an incidence of approximately 1:800 live births. More than 90% of cases result from maternal nondisjunction,

but some cases originate from translocation or mosaicism. Some studies reveal that up to 20% of children with MR suffer from Down syndrome (41). Affected children have an average IQ of 50, and diagnosis often is based on clinical findings, such as simian crease, hypotonia, epicanthal folds, flat occiput, macroglossia, up slanting palpebral fissure, absence of startle reflex in the neonatal period, increased space between the great toe and second toe, and congenital heart diseases, such as endocardial cushion defect and ventricular septal defect. Karyotyping is essential for confirming the diagnosis and determining the underlying genetic mechanism.

2.5.1.8 Foetal alcohol syndrome

The foetal alcohol syndrome consists of a group of physical, behavioural and cognitive disorders observed in children exposed to alcohol while still in utero. It is one of the most common causes of MR in industrialized countries, with up to 8% of MR cases being affected. Clinical features of this syndrome include typical facies, thin upper lip, flat and long philtrum short palpebral fissures, ptosis, upturned nose, and flat midface. Additional characteristics are cleft palate, prenatal and postnatal growth delay, microcephaly, agenesis of the corpus callosum, congenital heart disease, and behavioural disorders.

Exposure during the first trimester of pregnancy interferes with organ formation and craniofacial development, whereas the development of the central nervous system is influenced throughout pregnancy due to continued neuronal maturation. The pathophysiology of this syndrome is not fully understood yet, but it seems to be related to the formation of free radicals with consequent cellular injury to developing tissues. Furthermore, evidence shows that early diagnosis and medications can help reduce secondary deficiencies.

2.6 Intelligence quotient

The degree of Intellectual disability is categorized by IQ scores. Intellectual quotients depend on intelligent scales. The Stanford–Binet Intelligence Scales, was the first English IQ test which was adapted from a test battery designed for school placement by Alfred Binet in France. Terman's test was also one of the first widely used mental tests to report scores in "intelligence quotient" form. ("mental age" divided by chronological age, multiplied by 100). The recent and current are scored in "deviation IQ" form, with a performance level by a test-taker two standard deviations below the median score for the test-taker's age group defined as IQ 70. In modern-day, intellectual disability is not based on IQ scores alone but the persons adaptive functioning is also considered.

It encompasses intellectual scores, adaptive functioning scores from an adaptive behaviour rating scale based on descriptions of known abilities provided by someone familiar with the person, and the observations of the assessment examiner who is able to find out directly from the person what he or she can understand, communicate, and such like. IQ assessment must be based on a current test.

The main distinction of ID from other disabilities is that clinically, ID is a subtype of cognitive deficit or disabilities affecting intellectual abilities, which is a broader concept and includes intellectual deficits that are too mild to properly qualify as intellectual disability, or too specific (as in specific learning disability) or acquired later in life through acquired brain injuries or neurodegenerative diseases like dementia.

2.7 Adaptive behaviour

Adaptive behaviour refers to skills developed to live independently. In order to evaluate adaptive behaviour, health experts liken the functional abilities of a child to those of other children of similar age. In order to measure accurately, adaptive behaviour experts use

structured interviews, with which they systematically elicit information about persons' functioning in the community from people who know them well.

There are many adaptive behaviour scales, and accurate assessment of the quality of someone's adaptive behaviour requires clinical judgment as well.

Certain skills are important to adaptive behaviour, such as:

- Daily living skills, such as getting dressed, using the bathroom, and feeding oneself
- Communication skills, such as understanding what is said and being able to answer
- Social skills with peers, family members, spouses, adults, and others•

Intellectual disability is a general term used when an individual's intellectual development is significantly lower than average and his or her ability to adapt to the environment is consequently limited. The condition varies in severity and cause. For many years the potential abilities of people with intellectual disabilities were poorly understood, and such individuals were often treated as inferior. In the academic environment, these children may be eligible for special education services for students with mild intellectual disability.

Over the last decade, several scales have been developed to evaluate the Quality of Care and Support (QOCS) in different settings. The Individualized Care Scale (ICS) was designed to evaluate patients' views on individualized nursing care for use in hospital environments (Suhonen, *et al* 2002). It can be used as an outcome measure of the quality of care or a tool for individualizing care (Suhonen *et al*, 2015). The service quality instrument (Hiidenhovi *et al*, 2011) is generic to the extent that it is suitable for assessing individual outpatient departments and for making cross-departmental comparisons. One of the instruments' strengths is that they have been developed using patients and staff perspectives. Yet, these scales were not developed specifically for persons with disabilities. In order to understand individual outcomes from health evaluations and social care for disabled people, it is important to standardize measures

to allow research across cultures. There is no such measure available currently to assess persons with intellectual disability.

In Ghana and among other sub-Saharan African countries service provision to persons with intellectual disability are poorly structured. The professionals within these centres the frontline professionals that care for the clients are, for the most part, registered nurses. Traditionally, their training and practice have been geared towards providing high standards of physical care with an emphasis on health, hygiene, and safety. However, over the past two decades, a paradigm shift has occurred in service provision for persons with intellectual disability.

The primary health care delivery for people with intellectual disability has been squarely placed in the hands of general practitioners (GPs) since the global shift from institutional to community-based care.

However, studies which assessed the care of people with intellectual disability have identified significant shortcomings (Beange 2016; Howells 2016). These studies demonstrate that people with intellectual disability suffer from an excessive number of unrecognized or poorly managed medical conditions. Similarly, many authors suggest there is a lack of adequate health screening and preventative care in this population (Being: 2016; Parmenter 2008; Barker & Howells 2010). Many barriers to the provision of healthcare have been identified or commented upon. Some commonly mentioned barriers are communication difficulties between care givers and patient; difficulties with accessing the health care system; poor remuneration for healthcare providers and the difficulties that short consultations times have on their wellbeing (Beange 2016). Negative attitudes held by the medical professionals also influence the quality of health care provision and GPs have been shown to have a limited view of their roles and responsibilities as health care providers for people with intellectual disability (Ineichen & Russell 2007; Kerr *et al.*, 2016).

2.8 Health Care and Disability

On a broad scale, every extended family has a disabled member, and many non-disabled people oversee providing support and care for their relatives and friends with disability. This has become a major problem especially when it comes to how to include and support people with disabilities (WHO, 2010)

At the Primary health care conference in Alma-Ata organized by WHO, the global health goal's main objective was Health. Several years later, this conference communities are still struggling with to achieve this object and majority of people are struggling to achieve this especially people with disability (WHO, 2010).

In order to achieve good levels of health, it is important to note that:

People with disabilities need equal health services for general health-care needs (e.g. health promotion and prevention services and medical care) like the rest of the population, including different needs in different phases of life. On the other hand, not all people with disabilities have health problems related to their deficiencies, numerous will require specific health-care services such as rehabilitation, on a regular or occasional basis and for limited or lifelong periods.

The main channels through which health care is provided by countries are through health systems which comprise of organisations, institutions, resources, and NGOs whose primary purpose is to promote, restore or maintain health. These systems depend solely on provision from Government. Health care is provided by a combination of public, private, traditional and informal sectors.

The 2008 World Health Report emphasizes the essential role of primary health care in achieving health for every person (WHO, 2008). Primary health care is essential health care made universally accessible to individuals and families at a cost they can afford. It is the first

level of contact with the national health system for individuals, families, and communities and brings health care as close as possible to where people live and work.

2.9 Barriers to health-care services for people with disabilities

The poor health that people with disabilities may experience is not necessarily a direct result of having a disability. Instead, it can be linked to difficulties in accessing services and programmes. It is estimated that only a small percentage of people with disabilities in low-income countries have access to rehabilitation and appropriate basic economic barriers – health interventions such as assessments, treatments, and medications often require out-of-pocket payments, presenting difficulties for people with disabilities and their families who are likely to have limited income for health care regarding the provision of health services to people with disabilities;

2.9.1 Physical and geographical barriers

Lack of accessible transport and inaccessible Introduction: Poverty and disability); buildings and medical equipment are examples of common barriers, as well as the limited health-care resources of rural areas (where many people with disabilities live)

2.9.2 Communication and information barriers

Communicating with health workers and the long distances to reach services in big cities may be difficult, e.g. a person who is deaf might find it difficult to communicate his/her symptoms to a doctor and health information is often not available in accessible formats, poor attitudes and knowledge of health workers about people with disabilities, such as picture formats for people with intellectual impairment; health personnel may have inappropriate attitudes, be prejudiced or insensitive and lack awareness and often lack the knowledge, understanding, and

skills to manage general health issues for people with disabilities and services – people with disabilities may be reluctant to use health services; many also have limited knowledge about their rights and health issues and about what health services are available.

Some people with disabilities may be more vulnerable to discrimination and exclusion than others. They may suffer double or multiple disadvantages, for example, due to the type of disability they have, their age, gender and/or social status and so find it more difficult to access health-care services. CBR programmes should be particularly mindful of the following groups: women, children and older people with disabilities; people with multiple impairments e.g. those who are both deaf and blind, or who have intellectual impairments, disabilities and HIV/AIDS, mental health problems, leprosy, or albinism (World Health Organization *et al.*, 2010).

2.10 Inclusive health

“Inclusive education” has become a widely recognized concept and is increasingly being implemented in education systems throughout the world. A new approach known as inclusive health has been implemented into the education systems throughout the world. This refers to education that welcomes all individuals all people with disabilities to participate fully in regular community schools or centres of learning. This concept is also included in the CBR concept which involves individuals to help them form part of the learning community.

Inclusive health means that all individuals can access health care irrespective of impairment, gender, age, colour, race, religion, and socioeconomic status. In order to make this happen CBR has to ensure that health care service providers have positive attitudes towards disability and people with disabilities and have appropriate skills, e.g. communication skills to accommodate the needs of people with different impairments.

2.11 CBR and the health sector

CBR programmes can facilitate access to health care for people with disabilities by working with primary health care in the local community, providing the much-needed link between people with disabilities and the health-care system. Many countries such as Argentina, Indonesia, Mongolia, and Vietnam have a ministry of health implemented through their primary structures. CBR programmes are directly linked with the health-care system – they are managed by the ministry of health and implemented through their primary health care structures. However other countries have CBR programmes are managed by nongovernmental organizations or other government ministries, e.g. social welfare, and in these situations, close contact must be maintained with primary health care to ensure that people with disabilities can access health care and appropriate rehabilitation services as early as possible.

CBR programmes identify, supports and advocate a number of key aspects of health care for people with disabilities. These programs involve health promotion, prevention, medical and rehabilitation, and assistive devices.

2.11.1 Health promotion

The focus of health promotion is to increase control over health and its determinants. The main aim of this is to strengthen the skills of individuals to make social, economic and environmental conditions better to improve its impacts on health.

2.11.2 Prevention

There is a direct connection between prevention and health promotion. This involves three main stages and these are primary, secondary and tertiary Prevention. Primary prevention involves avoidance, secondary prevention involves early detection and early treatment while tertiary prevention involves rehabilitation measures (World Health Organization, 2010a).

2.11.3 Medical care

The use of medical care is also a very important aspect in CBR it involves early identification, assessment, and treatment of health conditions and their resulting impairments. This aims at curing or limiting their impacts on individuals. This can take place at the primary, secondary or tertiary level of the health-care system.

2.11.4 Rehabilitation

Rehabilitation is a set of measures which enables people with disabilities to achieve and maintain optimal functioning in their environments; it is relevant both for those who acquire disabilities during their lifetime and for those who have disabilities from birth. Rehabilitation services range from the basic to the specialized and are provided in many different locations e.g. hospitals, homes and community environments. Rehabilitation is often initiated by the health sector but requires collaboration between all sectors.

2.11.5 Assistive devices

Persons with disabilities learn to adapt to the changing environment and use devices that have been designated to help perform tasks. Some common types of assistive devices are: mobility devices (e.g. walking sticks, wheelchairs), prostheses (e.g. artificial legs), orthoses (e.g. hand splint), visual devices (e.g. glasses, white canes) and hearing devices (hearing aids). For assistive devices to be used effectively, it is very necessary to take note of their provision which includes user education, repair, replacement and environmental adaptations in the home and community (World Health Organization, 2010b).

2.12 Attitudes Towards Persons with Disability in Ghana

Ghana continues to face the various forms of discrimination even though it has signed, ratified and adopted various international agreements including the Convention on the rights of PWD

and the African Decade of the Disabled Persons. Even though the main aim of these agreements is to protect the fundamental freedoms and human rights of all people with disability and to promote and respect their in-built dignity. Research has shown that people with disability are faced with challenges including low self-esteem, limited mobility, high dependency and poverty, lack of access to education, health care and other social services (WHO, 2011). Apparently, PWD are unable to fully and effectively participate in the Ghanaian society compared with persons without disabilities. Most are regarded as unproductive and incapable of contributing to national development, while others believe their unfortunate circumstance is a curse or punishment from God.

The disability movement and civil organizations in recent years have made efforts in pushing forward the disability agenda. This issue of disability in Ghana has evolved from being a human right to a developmental issue because of its link to poverty.

2.12.1 Policies supporting disability in Ghana

The government in 2006 passed the Persons with Disability Act (715) which deals with issues such as rights, education, health care, employment, transportation, housing, medical rehabilitation services, generation and dissemination of relevant information and participation of PWD in cultural activities.

Secondly, the National Council for persons with disabilities was established in accordance with Article 41 of the Persons with Disability Act 2006. In addition to these other initiatives include such as: 3% allocation of the District Assembly Common Fund (DACF) to assist PWD, and the Ghana Shared Growth and Development Agenda (2010 – 2013) Volume I which aims to develop and implement an action plan to fulfil the provisions of the Persons with Disability Act 2006 and develop social interventions for PWD.

In Ghana studies by Avoke (2001) and Ocloo (2002) explained that the mere birth of a child with disability begins to question the living and dead leading to the perceptions such as the child or parent has offended the living and or the dead. People begin to distance themselves from such families with children with disabilities. Some other have the perception that the god has visited them in the local settings. Others also see this as a threat to the peace and stability of the community as well as the prized role of the child's future in performing basic duties in society.

To safeguard against a child being born disabled, pregnant women in certain parts of Ghana are subjected to various kinds of taboos. For instance, in the Brong-Ahafo region, pregnant women are barred from eating fish caught from a river called "nsuokoraa". This stems from the belief that the river is a god and the fishes are its children. It is believed that pregnant women who eat fish from this river could give birth to children with intellectual disabilities. As a sign of punishment, this could lead to isolation or divorce since the pregnant woman has disobeyed a taboo to invoke a curse upon the family (Baffoe, 2013).

Similar to perceptions of ancestral punishment, notions of productivity places emphasis on values such as the ability and skills of an individual to "physically" contribute to the family and community. Historically, children with intellectual disabilities are seen as unproductive people who would hinder social and economic progress. Only individuals who are considered productive could live and as such, children with impairments were killed or left on anthills, in rivers or forests to die.

It can be argued that today, children with intellectual disabilities face similar situations though stories of killings are not heard of. Perhaps, because of enlightenment and respect to international calls to end all forms of human rights abuses. Even though children with intellectual disabilities are no longer killed physically, they seem to be "killed" emotionally

through dehumanising names, which make them victims of mockery. For instance, among the Akans (Ashanti Region) in Ghana, people with intellectual disabilities are referred to as “*nea wanyin agya n’adwene ho*” meaning, “feeble-minded.” Two other ethnic groups, the Ewes (Volta Region), and the Gas’ (Greater Accra Region) refer to people with intellectual disabilities as “*asotowo*” and “*buulu*” meaning; idiots and stupid respectively. Further to these cultural ideologies, people with Down syndrome in Ghana are referred to as “*nsuoba*”, meaning water children (“*nsuo*” means water and “*ba*” means child).

Traditionally, these are very offensive and dehumanizing labels which worsen the plight of people with intellectual disabilities (Agbenyegah, 2003).

In addition to derogatory labels, it has been reported that people with intellectual disabilities are not treated with respect. From his studies on “*Stigma, Discrimination, and Marginalisation: Gateways to Oppression of Persons with Disabilities in Ghana*”;

Baffoe (2013) argued that persons with intellectual disabilities in Ghana experience disrespect, societal exclusion, and a devalued self-worth. The study pointed out that stigma attached to persons with intellectual disabilities in Ghanaian societies has created barriers for their inclusion in community life. In addition, participants in the study experienced disrespect in hospitals and faced both physical and cultural barriers in society. The author argued that social exclusion can be thought of as problem that has to do with respect for people with intellectual disabilities and supported the need for community campaigns aimed at eliminating negative treatments towards persons with intellectual disabilities in Ghana ‘I find this discussion important since the findings contribute to an understanding of how respect impacts on efforts at social inclusion for children with intellectual disabilities.

Another Ghanaian study by Kassah (2012) drew attention to how disabled children in Ghana experience various forms of abuse. Dwelling specifically on labelling, the author reported that

because the children were labelled and viewed as non-humans, they experienced various forms of emotional, physical, social, and capital abuses. One of the largest problems the study addressed was how social abuse was experienced through restriction in participation of social life and isolation. The study pointed out that; physical abuse was in the form of physical assaults such as unprovoked beatings, and capital abuse was experienced through practices that led to the killing of disabled children. These abuses disturbed the children emotionally since some of them were physically separated from their parents and other members of the community owing to their impairment. Kassah's (2012) study confirms the importance of eliminating cultural barriers at participation for children with intellectual disabilities and advocated for a change in societal environments including the way in which people with disabilities are perceived.

In addition to culture, some Ghanaian literature also addressed the role played by religion in the lives of families who have children with disabilities. Traditionally, the various forms of religions in Ghana are traceable to beliefs in God or gods. However, religious perceptions on intellectual disabilities vary and the following illustrates the dynamics: Among the Ga (Southern Ghana), the laws of reincarnation are followed and people with intellectual disabilities are the reincarnation of their ancestors. The belief is that people with intellectual disabilities were offended during their previous life and the community has been given another opportunity to care for them. As a result, they are treated with caution, kindness, and patience.

On the contrary, the Ashantis of central Ghana detest any form of defects and see it as a punishment from the gods. Intellectual disability is considered a major disability and as such, children with impairments are considered full members of the society. Also, people with other forms of disabilities such as epilepsy are not allowed to be chiefs (Danquah, 1997).

Similar to the Ashanti's, people in the Northern and Volta regions of Ghana also see disability as a punishment for sin or wrongdoings. As a result, these regions are known to have “powerful” traditional healers who can rid evil spirits from their members through various charms and amulets.

The literature on support from networks acknowledges that support from immediate families and friends are essential to assist parents who have a child with disabilities (Nufeld, 2002; Beckman (1991) as cited in McKenzie, 2007). In Ghana, other possible forms of informal supports include kinship and community members. Kinship determines the rules, duties, and obligations of individuals and groups in all aspects of life and social interactions in Ghana (Nukunya, 2003). The family consists of tribes, clan and lineage and the head of the lineage are responsible for making important social decisions for the family. For instance, important decisions such as whether a child with an intellectual disability should be allowed to work on the family farm or be “hidden” are determined by the kinsmen. Even though this aspect of kinship is changing owing to urbanization, they are still very strong and determine social etiquettes, family obligations, and social responsibilities. Grandparents are another vital source of family

support. Leung and McDonald (2001) referred to the support offered by grandparents as very significant especially in “*dual career families*”. What is however not known is the extent to which grandparents provide support to their grandchildren with intellectual disabilities.

2.13 Prevalence of intellectual disability in Ghana

As part of the 2010 population and housing census, intellectual disability was studied and thoroughly assessed. From these studies, there is the need to plan effectively for special need of people with this kind of disability.

2.13.1 Intellectual Disability and Age in Ghana

It was noted that the proportion of people with intellectual disability tends to increase as their ages increase. The prevalence rates ranged from 0.3% (among the 0-4, 5-9 and 10–14) to 1.1% (among 65+ age group). Generally, the prevalence of intellectual disability is higher in the rural (0.5%) than urban (0.4%) areas and among males (0.5%) than females (0.4%).

2.13.2 Intellectual Disability and Marital Status in Ghana

Statistics from this indicates that 0.5% of the population of the marriage age had intellectual disability. The prevalence rates are high among males and females who were either separated, divorced or widowed. Generally, slightly higher proportions were registered among residents of rural than urban areas.

2.13.3 Intellectual Disability and Educational Characteristics in Ghana

0.5% of the entire population of school-going age had intellectual disability. People without formal education recorded the highest prevalence (0.9%) of intellectual disability. A similar pattern was observed among males and females as well as residents of both urban and rural localities (Ghana Statistical Service, 2012).

2.13.4 Intellectual Disability and Region of Residence

The census showed that there are regional variations in the prevalence of intellectual disability. Volta Region has the highest rate (0.7%) of people with intellectual disability, followed by Eastern Region (0.6%). In terms of urban-rural dimension, the Volta Region had 0.6% and 0.8% in the urban and rural areas respectively (Ghana Statistical Service, 2012).

Volta and Eastern Regions registered the highest proportions of intellectual disability among both males and females even though females had a higher prevalence than males in each of the two regions.

2.13.5 Intellectual Disability and Ethnicity

The census shows that the highest prevalence of intellectual disability was registered among the Ewe and the Ga-Adangbe (0.6%) ethnic groups followed by the Guans and Gurmas (0.5%). Among the males and females, the prevalence rates were the same for the Ewes and the Ga-Dangmes. Similar patterns can be observed among both urban and rural localities although the prevalence rates registered in the rural localities are higher among some ethnic groups.

The census reported that Intellectual disability was high among the aged population and for that matter may be attributed to the ageing process. As one ages the body becomes less resistant to certain kinds of ailments and some functions tend to recede in its ability to function properly. Thus, aging may be associated with the lowering of ones IQ (Burke, 2013) which is one of the forms of intellectual disability. Also, the finding that there are more separated and divorced people with intellectual disability may be attributed to the psychological trauma that these people may encounter as part of the separation or divorced. Usually when people loose their partners, they may be psychologically disturbed that it may lead to intellectual disability (Morris, 2004). This tends to affect the intellectual health of the individual. Similarly, Siminski (2003) have intimated that the pain for some partners during divorce and separation may be so severe that immediate rehabilitation is needed to prevent the development of intellectual disability.

From the report emerged from the results that people without formal education have a higher proportion of people with intellectual disability. This finding may explain why they have not been able to progress in terms of formal education since their IQs may be too low to

comprehend basic things in school. This finding is similar to observations made by other studies. For instance, Armstrong (2003) and Madriaga (2007) indicated that intellectual disability, especially low levels of IQ is more prevalent among people with no or little education. Burke (2013) further argued that intellectual disability may hinder one's ability to fully access the formal educational system and hence people with intellectual disability may have little or in some cases no formal education experience especially in developing countries.

The results show that the not active population has higher prevalence of intellectual disability than those employed. According to Kassah (2012) people with disabilities are usually not considered as active workforce because of their disability. Also, the results indicate that there is more of the non-active workforce with intellectual disability in rural areas than urban areas.

People with no religion have the highest prevalence of intellectual disability. Perhaps their lack of belief makes them less concern about disability. Watters (2010) suggests that illness and disability in Islam are not viewed as punishment, but rather as an opportunity to endure suffering to receive Allah's grace. Christianity, on the other hand, views illness and disability as challenges and tests to overcome. In both religions, disability is a test of faith (Schuelka, 2013).

The highest prevalence of intellectual disability was reported among the aged females and residents of rural localities. There were high proportions of separated and divorced people with intellectual disability (1.0%) than those in the other marital categories. People without any formal education have the highest prevalence of intellectual disability (0.9%).

Generally, the prevalence of intellectual disability is higher in rural than urban localities. Within the 99 working-age population, 0.5% has intellectual disability with higher prevalence among rural residents (0.6%). In terms of regional variations, the Volta Region has the highest prevalence of people with intellectual disability (0.7%). In the prevalence of intellectual

disability is higher in rural areas than urban areas across the ten regions of Ghana. Intellectual disability was more prevalent among males and females of the Ewe and the Ga-Adangbe ethnic groups in both urban and rural localities.

CHAPTER 3

METHODOLOGY

3.1 Introduction

This study adopted an exploratory research approach. According to Robson (2012), an exploratory study is a valuable tool for explaining what is happening and to seek new insights and assess an occurrence. The researcher adopted this type of research design because it will help query what is already in existence, describe fresh insights, and raise questions that will facilitate the research assessment from a new viewpoint. This research design allowed the researcher to adopt a qualitative study approach to the data collection and analysis. The researcher thus employed the in-depth interviews approach to collect data to allow all interested parties and stakeholders to understand the findings and recommendations of the study from a non-statistical perspective. The researcher held in-depth interviews with both parents of children with intellectual disabilities and health workers at the primary health level until they reached a saturation level, that is, receiving the same kind of information as given in previous interviews by participants.

3.2 Data Collection Techniques and Tools

To ensure that accurate and reliable information on the perception of the quality of care for persons with intellectual disability is obtained, the study adopted the purposive sampling technique. The choice of the purposive sampling technique was motivated by the fact that the information on the perception of the quality of care for children with intellectual disability is specific and therefore respondents with the requisite experience will be required to obtain data that is reliable and relevant to the study.

Two parents of children with intellectual disabilities were reached within the Adentan Municipality through the community clinic of the Multikids Inclusive Academy at Adjiringano. Three other parents were identified through a Community Health Nurse at the Amanfro Health Centre, with two additional parents reached outside of the municipality through the personal network of the researcher.

Primary health workers were sampled from the Amanfro and Nii Ashale sub-municipals of the Adentan Municipality with the support from the Municipal Health Directorate.

A self-structured and administered interview guide was used as the data collection tool. It was administered by the researcher using the Voice Recorder Pro App on a Samsung Galaxy A5 phone to record the interviews for transcription and analysis. The interview guide covered all the areas of the research questions that we were seeking answers for.

3.3 Study Population

The study population was made up of parents of children with intellectual and developmental delays such as cerebral palsy, Down syndrome, West syndrome or even one that has not been diagnosed but parents and researcher attested to the fact that the child has intellectual and developmental delays. Interviews were also conducted with primary health workers from the Adentan municipality

3.4 Study Variables

The variables that define the scope of the study include:

- Perception of the quality of care for children with disabilities
- Health workers' knowledge and attitudes to the management process of care for children with intellectual disabilities
- Parent's understanding of disabilities, especially the one their child has

3.5 Sampling techniques

Considering this is a qualitative study seeking to explore the understanding and perception of the quality of care for children with intellectual disabilities from the perspectives of parents and health workers, we knew that the findings for this study will provide an in-depth knowledge in the research area and not necessarily to generalise but at the same time provide background data for further studies in the future in the area. The parents were therefore sampled using a snowball approach where one mother told us about another they knew, and a therapist led us to other parents. However, with the primary health care workers, a convenient sampling approach was adopted.

3.6 Pre-testing

The interview guide was pre-tested at the Shai Osudoku District Assembly where one health worker and one parent were interviewed to check for the clarity of the interview guide, reliability and understanding of the questions to eliminate poor phrasing as well as to estimate the time of each interview would take

3.7 Data Analysis

Information gathered from the interviews were transcribed into word documents and uploaded into the Dedoose online software – <https://app.dedoose.com/App/?Version=8.1.8> (Version 8.1.8). These were then coded into themes based on the research questions and objectives of the study and analysis conducted accordingly. In Saunders, *et al.* (2007), analysis is the ability to break down data and to clarify the nature of the components and the relationship between them.

3.8 Ethical Consideration

The researcher had ethical clearance from the Ensign College of Public Health Ethics Committee and also took the required steps to secure the Ethics Committee as well as administrative approval from the Ghana Health Service through the Adentan Municipal Health Directorate for the facilities from which the respondent health workers were sampled.

The researcher ensured that participants in this study gave informed consent for their participation through the administration of the informed consent before each interview. Required steps were taken to ensure that the interviews were conducted to protect the privacy and anonymity of participants. Assurances were given to participants to know that they can decline to respond to any question at any point during the interview.

3.9 Limitations of the Study

One of the challenges the researcher encountered was the access to and collection of data from the participants from the two arms of this study, especially so for parents due to the stigma that surrounds intellectual disability in the country. This situation compelled the researcher to limit the study to views and opinions of participants who were willing to share their experiences (parents of children with intellectual disabilities and health care professionals from the primary healthcare level), and in the case of parents, this extended beyond the Adentan municipality with one parent each interviewed in Dodowa and Kpong respectively. However, steps were taken to ensure that these limitations did not affect the findings/outcome of this research.

comprehensive healthcare implementation at CHPS
 frequently seen disability cases
 Reasons for lack of decentralization
 Parent's/caregivers knowledge
 medical practitioner assessment of children with disability
 challenges to providing care
 types and examples of disabilities
 Types of services offered
 what is CBR
 Health needs of children with disabilities
 Healthcare workers' knowledge
 Recommendations
 what is it Cost of care
 how can it be done Counseling
 Knowledge
Perception and attitudes
 Recommendations for CBR
 The birth/diagnosis event
 Perception of quality of care
 Comprehensive care
 Alternative forms of care
 Parent/caregiver support wear-out
 nurses description of disabilities
 Level of attention given to children with disabilities

CHAPTER 4

RESULTS

4.1 Introduction

This section presents the results obtained from the study as well as the interpretations of these results. The results are presented descriptively and in themes in the form of quotes to support the various themes. The results are organized according to the study objectives and the research questions.

4.2 Demographic characteristics of participants

Nine (9) health workers from three (3) facilities as well as seven (7) parents participated in the in-depth interviews for this study. The participants in the study were either health workers at the primary level of health delivery or are parents who have children with intellectual disabilities. The health workers who participated in the study have working experiences ranging from 1 – 26 years respectively. Parents who participated in the study also had children ranging between the ages of 1.5 to 12 years. The interviews with the health workers were conducted in the English language however, those for the parents were conducted in English, Twi and Ga-Dangme respectively (field data) as shown in Tables 4.1 and 4.2. There were three categories of health workers who participated in the study.

Table 4.1: Participants' characteristics (health worker)

Health workers			
Category of health personnel	Number interviewed	Facility	Number of years of experience
CHN	2	Amanfro & Nii Ashale Health Centres	7, 8
GN	3	Multikids Inclusive Academy, Amanfro, Nii Ashale Health Centres	8, 8, 1
Midwife	2	Amanfro & Nii Ashale Health Centre	3, 26
Physician Assistant	1	Amanfro Health Centre	13
Speech Therapists	2	Multikids Inclusive Academy	2 each

Table 4.2: Participants' characteristics (parents)

Parent Age	Marital status	Employment	Child condition	Child age
54	Separated	Self-employed	Down syndrome	8
40	Married	Unemployed	Down syndrome	12
32	Married	Self-employed	Down syndrome	3
44	Separated	Secretary	Cerebral Palsy	6
32	Married	Seamstress	Cerebral Palsy	6
33	Separated	Hairdresser	Undiagnosed	12
32	Married	Hairdresser	West syndrome	1.5

4.3. Objective 1: Healthcare needs of children with intellectual and developmental delays

There were about three major themes that emerged under the health needs of children with disabilities (and their parents), these are as follows:

4.3.1 Physical health needs

Respondents reported that most children with intellectual disabilities tend to have developmental delays in all areas of their lives. Depending on the specific condition of the child, this health need may be more pronounced in one than the other but both parents and health workers agreed on the following health needs for children with intellectual and developmental delay. Parents and healthcare workers identified physiotherapy, occupational and speech and language therapies as some of the important services needed by children with intellectual and developmental delays

"...We were just referred to the physio department with the explanation that she is a special child... because my child needs physio to be able to walk and do other things". (Mother of a 6-year-old child with Cerebral Palsy, Nanakrom, Ashale-Botwe)

Another mother who was concerned with remedies to get her child well also recalled that she was advised to seek physiotherapy care by nurses.

“But she told me, I should send her to the physio department and she will be fine” (Mother of a 6-year-old child with cerebral palsy, Lakeside Estate).

A school speech therapist at suggested basic needs of children with intellectual and developmental delays to include physiotherapy, speech and occupational therapy

“Well, we (the multi-disciplinary team at MKA) offer these services to members of the community who have children with special needs as a way of corporate social responsibility. We offer physiotherapy, speech therapy, occupational therapy” (Speech therapist, Multikids Inclusive Academy).

4.3.2 Clinical health needs

Clinical Health needs for mental and developmental delayed children were also identified by respondents. Side effects of certain drugs and medications tend to be clinical needs of some parents. A mother of a 6-year-old child with cerebral palsy from Lakeside Estate recalled

“..... because the drugs that they were asking me to buy for her had so many side effects and it seemed to relax her only for hours and then the constriction and spasms come back, and these are drugs that she will have to stay on for a long time”. (Mother of a 6-year old child with cerebral palsy, Lakeside Estate)

Two mothers of children with Down syndrome also reported recurring infections of their children.

“You know children with Down syndrome, their immune system doesn’t build early so she was sick here and there, so I got this paediatrician in church who took a keen interest in her health..... She kept on getting all manner of infections while we were also checking on the function of her heart.” (Mother of 8-year-old child with Down syndrome, Dodowa)

“.....in the early days we were going to the hospital a lot with one or the other health condition but that ceased a bit from when she was about 5years old” (Mother of a 12-year-old child with Down syndrome, Ashale-Botwe)

4.3.3 Psychosocial health needs Sadness and depression

Some few mothers expressed psychosocial needs for both their children and they as caregivers that should be aimed at addressing depression and sadness.

“.....and sometimes I can see she herself is sad or depressed because you find her sitting and silently crying and even if I ask what is wrong, she cannot tell me.” (Mother of a 12-year-old child with undiagnosed Intellectual and developmental delay, Amranhia)

4.4 Objective 2: Health workers’ knowledge and perception of the processes of management of the health needs of children with intellectual disabilities

Knowledge of healthcare workers were measured using questions that gave them the opportunity to mention some disabilities that they know, whether these fall under physical or intellectual and developmental delays and to describe physical features of some these disabilities they mentioned. There were questions also in the interview guide that asked about what the health workers understanding of managing the health needs of children with intellectual disabilities especially are. The following are some of the themes that emerged.

4.4.1 Types and frequently seen disabilities

To test knowledge of the health workers interviewed on the various forms of disabilities, they were asked to name conditions that could lead to disabilities especially early on in life as shown in table 4.3.

Table 4.3: Knowledge of disabilities by health workers

Disabilities mentioned or described by health workers	Description	Physical or intellectual and developmental delay	Seen before
Down syndrome/mongolism	<i>"Children with Down syndrome have a moon face, eyes are set like a cat's, they have lower sitting ears"</i> - Midwife with 26 years' experience <i>"people with brain problems that they cannot function well as a normal human being, with their ears low set eye"</i> - Principal Physician Assistant with 13 years' experience	Intellectual and developmental delays	Yes
Autism	<i>"the autism, those people, some of them it depends. Me what I know is that some of them they may walk, they may do some few things on their own but it's like that they behave differently from the normal child"</i> - CHN with 8 years' experience <i>"Autism is also similarly to cerebral palsy, but for them it seems theirs is better than cerebral palsy"</i> – Midwife with 3 years' experience <i>"... With children who are autistic, mostly from birth you don't see it, "it's during the developmental stages that the child is not developing at the rate that the child is supposed to, mostly in speech, in activity, in... like the child is not able to fit in the society"</i> – GN with 8 years' experience	It is both because it affects the way the child behaves and even walk It is more behavioural than intellectual	Yes
Cerebral palsy	<i>"Their behaviour is different from how we those who don't have cerebral palsy behave. Sometimes, I don't know, if I may (asking if she can demonstrate – she demonstrates someone with constricted arms, a neck that is to one side of the body while shaking at the same time), and sometimes, you see the mouth cannot be dry completely"</i> - Midwife with 3 years' experience	Physical	Yes
Physically challenged	<i>"Physically challenged who cannot do anything"</i> – CHN with 8 years' experience	Physical	Yes
Blind	<i>"I know for the vision and sight, they are not able to see or maybe partially"</i> CHN with 8 years' experience	Physical	Yes
Hearing & speech impaired	<i>"with hearing impairment, they may see but cannot hear sounds"</i> - CHN with 8 years' experience	Physical	Yes

From the above table, of the health workers sampled, it was only 2 (midwife with 26 years experience and GN with 8 years experience) who could clearly indicate appreciable knowledge of the disabilities they described. The rest used terms that described other conditions. For example, a midwife with 3-years' experience says, *"Autism is also similarly to cerebral palsy, but for them it seems theirs is better than cerebral palsy"* and that these conditions are more of a physical disability than an intellectual one. This clearly shows the knowledge gap that needs to be addressed.

4.3.2 Health worker assessment of children with disabilities

This theme sought to see per the above knowledge expressed by the health workers interviewed, how they would proceed to assess or manage the health needs of a child with disabilities, especially, intellectual disabilities. The following are some of the findings that emerged:

“when a child is born, we do a physical examination for them using the Apgar score to see if everything is ok with the child. Where a noticeable disability is identified, and it is beyond what we can do anything about, per the referral structure, we refer to the next level of care” – Principal Physician Assistant with 13 years’ experience

“There are certain conditions that maybe when the condition is noticed earlier, the parents/guardian can be counseled on how to handle the child. But in our Ghanaian setting where we don’t have so many pediatricians in the system, when a child is born with a disability, then the child must be referred.....But basically, a pediatrician must assess the child and whatever first aid or care must be given to the child, given immediately” – General Nurse with 8 years’ experience

“those on the job also need practical placement where they get to see some of these cases and learn how to handle the additional health needs they present” – Speech therapist with 2 years’ experience

4.3.3 Types of services offered and perception of quality of care

We asked the health personnel what the types of services there were for children with intellectual disabilities and the following are their responses

“I think some of the key services should also be specialized so that district hospitals could have the specialist like, speech, physio and other therapies” – speech therapist with 2 years’ experience

“Well we (the multi-disciplinary team at MKA) offer these services to members of the community who have children with special needs as a way of corporate social responsibility. We offer physiotherapy, speech therapy, occupational therapy” – Speech therapist with 2 years’ experience.

On the issue of quality of care for children with intellectual disabilities, this is what participants had to say:

“they just kept writing medicine upon medicine for me to buy and these were expensive but also there was no change in her condition. I was not allowed to breastfeed her, she only had IVs running in her vein and when she gets the seizures, she bleeds from where the cannulas are inserted. This broke my heart as a mother” – Mother of an 18-month-old child with West syndrome

“....it feels like it is a chore for them to care for her, so they don’t do it joyfully. And the painful part about it is that, when you see them interact with other children or families whose children are not like mine, they do better; smiling and joking with the kids” – Mother of a 12-year-old child with Down syndrome

“everybody loves to associate with positive stuff, nobody wants to be associated with any negative thing but then these children are the ones who need special care, but we tend to abandon them” – RGN with 6 years’ experience

4.4 Objective 3: Healthcare barriers confronting quality of care for children with intellectual and developmental disabilities

Some of the barriers to healthcare for families raising children with intellectual disabilities as observed in this study include:

4.4.1 Cost of care

Health workers and parents who participated in study all pointed to the fact that raising children with intellectual disabilities can be very expensive and this therefore becomes a barrier to accessing health care for these children. Below are some excerpts that support this assertion

“.....some parents because of financial problems may not be able to and will just leave the child at home” – CHN with 7 years’ experience

“they just kept writing medicine upon medicine for me to buy and these were expensive but also there was no change in her condition” – Mother of an 18-month-old child with West syndrome

“...Her own is spastic so the muscles are overly toned and always contracting, and the drugs that are there are to help the muscles relax but they are expensive, very, very expensive and we have to buy it every month! I can’t afford it” – Mother of a 6-year-old child with cerebral palsy

“.....we were in Korle-bu for over a month, while there, every night we had to buy some medicine that cost GHS 80.00, for the one month” – Mother of a 12-year-old child with Down syndrome

4.4.2 Perceptions and attitudes to disability

Almost all the participants in this study alluded to the negative perception of disabilities in general and intellectual disabilities especially. This negative perception was seen by them as more cultural than to do with the individual. The following are some excerpts to support this

“In Ghana we have a believe that children with disabilities are.... some even believe such children are spiritual children and are abandoned in the forestin a case where there are two clients, one with and the other without disability, everyone is in a hurry to treat the one without disability. People find it difficult to relate to children with disabilities” – GN with 6 years’ experience

“The extended family did not really understand because there have been births in the family and no one has a child like mine so at some point my husband was advised that we should get rid of the child, but he refused and only told me about this much later. The reason he said they gave was that these children are spiritual children and things will never be better until they are gotten rid of” – Mother of a 12-year-old child with Down syndrome

“The father rejected us saying ‘look at the child you gave birth to, she is a problem’” – Mother of a 6-year-old child with cerebral palsy

“It was while we were in Kumasi that one of the nurses on the ward rounds told me that she thinks that this could be spiritual, so I should ask for us to be discharged so I can seek spiritual help” – Mother of an 18-month-old child with West syndrome

4.5. Objective 4: Alternative forms of care for children with Intellectual and developmental disabilities

The alternative forms of care sought after by parents of children with intellectual disabilities is spiritual either in the form of prayer camps and prophets or traditional healers

“So, I decided to stop and rather pray that God will help me to take care of her, because I pray a lot, I’m a very prayerful person” – Mother of a 6-year-old child with cerebral palsy

“.....we went to the church as a last resort because we could not get the money for the deposit for the treatment at Korle-Bu” – Mother of a 12-year-old child with Down syndrome

“when we came to Accra we went from one spiritualist to the other, one prayer center to prayer center but still I didn’t see any improvement so now we are just home to see what God will do”

– Mother of 18-month-old child with West syndrome

“so, I started praying and take her to church. It was at one of those prayer sessions that I was told it was a ‘bad disease/spiritual condition’” – Mother of a 12-year-old child with an undiagnosed intellectual and developmental delay

CHAPTER 5

DISCUSSION

5.1 Introduction

This chapter discusses the results from the analysis of the data. It also compares findings from previous and similar work in the study area. This study used qualitative methods to explore the perception of the quality of care for children with intellectual disabilities from both parents and health workers perspectives in the Adentan Municipal Assembly of the Greater Accra region of Ghana.

5.2 Health Needs of children with Intellectual and Developmental Delays

The study found out that both parents and health workers at the primary healthcare levels did agree that children with intellectual disabilities have varied and complicated health needs. These health needs range from physical, clinical and emotional/psychosocial. The respondents also agreed that the complexity of the health needs varies from individual child to the next depending on the specific condition/disability. This requires a multi-disciplinary team to be able to adequately meet the health needs of these children and their families. This finding is in line with the work done in the US by (Denboba *et al.*, 2006), which points to the range of services required by children with intellectual disabilities and the need for partnership between their families and the health/allied service providers.

Although both parents and health workers who participated in this study alluded to the diverse and convergent health needs of children with intellectual disabilities, the health workers were quick to admit that they do not have the requisite skills to meet these needs at the primary health care level. This was clear in the data gathered where health workers were asked to show their knowledge of disabilities in general and intellectual disabilities specifically by mentioning and describing the disabilities they know. It was clear as shown in the results above that some

of the descriptions and the names of the disabilities mentioned do not agree, in the sense that most of the health worker participants could not clearly state which disability is physical or intellectually and developmentally delayed in nature. This clearly points to the fact that there is a knowledge gap in identifying the various forms of disabilities and the care required for it at the primary health level. This finding is also in agreement with the work done by (Ervin *et al.*, 2014), that showed that most children with intellectual disabilities received care from professionals who are not fully trained on the health needs of such populations.

Our findings also showed that for most of the health workers interviewed, they seem to have a fair idea of what is supposed to be done especially when a child is born with noticeable features of disability. However, there is the assumption that it is supposed to be done by someone else in a tertiary facility, but this also points to the fact that these health workers at the primary health level lack the requisite skills for supporting families and their children with intellectual disabilities at the primary health delivery level. And this is also because looking at the training curriculum for the various health workers for the primary health level like the Registered Nurses, the Community Health Nurses and the Midwifery training curriculum, there is nothing in there that teaches how to identify and take care of these individuals at the community level. The only course that seems to run through is the Community-based Rehabilitation (CBR), this, however, does not go into details of how to provide essential services at the community level and where to refer when beyond their capacities.

5.3 Perception of the quality of care

Unfortunately, when it comes to the specialized services provided for families and their children with intellectual and developmental delays, these are all found in the secondary and tertiary referral facilities. This clearly puts barriers to access health care access for families and

their children with IDD. The reluctance of primary health workers to even attend to children with IDD that are brought to such facilities for care was noted as shown in the results above.

We noticed that at the primary health care level, health workers would rather attend to a family with a sick typical child than assist the family with a child with intellectual disabilities. The health workers we interacted with insisted that this is more human nature than it is a professional lack of empathy or competence. But one would assume that the professional training received by these health workers will rather make them want to assist those that clearly present with needs instead of letting their human nature overcome whatever training they may have received. In a similar study carried out in Nigeria for dentists, some of them stated that their reluctance to take care of children with special needs is because of reasons like inadequate training, general discomfort around children with special needs and the inability of such families to pay for their services as shown in (Oredugba and Sanu, 2006). This work showed dentists clearly stating why they would be reluctant or choose not to treat a child with especially intellectual disability as it can be tedious and challenging due to the fact that such children are uncooperative which can lead to spending so much time on one case, they are just not interested in such cases or it is simply too emotional for them to take care of such children. Although this study was conducted with specialists, dentist, we noted that the reasons they gave are like those given by the participants of this study although they operate at the primary health care level.

5.4 Healthcare barriers

Families raising children with intellectual disabilities face a lot of barriers to healthcare. These include the barrier of cost, perceptions, and attitudes to disabilities and accessibility to specialist care. As mentioned earlier, children with intellectual disabilities have several health conditions that require a coordinated effort in addressing these. Once there is partnership between the primary health care provider and the parents/guardians of children with

intellectuals' disabilities, the coordination for the care of such children is better. However, it is important to note that the barriers identified are real. The barrier of cost includes transportation, cost of care and medicine due to the frequency with which such families will visit the health facility. Most of the cost parents incur tends to be out-of-pocket as most of the additional health needs that these children may have are not covered on the National Health Insurance scheme in Ghana. This finding seems to be in unison with the work done in the US on caring for children with special healthcare needs (Sadof and Nazarian, 2007).

There is also the barrier of access – in Ghana, most of the specialist care can be found in one of the three (4) teaching hospitals that we have, i.e.: Korle-Bu Teaching Hospital in Accra, Komfo Anokye Teaching Hospital in Kumasi, the Tamale Teaching Hospital, Cape Coast Teaching Hospital or any of the Regional hospitals. If a family with a child with intellectual disabilities live in one of these peripheral and hard to reach communities, the challenge of cost, transportation and even the decision to go to any of these facilities becomes a huge barrier that will, in turn, give that child a poor health outcome.

One of the huge barriers that families of children with intellectual disabilities face is that of perceptions and attitudes to disabilities in general and intellectual disabilities especially. This perception cuts across all spheres of society hence you will have health workers advising parents to take their children from the hospital and seek traditional/spiritual cure for the child. The stigma and discrimination because of this poor perception and attitudes to disabilities put so much burdens on parents and families raising such children as indicated earlier (Baffoe, M., 2013).

Overall, we can say that parents of children with intellectual disabilities are not satisfied with the kind of care they get at the primary health level as well as health workers at this level also admitting their lack of skills and adequate knowledge when it comes to providing care for these

children and their families. It is very important to equip primary healthcare workers with the requisite skills and knowledge to be able to support families with their children as well as be in the position to refer cases when the need arises. Healthcare workers at the primary level can only be able to do effective referrals if they have the needed knowledge about the conditions that fall under intellectual and developmental disabilities and the secondary health needs that these conditions bring on. Every child with a disability and therefore intellectual disability stands to benefit from the early intervention package of care very early in their lives to improve their overall health and life outcomes. It is therefore essential that the healthcare workers at the primary health level are equipped to provide some basic form of the early intervention services at the community level as stated in the CBR guideline (*CBR Guidelines Community-Based Rehabilitation, 2010*).

CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

6.1 Introduction

Children born with intellectual and developmental delays face a lot of challenges which does not only put so much burden on them as growing children but also put an enormous burden on their parents and caregivers in general. Every parent expects to give birth to typical children when they are pregnant and so the challenge of dealing with a birth outcome that is different from what we envisaged is challenging. However, this is compounded when a parent does not know that there may be something different about their child because they have not been told by the primary healthcare worker, who is the first point of contact at the community level simply because the primary healthcare worker lacks adequate knowledge about the child's presentation.

6.2 Conclusion

There are children being born all over the country with intellectual disabilities who may never access healthcare from any of the tertiary facilities where we have specialist care because they may be in hard to reach communities in the peripherals. It is therefore very necessary to empower the primary healthcare workers to be able to provide the additional healthcare services required by such children and their families and where necessary should do effective referral to the next point of service provision without parents getting frustrated with the system and giving up

This situation does not empower the parents and family to accept and adequately support that child. In Ghana, the general knowledge of disabilities that people have is that of the

classic/traditional disabilities of the hearing and speech impaired (deaf and dumb), the sight impaired (blind) and the physically challenged (disabilities affecting the limbs, lower or upper extremities). However, there is very little known about intellectual disabilities and how they present even among the healthcare workers at the primary healthcare level.

To make universal healthcare accessible to all through primary health care, we need to make a conscious effort as a country to prepare for and provide targeted healthcare for children born with intellectual disabilities at the community level.

6.3 Recommendations

Implementation

Considering the Ghana Health Service is championing the Universal Healthcare through primary healthcare through the Community-based Health Planning and Services (CHPS) system, there is a need to work through the District and Municipal Health Directors of Health to empower the health workers that are posted to the CHPS compounds and the health centres with the requisite knowledge, on-the-job training to acquire the skills to be able to cater for the healthcare needs of families raising children with intellectual disabilities at our community level. This will also be a source of data for the country to be able to get some reliable country-wide data on some of these intellectual disabilities and their occurrence in the population.

Policy

As a country, to be able to empower persons living with disabilities, we need to begin to plan with them in mind. There are children born with intellectual disabilities to poor families who cannot afford daily meals and therefore the additional health needs of these children born with disabilities. It imposes more burden if such children are given incentives to support them become productive by providing access to free specialist health care as well as free inclusive

education. This will go a long way to make this child to get the needed services and skills to grow up to become productive individuals for mother Ghana instead of burdens for their families. This also requires that we review our colleges of education and health and allied health sciences institutions' curricular to be sure that before this personnel come out of schools, they have acquired the requisite knowledge and skills and an inclusive mentality and approach to the way they render services to this minority group in our society

Research

Although this research provided data for understanding the perceptions of the quality of care for children with intellectual disabilities through the experiences of parents and health workers at the primary health care level, it is a qualitative study, so its results are not representative and therefore cannot be generalized for all. There is a need for further studies in this area in Ghana to generate both qualitative and quantitative data for multiple interpretations and applications.

REFERENCES

- Alaszewski, A. Gates, B. Mother by, E. Manthorpe, J. and Ayer, S. (2011). Educational Preparation for Learning Disability Nurses within the Multi-professional, Multiagency Team. London: English National Board for Nursing, Midwifery and Health Visiting.
- Agbenyega, J. (2007). Examining Teachers' Concerns and Attitudes to Inclusive Education in Ghana. *International Journal of Whole Schooling*, 3(1).
- An Action on Disability and Development (ADD) (2005). Challenges faced by People with Disabilities (PWDs) in utilizing HIV/AIDS communication and Related Health Services in Uganda.
- Armbruster, Margaret E. (1992). *The Civitan Story*. Birmingham, AL: Ebsco Media. pp. 74–75.
- Baffoe, M. (2013). *Stigma, Discrimination & Marginalization: Gateways to Oppression of Persons with Disabilities in Ghana*, West Africa. *Journal of Educational and Social Research* Vol. 3 (1) January 2013
- Barker, P. Howells K., (2010). *The Tidal Model: From Theory to Practice*. Newcastle: University of Newcastle.
- Bagner D.M.; Eyberg S.M. (2007). "Parent-child interaction therapy for disruptive behaviour in children with mental retardation: A randomized controlled trial". *Journal of Clinical Child and Adolescent Psychology*. **36** (3): 418–429. doi:10.1080/15374410701448448. PMID 17658985.
- Beange B, (2016). *Health Matters for People with Developmental Disabilities: Creating a Sustainable Health Promotion Program*. Baltimore.
- Burke, J., Bezyak, J., Fraser, R. T., Pete, J., Ditchman, N., & Chan, F. (2013). *Employers' Attitudes Towards Hiring and Retaining People with Disabilities: A Review of the Literature*. *The Australian Journal of Rehabilitation Counselling*, 19(1), 21-38. doi:http://dx.doi.org/10.1017/jrc.2013.2

- Campbell F.A.; Ramey C.T.; Pungello E.; Sparling J.; Miller-Johnson S. (2002). "Early childhood education: *Young adult outcomes from the Abecedarian Project*". *Applied Developmental Science*. **6**: 42–57. doi:10.1207/s1532480xads0601_05.
- Chan, C. C. H., Lee, M. C., Yuen, H. K., & Chan, F. (2008). Attitudes toward people with disabilities between Chinese rehabilitation and business students—An implication for practice. *Rehabilitation Psychology*, *47*, 324-338.
- Daily DK, Ardinger HH, Holmes GE (February 2000). "*Identification and evaluation of mental retardation*". *Am Fam Physician*. *61* (4): 1059–67, 1070. PMID 10706158. Archived from the original on 2010-12-04
- Elwan, A. (1999). Poverty and Disability A Survey of the Literature *Social Protection Discussion Paper Series*: Social Protection Unit, Human Development Network, The World Bank.
- Felce D, and Perry J. (2015). Quality of life: Its definition and measurement. *Research Development Disability* 2015; 16(1): 51–74.
- Harris Interactive Inc. (2010). National Organization on Disability. *Harris Survey of Americans with Disabilities*. New York, NY: Harris Interactive Inc.
- Hay I.; Elias G.; Fielding-Barnsley R.; Homel R.; Freiberg K. (2007). "*Language delays, reading delays and learning difficulties: Interactive elements requiring multidimensional programming*". *Journal of Learning Disabilities*. **40** (5): 400–409. doi:10.1177/00222194070400050301. PMID 17915494.
- Hiidenhovi, H., Laippala, P., and Nojonen, K. (2011). Development of a patient-orientated instrument to measure service quality in outpatient departments. *Journal of Advanced Nursing*, *34*(5), 696–705.
- Hodapp, R.M., & Burack, J.A. (2006). *Developmental approaches to children with mental retardation: A second generation?* In D. Cicchetti & D. J. Cohen (Eds.), *Developmental psychopathology*, Vol. 3: Risk, disorder, and adaptation (2nd ed., pp. 235–267). Hoboken, NJ: Wiley.

- Howells, G. (2016). 'Are the medical needs of mentally handicapped adults being met? *Journal of the Royal College of General Practitioners*. Vol. 36, pp. 449-453.
- IACAPAP Textbook of Child and Adolescent Mental Health. 2015. ISBN 978-0-646-574400. Archived from the original on 2015-08-13.
- Iezzoni, L. I., Davis, R. B., Soukup, J., and O'Day, B. (2003). Quality dimensions that most concern people with physical and sensory disabilities. *Archives of Family Medicine*, 163, 2085–2092.
- Ineichen, D. M., & Russell, C. (2007). Micro-insurance: Extending Health Insurance to the Excluded. *International social security review*, 52(1), 71-97.
- Kalachnik, JE.; Hanzel, TE.; Sevenich, R.; Harder, SR. (Sep 2002). "Benzodiazepine behavioural side effects: review and implications for individuals with mental retardation". *Am J Ment Retard*. **107** (5): 376–410. doi:10.1352/0895-8017(2002)107<0376:BBSERA>2.0.CO;2. ISSN 0895-8017. PMID 12186578.
- Kassah, A. (2012). Abuse of Disabled Children in Ghana. *Disability & Society*, v27 n5 p689-701 2012.
- Kerr, C., Boerma, T., Evans, D., Harries, A., Lienhardt, C., McManus, J., Zachariah., R. (2016). The World Health Organization 2013 Report: *Research for Universal Health Coverage*: World Health Organization.
- Kemp C.; Carter M. (2002). "The social skills and social status of mainstreamed students with intellectual disabilities". *Educational Psychology*. **22** (4): 391–411. doi:10.1080/0144341022000003097.
- Lawthers, A. G., Pransky, G. S., Peterson, L. E., & Himmelstein, J. H. (2003). Rethinking quality in the context of persons with disability. *International Journal for Quality in Health Care*, 15(4), 287–299.
- Lin, P. Y., Lin, L. P., & Lin, J. D. (2010). Hypertension, hyperglycemia, and hyperlipemia among adolescents with intellectual disabilities. *Research in Developmental Disabilities*, 31, 545–550.

- Maes, B, L. Geeraert and B. Van den Bruel, (2010). 'Developing a model for quality evaluation in residential care for people with intellectual disability'. *Journal of Intellectual Disability Research*. Vol.44, Part 5, pp. 544-552.
- Marmot, M., Friel, S., Bell, R., Houweling, T. A., and 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
- Matson J.L.; Matson M.L.; Rivet T.T. (2007). "Social-skills treatments for children with autism spectrum disorders: an overview". *Behaviour Modification*. **31** (5): 682–707. doi:10.1177/0145445507301650. PMID 17699124.
- Mash, E., & Wolfe, D. (2013). *Abnormal child psychology*. (5th ed., pp. 308–313). Wadsworth Cengage Learning.
- Muhammad Iqbal, Muhammad A. Baig, Munir A. Bhinder, M. Y. Z. (2016) 'Factors causing mental retardation', (October).
- Mugilwa, L. O., Wasala, W. O., and Oyugi, L. N. (2015). Health care service utilization in Kenya. Colombo, Sri Lank: Poverty and Economic Policy (PEP) Research Network's Poverty Monitoring, Measurement and Analysis (PMMA).
- Nocon, A., and Sayce, L. (2008). Primary healthcare for people with mental health problems or learning disabilities. *Health Policy*, 86, 325–334.
- Nordhaus, W. D. (2012). The health of nations: the contribution of improved health to living standards: *National Bureau of Economic Research*.
- Nukunya, G. K., (2003), *Tradition and Change in Ghana: An Introduction to Sociology*, (2nd Edition), (Accra, Ghana Universities Press).
- Parmenter T., R., (2008). Quality of life of people with developmental disabilities. In: Bray NW (ed.), *International Review of Research in Mental Retardation*, Vol. 18, Academic Press, Inc., 1992: 247–287.
- Peters, D. H., Garg, A., Bloom, G., Walker, D. G., Brieger, W. R., & Hafizur Rahman, M. (2008). Poverty and access to health care in developing countries. *Annals of the New York Academy of Sciences*, 1136(1), 161-171.

- Ramey S.L.; Ramey C.T. (1992). "Early educational intervention with disadvantaged children—To what effect?". *Applied and Preventive Psychology*. (3): 131–140. doi:10.1016/s0962-1849(05)80134-9.
- Rimmer, J. H., Riley, B., Wang, E., Rauworth, A., and Jurkowski, J. (2014). Physical activity participation among persons with disabilities: barriers and facilitators. *American journal of preventive medicine*, 26(5), 419-425.
- Roy Porter; David Wright (7 August 2003). *The Confinement of the Insane: International Perspectives, 1800–1965*. Cambridge University Press. ISBN 978-0-521-80206-2. Retrieved 11 August 2012.
- Sherr, E. H., San, C. and Francisco, S. (2014) 'Mental Retardation / Intellectual Disability', 3, pp. 114–118. doi: 10.1016/B978-0-12-385157-4.00436-X.
- Shin G., and Moon, S. (2008). Quality of care and role of health insurance among non-elderly women with disabilities. *Women's Health Issues*, 18(4), 238–248.
- Slikker, J. (2009) 'Attitudes Towards Persons With Disability In Ghana', VSO Ghana, (May), p. 82.
- Siperstein G.N.; Glick G.C.; Parker R. (2009). "The social inclusion of children with intellectual disabilities in an out of school recreational setting". *Intellectual and Developmental Disabilities*. 47 (2): 97–107. doi:10.1352/1934-9556-47.2.97. PMID 19368488.
- Suhonen, R., Leino-Kilpi, H., and Va'lima' ki, M. (2015). Development and psychometric properties of the Individualized Care Scale. *Journal of Evaluation in Clinical Practice*, 11(1), 7–20
- Suhonen, R., Va'lima' ki, M., and Leino-Kilpi, H. (2012). Individualized care from patients', nurses' and relatives' perspective—A review of the literature. *International Journal of Nursing Studies*, 39, 345–354.
- "The ARC Highlights — Beyond Affliction: Beyond Affliction Document". Disabilitymuseum.org. Archived from the original on 2010-07-11. Retrieved 2010-06-29.
- Vasconcelos, M. M. (2004) 'Mental retardation', pp. 71–82.
- Van der Schuit M, Segers E, van Balkom H, Verhoeven L (2011). "Early language intervention for children with intellectual disabilities: a neurocognitive perspective". *Research in*

Developmental Disabilities. **32** (2): 705–12. doi:10.1016/j.ridd.2010.11.010. PMID 21159487.

Wickham, Parnell. Encyclopedia of Children and Childhood in History and Society. Archived from the original on 28 September 2010. Retrieved 8 October 2010.

WHO (2010) '*Health component CBR Guidelines*', p. 79.

World Health Organisation (2013). *What is a disability?* Retrieved 12/05/2018 from <http://hcdg.org/definition>

World Health Organization. (2010). *Community-Based Rehabilitation CBR Guidelines Health Sector*. Switzerland: WHO publications.

Wolf Wolfensberger (January 10, 1969). "The Origin and Nature of Our Institutional Models". *Changing Patterns in Residential Services for the Mentally Retarded*. President's Committee on Mental Retardation, Washington, D.C. Archived from the original on May 12, 2006.

Zimba Yvonne 2015. Disability welfare & development cooperation: Zambia & Finland. Global, South, March 11, 2015. Accessed on 24/9/2015

<http://www.gsdmagazine.org/disability-welfare-developmentcooperation-zambia-finland/>

Baffoe, M. (2013) 'Stigma, Discrimination & Marginalization: Gateways to Oppression of Persons with Disabilities in Ghana, West Africa', *Journal of Educational and Social Research*. doi: 10.5901/jesr.2013.v3n1p187.

CBR Guidelines Community-Based Rehabilitation (2010). Available at: www.iniscommunication.com (Accessed: 18 October 2018).

Denboba, D. *et al.* (2006) 'Achieving Family and Provider Partnerships for Children With Special Health Care Needs', *Pediatrics*, 118(4), pp. 1607–1615. doi: 10.1542/peds.2006-0383.

Ervin, D. A. *et al.* (2014) 'Healthcare for Persons with Intellectual and Developmental Disability in the Community', *Frontiers in Public Health*, 2(July), pp. 1–8. doi: 10.3389/fpubh.2014.00083.

- Esmaeeli-Nieh, S. and Sherr, E. H. (2014) 'Mental Retardation/Intellectual Disability', in *Encyclopedia of the Neurological Sciences*, pp. 1090–1094. doi: 10.1016/B978-0-12-385157-4.00436-X.
- Ghana Statistical Service (2012) '2010 Population and housing census: Final results', *2010 Population and Housing Census*. doi: 10.1016/j.adolescence.2008.08.001.
- Iqbal, M. *et al.* (2016) 'Factors causing mental retardation', *Asian Journal of Natural & Applied Sciences*, 5(October), pp. 28–37.
- Oredugba, F. A. and Sanu, O. O. (2006) 'Knowledge and behavior of Nigerian dentists concerning the treatment of children with special needs', *BMC Oral Health*, 6, pp. 1–8. doi: 10.1186/1472-6831-6-9.
- Sadof, M. D. and Nazarian, B. L. (2007) 'Caring for Children Who Have Special Health-care Needs: A Practical Guide for the Primary Care Practitioner', *Pediatrics in Review*, 28(7), pp. e36–e42. doi: 10.1542/pir.28-7-e36.
- Suhonen, R., Välimäki, M. and Leino-Kilpi, H. (2002) "'Individualised care" from patients', nurses' and relatives' perspective - A review of the literature', *International Journal of Nursing Studies*. doi: 10.1016/S0020-7489(02)00004-4.
- Vasconcelos, M. M. (2004) 'Mental retardation', pp. 71–82.
- WHO (1948) 'Constitution of WHO', *Official Records of WHO*.
- WHO (2010) 'Health component CBR Guidelines', p. 79.
- World Health Organisation (1996) *ICD-10 guide for mental retardation*, WHO.
- World Health Organization (2010a) 'CBR Guidelines: Health Component', *World Health Organization*. doi: ISBN 978 92 4 154805 2.
- World Health Organization *et al.* (2010) *CBR Guidelines*, World Health Organization Press.
- World Health Organization (2010b) *Introductory booklet: CBR Guidelines*, World Health Organization. doi: ISBN 978 92 4 154805 2.

APPENDICES

Appendix A – Participant consent form

I. Introduction

- Greetings and thank you for your audience. This in-depth interview is to assist us in understanding Ghana's response to the health care delivery for persons with intellectual disabilities
- This assessment is being conducted by Ms. Debbie Mangortey as part of her requirements leading to the award of a Master's in Public Health degree from the Ensign College of Public Health, Kpong. Your participation is very important because you are one of the relevant stakeholders regarding Health care delivery in Ghana. There are no right or wrong answers to any of the questions. Feel free to express your ideas, opinions, or experiences.
- This study has been approved by the Ensign College of Public Health's Ethics Committee. If you have any concern about the conduct of this study, your welfare and rights as research participant or you have questions, you may contact my academic supervisor, Dr. Reuben Esena on 054 301 290
- As you may have noticed, there is a recorder in my hand. We hope that having a recorder will not make you feel uncomfortable. We want to make sure we capture all your ideas and that we do not miss any of the valuable information you may offer.
- Please be assured that your individual comments here today are confidential in the sense that we will not identify you by name or your statements. We would like you to sign an informed consent form to ensure/affirm your voluntary participation in this discussion.
[ADMINSTER CONSENT FORM AT THIS POINT]
- Do you have any questions so far?

Appendix B – Interview Guide

II. Background information

1. Sex: Male [] Female []
2. Where do you live? _____
3. What religion do you profess please?
4. How old are you please? a. Christianity [] b. Muslim [] c. Traditional []
d. Others (specify): _____
5. Marital status of parents Married [] Divorced [] Widowed []
Separated [] Never married/ single []
6. What is your professional title? (RN/GN/CHN/PA/Midwife)
7. How many years of experience do you have please?
8. What facility is this?
 - a. What is your role here?

III. What happens

1. Please tell me what happened when a child is born, (either in the community or at the facility), or diagnosed with the disability?
 - a. How is that recorded?
 - b. Do you, your staff or colleagues have the skills, knowledge and resources to counsel?
 - c. How was the parent/caregiver counselled?

IV. Knowledge

1. Can you please give examples of disabilities you know?
 - a. Please describe the physical or noticeable features of these disabilities mentioned above

- b. Which of these would you say are physical or intellectual and developmental delay related?
- c. Which of these do you see at your facility or during home visits?

V. Comprehensive/integrated care

1. What do you understand by the term Comprehensive care?
 - a. What do you think about comprehensive care especially for children/persons with disabilities?
 - b. How can this be implemented at the various levels of primary healthcare?
 - i. CHPs
 - ii. Health Centres
 - iii. District hospitals
2. Please tell me what you know about the Community-based Rehabilitation (CBR) program
 - a. How would you say you have participated in/implemented CBR activities in the community you work in?
 - b. What resources do you think is needed to effectively implement the CBR?
3. What will be your recommendations for the implementation of?
 - a. Comprehensive/integrated care?
 - b. Community-based Rehabilitation (CBR) program
 - c. Support for the health needs of families raising children with disabilities at the community level

Thank you for your time

OUR REF: ENSIGN/IRB/M4
YOUR REF:
Tel: +233 245762229
Email: irb@ensign.edu.gh
Website: www.ensign.edu.gh



P. O. Box AK 136
Akosombo
Ghana

Tuesday, 13 November 2018

INSTITUTIONAL REVIEW BOARD SECRETARIAT

Debbie Mangortey
Ensign College of Public Health

Dear Miss Mangortey,

OUTCOME OF IRB REVIEW OF YOUR THESIS PROPOSAL

At a meeting of the INSTITUTIONAL REVIEW BOARD (IRB) of Ensign College of Public Health held on 1st November, 2018 your proposal entitled "**Perception of Parents on the Quality of Care for Children with Intellectual Disability by Healthcare Professionals in the Adenta Municipality, Ghana**" was considered.

Your proposal has been approved for data collection in the following settings:

1. Provide consent and assent forms.
2. Title of the study should include the region.
3. Should provide tools for the study.
4. Should clearly indicate how data was going to be collected.
5. Should indicate how and where children with intellectual disabilities and their caregivers will be identified.
6. Should seek permission from GES if the study will include schools.

We wish you all the best.

Sincerely,

Dr (Mrs) Acquaaah-Arhin
(Chairperson)

Cc. President, ECOPH
Cc: Academic Registrar, ECOPH
Cc: Head of Academic Program, ECOPH

BOARD OF TRUSTEES:

Mrs. Lynette N. Gay - Chair, Prof. Agyeman Badu Akosa- Vice Chair, Dr. Stephen C. Alder, Prof. Michael Hardman, Dr. Kwesi Dugbatey (Emeritus) , Prof. Tsiri Agbenyega, Dr. Daniel Ansong, Togbe Afede XIV, Mr. Kyle Gay