

**Disabled But Not Unable; Agency and Children with Physical Disability, a Case Study in
Ghana**

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DECLARATION

I hereby declare that, but for other works that have been cited and are duly acknowledged, this thesis is my own original work.

.....

Mispah Mawusi Mamah

DEDICATION

I dedicate this thesis to my family for their immense support. Most especially to my late father, Paul Y. Mamah, I wish he could have waited a bit longer to share in my joy and success of this work. Nevertheless, I am always appreciative of his parental guidance.

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ABSTRACT

Children with disabilities in most Ghanaian societies are considered burdens, victims of circumstances, who deserve nothing but pity. Coupled with this is the long standing cultural construction of disability as a punishment from the gods. Consequently children with disabilities are mostly excluded from the mainstream society and are denied opportunities to explore their abilities, skills and potentials. Many studies in the field of disability have focused mainly on the disturbing situations of children with disabilities. This study sought to explore agency of children with physical disability by looking at how they navigate their experiences of disability amidst restrictions and complexities of disability in their everyday lives. The study further explored the children's perspective of their disability. The study was conducted in the context of two regular schools in Ghana. Children with physical disability, most of whom have mobility difficulties formed the main informants. The general methodological approach employed was qualitative. Methods used include individual interview, diary and participant observation. The study was informed by the perspectives of the Sociology of childhood.

The findings in this study suggest that the children's perception about the causes of their disability could to some extent shape how they navigate experiences of disability. The study also reveals that the children employed overlapping perspectives; the medical model of disability and social model of disability in constructing their disability. While alluding to the fact that their body's malfunction place limitation on their abilities in some ways, they also believe that failure of the society to give consideration to their condition is disabling. The study further suggests that children with physical disabilities are social agents who exercise their agency in myriads ways. Nevertheless factors such as poverty, discrimination, absence of proper structures constrain how the children negotiate their agency.

LIST OF ABBREVIATIONS

CBRP	Community Based Rehabilitation Program
FCUBE	Free Compulsory Universal Basic Education
GFD	Ghana Federation of the Disabled
JHS	Junior High School
NGO	Non-governmental Organization
PWD	People with Disabilities
SHS	Senior High School
UNCRC	United Nations Convention on the Rights of the Child
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children's Emergency Fund
WHO	World Health Organization

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CHAPTER 1

INTRODUCTION

1.1 Choice of Topic

Growing up in a society where children with disability are seen as lesser humans have shaped my perceptions of abilities of such children. In my career as a teacher, I have seen some physically challenged¹ children being active, independent and participating in most activities just like any able-bodied child. I remember a physically challenged boy in one of the schools I taught who was the number one goalkeeper of the school and represented the school in most football games to the point that he was selected to represent a zone in inter-zonal sports competition. However, I was still clouded in society's perception of children with disability as being burdens, dependent and incapable of living a normal life until I started Mphil in Childhood Studies in Norway where the focal idea is that, children are active social actors, capable of contributing and navigating their lives even in difficult circumstances. I began questioning my perceived perception of children with disabilities. I wondered, can children with bodily limitations be active social agents? Why are so many physically challenged children begging on streets as a means of survival in Ghana? Why are many of them neglected by their families and seen as burdens on their families who are already living in abject poverty?

My quest to find answers and finally deciding to do research focusing on agency of physically challenged children in Ghana was further informed by some articles I read that pointed to the knowledge deficit of how disabled children are capable and can actively be involved in constructing of their lives (James, 2009; Klocker et al., 2007; Linton, 1998). Linton (1998) commented, the field of disability is even more marginal in academic culture than disabled people are in civic culture, the enormous energy society expends keeping people with disability in subordinate position is matched by the academic's effort to justify that isolation and oppression. Klocker et al. (2007) also stated that agency of disabled children still remains an important under researched area especially in the global south where there are strong prejudices associated with disability and fewer support system for children with disability.

¹ Physical disability

1.2 Statement of Problem

According to The World Health Organisation (WHO), there are more than 600 million disabled persons in the world, of which approximately 80 % live in low-income countries. Even though, no accurate national survey has been carried out to determine the disability rate in Ghana, WHO estimates the disability rate of Ghana to be between 7 and 10 %, which equates approximately 1.55 – 2.2 million people in the country to be disabled (GFD, 2015). In most developing countries, including Ghana, disabled persons constitute an impoverished marginalised group, characterised by lack of access to public health, education, and other social services that would ideally support and protect people with disabilities. Persons with disabilities have generally lower incomes and mostly suffer from poverty. Majority live at the mercy of their families throughout their lives. Since the management group are themselves poor, disabled persons are often underfed and some out of desperation resort to begging (Kassah, 1998, 2008).

People with disabilities in Ghana are often regarded as unproductive and incapable of contributing in a positive way to society. They are rather seen as constituting an economic burden on the family and the society at large, which leaves them in a vicious cycle of poverty. Munyi (2012), describes the situation of persons with disabilities as hopeless and helpless. In developing countries there are few strong disability movements actively working to improve the living conditions for people living with disabilities. Disabled persons are often only weakly represented in civil society.

Though in recent times, efforts are been made to ensure the rights and welfare of disabled in Ghana, for example the Disability Act was passed in 2006, to guarantee the rights of persons with disabilities, Community-Based Rehabilitation Program (CBRP) to provide material assistance for the disabled. However most of these initiatives focus on provision of material resources hence children with disabilities still remain in a vulnerable and dependency position. Furthermore, in Ghana, existing research on disability in general is very limited and more specifically on children with physical disability is barely adequate. Accounts from the literature have shown that previous studies on disability mainly focused on historical and cultural construction of disability, disheartening conditions of people with disability and failing rehabilitation programs (Avoke, 2002; Kassah, 1998, 2008; Tinney, Chiodo, Haig, & Wiredu, 2007). This reveals the paucity and little attention that existing research has paid to agency and resilience of physically challenged

children to navigate their experiences of disability amidst the complexities surrounding disability in the context of Ghana. Agency of children with disabilities has been under explored both in academics and social sphere. As such there is knowledge deficit of how disabled children are capable and can actively be involved in constructing their lives. There is, therefore, a need for a study to explore agency of children with disability looking at whether and how these children, use agency to navigate their experiences of disability amidst the complexities surrounding disability in Ghana.

1.3 Research Aim / Research Questions

This research sought to explore agency of children and young people² with a physical disability. With particular attention to children with mobility difficulties, looking at whether and how these children, use agency to navigate their experiences of disability in their lives, amidst the complexities surrounding disability in the context of Ghana. In order to achieve this aim, 8 weeks fieldwork was conducted where qualitative methods including interview, diary and participant observation were used to collect data. The main research question is: **How do children with physical disability navigate their experiences of disability amidst restrictions and complexities of disability in their everyday lives?** More specifically the research addresses the following interconnected questions:

- What are disabled children's perspectives of their disability?
- How do children with physical disability negotiate experiences of disability in their daily lives?
- What are disabled children's experiences of interactions with non-disabled persons?
- How do disability and agency interplay in the lives of children with a physical disability?

1.4 Thesis Outline

This thesis is organized into chapters as follows: *Chapter 1* introduction, including this section, briefly highlights my choice of topic, problem statement, and outline the aim of the research and research questions explored. *Chapter 2*, describes the context and the background of the study, highlighting demographic features of the study area, the educational system in Ghana and policies

² Considering the context in which the study was conducted, the age group of the participants could be referred to as young people. However, throughout this thesis, I refer to them as children bearing in mind the declaration of the CRC

underpinning education of disabled children. The chapter also draws attention to cultural constructions of disability in Ghana, disability situation and policies and programs for disabled in Ghana. *Chapter 3* follows with a discussion on conceptual and theoretical framework underlying the study. The key concept as agency of children is briefly discussed and contextualized. Models, theorizing disability are also presented in the chapter. *Chapter 4* describes research methodology thus my research design, the process of fieldwork, methods of data collection and analysis as well as methodological and socio-ethical dilemmas I faced during the process of the research, and how I negotiated those challenges. I present in *chapters 5 & 6* the analysis and discussion of the research findings which are organized based on the research questions and emerging themes from the study. Finally, a summary of the entire thesis, concluding interpretations and recommendation for further study is presented in *chapter 7*.

CHAPTER 2

CONTEXT / BACKGROUND OF THE STUDY

2.0 Introduction

Over the years, perceptions towards disability have varied greatly from one community to another. Societal perceptions and understanding of disability and treatment of persons with disabilities are continually evolving, however, remains socially constructed. In line with this, it is important to be aware of the material conditions, cultural orientations and contextual influences of a particular study area to help provide a better understanding of the outcomes of a research. This chapter provides background information of the study area highlighting structural, cultural, social and legal framework as the starting point of my study.

2.1 Demography

The study was conducted in Ghana specifically in the North Tongu District, one of the twenty-five (25) Municipalities and Districts³ in the Volta Region of Ghana. Its Administrative capital is at Battor Dugame. The district shares boundaries with Central Tongu District to the east, to the west with Asuogyman and Dangme West Districts respectively, and to the south with Ada West District (Ghana Districts, 2015). The population of the district stands at 89,777 according to the 2010 population and housing census. The district recorded disabled population of 4.3% in the 2010 population and housing census. Out of the total disability figure, 22.8 % are physically disabled, the second highest form of disability in the district. The census report also indicates that a large number of disabled persons, 3 years and older have never attended school. The majority of those who have attended school, have only attained primary, middle school and junior high school as the highest levels of education whilst insignificant figures were recorded at senior high school and other higher levels of education (Ghana Statistical Service, 2014).

The people of North Tongu are predominantly farmers, mainly engaging in crop production, forestry and fishing. The district is divided by a stretch of the Volta River with communities lying along opposite sides of the river. Popular means of transportation are by vehicle, motorbike and

³ The Districts of Ghana are second-level administrative subdivisions, below the level of regions. The District Assemblies are either Metropolitan of population over 250,000, Municipal, population over 95,000 or District, population of 75,000 and over.

boat. Road network in the district is basically feeder of which most are untarred commonly called rough road (Ghana Statistical Service, 2014).

2.2 Educational System in Ghana

The educational system in Ghana is broadly divided into three levels. Starting from basic education, secondary cycle and tertiary levels. Basic education is compulsory and free. It spans for 11 years, made up of 2 years of Kindergarten, 6 years of Primary School, and 3 years of Junior High School (JHS). After JHS, students may choose to go into different streams at secondary cycle comprising Senior High School (SHS), and Technical, Vocational Training school or enter into an apprenticeship scheme. The secondary cycle level is normally a three or four year course which prepares students for further education or employment. At the end of the three year senior secondary course, students are required to sit for the West African Senior Secondary Certificate Examinations (WASSCE). Tertiary level is made up of universities, polytechnic and other higher institutions that award diplomas (Ghanaweb, 2015).

English is the official language of instruction throughout the Ghanaian educational system. Students may study in any local languages for much of the first three years, after which English becomes the norm. Students continue to study a local language and in some schools French as classroom subjects through at least JHS form three⁴. All textbooks and materials are in English. A great number of schools in Ghana are residential (boarding), where students live in the school premises all through. However, some boarding schools also have day students who return home after school session every day. The common practice in boarding schools is that the school authorities provide accommodation and meals for the students. But there are some schools that only provide accommodation while the students provide meals themselves, and this was the case in one of the schools where my study was conducted. Schooling in Ghana is often characterized by morning to afternoon periods of instruction in the classroom with breaks. Students usually appear in standardized uniforms. A normal school day starts with cleaning up the school compound and classrooms by students before lessons start.

⁴ Junior High School form three is equivalent to grade 9

2.3 Educational Policies Underpinning Education of Children with Disability.

Free Compulsory Universal Basic Education (FCUBE), was introduced in 1995 to make basic education free and give the opportunity to all Ghanaian children including children with disabilities and the poor to have access to school (Akyeampong, 2009). There are many other policies adopted by past and present governments geared towards promoting education for all Ghanaian children. For example, policies such as free school uniform, school feeding program and elimination of schools under trees, are intended to get many children into school.

Principally, the educational system in Ghana has been shaped by international frameworks such as Education for All, with a focus on inclusive education. Inclusive education involves a process of strengthening the capacity of schools to reach out to all learners (UNESCO, 2008). Inclusive education is, therefore, an overall principle that should guide all educational policies and practices. Starting from the belief that education is a fundamental human right and the foundation for a more just society and particularly give the opportunity to those who have traditionally been excluded from educational prospects including children with physical disability (Acedo, 2009). The Ministry of Education adopted inclusive education as a means of providing special education in Ghana, as such most regular schools in Ghana admit children with disabilities. However, there are few schools that are purposely established for children with special needs (for example Akropong School for the Blind and Three Kings Special School at Battor).

It has been observed that efforts by the government to get children of school going age into schools have yielded results. There have been improvements in enrollment and initial access at the basic education level (Ananga, 2011). While basic school enrollment in Ghana has improved significantly in recent years, one of the challenges now has been high cases of school dropout. Several factors are linked to this. For example, socio-economic backgrounds are said to be a key contributory factor to drop out. The cost of schooling impacts on household decisions around access and retention. Where households cannot afford schooling costs, children may suspend schooling pending a solution (ibid). Also, school related issues such as hostile school environment, lack of support at school and school practices and processes that children consider unsuitable could result in drop out (Hunt, 2008 cited in Ananga, 20011).

2.4 Cultural Construction of Disability in Ghana

Traditional beliefs have largely influenced attitudes toward the disabled in Ghana. Religious beliefs have played a role in alienating and suppressing people with disabilities, to the extreme of even killing them. In the past and still existing, illness and disability are often conceptualized as being the result of evil influences or disobedience to the gods (Tinney et al., 2007). Disability has been strongly linked to religious or magical ideas, where evil was placed on an individual from the gods. For example among the Nankanas in the Upper East region of Ghana, children born with disabilities were given names such as *chichuru* or *kinkiriko*, meaning spirit children (Allotey & Reidpath, 2001). Similarly among the Akpafus, in the Volta Region of Ghana, cataract or ‘Kobi’ (as it is known among them) is considered as a result of sins committed by an ancestor. And the development of a cataract is a way by which living relatives can atone for the sins of their ancestors (Avoke, 2002). Consequently, many parents and children were, therefore, blamed for bringing disability on themselves, as a child with a disability is seen as a curse, the result of witchcraft or punishments from God (ibid).

Notwithstanding the increasingly broader framework for understanding disability for reasons such as Christianity, which have to some extent diluted the effect of traditional belief systems (Avoke, 2002), advances in medical knowledge and an ever more westernized approach to congenital and acquired disabilities, conceptions of disability as spiritual still exist (Tuakli-Wosornu & Haig, 2014).

Linked to the notion that disability is a curse or punishment from the gods, many Ghanaians avoid marrying anyone who is a disabled or from a family with a disabled member. Even though not strictly practiced as it used to in the past, because of increasing number of teenage pregnancies, premarital affairs or decrease in arranged marriages, before marriage, some families still investigate the background of would-be wife or husband. This is to make sure that they do not have a history of disability or any serious disease and even if a marriage takes place without the prior knowledge of the parties involved that there is a disabled person in the family, finding out later can constitute sufficient grounds for divorce (Kassah, 2008).

Popular conception about people with disability in the Ghanaian society is that they are feeble and are burdens. Corbett (1996) cited in (Avoke (2002) pointed out that children with disability are considered less humans and subsequently they are vulnerable to inhumane treatment. Historically such endeavors as war and military demands were reserved for individuals considered to be healthy and are being regarded as an asset to communities, but people with disabilities were excluded as they were not considered healthy and normal (Avoke, 2002). In a similar vein, people with disabilities were and are still being denied leadership positions. In most societies in Ghana people with disabilities are a misfit to assume chieftaincy positions (Munyi, 2012). I argue that not only has the exclusion of people with disabilities from leadership position limited to chieftaincy institution but cut across all spheres in the Ghanaian society. For example never has it been recorded that an individual with a disability has assumed any high ranking position as the president, chief justice or speaker of parliament in government.

Miserably because of a family's shame of this perceived curse, children with disability are often kept home from school and outside social settings. Many at times, disabled children are hidden and are not welcomed at public places or gatherings. More obvious is that, avoidance, rejection, and discrimination in public places limit social mobility of people with disability. Such negative attitudes shun persons with disability away from society as they may isolate themselves from family, friends, schools, and other opportunities for social interaction. Consequently, this inhibits educational attainment and appropriate social development in children with disabilities (Tuakli-Wosornu & Haig, 2014).

2.5 Disability Situation in Ghana

According to Kassah (2008), disabled people in Ghana are considered one of the largest disadvantaged groups, many disabled Ghanaians are poor, receive little education and limited medical care and have difficulty feeding themselves. They have limited employment opportunities and are often excluded from active participation in making decisions in matters concerning them (Kassah 1998).

In terms of education, Morley and Croft (2011) emphasized that, in many sub-Saharan African countries being disabled at least doubles the chance of having never attended school, those who

do start school are at increased risk of ‘dropping out’ before completing basic education. The situation of disabled in Ghana is not far different from many sub-Saharan African countries. Kassah (2008), indicates that most disabled children drop out of school as a result of discrimination and inability to pay school fees and resort to begging on the streets as a means of livelihood. Another study in Ghana has shown that when compared with able-bodied individuals, people with disabilities have higher rates of under education, including total years of education and primary education percentage completion rate. This is compounded by teachers’ lack of special education and training for students with physical and/or intellectual impairments (Tuakli-Wosornu & Haig, 2014).

The study by Tuakli-Wosornu and Haig (2014), also revealed a correlation between disability and poverty. Persons with disabilities (PWD) in Ghana have higher poverty rates as assessed by asset deprivation and medical/total monthly expense ratio. The fact that educational attainment remains significantly lower for those with disability clearly points to consequences as poverty because education is said to directly impact economic potential. Connected to the poverty of the disabled, is restricted employment and limited income-earning opportunities which may be due to discrimination, lack of education, unavailability of job opportunities, work experience and confidence. Excluded from mainstream social, economic and political opportunities throughout their lives and facing significant financial costs related to their impairments, disabled people, and their households are frequently dragged further and further into poverty (Yeo & Moore, 2003).

Compounding the deplorable situation of the disabled in Ghana is the physical milieu which lacks key accessibility tools that enable social inclusion. To start with, the topography of Ghana is generally uneven, unpaved or dirt roads, unfinished or absent walkways makes navigation with or without crutches, ambulatory aids, and wheelchairs difficult or impossible. Institutions including schools, stadiums, hospitals, and workplaces are usually inaccessible even with adaptive equipment. Maneuvering stairways and narrow doorways without accessibility tools such as ramps, lifts, and generous dimensions are difficult with or without adaptive equipment. Often, Ghanaians with physical and/or intellectual disabilities require external assistance from friends and/or charitable strangers to move through inaccessible cities, towns, and neighborhoods. For

those with visual impairment, public spaces rarely feature braille⁵ or enlarged text (Tuakli-Wosornu & Haig, 2014).

Apart from the landscape and buildings, public vehicles also pose mobility challenges for the disabled, most especially the physically challenged. Popular means of mass transport include private-owned public buses, both large and small. These buses are often crowded, and inaccessible, tro-tros⁶ and public coach buses are without standard accessibility tools. Additionally, the physical demands of traditional activities of daily living such as food preparation (pounding fufu, grinding paper), manual laundering, farming, and homemaking are challenging for the disabled in Ghana.

2.6 Policies and Programs for People with Disabilities

In response to appalling conditions of the disabled, global efforts have been taken to protect rights of disabled and foster integration and inclusion into mainstream society. Ghana as a country has also taken some steps to better the conditions of the disabled. In this section, I highlight some legal instruments and programs that have been instigated.

2.6.1 United Nations Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disability is an international human right treaty which came into force in 2008. Its main purpose 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 (CBM, 2015).

The Convention is intended to facilitate the global movement away from viewing persons with disabilities as objects of charity, medical treatment and social protection towards viewing them as full and equal members of society, with human rights. Ghana ratified the convention in 2012, affirming its commitment to respect the human rights of all its citizens, including those with disabilities. This action was described as an important first step to ensuring that persons with disabilities in Ghana will be treated as equal citizens, with equal rights (Watch, 2012).

⁵ A system of writing for the blind in which letters are represented by raised dots

⁶ Public vehicular transport within big cities

2.6.2 United Nations Convention on the Rights of the Child

Article 23 of the UNCRC talks about rights of children with disability, it states in 23 (1) “States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community”. Ghana was the first country to ratify the UNCRC in February 1990. Since then, past and present governments have made efforts to internalize the provisions in the convention into its domestic laws. Among legislations passed is Children’s Act, 1998 (Act 560). The children’ Act has been considered the most visible outcome of the UNCRC and one of the strongest examples of government’s commitment to children’s rights. The passage of the Act led many to hope that this would represent a real turning point in the progress of children’s rights and welfare in Ghana (Twum-Danso, 2009). Article 10 of the Children’s Act outlines rights of disabled children but with foreseen impossibilities. It states:

10. (1) *No person shall treat a disabled child in an undignified manner.*

(2) *A disabled child has a right to special care, education and training **wherever possible** to develop his maximum potential and be self-reliant.*

2.6.3 Persons with Disability Act, 2006 (Act 715)

The passage of the Persons with Disability Act, 2006 (Act 715) has been described by some scholars as a noteworthy milestone in Ghana’s human rights discourse. This is because it gives the hope that it will improve the life of persons with disability to enable them to be part of mainstream society (Asante & Sasu, 2015). The Act covers key thematic provisions such as accessibility, employment, and education for PWDs amongst others. Among the rights included in the Act are; the right to a family life, the right to participate in social or recreational activities, the right to equal living conditions, the right to access to public places, and the right to freedom from exploitation, abuse, and discrimination. The Act put a huge responsibility on government and the public to make all public places such as schools, hospitals, hotels, shops etc. accessible to persons with disability within a period of ten years. However, the 2011 human right report by the Commission for Human Rights and Administrative Justice (CHRAJ) has shown that most schools, healthcare centers, and privately owned public places were unequipped to be accessible and accommodate the needs of persons with disabilities (World Press, 2015).

2.6.4 Institutions and Structures

Many organizations for PWDs have been established to champion the plights of the disabled in Ghana, the most prominent of which include the Ghana Federation of the Disabled (GFD) (1987), an umbrella organization encompassing the Ghana Society of the Physically Disabled (1980), Association of the Blind, National Association of the Deaf, Parents Association of Children with Intellectual Disability and Association of Persons Living with Albinism. Other institutions providing services to the disabled are Ghana Research and Advocacy Initiative; the Orthopedics Training Centre; and multiple outfits supported by the Salvation Army and Catholic, Anglican, and Presbyterian churches (Tuakli-Wosornu & Haig, 2014).

2.6.5 Community-Based Rehabilitation

The World Health Organization has recommended the Community-Based Rehabilitation as an antidote to the poor coverage of rehabilitation facilities in the developing countries. This attempt is to make it possible for disabled people to receive the help they need to be able to go about their daily activities aided by trained personnel from their own communities (Kassah, 1998). This was grounded in the assumption that a disabled person should be able to look after him or herself, move around the house and village, attend school, do a job and carry out household activities, enjoy family life and take part in community activities (ibid). Based on this recommendation, Ghana initiated the CBR program in the 1990s through the Ministry of Employment and Social Welfare, in collaboration with health and education ministries, Non-Governmental Organizations (NGOs) and Organizations of disabled people, (Kassah, 1998; Kuyini, Alhassan, & Mahama, 2011). The program is aimed at improving the quality of life of children, youth and adults with disabilities, through the mobilization of community resources, provision of services, and the creation of educational, vocational and social opportunities (Kassah, 1998).

Sadly, reports indicate that the CBR program has been unsuccessful largely because of deeply entrenched conceptions of disability as evil and social stigma. It was observed that disabled persons and their families did not patronize rehabilitation services due to the stigma that comes with disability in Ghana. The majority of the disabled live in rural areas, where the stigma of disability may be more pronounced and the disabled persons would instead drift to urban areas

to beg for food and money, rather than seek rehabilitation (Tinney et al., 2007; Tuakli-Wosornu & Haig, 2014). To me, one underlying reason of this stigmatization could be that the CBR program focused on need and incapability of disabled thereby highlighting the already existing assumption that the disabled are weak, deserving pity and charity rather than projecting their capabilities and achievements. Stressing the importance of recognizing the abilities of the disabled, Tuakli-Wosornu and Haig (2014), acclaims that programs and campaigns that underscore achievements and abilities of disabled might be more effective than those that begin and revolve around the assumption of need and incapability.

2.6.6 District Assembly Common Fund

This fund is a form of a grant from the Central Government to assist District Assemblies in their development efforts. District Assemblies Common Fund was created under section 252 of the 1992 Constitution of Ghana. In July 1993, Parliament enacted the District Assemblies' Common Fund Act (Act 455). Under this Act, Parliament is annually required to allocate a certain percentage of the total revenue that accrues to the nation to the District Assemblies for development (Ghana District, 2015). Currently, 3% of the District Assembly Common Fund is reserved for persons with disabilities. The intention of the funds allocated for persons with disabilities is to support them with income generating activities, to provide educational support, to help disabled persons assert their rights and as well as help them have access to essential aids and equipment. However, a recent study shows that only a few people with disabilities know about the fund let alone how to access it (World Press, 2015).

CHAPTER 3

THEORETICAL PERSPECTIVES

1.0 Introduction

This chapter discusses theoretical frameworks that shape my research. The study is grounded in the theoretical perspective of the Sociology of Childhood. To start with, I briefly discuss the background to the sociology of childhood, after which I foreground key concepts embedded in the framework and how they are relevant to my research. These include childhood as a social construction and children as social actors and agency. I also in this chapter discuss models of disability and how each model positions children with disability. Finally, I incorporate the rights perspective which sees children as right holders.

3.1 Sociology of Childhood

Until the emergence of the sociology of childhood in the 1980s, research on children was concerned with key themes; rationality, naturalness, and universality (Prout & James, 1997). The works of developmental psychologists popularized the idea that childhood is universal and natural phenomenon (Jenks, 2004). Embedded in this view is that the child developing into an adult represents a progression from simplicity to the complexity of thought, from irrational to rational behavior. Thus, rationality is the hallmark of adulthood with childhood representing the period of apprenticeship for its development. Within this, children's competencies and intelligence were measured by standardized developmental norms based on average abilities and performances of children at a certain age in a particular task or activity. In such a conceptual scheme children are marginalized beings awaiting temporal passage, through the acquisition of cognitive skills, into the social world of adults (Prout & James, 1997). Thus, the universalism of childhood allowed for standardization and normalization. Similarly, this ideology of standardization and normalization is reflected in representations of disability as an abnormality, malfunction, and deviation from health conditions that limit performance (Holt, 2004; Michailakis, 2003). Children with disabilities are scaled on societal standards of able-bodied children (normal) and any deviation or mind-body differences are considered abnormal.

However, the emergent of the new paradigm; sociology of childhood deconstructs and reconstructs the traditional conceptualization of childhood. There has been a shift in understanding of what it is to be a child and how this varies across time and across societies (Mayall, 2000; Prout & James, 1997). Leading to this shift was social occurrences which made it clear that children's experiences differ across space and time. Consequences of war, famine and poverty in the developing world gradually raised awareness that some children do not inhabit the western idyllic world of happy protected innocent childhood (James, 2009). Hence, childhood is seen to be a social and cultural phenomenon that has no universal validity. In addition, the sociology of childhood moved children from being objects of adult work, to be seen as competent, contributing social actors. Furthermore the idea that adult views are sufficient for defining children's needs gave way to the understanding that children's own wishes and expressed needs are relevant to the construction and implementation of social policies and practice (Mayall, 2000).

My research process was shaped by the ideas of the sociology of childhood. Firstly, I find it important that children are to be studied in their own rights and researchers should simply not use adults' voices as proxies for studying children. In line with this, my study sought to explore how children with physical disability navigate experiences of disability mainly from the children's own point of view rather than just listening to their parents and teachers. Furthermore, contrary to the traditional conceptualization of childhood as natural and universal phenomenon, my study was informed by the understanding that children's experiences of disability are individually unique, influenced by social circumstances. The discussion that follows highlights further, the social construction of disability.

3.1.1 Childhood and Disability as Social Constructions

“Childhood does not exist in a finite and identifiable form”(Jenks, 2004, p. 89). A core crux within the sociology of childhood is that there is no universal childhood. The implication is that childhood differs across time and space. Gittins (2004) argues, even the very definition of a child varies historically and in different societies; a child has been defined sometimes by physical and /or sexual maturity, legal status or chronological age. For example in western countries, a child may become economically active now at 15 or 16 whiles in the past and still in some developing countries children as young as 5 or 6 go out to work. The notion that childhood is socially

constructed stresses the diversities of childhoods that are contextualized in social and cultural settings as well as within everyday life (Kjørholt, 2004). Jenks (2004, p. 89) argues in the same line that “knowledge about the child and its life world depends on the predispositions of a consciousness constituted in relation to our social, political, historical and moral context”. This suggests that children have different and unique experiences shaped by varying context within which they live.

Juxtaposing the idea that childhood is socially constructed to disability studies, there is a correlation. From a childhood as a socially constructed point of view, disability can be socially constructed (Llewellyn & Hogan, 2000). Children’s experiences of disability are wrought by the social, political, historical and moral context in which they live. Within this milieu, childhood as social construction provides an understanding of how the particular context within which my participants (children with physical disability) live shapes their experiences of disability and how this influences their agency. From this perspective, it is possible to erode conventional standards of judgment about normality and disability. Thereby reject universal statements that point to the incapability of children with physical disability.

3.1.2 Children as Social Actors and Agency

Within the sociology of childhood, children are seen as beings and social actors. Conceptualizing children as social actors implies children are active in constructing of their own lives, the lives of those around them and the society in which they live. Hence, children are not just passive subjects of social structures and processes (Prout & James, 1997). Rooted in the concept of social actor is the notion of agency which is understood to be “individual’s own capacities, competencies and activities through which they navigate the contexts and positions of their life worlds, fulfilling many economic, social and cultural expectations, while simultaneously charting individual or collective choices and possibilities for their daily and future lives” (Klocker et al., 2007, p. 135). Reflecting on this assertion, it can rightly be said that children are not merely objects under the control of adults but are actively empowered beings capable of influencing their own lives and that of those around them. Furthermore, children as social agents negotiate institutions and spaces they encounter as they create their own experiences and form relationships with the world around them (James, 2009; Jenks, 2004).

The concept of agency emphasizes children and young people's competence. By this, they are viewed as thinkers and doers (Klocker et al., 2007). This involves recognizing children's ability to reason and take action or make decisions in different circumstances they find themselves. The idea that children are competent beings questions childhood as a period of irrationality, progressing from irrational to rational, thus children as human becoming. To date, scholars within the Sociology of Childhood increasingly sharpen the debates on children as competent social actors. They continue to unravel children and young people's agency across different contexts. For example Corsaro, (2005) cited in James (2009), developed the term interpretive reproduction to express children and young people's innovative and creative ways of participating in society. The term reproduction here signifies a two-way process rather than a linear or a passive process where children and young people simply internalize culture and society. As children learn existing cultures, they strive to interpret and make meaning out of it and in that process produce their own cultures. By this, children and young people actively contribute to production and reproduction of culture. This process demonstrates children and young people's agency.

Nilsen (2009), used socialization as a dialectical process of adaptation and resistance to illustrate children's agency. She argues children are agents of socialization. To her, though resistance does not necessarily lead to considerable changes in the adult management of children's everyday lives, children gain control over some of their everyday experiences due to their actions of resistance. Children can conquer some free space and create alternative experiences in line with their cultural practice, values, and priorities.

Primarily, my study views children as social actors, competent, and active participants in constructing their lives. Hence, they are capable of presenting their feelings, views, and experiences. This position was reflected in my choice of methods: diary and narrative interview offered the children the opportunity to express their feelings and experiences in their own words. Nonetheless, the study particularly relates to the argument made by Klocker et al. (2007), that even though in some contexts agency remains invisible, denied or suppressed by restrictive circumstances, evidence of agency often exists and should not be ignored or overlooked. They reiterated, populations generally considered powerless do not entirely lack agency but maintain

alternative forms of power constituted in complex webs of informal (invisible) networks of resistance put up against prevailing restrictive power relations. This knowledge was important in exploring how children with physical disability maintain agency in alternative forms regardless of the restrictions that their disability put on them. I draw on the concept of “thick and thin” agency (Klocker et al., 2007) to ascertain factors that enhance or reduce (thicken or thin) agency of children with physical disability. Furthermore, I adapted the elements of agency (ibid) to explore the interplay of the various factors in shaping agency of children with physical disability.

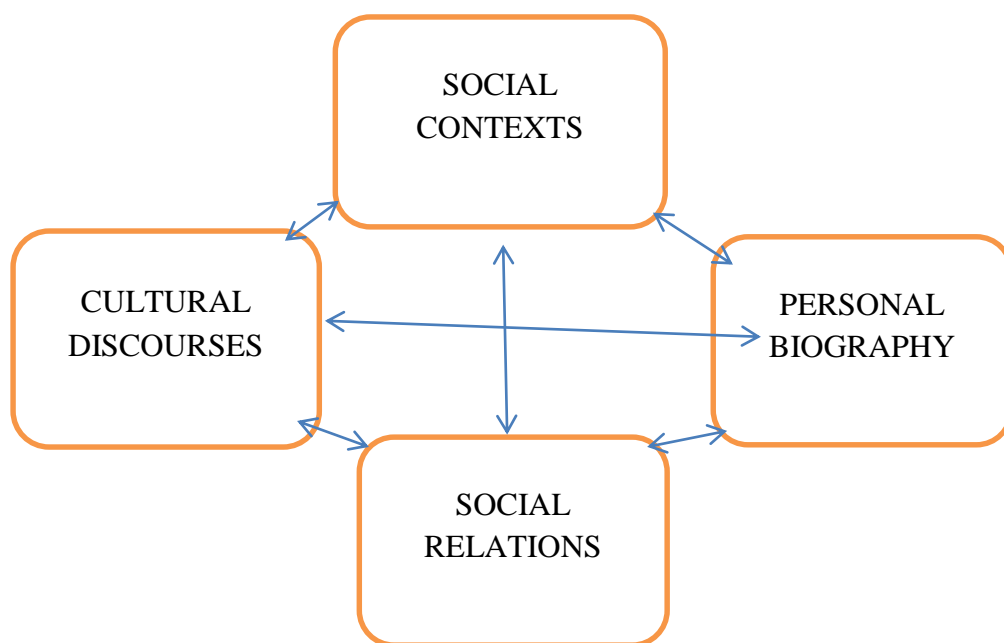


Fig. 1 Adapted elements of agency from Klocker et al. (2007)

3.2 Models of Disability

A close look at relevant literature within disability studies indicates that there is no agreement on how the concept of disability should be understood. There are several competing debates, each describing disability from a differing perspective. In this section, I discuss two models of disability; medical model and social model. Alongside the theoretical discussion on these models, I have tried to contextualize their arguments into the Ghanaian society.

3.2.1 Medical Model

The medical model views all disability as the result of some physiological impairment due to damage or to a disease process. This idea emanates from the disease model used in medicine, which predisposes practitioners to think of a condition, which needs appropriate treatment (Llewellyn & Hogan, 2000). For example, the problems arising from the care of children with physical disabilities have been the province of medicine, to be treated by professionals with a medical training (ibid). The point of departure of the medical model is the focus on individual with the disability, as it is believed that the individual is handicapped independent of the prevailing environments (Michailakis, 2003). In the words of Michailakis (2003), the individual is thought to be incapable of performing certain activities due to one or more functional impairments, and obstacles to participation are situated, primarily in the individual, since it is the individual who lacks certain capacities that are necessary to attain autonomy. Accordingly, whether an individual is disabled or not depends on his/her clinical status. Thus, disability is an individual's incapacity of medically verified facts.

Furthermore, the medical model presents disability as a personal tragedy or abnormality which is located within the body or mind of the person with the disability. Consequently, this abnormality could be treated by different kinds of therapy of the body or through rehabilitation with the intention to transform the disabled into more "normal" beings (Holt, 2004; Llewellyn & Hogan, 2000). Within this is the connotation that all children with impairment are automatically handicapped or handicap their families (Hutchison, 1995 in Llewellyn & Hogan, 2000). In the medical model, impairment is viewed as a limitation of the individual. Clearly, a distinctive trait of the medical model is the emphasis on the body's malfunction and the need for medical intervention or rehabilitation.

This model has been problematized because it reduces the influence of political, economic and social factors on the individuals. Simply put, the individual is handicapped independent of the prevailing environment. Holt (2004), points out that this assumption has serious implications for disabled people, leading to a host of interconnected socio-spatial marginalization and exclusions. Holt adds, by this model, disabled people's lives are devalued, thus, they are seen to have lives not worth living and this has led to attempts to eradicate mind-body difference. Llewellyn and Hogan

(2000), further argues that the emphasis on the body's abnormality is misplaced, as any view of what it is to be normal carries also implications concerning societal acceptance. Moreover, disabled people themselves quite naturally reject being described as abnormal.

The medical model is mirrored in the Ghanaian society. Many people believe that problems faced by disabled are due to their impairments or physiological limitations. This perception is evident in the works of many NGOs assisting disabled in Ghana. To illustrate the Community Based Rehabilitation program mentioned in the previous chapter was established to help disabled persons live "normal" life as possible (Kassah, 1998). We see here that the primary focus is on the individual with a disability. By providing disabled persons with material and medical needs they would be able to live improved quality of life. Highlighting the body's malfunction or abnormality is quite pervasive in the cultural representations of disabled persons. As indicated earlier, disabled persons are mostly excluded from the society in matters such employment opportunities, active participation in making decisions in matters concerning them, war and military demands because they are considered neither healthy nor normal (Avoke, 2002; Kassah, 1998).

3.2.2 Social Model of Disability

Within the social model, disability only exists in so far as it is socially constructed and imposed on people with impairments (Llewellyn & Hogan, 2000). The model emerged as a critique of the medical model. It is argued that disability is not an outcome of bodily pathology, but of social organization. It is socially produced by systematic patterns of exclusion that were quite literally built into the social fabric (Hughes & Paterson, 1997). Significantly, the social model of disability destabilizes the location of the cause of disability, from the individual to society. The focus in this model shifts to society. It places the problems of people with disability into the collective responsibility of society as a whole rather than the individual. Scholars within the social model argue that disability emanates from society and emphasizes that social circumstances can influence the level of disability observed (Llewellyn & Hogan, 2000).

Contrary to the medical model, the social model connects demands and requirements from society with whether an injury or impairment becomes a handicap or not. Michailakis (2003) maintains, restrictions or disadvantages experienced by the disabled do not originate from some biological or physiological determination. Such restrictions are culturally, socially, economically and politically

constructed. Michailakis adds, much of the limitations that are inflicted upon individuals with impairments are neither natural nor inevitable consequences of their capabilities, but rather must be seen as the results of a failed social policy or being the failures of social institutions to take into account certain individuals' particular conditions. Accordingly, disability becomes equivalent with oppression by social and institutional structures within which certain physical, emotional and intellectual differences are identified and treated in a certain way. Hall, (1995 cited in Llewellyn & Hogan, 2000) highlights that people with physical disabilities point out that they are disadvantaged by the attitudes of society more than by their loss of function. Shakespeare, (1998 cited in Avoke, 2002) also emphasizes, it is social barriers which create disability, and that the difficulties of living as a disabled person are due to discrimination and prejudices, rather than impairment. In a broader sense, the social model associates disability to "all the things that impose restrictions on disabled people; ranging from individual prejudices to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on" (Oliver 1996, in Avoke, 2002 p.772).

The social model has been critiqued on the basis that by attempting to deliberately oppose the reductionist biologism of the medical model, it has ignored the corporeality of painful and problematic mind–bodies. Also, the model under-represents 'difference' between disabled people, both due to differing mind–body characteristics and individuals' various locations within a host of 'axes of power (Holt, 2004).

Within the Ghanaian context, the social model is gradually gaining weight. There is a greater realization that governmental policy, state authorities, and institutions are key factors in the formation of structures that reduce barriers in disabled people's daily life. This is evident in policy adjustments by the government in recent times. For example, just to mention a few, the enactment of the Disability Act (Act 715), allocation of 3% of District Assemblies Common Fund to disabled, and inclusive education. NGOs and civic society organizations also increasingly advocate for change in societal attitudes towards the disabled.

3.2.3 Combining Perspectives

The data from my fieldwork is much more skewed towards the social model of disability. Nevertheless, the insight from both the social and medical models discussed above is relevant for

understanding the lives of my participants. I argue that there is an overlap between the two models. To some extent individual effort plays an important part in overcoming challenges of disability. Personal traits such as will-power and courage are a positive catalyst to subduing the barriers and restrictions imposed on children with disability. As mentioned earlier in this chapter, children, and young people maintain their agency in alternate forms even under suppressed and restrictive circumstances. Thus, the individual with the disability negotiates life by adapting to his/her environment or prevailing circumstances. Moreover, it is evident that, even though children's experiences are shaped by cultural and social factors, children's experiences are not the same even in the same societies. Children and young people's experiences of childhood are individually unique even in the same context. This demonstrates that the individual also has a responsibility towards overcoming challenges of disability. I contend that combined efforts, thus individual and societal efforts are necessary to reduce the barriers and restrictions faced by disabled children.

3.3 Rights Based Approach

Discourses connected to the promotion of children's rights have taken center stage globally in recent years, most especially since the adoption of the United Nations Convention on the Rights of the Child in 1989 (UNCRC). The convention explicitly recognizes the world's youngest citizens as right holders and acknowledges the fundamental connection between the well-being of children and the strength of societies (Unicef, 2015). The rights-based approach is an all-encompassing perspective on various rights of children. But for the purposes of this study, I contextualize my discussions on two of the key principles of the UNCRC relevant to my study.

3.3.1 Non-Discrimination

The principle of non-discrimination is emphasized in Article 2 of the UNCRC, it urges states parties to respect and ensure the rights set forth to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, color, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other statuses. The principle of non-discrimination is usually connected to the concept of equality, thus equal opportunities for all children including marginalized groups of people in society. In my study, I highlight different areas where equal opportunities are vital in the lives of children with physical disability. For example in terms of

equal opportunities for education, section 17⁷ of the Disability Act, 2006 of Ghana clearly indicates that it is necessary for schools and institutions to have facilities and equipment that will enable persons with disability to fully benefit. The discussions in the analysis chapters point out how structural deficits such as muddy roads, the absence of ramps etc. reinforce discrimination and how these serve as restrictions in the lives of children with physical disability.

3.3.2 Rights to Be Heard

This principle is clearly embedded in Article 12 of the Convention. It states that the child who is capable of forming his or her own views has the right to express those views freely in all matters affecting the child, the views of the child should be given due weight in accordance with age and maturity of the child. Giving children the rights to be heard by extension is linked to self-determination and participation. Speaking of children and participation, Kjørholt (2002) comments, the right to participation is to empower a disenfranchised group in society, replacing the notion of the vulnerable and dependent child with the competent child who is given the right to participate in society to a certain degree. In this research, the children with a physical disability having the right to participate in society, for example, participating in school activities both curricular and extra-curricular is seen to be pivotal to displaying their agency.

At the heart of the debates on children as citizens lies the notion of inclusion and exclusion (Moosa-Mitha, 2005). Citizenship may connote membership in society realized through participation in citizenry obligations and an acknowledgment by others in society of one's membership (ibid). But in many societies there exist normative institutional practices that define the mainstream culture of the society that serves to include and exclude certain people from participating and belonging to communities of which they are citizens, on the basis of their difference (ibid). This assertion indicates that whereas seeing children as citizens or right holders may mean inclusion, at the same time certain normative practices may exclude them from participating in society. Contextualizing this idea in my study, inclusive education, for instance, is one-way children with physical disability are included in the mainstream education but that does not necessarily mean that they participate

⁷ The Minister of Education shall by Legislative Instrument designate schools or institutions in each region which shall provide the necessary facilities and equipment that will enable persons with disability to fully benefit from the school or institution

in school activities to fully benefit them. My study looks at how inclusion may not necessarily mean participation by taking into account certain institutional structures and practices that turn to exclude children with physical disability from participating in school even though they are included in the mainstream schooling.

3.4 Related Research

A look at some related research of disability studies in Ghana served as a backdrop. Even though earlier research in Ghana have not ostensibly explored how children with physical disability navigate their experiences of disability, thus how these children display agency under restricted and suppressed circumstances, which my research sought to do, the way these researches inform the discussions in my study is readily apparent.

A study conducted by Mock, Boland, Acheampong, and Adjei (2003) reveals mixed responses regarding their abilities from persons who have acquired some form of disability in their life. Whilst indicating that their disability decreased or eliminated their ability to perform their previous usual activities, they also reported that they could perform such usual activities at a normal level despite the disability. For example, their study highlighted that some participants with major disabilities were persons with severe limps that limited their ability to walk, but who still were able to carry out their usual daily activities and work. Participants in my study expressed a similar thought, as they acknowledged facing some limitations as a result of their disability, however at the same time they can still perform some usual activities despite their disability.

In the same study, Mock et al. (2003) point out economic consequences of disability. According to them, disability has economic implications for individuals and or their families. Persons with disability and their families suffer economic burdens due to their reduced productivity and associated cost of medical treatment. A related study by Reynolds (2010) seems to point to a similar argument that, children with disability are a burden on the family. It is expected that every child must grow normal, attend school normally, grow into life, work and take care of the family. And when someone becomes disabled it becomes a liability on the family. In my study, poverty comes across as cause and effect of disability. A look at my data suggests that poverty in one way can push or be a causative factor of disability and in another way can be a consequence of disability.

Another issue raised in previous studies, which reflects in my study is the change in perspective on causes of disability. In Reynolds (2010) study, other factors such as birth defects, sickness, accidents were mentioned as causes of disability in addition to spiritual causes of disability. This perspective is echoed in my study as most of my participants attribute their disability to either sickness or accident.

Furthermore, a research by Agbenyega (2007), uncovers loopholes in the inclusive education in Ghana. He argues that there is a misplaced emphasis on changing school culture and organization as against providing resources and building the capacity of both special and regular schools to offer new opportunities for pupils who experience learning difficulties. Agbenyega (2007) further argues that beliefs about disability, ethnicity, attitude and concerns of teachers can influence the practice of inclusive education, the quality of educational materials and instructions students receive. He claims that teachers in regular schools who feel unprepared and fearful to work with learners with disability display frustration, anger and negative attitude towards inclusive education. As already indicated in this chapter, building on Agbenyega (2007) I contend that children with physical disability in the inclusive schools do not necessarily benefit fully.

CHAPTER 4

METHODOLOGY

4.0 Introduction

This chapter describes the methodological process starting from research design, the access process, research role and methods of data collection. My choice of research methods was shaped by the theoretical perspective that children are competent social beings who are capable of expressing their own views. I further elucidate ethical reflections and challenges I faced during the research process. I conclude the chapter with a brief description of the analytical process.

4.1 Research Design

Right from the onset of this research, use of appropriate methods has been a central concern. Since the research aimed at exploring lived experiences of children, thus how physically challenged children navigate their experiences of disability, I adapted qualitative research approach. My choice of qualitative methodological approach was to enable me to explore a wider array of dimensions of the social world of the children, including the texture and weave of everyday life, their understandings, experiences, and imaginations (Mason, 2002). I conducted eight weeks fieldwork in two Senior High Schools in the North Tongu district. This site was chosen on the premise that, I am quite familiar with the area, the nuance of the people, and language.

Moreover, having been a teacher in the district for four years, I have developed networks that could facilitate access to the site. Nevertheless, this came with its challenges as would be described in proceeding sections. Furthermore, I focused on senior high school because of my assumption that disabled children in senior high school amidst restrictions and complexities might have exhibited agency and determination, therefore, are most suited for the research topic. In addition, I purposefully chose regular schools for this research with the aim of exploring how physically challenged children function in the regular school system together with non-disabled children. For instance, how they interact with other children and are able to use same material spaces and structures such classrooms, furniture, washrooms etc.

4.2 Access

Before leaving Norway for the field, I had already got contact numbers of my prospective participants. Right after the proposal for the research was approved, I contacted a teacher in one of the schools, explained to him the purpose of the research and the targeted participants I am looking for. From the beginning, he was skeptical if I would be able to get participants based on the criteria I gave him, but he later found out that there is a disability association in the district whose leader is a teacher. After talking to the leader of the association, he sent me contact numbers of six children with the schools they attend. Upon arriving at the research site, I found out that some of my prospective participants had just completed school and had left the community. This situation left me disappointed as I was psychologically certain that I was halfway through getting access to my participants.

Having in mind that researcher should be reflexive, adaptable to changing and emerging situations on the field, I quickly decided to approach the school authorities as if I have no previous knowledge of the intended students nor no contacts of them. The introductory letter from NOSEB and my student ID card were very helpful in identifying me as a student researcher and getting accepted. Nevertheless getting access to the children was not without any difficulties. It is argued that accessing relatively small or privately run environment can sometimes be difficult (Fine & Sandstrom, 1988). Here, I would like to mention an experience I had in one the schools. After explaining to the headmaster what the research is about and the targeted participants, he instantaneously raised concerns about the sensitivity of the research. He then made the guidance and counseling coordinator informed the children about the research before I met them. *“The guidance and counseling coordinator must first psychologically prepare the children before you see them,”* he said (field notes). This experience affirms the argument made by Cree, Kay, and Tisdall (2002) that, any research into a sensitive topic is bound to bring its own problems and that researchers can get access to children only with the co-operation of a number of different gatekeepers, without this there can be no research.

4.3 Research Participants

In all, seven physically challenged children aged 15-17, two teachers and one official from the district education office participated in the study. Purposive sampling method was used in recruiting the participants. The purposive sampling technique is the non-random or deliberate choice of an informant due to the qualities the informant possesses (Tongco, 2007). The sampling of child participants was done with the help of the school authorities. They assisted in identifying the children who met the sampling criteria of being physically challenged and below the age of 18. I recruited the adults participants based on their role towards the children: two teachers as guidance and counseling coordinators who closely work with the children and one official from the district education office as the officer in charge of special education. Child participants consisted of four boys and three girls. Six of the children have their disability in the lower parts of the body thereby giving them mobility difficulties, whilst one has problems with the arm. I find it worth mentioning that all the children in my study acquired their disability, none was born with a disability. Three out of the seven children commute from home to school every day whilst the other four live in school accommodation but provide their own meals.

Table 1: Summary of participants

Child participants				Adult participants	
Name	Age	Gender	Part with impairment	Teachers	2
Abi	15	F	Hips	Education officer	1
Kojo	17	M	Legs		
Naa	16	F	Legs		
Mawuena	16	F	Legs		
Kabu	15	M	Legs		
Kofi	17	M	Legs		
Frank	17	M	Arm		
Total number of participants: 10					

4.4 Research Role

Situating myself in the research and establishing my position as a student researcher was complicated by my previous position as a teacher in the research area. Both students and teachers in the schools accorded me respect and preferred calling me madam⁸ rather than call me by my first name which prospectively would put our relationship on equal terms. Some people who knew me personally often requested I spent time chatting with them about issues mostly not related to my research. Such pleasantries reminded me of my previous position as a teacher. I continuously had to remind myself and my participants of my position as a researcher. On one occasion, I overheard a student called one of my participants, pozo⁹, whilst the participant walked away quietly, I approached the student and made him see reasons why he should not call people with disability derogatory names. Though I spoke to him in a kind manner, at that moment I forgot that I was not a teacher and that I had no authority to question student's actions in the schools.

Such situations made me question my research role a number of times. However, such engagements developed into good social relations and mutual trust, which became a space in which I could negotiate my multiple roles during the research process. Over time, I earned trust and friendship not only from my participants but also of other people in the schools. This experience shows that research is characterized by uncertainties and the fluidity of its unfolding directions (Abebe, 2009), poses ethical dilemmas of drawing the line between what is ethically right and wrong.

Being in the field and doing research, for me was something more than an academic pursuit. I developed attachment and became involved in the children's lives. My involvement in the children's lives presented moral and ethical dilemmas, which left me with the complex decision of finding balance. For example, I struggled with the paradox of playing the friendly adult role as a way of building rapport on one hand and saying goodbye after a short period of friendship on the other hand. I inwardly felt sad about the difficulties of maintaining our friendship beyond the research duration.

⁸ A popular title for female teachers

⁹ Nickname for the lame

4.5 Data Collection Methods and Techniques

One main consideration for this research was ensuring children's participation, as this was to enable them to express their own views. To achieve this, a combination of participant observation, diaries and interviews were employed in data collection. A combination of techniques was employed with the aim of making the data generation process fun and interesting for the participants as well as generating useful and relevant data (Punch, 2002). Furthermore, owing to the fact there is no single perfect tool for collecting data, a combination of different tools helped offset the weaknesses of one method with the strengths of others (Abebe, 2009).

Important in analyzing data is social and contextual influences on the construction of data. This entails understanding how research subjects modes of expression are influenced by setting and means of data collection (Backett-Milburn & McKie, 1999). On the field, researcher's diary and standard observation sheet were used to capture contextual and material conditions that could influence the data. My observations, feelings, impressions and general comments about the fieldwork were recorded in the researcher's diary. Standard observation sheet (see appendix V) was used during interview sessions to take record of dates, duration, setting, weather conditions, both the participants and researcher's disposition.

4.5.1 Participant Observation

Observation is highly valued and effective research method, described by Ennew et al. (2009) as the basis of all good research. It enables researchers to acquire knowledge of participant's everyday routines, informal knowledge and embodied practices, information that is not easily obtained through other methods (Langevang, 2007). Punch (2002), also points out that observation is a useful technique to strengthen the reliability of the information provided by the participants. Ennew et al. (2009) argue that, observing participants provide valuable information throughout any research process, and it is vital for understanding the context of data, as well as for writing an interesting and believable report. This is also noted by Mauthner (1997), participant observation allows a researcher to see what participants chose to do at particular times, how they make choices and whom they chose to be with in particular activities.

During the entire fieldwork, I spent time to observe the children both in the classroom and outside classroom, how they negotiate life, their challenges and coping strategies and their relationship with non-disabled persons. When observing the children, I took note of their general composure in the school, who they walk with and where they go. I also tried to observe the children's attitude towards school. I noted in my diary, overhead comments and the children's reactions to remarks from their non-disabled colleagues. For instance notes from my diary reveal that a general reaction of my participants to derogatory comments such as *Pozo* is to quietly walk away.

Furthermore, observation as a method was used concurrently with interviews and this enabled me to note non-verbal communications; bodily gestures and participant's reactions to different issues discussed which provided me with additional insight. Before going to the field, I reflected on the ethical issues that might come up as a result of being a participant observer. For example Hill (1997) argues that it can be challenging for the adult researcher to be a fully participant observer, taking on the same roles as children. Also noted by Christensen (2004), children are very sensitive to adult-child differences and it is important to develop a genuine interest and trusting relationship with the children and maintain a balance while acting as a 'responsible adult' rather than pretending to be a child.

For this research, not only was there the tendency for unequal power relation between child-adult researcher but also between physically disabled- nondisabled. Engaging in some activities of the children as a non-disabled person might raise some ethical issues regarding respect and dignity of their condition. I beforehand reflected on how to find the balance to avoid the tendency of being perceived as patronizing and insincere. But this was rarely the case since there was hardly any other activity apart from classroom activities during the time period I was there. Students were busily preparing for the end of term examination and it was raining most of the time so it was difficult to perform any activities outside the classrooms in muddy grounds. However, this does not undermine the fact that observation as a method was useful in enriching this research with valuable data.

4.5.2 Diaries

I used solicited diaries where I provided the children with notebooks and pens to keep a record of activities they engaged in for a period of two weeks. Solicited diaries are “accounts produced specifically at the researcher's request, by an informant or informants” (Bell 1998, in Meth, 2003 p. 2). The diaries provided information about everyday routine aspect of the children’s lives, and the support systems available to them. In the diaries, the children recorded their daily activities such as personal studies, scrubbing, going to church etc., where those activities were performed, who was with them and the role the person played.

As solicited diaries involve recording and discussion of personal issues, it obviously raises ethical concerns of privacy of the participants. However, the issue of privacy was minimized as I provided a format devoid of detailed personal information (see appendix). Moreover, the participants were aware that the diaries are for external consumption, in this case, they had the opportunity to reflect on what they wish to record and not to record (McGregor, 2006; Meth, 2003). For instance, none of the participants provided any information on when and how they bathed, or when with a girlfriend or boyfriend.

It is indicated by McGregor (2006), that diaries can be empowering and therapeutic and can be an opportunity to express built-in emotions, sensitive, unspoken and taken-for-granted assumptions. Some of my participants used the opportunity to express their emotions. *“She is very harsh on me if I ask her something like money she will not give me unless I work myself before getting it”* stated one of the participants. Meanwhile, there was no column in the format that requires such information. One other participant used extra pages in the notebook to narrate her life story; how she became disabled, challenges and how she hopes to get back to how she was.

Using diary as a method in this research was quite effective in limiting unequal power relationship between me as adult researcher and child researched (Langevang, 2007) since I was physically absent from the context in which the diaries were written. It was obvious some of the participants were much more comfortable writing the diaries than having a one-on-one conversation with me during the interviews.

Nevertheless, I faced some methodological challenges in using diaries. As stated earlier, some of the participants provided information that was not required, even though valuable but challenging preparing the data for analysis. In another vein, a few of the participants did not prepare the diaries for the entire 2 weeks, reasons may be it was boring and time-consuming as they have to record repeated patterns as well as prepare for the end of term examination.

4.5.3 Individual Interviews

I used Semi-structured interviews to explore the children's lived experiences; how they negotiate life daily, challenges and their experiences of interacting with non-disabled persons. It has been emphasized that interviews with children are more beneficial when it is considered as a conversation, that is, when children are listened to and provided with the opportunity to be heard (Gollop, 2000). With this in mind, I structured the interviews in narratives, as narratives create realities people inhabit (Gudmundsdottir, 1996). This approach gave the participants the opportunity to vividly describe their experiences including specific facts as dates and events that have a significant impact on their identity and life trajectory.

Suggested by Langevang (2007), life-story interviews or narratives are particularly suited for exploring how young people confront and negotiate changing circumstances. In this case, how the children transition from abled-bodied children to disabled children. The life of children with physical disability in Ghana is full of critical moments, for example, the initial stages of impairment and early intervention strategies. And structuring the interviews in narratives was advantageous in exploring and uncovering complex nature of their critical moments and how they negotiate such moments. For instance, it was clear from most of the interviews that the initial stages of impairment were full of shock, confusion, economic drain, disappointment, hopelessness, and trauma.

During the interviews, participants were allowed to control the flow of the narratives as far as possible, nevertheless interview guide was used to direct the process (see appendix I and II). Even though narrating some events and moments was quite emotional (Langevang, 2007), for some, it was comforting for them to know that someone is interested in their story and listening to them. It was an opportunity to talk about part of their life that they normally do not tell others. This was

the case for one of my participants who stated; *“Whenever I remember I feel sad so I don’t tell people by heart, but I will use this opportunity to tell you”*.

Narrative or life history interview proves to be therapeutic in this research. As the participants tell painful, distressing and emotional moments in their lives, they are comforted knowing that someone listens. It was touching for me to see my participants after shedding tears during the interview, smile, happy and full of gratitude after the interview session. They were appreciative of me being interested in their stories and for having time to listen to them. *“Thank you for having the heart and time to get close to people like us, to know about our challenges and what we go through,”* says a participant.

To be able to get divergent views on the research topic, two teachers and one official from the district education office were also interviewed. Through these interviews, I sought to explore their perspectives on the challenges the children with physical disability face and the support systems available for them. Themes related to opportunities in the schools to enhance active participation of the children with physical disability and interaction between the children with physical disability and the non-disabled were also explored. The interview with the adult participants was also structured in narratives. This was to allow the participants to relate any experiences or encounter they have had or witnessed about the children. All the interviews were audio recorded with the consent of the participants, except one where the participant was not comfortable being recorded.

Table 2: Overview of research methods

Method	Participants	Subject explored
Observation	All	Observe children's daily experiences eg. Relationship with non-disabled persons
Diaries	7 Children	Explored children's routine activities
Individual Interview	7 Children, 2 teachers and 1 official	Explored both adults and children's perspectives of lived experiences of disabled children

4.6 Ethical Consideration

Along with the growing interest in researching with children and understanding children's world from their own perspectives, researchers have become increasingly concerned with ethical issues involved. This has become more relevant with the recognition that children are right holders (Backett-Milburn & McKie, 1999). Ethical standards are vital in any research not only with the interest of the participants in mind but also to protect researchers (Alderson & Morrow, 2011). Throughout the entire research process, I continuously reflected on potential ethical issues common in any research and particularly those that are unique to my participants as disabled children. I present below ethical issues; informed consent, privacy and confidentiality, power differentials and reciprocity that I was confronted with during the research process.

4.6.1 Informed Consent

Common to research with children is the issue of informed consent of third persons mostly called gatekeepers who have to decide whether the children participate or not (Einarsdóttir, 2007). Since the research was conducted in a school setting, I had followed all the bureaucratic procedures in the schools. First, I got approval from the schools' administration, then from the guidance and counseling coordinators and the individual participants. It was my utmost concern to get consent from parents of my child participants but this was not possible because it was difficult to contact

the parents who lived in towns different from where their wards are. Attempts made to contact them on phone proved unsuccessful. I therefore heavily relied on the consent from the children themselves and the school authorities since the school authorities are responsible for all children in school.

As said by Alderson and Morrow (2011), consent must be voluntary which means it must be given freely without pressures such as coercion, threats or persuasion. In order to get voluntary consent from my participants, I clearly explained to them what the research was about and the consequences of participating in the research and their right to withdraw from the research whenever they feel like they could not continue. All my participants voluntarily consented to participate. This may be because for some, it was the first time opportunity to participate in a research or because someone is interested in learning about them.

Considering that some of the participants may not be comfortable with written consent (Abebe, 2009), I made provision for both written and verbal consent, however, all my participants gave written consent (See appendix III and IV). Asking my participants for their consent was a continuous process during the entire data collection period. I always asked for the participants consent when using various research tools. For example, when seeking consent to use diaries, the participant who has an impairment with his arm expressed concerns about the beauty and clarity of his handwriting since he now uses the arm he was not originally using for writing. But upon explaining to him my aim of using diaries, and assuring him that I was not going to judge his handwriting nor interested in the beauty of his handwriting, he consented.

4.6.2 Privacy and Confidentiality

Upholding the principles of privacy and confidentiality is paramount in any research with children (Leyshon, 2002). In this research, maintaining privacy and confidentiality of my participants was one of the obstacles I faced right from the first day of fieldwork. Finding an appropriate place without interference to meet my participants for the first time was problematic since there were less private spaces in the schools. In one of the schools, after a long deliberation with the Guidance and Counselling Coordinator, he suggested a section of the school library that is less patronized by students, which he uses sometimes. However after holding the first meeting, I found it not

convenient for conducting interviews since frequent visits of students to the library caused distraction and may also threaten adherence of confidentiality. So even though that section of the library is less patronized by students, distractions from people going and coming to the library, noise from footsteps and whispering among students make it inappropriate for conducting interviews that demand some level of concentration.

As argued by Leyshon (2002), to find appropriate places where children can participate in interviews, there is the need for a degree of planning and being prepared to take opportunities when they arise. I was flexible and always ready to conduct interviews whenever and wherever appropriate. I conducted some of the interviews in empty classrooms, in such cases, I waited long hours in the school premises till school closed since seeing me around was to remind the participants of the appointment for an interview. I also conducted some interviews in ‘less private spaces’ (Abebe, 2009), under trees in open spaces. Notwithstanding, the interviews were less distracted, as meetings of such nature; teacher –student meetings are common and rather seen as private.

To protect the data from being tempered by any third party, recorded interviews and pictures were immediately transferred to my computer which is always protected with a password. Other forms of data collected such as diaries and my notes were stored in an envelope and sealed such that no other person can assess them. Anonymity was ensured throughout the research process. Real names and exact locations have not been disclosed in the presentation of this thesis, names of participants and other names mentioned during interviews were changed during transcription. Whereas in writing notes, I used fictional names to identify the characters so no one else could recognize or trace them.

4.6.3 Power Differentials

The nature of adult-child relationship presents a considerable challenge in research with children (Irwin, 2006). In the Ghanaian culture, children are trained from a very early age that they must respect and obey all elders, be humble towards adults, and take their advice. They are not expected to challenge adults and certainly, not expected to question what they are told to do (Twum-Danso,

2009). Such orientations push children to adult dominated position (Punch, 2002), where children are obliged to do or say what pleases adults.

One of the paradoxes which arose during my fieldwork was negotiating unequal power relations with the children. As mentioned earlier, I used my networks as a teacher in the research territory to facilitate access to the research site. This approach in one way played to my advantage, but on the other side placed me in a teacher-student relationship with my participants. At the initial stages, this situation in a way deepened unequal power relationship between me and the participants. I was being called madam as some students and teachers have recognized me as a teacher from another school. This experience made me realized that as a researcher, it is important to consider my actions in a larger perspective since certain actions which seems advantageous might play against me in another vein. But as I continually corrected them that I am currently not teaching and I am there as a student researcher, over time they began to see me more as a researcher rather than a teacher.

Furthermore, I tried to minimize my power by adopting friendly role (Mandall, 1991 in Abebe, 2009), where I presented myself simple and approachable not only to my participants but all in the schools. Some of my personal traits played to my advantage. I naturally like smiling, so it was quite natural for me to laugh and smile with my participants and subsequently develop friendship and trusting relationship. As argued by some scholars that, one-on-one interview with children may be intimidating and inhibiting hence potentially could deepen unequal power relations (Hill, 1997), there were times especially during the beginning of the interviews that I observed that a few of the children were shy and preferred not to talk. I overcame this by assuring them that there are no rights or wrong answers, I valued their views, and that it is their perspectives that were most relevant for the research. In situations where I realized they lack vocabulary and feared making mistakes in English, I encouraged them to use their local language with which they were comfortable.

4.6.4 Reciprocity

The principle of reciprocity, underlines all social relationships in Ghana (Twum-Danso, 2009). It is culturally appropriate in Ghana to give gifts to express heartfelt thanks without expecting anything in return. Whilst some scholars do proscribe reciprocity in research, considering it to be

information buying which presumably generates false data (Aptekar & Heinonen, 2003), others see the research process as a two-way street (Grenier, 2000 in Abebe, 2009). In this vein, it is imperative the research process puts both the researcher and the researched in co-beneficiary position. As the participants devote their time, effort, experiences, and wisdom to inform and shape the researcher's study, the researcher, in turn, is susceptible to variable involvement and apathy from participants. These include compensating the researched with service, material, monetary payments or communicating research findings back to both participants and policymakers and to use the findings to improve the lives of the participants (Abebe, 2009; Trainor & Bouchard, 2013).

My experience in the field attests to this assertion. Regarding reciprocity, a teacher in one of the schools asked; *“what will be their [children] benefit? They might shun other researchers if they have not gained anything after sharing their secrets with you”*. This statement might imply exchanging ‘secrets’ as he called it with material gain but I considered it appropriate compensating the children for their efforts and time, most importantly buying out time every day to write the diaries for a period of two weeks when they were seriously preparing for their end of term examination.

No doubt I identified major needs such paying school fees, and some of the participants have openly asked my assistance for surgery, but considering my position as a student researcher, I donated pens and exercise books to my participants which were economically within my means. Like Abebe (2009), I saw myself involved in the children's lives at different spheres of life. I developed some attachment with most them and became interested in their welfare in general. My relationship with some of the children was much more than a researcher-researched relationship. I most often called to check on them and find out how they were coping with school work and life in general and some of them did likewise, they called to check on me even after the fieldwork. Rightly described by Katz, the research relationship involves the research, the researcher and the researched tightly bound together and the boundaries become redefined and continuously blurred during fieldwork (Katz, 1994 in Abebe, 2009).

During my fieldwork, I sometimes find myself in compelling situations that I could not resist giving financial support. For instance on one occasion after an interview, I discovered that my participant was going to drink tea for supper because it was too late for her to cook any heavy meal. The worst part was that it had rained heavily for hours, and we both had struggled through mud slippery grounds to get to her hostel. Considering the fact that had it not for the interview, she could have left for her hostel before the rain and might have prepared a meal, I felt it was insensitive and inconsiderate if I let her go without any help. So I gave her money to buy food for supper. Even though I was not under any obligation to provide supper for her, I felt it was just right to reciprocate for her time and effort.

4.7 Challenges in the Field

My experience on the field was an interesting and a memorable one which I will never forget. To a large extent, the fieldwork was successful but not without challenges. One of the major challenges I faced was to reshape the focus of my research. Before leaving for the field, I had planned to involve parents in the study. It was my intention to also explore parents' opinion on how their disabled children navigate their experiences of disability. But on getting to the field this became a challenge. I realized that most of the parents resided in towns far away from the towns I conducted the research, it was, therefore, difficult to involve them in the study due to a limited period of time for the fieldwork and high cost of traveling from one town to the other to meet them. It was also my plan to observe the children at home to get firsthand information on how they negotiate life at home and their relationship with other members of their families. However, this was also not possible since most of the children resided in the school premises and could only go home for weekends twice within a term and at term endings.

Another challenging situation in the field was movement to and from the research site. For comfortability, I stayed in my previous apartment in a nearby town which I had already paid for. But this required that I commute to and from the schools every day either by a motorbike or taxi. Sometimes it took me long hours under the scorching sun to get a taxi or motorbike. On some occasions, drivers took advantage of the fact that I was running late and charged me exorbitant fares. In addition, both schools were located off the main road so I had to walk 5 to 10 minutes off the main road to the schools. Being in the field in the months of June and July, which is raining

season in Ghana, made it much more challenging. I walked through muddy roads and sometimes beaten or delayed by rain. It was quite a tiring adventure. I always got home exhausted.

4.8 Data Analysis, Interpretation, and Write-up

The analysis is an integral part of the research process. It has been emphasized by Hammersley and Atkinson (2007), that analysis is a continuous and on-going process throughout the entire research and not a distinct stage. Whilst in the field, I tried to make meaning out of my observations. I made deductions from behaviors, situations, informal conversations and formed cues and themes such as discrimination and participation as the basis for interpretation. My familiarity with the research context was quite significant as it accorded me an added advantage of being able to relate to realities and experiences of my participants.

After the fieldwork, I made a list of data I had collected. I transcribed audio recorded interviews. Even though time-consuming, transcribing the interviews myself was helpful in becoming more familiar with the data as well as facilitates the analysis process. The transcription was done verbatim, this was cumbersome as I had to replay the recordings severally to be able to capture every word and expressions such as laughter. This was done with the aim of strengthening the reliability of the data. In other words, I tried to minimize any misinterpretation due to mishearing (Brinkmann & Kvale, 2015). Transcripts were then read many times to identify emerging themes, patterns, similarities, differences and inconsistencies in various participants' responses. During the write-up process, I repeatedly went back to listen to the audio recordings to remind me of the context in which particular phrases or words were said. This process was quite useful as it helped me grasp a clearer understanding of some responses I could not understand just by reading the transcripts. In presenting the analysis chapters, I used excerpts from the interviews to back up discussions on various themes that I generated from the data.

CHAPTER 5
ANALYSIS AND DISCUSSION
PERSPECTIVES AND DAILY EXPERIENCES OF DISABILITY

5.0 Introduction

This chapter presents and discusses perspectives and experiences of children with physical disability. The chapter aims to answer the first three research questions mentioned in chapter one; what are disabled children’s perspectives of their disability? How do children with physical disability negotiate experiences of disability in their daily lives? What are disabled children’s experiences of interactions with non-disabled persons?

Among the issues highlighted in the chapter is how perceptions about causes of one’s disability impact experiences of disability. Discussions in the chapter are informed by data from individual interviews, diaries and my observations the field. Theoretical perspectives and relevant literature are also integrated into the discussions.

5.1 Causes of Disability

Noted from the data none of my participants were born with a disability, however, different circumstances led to their disability at some point in their childhood. The data revealed that accident and illness were the main causes of the children’s disability.

Describing how she became disabled, Mawuena a 16-year-old girl says:

“at the age of eight, when we closed from school one day, a colleague said there is oyster mining site¹⁰ in the area so they are going there to see how it is done. I told my mom that I would go too, she said no but I went. And whilst there, a container of oyster fell on my leg and my leg got broken which caused my disability”

Another participant who also became disabled through accident narrates:

“One day, we were going to school farm¹¹, and I joined one of my friends on a motorbike. On our way, a dog ran across us and my friend applied the brakes so fast that we both fell

¹⁰ A site by the river bank where oyster is harvested

¹¹ In Ghana especially in the rural area, some schools have farms where the school children weed. At times individuals contract schools to work on their farms

together with the motor-bike. And my leg got broken in the process” (Naa 16 year’s old girl).

My study corroborates other studies conducted in Ghana that, accident is one of the causes of childhood disability. It was revealed that burn-related injury and long-term injury from transport accidents are some of the common etiology of physical disability among children (Forjuoh, Guyer, & Ireys, 1996; Mock et al., 2003).

Illness is also one of the risk factors of childhood disability. A study in Africa shows that the malaria disease could cause various forms of impairments including hemiplegia/ hemiparesis, which is a weakness in one or both limbs on one side of the body, speech disorders, blindness and hearing impairment. In some cases, severe malaria may result in cerebral palsy also called spastic paresis where children have a generalized increase in muscle tone and become severely disabled (Snow, Craig, Deichmann, & Marsh, 1999). My study indicates how illness could cause childhood disability as some of my participants associate their disability to illness. For example, Abi a 15-year-old girl states:

“I was suffering from rheumatism, so I went to school and I started experiencing the pains again on one of my legs. Later I was told [doctors told her] my hip bone shifted from its position. From that day, I wasn’t able to walk as normal as I used to and walking as a disable but I wasn’t a disabled before”.

There is a growing medical knowledge about disability in the Ghanaian society (Tuakli-Wosornu & Haig, 2014). Increasingly, more and more Ghanaians are becoming aware of other causes of disability other than the superstitious belief that disability is a punishment from the gods. Notwithstanding, there still exists spiritual conceptions of disability. Kojo a 17-year-old participant ascribed his disability to juju¹².

“They tried to kill my father so they went and set the thing¹³ at his shop. That day I picked the shop key from dad and ran ahead to open the shop, upon getting there I felt something under my feet like thunder, so when my father got there I told him that there is fire here so we went home. About two weeks later there was a boil on my left leg, and about a month

¹² A charm

¹³ The charm

later it busted and became a big wound. The pain became severe so I was sent to the hospital and I stayed there for one and half years”.

I find it worth noting that, regardless of Kojo’s assumption that his disability was caused by juju, he was still sent to the hospital for medical care contrary to the common practice of consulting a spiritualist for a cure. In this case, his Christian faith might have informed this action as Kojo later stated that “*God knows the reason why he let this happened*”. The decision to seek medical intervention for Kojo appears to be in line with Avoke (2002) claims that Christianity has to some extent diluted the effect of traditional belief systems of disability. In Ghana, most Christians believe that even though prayer can heal all sicknesses, there is still the need to seek medical attention. Hence, it is not uncommon for some to combine medical intervention with prayers for a divine cure.

The children’s perception about the causes of their disability has to some extent influenced how they navigate experiences of disability. Mawuena who attributed her disability to an accident constantly blames herself for her disability. She believes that she is paying for disobedience to her mother’s warning. She mostly becomes bitter, isolate herself and cry. When asked how she feels about derogatory comments such as “she is not beautiful” she remarked:

“I blame myself. When I was a child and my mom advised me, I disobeyed and that is what brought my situation. If I had listened to my parent’s advice and I did not go [to the oyster mining site] this would not have happened, so when they call me names I blame myself and all that I do is cry!

On the other hand, Abi whose disability was as a result of illness (rheumatism) keeps a hoping attitude. She believes that it is no fault of her that she got sick. She continually hopes that one day a Good Samaritan will support her for a surgery which doctors assured will correct her situation. She believes her experiences of disability would be over once she undergoes surgery.

With smiles on her face Abi says:

“Yes, the doctors said there is something to be done about my situation. They told my parents to send me to Korle-bu hospital¹⁴ for some operation for them to bring the bone back, but because of financial problems we are not able to go till now”.

Hope for a better life¹⁵ is evident in how Abi negotiates life, particularly in her interaction with people. I find it motivating that she mostly smiles and interact well with strangers, people she hopes can help her. I noted from my diary that she was particularly nice and open the first time I met her which I thought was rare. In Ghana, because of discrimination and bad attitude towards the disabled, most children with disability are skeptical about interacting with strangers. They only become open with people they know and are assured of being treated with respect. Abi’s actions could be interpreted to mean that perhaps she does this in an attempt to win people’s favor. Also, her readiness to ask for help shows how eager and hopeful she is to get back her previous life and I take this to mean that her perception about the cause of her disability and doctor’s assurance that her situation can be corrected gives her hope for the future, something to look forward to. Abi’s desire and eagerness to get back her previous life is evident in her final words in the interview with her:

“To me am just praying for help, so if there is something you can do to help me, am just asking for help because this is not how I was and I want to change, there are some things I used to do which I cannot do now and it really hurts me a lot, so if you are having some help”.

5.2 The Children Constructing Their Disability

Noted from the theory chapter, there are competing debates on how disability could be understood. Each of these debates emphasizes differing perspectives of disability. For example, the medical model places emphasis on the individual thus the body’s malfunction as the root source of disability, whereas social model emphasizes societal imposed restrictions as the main source of disability. Participants of this study are of course unaware of the academic debates, subscribe to multiple understandings of disability. They seem not to draw any dichotomy as to whether their disability is solely a result of the body’s malfunction or societal restrictions.

¹⁴ A major hospital in Ghana

¹⁵ Life without disability

5.2.1 I Used To

All the seven children who participated in this study, recognize the limitations their body's malfunction place on them. They expressed concerns about activities they used to do as able-bodied children which they are not able to do now as a result of their body's malfunction. The participants describe some changes that their transition from abled bodied children to disabled children has brought in relation to their abilities. The following excerpts from the interviews with the participants contain examples of changes occurring in their abilities as a result of their disabilities. Abi says:

“Sometimes I force to do things I used to do in the past but am not able to do them as I used to do in the past, like running. Before I became disabled, I used to play, me I like playing games like football running but, now I can't do them so anytime my friends are playing, then I also try to do some, but it's difficult because of my condition so I don't do them”.

Naa a 16 years old girl also indicates that her disability has had some effects on her abilities. She says:

“I feel pains when am walking and when I stand for long. First [before] when I didn't have the thing¹⁶ I go to farm and weed a lot, but now I can't weed much because of my leg. That time I played volleyball, but now I don't play because of my leg”.

These excerpts above reflect a causal relationship between the body's malfunction and inability to perform certain activities. A possible interpretation of the expression *I cannot do (... ..) because of my leg* is that, the body's malfunction or impairment places some form of a handicap on the individual. This assertion by the participants appears to resonate with the medical model which locates the problems of people with disability within the individual. As the individual is thought to be incapable of performing certain activities due to one or more functional impairments, and obstacles to participation on equal terms are situated primarily in the individual, since it is the individual who lacks certain capacities that are necessary to attain autonomy (Michailakis, 2003). Nevertheless, this does not necessarily equate impairment automatically to handicap. The words of Abi and Naa: *am not able to do them as I used to do in the past* and *now I can't weed much*

¹⁶ She was referring to impairment in her leg

respectively, imply that they are still capable of performing some activities they used to do when they were able-bodied but probably not to the same measure.

Furthermore, the children indicate suffering pain as a consequence of their disability. For example Kabu a 15-year-old boy who expressed similar concerns as the other participants stressed that:

“I have difficulty in fetching water, I feel pains when walking, I liked playing football but I don’t play again because of my leg (.....). My leg hurts whenever I tried to play football”.

Regarding suffering pains, some critics of the social model describe physical pains associated with disability as a reality which should not be overlooked. It is argued that by attempting to deliberately oppose the reductionist biologism of individual tragedy model, the social model has ignored the corporeality of painful and problematic mind–bodies (Holt, 2004). The children’s indication of suffering physical pains ensuing from their disability seems to reflect this argument.

5.2.2 Constructing Disability Socially

In another vein, my participants associate some challenges they face as physically disabled children to social and institutional structures which are not friendly to their condition. Participants mentioned the physical environment as posing accessibility problems. Muddy roads and grounds, the absence of ramps and steep stairs place restrictions on their movement. Most of the participants find it particularly difficult to move about when it rains. They carefully stay away for hours to prevent falling and hurting themselves.

Mawuena states:

“When it rains, the road is full of mud so for me to go to the hostel is difficult, so I have to wait for some minutes before I leave, sometimes I have to find a stick to support me”.

Kabu also states that:

“I am not having stamina so when it rains, I have to stay where I am till the grounds is good for me to walk (.....). Even if it takes long hours”.

Kofi a 17-year boy who commutes from home to school says that he *stays away from school when it rains*.

Participants also indicate that using school facilities such as washrooms is difficult for them since the facilities are not designed with the physically challenged in mind. Kabu tells me he is not comfortable using the toilet because he has to squat which is difficult for him, so he sometimes does not use the toilet for 2 or 3 days. Another participant Naa also points out that sitting in a wooden desk for long hours is tiring.

These responses from my participants turn to be in line with the social model, which proclaims that much of the limitations that are inflicted upon individuals with impairments are neither natural nor inevitable consequences of their capabilities. But rather must be seen as the results of a failed social policy or being the failures of social institutions to take into account certain individuals' particular conditions (Michailakis, 2003). My participants' responses clearly show that the bad terrain, absence of ramps, uncomfortable toilets etc. turn to be disabling them. This may be an indication that, if social policies and structures are designed taking into account conditions of physically disabled persons, much of their challenges would be reduced.

As already mentioned, the physical environment limit the movement of the children which makes it quite difficult for them to put up with the pace of activities to perform in the schools. For example one participant indicates that he does not usually go to the library because there are no ramps and the stairs are high and difficult to climb. The children also feel left out regarding sporting activities, a few of them indicate that they try to participate but mostly are hesitant because of mockery and fear of getting hurt since the schools have no sporting equipment specifically designed for them. One participant states:

“I try to participate but hmmm, it really hurt me a lot, some activities like playing football or running if I do it I may experience the pains few minutes after, I just prevent myself from participating”.

5.2.3 Multiple Perspectives

The discussions above shows that multiple models can be employed in understanding disability. From this study disability is understood from overlapping perspectives of the medical model and the social model. For my participants, their disability can be constructed as individual impairment and the same time as societal restrictions. For this reason, efforts in mitigating the challenges and problems faced by the disabled must come from both the individual and the society. This assertion is quite obvious when Kofi a 17 years old boy was talking about failed policy which was intended to give financial support to the disabled. He said:

“Well I have no control over that [government policies] but what I can do to help myself so I can have a bright future is what am doing¹⁷”.

To this participant, he thinks he has an individual responsibility just as the society’s responsibility towards overcoming challenges of disability. And even when society fails its part, he is determined to play his part so he can have a bright future. This participant’s determination to succeed ties in with the assumption that, courage, independence, willpower are all lauded when a disabled person proves that overcoming a disability is a matter of individual effort (Johnston, 1994 cited in A. Llewellyn & K. Hogan, 2000). Hence, this study suggests that as much the society must be adapted in order to reduce or avoid the disabling effects on children with disabilities (Michailakis, 2003), individual effort is also necessary to subduing the barriers and restrictions imposed on children with disability.

5.3 Poverty and Childhood Disability

Poverty may be explained as having limited access to adequate healthcare, food, education, shelter, employment, and often enduring hazardous working conditions (Yeo & Moore, 2003). Bearing this in mind, the analysis of my data shows a relation between poverty and childhood disability. Not far from the findings of previous researches on disability in Ghana (Kassah, 2008; Mock et al., 2003; Reynolds, 2010), my study suggests that there are economic implications of disability. The children in my study indicate that there were and still are high financial cost to their families resulting from the disability. Much of which was spent on seeking medical intervention. Kojo who was hospitalized for one and half years says that his parents had solely taken care of his hospital bills and the sudden death of his father made matters worse. He stated:

¹⁷ He is schooling to have a bright future

“It became difficult for my mom and elder siblings to buy my drugs and pay for my reviews in the hospital”.

For Abi who suffered rheumatism, it was so expensive to pay for her medical care. She says: *my parents don't have money for my surgery.* And because the parents have already spent so much money on her and her younger brother whose arm got broken during birth, the parents could not afford to pay for her surgery. When asked whether she still goes for check up in the hospital she answered:

“No, always when I go to the hospital, I am only given Bico¹⁸ and multivite. So anytime I feel the pains, I am already having the medicine, so I take the medicine to stop the pains sometimes too I take fpack¹⁹ to reduce the pains”.

The above cases point to the fact that, poverty compromises the health of persons with disability. For example in Abi's case, what she needs is a surgery to correct her situation, but because of limited resources, she takes medication to relieve her pains. In a hindsight, such medications only work for a short moment and could bring other health consequences which may compound the already difficult situation. A similar assertion was made by Graham, Moodley, and Selipsky (2013), poverty compounds the challenges faced by people with disability.

Not only do the families of children with physical disability bear expensive medical treatment but also face challenges in terms of productivity. Families invest time and energy taking care of these children especially at the beginning stages of transition from able-bodied to being disabled. Many at times, parents spend a lot of time at the expense of work and business, seeking for different interventions in their quest to find a remedy for their wards. This may consequently lead to loss or limited income and inability to satisfy the needs of the family. For instance in Kojo's case, his father's shop suffered a great deal because the father was always at the hospital. Finally, the shop was closed and the family later relocated to their hometown where there was a lower cost of living. Similarly, this was the case for Abi whose family had to relocate to their hometown because the mother's business was no more doing well. As a result, the family had to cut down on other expenses such as rent. And since the family got their own house in their hometown it was reasonable to move even if there were other implications.

¹⁸ Multivitamins

¹⁹ Pain-killer

5.3.1 Poverty as a Cause of Disability

The discussions in the section above demonstrate how disability may contribute to poverty due to high financial involvement associated with providing treatment which may drain resources. Also, there may be a reduction in productivity as time and energy for work is sacrificed for taking care of the disabled family member. The study also suggests that in some cases poverty situations may cause disability in the first place. Children living in poverty usually have limited health care, lack proper education and in some cases engage in hazardous work. All these situations increase the risk of illness and injury which may in turn cause disability. The extract below is a typical example of how economic hardships can push children to engage in work that may accidentally result in impairment.

When I got to JHS form three, my parents did not have money to pay my registration fee²⁰. I did not want to stop school or wait for next year. So I went to the bush to cut trees to make charcoal to sell and get money to pay my registration fee. When I was cutting the tree for some time I told me younger brother to push the tree. I didn't know that it was going to fall quickly. Suddenly the whole tree fell on me so my brother ran and called some people weeding in a farm close to the place and they came to help me. And that is why I walk like this because the doctors say the accident affect some bones in my legs. (Kofi a 17years old boy)

In Ghana and in many countries in the global south, children and young people engage in various forms of work to support themselves and their families. Studies have demonstrated the benefits that children may accrue from work. For instance, it is argued that children's work provides apprenticeships and transmits skills, as well as socializing children into adult roles. More so culturally bounded notions of responsibility are linked to how children perceive the opportunities and constraints facing them and to the decisions they make about their work and future life chances (Abebe & Bessell, 2011). Nevertheless, children's work should not be romanticized to bring only benefits. The toll of heavy labor on young bodies, use of dangerous tools and machinery, contact with fertilizers and pesticides, sheer exhaustion and, in the long term, forgone schooling, may all impact negatively on health (O'Donnell, Rosati, & Van Doorslaer, 2005).

²⁰ A fee paid in order to sit the Basic Education Certificate Examination

A research in Ghana reveals that children of poor households are much prone to engage in harmful child labor than other children (Blunch & Verner, 2001). This points out that, poverty is a high determinant of children engagement in work that is harmful. This is reflected in the Kofi's case presented above. Due to the inability of his parents to bear the expenses for his education and his decision about his future life chances, Kofi was propelled to engage in work that accidentally resulted in his disability.

Analysis of my data also reveals that disability could result from poor medical care which could be linked to the high cost of medical care. The high cost of medical care in most cases deny the poor from receiving the needed medical attention. This sometimes led to further health complications which could have been prevented. The case of Frank a 17 years old boy presented below illustrate this.

***Mispah:** Do you mind telling me how you became disabled?*

***Frank:** when I was eight years, one day I woke up and there appeared rashes on this arm (the arm was shown to me) and after some time the rashes turn into a wound. After the wound healed the arm remain like this, I can't straight this arm.*

***Mispah:** did you go to the hospital?*

***Frank:** yes we went to the hospital but that day we didn't have enough money so the doctor just gave me a pain killer.*

***Mispah:** so what happened?*

***Frank:** after about 2or 3 weeks my parents got some money so we went back to the hospital but the doctor said the arm has turned into a big wound and he cannot do anything about it so we should go to a bigger hospital in Accra.*

***Mispah:** and did you go?*

***Frank:** yes we went and the doctors there said they have to cut my arm but my parents refused.*

Shown in the examples above, it is quite evident that poverty can perpetuate occurrence of disability. In both situations of Kofi and Frank, the occurrence of impairment could have been

avoided if there were the financial means to satisfy the basic needs of the children. From my data, I argue that not only is poverty a consequence of disability but poverty in one way or another perpetuates disability.

5.3.2 Poverty Complicates Experiences of Disability

This study suggests that children with disability experience poverty through myriad ways either as a direct or trickling effect of their disability. They have limited access to adequate health care because their families cannot afford their health care. They also have difficulties in meeting their educational needs. Paying of school fees and provision of other educational materials such as books, uniforms, and feeding are common challenges faced by the children. An experience narrated by a teacher during the interview session with him further illustrates how poverty shapes and makes the experiences of disability more complicated. The participant in question was punished for reporting late to school when the school term began, which was as a result of an inability to raise money for school fees and other expenses.

“It was at the very beginning of this term that I received a complaint that Mawuena was given grounds work²¹, I know normally she is exempted because of her condition, it is difficult for her to weed, as she has to bend. So as the guidance and counseling coordinator I asked the friends to assist her but according to them, the teacher said everyone must take the work because she knew she is disabled but did not come to school early or did not report early, so no one should take the work or punishment for her. I consulted the teacher in question and explained things to him and he understood me, so she was allowed to discontinue the punishment.

During the interview session with Mawuena, she confirmed the incident. She explained that the reason behind her reporting late to school was financial difficulties. Her parents were unable to raise money for school fees, hostel fee and feeding by the stipulated date and she had to wait for extra two weeks for her parents to raise the money. She lamented and in her own words says *hmmm²² if my parent should have money, I would not have this experience.* The expression *hmmm*

²¹ Weeding

²² Expression to show sadness

shows how sad it must have been for her to go through that ordeal. Evidently limited means to satisfy basic needs of children with disabilities make their experiences of disability more difficult.

Mawuena's experience is one but many of such situations of poverty that children with physical disability go through in their daily lives. During my fieldwork, I observed the case of another participant, whom I noted was almost absent from school on many of my visits to the school. So during the interview session with him, I politely asked why I hardly see him in school. In response, he made it clear that he skips school whenever he does not have money to buy food at school.

5.3.3 Disability a Burden on Families?

This study resounds the research by Mock et al. (2003) that, undoubtedly there are economic consequences of disability that may be challenging for the families who are already living in poverty and even for families with reasonable income. Nevertheless, children with a physical disability do not necessarily constitute economic burdens or liabilities. These children are not totally dependent and incapable of contributing to their family's welfare. The physically challenged children who participated in this study, in varying degrees support their families and themselves in ways that able-bodied children of their age likely do. To illustrate, Naa assists the sister in the farm and also sells tomatoes during vacations, Abi sells in her mother's shop every weekend, Kojo barber's for his colleague students in return for assistance in cooking or fetching, water etc.,. He also repairs shoes during vacation. Kofi with his friends makes boats and fishing net. Whilst such actions remain invisible and overlooked by society as ways by which children with physical disability demonstrate their abilities, I contend that these are but many ways disabled children exercise their agency.

Even though children with a physical disability may be limited in some aspects of life, they find means of exercising agency. Argued by Klocker et al. (2007) people generally considered powerless do not entirely lack agency but maintain alternative forms of power. Applying this thought for example in Kojo's case who barber his colleagues in return get assistance in performing some other activities he is limited in done, I take it that he creates other forms of exercising his agency. Further discussion on agency can be found in the next chapter.

5.4 Experiences of Discrimination

The Convention on the Rights of the Child and national legal documents, for example, the Disability Act of Ghana 2006, Act 715, explicitly prohibits any form of discrimination against persons with disabilities. Yet this research suggests that children with physical disability experience various forms of discrimination. Analysis of the data reveals different forms of discrimination faced by the participants. These I categorized into structural, institutional and attitudinal forms of discrimination.

5.4.1 Structural Discrimination

Structural discrimination is one common form of discrimination faced by children with physical disability. By using the term structural discrimination, I refer to an unfriendly physical environment that turns to systematically marginalize children with physical disability. This involves muddy roads, classroom and office buildings without ramps or lifts, inconvenient toilet and urinals, furniture, open spaces etc. As mentioned earlier, the study area is a mud prone zone, roads, paths and open spaces are always filled with mud when it rains and as such it is very challenging for children with physical disability especially those with mobility difficulties to move from one place to another whenever it rains. Both schools have one classroom building each with ramps, all the rest including the office buildings have no ramps. Each school has one KVIP²³. This type of toilet does not have any flap to sit on. It requires one to squat and no use of water to flush. Furniture in the classrooms is dual-desk made of wood.

Regarding educational facilities, the Disability Act section 17 recommends provision of necessary facilities and equipment that will enable persons with disability to fully benefit from the school or institution. However, it is quite clear that not much has been done in this respect. This appears to illustrate that it is social barriers which create disability. And the difficulties of living as a disabled person are due to discrimination and prejudices, rather than impairment (Shakespeare 1998 cited in Avoke, 2002). The bad terrain and absence of proper facilities serve as an obstacle to the freedom and movement of children with physical disability. The practical steps that the children take, such as *wait for the grounds to get a bit dry*, or *get a stick for support* or *not using the toilet*

²³ Kumasi Ventilated-Improved Pit- type of toilet that collects human feces in a hole in the ground.

for 2 or 3 days, exemplify their ability to negotiate such structural challenges. Nevertheless, it should not be undermined that such structural deficits reinforce discrimination and further serve as restrictions in their lives.

5.4.2 Institutional Discrimination

Institutional discrimination is the process by which established laws, policies, norms and practices sideline persons with disability. In recent times, several legal documents adopted by the Government of Ghana contain either a few articles or in its entirety seem to fight for equal opportunities for persons with disability. These legal provisions on the face value seem perfect but their practicality is far from reach. Taking the Disability Act, for example, section 18 states that:

The Government shall

- 1. Provide free education for a person with disability, and*
- 2. Establish special schools for persons with disability who by reason of their disability cannot be enrolled in formal schools.*

A possible interpretation of this provision is that persons with disability have free access to education at all levels since no particular level of education is specified in the provision. However, research has shown that some children with disability drop out of school due to constant harassment from school authorities for non-payment of school fees (Kassah, 2008). Currently in Ghana, in paper all levels but basic education is free. But it is not free in practice. The basic education comes with subsidiary fees like examination and sports levies which are paid by parents or guardians. Disabled children in all other levels of education in Ghana pay exact school fees as any able-bodied children. And mostly the cost of their education is the sole responsibility of parents. In this research, out of the seven disabled children who participated, only one admitted being sponsored by a church organization. The rest of the six children reported that their parents or immediate families struggle to pay for their education. Undeniably, failure to effectively implement policies to reduce the cost of education is a major source of the problem that turns to sideline children with disability from exercising their right to education.

Further, it is obvious that most disabled persons are unaware of the policies and programs that are intended for them. It was reported that that only a few people with disabilities know about the 3%

of the District Assembly Common Fund reserved for persons with disabilities let alone how to access it (World press, 2015). This assertion is similarly reflected in my study. One participant reported:

“There was a time some people came from the North Tongu District and told us to write our names and our problems and that we shall be given a scholarship, but since then we haven’t heard anything from them”.

Another participant remark:

“I remember when I was in form one [Senior high school, year one], people from the North Tongu district gave us a form to fill and write what we need but we haven’t received anything”.

From these and similarly responses from the other participants, I presume that the participants are not very much informed about such provisions intended for them and as such persons responsible for implementing such programs take advantage of their ignorance and put them in perpetual hope but despair.

One officer from the district education office, the only participant who admitted knowing about the 3% District Assemblies Common Fund for the disabled, indicates that it is quite difficult to access the fund, stating that the bureaucratic procedures involved are quite complicated. This makes it difficult for the disabled children and their families who are already disadvantaged to go through the process of accessing the fund. No doubt bureaucratic processes and practices reinforce discrimination against children with disabilities.

Furthermore, the children also experience discrimination within the local institutional setting. Regulations and practices in the schools sometimes disregard the bodily difference of the children. From the diary data, the children indicated performing such activities as weeding, scrubbing etc. in the school. Finding out how the children navigate through performing such activities that seem unsuitable to their condition, it came out that most of the children performed such activities because the schools rule demanded. This means that even though the children had difficulties performing such activities, they did so because they were obliged. In this case, the schools rules

and practices give no recognition to the bodily limitations of the children. Putting this into the perspective of the social model of disability, the children face discrimination as a result of failures of social institutions to take into account certain individuals' particular conditions (Michailakis, 2003).

However, I wish to point out that the children turn such situations into spaces where they exercise their agency. As argued by Nilsen (2009), children's resistance to authority is both an opposition and empowerment. Through actions of resistance children gain control over some of their everyday experience, and by this conquer some free space and create alternative experiences in line with their values and priorities. This is illustrated by the extract below.

“When I came to the school first, I asked permission from the headmaster to be exempted from weeding and he accepted, but as time went on seniors and teachers started disturbing me. Even when I explain to them that I have permission from the headmaster, they don't accept. They normally say the headmaster has not given them any information regarding that. So what I do now is, I also bring cutlass and be with my colleagues. As they weed, I just pretend to weed, then I tell them to write my name and that ends it” (Kofi 17 years old boy).

Even though the headmaster had already granted permission allowing the participant to be exempted from weeding, to this participant, open resistance to seniors and teachers constitute disobedience to authority which is against the cultural values in Ghana. The Ghanaian culture requires that children respect and be obedient to all elders and do not challenge or question what they are told to do (Twum-Danso, 2009). Hence through subtle resistance, this participant creates alternative means of taking control over his daily experiences. This exemplifies one way that children with physical disability can be active in constructing their own lives and the lives of those around them, hence are not just passive subjects of social structures and processes (Prout & James, 1997).

Furthermore, norms regarding leadership positions in the schools, in practice turn to exclude the children. Holding leadership positions in schools is one way children assume responsibility and participate in decision making. Such opportunities may serve as training ground for shouldering

much high responsibilities as adults in the society. There are several leadership opportunities for children in Ghanaian schools. A teacher interviewed described opportunities for leadership positions in his school to be inclusive. He states:

“Any student duly qualified is allowed to file nominations (.....) I have seen few disabled students assume leadership positions in the school. But they slightly feel intimidated so they normally don’t come out to even contest. Because students aspiring for positions would have to campaign vigorously before they are voted for”.

In this situation, even though children with disabilities are allowed to hold leadership positions in the schools, but they are technically excluded because of the vigorous nature of the processes involved.

5.4.3 Attitudinal Discrimination

Belief systems shape any human interactions. Argued by Yeo and Moore (2003), society holds low expectations of disabled people. This kind of beliefs about the disabled shape people’s behaviors and attitudes towards them. My participants indicate experiencing attitudes and behaviors that are discriminatory in their daily interactions in school, at home and in the community at large. When I asked Abi to describe her relationship with her family, she points out that the mother and the younger sister say things that hurt her so much especially when her sister is doing certain things that she finds difficult to do.

In this scenario, Abi’s sister’s abilities are the standards against which her abilities are measured. And falling short of this implies she is incapable. In the critiques of childhood universalism, it is contended that standardization promotes marginalization of children’s competence and intelligence (Prout & James, 1997). This is likely so when children with disabilities are scaled on societal standards of able-bodied children. Setting universal standards for children who have different limitations and abilities reinforce discrimination. Children who fall short of such standards get their self-esteem hurt. This on a local level is reflected in Abi’s case, it appears Abi is expected to meet a set standard by her mother and the sister. Thus, she should be able to do all that the sister could do. Abi further states:

“My sister tells me, I am expecting someone to do things for me and that am depending on someone. Meanwhile, it’s not like that, am not expecting that. It hurts me so much”.

Judging from Abi's tone of voice when she was talking about this, I understood that she feels disappointment at her inability to do certain things because of her mother and sister's attitudes towards her.

In a similar vein, Mawuena's scenario²⁴ discussed earlier illustrates how children with physical disability face discrimination, as people deny them the opportunity to be heard. Further probing into the case revealed that the teacher who punished her, assumed Mawuena was taking advantage of her disability to misbehave, saying that Mawuena thinks she would not be punished if she misbehaves. Finding out from Mawuena why she did not explain to the teacher her reasons for reporting late, she remarks: "*he didn't give me the chance to explain, and even if I explain he won't accept*".

I argue here that, rather than jumping into conclusion that children with disabilities take advantage of their situation to misbehave, it is important to first give them the opportunity to explain the reasons behind their actions. This is also as stated at article 12 of the CRC; the child who is capable of forming his or her own views has the right to express those views freely in all matters affecting the child, the views of the child be given due weight in accordance with age and maturity of the child.

Labelling or name calling is another form of discrimination faced by the children. Labels serve as identifiers, they prescribe and attribute particular characteristics to things. Labels are so powerful that they sometimes encourage us to act irrationally thus diminishing our sense of judgment when we yield to them (Agbenyega, 2003). The children in this study have to deal with various forms of name calling in their daily interactions with people. Comments such as *ugly girl* or *you are not beautiful*, *Pozo*, *wormetor*²⁵ often become their household names. Young and old alike use these words to describe them. In the following excerpt from an interview with one of my participants, it is quite clear that as much as children with a physical disability know that they would be labeled it is very hard to get used to such names.

²⁴ See page 54

²⁵ Local expression which means disabled

Kabu: *When they call me names I feel like that is not the aim of coming to school, so even if I report I won't get anything from it. So I just forget about it and move on with my life.*

Mispah: *So in your mind, you feel like no matter what they say you are here to school, so you tell yourself that you are coming to endure all the name calling and discrimination.*

Kabu: *I tell myself like that, I know definitely they will call me names before I came to the school.*

Mispah: *So it means that you are prepared that, well, of course, they will definitely call me some names so let just get used to it.*

Kabu: *No it's not like let me get used to it, but I just forget and walk away.*

From the data, bad attitude towards children with physical disability negatively impacts on their social life. They have few friends and prefer to isolate themselves for fear of embarrassment. The following quotes from the participants illustrate this assertion.

A participant says *"sometimes I sit alone I don't want to go to anybody for anything"*.

Another states *"if they try to disgrace me and hurt me, if they are doing something and I have some idea about it I can't go close to them and say anything, because I think they may throw some things back at me again and because I don't want to take any insult from them I prevent myself from them"*.

Yet another says *"I don't make friends in the school I see them as colleagues"*.

CHAPTER 6
ANALYSIS AND DISCUSSION
AGENCY AND CHILDREN WITH PHYSICAL DISABILITY

6.0 Introduction

This chapter discusses my final research question; how do disability and agency interplay in the lives of children with a physical disability? Using data from interviews, diaries and observation, I explore how children with physical disability exercise agency in their everyday lives. For example, I highlight how these children display agency as they perform household chores and use the space around them. Also, I look at the interplay of disability and agency, by focusing on thick and thin factors thus opportunities and limitations on agency.

6.1 Agency in Everyday Actions

Describing children and young people as agents is to view them as ‘thinkers’ and ‘doers’ (Klocker et al., 2007). This means children are capable of reasoning and taking actions less dependent on adults. My research suggests that not only are children with a physical disability simply constrained by their impairment but face social and structural forces that they have to deal with in their daily lives. Yet they exercise some form of negotiated agency. In analyzing the data from the field, I focus on four areas where the children exercise their agency. These are household chores, place and space, human interaction and competence.

6.1.1 Household Chores

The data reveals that the children perform a number of different kinds of chores. Ranging from sweeping, scrubbing, fetching water, weeding, ironing, washing, cooking etc. Even though the children indicate difficulties in performing some of these chores, they make the effort themselves to do the chores as expected of any children in Ghana. They are not totally dependent on other people. Such is the demonstration of their abilities to be active in the construction of their lives. Kojo’s example mentioned earlier, that he uses his craft as a barber to get some of the chores done for him, which is a display of agency in itself further states that

“Sometimes my friends help fetch water for me, sometimes iron my clothes. I normally wash my clothes, because we cook ourselves, mostly my friends help, but sometimes I try to do it myself to see how best I can do it, I look at how they do it and I also do it”.

The example of Kojo indicates that even though the children receive assistance from friends and colleagues, they sometimes do the chores themselves. Furthermore, the children devise their own strategies to adapt to prevailing circumstances. The extract below illustrates this.

I always fetch my own water, even if I ask juniors to fetch for me their school mothers prevent them. So if the tap is not flowing in the hostel I go to the headmaster’s bungalow to fetch water. Carrying the water in a big gallon is difficult for me so I carry it in small gallons and go two or three times. And cooking too, it is difficult for me to be cooking every day so if I don’t have food, I prepare food that can take me throughout the week. (Mawuena)

This extract taken from the interview with Mawuena demonstrates that she uses her power of reasoning just like any individual. Her physical impairment does not render her incapable of thinking. Instead of playing the victim of her circumstances, she uses her power of reasoning to devise strategies to navigate her challenges. Reasoning that fetching water with small gallons two or three time which she is capable of doing rather than complain and stay without water or prepare food for a week rather every day is a manifestation of agency.

6.1.2 Place and Space

It is important to point out that the ability of physically disabled children to make sense of their environment and negotiate spaces around them is a demonstration of their agency. Analysis of the data has shown that the children with physical disability have the ability to negotiate their environment despite structural limitations. As noted already, my study area has bad terrain; muddy roads, buildings without ramps yet these children navigate life in this environment.

Narrating how he walks whenever it rains, Kojo indicated that he has more advantage over even the able bodied. He states: *“one advantage I have is my crutches, where there is a lot of water I just put the crutches in the water and jump over the water”.* Kojo further adds that even though he falls sometimes he sees it as normal because the able-bodied also fall sometimes. Furthermore,

the decision by some of the children to *wait for the ground to get a bit dry or get a stick for support* exemplify the children's ability to create safe spaces (James, 2009), for exhibiting their agency.

Another participant, Naa describes what she does when she gets tired of sitting on the wooden desk through long hours of class.

"I ask permission to go out to urinate and then I take a walk for few minutes".

Naa knows that she is allowed to ask permission to go out to urinate so she takes advantage of the situation to go out and take a walk even when she does not need to urinate.

This example ties in with the argument made by Nilsen (2009), that children can conquer some free space and create alternative experiences in line with their cultural practice, values, and priorities.

6.1.3 Human Interactions

The daily actions of the children with a physical disability within the socio-spatial spaces are also shaped by their interaction with people both young and old. Within this milieu, are hierarchical relationships even though limiting offers the opportunity to the children to exercise their agency. The school setting is characterized by different kinds of hierarchical relationships. For example teacher-student and senior-junior relationships. These various kinds of unequal power relations have varying degrees of impact and generate different forms of responses from the children. This Klocker et al. (2007), termed reactive agency which involves subtle resistance of authority. The scenario described in chapter 5, where the participant uses pretense as a way of resistance against teachers' authority to weed is a typical example of reactive agency. As mentioned earlier, open resistance or openly refusing to weed could constitute disobedience to authority which is against the cultural values in Ghana.

In another vein, participants respond differently to authority from their colleague students. To illustrate a participant states:

"When seniors punish me to scrub the bathhouse or the toilet, sometimes I just refuse to do the work". (Kabu)

This point to the fact that children and young people's agency and negotiation of unequal power relations is not static but changes (Klocker et al., 2007). The children are able to differentiate different sources of power and give a reactive response accordingly.

It is not, however just within the context of unequal power relations that the children's agency thus their ability to act creatively manifest. They also exercise their agency in interaction with their peers. Not refuting my earlier assertion that the common reaction of the children towards derogatory comments and actions is to walk away, yet I wish to suggest here that the children have the ability to draw the line and stamp their authority. In the extract below, the participant demonstrates his ability to take actions against deprecating behaviors from his colleague students, in effect saying no to such behaviors and that he deserves respect and dignity.

I woke up one day and I realized my crutches were missing. So ask my roommates but nobody seemed to know where it was. Then a boy from another room came in and said he saw the crutches in his room. Later I got to know the person who took my crutches there when asked him why he did that he said he was only joking. So I told him I don't like that kind of joke. Instead of him to apologize he started insulting me, using words to describe my leg and even said God is punishing me for my bad behavior. I became annoyed, so I reported the case to the senior house father²⁶. The senior house father also reported the issue to the headmaster and guidance and counseling coordinator. The school authorities wanted to sack the boy from the school but I pleaded on his behalf. But he was punished to weed. And since that time he became my friend. He helps me sometimes in fetching water and he sometimes warns people who make fun of me.

In addition, the children also exercise agency in terms of choice of association. They are able to determine who to associate with, who to choose as a friend and what they expect from their friends. Regarding this Abi says “*I like getting close to those who encourage me when I am doing something*”. Naa says “*I have one friend because she understands me and helps me*”.

6.1.4 Competence

As noted in the theory chapter, agency is “ an individual's own capacities, competencies and activities through which they navigate the contexts and positions of their life worlds, fulfilling

²⁶ A teacher responsible for the welfare of student living in hostel

many economic, social and cultural expectations, while simultaneously charting individual or collective choices and possibilities for their daily and future lives” (Klocker et al., 2007, p. 135). Exhibiting one’s competencies, therefore, is an integral form of exercising agency. Based on this I find it necessary and intriguing to discover how the children with physical disability display their competencies. I attempt to explore how the children demonstrate their skills and talents in various forms without necessarily focusing on how well or efficient they are.

It is quite obvious that the children demonstrate their competencies in the choice of subjects they study. Getting to know that Frank whose impairment is in the hand, studies technical skills, I was so much intrigued to understand his reasons for choosing this subject. In the Ghanaian curriculum, technical skills involve carpentry work, drawing building plan and bricks laying. And in all these the use of both hands is vital. During the interview with Frank, he explains that he enjoys drawing houses and that is the main motivation for choosing the subject. He, however, points to some challenges he faces. For example in terms of drawing, it is a challenge sometimes to hold the set square²⁷ with one hand and use the pencil with the other hand. He notes that he sometimes ask for help from his colleagues which delays his work sometimes but he is determined to study the subject because he wants to become an architectural designer. Commenting on how Frank performs in the subject, the teacher I interviewed from Frank’s school states: *“I can’t confirm how good he is in doing the subject but I think he is doing well if not he would have been repeated”*. Whatever be the case, for Frank, the limitation on one of his hands does not completely erase his competencies in drawing.

The scenario below from my field observation shows how Abi, another participant also demonstrates competence in her subject area.

Abi was having practical class in Sculpture with her classmates. I approached and asked what they were doing. One student responded that they have been given an assignment to mold an object of their choice. Then I asked Abi what she chooses to mold. Before Abi could answer, another student responded saying madam she is molding flower pot, she is very good and fast. She is almost

²⁷ Drawing instrument

finished. Madam, she is the best in the class!!” Observing them I realized that some of the students were still kneading mud but Abi was working on an object which looked like a flower pot.

Abi seems not to allow her disability to do away with her skills. She displays her skills and talents in artwork, her chosen field of study. Abi tells me in the interview with her that her hobbies are weaving and drawing and she is studying Visual Arts²⁸ to build on her skills.

The children also demonstrate their skills and abilities in other areas other than school work. To exemplify, Kojo demonstrates his competencies by barbering his colleagues and even himself. He states: *“I may not like the way someone would do it for me so I cut my own hair. I just take a mirror and my equipment then I barber myself”*.

6.2 Factors Shaping Agency

In this section, I direct the discussion to factors that influence the children’s ability to act. The concept of agency raises a number of questions about whether all children have the same capacities and opportunities to exercise their agency. What might encourage or inhibit particular children from exercising their agency and under what circumstances? Klocker et al. (2007) contend that factors such as age, poverty, gender, ethnicity etc. can enhance or reduce children and young people’s agency. Put simply, as children negotiate their agency, they are either encouraged or inhibit “thicken and thin” (ibid) by certain circumstances. In discussing these, I adapted the elements of agency (Klocker et al., 2007) to help explore and discuss the dynamics that interplay in shaping agency of the children with physical disability. These are social context, cultural discourses, social relations and personal biography.

6.2.1 Social Context

Childhood as a social construction emphasizes the diversities of childhoods that are contextualized in social and cultural settings as well as within everyday life (Kjørholt, 2004). Knowledge about the children and their life world depends on the predispositions of a consciousness constituted in relation to social, political, historical and moral context (Jenks, 2004). Understanding physically disabled children’s agency requires a critical look at the social context within which they live.

²⁸ Visual Arts involves sculpture, textiles, general knowledge in arts.

This assumption is congruent with the social model of disability which puts social circumstances at the core in the lives of children with disability (Llewellyn & Hogan, 2000). In other words the social environment positively as well as negatively impact physically disabled children's ability to act or be actively involved in constructing their lives. Simply put the social context in which the children live either encourages or inhibits the way they negotiate agency.

The school, as a social institution, has an overwhelming significant influence on how the children with physical disability exercise their agency. In the previous chapters, I gave a preview of the schools as the context within which the children live. Noted, the school's physical environment generally disadvantaged physically disabled children. The schools lack structures such as ramps, convenient toilets, comfortable furniture etc. that the children need in their everyday lives. In addition, the bad terrain; muddy roads and grounds present a challenge to the children anytime it rains. Situations as these put a limitation on the children's movements as well as give them discomfort, hence constrain agency of children with physical disability.

A pertinent but obvious observation was that classroom seating arrangement appears to promote fruitful interaction between the children with physical disability and non-disabled children. In the classrooms, the children seat in pairs in a dual desk and it gives them the chance to talk to or ask for help from their mates or vice versa. I wish to emphasize however that the children with a physical disability may be better positioned to exercise their agency if the schools and their structures are adapted to meet their needs. For example availability of ramps can facilitate their movement.

Many studies conducted in the global south and in Ghana reveal that disabled children live in poverty and experience extreme hardship (see Mock et al., 2003; Nithi & Hasina, 2014; Reynolds, 2010; Yeo & Moore, 2003). In all these studies, poverty is presented as a barrier to meeting the daily needs of disabled children. For example Nithi and Hasina (2014), points out that despite other social disadvantages poverty, in particular, was weaved into the stories of mothers with disabled children. The prohibitive cost of medical care, inability to access assistive devices such as wheelchairs and the high cost of transport to access early intervention and therapy programs

present on-going difficulties to these mothers. And it becomes more difficult when key members are unemployed or experiences employment insecurity.

In my study, poverty permeates through the narratives of my participants. Most of the children associate their inability to perform certain activities to financial difficulties. For instance, Abi whose hobbies are weaving and drawing clearly points out that she is limited by appropriate tools.

“Sometimes I don’t have the things I need for the drawings and the paintings. I am not having the appropriate tools and the materials for my work. And because my parents don’t have money to buy the correct tools for me, I use the tools I have and sometimes the work doesn’t come out well”.

Clearly Abi’s inability to acquire appropriate tools put a limitation on how well she could develop her talents. However, presumably, it might sound unreasonable for Abi’s parents who have difficulties in meeting basic needs such as food and hospital bills to prioritize purchasing drawing tools. Abi’s case is one example of many children with disabilities who have varying abilities but are left undiscovered and unexplored due to poverty. On the other hand, it is quite likely that if these children are put in an affluent society where they have more opportunities, their abilities may be much explored.

Also, there are times that the children miss out on school because of non-payment of school fees or lack money to buy food at school. Arguably missing out on school could affect their performance in school as they miss classes taught for the day.

I wish to argue here that poverty is one of the main factors that inhibit agency of children with physical disability. Yet I do not want to claim that children with physical disability who live in poverty do not have agency. No doubt, in earlier sections of this chapter, I have already presented some ways by which my participants negotiated their agency. Rather I would like to emphasize the point that children’s agency may be shaped by the social context in which they live. And that physically disabled children who live in societies with more opportunities are better positioned to exercise their agency.

6.2.2 Cultural Discourses

As mentioned in the background chapter, in Ghana disability in the past was linked to evil. Disability was believed to be a punishment from the gods and children with disabilities were seen as lesser humans and subsequently subjected to inhumane treatment. This belief led to many parents and children being blamed for bringing disability onto themselves. There is the assumption that the belief that disability is caused by evil or as a punishment from the gods is currently fading out (Avoke, 2002). Nevertheless, traces of this belief is still present in representations of disability today.

Some parents with disabled children today still feel ashamed of their wards disability and most often keep them from school and other social settings. Many at times disabled children are hidden from public places or gatherings for obvious reasons of avoidance, rejection and discrimination. My study suggests that rejection and discrimination are also reflected in the physical design and terrain as many public places do not appear welcoming to people with disability. Situations as these limit social mobility of people with disability. Not over emphasizing, presenting people with disability as not accepted in public places shun persons with disability away from society as they isolate themselves from family, friends, schools, and other opportunities for social interaction. As indicated, many of the participants have few friends and most often isolate themselves from school gatherings. As a result, this inhibits educational attainment and appropriate social development in children with disabilities (Tuakli-Wosornu & Haig, 2014).

Popular conception about people with disability in the Ghanaian society is that they are feeble. Historically, people with disabilities were excluded from such endeavors as war and military demands because they were not considered healthy and normal (Avoke, 2002). Also, in most societies in Ghana people with disabilities are a misfit to assume chieftaincy positions (Munyi, 2012). So it is today, these conceptions about people with disabilities write off voices of persons with disability in major decisions. They are not seen nor heard in the society consequently because they are denied opportunity to hold leadership positions. As already exemplified in this study, even though per the schools policies the children with physical disability can hold leadership positions, the practicality is far from the truth.

Persons with disabilities are also generally conceived as burdens and victims in need. Many avoid marrying persons with disability for fear that they would be overburdened. This assumption is reflected in the supportive services designed for them. For example, Community Based Rehabilitation program point of departure revolves around the assumption of need and incapacity (Tuakli-Wosornu & Haig, 2014). The assumption of being burdens is reflected in cases of some of the participants. To illustrate, Frank says his grandmother that he lives with thinks that at his age, he should be able to work and support himself and also take care of the grandmother. Frank further states that his mother is also harsh on him and she expects him to work and get money for his upkeep. This kind of representation of persons with disability turns to make them feel worthless. It does not inspire them to explore their abilities and hence limit their negotiation of agency.

6.2.3 Social Relations

Argued by Klocker et al. (2007) a young person's state of mind, confidence and perceived ability to act is also affected by the influence of other people. In physically disabled children's lives, there are a number of different actors, all of whom have varying degrees of impact on their abilities to become agents in their own lives and societies. These actors include parents, friends, and peer groups, authority figures such as teachers, intervention services providers and researchers. In this research, the children's relationship with non-disabled persons was explored with a focus on their interaction in school and at home. In the schools, attention was placed on the children's interaction with colleague students and teachers and at home relationship with parents and siblings and any other close associate was of interest.

From the data, it is quite evident that some of these relationships turn to be a source of inspiration and encouragement to the children. Kojo talks about relationship with his family as the one that makes him feel loved and valued. He indicates that his family frequently visits him in the school and anytime he goes home for vacation, the care and love shown to him by his family make him wish he would not come back to school. Kojo also notes that his sister who once hated him for his disability now showers him with love and she has now become his closest sibling. When I asked how he feels about that, he remarks:

“Now I am happy. Everybody in my family now loves me and cares about me, and that encourages me to study hard because I don’t want to disappoint them”.

Kojo further describes a pastor friend as a role model and he inspires him greatly.

“Pastor Ken²⁹ loves me so much, he tries to come to the school, sometimes Saturdays to check on me (.....). It energizes my soul. Previously, I didn’t know what I was doing. I was thinking about my disability so I didn’t know what I was doing. But since I met that pastor, I just set that target to become like him. He called me one day and told me what he went through, how situations were difficult for him but he passed through and now he travels to outside Ghana always. He can fly today and come back today. So I put that pastor as my goal, to see as my star whether rain or shining when God permits and I am alive, I have to either climb more than him or be at the same level like him”.

Responding to the question whether there are particular persons she likes, Abi mentions one of her teachers and two friends in her previous school. She explains that her reason for liking these people is that they are people who encourage her.

“when we were at our previous place, my condition wasn’t serious like when we came to this place so if they are doing some activities in the school and they think I can also take part they advise me to take part”.

From the above narratives, it is obvious that when family and friends show care and love for children with physical disability, it positively influences them. In other words secure and affectionate relations provides a sound foundation for the children to explore themselves. In this case, the children feel cared for and this provides a leverage for negotiation of agency. A positive recommendation from family and friends builds their confidence and self-esteem and likely brings out the best in them. In addition, friendly and up building attitudes towards children with a physical disability may attract them to interact more with people and possibly they would be more willing to open up and express their feelings and thoughts.

²⁹ Name changed

However in the children's accounts, unthoughtful and hostile attitudes of people make them coil back and keep to themselves. Inconsistent familial relations hinder the children's development of self-worth and make them feel of lesser value. For example, Abi mentioned earlier, who revealed not having a good relationship with her mother and younger sister gets affected by this.

“My younger sister sometimes says some things that hurts me so much. And when my sister is doing things that I can't do for now my mom says certain things that hurt me a lot (.....) my sister tells me I am expecting someone to do things for me and that I am depending on someone meanwhile it's not like that, I am not expecting that. It hurts me so much”.

As I already mentioned, judging from her tone of voice, Abi gets disappointed by her inability to perform certain tasks that her sister does with ease. Such actions from her family make her feel less of a value compare to her sister. When children with physical disability experience such treatment from family, it undervalues their competence and abilities and as such it does not create room for further exploration of their capabilities. No doubt unsupportive familial relations inhibit disabled children's agency.

It is argued that general school ethos, thus distinctive climate, spirit and feeling of place is a significant contributor to the social success of children with disability included in regular schools (Baker & Donnelly, 2001). Analysis of my data reveals that the schools' ethos, generally prove repeling to the physically disabled children's agency.

On a daily basis, children with physical disability are humiliated, called names, labeled and discriminated by their colleague students. In the children's accounts, there are several instances where they feel disrespected. Mawuena indicates that the girls in her hostel always try to pick fights with her. Nobody helps her fetch water but when she does, other girls use it. And when she complains then they pick fight with her and insult her and describe her as not beautiful. In an attempt to avoid such confrontations, Mawuena coils back and keeps to herself. She states:

“Sometimes I sit alone I don't want to go to anybody for anything”.

Also, teacher-student relationships are sometimes characterized by authoritarian, unfair treatment of the children. Style of discipline has elements of aggression, minimal explanation of offense

committed and most often no opportunity for the children to explain reasons behind their actions as exemplified in the scenario between Mawuena and a teacher.

6.2.4 Personal Biography

Individual disposition shapes how a child negotiates agency. An individual young person's ability to act is related to the constraints she or he faces on a daily basis (Klocker et al., 2007). Such constraints may be linked to biographic characteristics such as age, gender and health status. For example for many, age might determine what kind of agency and how much freedom one has to exercise it (James, 2009). In their work, Klocker et al. (2007) also emphasize that agency and young people's negotiation of unequal power relations change over time and space especially over the life course, whereby older siblings tend to exert more agency than younger ones. Similarly, in this research, disability and on the other hand will -power are seen to have influenced how the children exercise their agency.

6.2.4.1 How disability shapes agency

As already illustrated in the findings, the children's disability status place some form of limitations on them. The children's impairment put restrictions on their movement. Ability to perform certain activities such as playing football, running and weeding was reduced. The children also experience other form of repercussions resulting from their disability. For instance suffering pain from sitting on a wooden desk during long classes and or experiencing discomfort for using inconvenient toilet.

All these circumstances inhibit the extent to which the children exercise their agency. There is no doubt that a child who does not visit the library because there are no ramps and the stairs are difficult to climb may well loose on extra information that his colleagues who use the library might benefit from. Likewise, a child who suffers discomfort for sitting on a wooden desk for long hours of class might well get distracted and may not benefit from the class. Furthermore, children with physical disability suffer emotional distress which affects their state of mind, confidence, and perceived abilities. This was particularly evident in my participants who have once lived the life of able-bodied children but are now restrained by their disability.

Kofi who once enjoyed doing sports so much states:

“It just pains me. I used to do all kinds of sport; volleyball, football, running, high jump, but now I don’t do them again.....so when they are doing sports I go home”.

Kofi’s tone of voice here reflects emotional frustration about a situation beyond his control. And his decision to leave school for home whenever there is any sporting activity could be interpreted as a way to escape the emotional stress he goes through watching his colleagues engaging in events he used to do.

Also, physically disabled children exclude themselves from participating in school activities for fear of being mocked. The extract taken from the interview with Abi exemplify this.

Abi: to me all that they do in the school, I can’t take part in them because of my condition

Mispah: not only sporting activities, because there are so many activities like cultural festivals, singing so many things.....

Abi: I don’t really want to join.

Mispah: you don’t want yourself to join them!! Why?

Abi: because of how I am now. I think that when I join them someone may say something bad that may hurt me a lot, so if they are doing those things I take myself away from them and stay at one place.

Mispah: but don’t you think there are some activities you can do.

Abi: yes I know I can but just that I don’t want to join them maybe they will say something that may hurt me.

I must say that impairment to some extent have made the children lose confidence in their abilities and tend to exclude themselves from school activities, even the ones they know they could possibly do. When children do not participate in activities such as sports and cultural festivals, they lose the opportunity to interact with other children on a different platform other than the classroom. In Ghana, such occasions as sports and cultural festivals offer children the opportunity to develop new friendships and share ideas and thoughts. Non-academic small groups and cooperative learning experiences are known to elicit interaction and develop greater interpersonal attraction between children that also generalizes to other settings (Baker & Donnelly, 2001). Mentioned earlier, the children tend to have few friends as many of them shy away from places they could find friendship.

6.2.4.2 Will- power

It is evident that my participants experience difficulties and restrictions in their lives, especially in the schools as a result of their disability, yet they employ what I call willpower to move on with life. Willpower may be explained as a very strong determination to do something. The physically disabled children in this study, display a strong determination not to dwell on the difficulties of their disability and become discouraged. It is as if they go by the biblical saying that “if you become discouraged in the day of distress, your strength will be meager”. The children’s strong determination shapes their decisions and everyday actions. Kojo tells me his goal is to study at the university. Even though he sometimes become overwhelmed with difficulties in the school and feels like quitting school, but he is determined to reach his goal. Any time he gets depressed he says to himself “*what will I become if I quit school*”.

Kabu also displays will-power in dealing with name callings. He feels such things are a distraction. He is in school to study and there is no point paying attention to things that would hurt him and depress him.

“When they call me names I feel like that is not the aim of coming to school, so even if I report I won’t get anything from it. So I just forget about it and move on with my life”

Based on my study, I argue that children who have will-power are more courageous and are better able to exercise agency even under suppressed or restrictive circumstances. As shown in this study, the children with physical disability face several challenges including lack of proper structures to meet their needs, failed policies and their bodily limitations. Yet they are determined to move on with life, work hard and create a better future for themselves.

CHAPTER 7

CONCLUSION AND RECOMMENDATIONS

7.0 Introduction

This chapter presents the summary of the study. First, the chapter takes a brief look at the study objectives, methodological approach used for data collection and the theoretical framework/perspectives that guide the study. It then outlines the summary of major findings of the study. The chapter finally looks at some policy implications and recommendation for future research.

7.1 Summary of Objectives, Methodology and Theoretical Perspectives

The study aimed at acknowledging agency in children with physical disability, looking at the way they navigate daily experiences of disability amidst restrictions in the context of Ghana.

The general methodological approach used was qualitative, which involved the use of diverse methods. This was useful in exploring wider dimensions of the children's everyday lived experiences. Ten individual interviews were conducted, seven with physically disabled children aged between 15 and 17, two with teachers and one with an official from district education office. Solicited diary was used to collect data on children's day everyday routine activities. Participant observation was employed in getting informal knowledge and embodied practices which also provided vital contextual information.

The study is shaped by the Sociology of Childhood. This theoretical perspective emphasizes that children's relationships and their cultures are worthy of study in their own right, independent of the perspective and concern of adult (Prout & James, 1990). It, therefore, means that children and issues concerning children should be studied from children's point of view. By so doing, children are being given voice and place in society. Consequently, physically disabled children formed the main participants of this study and the issues that came out reflect their experiences and thoughts, although three adults were interviewed in order to get divergent views.

Furthermore, sociology of childhood stresses that childhood is a social and cultural phenomenon that have no universal validity. This implies that children and their life world are constituted in relation to social, political, historical and moral context (Jenks, 2004). The concept of childhood

as a social construction was useful in providing an understanding of how the different contexts shape the children's experiences of disability. For example findings of the study shows that poverty as a social context within which my participants live makes their experiences of disability more complicated and more challenging.

Vividly engaged in this study is the concept of children as social actors and agents, which denotes that children are active in the construction of their own lives, the lives of those around them and of the society in which they live. Children are not just passive subjects of social structures and processes (Prout & James, 1990). Theorizing children as social agents also implies recognizing children's competencies and capabilities. This study attempts to highlight competencies and capabilities of children with physical disability. The study particularly relates with the notion that agency exists and should not be ignored even though it may remain invisible under suppressed or restrictive circumstance (Klocker et al., 2007). Also, the concept of thick and thin agency was used to highlight the dynamics that interplay in shaping the children's negotiation of agency.

Two models of disability were applied in the study to help provide an understanding of disability and how this affects experiences of disability. The medical model presents disability as a personal tragedy or abnormality which is located within the body or mind of the person with the disability. The model sees disability to automatically handicap the individual in one way or the other. It is for this reason that the individual is incapable of performing certain activities. The barriers to equal participation in society are seen as primarily situated in the individual, as the individual lacks certain capacities necessary for autonomy (Michailakis, 2003). Clearly, a distinctive trait of the medical model is the emphasis on the body's malfunction. The social model of disability, on the other hand, proclaims that disability only exists in so far as it is socially constructed and imposed on people with impairments (Llewellyn & Hogan, 2000). The social model shifts the attention from the body's malfunction to societally imposed restrictions. By extension, the social model associates disability with all the "things that impose restrictions on disabled people; ranging from individual prejudices to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on" (Oliver, 1996 in Avoke, 2002 p.772). In applying these models in my study, by far I tried to avoid engaging in the academic debates proving which model best describes disability. Simply put, these models were however not applied in this study individually in their entirety but as combined perspectives.

In another twist, I engaged the rights-based approach, drawing insight from the UNCRC and Ghana's Disability Act 2006, Act 715. My focus here was on two of the key principles of the UNCRC which are relevant to this study; the principle of non-discrimination and the rights to be heard.

7.2 Summary of Study Results

In this section, I present summary of key findings from the study. Themes coined from the analysis form the basis for the discussions.

7.2.1 The Children's Perspectives of Their Disability

7.2.1.1 Causes of disability

Most of my participants indicate that their disability was caused by either sickness or accident. One participant ascribed causes of his disability to spiritual means. Nevertheless, all the participants sought medical attention as the primary intervention strategy. This reaffirms the findings of similar studies that there is a growing medical knowledge about disability in the Ghanaian society. The findings also show that although Christianity and western influence have diluted the effects of belief systems about disability, spiritual connotations to disability still exist in Ghana (Avoke, 2002; Tuakli-Wosornu & Haig, 2014).

My study further suggests that perceptions about the causes of disability could influence one's attitude to how experiences of disability are navigated. The study illustrates how people who believed they became disabled through a personal fault of theirs may blame themselves and this may impact how they handle challenges resulting from their disability. As already mentioned in chapter 5, Mawuena who believed her disability was as a result of disobedience to her parent's warning, continually blames herself. Consequently, she is usually bitter, isolate herself and cries especially when she is faced with challenges ensuing from her disability. On the other hand, another participant who became disabled resulting from sickness which she believed was no fault of hers, keeps a positive attitude. She is hopeful and believes that her experiences of disability will be short lived once she undergoes surgery which doctors assure her can reverse her situation.

By highlighting this, I am of course not in any way trying to generalize that people who acquire disability through a personal fault are self-accused, and those who become disabled as a result of sickness maintain a positive attitude since this is a much smaller study. Nevertheless, this calls for a much grander research to explore all the nuances and the dynamics involved.

7.2.1.2 Constructing disability

In my analysis, the participants constructed disability from overlapping perspectives. The participants alluded to physical pains associated with their disability, reported suffering pains when doing physical activities such as walking, fetching water or sitting for a long period of time. This seems to reflect the assumption that, it may be problematic to completely rule out the bio-medical consequence of disability on the individual (Holt, 2004). Most of the participants indicate experiencing some form of limitation on their abilities as a result of the bodies' malfunction. They draw attention to certain activities such as playing football, running, weeding which they used to do with ease, but now find it difficult because of limited abilities as a result of the impairment. The limited abilities experienced by my participants partly reflects assumptions in the medical model of disability. However as argued in the analysis chapters, data from the study does not necessarily equate impairment automatically to handicap as suggested in the medical model (see theory chapter).

At the same time, the participants also point to some disabling situations within the society. By so doing, they add social dimensions to their disability. The participants describe the physical environment to be restrictive to their mobility. They mentioned that absence of ramps, muddy roads and grounds limit their movement. The participants also feel that certain school structures, for example, toilets and furniture are disabling to their condition. My participants, subtly blame the government for some of the challenges they face. They referred to the failure of policies to take care of their needs as a challenge in their daily lives. For instance failure of the government to take care of their educational and medical needs makes their experiences of disability more complex and challenging. By this, my participants imply that the system in itself is disabling them. The thoughts expressed by my participants appear to mirror the social model perspective of disability.

Consequently, this study suggests that disability could be constructed as both limitations resulting from the body's malfunction and societal restrictions. Therefore, disability could be an interface between individual and social factors.

7.2.2 Negotiating Daily Experiences of Disability

Being physically disabled in the context of Ghana is challenging. My participants are not only constrained by their body's malfunction but also face societal restrictions in their everyday lives. However, the study reveals that the children adapt various strategies to navigate their daily experiences of disability. The children creatively devise alternative ways to go through life despite the prevailing restrictive circumstances. For example, most of the children took practical steps such as wait for the grounds to get a bit dry whenever it rains before they move or get a stick for support. Some of the children also avoid frequent use of the uncomfortable toilets. Even though there might be concerns about the health effects of this practice, yet at the moment, it appears to be an alternative means of minimizing the pain from regular use of uncomfortable toilets or better still avoid further injury. These kinds of actions taken by the participants appear to have been the ways by which they overcome the challenges posed by the unfriendly physical environment they live. Through these actions, the children actively get involved in constructing of their own lives and not just passive subjects of social structures (Prout & James, 1997). By doing so, they exercise their agency. I relate this finding with Klocker et al. (2007), argument that children and young people under restrictive circumstances still find alternative ways to exercise their agency.

In Ghana performing household chores is part of children's everyday experiences. My participants demonstrate the ability to perform household chores as expected of any Ghanaian child despite their limitations. They always make the effort to perform these chores by themselves rather than always being dependent on other people. In cases where doing some of the chores become extremely difficult, some of the children seek assistance from their friends and family. It is worth noting that some of the participants sometimes use their skills in other areas to get the chores done for them.

Interaction with non-disabled persons is part and parcel of disabled children's lives. As reported in the analysis chapters, my participants face discrimination, unthoughtful attitude, labeling, and name calling in their daily interaction with non-disabled persons both at school and at home. The

study reveals that as the children try to navigate these experiences they develop their own culture. Most of the children exhibit similar reaction when confronted with labeling and name calling for example. They preferred to quietly walk away from any such confrontation to prevent fights and possibly further humiliation. However, sometimes the children employ subtle to open resistance to such unthoughtful behaviors from non-disable persons. Most of the participants explore and conquer some free spaces (Nilsen, 2009), and are able to distinguish different sources of power and react accordingly. The participants display the ability to draw the line and stamp their authority that they deserve respect and dignity.

7.2.3 The Children's Experiences of Interaction with Non-Disabled Persons

The study shows that the children's relationship with non-disabled persons is significant in shaping their state of mind, confidence and their perceived ability to act. Recurrent throughout the study, different actors such as parents, siblings, school mates, friends and teachers have varying degrees of impact on the children's abilities to become agents in their own lives and in their societies. The participants express mixed feeling regarding interaction with non-disabled persons. While they feel more secured in relationships that offer love, care and respect, they abhor attitudes that are disrespectful and discriminatory. Most of the participants indicate, they feel at home and are able to interact well with their families and friends because of the love and care they receive. A secure and affectionate familial and friendly relation provides a sound platform for building their confidence and self-esteem.

In addition, the children indicate that they exercise discretion when choosing associates. Most of the children, develop friendships based on support, encouragement and mutual understanding and respect for both parties. They would prefer to live isolated lives rather than to form friendships that offer nothing but mockery and disrespect. For such reasons most of the participants report to have few friends.

7.2.4 The Interplay between Disability and Agency

The study suggests a two-way correlation between disability and negotiation of agency. This implies that disability shapes negotiation of the children's agency and on the other hand agency to a great extent influences the children's experiences of disability. As shown in the analysis chapters, disability put some limitations on the way the children display their abilities, skills and talents. For

example, their ability to perform physical activities like playing football, running, weeding etc. is reduced. Also, the emotional stress associated with disability especially for my participants who were once able-bodied, affects their state of mind, confidence and perceived abilities. The children sometimes lose confidence in their skills and abilities. As such, this feeling of perceived inadequacy negatively impacts the children's negotiation of agency.

Furthermore, the associated social repercussions of disability adversely play on the children's negotiation of agency. This study and many other studies suggest that there are economic implications associated with disability (Bonnie, 2014; Kassah, 2008; Mock et al., 2003; Reynolds, 2010; Tuakli-Wosornu & Haig, 2014; Yeo & Moore, 2003). The high financial cost associated with care and treatment of disability drags disabled and their families further and further into poverty (Yeo & Moore, 2003). In addition, failure of the government to efficiently implement social policies for persons with disabilities contribute to the economic burden on the families with disabled. As a result, meeting the basic needs such as education and medical care of the disabled children becomes more and more challenging. As already highlighted in the previous chapters, some of the children report in school late when school term begins due to the inability of parents to raise money. Some of the children also regularly skip school for not having money to buy food at school. In such circumstances, both physical and emotional stability of the children could be disrupted. They may lose focus, hope and give up on life. All these situations limit opportunities for the children to exercise their agency.

The study also shows that the children experience attitudinal discrimination as a result of their disability, which serves as an inhibiting factor for negotiating agency. For fear of been mocked, the children tend to isolate themselves and shun away from opportunities for social interaction. Subsequently, the children may miss out on educational attainment and appropriate social development (Tuakli-Wosornu & Haig, 2014).

My study suggests that one of the greatest challenges the children with physical disabilities face in exercising their agency is the physical environment. From the study, it appears government has not been able to provide appropriate structures such as ramps, paved walkways, disability friendly toilets etc. as expected. The absence of these structures to meet the needs of the disabled children have potentially restrained opportunities to exercise their agency.

In another vein, the participants display a high degree of agency in navigating daily experiences of disability. The participant's ability to engage in household chores, the way they demonstrate their competence both in school and in making decisions, how they make sense of their environment and negotiate spaces around them despite structural limitations and their ability to handle negative attitudes from non-disabled persons cannot be underestimated. Furthermore, the children's will-power thus their determination not to allow their disability render them hopeless but move on with life and create better future for themselves cannot be over-emphasized. I would suggest here that such display of agency by the children have to a great extent made the difficult experiences of disability in the context of this study bearable. Even though the children have limited opportunities to exercise their agency, the ability to negotiate some form of agency as illustrated earlier gives them a sense of fulfillment and the confidence to forge ahead. This seems to confirm the point that success of agency is related to an individual's perceived sense of being able and to his or her confidence (Klocker et al., 2007).

7.3 My Concluding Thoughts

Article 28 of the CRC accord all children right to education. Also, chapter 5 of the 1992 constitution of Ghana mentions education as fundamental human rights for all citizens. Specifically, article 25 (1) states that all persons shall have the right to equal educational opportunities and facilities. The government of Ghana over the years have adopted educational policies and programs in the realization of this right. As noted, one of such policies is the inclusive education which is intended to give all children including children with physical disability education. In line with this, most schools in Ghana admit children with physical disabilities.

Considering the aims of inclusive education; to reconstitute the school environment and strengthen the capacity of schools to create equal opportunities for all learners (Acedo, 2009; Bonnie, 2014; UNESCO, 2008), I note here that inclusive education is a positive step for integration of children with physical disability into the mainstream society. While this is true, it also raises a number of questions; does including these children automatically means they are fully exercising their right to education? Are the schools equipped enough to meet the needs of children with disabilities?

It is noted that in some parts of the world the focus of inclusive education is primarily on providing access to schools with less attention on creating the educational environment with equal opportunities (Agbenyega, 2007; Bonnie, 2014). Similarly my study suggests that even though children with physical disability in Ghana have access to regular schools, yet technically face exclusion on the basis of their bodily differences. Practicalities in the schools make it hard for them to have a sense of belonging and participate fully to their benefit. Moosa-Mitha (2005) points out, normative institutional practices may exclude certain people from participating and belonging to communities of which they are citizens, on the basis of their difference. My study reveals that structural challenges and certain practices turn to hinder physically disabled children's full participation and benefit from their education. It appears the schools are not well resourced to meet the specific needs of children with physical disability.

7.4 Recommendations

The government of Ghana continually makes efforts towards improving the lives of the disabled by ratifying international conventions and initiating national legal and policy documents. However, there has been setbacks in implementation. This may be linked to lack of proper supervision, monitoring and evaluation, non-involvement of the beneficiaries and complicated bureaucratic procedures. This, therefore, implies that along with the written documents, the government must devise proper mechanism for implementation. For example, the inclusive education is a great step to integrating children with disabilities into the mainstream society. But as already mentioned, it appears the schools are not well equipped to support and create equal opportunities for participation for disabled children. This, therefore, suggests that it is important for public authorities to build the capacity of institutions working with disabled people so that they can meet their needs.

It is quite evident from the study that, children with disabilities are competent social agents capable of constructing their lives and contributing to society. In other words, though they are limited by their disability in some ways, they are not completely incapable and are not entirely dependent on others for their survival. Thus, social policies towards improving the welfare of children with disabilities by government and non-governmental organization could be more successful if directed at highlighting their skills and potentials so they can become independent.

This study and other researches (see Tuakli-Wosornu & Haig, 2014) show that generally there have been progress towards accepting the disabled in the Ghanaian society, however, socio-cultural constructions of disability and negative attitudes that turn to discriminate and exclude the disabled still exist. And for the disabled citizens to be fully integrated into the Ghanaian society, there is the need for all stakeholders including, government officials, civil society organizations, media and individuals to continually preach acceptance and respect for the rights of persons with disabilities. This could be done right down from the basic schools, in religious gatherings, during traditional festivals and any other public occasions.

As highlighted in the study, there is a relationship between poverty and disability. Poverty comes across as a cause or a consequence of disability. This calls for the strengthening of the social welfare system through social intervention programs that can alleviate poverty in general. This may help reduce occurrences of childhood disability as well improve the livelihoods of persons with disabilities.

Perhaps, it will be useful to replicate this research in other parts of Ghana and on a much larger scale. This may be useful in exploring how different context and diversity within Ghana may shape experiences of disability. Furthermore, as sexual desires begin to develop during teenage years, it will be interesting to explore sexuality of young adults with disabilities. In addition, future research may turn attention to how widespread NGOs are in Ghana. Based on my observations during this study, it appears NGOs are concentrated in some particular parts of the country than other parts. Such a research may also explore impacts of NGO interventions on the welfare of persons with disabilities. Findings from such studies may help to further provide appropriate interventions aimed at improving the life conditions of persons with disabilities through harnessing the development of skills instead of short term solutions to their vulnerabilities.

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APPENDICES

Appendix I

Interview Guide for Child Participants

Thank you for your decision to participate in the study. We shall be discussing your experience as a physically disabled person, challenges, coping strategies and your views on your relationship with non-disabled persons. Please feel free to express your feelings, you have a right not to answer questions you are not comfortable with or call for a discontinuation of the interview.

Background /general issues

I would like to know a little about you.

- Your age, family composition and what your parents do for living.
- Do you mind telling me how you became disabled?
- What in your view is disability?

Experiences of disability

Tell me about your experiences as a disabled person

- What is your normal day like?
- Can you share with me any moment or events that impact your life?
- What challenges do you face as a result of your disability?

Coping strategies/support systems

How do you cope or overcome your challenges?

- What part does self-determination or resilience plays in coping with your challenges
- Do you receive any support?
- From whom do you receive support?
- What kind of support do you receive?

Interaction with non-disable persons

Describe your relationship with non-disable persons

- How do you feel about your relationship with non-disable family members and peers at school?
- What impact does interaction with non-disable persons have on you?

- Is there any particular person(s) you like most?
- What are the reasons for liking that person?
- Are there any other ways you wish to be treated?

Is there anything else you would like to share? *I appreciate listening to your experiences and views. Thank you for your time, best wishes!!!*

Appendix II

Interview Guide for Adult Participants.

Thank you for your decision to participate in the study. We shall be discussing experiences of physically disabled children; challenges, coping strategies, support system available and your views on their relationship with non-disabled persons. Please feel free to express your feelings, you have a right not to answer questions you are not comfortable with or call for a discontinuation of the interview.

Background /general issues

I would like to know a little about you.

- How long have you been working as a teacher in this school
- Have you ever taught or currently teaching a physically disable child?
- Do you live with other members of the family? How many and how related are they to the child?
- Do you mind telling me how he/she became disabled?

Experiences of disability

- Can you share with me your experiences of any moment or event involving physically disable child that touched you?
- What challenges do you think physically disable children face?

Coping strategies/support systems

How do physically disable children cope or overcome challenges of their disability?

- What are the support systems available for disable children in the school?
- What kind of support do they receive?
- How friendly is the school environment for physically disabled children?
- What part does self-determination or resilience plays in coping with their challenges?

Interaction with non-disable persons

Describe the nature of interaction between the disable children and non-disable persons in the school

- Tell me about your experience of a situation where disable children were engaged in an activity together with non-disable children

- What opportunities are there for disable children to interact with non-disable members of the school community?
- What impact does interaction with non-disable persons have on them?
- How do society make these children feel important and useful

Interplay between disability and agency

- What are the restrictions that disability place on the development of the children?
- How do competencies and capabilities of these children reduce the restrictions they face as result of their disability?

Is there anything else you would like to share?

I appreciate listening to your perspectives and views. Thank you for your time, best wishes!!!

Appendix III

Informed Consent Form for Child Participants

My name is Mispah Mawusi Mamah, I am a student and I learn about children's everyday lives. I am here because I am interested in learning about your experiences as a disabled child, challenges you face as a result of your disability and how you deal with those challenges. I am also interested in hearing your thoughts about how you perceive your relationship with non-disabled persons and how it affects you.

I am doing this study for academic purposes hence what you tell me will be published, however, I assure you that your identity will not be revealed. Your participation in the study is voluntary and if at any point you do not want to participate or anything you do not wish to share with me feel free to do so. Please note that I am a student researcher and I do not promise to reward you for participation.

Please tick (✓) in the box if you want to participate or mark (X) if you do not want to participate.
Thank you.

Appendix IV

Informed Consent for Adult Participants

Research topic: *Disable But Not Unable; Agency and Children with Physical Disability, a Case Study in Ghana*

My name is Mispah Mawusi Mamah, I am a student at Norwegian University of Science and Technology where I am pursuing MPhil in Childhood Studies. I am conducting a study on agency of children with physical disability, focusing on how they negotiate experiences of disability amidst the complexities surrounding disability in the context of Ghana. I am particularly interested in hearing your thoughts on how these children cope in the school environment with structural deficits for children with disability and how interaction with non-disabled persons within the school affects them.

There are no known risks associated with this study. Your identity will not be revealed in the publication of the findings of the study, your privacy and confidentiality is assured. Participation is voluntary, you may withdraw from participation at any time. Please note that I am a student researcher and I do not promise to reward you for participation.

Please sign below to show that you have voluntarily agreed to participate in the study. You may also give verbal affirmation.

Signature

Date

(Participant)

Signature

Date.....

(Researcher)

Appendix V
Standard Observation Sheet

Research tool:

Date:

Time: From To

Setting:

Factors that may influence data collection-

Disposition: (eg. Sickness, tiredness, mood etc.)

 Researcher

.....

.....

 Participants

.....

.....

Physiognomies of the setting: (eg. Enclosed, open, noisy etc)

.....

Weather.....

Other.....

.....

Appendix vi

Letter of Introduction

To whom it may concern

Our consultant:
Rannveig Singaas
Senior Executive Officer
Telephone no.: +4773596357
E-mail: rannveig.singaas@svt.ntnu.no

Dated:
2015-04-24

Our ref.:

Your letter dated:

Your ref.:

LETTER OF INTRODUCTION

We hereby confirm that Mispah Mama, born 15 January 1982, is a student in the programme *Master of Philosophy in Childhood Studies* at Norwegian Centre for Child Research, Norwegian University of Science and Technology, Norway. She will undertake her fieldwork and data collection from 17th June to 8th August 2015, on the topic:

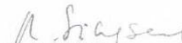
Disable But Not Unable; Constructing Agency of Children with Physical Disability

We would be grateful for any assistance given to her during this process. This includes granting interviews, assisting her in making appointments, handing out materials and making information accessible to her. We ensure that the information collected is treated confidentially, and that the fieldwork bears no costs on the institutions and persons visited.

Yours sincerely,



Randi Dyblie Nilsen
Professor and Supervisor



Rannveig Singaas
Senior Executive Officer

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Appendix vii
Sample Diary

TIME	ACTIVITIES	LOCATION	WITH WHOM	ROLE OF THE C
3:30pm 7:40p	Playing football with my friends in the school compase.	school compase	my friends in the compase.	Helps me to entertain
2:40pm	Reading my story books at the compase.	School hostel.	my Brother in the hostel.	Helping to enter for the day.
9:30am	Playing football in the school hostel.	school hostel	my friends in the school hostel.	To entertain and send about
4:30pm	Reading my story books.	School hostel	my Brother in the school hostel.	washing my school.
1:7pm	washing my cloth.	School hostel	my friend in the school hostel.	fetching water to wash my
6:00am 6:00am	washing my uniforms	School hostel	my Brother in the school hostel.	fetching water to wash my
4:30pm	Barbering my friends hairs.	School hostel	my friends in the school hostel.	washing my during the day,
6:30am	Ironing my school dress	School hostel	my Brother and my friends.	fetching water bath.
6:48pm	Reading my story books.	School compase	my friends and my brother.	showing the among our self
12:50pm	Cutting down my hair.	School hostel.	my self.	Buy me the
4:30pm	Playing football.	School compase.	my friends and over people.	To entertain the day to be
3:00am	We went to excelsior	mountain	with the school	To helps me