

**NORWEGIAN UNIVERSITY OF SCIENCE AND TECHNOLOGY,  
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MASTER THESIS**

**LIVING WITH A DISABLED CHILD: EXPERIENCES OF FAMILIES WITH  
DISABLED CHILDREN IN THE DANGME WEST DISTRICT (GHANA)**

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## **DEDICATION**

For the birth of me you couldn't continue your schooling and vowed you would ensure I get to the heights you dreamed of but never reached. Mum, this is in honor of your endless efforts to get me there.

I also dedicate this work to my kids, Evangeline, Jethro, and Emmanuel, and my husband.

You are the dearest of my life.

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*The Road has been long, the path has been rough, but you have all contributed to make the journey come to an end.*

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## ABSTRACT

The general observation of the plight of disabled children and their families in Ghana necessitated this study, which aimed to delve into the experiences of families with disabled children in Ghana as a means of bringing to light what it means to have and live with a disabled child in the Ghanaian context. Using semi-structured interviews as guide, participant observations, informal conversations and narrative analysis, this study explored the experiences of four families with disabled children in the Dangme West District. It explored their experiences of living with the child, drawing on the practical, social, and economic challenges encountered, how they are coping in the face of these challenges, and their perceptions as regard the future of the child. Background data was gathered from institutions and the various communities of the participating families. The focus was mainly on the main caregivers, who in this case happen to be the mothers, but other members of the family were also engaged in informal conversations. Findings show that these families experience stigma, financial strain, strain on family relationships, and lack of institutional support. These findings were discussed mainly through the lenses of the two sub-models of the social model of disability; the cultural model which shed light on the stigma and stigmatization that these families experienced and the structural model, within which the lack of institutional support was discussed. It was recommended that much more need to be done by disability organizations and government institutions to educate the Ghanaian society on the causes of disability through the mass media and also remove negative images of disabled people from the media. Other suggestions include the need for early intervention structures, resourcing of schools and preschools that can accommodate disabled children, and the establishment of parent support groups.

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# 1 INTRODUCTION

## 1.1 PROBLEM STATEMENT

According to United Nations statistics, around 10 percent of the world's population, or 650 million people, are born with or live with a disability. An estimated 120 to 150 million of these are children (Hodkinson & Vickerman, 2009). As has been observed, disabled children are most vulnerable in every society and in most cases depend on family members. Research has attested to the nature of the experiences of disabled people and their families. The dominant findings are that disabled people and their families in any part of the world usually experience emotional, social, economic and political challenges in the form of stigmatization, discrimination, financial strain, lack of access to social, educational and health facilities, and marginalization (Beverly & Alvarez, 2003). These challenges are more profound in third world countries, Ghana inclusive. In Ghana, disability is found to be a seriously stigmatizing condition due to the cultural beliefs attached (Tinney, Chiodo, Haig, & Wiredu, 2007; Avoke, 2002). In this regard, disability by birth or in the course of life is usually interpreted as punishment from God or the gods for one's wrong doing, that of a family member or by the community (Avoke, 2002; Kassah, 1998). In some cases, people with disabilities are hidden by family members from the wider community (Kassah, 1998). Even in extreme cases, children with disabilities are killed to avoid the shame it brings to the family (Avoke, 2002). These findings indicate that the rights of disabled children in Ghana may be violated and that they are at risk of suffering psychological and physical violence, and lack of education.

Research into the situation of adult disabled persons in Ghana show that they face economic difficulties like unemployment, exclusion from mainstream education and lack of access to

social, health and infrastructural facilities (Ghana Federation of the Disabled, 2008). Moreover, since most disabled persons live with and depend on their families in Ghana, these difficulties also relate to the family. A high demand of care required in living with a disabled family member may result in the inability of family caregivers to work, and together with high medical costs, this can lead to severe financial difficulties.

Literature search shows that research on disabled children and their families in Ghana is barely existent. This is confirmed by various disability organizations in Ghana that I contacted (eg. Ghana Federation of the Disabled; New Horizon Special School). From them, I learned that there is minimal mention and advocacy for children with disabilities and their families in Ghana, and also minimal data and literature on disability issues in general. I was made aware that disability research is basically not an area of interest to researchers, especially in Ghana. In a rare study to evaluate the services available in Ghana for children with communication and other impairments, and to investigate how perceptions of disability affect these services, Garvens, Ntarangwi, and Haskill (2006), based on their findings, point out the need for research into families with disabled children. They make a strong call for future research to investigate parents and family members' perspectives on disability, their values, needs, and plans for the disabled child's future. This study is in response to the call.

## 1.2 STUDY OBJECTIVES

### ***1.2.1 Main Objective:***

This study mainly aims to delve into the experiences of families with disabled children. It thus seeks to increase the knowledge about what it means to have and live with a disabled child in the Ghanaian context.

### ***1.2.2 Specific Objectives***

This study aims to examine parents' and caregivers' perceptions on disability as a phenomenon and to explore their experience of having and living with the disabled child. These experiences include the practical, social, and economic challenges encountered, and how they are coping. It further seeks to learn about their future outlook as regards living with the disabled child.

## 2 BACKGROUND AND RELATED THEORY

### 2.1 CONCEPTUALIZING DISABILITY

#### 2.1.1 *The Medical Model*

The concept of disability has been defined in terms of mainly two models; one viewing disability through medical lenses and the other from a social perspective. According to the medical model, also known as the traditional model (Moore, 2002), or individual model (Barnes & Mercer, 2010) developed by medical professionals, disability is considered an individual as well as a biological problem (Oliver, 1996). In this sense, a disabled person is defined as one who cannot perform some function because of some bodily defect (Williams, 2001). This perspective of disability has been challenged by disabled people who have come up with a more social perspective of disability (French & Swain, 2008).

#### 2.1.2 *The Social Model*

According to this model, disability is not solely an individual problem. Rather, disability is defined to include the shortfall in society's provision for environmental and political structures that will aid normal living for disabled people (Oliver, 1996). The social model also takes into consideration the influence and role of cultural interpretations of disability (Reinders, 2008). Oliver (2004) simply defines the social model:

In the broadest sense, the social model of disability is about nothing more complicated than a clear focus on economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment- whether physical, sensory or intellectual. The barrier disabled people encounter include inaccessible education systems, working environments, inadequate disability benefits, discriminatory health and social

support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images of the media – films, television and newspapers. Hence the cultural environment in which we all grow up usually sees impairment as unattractive and unwanted. (p. 21)

In this case then, the social model has within it two sub models; the structural model, encompassing the political, economic and environmental barriers, and the cultural model (Priestley , 2003).

### ***2.1.3 The Structural Model***

This model implies that society has instituted mechanisms that bar persons with disability from normal living. These include norms, legislations, ideologies, physical barriers within the environment, and institutional discriminations (Priestley, 2003). As such, activists in this tradition have propagated the need for disability friendly structures in the physical environment. Likewise, there has been advocacy for appropriate legislations that promote the full participation of persons with disability in social and economic activities.

### ***2.1.4 The Structural Model in the Ghanaian Context.***

In Ghana, for example, Article 29 of the 1992 constitution spells out clearly the need for the protection of the rights and wellbeing of persons with disability. However, it is just recently that there has been intense advocacy for these ideals by such organizations as NGOs like Voluntary Service Overseas, and the Ghana Federation of the Disabled. The passage of the Disability Bill into Persons with Disability Act in June 2006 and the institution of the National Council on Disability on April 7 are products of these efforts (Persons with Disability Act Handbook, 2006). The purpose of the Act is to provide guidance for the related institutions as regards how to attend

to the needs of the disabled (Ghana Federation of the Disabled, 2008). The Ghana Federation of the Disabled outlines twelve specific aims of the act:

“to educate Ghanaians on the rights, potentials and responsibilities of both society and PWDs, to generate and disseminate relevant information on disability, to create an enabling environment for the full participation of PWDs in national development, to ensure access of PWDs to education and training at all levels, to facilitate the employment of PWDs in all sectors of the economy, to promote disability-friendly roads, transport and housing facilities, to ensure access of PWDs to effective health care and adequate medical rehabilitation services, to ensure that women with disabilities enjoy the same rights and privileges as their male counterparts, to ensure that law enforcement personnel in cases of arrest, detention, trial and confinement of PWDs take into account the nature of their disabilities, to encourage full participation of PWDs in cultural activities, to ensure access of PWDs to the same opportunities in recreational activities and sports as other citizens, to promote Community Based Rehabilitation Programs as a means of empowering and ensuring the full participation of PWDs in society. (Disability situation in Ghana, para. 8)

The Council is also to oversee all the operations of disability related activities and also as an advisory body for the government as regards disability matters (ibid).

Notwithstanding, there are still various problems lingering at the moment for persons with disabilities and their families. For example, the only National Assessment and Resource Centre for Children with Disabilities and Special Educational Needs is in shambles due to lack of funds (Ghana News Agency, 2010a). Not only is the wooden structure that houses the

centre leaking badly due to heavy rains, the electrical gadgets used for diagnoses have also been affected. The institution was established to provide services for the detection of early childhood disabilities and special educational needs (ibid). According to the head of the centre, the condition of the centre has made it unattractive to clients –in this sense, the parents or caregivers of children with disabilities. In their speech to the Ghana News Agency, both the Head and his deputy stressed the need for government to come to their aid. They further emphasized the need for a change in attitude towards persons with disabilities by society. To them, superstitious beliefs have clouded the interpretations of disability by most people in the Ghanaian society (ibid.).

In terms of effective health care for persons with disabilities, there are currently no laid down provisions specifically designed for persons with disabilities. (Slikker, 2009). Generally, there is a National Health Insurance Scheme, which covers most ordinary diseases and some types of accidents. This scheme does not cover rehabilitation services, appliances and prostheses, which makes its benefit to persons with disabilities limited. (Ghana Federation of the Disabled, 2008; Slikker, 2009). In addition, the information about this insurance is not designed for persons with disabilities (ibid).

Moreover, as regards education for persons with disabilities, the Ministry of Education has a special education division, which aims to increase access to quality education and to train young persons with disabilities and children with special educational needs, leading to employable skills for an economic and independent living (Slikker, 2009). Currently, the division has twelve primary schools and one secondary school for the deaf in Mampong in the Eastern region, two schools for the blind in Wa in the Upper West Region and Akropong in the Eastern Region. There are nine schools for children with an intellectual disability, with their educational focus on training in social behaviour and activities for daily living skills.

The Ministry also runs three assessment centers, seven regional mobile centers for children with learning difficulties and other development problems (ibid).

Among other countries, Ghana has embraced the ideals of the Salamanca statement (1994) of inclusive education for persons with disability; key among the proposed ideals is the need for regular schools to be made available to special needs children as a “means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all” (Gyimah & Vanderpuye, n.d, p. 2). The Ministry of Education has thus aimed to make possible the enrollment of children with non-severe special educational needs into mainstream schools by 2015. In line with this, the special education division has initiated pilot projects in a number of regions in the country since 2003 (Gyimah & Vanderpuye, n.d.; Slikker, 2009). But as it seems, there are various challenges in the implementation of the inclusive education policy. Among many identified challenges are the lack of specialized teaching skills of teachers, inaccessible curriculum, curriculum inflexibility, architectural barriers, negative public perceptions of and attitudes towards persons with special educational needs, and poor involvement of parents and community agencies (Agbeke, 2005; Slikker, 2009; Ofori-Addo, Worgbevi, & Tay , 1999; Kuyini & Desai, 2007).

Moreover, despite the efforts of the Ministry of Education and its special education division to implement the inclusive education policy, it is estimated that out of 804,000 school age children with disabilities, only 4109 are in either mainstream or segregated schools. Hence, only 0.5 % of the population of children with disabilities get any form of education (Slikker, 2009).

Also, observations of the chairman of the National Council on Disability confirms that there has been very little implementation of the ideals of the Persons with Disabilities Act (Simpson, 2010). According to him, the Council is therefore currently in the move to get the

Act into force. Further, they have at the moment been successful in getting government to institute a free education policy for all disabled children. This was announced by the president in his 2010 state of the nation address. In addition, they are working to get the transportation ministry committed to getting buses with lifts for the convenience of the disabled (ibid.).

Furthermore, there is much evidence that most disabled people are discriminated against in terms of employment opportunities (Nyarko, 2010; U.S Department of State Bureau of Democracy, Human Rights and Labor). There is hope, though, with the establishment of a center for employment of persons with disabilities (Ghana Federation of the Disabled, 2008). There is also currently a project to train and empower persons with disabilities (Nyarko, 2010)

### ***2.1.5 The Cultural Model***

In current times, the social model of disability has been dominant in defining and explaining disability as well as practical work in the disability domain. It is worth noting as the literature shows, however, that the emphases over the years have been on the structural model of disability with little emphasis on the cultural influences on defining and explaining disability. Disability theorists such as Shakespeare (1997) and Corker (1998) have raised arguments in this regard (Thomas, 2002). For as Thomas (2002, p. 49) emphasizes, “all social phenomena including disability and impairment should be understood to be woven through, and out of cultural ideas and discursive practices: there is no ‘reality’ independent of ideas concerning it”. Culture is defined as the way of life of a people. It encompasses their values, norms religions etc. (Williams, 1983; Giddens, 1989). In a sense, culture refers to how a group of people perceive life. Thus, it becomes necessary that disability as a concept should be

explained, incorporating its cultural dimensions. For as Coleridge (2000) simply puts it, “disability is defined by culture” (p. 23).

### ***2.1.6 The Cultural Model in the Ghanaian Context***

Generally in Africa, cultural ideas and explanations of disability are deeply engrossed in the traditional belief system, where disability is attributed to supernatural or divine causes. (Makanjiola 1987: as cited in Gureje & Alem, 2000; Anderson, 2004; Ingstad, 1995). This is the case in Ghana as well (Oliver-Commey, 2001). Traditionally, Ghanaians believe in a supreme God, creator of the earth and the source of all good and evil. The supreme God is the highest of a hierarchy of entities that makes up the spirit world. The other components are the lesser or smaller gods, ancestors, witchcraft and magic (Salm & Falola, 2002).

#### The supreme God

Just like in Christianity or Islam, traditional believers pray to God for protection or to show appreciation for their wellbeing. The supreme God is seen as kind. However, he is also believed to be capable of punishing those who do not live according to the rules of society (Salm & Falola, 2002).

#### The lesser gods

Since it is believed that the supreme God is too far away, he is then worshipped through the smaller gods or lesser gods, who are believed to reside in trees, rivers mountains etc. These lesser gods can vent their anger on any people or family who offend them in the form of breaking taboos, or not fulfilling promises to the gods. Misfortunes that follow their anger include illness, famine, drought, death etc. Most of the lesser gods form a core of a community’s belief system (Salm & Falola, 2002).

### The ancestors

Following the lesser gods in the hierarchy are the ancestors, who are believed to be the living spirits of people who have lived honorably in a community. Though the ancestors are spirits, it is believed they are capable of influencing the affairs of living beings. The ancestors foster moral life of society through enforcement of regulations and taboos. The ancestors are also capable of bringing goodwill and prosperity on people. In the same way, they can punish any family or people that behave contrary to the moral demands of the community or lineage (Salm & Falola, 2002)..

### Living people with spiritual powers

Witches are also believed to be humans who have supernatural powers that can cause evil to other people such as diverse illnesses, poverty misfortunes, and death, among others (Salm & Falola, 2002)..

With the advent of other religions like Christianity and Islam in Ghana, the strong adherence to the traditional belief system has reduced. However, it is also worth knowing that this belief system still influences the worldview of most Ghanaians in all spheres of life, including even those who profess to be Christians or Muslims (Salm & Falola, 2002).

In regard of the above, disability can be explained in terms of supernatural causes. A child born with a disability may be considered to be as a result of the anger of the gods or by evil forces. For example, children born with Down syndrome in some tribes are considered to be children of the river gods (Dogbe, 1995 as cited in Agbenyega, 2003). Similarly, in some tribes, it is believed that people with epilepsy are those tormented by evil spirits or demons.

Again, among the Akpafus, a tribe in the Volta region of Ghana, cataract is considered a disease caused by the gods to express their anger in response to an offence by an individual or a member of a family (ibid). This belief is common in the northern region as well. In some communities, some animals are revered because they are believed to possess certain powers (Agbenyega, 2003). Any mischief done to them can result in the birth of defective children. In Ghana, it is generally believed that some people can make riches by using parts of their bodies or those of their close relations. Hence, the part used or exchanged can be defective. Thus any disabled member in a well-to-do family, in some cases, are explained in this term (ibid). The exchange, as believed, is done through the spiritual realm which manifests in the physical realm- the presence of the wealth and that of the defect or disability. Furthermore, it is believed that anyone being offended can pay a witchdoctor to curse or cast a spell on the offender or its family, resulting in the offender or some member of his family being disabled (Anderson, 2004).

Though it is believed that these traditional beliefs and practices are waning in recent times, in a recent news article, it was confirmed by the head of an NGO that the dejection and killing of disabled or defective children, labeled as spirit children, is still persistent in the Bongo district of the Northern region of Ghana (Ghana News Agency, 2010b).

## 2.2 DEFINING STIGMA

### 2.2.1 *What is Stigma?*

The word stigma derives from the Greek, meaning 'mark'. (López-Ibor Jr., Cuenca, & López-Ibo, 2008; Simon, 1992). In Ancient Greek usage then, the word referred to a mark on the skins of individuals or a group of people who were seen as outcasts or inferior. Originally these marks were made on slaves or on criminals to make them stand out and be known as

such (Moloney, 2005; Simon, 1992). The word in its contemporary usage is credited to the sociologist Ervin Goffman (Reiher, Heinrich, & Roberts, 2008). In his classic book *Stigma: Notes on the Management of Spoilt Identity*, Goffman (1963) theorized that it is characteristic of society to create categories of people on grounds of normative expectations - differentiating the 'normals' (those who fall within the norm) from the deviants (those who possess some differentness and fall short of societal expectation) (Carnevale, 2007). Stigma, as Goffman (1963; p. 3) defines is any "attribute that is deeply discrediting and that reduces the person from a whole and usual person to a tainted and discounted one". Thus stigma connotes something disgraceful about an individual. As Goffman further stressed, these attributes are socially defined and consequently differentiates what is accepted as normal from what is not. Stigma is then not a feature of any physical characteristic but rather develops as a result of social reactions to such characteristics. As such, stigma, according to him, develops through relationships; in this case that of the individual and the society.

Goffman described three types of stigma. These include bodily or physical deformities, behavioural attributes or "blemishes" of individual character such as dishonesty, homosexuality and alcoholism, and attributes of belonging to particular groups or associations like race or religion. Goffman further added that the stigmatized individual can manage his status through information control.

### ***2.2.2 Managing Stigma***

The stigmatized respond to their situation by trying to manage their stigmatic condition through what he called information control. Three management strategies are often used in this regard, according to Goffman. These include passing, covering and withdrawal. Passing involves efforts by the stigmatized person to manage information in order that they can pass as normals, be it partially or fully (Carnevale, 2007). This can be by concealing information

about one's attribute where possible, or by altering or eliminating the stigmatic condition such as having surgery. Covering involves trying to lower the effects of one's stigmatic attribute (Cree et. al., 2004). Withdrawal occurs when the individual tries to isolate him or herself from situations that will make him identifiable (Carnevale, 2007).

### ***2.2.3 Courtesy Stigma***

Further, Goffman theorized that stigma does not only affect the person with the difference but spread on to people whom the discredited person has some close association such as family members (Fjone, Ytterhus & Almvik, 2009; Norvilitis, Scime, & Lee, 2002). This is what is known as courtesy stigma, a phenomenon which hasn't been much researched (MacRae, 1999). This group of people known as the wise, according to Goffman, is "normal but different" (Birenbaum, 1970). As he cited, this group of people could include the 'loyal spouse of the mental patient', 'the daughter of the ex-con', 'the parent of the cripple', 'the friend of the blind man', and 'the family of the hangman' (Goffman, 1963, p.30). They have insight into the situation of the afflicted person and can sympathize with them as well as offer them help (Gray, 1993).

### ***2.2.4 Managing Courtesy stigma***

According to Goffman then, persons with disabilities are at risk of stigmatization and this is also the case for their families. This group of people also use several means of information control to manage their situation. The passing and covering strategies mentioned earlier are also employed by these people.

Studies by Birenbaum (1970), (1992), MacRae (1999), Falk (2001), and Norvilitis, Scime, & Lee (2002) have all confirmed the experience of courtesy stigma by families of people with some disabilities (Norvilitis et. al Norvilitis, Scime, & Lee, 2002).

## 2.3 THE FAMILY SYSTEM IN GHANA.

### 2.3.1 *Structure of the Family*

The Ghanaian family is the fundamental social unit. It is made up of both the nuclear family and the extended family systems (Weatherly, 2008). The nuclear family is made up of mother, father and children. The extended family, on the other hand, comprises a nuclear family together with all other close relations such as uncles, aunts, grandparents and cousins and forms the foundation of the Ghanaian society (Ham, 2009). It could sometimes span three to four generations. Each extended family is organized around a common ancestor (Weatherly, 2008). As Nukunya (1997) defines, the extended family can describe a social arrangement in which an individual has extensive reciprocal duties, obligations and responsibilities to relations outside his immediate (nuclear) family. In a sense, the nuclear family, made up of parents and children is inseparable from the extended family in structure and function in Ghana (Ankomah, 1997). For as a saying goes, Ghanaian families are a crowd (Salm & Falola, 2002).

Generally, in Ghana the size of a family comprises more than parents with their children (Ardayfio-Schandorf, 2006). Thus usually in the rural areas it is typical for a household to be made up of nuclear family members as well as extended members (Weatherly, 2008). A residential compound could be made up of three or four generations. In this sense, it could consist of a couple, their grown up children and their spouses and children. It could also be made up of a number of extended members. In the urban setting, the family structure is nuclear. However, it is not uncommon for extended family members, such as nieces and nephews to be staying with a family (Arthur, 2008).

### ***2.3.2 Function of the Family: Marriage and divorce as social arrangements***

Functionally among others, a major role of the family is its function in key life transitions such as birth, puberty rites, marriage and death. In the case of marriage, the family plays a significant role, in that the man needs the approval of his parents before choosing a partner (Ankomah, 1997). Usually, it is a man's family that initiates marriage proposal to a woman's family. This is done after the family has made investigations into the proposed family's background to check whether there are any bad traits or diseases, especially epilepsy, mental disorders and other defects and disabilities in the family (Ardayfio-Schandorf, 2006). In actual fact, these investigations are also done by the woman's family. In earlier days it was the responsibility of the man's parents to choose a partner for him with support from the wider family i.e. extended family members. Nowadays, it is usual for a man to choose a partner after which he seeks the approval of his family.

The extended family system, acknowledged by customary law can legalize marriage. This is after the marriage rites and ceremonies have been performed involving the family members of both partners. This is one among three kinds of forms of marriage accepted by law in Ghana (Nukunya, 1997). At this point, it is quite clear that marriage in Ghana is a union between two families rather than individuals (Nukunya, 1997; Ardayfio-Schandorf, 2006). It becomes extremely difficult for an individual to marry a partner in cases where key members of the family do not agree to the decision (Ardayfio-Schandorf, 2006; Ankomah, 1997).

In the same way, divorce is usually not a couple's decision alone. Divorce proposals usually have to be made to the other partner's family. The families then make efforts to solve the problem that led to the proposal. It is only after several efforts made by the families of both spouses to settle the issue has failed that divorce will be granted or sent to the law courts (Okoledah, 2005). Divorce is usually initiated and granted in cases of childlessness, laziness,

adultery, accusation or suspicion of witchcraft, disrespect of in-laws, and irresponsibility on the part of the man (Ankomah, 1997).

### ***2.3.3 Function of the Family: Children in the family***

Also, like most typical families, the Ghanaian family functions as a body for procreation, socialization of children, provision of economic and emotional support for its members and maintenance of social security, as well as care for younger members (Nukunya, 1997). Children are highly cherished in the Ghanaian society (Coe, 2008; Ardayfio-Schandorf, 2006). They are considered a symbol of wealth, as well as of respect and status, and the continuation of the lineage (ibid). In addition, childbirth is a sign of a woman's normality and healthiness (Ankomah, 1997). A woman who does not have a child could be accused to be a witch who has "eaten" all her children (Coe, 2008; Ankomah, 2007). It is generally expected in the Ghanaian society, therefore, that a couple have children after marriage (Ardayfio-Schandorf, 2006).

Though producing children is a couple's affair, raising and socializing them is jointly the responsibility of immediate as well as extended family members (Nukunya, 1997; Weatherly, 2008). Thus a child belongs to the whole family both immediate and extended. Immediately a child is born, family members of both parents troop in to help in attending to the child for a period of time. Also, in case of illness death or any circumstance that renders any parents incapable of taking care of their children, it is expected that other members like aunts, uncles, grandparents, or other elderly members in the kinship take up the responsibility of caring and raising these children (Arthur, 2008; Coe, 2008). Even older siblings are responsible for the care of younger ones. Similarly, the younger members are responsible for the wellbeing of the aged. One Ghanaian saying literally means that as your parents help your teeth to grow

you must also help them for theirs to fall out. This means that one is responsible to take care of one's parents after they have taking the pains to raise him or her.

The Ghanaian family, in general, transcends a nuclear family by structure. By function, the Ghanaian family is at the centre of the welfare of the individual, socially and economically – the care of the young and old, and the sick are key responsibilities of the family (Nukunya, 1997). Likewise, the family is responsible for its less privileged members. In a sum, the family is the primary social welfare system in Ghana.

### 3 METHODOLOGY

#### 3.1 INTRODUCTION.

The field of psychology has to a large extent been associated with quantitative research. However, in recent times, the tendency to adopt the qualitative approach is increasing.

For as Ashworth (2008) asserts, the fact that human experience happens to be a central theme in psychology leads almost necessarily to qualitative research.

Qualitative research is most of the time informed theoretically by the philosophical tradition of social constructivism, which derives from the broader and general constructivist philosophy of science. Generally, constructivism assumes ontologically that though there are realities in the world, we construct our own understanding and knowledge of the world through experiences within specific contexts, and by a reflection on these experiences (Guba & Lincoln, 1994). Therefore, constructivism proposes that the process of acquiring knowledge in the context of research, particularly in the social sciences, is a subjective and transactional activity through which findings are created in the process of an interaction (Guba & Lincoln, 1994). Methodologically then, as Guba and Lincoln (1994) continues, social scientific inquiry is hermeneutic and dialogical in nature. By this, individual constructions can be elicited and refined only through interactions between and among respondents and researcher.

Specifically, social constructivism further adds that all human experiences are dependent on social and historical contexts. In addition, it argues that social phenomena are not static as can be assumed of physical phenomena. Social phenomena are thus dynamic and cannot be measured in specific ways but rather, can be understood within specific social and historical contexts (Langdrige, 2004).

## 3.2 SOCIAL CONTEXT AND STUDY PARTICIPANTS

### 3.2.1 *The Researcher*

I, the researcher, have lived all my life in the country where this study took place. I am a woman and had two children at the time I did this research. As an inhabitant of Ghana, I had a certain understanding of how persons with disabilities and their families are perceived before the study was undertaken. I knew that it can be a difficult experience for families to have a disabled child. I had further observed that though there is an upsurge in advocacy for persons with disabilities, this is narrowed in favour of adults with disabilities. In my experience, very little is mentioned about children with disabilities and their families. The families of children with disabilities in Ghana are what I would call the unheard voices. I was thus inspired to bring their voices to light by engaging in this study.

### 3.2.2 *Participants*

Making decisions about which people to include as participants in a study also involve considering which events to observe as well as the kind of settings and processes that would be incorporated in the study (Punch & Punch, 2005). Moreover, it is usually not possible to study everyone everywhere doing everything (ibid.). Thus, though the problem under study is general to the Ghanaian context, there was the need to concentrate on a specific setting. In this case, a rural setting was chosen since the traditional belief system of Ghana, which influences attitudes towards disability is more profound and adhered to in the rural areas (UN Human Rights Council, 2008). Moreover, it can be generally observed that the plight of persons with disabilities and their families is more intense in the rural areas due to poverty, and the lack of services that supports persons with disabilities and their families. (Kassah, 1998). Further, the Dangme West District was chosen because, I have personally lived in this district for some time and thus quite familiar with the area.

The Dangme West District is one of the ten districts in the Greater Accra Region of Ghana and located in the southeastern part of the country. It has a total land area of 1442 square kilometers. Its capital is Dodowa, which is about 25 kilometers from Accra, the capital of Ghana. The district is divided into four sub-districts namely, Dodowa, Prampram, Great Ningo and Osudoku. There are about 110 towns in the District. According to the latest census in 2000 there are 96,809 people living in the district. Most of the population live in scattered small communities of less than 2000 people with poor access roads. The district is largely rural. Thus the dominant occupation of the people is agriculture involving 58.6 % of the population. The agricultural activity though is mainly subsistence farming, livestock raising and fishing. The next major source of livelihood for the people is trading involving 22.1 % of the people. The district is generally characterized by widespread poverty. The deprived status of the district has resulted in most of its inhabitants migrating to find jobs (Dangme West District; Ghana Health Service; Ghana-Netherlands Health Research for Development Programmes).

To study the experiences of families with disabled children in the Dangme West District, four families, each with one disabled child were recruited. To begin our search, I and the research assistant went from community to community making contacts, first, with the community heads to obtain permission before making contacts with families of interest. As the researcher, I explained to these community heads what the research was about, generally. In one of the communities, we were required to pay a token to the village head before being granted permission to proceed with our search. After getting permission from each community, I and the research assistant proceeded to recruit participants. In this case families with disabled children. Any family with a child with any type of disability was deemed qualified for the study. Specifically, I was interested in families with young children with age ranges from birth to nine thereabout. In two of the families, the disabled children had leg

deformity; in the third family the child was blind. The last family had a child with a lip and cleft palate defect. Two of the families lived in a town setting while the other two were recruited from two separate villages. It is worth noting, however, that the whole area from which the participants were recruited is a rural area as stated earlier and culturally homogenous in the sense that they all speak the same language with very little variations.

### ***3.2.3 The Research Assistant***

As already mentioned, I recruited a research assistant from the Dangme West District for this study. This was in order to further the communication with local people. The assistant holds a diploma in accounting and is one that I have known personally in the community. Being a native as well as an educated person in the community made him ideal as an assistant for the study. I would have to admit that he brought a lot of insight to the study. His command over the local language made it quite easier for us to get through and be accepted in the communities. Moreover, he personally gave a lot of information as regards the cultural beliefs and traditions of the local area. I considered that his involvement could have the possible effect of participants holding back some information due to his presence. As it turned out, all participants expressed that they were generally comfortable with his involvement both during the periods of observation and the main interview sessions.

## **3.3 STUDY DESIGN AND METHODS**

The choice of methodological approach in research should depend on what the study aims to discover (Silverman 2006). In view of the aims of this study, a qualitative approach and its associated methods were adopted. As stated, qualitative research aims at understanding how people interpret their experiences, the way they construct their world and what meaning they

attach to these experiences (Merriam, 2009). This study mainly aimed to delve into the experiences of families with disabled children as a means to bring to light what it means to have and live with a disabled child in a specific context; a rural Ghanaian context. The main method for the study was interviewing, which was contextualized by such methods as informal conversations and participant observation.

### ***3.3.1 Participant Observation***

The methodology of participant observation seeks to uncover, make accessible, and reveal the meanings (realities) people use to make sense out of their daily lives. Hence, participant observation provides a context within which to situate the meanings people attach to their experiences. Before the interviews, I stayed in the locality of the study and tried to familiarize myself with the daily living of each family by participating in their daily activities as well as observing the interactions between the disabled child and members of the family with a focus on the interaction between the main primary caregiver and the child. I also gave attention to the relationship between the participating families and their neighbours in the communities. I spent a week with each family and had the interview session on the last days of the week. Of course, this study was not a purely ethnographic study. Thus participant observation was not the main method for the study but a context for the interviews. It was a means of gathering contextual information within which to situate and understand the narrations of participants. This was done as a means of drawing more information about living with the disabled child in practicality. Secondly, these observations prepared me for the interview session.

### ***3.3.2 Informal Conversational Interviews***

Rubin and Babbie (2009) have defined the informal conversational interview as an “unplanned and unanticipated interaction between an interviewer and a respondent that occurs naturally during the course of observation” (p. 103). Thus, to respond to what is observed during the periods of observations, spontaneous questions were asked as and when the need arose. Informal conversations were initiated with the main primary caregivers of the disabled child, significant others within the family frame, as well as with some community members. These conversations were mainly prior to the main interview session. Thus the informal conversational interviews guided questioning in the form of follow ups during the main interview session. I also had informal conversations with key persons in the various organizations visited. These were in the form of general questions about disability and were further narrowed down to specific questions about the experiences of families with disabled children.

### ***3.3.3 Field Notes***

DeWalt and DeWalt (2002) notes that the main mode of capturing data from participant observation and informal interviewing is by writing field notes. Apart from making notes on the observations made during the periods of participant observation, the informal conversations and the main interview session, I also made notes on all other information that was deemed relevant or of interest to the study so as not to lose it in memory. For example, I made notes on the general observations made during the recruitment period taking note, especially, of the field challenges encountered.

### ***3.3.4 In-depth Interviews***

In-depth interviews were held on an individual basis with the various parents who happened to be the main caregivers of the children with disabilities. This was done with the aid of a

semi-structured interview guide (Appendix). This guide was created using some sections, some of which were adjusted, of an interview guide used for an early intervention program cited in Seligman and Darling (2007, p. 365-366).

#### Interview guide

The guide was structured into four broad thematic areas namely, their perceptions on disability as a phenomenon, how their experiences have been since the onset or discovery of the child's disability, how they are coping, and their perceptions of life with the disabled child in the future. This guide was used in order to create room for probes and also to keep the interviews within the purpose of the study.

#### Carrying out the interviews

With two of the families, the interviews were held in their homes. The main caregivers from the other two families preferred the interviews were held at somewhere else other than at home. With the help of the research assistant, we got a location that was a bit away from town. Though the interview guide was structured in English, the interviews were mainly held in the local language. Personally, I understand the local language but the research assistant, being a native understands it better than I do. With his help, we were able to make respondents have maximal understanding of the questions, in that he contributed in giving further explanations of some questions in the local language when necessary. He was also instrumental in getting other technical items in place such as the setting of the tape for the interviews. The interviews lasted averagely for an hour. The shortest spanned fifty minutes, and the longest was about an hour and fifteen minutes. We provided snacks during interviews as refreshment for the long sessions.

I found the interview session very interesting in the sense that, as a young researcher, I was forcing my way to get the respondents to answer the questions on the interview guide. But this was not easy since the respondents took much control of the answering by telling me what is most important about their experiences in relation to having and living with the disabled child. Even when I asked about other questions, some of the respondents would revert to talk more about other issues that they have already talked about. This made me realize that a purely narrative interview, which gives respondent much more room to articulate their own narrations, could have suited a study of this nature.

### ***3.3.5 Other Sources of Data***

Having in mind the intention to subject data collected to narrative analysis which requires that as much contextual data is collected in order to understand narrations of study participants, I made the effort to collect as much contextual data as possible by contacting institutions and organizations like Ghana Federation of the disabled, The Department of Social welfare, New Horizon Special School and the Dodowa Health and Research Centre. I also looked into internet sources, and Library databases. It was unfortunate that there was very minimal data on the subject of study in Ghana. Very little literature existed, generally, on the issue of disability. It was very striking when I went to the Dodowa Health Research Centre and could not get a single document of any study done in the area of disability. Generally, the main research focus of the centre was primarily on malaria research. This lack of data made me convinced that the current study is much needed.

### **3.3.6 Data Management**

The interviews were tape recorded. In all, interview data collected was about four hours and five minutes. I transcribed the interviews as accurate as possible from the local language into English. I thought it was necessary to transcribe the data myself since I considered it as being part of the data analysis process. Doing it myself also gives me the opportunity to draw on the context, the atmosphere and nonverbal cues of the interview sessions. After the several weeks of transcription, it ended with about fifty pages of data. Field notes also amounted to ten pages. It is worth admitting that the transcribed product of the interview is a 'joint production' by researcher and interviewee (Mishler, 1986). First, the questions, answers and probes that characterized the interview sessions was undoubtedly a two-way process, with my interrogations creating constraints in relation to what participants were telling. Moreover, the translation process was a way of interpreting, to some extent, the meanings of the information given by participants.

### **3.3.7 Data Analysis**

Narrative analysis

*“When research participants are asked to talk about themselves, about their experiences, or to explore some aspects of their life, they invariably use a narrative mode of organization, i.e. participants will provide accounts that inevitably take on a story structure”.* (Hiles & Čermák, 2008).

The use of the semi-structured interview guide generated story-like data. Respondents were telling long stories and giving detailed descriptions of related events in accounting for their experience of having and living with a disabled child. Hence, the analytic approach adopted in this study was narrative analysis. I further considered narrative analysis most appropriate

because my methods of data gathering yielded rich contextual information, which according to Murray (2008) is a major requirement for the approach.

Narrative analysis in social science research is basically about analyzing stories. It begins with the assumption that we live in a storied world. Moreover, people, to a large extent make sense of their experiences, and communicate these experiences in the form of stories (McLeod, 2001). In Atkinson's (2007) words, "We are a storytelling species. Storytelling is in our blood. We think in story form, speak in story form, and bring meaning to our lives through story. Our life stories connect us to our roots, give us direction, validate our own experience, and restore value to our lives" (pp. 224) In narrative analysis, the researcher collects narrations of events about personal experiences from respondents, restructure these events by drawing the causal links between them, and retells the story finally. As Riessman (1993) acknowledges, traditional methods of analysis in qualitative studies usually fracture data by only using bits and pieces of data. Thus narrative analysis with its emphasis on sequence of narrated events and pulling together the causal links between these events provides a holistic approach to data analysis. Moreover, it acts as a means through which the many "layers" of meanings embedded in interview data are retained (Wiles et. al., 2005).

As said, the nature of data collected called for the employment of narrative analysis. Being a novice researcher, I sought to find a structured guideline. But unfortunately, due to the varied approaches to the method, I was left confused as regards how best to approach the data. I thus resorted to extensive reading to get a grip of the method and took the challenge to draft an analytic frame. My core aim was to give as much voice to the narrators as much as possible and ensure their constructions are made as bare as possible. My analytic approach was informed by Riessman (1993), Polkingehorne, Murray (2008), and Hiles and Čermák (2008). For Polkingehorne (1995) narrative analysis is a process where "Researchers collect

descriptions of events and happenings and synthesize or configure them by means of a plot into a story or stories” (p. 12). The general approach to my analysis was to configure the elements of the narrations of the respondents given during the interview. In addition I used the data collected through the observations and informal conversations as context to construct a story for each participant and retell these stories, making evident the key issues of concern to participants according to my interpretation. This approach, which Polkinghorne (1995) identifies as narrative analysis does not exclude the analysis of narratives which he distinguished from narrative analysis.

#### Step by step analysis

The transcribed interviews were read thoroughly and repeatedly to get a general view. I then wrote a summary of all the narratives to identify its beginning, middle and end dimensions in order to familiarize with the general structure of the narratives (Murray, 2008). Having familiarized myself with the structural dimensions of the narratives, I proceeded to usher the transcribed text into what Hiles and Čermák (2008) calls the working transcript, or in my view the beginning of the actual analysis. By this, I arranged each participant’s narrative in the left margin of each page of text, leaving a wide margin to the right, where I made notes on the key issues and themes the narrators talked about. The analytic process generally involved a back and forth movements across the text to establish connections between the various parts. As Murray (2008) admits, narrative analysis requires the analyst to play with the account. In my analysis, I tried to pay attention to both the how and what of the narratives. In other words, I focused on both what was told as well as how it was told. Further, I made the effort to make the ambiguities in the respondents’ stories as bare as possible. Finally, I made a comparative analysis to draw out the differences and similarities in the stories and discussed the recurrent themes. All these were done using the other sources of data as context. Having in mind the criteria for a sound qualitative research, the final write

up was done showing a blend of description and interpretation. Further, with the aim of making respondents voices heard as much as possible, I included extensive quotes from their narrations in the write up. This was also to give the reader ‘a rich sense of context’ (Pitney & Parker, 2009).

### 3.4 VALIDITY AND RELIABILITY (TRUSTWORTHINESS)

Reliability refers to the extent to which research findings are replicable and stable. On the other hand, validity describes the ability of research to measure what it seeks to measure (Elliot, 2005). These concepts are the main tools for evaluating the goodness of research. There are arguments as regard the relevance of these concepts in qualitative research due to the emphasis on measurements, which have been argued to have no place in qualitative inquiry. Notwithstanding, most scholars like Elliot (2005) agree that there is the need for qualitative researchers to ensure the accuracy of their research. In line with this, the alternate term in which qualitative research is evaluated is trustworthiness (Lincoln and Guba, 1985; Elliot, 2005).

#### Trustworthiness

According to Lincoln and Guba (1985), to ensure trustworthiness is to convince the reader that the findings of a study “is worth paying attention to” (p. 290). To ensure trustworthiness, they identified four criteria; credibility, transferability, dependability and confirmability. These they further suggest could be ensured through the strategies of member checks, audit trail, peer debriefing, negative case analysis, triangulation, peer review, prolonged engagement, and thick description. Most of these suggestions were incorporated in this study. For example, the triangulated data collection methods of participant observation, informal conversations, and the interviews were collectively resourceful in ensuring some

level of accuracy in the reported finding. This was not, however, to necessarily confirm the narratives of the main informants but to gain as much contextual information as possible in order to establish maximum understanding for these narratives as well as for the study as a whole, having in mind the aim of the study; to establish an understanding of what it means to have and live with a disabled child in the a Ghanaian rural context.

Secondly, I had stayed in the setting of the study earlier. This together with the participant observation sessions, which spanned a period of four months, made me quite familiar with the setting. My weeks of engagement with the participants made us establish rapport and trust. For the main caregivers who happened to be mothers, my position as a mother also contributed in this regard. This ensures, to some extent, a possibility of them involving me in the true realities of their experiences.

Also, though the questions for the interviews were in English, all the interviews were held in the local language. To close the gap between the two languages and to ensure maximum understanding of questions by participants, the research assistant was instrumental with his excellent proficiency in both English and the local language of the area of the study. In addition, analysis of the data was done with close guidance by my supervisor and was made available to other colleagues for comments, suggestions and review. After collecting the data, it was not possible to present it to respondents, since the transcription was done farther away from the setting of the research. I left Ghana a few days after the data collection to Norway, where I am studying to work on the data. Notwithstanding, having anticipated such a problem, I and the research assistant made efforts to get a little more clarifications from the participants on issues that we thought needed a bit more explanations during the interviews and shortly after, before I left for Norway.

### 3.5 ETHICAL CONSIDERATIONS

In social research, there is the need to adhere to certain ethical constraints. Ethical considerations as regards informed consent, confidentiality and anonymity, and freedom of withdrawal were core to the research process, as were the personal dimensions of research ethics. This study is approved by the local ethical committee in Ghana and by the Norwegian Ombudsmann for privacy in research. The study was started only after certification of approval has been received.

#### *3.5.1 Informed Consent*

Informed consent is the act of seeking the permission of research participants after having given them full knowledge of the study and the consequences of participating (Piper & Simons, 2005). In line with this, with the aid of the consent form, the participating families were fully informed about the study. They were completely made aware of what the study was about, the procedures that will be incorporated as well as possible risks and benefits of the study. Thus participants were made aware that the researcher would take part in the daily activities, make observations, ask informal questions and also have a main interview session which would be tape recorded. These, they were informed, will be done with the involvement of a research assistant. This implied an encroachment in their privacy to some extent. Families were, however, assured that this would be quite minimized. Further, they could draw the attention of the researcher if this in not adhered to. To reduce discomfort during the interview session, participants were made to make a choice as regards where to have the interview. Participants were made aware that there were primarily no immediate material benefits from the study but rather possible long term benefits through the dissemination of findings to various organizations as a means of bringing the nature of findings to light.

Participants were further made aware that they could withdraw at any point in the course of the study. The informed consent form used in this regard was an approved template from the Ethical committee in Ghana.

### ***3.5.2 Anonymity and Confidentiality.***

Assuring participants anonymity and confidentiality is a means of protecting them (Brinkman & Kvale, 2008). Ensuring anonymity is to protect the identity of participants whilst confidentiality involves keeping secret information acquired from a study (Gravetter & Forzano, 2008).

In the current study, participants were clearly assured that any information given will not be revealed to a third party with the exception of the research assistant and possibly the supervisor. Further, there will be no disclosure of the true identity of participants in the form of name, place or location. Practically then, the tapes that contained the data were safely kept with the researcher alone having access to them. The specific names of the villages in which the participants were dwelling were not disclosed. In addition, I have changed the names and some of the personal information as presented in this study so as to avoid any means of making participants identifiable.

## **3.6 FIELD CHALLENGES**

A major challenge I encountered while on the field was as regards getting ethical clearance in Ghana. As I got to know, there are specific times for the board sittings. Thus the next available sitting was not favorable for the early commencement of the study. In order to abide by the general principle of getting ethical approval before beginning a study which requires it, I waited for the approval before commencing the study.

Moreover, though the company of the research assistant contributed in our acceptance in the villages, this was not without limits. In order to protect their pride some of the villages were not receptive of us due to the nature of our quest; searching for families with disabled children. For example, in one of the villages, the village head whom we were introduced to actually told us that he can swear that they don't have any such children and their families in the village. His tonation, choice of words in the local language and composure towards us made us feel as if we were searching for something unclean.

It does happen that some smaller private organizations go to some villages, take photographs of the disadvantaged people to solicit for funds from donors with the aim of using these funds to help these people but never actually use much of the funds for the said purpose. In one of the villages, therefore, we were perceived as such people until we explained that I am a student researcher seeking to collect data for my master thesis.

Another practical challenge arose in the course of the study. In one of the cases the couple was having heated marital problems which I witnessed myself while I was engaged with them. It was thus a challenge engaging with the couple together. Since my focus was on the main caregiver of the disabled child, I engaged with the mother and had casual talk with the father separately. But interestingly, the father wanted to know what the mother had talked to me about . In fact, it was a major challenge for me because if I had told the father everything his wife had told me, I am convinced it would have worsened the already boiling spousal conflict. The wife had talked extensively about his maltreatment of her as a result of having the disabled child. To play safe, I informed him about some aspects of what his wife talked about; the fact that they have had challenges as a result of having the child and having done everything possible to get the child healed. These aspects, I believed, were not controversial. Personally, I must say that my resources for handling critical situations were highly tasked. The situation required some amount of wisdom to avoid creating a problem.

Another challenge was as regards expectations from participants for financial help. Having knowledge that I had come from Europe to conduct the study, the general belief is that I had come with a lot of money. I suspected that some participants expected that I could help them get their children's defects and disabilities corrected. In fact, the state in which I found some of the disabled children appealed to my emotions. The condition of the child who had the cleft palate defect was disheartening and made me wish I had the resources to help them get the operation done for the child. Financially contributing to these families would have been argued as manipulating the respondents. But in a rural setting where most of the people are poor, these expectations are common. I have even heard about research experiences in other rural settings where possible respondents request they are giving some tokens before they participate in a study. As stated earlier, in one of the village communities we were required to pay a token by the village head before being allowed to continue our quest in the village.

## 4 FINDINGS

### 4.1 REPORT FROM INSTITUTIONS

Before spending time with the families and interviewing the caregivers, I tried to visit some institutions in order to familiarize myself with the general and current state of disability issues in the country. I thus visited Ghana Federation of the Disabled and the Department of Social welfare. I also visited the New Horizon Special School and Dodowa Health Research Centre.

#### *4.1.1 Department of Social Welfare*

At the department of social welfare, I was linked to the deputy director of the department, who was also in charge of disability issues. He was very happy I also have an interest in disability research since, as he asserted, there are just a handful of disability researchers in the country. I started by inquiring about his perception of the nature of the experiences of families with disabled children. According to him, the main problem for such families is the stigmatization that comes with having a disabled child. He added that sometimes due to the stigma attached to having disabled children, most families don't bring the children out very much to seek medical and social help from professionals. He also asserted that financial strain is very common in such families due to medical costs and the engagement of care by parents which hinders their work. He further discussed the persons with disability act that has recently been passed. He also noted that as regards provisions for children with disabilities and their families, very little has been done, though provisions for their wellbeing has been 'beautifully' spelt out in the Act. For example, there are no screening facilities for such children, especially in the villages. To him, if there were more researchers in the area much

of the experiences of persons with disabilities together with their families would be brought clearly to light. He emphasized the fact that there is a need to train parents themselves as regards how to handle their children. He then gave me some useful documents like a copy of the Disability Act as well as some studies they have done at the department.

#### ***4.1.2 Ghana Federation of the Disabled.***

Before going to the field, I called the director of this organization and informed her about my study. Right away she also congratulated me for having had an interest in the study area. As she said, what they lack most as an organization is data. This lack impedes most of their activities. As I got to the field, I visited the office of the organization but met her absence. I was then introduced to the administrative secretary and asked him, generally, about the state of disability issues in the country. He also touched on the fact that the Persons with disability bill has been passed into an Act and the fact that a council has been set by the government, currently, with a main function of advising the president as regards disability issues. He also made me aware that the major problem of persons with disabilities is the socio-cultural influences on the perceptions of disability in the country. Due to this, he informed, they as an organization are working within the frames of the social model of disability. He also informed that there is currently an academic program in the area of disability in one of the universities in the country. To him this is quite positive.

I then inquired what he perceives to be the nature of the experiences of families with disabled children. To him such families really go through a lot of difficulties since there are just a few schools that can accommodate these children and lack of adequate organizations that can support such families. He asserted though that there is one parent support organization in the name of Parents Association of Children with Intellectual Disabilities in Ghana. I therefore

inquired how well this organization is known in the country. He admitted that the organization is quite young and is not so well known. I therefore suggested that there could be a bigger organization that brings together parents of all children with some form of disability, with branches in every part of the country. He acknowledged this was a good idea and suggestion which he noted. He further showed interest in knowing what the situation was like in Norway as regards persons with disabilities. I made him aware that though I don't know much I know the emphasis here is mainly on independent living for persons with disabilities. I therefore, promised getting the organization some documents as regards his quest when I get back to Norway.

#### ***4.1.3 New Horizon Special School***

I chose to visit the New Horizon Special School because I realized there was no such institution in the area for the study, the Dangme West District. I intended to discuss with the proprietress and founder of the school what her perceptions are as regards the experiences of families with disabled children. Making a schedule with her became a bit problematic since she was quite old and did not stay quite long at the office very often. The day for the meeting happened to be the vacation day of the school. Hence, the children were having a party as we got to know. In order to make my visit there a lively one and also to create room for maximum interaction with the staff and the students, with the help of the research assistant I bought some few things which we presented to the school and the children. We were then shown some of the handicrafts that the children have been taught to make. In our interactions with some staff members, they admitted that handling most of these children is quite difficult. However, due to the fact that they have been trained for such a profession, it becomes quite manageable. Their inspiration has also been the fact that these children show some development, behaviourally and intellectually, from time to time. For them, this inspires

them. In my talk with the proprietor she admitted that she had the inspiration to set up the school being a mother of an intellectual disabled child herself and thus knowing how the experience is for such mothers and parents in general. She regretted the fact that it would have been good if we had met with some of the parents of the school children. As she informed, one mother had been to the office crying for her child to be admitted to the school. But as she said, this woman had no financial means what-so-ever to pay for the child's fees and expenses. She said one challenge of the school is that of finance and that it has only being sustained by donations from organizations and contributions from parents.

#### ***4.1.4 The Dodowa Health Research Centre***

I went to this centre to get some descriptive data as regards the incidence of disability as well as any other document that could be of relevance to the study. Unfortunately, I was disappointed since there was not a single data as regards disability in general in their database. The director suggested I go to the Department of social welfare where I could get information. I realized she felt quite uncomfortable this was the situation.

In addition to the information achieved from the visited institutions, I got a lot of background information casually from various people like some friends and other people, some of which I knew in the study area. These include two professionals (both medical doctors, one of whom I have known). These, together with my own experiences in the country for the study, as well as other documents collected act as rich background information for the study.

Interestingly, their (organizations and peoples interacted with) perceptions about the subject of the study were not too far from each other, and this gave a general idea of what the experience is for a family with a disabled child. Some of the main issues seem to be stigma,

financial strain, and lack of public facilities for such children which results in burden in terms of care on families.

#### 4.2 MAIN FINDINGS

The four families involved in this study were all from the Dangme district. As has been specified, the main person of focus was the primary caregiver. The primary caregivers in all the four families were the mothers. Hence, my main interest was in their stories about the family experience of having and living with a disabled child. In the process of analyzing the interviews, the observations I made during my engagements with the families and the informal conversations I had with a few other family members and the community served as context. When I was constructing the narratives, I made efforts to do this flexibly, so as not to make it seem as if I'm trying to confirm their stories, having in mind that narrator interpret the past in stories, rather than reproduce the past as it was (Riessman, 2001).

As per the structure of the semi-structured interview guide the mothers told their stories within the frame, ranging from when they had the child or first discovered the child's condition through their experiences living with the child within the family and community context, and their future perceptions about the child. There were similar plotlines in the mothers' stories. In two of the cases, the men disappeared after the birth of the child, in one case the couple was having serious marital problems. In the last case, the couple was living together but was having problems with the extended family relations. All the mothers perceived disability from cultural (religious) and medical lenses. It was also obvious that the care of the disabled child came with stressors such as financial strain. The belief in the local area is that, in terms of having defective children, the blame goes to the woman and her family since she is the one who carries the pregnancy.

#### **4.2.1 Mabel: ‘my husband’s family...’**

Mabel is a 30 years old woman living with her husband and two kids. The first, the disabled child, is six, the second is four. The disabled child had deformed legs which made it impossible for her to walk without clutches. At home, this child appeared to be very active, trying to do things for herself. To me, she seemed a very happy child, giggling and laughing most of the time. Mabel happens to be the main caregiver for her kids, with some support from her husband. The disabled child is in school with the second yet to start school. Despite being the care giver of the three young children, she does work to supplement the husband’s income.

Mabel and her family live in an isolated compound a bit farther from the rest of the village. During the interaction with her, I learned that they had to relocate to such a place because of the maltreatment from the husband’s family.

In our search for participants in Mabel’s village, I and the research assistant happened to inquire from a house which happens to be that of Mabel’s in-laws. As we inquired whether there is a family with a disabled child living in the house, they immediately made us aware that they have one. It so happened that Mabel approached the house while we were there. Immediately, one woman from the household said “there she comes”, in a manner that similarly describes a culprit. This incident seems to forecast what we later found to form the core of Mabel and her family’s story.

Being her first child, Mabel in no way expected to have a child with any disability. As she said “...I didn’t understand why people give birth to normal children and I had to give birth to a child with a defect”. As may be the initial reaction of many mothers who unexpectedly give birth to a disabled child, Mabel was shocked about the condition of the baby. It was a

traumatic experience for her, which made her grieve for some time. As she describes the experience:

*I gave birth in the night and hence didn't see that the child had a defect. I was only told I have given birth to a girl. But as I woke up and lifted the baby, I realized there was a problem with the child's leg. I seriously exclaimed with disappointment. I tried to find the nurse but couldn't. In fact I felt like dying. On seeing the nurse, I asked whether she has seen the problem with the baby's leg.*

From Mabel's further story, we can infer that it was also a difficult circumstance for her husband to learn about the condition of the child. Mabel narrates that he was cold towards her for some weeks after getting to know the child has some defect. However, throughout the interview, Mabel gives the impression that her husband overcame the shock and disappointment and has since been supportive of her. This is evidenced in her continuous reference to 'we' instead of 'I' to my questions directed to her personally.

The birth of the disabled child quickly became a source of conflict between Mabel and her husband's family. In actual fact, much of Mabel's narrative was centered on her experiences with her in-laws after the birth of the disabled child. First of all, Mabel's mother-in-law was the first visitor to see the child's defect at the hospital. According to Mabel, the mother-in-law pushes the blame to her; having the disabled child could possibly be as a result of Mabel's association with disabled people. Mabel used to feel sorry for them and give them alms when she saw them begging by the roadside:

*However, after having this baby my mother-in-law advised that I should not give them any alms because that could birth be the reason why I have given birth to a child with a leg deformity.*

Mabel keeps coming back to her relation with the extended family. She even diverts to answer some of my questions to talk about her experiences with her in-laws. Thus, her experience with them is obviously at the heart of her story. At an early stage in the interview when I asked how she thinks people in the village perceive disabled people, Mabel limits my question to her experience with the in-laws and introduces her narrative:

*Well, in relation to my case, as I had this child, my husband's family members advised that the child be suffocated in water to die since no one has such child in the village*

This was a suggestion which she and her husband resisted. This suggestion has however resulted in a loss of confidence between her and the relatives of her husband. At this point in the interview, Mabel had already informed me that it happens that the elderly women who act as traditional midwives suffocate the newborns with defects to death in avoidance of the stigma attached. The only disabled child she had heard of in her village was told to have suffered from this treatment. This is the context of Mabel's experience as she came home with her baby:

*I was sleeping in the night and woke up and realized my baby was not there. I thus tried to search for my baby up till morning. By then my mother-in-law came with the baby explaining that they sent the baby to a herbalist who could possibly do something about the child's deformity*

After this, Mabel seems to increasingly perceive her in-laws as hostile and antagonistic to her:

*Hmm since the birth of this child my husband's family has been very cold towards me. Even now now they don't relate to me well.*

She told various stories which illuminated her perception of them as unfriendly. One such story takes place after her second child is born. This story also sheds some light on her relationship with her husband:

*When I became pregnant for the second time they predicted I would possibly have a similar child. They therefore advised him to divorce me but he refused and insisted on staying with me. We have been living together since.*

Another story is about how the child came to walk with clutches

*It was around the fourth year of the child that a missionary organization came to the village and decided to help us to have a surgery for the child which made it possible for her to walk with clutches. But earlier on she couldn't walk but crawled on the ground with both legs and hands. They saw her crawling on hands and legs, playing with the other children by the river. They therefore came home with her and told me that they can help to get the child operated on so that she can at least walk with clutches.*

This story however, also turns out to be focused on the in-laws as Mabel continues:

*When my husband's family members heard about this, they told them that I will run away and leave the child when we go to the place for the operation.*

Some aspects of what Mabel says during the interview raises, however, questions as to whether her understanding of her in-laws is in concordance with how they perceive and treat the child. This is the story she told when I asked whether she has had any problems with care of the child:

*Well the only major problem she has had was asthma but it's now okay. I think this was caused by one of my sisters-in-law. She had asthma and had also gotten a new baby. One time I left the baby in her care and on returning was told she breastfed my baby. It was after this incident that my baby started having asthmatic symptoms.*

One begins to wonder whether a disease such as asthma is transmittable through breastfeeding as Mabel seems to portray. My response to this was:

*Eei this is a bit strange for my hearing*

I think she thinks the sister-in-law purposely gave the baby asthma as is indicated in her next response:

*Yes. Everyone wondered why she did that.*

She seems to mistrust her in-laws to the extent that an act which could otherwise be interpreted as a sign of concern for a hungry baby, for her is a deliberate act of wickedness; to infect the disabled child with asthma.

Mabel continuously prevented the orderly flow of the interview by telling me what is most important in her experience. Even when I asked about community reactions to the birth of the child she still continues to talk about how badly she has been treated by her in-laws and what she had to do to end the hostility:

*In the beginning my mother-in-law and the rest of the family members attended to us but for just a short while. For most of the time they treated me very badly, which made me leave the house to stay with my mom in Togo because I didn't feel comfortable in the house. They were very cold to me because they had cautioned the man to divorce me, which he was not ready to do. He therefore asked that I come back from Togo but I told him to relocate from the family house, which he did.*

This explains why Mabel and her family were living farther away from the rest of the village.

True to Mabel's initial worries at the hospital, the birth of the disabled child was news for the village folks. People who came to visit at home were interested to see the child's deformity to the extent of taking off the covering from the child's legs. To Mabel, this was uncomfortable

and a sign that people came to pry rather than to greet the new baby. Community living was thus a challenge for Mabel. She narrates experiences of stigmatization in the community towards herself as well as the child. This has threatened her social life resulting in withdrawal:

*As it is, I know how the members of this community are, so I usually don't try to get so close to them. Because with the least thing people pick on me and assault me verbally. Because of this I try not to get too engaged with people*

The stigmatization is also something she wants to protect the child from:

*Of course there are some social activities I cannot avoid attending like funerals. However, I try to rush back home on attending these activities because I know she will definitely come there and its likely people might stigmatize her. In actual fact they do stigmatize her in such situations.*

The mistrust Mabel has of the husband's family members also seems to cross over to the community members. For example, despite the fact that she and the husband were living farther away from the rest of the community, she still feels insecure:

***How about your work, has the child's condition affected your work in anyway? To some extent. I have to make sure she goes to school before I leave the house to go to work. Moreover, I usually don't want to leave her alone by herself because I fear someone might do something to her. Something like what exactly?***

*Just anything. Because of the way the community is and the way some of them treat me I don't feel quite secure to leave her alone. Moreover, someone once hanged himself around this area so sometimes I fear.*

For Mabel, her personal life has changed after having the child: she is weakened by the occurrence and what she used to be in terms of her desires and social life:

*Hmm. Because of the child's condition I have lost interest in almost everything, fashion, engaging with friends in social activities among others. This is also because I don't have any much money for engaging in any such activities.*

Despite the challenges and the circumstances Mabel and her family finds themselves in, they seem to be coping well. For though Mabel throughout her story presented herself as a victim and as one who has been marginalized in the community, she also describe herself as emotionally sound at the time of the interview. This is not surprising because, in a setting where women who give birth to children with disabilities may end up losing their marriages or husbands, Mabel was lucky to have a supportive and loving husband that creates a comfort for her, consequently buffering the discomfort that arises from treatments from her husband's family and the rest of the community.

As regards the child's future, Mabel has fears both in the near and distant future. First, she envisages practical difficulties and challenges ahead for the child:

***How do you perceive living with the child in the future?***

*Well I begin to worry about her puberty years, I think about how she will manage with her menstrual periods. I sometimes feel that I will have to be helping her throughout this stage.*

Part of her fears is tied up with the problems existent in the community; an issue of sexual abuse:

*I also fear she might fall prey of sexual abuse which is very rampant in our village. Teenage pregnancy, it is one of the major problems in this village. You know, because there aren't any much jobs most families cannot meet their needs. Due to this, most of the young boys in this village have taken advantage of this and have been deceiving the young girls with the little moneys they get from selling farm produce.*

In addition, Mabel also worries about her daughter's future marriage. She wonders whether with such deformed legs any man will be interested in her daughter. This is ironic to the

above narrative; though there is a possibility of the young men being interested in abusing the disabled girl sexually, there is the fear of an impossibility of some man expressing interest to marry the disabled girl as young woman. This is clearly in line with the situation of disabled women, as I have observed, in Ghana. Notwithstanding, Mabel perceives a generally bright future for her child. This she thinks is guaranteed through good education, which they would ensure they provide for the child at all cost. At the same time, Mabel holds on to the hope that her child will one day be like other children.

*I sometimes wish she is like any other normal child. I therefore hope and trust that by God's grace she will one day go through an operation that will make her walk.*

#### **4.2.2 Doeyoo: 'I am managing'**

Doeyoo is 42 years and has three kids. The first is 15 and in secondary school. The second is 9 and the last, the disabled child, is 2 years and a couple of months. He is small for his age and looks like a year old. This baby was born with a lip and cleft defect. As a baby, he couldn't suck the breast. He thus had to live on formula. When I was with them, I observed that the child was sometimes in pain when eating. Due to this, he couldn't eat certain foods. To me, he didn't look very healthy in appearance and I noticed that he coughed very often. According to the mother, he used to have convulsion but is quite better now. The child seemed very attached to the mother. When I interacted with him and the mother, he did seem to understand what was said. He himself couldn't talk well though, but rather made sounds. In the everyday living, the child mainly interacts with his mother and siblings. He does not get too close to the other children in the village. The father of the child was not present as at the time of the study. I was informed he left and never came back after the child was born and named. He has therefore not been supportive in providing for the needs of the family. The

mother has been the main carer and provider for all her children since he left. Doeyoo does two different jobs to keep the family going. In the morning after the two other children have left for school, she goes to her farm to work, taking along the disabled child with her. In the afternoon she sells some of the produce by the main road to travelling vehicles. In addition to these two jobs, she also goes to the city during the weekends to buy things that are not available in the village and sells them to the village folks. All the efforts she makes to earn an income for the family made me see her as a very hard working woman.

Doeyoo and her children live in the centre of a village situated close to a larger town. Their house is just a single double room thatched house with a little shade extension, acting as the kitchen. On staying there, I realized that almost everyone in the village, from children to adults, could speak some amount of English. This created the impression in me that most people have had at least some education, though they were mainly into farming.

Unlike the other women in this study, Doeyoo gave birth at home and not in the hospital.

*I delivered at home and then called some of the elderly women to help bathe the baby.*

The elderly women who came to assist her made Doeyoo aware outright about the child's condition.

*After bathing the baby they informed that the child had a lip defect.*

Immediately, she became worried and begun to search for causes:

***Why were you worried?***

*Because I have given birth to other children who didn't have any defect and was worried why this child has. I had thought this could be as a result of an experience I had in the sixth month of pregnancy. I started feeling dizzy with stomach pains but it stopped after some days.*

Although she links up the cause of her son's condition to possible medical conditions, she also perceives the child's defect in the light of her belief system:

*I was very worried but I thought probably that is how God created him.*

In other words, anyone with a disability or defect was created as such by God. This means that it is natural that some people will be born with defects. As I was informed by the village secretary in Doeyoo's village, in the past having a disabled child is interpreted from within the spectacle of traditional religious beliefs. However, in current times things are changing due to the influence of Christianity and education.

Some of Doeyoo's concerns about the child's condition right after diagnosis were of a practical nature:

***What kind of things have you worried about since you first learned about the child's disability?***

*Well I was thinking about how he will be able to suck the breast.*

As we have seen, this worry was relevant as sucking was to become an actual problem. Some of her initial worries were also related to possible problems of a social nature:

*I was also worried about the fact that people might laugh at him with it when he grows.*

To Doeyoo herself, it posed a social challenge and discomfort to have and be with a different child. But she admits she has now overcome this challenge and has accepted the condition of the child:

***Has the child's disability affected you or any family member in a way?***

*Of course I was very worried about the child's lip when I had him and don't feel comfortable with him in any social gathering but now I'm okay because I'm not the only one in this situation. I have realized that it is a disease (defect) so I have accepted it as such.*

Though she did not actively inform members of the community about the condition of her child, the news reached them:

*They got to know but haven't reacted in any way to make me feel bad.*

Rather, they have supported her in several ways. For example, informatively:

*When I had the baby some community members who came to see the child advised that I can take the child to the biggest hospital in the city where the lips can be fixed.*

Doeyoo did follow this advice and even had an appointment at the hospital to have the corrective operation for her child. However, she missed out on the appointment because she did not have the necessary financial means to pay for the operation.

The community members have also supported Doeyoo Emotionally:

*Well, when I first had the baby those who heard came to encourage me and still encourages that I take it cool*

They are also supportive by helping in care giving:

***How about members in the community or neighborhood? They also help sometimes. In what way?***

*I can leave him with someone when I want to go somewhere*

Doeyoo's relation to her church has diminished since the birth of her child. According to her, she has not contacted them for help and thus they are not aware that she might be in need of financial or any other support.

Thus, unlike Mabel who had a tough time in her village, the story seems to be different for Doeyoo. She reports that community members have been supportive right from the birth of the child through to the time of the study. Doeyoo throughout her narration portrayed herself as an independent person who is in control of herself and her situation. She does not show very strong emotions attached to her discovery of the child's condition and seem to be coping well through strategies like faith in God and the engagement of her work routine.

But the story told by Doeyoo also has a different side to it. Throughout the interview, she expresses a strong yearning to get the lips of the child operated upon and this is a recurring theme. As the early visit to the hospital confirms, it would be possible to fix the lip and thus improve the health of the child. They even had an appointment and everything was set:

*They did all the diagnoses and made an appointment for us to come the next week with two million cedis.*

However, she seems to be helpless in that her financial means couldn't permit any surgery for the child. In terms of finance though, which happens to be her main challenge, no community member has contributed even though she portrays them as very helpful. Moreover, in such dire need to get the child's lip fixed, the question why Doeyoo does not request for help from her church arises.

***But are they aware that you have such a child and need financial support?***

*No I haven't told them or requested for help. Why? I just didn't want to.*

She does not want to ask her fellow church members for help or even inform them that she is in need of financial support. In contrast to this, throughout the interview, she kept requesting financial help from me to get his sons lip operated on. This makes me feel that the positive light in which the community was portrayed was not enough to justify the absence of feelings of stigma by Doeyoo in the community.

As regards her perceptions about the child's future, Doeyoo, like Mabel, believes education is the key to a successful future. Notwithstanding, most of the children of her little child's age in the village were in preschool, but he wasn't. It turned out that this is due to Doeyoo's fear of mockery of her son by other kids:

***How do you perceive the child in future? I feel that if I'm able to get him to school, he will be somebody in future. Why is he not in school since it matters to you? Well I want to handle***

*his problem first. Why can't you take him to school now? I fear that the other children might laugh at him or say abusive words directed towards his defect*

Doeyoo did not explicitly inform about her husband's reaction to the news of the child's condition. But deducing from what she told, the husband dissented her after the birth of the disabled child. This was confirmed by Doeyoo's brother whom I talked with. Currently, I have information that the husband wants to come back to her after having news that the child has gone through a corrective operation.

#### **4.2.3 Afia "and her mother"**

Afia is a 35 years old woman. She has two children, the first of which she had in a previous marriage. This child is now living with the father. The second is the disabled child who was born with a leg deformity and was about a year and a month old when I first met him. At the time of the study, this child hadn't walked yet though he tries to but couldn't due to pain in the leg. Afia sells local food in the evenings at the night market; this is her contribution to the livelihood of herself and that of the child. She told me that the reason why she wasn't doing any major paid work was because she needed to give her son extra care due to his condition. Afia lives with her sisters and mother in the same household. They are a major source of help for her in terms of taking care of her son both practically and economically. The family lives in the centre of town, just a little away from the main road. The house as I saw it seemed as if it will come down in the next moment. This part of town was almost the busiest since it was very close to the main road as well as the night market. Her mother sells soft drinks in the house. According to her, she has been supporting Afia and her child with the little earning from her trade.

The father of the child was not available during the time of the study. According to Afia, the father of this child couldn't get a job in the town so he had left. However, he does call to ask how the child is doing. Afia's mother confirmed that the father left after the birth of the child and therefore does not make any financial contribution.

The community where Afia and her family live seems to be such that everyone knows every other persons story. I suspected some of the neighbors wondered what exactly I was engaged with the family for. Much of Afia and her families narrations were centered on a quest for restoration of the child's leg through an operation. The nature of the leg problem is such that it can be corrected, but the treatment has been impeded by lack of funds. For example, in my conversations with the grandmother of the child, she informed that they have been striving to raise money to get the child's legs operated on but with no success. As she said, she has used much of the money she earns from her work to look after them after delivery. Hence, she does not have much to offer for the operation. In her words,

*Now the business is not doing well as it uses to be because of the financial hardship these days. Hence, I cannot earn as much as I should. If it had been in those days when business was good, I would have been able to bear the cost. This child's leg worries us a lot. When you go to the hospital they don't even look at your face if you don't have enough money to pay for the services.*

A younger sister of Afia also confirmed that they were all very worried about the child's leg and they are still worried now that they have not gotten the money to get the operation done.

I deduced from their interactions with me that they had expectations of some financial help from me, knowing I came from abroad to conduct the study.

Afia presented her pre-birth pregnancy experience as a time of difficulty both financially and emotionally: First, the pregnancy was unexpected. Furthermore, it came about during a time when neither she nor the father had financial preparedness to cater for the needs of a child. She felt these difficulties burdening to the extent that she considered abortion at the time. She made this evident when I asked about whether she anticipated that the child will have any defect:

*I wasn't thinking at all that he might have any problem of any kind. Never did I ever think of any such thing. What was most difficult for me was as regards preparations for the child since the father was not working. I nearly aborted the pregnancy but decided to just keep.*

Thus news of the child's defect seems to compound on her emotional state. This is her narration of the hospital experience. At the time she still had contact with her in-laws:

***How did you get to know about the Child's disability?***

*At the hospital, I wasn't told that the child had a defect immediately after birth. After the child had been dressed and brought to me, it was my sister-in-law on visit who realized that the child had a defect with the leg and told me about it. In fact it was very difficult for me on seeing the twisted leg so I immediately call one of the nurses in order to inquire about what happened to the child's leg. According to her this is how the leg of the child was from birth.*

In her description of her reactions on discovering the child's leg problem, we learn that even if the hospital staff had made note of the leg problem, they did not talk with Afia about it until her sister in-law noticed it. At this point, the nurses tried to comfort her:

***So as you just said you were not told at the child's entire defect?***

*Yes they didn't tell me anything about the child's leg. It was later that the midwife who helped with delivery came and advised that it is not any big problem but that we should not*

*try to do anything about it for now but send it to the St. Joseph's hospital where it could be cured. So I shouldn't cry. Moreover I'm not the first person to have been in such a situation.*

Like in the case of Mabel and Doeyoo, Afia intensely seeks to know the cause of the child's defect

*Immediately, I asked her what might have been the cause of this. As she said this could be caused by sometimes the child folding his legs in the womb and the like. She emphasized that this is why they usually advice the progressive scanning of the baby during pregnancy.*

Implicitly, the midwife seems to blame Afia for possibly skipping scanning of the baby. Afia herself seems to take on some level of responsibility as she continues by reflecting on how frequent she visited hospital during pregnancy and acknowledging that she didn't take enough scans:

*In my case I didn't do any scanning at the earlier stage of pregnancy because I started going to the hospital from the fifth month of pregnancy so I took only a single scan at the seventh month.*

On a general question about causes of disability early on in the interview, she had pronounced that she believes self induced abortions and lack of prenatal attendance and care can result in the birth of defective babies. Thus, asking several questions from the health professional about the causes of the defect, explicitly accepting some responsibility, her own believes about causes of having children with defects and the fact that she had earlier considered abortion together make me conclude she has a sense of guilt, a theme which was recurrent in her narration.

Aside this, Afia has intense feelings of shame about the child's defect and made efforts right away to resist the spread of the news in the community. This was evident in her narration about her reactions after the discovery:

*Eei it was not easy at all for me. When people come to visit I tell them the baby is asleep. I don't want them to see his legs. **Why?** Because I know they will go about telling people about his leg.*

This shameful feeling was so intense for Afia such that, to her, having stillbirth or having terminated the pregnancy would have been better as it seems less shameful as compared to having a child with a defect:

*In fact I thought it was better I have lost this child or better aborted it because I was very much bothered about how people will react. I use to ask myself a lot of questions.*

Her worries are directed to the future of the child and how he might not be similar to other children:

*What really bothered me so much was the fact that the child might not be able to wear shoes like other children or be able to walk.*

Just like Mabel, Afia's concerns are directed at practical aspects as well as towards the social challenges associated with the shortfall of normalcy. Specifically, she keeps coming back to the issue of the child not being able to wear shoes.

*Hmm it is not easy at all. Especially when I look at his legs and think about the fact that a baby of his kind cannot wear shoes. Moreover I kept thinking about why my child should have a defect and not as normal as other children. I was further thinking about what people would say.*

Afia continues by giving example of what the typical family reactions might be; implicitly searching for causes from the other spouse's family:

*... For example in such a situation family members of the man might question the father of the child, claiming that such a defective child has never been born in the family.*

This may lead to distancing which happened in her case:

*In my case, my husband's family members came to visit for some time. They however stopped coming when they detected the child's defect.*

Afia's in-laws seem to implicitly blame her family for the child's condition, and possibly try to avoid being associated with the defect by avoiding further visits to the child. Similarly troubled Afia's mother was looking for possible causes of the child's condition from the husband's family:

*For my mum it was difficult for her to take. She keep emphasizing and complaining about why I have given birth to such a child, whilst no one has ever had such in the entire family. She keeps wondering whether the father of the child had done something evil.*

In this case, we specifically see the idea pronounced that a problem in the child can occur as a result of evil deeds in the parent.

Afia's numerous use of phrases such as "it is not easy at all", "it was not easy at all", throughout the interview, as well as her financial challenge, makes me see her as one in distress. This emotional distress is compounded on by her mother's complaints:

*My mum as usual makes me cry so much because anytime she is bathing the child she keeps talking about her disappointment. This makes it very difficult for me.*

At the time of the interview, I did not take the opportunity to ask Afia about what exactly her mum's disappointment was about. However, in an informal conversation, a community member, who happened to be a friend to Afia's mother, told me something to shed some light on this. According to this woman, there is some tension between Afia and her mother about Afia's previous husband. He had wanted to come back to her, but she refused him and instead, got herself engaged with the man who later became the father of the little boy with

the leg problem. This relationship was not supported by Afia's mother. Thus Afia's mother's disappointment could well be understood in light of this story: "you (Afia) chose to be with this man instead of your previous husband. Look at what you have ended up with". This also, to some extent, could make understandable Afia's subtle feelings of guilt as regards the child's condition.

Although Afia tried to avoid the spread of the news about her child's leg, it was heard of by the community members and became the talk of town, an occurrence that she was disturbed about:

*For other people it's been gossips about me and the child that ways me down*

To be able to cope with life with the child as well as live peacefully in the community, Afia describes herself as staying low and minimizing social activities:

*Staying away from too much social interaction has also helped in staying with the child. I don't try to do things that will elicit any abuses from people. I usually don't go to social gatherings like church and the like. I sometimes go out but try not to mingle.*

***Why don't you feel free to go out and mingle?***

*Of course because of what people will say, how they will look at you and the like.*

Afia continued her narrative about community living by citing another example of stigmatization in the community, showing that even minors could directly be stigmatized:

*As I have said, I usually don't mingle with a lot of people but there is one child in this neighborhood who I feel is badly treated by neighbors. People use to insult her with the least thing she does using abusive words that described her deformity. Sometimes she might just be crying...sometimes she might just be crying.*

After making the last statement "Sometimes she might just be crying...sometimes she might just be crying" in a slow and low tone, I realized, at this point in the interview, that Afia was

getting emotional and sad about the described situation. To admit, I myself was imparted upon by this information but had to hold myself together and balance my emotional reaction. Episodes like this may explain why she worries about how her son will be treated by local people in the future.

Running through Afias story is the notion that the leg problem of her son could be treated if the family had the necessary financial means. Like in Doeyoo's case, Afia could have asked for financial assistance from her church or from a social group of which she is a member but declined from taking this opportunity. The reason, she expresses, is her feelings of shame which made her withdraw socially:

*I'm a member of a religious as well as a social group. But the fact of the matter is that I feel very ashamed to approach them with request for help in this situation. I feel my child's condition would be talk of the group. Meanwhile it could be likely they might not help too. Usually however they use to help members when they have a problem. But I didn't feel okay telling them about my Child's impairment. I even stopped going for meetings and also stopped going to church.*

The feelings of shame even made her explicitly refuse to accept help from the congregation

*Of course when my pastor got to know about the child's condition, he decided to inform the entire church in order to get members to contribute money for me. However, I disapproved of this because I didn't want so many people to know about the Child's condition.*

Although she has not set her hope for the restoration of the child's leg totally aside, Afia also takes inspiration from the successes of other disabled people and strongly envisages a bright future for her son:

*I see him as a very intelligent child and if am able to accept him as he is and support him he will become self sufficient and independent and a responsible person in society. I don't want*

*him to be like those disabled people who beg on the streets. I remember this documentary that was usually shown about disabled persons on television sometime ago. There was one which I remember very much involving a lady who had no hands and but had legs which she used to do a whole lot of things; she could weave with the legs, sew clothes, cook, bathe her baby among others. She was totally independent. Her case is more serious than that of my son. I therefore believe my son can be independent.*

From what she says, we see that she is aware that a lot depends on her own ability to accept the child as he is. With regard to her own ability to face the situation she looks to other mothers with disabled children:

*But then I use to encourage myself with the case of the lady I told you about whose child has a worse condition. If she has been able to come out after months of staying indoors, then I should be able to go out confidently with my child.*

However, her optimism about her son's future is not without limits. This make, to some extent, Afia's thought about her son's future seem inconclusive; she still worries about the son's disability and the possibility of him not attaining physical normalcy, which she so much desires for him.

*Well I will say that I am not very happy especially when I think about the fact that he should be walking whilst he is not. I really worry about his walking and this makes me think a lot because I can see that he wants to walk but feels pain in the leg any time he tries to step on it. I sometimes also encourage myself with the fact that there are a lot of disabled people who are living independently and have made impact in society. then it is therefore likely that he will grow to become a responsible and profitable person. However, I still feel sad about the fact that he might not be able to walk.*

Afia describes her own experience as a transformational one; her thought about disability has changed:

*When I was younger, we used to laugh at and mock people with defects and disabilities. We thought they were less human. However, after having this child I have got to know that that is not the case.*

#### **4.2.4 Sara: Spousal conflict**

Sara is a 30 year old woman living with her husband and a 9 months old blind daughter. She used to work but is now home taking care of the child. Her husband is a business man. Her daughter was her first and only child but the man as I was told by a community member has had other children from a previous marriage. Their child was born without eye balls which rendered her blind.

I was introduced to Sara and her family by Afia, who beforehand gave me a lot of information about them. Afia told me that Sara stayed indoors for months after giving birth to her daughter, grieving about her condition. Eventually, after months of grieving she was able to come out and live normally. Because of this Afia considers Sara as her heroine. My first meeting with Sara and her family was in her husband's own house. However, on the next meeting with the family, I was told she had left the house and gone to her father's house. This relocation was due to some misunderstandings between her and the husband. Hence, I couldn't interview both spouses together. Subsequent meetings with her were in her father's house, which was not too far from the husband's house. Sara's father was quite suspicious of me and asked several questions to verify who I was. I suspected this possibly had to do with me being introduced to him by Sara's husband. The tense nature of the relationship between the families may have made Sara's father suspicious of me.

Though my main informant was Sara as the primary caregiver of the child, I also had informal conversations with her husband. In my conversation with him, he confirmed that

they have marital problems. Furthermore, he felt Sara's family members threatened the marriage.

This tension between the two families turned out to be a recurrent theme. As we have seen in the stories of the other women as well, the in-laws tend to distance themselves from the misfortune of having a disabled child in the family:

*When I had her I was very worried with the fact that my husband and his family members didn't come to visit at the initial stages.*

Much of her narration was mainly about her husband's change of behavior and maltreatment of her.

*Since I had this child this, man hasn't been happy. With the least thing he picks a quarrel. That is why I often stay in my father's house.*

In my informal conversations with her before the main interview, she made clear that he does not allow his friends to visit him at home any longer. To her, his behavior even deters close neighbours who are willing to help her in care giving. Even her family was barred from staying close.

*My husband doesn't allow anyone to come home especially my family members though they wish to come. That is why I feel comfortable staying in my father's house very often.*

In my conversations with the husband, he also confirmed that the child's condition has been a challenge for him and the wife. His point was that he tries to make sure the child is fine and that nothing happens to her. As he explained, the quarrel that led to Sara leaving the house was because he had questioned her about been informed by a neighbor that she went out with the child in the rain without an umbrella.

According to Sara, her husband's involvement in care giving is minimal; even when he helps it is done in pretence of what he usually does:

*Well he helps sometimes. In most cases, however, he does so when visitors are around. Sometimes the child would be crying but he will not make any effort to attend to her*

Sara, like the other three mothers in the study, discovered her daughter's disability with shock. Like the other two who gave birth at the hospital, she was not immediately told about the child's condition:

*When I had the child at the hospital I wasn't told immediately when the baby was brought to me. I thought she was asleep but I realized she has closed the eyes too tightly when I was feeding her. That was when I called one of the nurses who told me that my daughter was blind but didn't tell me immediately because they felt I would be worried.*

Though Sara did not explicitly vibrantly look out for causes of the child's defect at the time, she implicitly looked for causes by comparing her state to her sisters who have succeeded in having 'defectless' babies:

***So what was your reaction at the time?** My sister, I cried because we are three sisters in the house. None has had any such child. Why should I be the one to have such?*

She also reflects on a dream she had before birth which could be interpreted to have some relation with her child's blindness. However, she did not pay much attention to the dream at the time. The reason why she had "overlooked" the dream was that her main worry was the desire to have a normal birth. Worries about the baby were not necessary because

*I have no expectations of having a blind child because I did a couple of scanning but I was not told of any defect detected.*

With regard to the causes of disability, Sara says that

*For most people they think it is because of something bad a parent might have done. Sometimes too I think it is due to illness of the mother during pregnancy.*

Sara's grief about the discovery was still persistent at the time of the interview. The grief is not related solely to the condition of her child but to her husband's maltreatment and abuse of her after having the child. We can see that his maltreatment is related to explanations of the child's condition:

*Even now I cry a lot because of how my husband treats me. My husband use to insult me that it is my fault that the child had such a problem. He even uses to tell me that I am a prostitute and this is what I get as punishment.*

It is also striking how the husband put forward his accusations in public:

*Sometimes he would stand outside and rain abusive words at me to the extent that the neighbors, passersby as well as workers at the lorry station would be looking at me. It makes me feel so ashamed that I usually leave and go and stay with my family for some time.*

Through these difficulties, Sara has been sustained by her family who were positive about the child's disability;

*For them they have been very supportive and encouraged me to accept the child as she is since all children are a gift from God. Sometimes I can cry to the extent that I forget I have to feed the baby. They have been the ones who have helped me in this situation. The main person has been my dad. My brothers also come for the child and play with her at times when I'm very down.*

Also, it is not all too bad on the husband's side. Sara does not hesitate to confirm that he has taken his responsibility by providing the child's needs:

*Financially, my husband has been quite supportive I have to admit.*

In my conversations with the husband, he told me that he usually feel reluctant to give the wife money because she doesn't do anything for him since she is almost all the time in her father's house. But he does try to provide money for the upkeep of the child. As he said, he is usually very busy with his work so he mainly makes sure he provides money for the care of

the child. According to him, they have tried several avenues, trying to get the child's eyes restored. In all these, he has been able to provide the money involved. This was confirmed by the mother.

Sara's narrative as regards community living seems ambiguous. She narrates experiences that can be interpreted as mockery by community members:

*In this community, they know very well that I have a blind child but when they see her tied at the back they keep asking whether I'm aware the child is asleep.*

At the same time, they are a source of consolation some times:

*Sometimes too they come and encourage me when they see how my husband uses to abuse me in public.*

The ambiguity is even made clear when I inquired whether she has experienced any discriminating attitudes by community members:

*No. I can go anywhere in the community. Just that usually people will be looking at you here and there. Some can even go to the extent of calling me to come so that they look at the child since they have heard there is a problem with the child. They make very many other comments that embarrass me. Because of this, I stay at home very often, or get a taxi to where ever I go. We don't even go anywhere much. Maybe going to the postnatal health center or the like.*

In addition, Sara was so down that she lost interest in any much social interactions:

*I just felt like staying more at home. I had no desire of mingling with friends here and there.*

Though Sara described herself as a spiritual person, which among other things have been a way of coping, it is interesting that like the other mothers, Sara's lost interest in social interactions even included a cessation of going to church, :

*Are you a member of a religious or social group?*

*Yes. But when I gave birth I stopped going to church but our pastor came home to encourage me. Other members of the church also do same.*

Keeping faith in God for a miracle, Sara believes and hopes that her child's sight will be restored, against the medical proof she is presented with by the health professionals:

*I use to take her to the hospital for review but they never tell me anything positive. They keep telling me that there is nothing that can be done about the eyes of the child because there are no eyeballs in the eyes. As they say, it's supposed to develop during pregnancy hence it's too late. But I tell them that I have been praying, hoping that God can help my child's eye open. When I say this they insist that there is nothing that any pastor or church can do about it. These are too discouraging for me so I have stopped going to the hospital.*

Though Sara keeps her hope for the restoration of her daughter's sight, she does not necessarily see her successful future tied up to her sight. She thus has plans through education to ensure a bright future:

*I learnt there is a school for the blind. I will therefore take her there when she is a bit grown. I learnt they look after the children very well.*

At the time of the study, Sara's daughter unlike other children of her age was not crawling, being a source of bother to her. Notwithstanding, Sara has seen a realistic light of hope about her daughter's sight, consequently bringing some delight in her:

*It has bothered me quite much. Just that I'm getting encouraged now because I suspect she is improving. At first you cannot see the white part of the eyes. However, now I can see the white part of it and a little of the black part.*

## **5 DISCUSSION: PULLING THE THREADS TOGETHER**

The aim of this study was to delve into the experiences of families with disabled children in order to bring to light what it means to have and live with the disabled child in a Ghanaian context, and also to establish an understanding about such an experience. The sub aims were to answer the following questions; what are the perceptions held by parents of disabled children as regards disability? What kind of challenges do they face? How are they coping? What is their outlook in terms of living with the child in future? This discussion is thus put forward in light of these questions and at the same time bringing out the main themes recurrent in the study.

### **5.1 CULTURAL UNDERSTANDINGS OF DISABILITY**

In this study, in all the cases, the birth of the disabled child is related to disruptions in the family and disturbances in the relationship between the family and the local community context. In the first place, it could be seen that though the birth of a child in the Ghanaian setting is typically a joyful experience for the whole family, the birth of these children were not celebrated. This is basically because they had some defects and disabilities. Secondly, the births affected both family structure and some aspects of functioning in the form of a strain on interrelationships between and among family members. Doeyoo's husband left, Afia's husband was told to have left the village though Afia herself did not say whether it was mainly because of the child's disability, Sara's story is characterized by tension between her and her husband, as well as between him and her family. Though Mabel enjoys much support and warmth from her husband, her relationship with her in-laws cannot be described as cordial. These reactions by family members as well as the mothers themselves could be

explained in view of the cultural belief system about disability in Ghana. These mothers and the other members of their families and those of their in-laws as well are feeling the courtesy stigma strongly. As it seems, the cause of the disability of the child is a question of the deeds of the parents and of the goodness and cleanness of their bloodline, both biologically and morally. This seems to be the main issue disturbing the family members within the context of their local communities. Sara implicitly declared how good her blood was and thus does in no way deserve to have a disabled child by comparing herself to her three sisters who have not had any defective babies. This then leads to an inference that she thinks the fault could have been from her husband's family. Her husband's behavior could also be interpreted as a response to the felt stigma of having the disabled child. Sara's information of a blind person in her husband's family could underlie the reason why he seems to be frustrated and rather vividly blames her for the child's defect which he claims is caused by her morally questionable behavior. In the case of Mabel, her in-laws predicted the chances of her having another disabled child and suggest her husband divorces her. Furthermore the mother-in-law suggested the disability could be a result of Mabel interacting with disabled people. This implies that the fault lies with her and not in their blood line. Afia's in-laws did not visit again after learning about the condition of the child. Her own mother was questioning the cause of the child's defect and seemingly struggling with thoughts about whether to blame the father of the child or her own daughter. Doeyoo seems to take on the responsibility herself for the situation of her baby and can be interpreted as being shameful and self blaming. She does not in any way blame her in-laws or community members, although she hesitates to ask for help and does fear that her child may suffer harassment from other children. Overall, the mothers seem to suffer more of the blame compared to the fathers. Sara felt her husband was full of blame and abusive toward her, Mabel's in-laws advised her husband to divorce her, Doeyoo's husband left her, and Afia's in-laws distanced themselves

after discovering the child's disability. Afia's husband was not present but this cannot necessarily be linked to the birth of the child, though Afia's mother made claims that this was the case. This may reflect the specific belief in the local area; that the mother, being the carrier of the child, is to blame when there is a problem with the child. Notwithstanding (and contrary to the tendency among the fathers), these mothers did not neglect their children, the source of their woes, in any way.

As can be seen, families perceive disability not far from the cultural interpretations of disability in the Ghanaian context as reported by other researchers (Avoke, 2002; Kassah, 1998); as a punishment of evil deed by a family member, in this case by the parents themselves. This was also evident in the mother's narratives about the other family members who were looking for the causes of disability. This study nevertheless reveals that these mothers also have some knowledge about the medical roots of disability. Afia gave examples of attempted abortions, Sara also made mention of inadequate prenatal care, Doeyoo relates the cause of disability of the child to an illness during pregnancy. However; they were all not able to overpower the cultural aspects about disability resulting in their intense initial emotional reactions and search for causes. Ideas of biological causes may also be merged with ideas of divine and other supernatural causes. This clearly shows the power of cultural definitions of disability which has been emphasized by Thomas (2002).

## 5.2 (COMMUNITY LIVING)- STIGMATIZATION AND OSTRACISM

As is evident in this study, the news of the birth of the disabled children is big news in the entirety of the various communities to the extent that visitors to the new baby seem to confirm the misfortune rather than to greet the new baby. For example, in Mabel's narration,

community members who came to visit the child, as is usually done, went as far as removing the covering from the child's deformed leg to confirm the heard news.

These attitudes of community members seem to be more intense than might be the case in the western cultures. This is because not only are the disabled families branded by society as different or possessing spoilt identity (Goffman, 1963), but they are also seen as guilty for something evil done by themselves or by a member of their family. Thus the experience of disability in a family is not just a deviation from the norm but also a shameful occurrence. This also explains the intra and inter-family stigmatization that characterized the family experience.

Consequently, the mothers may see no other choice but to isolate themselves from social activities within the community. Mabel tries not to engage with people because she will possibly be assaulted with the least provocation. There is also the need to minimize attendance of social gatherings to avoid stigmatization of the child who would follow her to such gatherings. For Sara, embarrassing comments by community members as well as the fact that her and her child's presence attracts attention makes her stay home often or even pick a taxi wherever they go. Afia has also stopped going to church and avoided social interactions and even if she does go out, tries not to mingle because of people's reactions: these were means of coping for these mothers. However, this way of isolation seems to be socially imposed.

Generally, the problematic nature of the cultural belief system to disability has been far more magnified than tackled; it stands tall in the hierarchy of the challenges faced by persons with disabilities. One way to start tackling it could be for Organizations of persons with disabilities to educate communities and society in general, for example, by providing education on the causes of disability through the media, as well as making efforts to challenge negative presentations of persons with disabilities in the media.

### 5.3 COPING

The stigma management techniques identified by Goffman (1963) are evident in these stories. The strategies of passing, where effort is made to control information about the stigmatic condition, as well as covering and withdrawal, were all utilized by these mothers and also by the other members of the family. All the families were aiming towards eliminating the stigmatic condition of their child. Mabel gave example of covering the child's legs to avoid visitors from seeing. Sara and Afia talks about avoiding much social activities to avoid stigmatizations.

On the broader family level, Mabel's case shows a negative coping effort by some family members which was shocking to me as a young researcher; the effort to eliminate not the stigmatic condition but the stigmatic being or carrier. By this, I mean the suggestions by Mabel's in-laws to get the child killed. This, Mabel informs, has been practiced in the village. The general literature shows that this act of infanticide used to happen in years past. However, this study has revealed that this act is still persistent in a region that is a few kilometers from the capital city which houses the seat of government. But Mabel and her husband did well by challenging this traditional way of coping effort in the village. This highlights on their joint and personal resources in coping; in this sense their strength for resisting a negative societal norm.

Generally, these parents draw on various strategies and resources to cope with their situation. One resource among them is the visibility of other disabled persons and their families. Afia clearly takes immense inspiration from Sara who she declares as her heroine for having been able to cope. They both narrated stories which highlighted the success of other disabled persons who are independent. This aggravates their hope for a successful future for their disabled children. This draws attention to the need for disabled persons to be made visible in society and thus challenges the typical practice of hiding or even eliminating them at birth.

Despite the family commotion evidenced in the narratives, for all the mothers, practical and emotional support from the other members of the family has helped them cope with the child.

#### 5.4 STRUCTURAL CONDITIONS

In the introductory part, we saw that the social model of disability focuses on the shortfall in environmental and political structures. In Ghana, some organizations such as the Ghana Federation of the Disabled, are working within this frame of reference in different sectors of society to ensure the relatively newfound rights of persons with disabilities.

The mothers' narratives show lot of deficiencies in the delivery of public services as well as an unavailability of them. With the exception of Doeyoo, all the three mothers had their babies at the hospital. As is supposed to be the case, all things being equal, the hospital is supposed to be the first agency to implement some immediate intervention mechanism in such a situation (birth of a disabled child). But as the narratives portray, the case was different for these mothers. All the three mothers were not told about the defects of their children. Interestingly in contrast, in the case of Doeyoo, she was informed by the traditional midwives immediately after the birth of the child. This somehow raises questions about how health professionals manage information in such situations. Of course it may usually be difficult to break the news of a disability of a child to parents. For example, in the case of Sara, the nurse actually told her they did not tell her immediately because she will be worried. However, literature has supported the fact that the way professionals inform parents about a child's disability has a tendency to influence their responses, reactions and coping (Gordon, 2007). Secondly, these mothers were not given much guidance and follow ups as regards how to manage with the child. In the cases when they were given guidance with regard to the

treatment of their child's condition, they were not able to benefit from it. This raises questions about the relationship between professionals and parents in such situations.

For Sara, she feels discouraged by the blatant claim by the health workers about the impossibility of a cure for her child and consequently had to stop going to the hospital. As Afia's mother informed, without one having the financial means for medical care or treatment it becomes difficult to be attended to at the hospital. For this reason they are still struggling to get the means to get the child's leg corrected. This further explains Doeyoo's situation: she was asked to pay an amount for the operation of the child's lips but couldn't raise the money and thus couldn't get the child's lip restored. As it seems, the hospitals these mothers attended had no resources to take care of the costs of the medical services they needed for their disabled children, of course the National Health Insurance Scheme only caters for minor diseases (Slikker, 2009; Ghana Federation of the Disabled, 2008). But was this actually the case? My interest and worry about Doeyoo's situation made me inquire a little bit more at the plastic surgery department of the biggest hospital in the capital city where Doeyoo was suppose to have the surgery for her child. In my talk with one of the doctors, he admitted that it is expected that parents pay for services for their wards at the department. However, he also made me aware that the department has sponsors which support their operations. Hence, in circumstances where parents cannot afford the cost of medical services, they are supported by the sponsoring unit of the department. But Doeyoo seemed not to be aware of this. I then began to reflect on the fact that there could be opportunities for these families to have their children treated, however they seem not to be aware of them, which again challenges the information giving efforts of some of the medical institutions.

Generally being residents of a rural district which was already poor, the economic difficulties of these families seemed to be overwhelming. I base this conclusion on my observations and as evidenced in their narratives. This was in line with the literature which confirms economic

difficulties in families with disabled children as well as the general information gotten from the various institutions visited. Not only were they having difficulties in getting the financial means to get their child's defects corrected, the demands of care also to some extent affected the family income in general. Doeyoo had three children to cater for single handedly in addition to the extra costs of taking care of the disabled child. Afia informs she is not doing any major work in order to make time for maximum care giving of the child. Mabel also gives the impression that they still lack resources to provide for the child's needs like clutches and the special shoes. She thus has to work in combination to being the main caregiver her children. This makes me look beyond the resources at the hospitals and to review other possible avenues that could be of help to these families. In Norway where I'm studying, for example, the social welfare system is well structured and situations such as those of these families are easily catered for. But unfortunately as the deputy director of the department of social welfare informed, there are no functioning laid down provisions in terms of finance to support families with disabled children in particular though much is being done to improve the living conditions of persons with disabilities.

As far as I know, it is therefore usual that these families draw financial and other supports from within the family resources, private organizations like NGO'S and religious groups. In Mabel's case they earlier on got help from a missionary organization which helped them with the first operation of the child which has made her able to walk with the help of clutches. But as the stories of Afia and Doeyoo show, the feelings of stigma might not permit some of these families to explore some of these avenues. Afia also had the opportunity by her pastor who offered to make efforts to get funds raised for her but rejected it. Doeyoo also decided not to ask for help from her local church. But then they were implicitly and explicitly asking me for financial help to get their children's defects corrected.

In Afia and Doeyoo's case, I believe it could be possible that they did not feel comfortable asking or accepting help from the local church because these churches were made up of community members, 'the stigmatizers'. Thus making their plight known to them is a way of doing everything but giving out information about the stigmatic condition which they rather want to control or avoid. A local church or social group is made up of natives of the village. On the other hand, a missionary organization is usually made up of foreigners. This makes me understand why they felt comfortable asking for help from me; I am not a known member of the community.

Parent support groups are usually helpful for families with disabled children (Wolraich, 2003). The case of Afia and Sara shows an attempt to connect. Afia sees Sara as her friend and thus draws some inspiration from her coping strength. She considers Sara her heroine. This points to the need to establish ways through which parents and caregivers of disabled children could connect. As the administrative secretary at the Ghana Federation of the Disabled informed, there is basically one parent support group for parents of children with intellectual disability. After doing this study, I feel confident that it was in the right place that I suggested such an organization should be established all across the country, involving parents of children with all types of disabilities. This study supports the fact that such organizations are needed even more in the rural areas since the intensity of cultural beliefs, which worsen the experiences of families with disabled children is high in the rural areas. If the mere sight or knowledge of other families with disabled children boosts morale for coping as these mothers admitted, then it will be much more beneficial when they are connected to these other families and sharing their experiences together.

In their narratives about the future of their children, all the mothers strongly believed despite their fears about the reaching of developmental milestones and health challenges of the children they could be independent and successful people in the future if only they could

afford to get them educated. In a setting where there are just a few specialized schools for children with disabilities. These mothers' desires could materialize if there are available specialized schools for children with disabilities or mainstream schools which are equipped to accommodate them. I wish to commend the government for the institution of free education for disabled children and the efforts by the ministry of education in their attempts to implement the inclusive education policy. But then there is still more to be done in terms of educating disabled children. There is the need to equip the resources of regular schools to make them accommodating for these children. Doeyoo informs she wants to get her child's lip fixed before sending him to school since she fears he will be stigmatized by the other children at school, should he be in school with the defect unfixed. This implies a possibility that parents' fears of stigmatization of their disabled children at school could possibly prevent them from sending these children to school. Efforts need to be given to the socialization of children at school to respect their disabled counterparts.

Moreover, three of the disabled children in this study were preschoolers and were all under the care of their mothers. I strongly believe that if there are preschools that could accommodate these children, the mothers could enroll their children and have some time from care giving. In my readings on the educational policies and national agenda for special needs education, I realized there is no clear cut information on the provision of preschool for preschoolers with disabilities. The emphasis is on school going children. I thus wish to use this medium to draw the attention of the ministry of Education to this need.

As can be seen, the mothers draw a lot of support practically like care giving of the child, in some of the cases, financially and emotionally from within the family system despite the chaos. This highlights the position of the family as the primary welfare system in Ghana. In their work within the frames of the social model, it becomes necessary that disability organizations give attention to the empowerment of families of persons with disabilities

through education, especially families with disabled children. As the administrative director of the Ghana Federation of the Disabled himself admitted, very little attention has been given to disabled children and their families though they are vibrant working to improve the living standards of persons with disabilities. I further wish to emphasize that the difficulties and challenges these families face go a long way to affect the wellbeing of these children. In order to adequately give attention to disabled children, it becomes necessary to work with families.

### 5.5 LIMITATIONS OF THE STUDY

Translation of data undoubtedly poses a threat to trustworthiness since there is the possibility of losing the exact meanings of some expressions. In this study, there was a similar challenge. There were no exact equivalent meanings for some of the local language expressions in the English language and vice versa. Thus there was no choice than to use near meanings. For example there was no local word that fits the definition of disability. Thus in this study the near word that could be used was impairment. Notwithstanding, I made extreme efforts to use the words and expressions that are most nearest to their translated counterparts.

Though the study context can be described as rural, it can be argued as not being a typical rural setting due to its proximity to the capital city. Maybe a study of similar nature could be done in a typical rural setting farther away from the Greater Accra Region where the cultural belief system could be thicker.

Generalizability of this study is limited due to the limited number of participants. The views of these mothers and the situation of their families might not be representative of the other

families of disabled children in the whole of the district or even in similar rural contexts country wide. Notwithstanding, this study shows a probable situation of the study context and it can be a guide for future research in similar domain and context.

## 6 CONCLUSION

### 6.1 CONCLUDING REMARKS

Using the data collection methods of open ended semi-structured interviews, informal conversations and participant observation has undoubtedly yielded a rich source of data, which subjected to narrative analysis has brought to the fore some understanding of what having and living with a disabled child could possibly be for a family living in a rural setting as that of this study in Ghana.

As the findings show, the families faced various challenges within the family frame, in the community as well as in the context of institutions in the form of strain on family relationships, stigma, financial strain, and lack of early intervention mechanisms at the hospital level and on the societal level. This clearly implies that it is not the presence of the disabled child that strain families but the strain is a result of several factors, that is, the way families react individually and collectively to the situation, community responses, as well as the nature of the resourcefulness of societal institutions to squarely support the situation. Thus the issues of concern for these mothers and their families are entrenched in both the cultural and structural dimensions of experiencing disability in the family. The call then is to the cooperate bodies concerned such as the National Council on Disability, nongovernmental organizations, the Department of Social Welfare, and the Ministry of Education to work together and first structure a frame for early intervention for disabled children and their families, spelling out provisions for their health and educational needs, and general wellbeing.

## 6.2 SUMMARY OF KEY RECOMMENDATIONS:

- I. Availability of early intervention structures and support
- II. Availability of adequate pre-schools and schools that can accommodate disabled children
- III. Availability of respite care for families with disabled children
- IV Availability of parent support groups across country and in localities, especially in rural communities
- IV. Education of society on causes of disability through the mass media.

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## APPENDICES:

### APPENDIX A: SEMI-STRUCTURED INTERVIEW GUIDE

#### 1) PERCEPTIONS ABOUT DISABILITY

##### A. The meaning of disability

- How do you understand disability (before identifying the child's disability)?
- What do you think are the causes of disability?

##### B.

- Did you know any disabled people, children with disabilities and their families?
- What did you think about them?
- Do you remember the kind of things you were thinking about before having this child? Did you ever think that he might have a problem of any kind?

#### 2) KNOWING ABOUT THE DISABILITY

- How did you get to know about the child's disability?
- What was your reaction?
- How did you feel this way?
- Why did you feel or react the way you did?
- What kind of things have you worried about since you first learned about the child's disability?
- Did you tell any family members, friends, or any significant people around you about the child's condition?

- What were their reactions to the news?
- What were their reactions towards the child?
- How did you feel about their reactions?
- Why did you feel this way?

### 3) LIVING WITH THE CHILD

#### A. Caring For the Child

- Are you the main caregiver of the child
- Do other family members or friends help in care giving?

Have you had any problems with the child- sleeping, feeding, handling or other areas of care?

- What are the things you needed and still need for the child?

#### B. Support Systems

##### Informal support:

- Do family members or friends live around? Do they help in anyway; care giving, financially, emotionally etc.?
- Are you a member of any religious or social group? How have they helped or contributed?

##### Formal Support:

- Do you have any professional support, eg. from medical workers, social workers etc.?
- How would you evaluate their support and services?

#### C. Living in the Community

- What have been the reactions of members in the community or neighbourhood?
- Have you experienced any form of discrimination in your community or in the wider society?

#### D. Impact Of Child's Disability

- Has the child's disability affected you or any family member in anyway? Emotionally, socially, behaviourally, and economically etc (feelings, social life, interpretations of the meaning of disability, employment and income, personal wellbeing; personal growth or deterioration)
- How would you evaluate these effects? Are they positive or negative?

Have you encountered any other challenges or problems as a result of the child's disability that you would want to talk about?

#### 4) COPING WITH LIFE WITH THE DISABLED CHILD

- How are you coping? What ways have you employed that has made it possible to live and take care of the child with the child?
- What resources help you to cope? What available things have contributed in making it possible for you to live with the disabled child?

#### 5) THOUGHT ABOUT LIFE IN THE FUTURE

- How do you perceive living with the disabled child in the future?
- Do you think the child would have an independent life as he grows and

become a responsible and self sufficient adult?

- What plans do you have to make this possible? Have you implemented these plans? If not, why? Do you need some resources to implement these plans? What are they? How do you think you can get these resources?

#### 6) FINAL REMARKS

- Do you have any other thing to add that have not been asked?
- What recommendations will you make to other families with disabled children?
- Do you have any other thing to tell society in general about disability?

Thanks for your time and participation.

## APPENDIX B: CONSENT FORM

## NORWEGIAN UNIVERSITY OF SCIENCE AND TECHNOLOGY

## INFORMED CONSENT STATEMENT

**Living with a Disabled Child: Experiences of Families with Disabled children**

## General Information about the Study

I'm a master's student from NTNU and about to begin my master's thesis project which is about how families with disabled children cope with the challenges associated with having a disabled child. In this study, I intend to explore what kind of challenges these families face in all spheres of their daily living since the onset of the child's disability and how they are coping. This study has been necessitated as a result of numerous findings evidencing the fact that families with disabled children usually experience diverse challenges than those with "normal" children.

## Procedures for the Study

I will employ two main methods, i.e. an interview, which will follow a period of participant observation. By this, I will stay around for some time and observe your daily experiences through participation in your daily activities. The interview will be recorded to help me save the information for the writing of the master's thesis. Data will be digitally recorded and saved on my computer locked with a password. All these will be done with the help of a research assistant.

### Anonymity and Confidentiality

I wish to assure that all information given in this study will not be revealed to a third party. Moreover; your names will not be used in the analysis of the data and the research report. Secondly, any information that can reveal your identity in terms of location will be avoided.

### Freedom of Withdrawal

I also assure you that your consent to participate is not fixed; you are free to withdraw at any time of the study. This could follow any feelings of discomfort in the course of the study.

### Benefit of study

Since there is not much documented information on families with disabled children in Ghana, any family with a disabled child who participates in this study contributes in bringing to light the nature of the experiences of families with disabled children in Ghana. Also, since findings of this study will be disseminated to reach such organizations and institutions as, NGO'S (eg. Save the children, Norway), Ghana Federation of the Disabled, Department of Social Welfare (Ghana), among others, there is the likelihood of these organizations coming to the aid of these families if need be, in terms of attending to their needs or building on their coping strengths. Moreover, as a student I wish to build a career as an advocate and researcher particularly in this area (disabled children and their families), since I have realized there is not much research in this area. Hence, any family that participates in this study strengthens my interest and capacity in this area, in the short term, and promotes advocacy for and research into disabled children and their families, in the long term.

### Possible Risks

Since I intend to familiarize myself with your daily activities in order to know more about your daily experiences, I foresee a challenge of invading your privacy. I will therefore, as a researcher, try as much as possible to minimize the degree to which I indulge in your privacy. In addition, I will make sure to protect any information drawn from your privacy. Above all, I will further ensure that you are comfortable with my presence right before the study.

Hence I'm here to recruit participants for this study and therefore wish you could be one.

If you agree to the terms of the study and consent to participate, you can sign below:

VOLUNTEER AGREEMENT

The document describing the benefits, risks and procedures for the research titled “Living with a disabled child: Experiences of families with disabled children in the Dangme west district” has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

.....

.....

Date

Signature or mark of volunteer

**If volunteers cannot read the form themselves, a witness must sign here:**

I was present when the benefits, risks and procedures were read to the volunteer.

.....

.....

Date

Signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

.....

Date

.....

Signature of Person Who Obtained Consent

## APPENDIX C: DEPARTMENTAL CONFIRMATION

 NTNU	Date 08.06.2009 dd.mm.yyyy	Our reference 2008/744/UCS	1 of 1
Faculty of Social Sciences and Technology Management Department of Psychology	Dated dd.mm.yyyy	Your reference	

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To whom it may concern

**Letter of confirmation - Priscilla Anum**

This is to confirm that Priscilla Anum, DOB May 30<sup>th</sup> 1983 Citizen of Ghana, is student at the master programme Mphil of Human Development, at NTNU, Norwegian University of Science and Technology, Department of Psychology.

She was awarded a scholarship through a quota programme Norway shares with Ghana, and was accepted into the two years programme in August 2007.

She is now going to Ghana to collect data's for her Masters Thesis.

Title of the thesis is "Living with a Disabled Child: Experiences of Families with Disabled Children."

The department hopes that relevant offices and individuals in Ghana will support her with the information and knowledge she might be looking for to accomplish this important task.

We appreciate your cooperation!

Yours sincerely  
*Unni Skrede Koen*  
Unni Skrede Koen  
Higher Executive Officer

 NTNU Trondheim  
Norwegian University of Science  
and Technology  
Department of Psychology  
7401 Trondheim

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Address	Org.no. 974 767 880 Email:	Location Bygg 12, nivå 5, NTNU	Phone +47 73 59 19 60	Our contact person Unni Christin Skrede
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## APPENDIX D: NSD APPROVAL, NORWAY

**Norsk samfunnsvitenskapelig datatjeneste AS**  
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

**NSD**

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Berit Overå Johannesen  
Psykologisk institutt  
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Dragvoll  
7491 TRONDHEIM

Vår dato: 10.06.2009      Vår ref: 21988 / 2 / AH      Deres dato:      Deres ref:

**TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER**

Vi viser til melding om behandling av personopplysninger, mottatt 11.05.2009. Meldingen gjelder prosjektet:

21988	<i>Living with a Disabled Child: Experiences of Families with Disabled Children in Ghana</i>
Behandlingsansvarlig	NTNU, ved institusjonens overste leder
Daglig ansvarlig	Berit Overå Johannesen
Student	Priscilla Anum

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

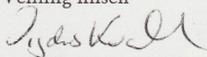
Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

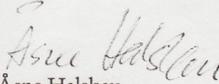
Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, [http://www.nsd.uib.no/personvern/forsk\\_stud/skjema.html](http://www.nsd.uib.no/personvern/forsk_stud/skjema.html). Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://www.nsd.uib.no/personvern/prosjektoversikt.jsp>.

Personvernombudet vil ved prosjektets avslutning, 15.05.2010, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

  
Vigdis Namtvedt Kvalheim

  
Åsne Halskau

Kontaktperson: Åsne Halskau tlf: 55 58 89 26  
Vedlegg: Prosjektvurdering  
✓ Kopi: Priscilla Anum, Herman Kragstveit 44 12, 7050 TRONDHEIM

## APPENDIX E: ETHICAL APPROVAL, GHANA

**NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH  
INSTITUTIONAL REVIEW BOARD**

(UNIVERSITY OF GHANA)

Phone: +(233) 21 500374 /501178  
Fax: +(233) 21 502182  
Email: Director@noguchi.mimcom.org  
Telex No: 2556 UGL GH



P.O. Box LG581  
Legon  
Ghana

My Ref. No: DF.22 8<sup>th</sup> July, 2009

Your Ref. No:

**ETHICAL CLEARANCE**

**FEDERALWIDE ASSURANCE FWA 00001824** **IRB 0001276**

**NMIMR-IRB CPN 050/08-09** **IORG 0000908**

On 8<sup>th</sup> July, 2009, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB), at a full board meeting reviewed and approved your protocol titled:

**TITLE OF PROTOCOL** : **Living with a disabled child: Experiences of families with disabled children in Dangme West Rural area (Ghana)**

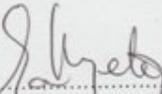
**PRINCIPAL INVESTIGATOR** : **Priscilla Anum (Student)**

Please note that a final review report must be submitted to the Board at the completion of the study. Your research records may be audited at any time during or after the implementation.

Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 7<sup>th</sup> July, 2010. You are to submit annual reports for continuing review.

Signature of Chairman:   
Rev. Dr. Samuel Agye-Nyampong  
(NMIMR – IRB, Chairman)

cc: Professor Alexander K. Nyarko  
Director, Noguchi Memorial Institute  
for Medical Research, University of Ghana, Legon

