SHUT UP!
- SOCIAL INCLUSION OF CHILDREN WITH INTELLECTUAL DISABILITIES IN GHANA.

An empirical study of how parents and teachers experience socialinclusion of children with intellectual disabilities.

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DEDICATION

This work is dedicated to my mother, Mercy Lartekai Ayin and my late father, Samuel Kojo Hervie, through whose foresight I am what I am today.

It also goes to my late uncle, Benjamin A. Ahulu who was my 'father' during the latter part of my life. Daddy, you taught me the importance of education and the tenacity to follow my academic dreams. As I write this page of dedication, I have memories of how you used to say you will dress like the Ashanti king and walk with shoulders high on the day I graduate with a Masters' Degree. You didn't live to witness this day but guess what?, I will be receiving this award at a place called Bodø in Norway and they don't have graduation ceremonies so I guess you wouldn't have worn your kente ☺. But all the same, I have lived the dream and thanks for your inspiration.

Finally, this work goes to all the children with intellectual disabilities in Ghana. Keep your dreams alive because all is not lost.

Vyda Mamley Hervie
Bodø, Norway.

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ABSTRACT

The aim of this study is to understand social inclusion for children with intellectual disabilities from the perspectives of parents and teachers. The specific context is to understand the inclusion of these children through meaningful participation in social activities. In-depth interviews were held with six biological parents of children with intellectual disabilities and six teachers who teach children with intellectual disabilities to explore their experiences on contexts that enhance or inhibit social inclusion for the children. In addition to this, literature on experiences of children with intellectual disabilities and conceptual models of social inclusion were referred to.

The results highlight the importance of context. Findings include cultural conceptions of intellectual disability which results in 'otherness' and lack of opportunities for meaningful participation in community activities. Other issues relate to lack of extended family support and the effect of having a child with intellectual disability on other family members.

The author argues that in order to fully understand social inclusion, attention must be given to the cultural contexts within which participants experience their daily lives.

Key Words:

Intellectual disability, parents, teachers, children, social inclusion /exclusion, community, culture.

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CHAPTER 1 INTRODUCTION

1.1 Choice of Topic and Research Problem

"…it is not the child's disability that handicaps and disintegrates families; it is the way they react to it and to each other' (Dickman and Gordon, 1985, p. 109)."

Parents face a great amount of challenge with almost everything in the world; and this include the desire to provide for their children in a safe environment that foster good physical, social and emotional growth. The demands of everyday life are however unknown and sometimes, families experience crisis in many forms. It is therefore not surprising that having a child with intellectual disabilities drive families in Ghana into a chronic state of chaos.

I was born in Ghana and a great amount of my knowledge and understanding of disability comes from growing up in a society where children with disabilities are not allowed to play with non-disabled children. Further to this, I had a niece called Yaayo (now deceased) who was very different from other children and always kept indoors. As a result, a curiosity developed in me to understand why she was never taken out to mingle with other children. When I asked my cousin why she always kept Yaayo indoors, her reply was that, [1]*"daa kɛ wɔ je kpo lɛ, mɛɛ kwɛɔ wɔ ni amɛ biɔ mi sajii ni haa ŋhwrɛ hoɔ ŋhe. Ni kɛ ŋkɛ le ta jatsu lɛ he lɛ , aheee nii"* (meaning, anytime we go out, people stare at us and ask many questions that make me embarrassed. And when she is with me, people don't buy the food I'm selling). When I asked this question many years ago, I didn't know anything about intellectual disabilities but later, I got to know that my niece was actually diagnosed with autism. But then, based on the answer I got, I grew up with the knowledge that people who look and behave different like my late niece must be kept out of public view.

In my adult life, my working experience in the field development with international Non-Governmental Organisations (NGOs) gave me the privilege to travel almost all over Ghana. Through my community work, I was able to experience the realities of community life and this also enlightened me on the various challenges faced by people with intellectual disabilities. For instance, in the local community where I worked, there was a case where a woman with Down's syndrome was denied access to

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[1] Statement is written in Ga local language. Ga is a local dialect spoken in South-Eastern Ghana.

be part of the Village Savings and Loans Association (VSLA). When I asked why she wasn't allowed to be part of the association, the community members said her disability was a sign of "bad luck" which would prevent the chances of the group from making profits. Somehow, this seemed to confirm my childhood experience that people with intellectual disabilities must indeed be kept out.

However, during practice learning experience as part of my study in Norway, students were taken on a tour to social service institutions such as Hus X, and Bodø industrial. During these tours, I was surprised to see what people with intellectual disabilities could do and their level of integration in Norwegian society. For instance, I got to know that some of the road signs, bills (GIRO), academic compendiums and parliamentary brochures were printed by people with intellectual disabilities. In fact, I actually saw a lady with intellectual disability (with her neck slightly hanging loose and drooling) who stood by a printing machine and pressed a flashing green light to make prints. This was very surprising for me because from my experience, such people are supposed to be kept from public view because they are bad luck!

I am aware that resources and opportunities in Norway cannot be compared to Ghana. Yet, my Norwegian experience constantly challenged my preconceived 'cultural' notions of people with intellectual disabilities and this raised a number of questions for me. For instance, I have been wondering how intellectual disability is understood and dealt with in different societies. Why is that, people who have intellectual disabilities in Norway can still contribute to national building whilst in Ghana, they are supposed to be locked up in rooms? And what are the reasons behind social exclusion of children with intellectual disabilities in Ghana? My encounter in Norway contributed to my quest for answers and the idea to do a research on social inclusion of children with intellectual disabilities in Ghana aroused in my mind. With this new passion and quest for answers, I also found my research question which is defined as: **How do parents and teachers describe possibilities and limitations for social inclusion for children with intellectual disabilities in Ghana?**

This is further explored through sub-questions such as:
- What are participant's experiences of social inclusion for children with intellectual disabilities?
- In what contexts do participants experience social inclusion/exclusion?
- What factors enhance or inhibit social inclusion for the children?

Since the life of the child has a greater impact on the life of parents as well as teachers and vice versa; the study will further explore how their experiences relate to the types of barriers and opportunities that exist within the community. From all indications, socialist feminists will support this field of study since it is also concerned with how society supports families. As argued by Arat-Kroc (2006b):

> *Child care should not be a private responsibility of the mother and father, but that society and the state should at least share in the work, cost, and responsibility of raising children (p. 86).*

In particular, this includes support to families with a child with intellectual disability to enable them have access to community resources and activities.

Also, as stated in the Ghanaian proverb, "*mo kome fɔɔ, shi mo kome kwɛɛ bi'* which translates as 'one person gives birth but its upbringing belongs to the community." This is to say that in this study, I will like to explore how participants interpret their experiences according to the realities of their daily lives in the community. By so doing; in sociological terms, I will try to discuss how social life is actually experienced by children with intellectual disabilities. In this way, the study will contribute to a deeper understanding of social issues as experienced by participants in their peculiar context.

1.2 Organisation of thesis

The remaining part of this is study begins with a brief discussion on inclusion, and how social inclusion and community are related to the study. This will be followed by how Key Terms and Concepts have been used in this study. A **Review of Previous studies will be discussed in Chapter Two** and the **Theoretical framework** will be presented in **Chapter 3**. A description of **Methodology and Research Design** will be discussed in **Chapter four**.

In **Chapter 5**, I will take my participants back to the pre-stages of their experiences with having a child with intellectual disabilities. This chapter will among others explore the realities of their experiences in relation to cultural conceptions of intellectual disabilities, belief systems and customary norms and values. In this stage, I will analyse participants' experiences and try to explore how they understand, interpret and ascribe meanings to social inclusion of children with intellectual disabilities.

Chapter 6 will build on Chapter 5 by delving deeper into how traditional perceptions on causes of intellectual disabilities impact on social inclusion/exclusion. By analysing this, I will explore participants' own interpretation of how these enhance or inhibit meaningful participation for the child with intellectual disabilities.

In **Chapter 7**, I will present a conclusion, main findings and suggestion for future research under way forward. This chapter will however start by providing a discussion on the theories discussed in this study with respect to the analysis.

1.3 Inclusion

Inclusion has been widely embraced as a laudable means of upholding and advancing the ideology of human rights (Inclusion International, 2009a; Rieser, 2007). Interestingly, this idea of inclusion is not limited to a discussion on policies. Rather, it recognises the centrality of increasing participation and reducing barriers to access. It advocates for the acceptance of people regardless of their differences by accepting that each person has a contribution to make in society irrespective of medical need, disability, race or gender (Dattilo, 2002). Schleien, Green and Stone (1999) argue that, the concept of inclusion comprises three levels ranging from a physical level to a social level. Social inclusion; the highest and final level can be achieved after physical integration and functional inclusion have been met.

While the ideas of these authors are impressive, what is uncertain is whether this conceptualisation of inclusion is shared by a number of countries and whether this concept is translated into local policy and practices. These are issues which this thesis will seek to explore in relation to Ghana.

1.4 Social Inclusion and Community: - how are these related to the study?

1.4.1 Community

Recognising the importance of context, it is relevant to explain what is meant by community and social inclusion in this study. From its Latin origin, "communis", community means common, public, shared by all. German sociologist, Ferdinand Tönnies (1887) is mostly accredited for presenting a precise explanation on "community" (gemeinschaft). In his work, Tönnies perceived "community" as a cohesive social entity within a larger society where there is a united will. He further

explained that family and kinship are perfect expressions of a community. From this explanation, it can be said that, for people with intellectual disabilities, the community refers to their life within the extended family and their engagement with neighbours and people within their towns or city.

1.4.2 Social Inclusion/Exclusion

Social inclusion for people with intellectual disabilities refers to having full access to activities, social roles, and relationships, as well as having valued presence and participation in society (Partington, 2005; Lemay, 2006). For most social scientists, the question of social inclusion and disability is a matter of theoretical perspectives. From Marxists perspectives, it is argued that people with disabilities have been excluded from the cycle of production since they are viewed as unproductive (Oliver, 1996).

From a psychoanalytic perspective, exclusion is an inborn reaction to "other" as a means of maintaining one's self intact. Thus, in instances where non-disabled people have rejected the disabled, it was in the interest of the former group to maintain their boundary as "normal" people and oppose association with the disabled (others).

Social constructionists also draw attention to social construction of disability According to this school of thought, rather than being born with a predisposition to recognise and categorise other, we learn to categorise through cultural practices (Shurmer-Smith and Hamman, 1994; Berger and Luckmann, 1966). This illustrates that cultural practices is significant to how disability is perceived.

In spite of the above varied perspectives, there is a common acknowledgement that social inclusion for people with intellectual disabilities is embedded with notions such as valued presence, equal opportunities, participation, mainstream society and a sense of belonging in a physical locality (Crane, 2002; Jaeger and Bowman, 2005; Lemay, 2006).

From the above discussions on community and social inclusion, it is obvious that the two terms are not straight forward. Yet, the terms cannot be avoided in this study. Since the study is focused on understanding experiences of participants, I believe that it is much safer to avoid taking a specific stance on how to examine these experiences.

Thus, for this study, the experiences of participants' determine what they mean by social inclusion and community participation. From this perspective, my interest is to understand how participants ascribe notions of social inclusion to the everyday life of

children with intellectual disabilities. In other words, less interest is attached to predefined notions of social inclusion.

1.5 Key Terms and Concepts.

Burstein and Duncan (2003) argued that, concepts are constantly in a terminological flux and in agreement with their argument; I believe that, it is important to identify how key concepts will be used in this study.

In this study, mothers will be generically referred to as parents. In Ghana, mothers may face additional burdens in caring for a child with intellectual disabilities owing to their subordinate position as women. Their situation may be compounded by the fact that, they are often seen as natural bearers and nurturers of children so they are mostly blamed for being the cause of intellectual disability in the child. In most cases, they internalise these feelings and engage in self blame. I therefore find it important to explore the experiences of mothers who face greater obstacles to social inclusion at the family level as a result of having a child with intellectual disabilities.

I distinguish between the term "impairment" and "disability". Impairment refers to the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical or social barriers. Disability on the other hand is the functional limitation within the individual caused by physical, mental, or sensory impairment (http://www.dpi.org/Constitution).

I find it important to explain these two terms to understand intellectual disability including both the medical and social models. Whereas the medical model focuses on impairment as the cause of an individual's problems, the social model is concerned with how society is organised and the ways in which it takes or does not take the needs of the disabled into account. This approach views disability as secondary to one's identity and does not define an individual against the standards of normalcy.

In this study, I will refer to "impairment" in its broadest sense as "disability" and I will take into account the social aspect of disability and how it relates to families, communities and the society at large. In this respect, the environment becomes a key factor. I agree with critics that the social model does not fully address all the elements of social inclusion. Thus for this study, this approach is being recognised as the *"starting point for discussion of issues"* on the social aspects of disability (Oliver, as cited in Tregaskis, 2004, p. 12).

Intellectual disability is not a new term and the concept of how to define and categorise people with intellectual disabilities has been affected by how people in different time periods and different cultures have understood and defined it. According to the American Association on Intellectual and Developmental Disabilities (AAIDD), intellectual disability refers to significant limitations in both intellectual functioning and adaptive behaviour. While it is enticing to use AAIDD's definition, for the sake of clarity, I will like to further this line of thinking with my conceptualised definition of intellectual disability. Thus, for this study, I conceptualise intellectual disability as:

> An *experience* of being restricted from full membership in society or activities of daily living due to an impairment or society's unwillingness to accommodate the individual with impairment through systems of beliefs, customary norms, values and attitudes.

The use of the term experience in this definition implies that having intellectual disability is not limited to the individual but incorporates the collective nature of Ghanaian society. For instance, when a child with intellectual disability is excluded from full membership or activities in society, the parent or family also experiences this exclusion. I hope that this definition provides a pragmatic path in suggesting that experience of intellectual disability is culturally bound.

Specifically, a child with intellectual disability will be broadly used to refer to a range of limitations in intellectual functioning and skills such as communication, taking care of him or herself and social skills. In this study, some of the participants had children with 'mild' disabilities and others experienced severe disabilities. I acknowledge that the degree of a child's intellectual disability will impact differently on family lives.

CHAPTER TWO: PREVIOUS STUDIES

2.1 Introduction

Accounts from the literature indicate that, for individuals with intellectual disabilities, being in a community does not necessarily mean being actively involved. Thus, there has been an increased concern to acknowledge that, for people with intellectual disabilities, living in a community includes an expectation for involvement in community activities and not just being community tourists (i.e. observe activities).

In Ghana, literature on disability in general and specifically, on intellectual disability is sadly lacking. Existing research on intellectual disabilities mainly focused

on integration of the children into mainstream education (Anthony, 2009; Agbenyga, 2007; Gyimah, 2006; Avoke, 1998). Accounts from the literature revealed that, previous studies were mainly from Western countries and reports by UN organisations. Information from these documents are however relevant to provide insights into previous work and give an understanding to this study.

I have organised the review in two parts. The first part looks at perspectives from Ghanaian oriented work and the second one focuses on accounts from Western studies on intellectual disabilities.

2.2 Ghanaian studies

One of the difficulties in discussing issues of intellectual disability in Ghana relates to a lamentable understanding of how its past history on intellectual disability continues to shape present consciousness. Historically and presently, Ghanaian society is intensely religious and identity is based on set of relationships between the living and the dead. Utley (2009) captured this by stating that; *the Ghanaian cannot be separated from religion, and religion cannot be separated from the Ghanaian"* (p. 46-7). Spirituality is the medium by which Ghanaians understand and make sense of their world. Traditionally, spiritual beliefs consist of a hierarchy ranging from the Supreme God (known as Nyoŋmo or Mawu), earthly gods (dzemawɔji or abosom), ancestral spirits and witchcraft (ayɛ) among others. The earthly gods play specific roles within the life of an individual, household, and community. For instance, the gods give warnings as a sign of punishment when an individual or society is out of order and protect its people and community when there is orderliness.

In terms of exclusion, Avoke (2001) and Ocloo (2002) explained that the mere birth of a child with disability calls into question an offence between the living and the dead and people try to distance themselves from the "offenders". Basically, there is no reason a family can give to explain why a child is born with a disability except that the anger of the gods has been visited on them. This is seen as a threat to the peace and stability of the community as well as the prized role of the child's future in performing basic duties in society.

To safeguard against a child being born disabled, pregnant women in certain parts of Ghana are subjected to various kinds of taboos. For instance, in the Brong-Ahafo region, pregnant women are barred from eating fish caught from a river called

"nsuokoraa". This stems from the belief that the river is a god and the fishes are its children. It is believed that pregnant women who eat fish from this river could give birth to children with intellectual disabilities. As a sign of punishment, this could lead to isolation or divorce since the pregnant woman has disobeyed a taboo to invoke a curse upon the family.

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

It can be argued that today, children with intellectual disabilities face similar situations though stories of killings are not heard of. Perhaps, as a result of enlightenment and respect to international calls to end all forms of human rights abuses; isolation of such children is the present way of deepening their isolation.

Even though children with intellectual disabilities are no longer killed physically, they seem to be "killed" emotionally through dehumanising names which make them victims of mockery. For instance, among the Akans (Ashanti Region) in Ghana, people with intellectual disabilities are referred to as *"nea wanyin agya n'adwene ho"* meaning, "feeble minded." Two other ethnic groups, the Ewes (Volta Region), and the Gas' (Greater Accra Region) refer to people with intellectual disabilities as *"asotowo" and "buulu"* meaning; idiots and stupid respectively. Further to these cultural ideologies, people with Down's syndrome in Ghana are referred to as *"nsuoba",* meaning water children ("nsuo" means water and "ba" means child). Traditionally, these are very offensive and dehumanising labels which worsen the plight of people with intellectual disabilities (Agbenyegah, 2003).

In addition to derogatory labels, it has been reported that people with intellectual disabilities are not treated with respect. From his studies on *"Stigma, Discrimination and Marginalisation: Gateways to Oppression of Persons with Disabilities in Ghana"*; Baffoe (2013) argued that persons with intellectual disabilities in Ghana experience disrespect, societal exclusion, and a devalued self-worth. The study pointed out that stigma attached to persons with intellectual disabilities in Ghanaian societies has created barriers for their inclusion in community life. In addition, participants in the study experienced disrespect in hospitals and faced both physical and cultural barriers

in society. The author argued that social exclusion can be thought of as problem that has to do with respect for people with intellectual disabilities and supported the need for community campaigns aimed at eliminating negative treatments towards persons with intellectual disabilities in Ghana

I find this discussion important since the findings contribute to an understanding of how respect impacts on efforts at social inclusion for children with intellectual disabilities.

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

In addition to culture, some Ghanaian literature also addressed the role played by religion in the lives of families who have children with disabilities. Traditionally, the various forms of religions in Ghana are traceable to beliefs in God or gods. However, religious perceptions on intellectual disabilities vary and the following illustrates the dynamics:

Among the Ga (Southern Ghana), the laws of reincarnation are followed and people with intellectual disabilities are seen as the reincarnation of their ancestors. The belief is that people with intellectual disabilities were offended during their pervious life and the community has been given another opportunity to care for them. As a result, they are treated with caution, kindness and patience.

On the contrary, the Ashantis of central Ghana detest any form of defects and see it as a punishment from the gods. Intellectual disability is considered a major disability and as such, children with impairments are considered full members of

society. Also, people with other forms of disabilities such as epilepsy are not allowed to be chiefs (Danquah, 1997).

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

For me, the role played by religion in connection with community life is worth considering since religious perceptions on intellectual disabilities may impact on decisions to allow them participate in community activities such as religious gatherings.

The literature on support from networks acknowledges that, support from immediate families and friends are essential to assist parents who have a child with disabilities (Nufeld, 2002; Beckman (1991) as cited in McKenzie, 2007). In Ghana, other possible forms of informal supports include kinship and community members. Kinship determines the rules, duties and obligations of individuals and groups in all aspects of life and social interactions in Ghana (Nukunya, 2003). The family consists of tribes, clan and lineage and the head of the lineage is responsible for making important social decisions for the family. For instance, important decisions such as whether a child with intellectual disability should be allowed to work on the family farm or be "hidden" are determined by the kinsmen. Even though this aspect of kinship is changing owing to urbanisation, they are still very strong and determine social etiquettes, family obligations and social responsibilities. Grandparents are another vital source of family support. Leung and McDonald (2001) referred to the support offered by grandparents as very significant especially in *"dual career families"* (p. 12). What is however not known is the extent to which grandparents provide support to their grandchildren with intellectual disabilities. Exploring this avenue is of interest to the study since it can contribute to the child's feeling of a sense of belonging or not.

2.3 Western studies

Within the context of Western studies, the centrality of social inclusion for people with intellectual disabilities has been captured as a consequence of deprivation in terms of restricted opportunities to fully participate in broader societal activities. For instance, Ouellette-Kuntz and Burge (2007) argue that, in Canada, even though people with intellectual disabilities tended to make greater use of community resources, they

are not necessarily involved in full participation of community activities. In a longitudinal study carried across Ontario, the authors reported that, for individuals with intellectual disabilities, the ability to get around and especially to be accepted by other citizens were still problematic (http:www.utoronto.ca/qol/final summary.pdf).

The above reality is however not unique to Canada. In a qualitative study on social inclusion for people with intellectual disabilities in UK, Hall (2010) argued that, people with intellectual disabilities continue to face barriers in community participation. The study identified that social inclusion for people with intellectual disabilities consists of three elements. These are; being involved in the community, maintaining reciprocal relationships, and having a sense of belonging. Community involvement refers to the use of community amenities and participation in structured recreation, leisure, religious and voluntary activities. For people with intellectual disabilities, developing and maintaining reciprocal relationships with family, friends and acquaintances in the community is a very vital aspect of their social inclusion (ibid). A sense of belonging is developed when a person is accepted by others, respected as an individual, has positive interactions with others, and is not excluded through marginalisation, teasing or bullying. Hall (2010) argued that even though community participation has improved, people with intellectual disabilities continue to face barriers to meaningful participation through the absence of quality services, lack of personal abilities and poor involvement in social activities.

McConkey, Walsh-Gallagher, & Sinclair (2005) also noted that, dignity accorded to the disabled and social participation is important for people with intellectual disabilities. The authors reported that most people with intellectual disabilities desire opportunities to socialise, develop friendships, and access community facilities and programs.

A shift in perspective on conditions of life for people with intellectual disabilities has occurred within research in previous years. Researchers such as Dennis and Chenoweth (2000) have captured positive life experiences of people with intellectual disabilities through inspirational narrations on de-institutionalisation and quality life achievements through community supports.

Perhaps in recognition of the past failings of institutional settings for people with intellectual disabilities in Scandinavian countries, advocacy groups led by Norway called on its governments to create normalisation-based policies guided by the principle of ensuring full citizenship and inclusion for people with intellectual disabilities

(Tøssebro et al. 2012). One of the Sections of the Norwegian Reform Act specifically provided guidelines on housing for people with developmental disabilities. It stated that, people with developmental disabilities who own or rent apartments can do so in their own names and they would pay for electricity, clothing, and fees associated with recreation and leisure activities. Ultimately, the goal was to ensure that people with developmental disabilities could have access to and participate in the same programs, activities and services as other citizens. Even though Norway is globally acknowledged for its progress in the normalisation process, authors such as Johnson (2002), Rustad (1999) and Sandvin, Soder, Lichtwark & Magnussen (1998) have argued that; on social measures, Norwegians with developmental disabilities have lives that are not normalised. Tøssebro and Lundeby (2002) confirmed this by concluding that, parents still struggle to get needed services from local townships even though some parents seem satisfied with services.

In an attempt to break barriers of access, the Norwegian Government's Official Report (NOU) 2001, served as a guideline to create strategies for achieving national goals of inclusion. A major achievement was the introduction of decentralisation and devolution of authority. In spite of its criticisms, decentralisation ensured that decisions have to be made in townships where local human services prioritize helping other people such as the disabled, children and the elderly. Perhaps Norway's experience with devolution of services can offer many lessons. One key lesson is the need for reform projects to understand the dynamics of social life and have resources and ability to arrange for an integrative social process.

While there is significant agreement in the above studies that normalisation, decentralisation and devolution are important to the successful implementation of integration for people with intellectual disabilities, other studies have drawn attention to how development of friendship can affect participation for individuals with intellectual disabilities.

In the case of friendship, Todd, Beyer, Felce and Perry (1994) incorporated friendship networks as a measure of community living for people with intellectual disabilities. These authors noted that, the degree of community participation and its related variables determine if people with intellectual disabilities feel cared for, valued and acknowledged to offer something to the community.

Another important issue raised in the literature was the need to pay attention to the emotions of families, especially the experience of mothers at the birth of a child

with intellectual disability. Authors such as Oecerman (2001) and Lessing and Strydom (2001) have argued that; when children are diagnosed with intellectual disabilities, their families experience various emotional turns which are further intensified by the multiple feelings of sorrow, grief, confusion and how to adapt to a new life. In all these emotions, families begin a long process of how to accept their child's disability and deal with it.

In an effort to identify universal characteristics of impairment, Wing and Gould (1979) outlined the famous "triad of impairment". In spite of difference in manifestation, the authors explained that children with intellectual disabilities have impairment in the areas of communication, socialisation and imagination. In general, the children are passive, active or "aloof" (detached or unfriendly). The authors concluded that, without necessary knowledge and understanding, such traits may create societal barriers and full inclusion of children with intellectual disabilities.

Adding to the work of Wing and Gould (1979); Groce (1999c) outlined three categories of beliefs which play significant role in how an individual with impairment functions in any given society. These are; beliefs on causes of the impairment valued or devalued traits in society and accepted roles as adults. Groce's (1999c) argument is that, perceived causes of impairments are complex and vary in cultures all over the world. Thus, an understanding of the beliefs is crucial to understanding attitudes.

The above body of literature captures a wide range of findings and discussion on studies about people with intellectual disabilities. Based on literature reviewed within the time frame of this study, one conclusion that can be consistently drawn from both Western and Ghanaian studies is that; full participation in community activities could be challenging for people with intellectual disabilities.

On the note of difference, studies conducted within Ghana highlighted the need to understand intellectual disability in terms of values of social life and cosmology.

Contrary to this, Western studies on intellectual disability are formed within the framework of a legislation that gives people with intellectual disabilities the same rights as others and must be integrated like ordinary citizens.

The variations within the above studies are important aspects to consider since they will have a bearing on how social inclusion is experienced and how these can have direct implications on the life of a child with intellectual disability in Ghana.

CHAPTER THREE: THEORETICAL FRAMEWORK

3.1 Introduction

In this study, I believe that theoretical approaches such as Systems theory, theories of stigma and social identity theories can provide a knowledge base to closely examine the interplay between societal structures and everyday experiences for understanding social inclusion/exclusion. In order to gain a wide perspective on the topic, I have adopted a mixture of theoretical sources incorporating a range of ideas from disability studies, sociology, psychology and education among others. The study draws from the work of prominent authors such as Healey (2012, 2005), Blaikie (2004), Goffman (1963), Mead (1962) and Brofenbrenner (1979). In terms of disability studies, the works of Priestly (2003), Oliver (1996), Barnes (2010), Ingstad (1995), Sandvin, Soder, Lichtwark & Magnussen (1998) and Tøssebro and Lundeby (2002) among others were read.

Underpinning the discussion on theories is a critical perspective which attempts to dig beneath the surface of dominant theories to throw new light on how some of the theories are resisted and transformed within the Ghanaian local context. The chapter therefore concludes with my constructed theoretical model which provides a critical edge for an understanding and appreciation of agency in the study.

This study will adopt a social inclusion framework incorporating the principles of access and equity. It frames the concept of social inclusion within the lived experiences of parents who have a child with intellectual disability and teachers who teach children with intellectual disabilities. I will attempt to illustrate the reality of participants' experiences by exploring how cultural conceptions enhance or inhibit social inclusion for the children. The study will look at how participants experience social inclusion from a Ghanaian perspective which is deeply influenced and shaped by historical perspectives and cultural ideological norms. This is realised through a "forbidden" relationship between the "non-disabled" and "disabled" in society; and the influence and power of the "non-disabled" to set the terms and expectations for the "disabled". This contributes to a consequential "othering" between "us" and "them" which creates barriers to social inclusion for children with intellectual disabilities.

Although Ghana is known for its cultural diversity, its commitment to diversity is highly debatable. The use of terms such as "contributing members of society", "people with sound mind" and "able-bodied members of society" illustrates the

importance of values attached to an individual's ability to feel "honoured" based on the level of contribution to society. Further to this, Ghanaians are known for extending a warm welcome at the birth of a new member of society. However, it seems that the warmth of this welcome is not extended to children born with intellectual disabilities. This could lead to various forms of separation between such children and other members of society. Li (2003) however argued that, social inclusion extends beyond eliminating barriers between "us" and "them" but also; closing social, physical and economic gaps. Consequently, employing a social inclusion framework in this study is particularly significant since children with intellectual disabilities often face exclusion on number of levels such as physical and social gaps.

3.2 Systems theory

Systems theory views people in the context of their environment (Healey, 2005; 2012). It posits that all organisms are systems, composed of sub-systems and these also comprise parts of a super-system. For instance, individual human beings are made up of systems such as respiratory and skeletal systems. These human beings are in turn part of sub-systems such as families and the latter is part of a super-system such as society. Healey (ibid) pointed out that, interactions between the various systems create characteristics not contained within separate entities. In other words, the systems interact and are linked to each other. While systems theory does not preclude concepts from the medical or psychodynamic theories from being applied simultaneously, it provides a theoretical framework that is generally congruent with roles played by people within a context.

In their discussion on systems theory, Thelen and Smith (1998) looked at the dynamic nature of the systems theory. The authors explained that systems theory was traditionally based on an assumption that the various systems seek to maintain a state of balance or equilibrium. They however argued that, human beings are active by nature and this implies that they should be considered within open systems and allowed to be dynamic.

Within the systems approach, the family is perceived as a unit embedded within other units and networks. Each family has a family system and this includes how the family has developed to cope with the day to day realities of living together as a unit

within society. In order to provide a specific context, the study will look at family systems as a specific system within the systems theory.

3.2.1 The socio-ecological model of the family

Considering the family within an ecological context was pioneered by Bronfenbrenner (1979). The theory looks at how a child develops within systems of relationships that form the child's environment. Bronfenbrenner (1979) explained that, relationships within the child's environment are a web of complex layers and each affects the child's development. In effect, any attempt to study how a child develops must not only look at the child and their immediate environment. Rather, it must also consider interactions within the larger environment. Like Thelen and Smith (1998), Bronfenbrenner (ibid) perceived human beings as active. His work emphasized the meaning of context in human development and he stressed the need for interaction between the human being within distant and close contexts. Even though it has been criticised that Bronfenbrenner's (1979) theory is inadequate to explain reciprocal relations within the systems (Lerner, 1998); his work on ecological theory provides a net of concepts for describing the effects of the environment on human development. Bronfenbrenner's (1979) ecological systems has been categorised into sub-systems namely micro, meso, exo and macro systems.

In applying the socio-ecological model to the study of families with disabled children, Hornby (1994) conceptualised the micro-system as patterns of roles, functions and interpersonal relations experienced by the family. The home is seen as the most significant micro-system in the life of the child and according to Bronfenbrenner(1979), it is important to consider how this setting impacts on the child's experience. For instance, does the child experience an active or passive role in the family as a result of having intellectual disability? Structures within the micro-system include family, neighbours and school. But for the purpose of this study, emphasis will be on the family as the primary contact for the child.

The meso-system has been explained as the existence of two or more micro-systems. The *"interrelations between two or more settings in which a developing person is actively involved comprises a meso-system"* (Bronfenbrenner, 1979, p. 25). This refers to a range of settings within which the family actively participates and it includes the extended family, neighbours, church and the local community. Various aspects of this sub-system can impact upon the family in various ways. For instance, in

Ghana, extended family members may accept or reject a child because he is intellectually disabled. This implies that informal support to the child may be provided or withheld as a result of disability. In addition to this, neighbours may support or stigmatise a family with a child with intellectual disability. At the higher level, there could be variations regarding the availability of services and resources between rural and urban communities.

Given the interactive nature of Ghanaian societies, it is interesting to study how the various components of the meso-system facilitate or deprive a child with intellectual disabilities from taking part in social activities.

The exo-system on the other hand comprises settings in which the child or family is not directly involved. However, events that occur within these settings affect the child or the family. These include the mass media, healthcare and education systems. For instance, by portraying disabled people as helpless, incapable or innocent, the mass media can influence societal attitudes towards them. Children with intellectual disabilities may not be directly involved at this level but they feel the positive or negative effects of such interactions.

Finally, the macro-system is explained as values inherent in social institutions. These include ethnic, cultural, religious and socio-economic values that affect how intellectual disability is viewed by both family members and society at large. For instance, the belief system of a society on disability determines if disabled people should be included or excluded from societal activities. This in turn affects structures within which a family with a child with intellectual disability functions. In effect, principles within the macro-system have a trickle-down effect on interactions at the micro and meso systems.

Given the cultural beliefs of Ghanaian society, I find this aspect interesting to help me understand the consequences of such belief systems in providing social support for the child with intellectual disabilities. At the macro level, it is also possible to see how institutional and societal structures work to systematically include or exclude children with intellectual disabilities. For instance, education is an important resource to enable individuals and groups train and function. However, structural barriers can be raised to prevent children with intellectual disabilities from accessing mainstream education when they are at the level to do so. This inevitably perpetuates exclusion both at the educational and social levels.

At the political and economic levels, factors such as policies and funding allocated to disability issues impacts on how families can access healthcare for their child with intellectual disability. As previously mentioned, the underlying tenet of the ecological model is that a change in any part of the system affects other parts of the systems. These perspectives are valuable to help me develop an insight into the real world of children with intellectual disabilities in Ghana by considering how they relate with the various systems, how the systems also relate with them and how they relate with society as a whole.

In this study, systems theory is used to give an understanding of how social inclusion occurs during interactions between children with intellectual disabilities and the various systems that support people in society. For instance, how do people within the various systems relate with a child as a result of intellectual disability? And how does this relationship enhance or prevent the child and his/her family members from accessing community facilities?

In spite of its significance, a number of criticisms have been raised against the family systems theory. It has been argued that there is lack of clarity about what specifically constitute a system, what its boundaries are and what comprises its attributes (Healey, 2012). Additionally, writers with emancipatory and feminist perspectives have argued that, the systems theory overlooks other factors such as structural injustice, abuse of power and societal inequalities with regard to age, gender and class (Healy, 2005; Wakefield, 1996b; McNamee and Gregen, 1992). In spite of its weaknesses, the family systems model offers a number of benefits to this study.

Firstly, the theory provides a framework for understanding and responding to people within their environments instead of considering them as people who live in a vacuum. This would enable me conceptualise experiences of families with a child with intellectual disability within the Ghanaian context. For instance, by focusing on the family, it is possible for me to avoid the general perception that the child with intellectual disability is a problem in the Ghanaian family; or the narrow view that the child is socially excluded by extended family members or society at large. Instead, consideration is necessarily given to analysing the interactions within and across the systems (Healy, 2005). In a nutshell, family systems perspective offers:

> *"…a way of seeing complex phenomena (the person in environment) in their interconnected and multi-layered reality, to order and comprehend complexity*

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and avoid oversimplification and reductionism." (Mattiani and Meyer, 2002, p.4)

Further, the idea of interacting systems implies that, human beings are born into certain environments with peculiar characteristics that affect interaction. The concept of societal perception and its impact on personal behaviour is therefore considered as an important part of the various systems. Such perceptions could result in stigmatizing attitudes which is the focus of the next discussion.

3.3 Stigma and labelling theory

For me, the most relevant aspect of Erving Goffman's (1963) work is how he conceptualized stigma as a trait of an individual or group that evokes negative responses. I understand this as a mark of social disgrace in which the marked person is tainted on the basis of attributes such as mental health problems, intellectual or physical disability or by virtue of belonging to an ethnic group. Goffman's strongest feature on this phenomenon is that a stigmatised self arises when there is an unacceptable discrepancy between what societies expect of a person and what a person actually is. Stigma therefore makes a person less desirable and different from the ones who are "normal" (Goffman, 1963, p.5). Goffman was quick to add that, during mixed social contacts, there is anxiety among the "normal" and the stigmatized. In most instances, anxiety on the part of the "normal" has to do with how to avoid the stigmatized person and the anxiety on the latter has to do with rejection and how to be accepted by the "normal". Goffman further explained that most cases of mixed social contacts give rise to categorisations in which the stigmatized person is treated worse or ignored. This feeling raises a question of acceptance of those stigmatized by the "normal". In his words, *the central feature of the stigmatized individual's situation in life can now be stated. It is a question of what is often, if vaguely, called 'acceptance" (Goffman, 1963:8).*

The core crux of Goffman's phenomenon on stigma is the feeling of inferiority which arises from the inability of the stigmatized individual (in this case, child with intellectual disability) to fulfil social expectations. Goffman further explained that, stigma is a public mark which can be noticed and it often results in spoiled identity. By spoiled identity, Goffman implied that stigma is an attribution which induces shame and

makes the "self" feel bad. Stigma therefore operates in relation to feelings arising from social interactions. Goffman captured this by saying that:

> The standards he (the person with stigma) has incorporated from the wider society equip him to be intimately alive to what others see as his failing; inevitably causing him…to agree that he does indeed fall short of what he really ought to be (p.7).

Some studies have demonstrated that higher levels of stigma are associated with lower levels of self-esteem (Abraham et. al., 2002). Other studies have contrasted this by asserting that, stigma may lead some people to become angry towards prejudicial treatment and this empowers them to advocate for fair treatment (Corrigan & Watson, 2002).

From Goffman's ideas, I deduce that stigma operates in relation to what others perceive about a child with intellectual disabilities and it is closely associated with feelings based on social interactions with others or in anticipation of how others will react. This understanding of stigma is important to enable this study explore how stigma attached to children with intellectual disabilities may lead to changed self identities and how this creates barriers for their inclusion.

Throwing more light on Goffman's work, Corrigan and Kleinlein (2005) conceptualised stigma and its linkage with discrimination. They perceived stigma as comprising of other components namely; stereotype and prejudice which leads to discrimination. Stereotype is seen as the collective concepts of groups which allow people to make quick generalizations about others. On the other hand, prejudice occurs when people agree with existing stereotypes and develop emotional reactions towards them.

Within this milieu, the concept of stigma provides an understanding of how societal responses to children with intellectual disabilities lead to their social exclusion as well as the exclusion of their families. For instance, Goffman (1963) further contended that, non-disabled people experience uncertainty and seek to avoid having stigma spread to them by avoiding close association with stigmatized individuals or groups. As a coping mechanism, stigmatized groups or individuals resolve to avoidance, acceptance or search for emotional and social support. From this perspective, it is possible for me to explore coping strategies adopted by participants as they experience stigma.

Of direct relevance to this study is how stigma may affect family members and teachers who are closely associated with a disabled child. Camp, Finlay and Lyons (2002) questioned the effect of stigma on the "self" by arguing that, for stigma to have a negative influence on the "self", the individual must first be aware of, and accept the negative self-perceptions by accepting that the identity relates to them and then apply the negative perceptions to themselves. This led to the introduction of concepts such as "felt" and "enacted" stigma. Felt stigma refers to how an individual internalises negative perceptions regarding themselves. Enacted stigma on the other hand refers to behaviours and perceptions by others towards the individual who is perceived as different.

The work of Camp et. al (2002) gives me an additional lens to view how stigma is accepted or internalised for children with intellectual disabilities and how this affects their ability to reach out for inclusion.

Borrowing from Goffman but adding their interesting aspect, Link and Phelan, (2001) argued that, without reference to power, the concept of stigma becomes very broad. Link and Phelan (ibid) emphasized that, stigma is culturally defined and this occurs when people who have power confer stigma on others. When this happens, things labelled "different" become culturally relevant, recognised and acknowledged as "different". In other words, when children with intellectual disabilities are negatively labelled as "different", it becomes accepted and this may lead to negative perceptions. On the other hand, when they are seen as "unique" and important regardless of their disability, they would be treated and accepted as such.

The above exposition on stigma, stereotype and prejudice are crucial to enable this study get insight into aspects of Ghanaian culture which makes stigmatizing the child with intellectual disability inevitable. In a nutshell, Goffman's pioneering work on stigma and contribution by other authors are intended to give insights into the real world of children with intellectual disabilities by considering how stigma affects their inclusion in society.

Closely linked to stigma is labelling which is perceived as tags ascribed to disabled persons as a result of their failure to meet certain competence standards expected from non-disabled members of society. For instance, a child with intellectual disability who experiences drooling needs frequent cleaning of the mouth and this can be seen as behaviour different from the norm or different from other children.

In applying the concept of labelling to mental health problems, Scheff (1984), argued that people in society adopt stereotyped images of mental disorder through social interaction. For instance, from childhood, people learn to use terms such as "nuts" and "crazy" to associate people with disturbed behaviours. Scheff (1984) believes that a label could create deviance as a consequence of society's response to the labelled individuals. In the case of intellectual disability, this implies that a diagnostic label could trigger negative social stereotypes and stigmatizing responses. According to this perspective, the label attached to an individual influences the way people think about the individual. In effect, once a child is labelled as intellectually disabled, he/she receives a set of general reactions from society which is usually negative in nature.

Edgerton's (1993) work on labelling throws more light on how labelling affects children with intellectual disability. In his study of stigma among people labelled "mentally retarded", Edgerton observed that:

> the label of mental retardation not only serves as a humiliating, frustrating and discrediting stigma in the conduct of one's life in the community, but it also serves to lower one's self-esteem to such a nadir of worthlessness that the life of the person is scarcely worth living (p. 132).

Although this evaluation may be overly pessimistic, there is substantial evidence that in Ghana, after children with intellectual disabilities have been labelled as "jimi jimi" or "buulu" (stupid), there is a decrease in expectations for their achievements and behaviours and this leads to a self-fulfilling prophecy of lowered outcomes. From this perspective, labelling can be viewed as a complex social process in which cognitive, emotional, and socio-cultural elements converge within a powerful situation.

The above discussions on labelling will be used to give an understanding of how labels given to Ghanaian children with intellectual disabilities affect their aspirations to make a difference in society. This would enable the study explore how this affects social inclusion for children with intellectual disabilities. From a labelling perspective, it is also important for this study to explore how children with intellectual disabilities have maintained their self-concept in spite of being labelled as members of a negative group.

3.4 Social Identity Theory.

Social identity theories generally demonstrate how identity is defined as a conception of the self and how knowledge about "who I am" is constructed in terms of

societal rules and values. George Hebert Mead (1934) pioneered the idea that, individuals are a product of their society and views about the "self" are shaped by the societies they encounter. Mead (1934) differentiated between the "I" and the 'me' to explain how the self is constructed through interaction with others. He argued that the self arises in relation to a generalised other known as the "me". "Me" is a cognitive object which is only known upon reflection. Under normal circumstance, people act in ways without necessarily being self conscious. However, when people take on the perspective of the generalised other, they try to act in ways that conform to systems of behaviour in the generalised other.

A practical example to understand Mead's theory will be to think of the child with intellectual disability in relation to community. In this situation, it is most likely that the views of the child about the "self" will be from perspectives of accepted norms and behaviours that constitute the community system.

Social identity theory explains that, people conceptualise themselves as members of specific groups and they take on aspects of the group's identity. By selecting an identity, the individual is associated with attributes that determine what is viewed as negative or positive. The outcome is an alignment of perceptions which generates a consensus on social cohesion and solidarity among community members. In effect, individuals must accept how society identifies them if they are to be accepted as its members.

I find above discussion on identity theory significant because it acknowledges the personal characteristics of a person with intellectual disability whilst recognising the role of the environment in shaping identity. Following Mead, it is possible for the study to explore how the concept of the "self" is perceived by children with intellectual disabilities and how knowledge about "who they are" are also constructed in terms of rules for interaction in society. From this angle, it becomes relevant to understand how identities demonstrate group solidarity and the risk of becoming an "outcast" when an identity is unacceptable to the group.

Another idea at the heart of Mead's discussion is symbolic interaction. From this perspective, human beings are seen as social beings who socially interact and the outcome of this interaction creates the cultural world in which the individuals live and identify themselves in society. In this sense, society is central to forming what the human being is. From a symbolic interactionist perspective, the societies in which individuals are born establish meanings through symbols and cultural conventions.

Individuals encounter society through various cultural units and the culture of a particular society influences human behaviour and the place of the individual in society. By positioning the study under symbolic interactionism, the study sets to explore how constructed cultural meanings in Ghanaian society guide actions and behaviour for social interaction. Thus, symbolic interactionism will provide insight into characteristics associated with intellectual disability and how this defines their status in society against the backdrop of the societal culture or worldview.

Summary

The theoretical discussions on family systems, theory of stigma, and identity theory have provided a body of knowledge to strengthen the understanding of the primary concepts of this study. The pioneers of the above theories have laid a foundation to help researchers look at social issues through different lenses.

Specifically, the above theories provide a framework for conducting analysis and help focus attention on different aspects of data. From all indications, my study is located within this body of scholarly work and I am therefore grateful to intellectual ancestors such as Goffmann, Scheff, Bronfenbrenner and Mead whose innovative work has provided insights into my studies.

However, within any field of studies, there is always room for an exploration of the subjective realm and the need to account for agency to influence deeper understanding. In the light of this, I will draw from the above dominant theoretical perspectives to construct my own model to serve as a framework for this study. This is presented in the diagram below:

THEORETICAL FRAMEWORK
A version of family systems, labeling theory and social identity theory with culture as a cross-cutting issue
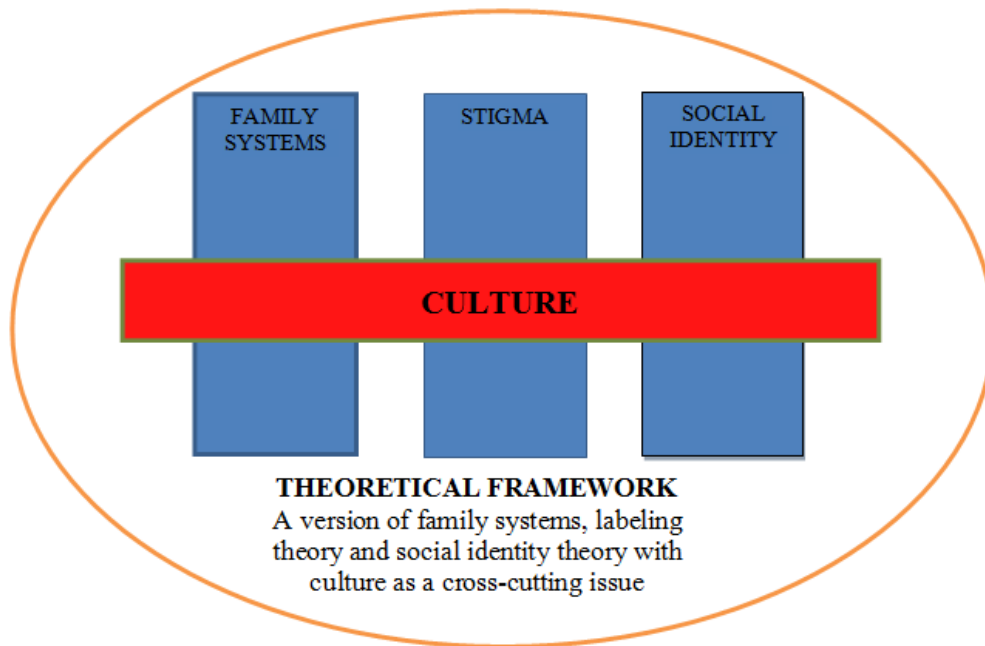
Theoretical framework for the study

Explanation

The above conceptual model and diagram was developed to provide a clear and well defined net of concepts for describing and understanding the effects of culture within the local context in which the study was conducted.

The central argument of this model is that, the meanings of family systems, social identity and stigma are specified, formed or altered within cultural contexts. It therefore assigns weight to the role of culture in perpetuating exclusion or inclusion in society. I argue that, within a social context, interactions within the various systems give a valid understanding of experiences of social inclusion. Participants' experiences are connected and interwoven with larger society and their experience of each system is dependent on the experience of the others. For instance, the family unit is seen as a system which interacts with other systems such as the neighbourhood, community and schools. Thus, the existing culture of one system cuts across the rest of the systems since they overlap. For instance, a child with intellectual disability could be excluded from social networks and extended family support due to cultural perceptions which generalises them as "others". At worst, this exclusion could also be systematic when children with intellectual disabilities are unable to access recreational and health facilities as a result of stigmatizing attitudes towards them.

The model emphasizes that, within the Ghanaian system, cultural perceptions are very powerful and family systems are strongly inter-connected. Owing to this interconnectivity and increased levels of interactions, it is useful to understand how cultural perceptions spread through the various components of stigma, social identity and family systems and relates at all levels to make inclusion difficult. By combining these different perspectives, this model recognises the complexity and reality of participants' experiences.

From these entwined angles, I argue that without a keen interest on the power of cultural conceptions, attempts at understanding social inclusion for children with intellectual disabilities in Ghana could be counterproductive.

CHAPTER FOUR: METHODOLOGY AND RESEARCH DESIGN
4.1 Introduction to approach to methodology

Silverman (2010) have argued that, in the field of social research, no single methodology is better than the other. However, given the complexities of the real world, it is important to choose a methodology that is relevant to the research problem at hand.

Since the aim of the study is to understand experiences of participants to reflect what social inclusion means for the children with intellectual disabilities, I think that it will be appropriate to adopt an approach that enables participants to tell their story in the subjectivity of their everyday life. In other words, my interest is to understand the notions of participants and not pre-defined notions of social inclusion.

Going by this reasoning, this study is comfortably placed under the research strategy named by Blaikie (2010) as abduction. This refers to the process of generating social scientific accounts from how social actors describe their way of life. According to Blaikie (2010), the logic of abduction is to discover why people do what they do by uncovering the symbolic meanings, motives and rules that provide their orientations.

Following the abductive strategy, this study is also influenced by phenomenology and this implies that; reality is perceived as a product of human experience and it is determined within a social context as a result of human interaction with the rest of the world (Crotty, 2003). By adopting a phenomenological approach, the study aims to capture the reality of participants and grounds analysis on participants' subjective experiences. In the course of my study, the logic of this approach emerged with every article, book and discussions I read on intellectual

disability and the data transcribed from conversation with participants. My attention was fully focused on meanings that emerged from my relationship with every piece of "object" ranging from the chapter of a book, data generation and observation of activities during the study.

4.2 Research Methods

In compliance with an abductive research strategy, the study is qualitative in nature. Specifically, I used in-depth interviews to explore participants' experiences. All interviews were unstructured and I mostly started with general questions by asking participants to tell me about their family background and their experiences of how the child is involved in family life. Once the conversation moved to a specific activity, I start asking probing questions to clarify how experiences were interpreted. Closed questions were only asked when participants were asked to clarify data such as location and time.

In specific terms, this study used an interview guide. This contained elements I want to talk with participants about but they were flexibly used as an ordinary approach. The exploratory and participatory nature of this approach was deemed appropriate as the research had focus on lived experiences.

In addition to this, my choice of an interview guide was to allow for variation and the sharing of unique and rich experience by each participant. I was cautious when probing into sensitive questions and I took note of body language and facial expressions to signal if participants were comfortable or not (Berg, 2009). This was very relevant when I had to ask parents to recount experiences about derogatory comments or negative attitudes towards their children. Throughout the interview, I acknowledged that the participants were experts and their perspectives were central to understanding their experiences. As such, I allowed the participants to share their experiences in their own words and I restrained myself from interrupting. Emerging themes and unclear statements were however probed with more questions to gain clarity and additional information.

Interviews were held at locations which were comfortable and convenient for each participant. Some participants were comfortable with being interviewed at their homes whilst others preferred to be interviewed at other locations such as the school library, or their offices. Seating was arranged such that participant and researcher faced

each other and I paid attention to the timing of the interview and took note of things happening around the interview settings.

Most importantly, interviews were conducted in a participatory manner in that; I encouraged participants to ask me questions as well. I found this aspect of the interview very interesting and challenging at the same time. The interesting part was that, I had to share my experience on efforts by Norwegian society/government to integrate disabled people in Norway. The challenging aspect was that, my experience in this field is relatively limited so I was very cautious of what I said and try to avoid any false impression. All processes were observed to ensure that participants' knowledge were valued and their stories were anchored in real meaning and experience of participants (Silverman, 2010; Berg, 2009).

Interviews were conducted in English, Ga or Twi. Most interviews however combined two or more of the languages depending on how participants wanted to express themselves. This flexibility with language allowed for rich data and participants were able to use local idioms and proverbs to capture their experience for a better understanding of their views.

The length of each interview session was flexible to accommodate the needs of the participants and this ranged from 1 to 3 hours. Some of the interviews were held in phases because some participants could not be available for more than 45mins. During such interviews, I provided a summary of previous interviews to enable the discussion continue from where we left off the previous day. Though this took a lot of time, it was very helpful as it created a high degree of safety knowing that participants agreed with views captured in previous interviews.

The interviews were however augmented with observation, participation in activities and other secondary data sources such as policy documents on disability, journal articles and Ghanaian proverbs and folk stories depicting stories of people with disabilities. The latter sources were deemed relevant to provide a rich source of local textual information to the overall data generated.

Owing to space constraints, I have shortened some interviews by using (…) to indicate the removal of sentences. In some instances, I have added words to clarify aspects of quotations in brackets.

Finally, I kept a personal diary for the purpose of recording detailed descriptions of the research process. The diary served as mirror through which I reflected on the research process and experimented with new ideas which later became important topics

for the study. For instance, the diary helped me reflect on an account which contained important data. This was my experience with one of the parents. From the moment the interview started, her attitude was defensive and she made it clear that she was a "big" public figure with years of experience in research. At the beginning, she gave very brief answers to my questions, kept probing about my interest in the subject and she did not seem to be enjoying the chat. I asked if it's ok to postpone the conversation but after a pause, she indicated that we could continue. I honestly made it known that I only have a keen interest to conduct a good study and nothing more.

Somehow, this made it easier for her to open up to me and her replies became progressive and she felt comfortable to tell me about her struggles in an effort to socially include her child. While this may not be an unusual experience in interviews, this particular aspect of the study helped me to realise that, participants may feel vulnerable after an interview especially when they start to reflect on what they have said. It was therefore important for me not only to build good rapport but to clarify issues that might lead to distress in participants. As it was in this case, I later got to know that this participant tried to avoid falling into "political minefields" (Malone, 2003, p. 798) by making sure that there were no political attachments to my studies and she wanted to be sure that her comments were indeed safe.

Another key point from my diary was the perspective of a teacher who lived in the same community with one of his pupils. In as much as this cannot be elaborated fully owing to space constraint, the teacher's experience raises a number of issues concerning the frustration of the children and families in their attempt to be meaningfully involved in community activities. The point raised by this teacher was the determination of mothers to help their children and the neglect of fathers. In his words:

> The fathers like to beat about their chest about their children; especially the male ones and they see it as a disgrace to have a child with intellectual disability so they decided to hide or isolate them or totally ignore them.

For me, the experience of this teacher speaks to the need for greater understanding on how issues of having a child with intellectual disabilities are dealt with by fathers especially in relation to social inclusion and their sense of worth and belonging in the community.

4.3 Research Design and fieldwork

4.3.1 Research location

As the capital city of Ghana, Accra is the converging point of most resources in the country. As such, it has a number of institutions that provide services for children with intellectual disabilities and these are patronised by people from other parts of the country. Accra therefore served as the central point to generate rich data on my research topic.

Secondly, given the practicalities of language, logistics and my familiarity with the city, conducting the research in Accra allowed for greater access to families of children with intellectual disabilities as well as the teachers who provide services for them. It was anticipated that snowball sampling would enable me identify a number of families from both rural and urban areas to enable me capture views across various geographical locations in the country. But owing to time constraints, this idea was not feasible.

Finally, the realities of financial constraints did not allow me to travel outside Accra for data. In spite of this, the diversity within Accra allowed me to speak with a wide range of participants who hail from other regions of the country such as Ashanti, Volta and Eastern regions.

4.3.2 Recruiting Participants

In an attempt to understand and experience the focus of my study, a seven week field trip was undertaken in Accra from September 11 to October 26, 2012. Permission letters were sent in advance to two schools that provide services for children with intellectual disabilities. Initial contacts were made with the head of the schools through the help of a manager from my former place of work in Accra. This manager personally delivered the permission letters on my behalf about two months prior to my arrival in Ghana. As protocol demands, the manager helped me to establish the first contact with the "big bosses" of the schools by introducing me personally to them. The heads of the schools then introduced me to key contact persons within the schools to help recruit participants.

Firstly, I explained details of the studies to the contact persons and discussed issues of confidentiality, ethics and expectations from participants among others. The

contact persons in turn explained the study to some parents and teachers and came up with a list of those who expressed interest to participate. I was then introduced to the interested participants and I established contacts with them for the interview.

4.3.3 Pilot study

As mentioned earlier, disability is deemed a taboo topic in Ghana and being aware of the difficulty involved in talking about it, I used the first week of my study to conduct a pilot study. The aim was to explore general feelings about the topic to appropriately structure the methodology. Meeting with the focal persons helped me to gain insights into appropriate terms and methods for data collection.

During my meeting with the focal persons of the school, it became apparent that some parents might request for a "synopsis" prior to the interview. This implied that I needed to make my interview guide available upon such requests.

Finally, it also came up strongly during the pilot study that tape-recording interviews might not be possible. The pilot study therefore helped me to structure my data collection methods and placed me in tune with possible practicalities on the field.

4.3.4 Challenges with informed consent

At a glance, informed consent seems a straight forward issue involving the provision of information about a study to enable participants make informed decisions about participation. My experience however reveals that, the process of informed consent is not straightforward in Ghana. Views about the importance of signed consent forms are varied but a key advantage is that; signed consent protects the researcher from future accusations from research participants and it is good evidence that research participants have been informed about the study (Comber, 2002).

However, in managing issues of signed consent in an oral society like Ghana, I had to critically reflect on the necessity of using a signed consent. As one participant said;

> *Sister, you said people will not know that you have interviewed me. But on this form, you want me to write my full name and sign. How is it possible that they won't know it is me?*

This comment made me realise that, the use of signed consent may compromise trust in confidentiality and anonymity which are vital to protect participants. Some participants raised concern that signing the consent forms would make information they provide

traceable to them and might make them vulnerable to investigation in case they make comments which relate to how public officials have neglected children with intellectual disabilities. Such participants however gave verbal consent to participate in the study.

Finally, some participants I spoke with could neither read nor write. For such participants, being asked to read and sign a consent form could be embarrassing. From my previous research experiences, I was aware that insisting on such formal means of consent prior to an interview can create a gap between the researcher and participants. This is because, the participants see the researcher as someone higher than them and this can go a long way to affect responses. This is what Berg (2006) referred to as establishing common grounds for effective conversation. Besides, I didn't have an ink for thumb print in cases where participants could not sign.

4.3.5 My Critical friends

Based on coursework and my experience of critical friends during this Masters' Degree program, I decided to put this to practice by asking three friends to act critically in this research process. I invited these friends to a meeting aimed at discussing my methods and approach to the study. Constructive criticism from my friends enabled me to learn from their ideas and this shaped how I generated data. For instance, one of my friends suggested that in order for me to have a "real taste" of observation, I should not be specific on when I would be present during activities at the schools. I was advised to obtain permission to participate in events and just show up. Even though this approach could be subjected to debate, it somehow helped to avoid artificial settings. On two occasions, I was able to have a natural experience of how the children interact with non-disabled children. This indeed added a more realistic angle to data and exposed me to new knowledge on claims made by the participants on social inclusion.

Also, my critical friends cautioned me to use the word [2]*"sɛbi taflatsɛ"* (excuse or pardon me) any time I have to mention a derogatory term when referring to disability. A more concrete suggestion was for me to always mention the name of the child when talking with parents. This is because, in Ghana, calling people by name is a way of making them feel human and the disabled are sometimes deemed "less human" by referring to them as [3]*'kwɛ'* (similar to saying "it"). Thus by mentioning the name of the child, I would avoid the risk of enforcing stereotypes that are "worthless". These

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[2] sɛbi taflatɛ is a polite word mostly used to precede a derogatory sentence or comment.
[3] In Ghana, words like "kwɛ" refers to objects so using it for human beings is derogatory

insights from my friends made me more conscious about the delicate nature of disability and helped me to avoid some mistakes during the field work.

The discussion with critical friends lasted for about three hours and as Ghanaian custom demands, I paid for lunch as way of thanking my friends for their input.

4.3.6 Reliability

Simply defined, reliability refers to:

"… the consistency or stability of a measure; if (the study) were to be repeated, would the same result be obtained." (Robson, 2002, p. 93).

In other words, saying that a finding is reliable is to argue that it is replicable. However, within the field of qualitative social science, it has been argued that the ability of an account to be replicable could be far from reality since interpretations of accounts are relative to a phenomenon. My understanding of this is that information generated can change due to several factors. For instance, a parents' response to the same question on social inclusion might change if services improve or the child's skills are enhanced. Needless to say, it has been argued that reliability can be addressed through procedures such as triangulation, use of mixed methods and testing of research tools (Silverman, 2010).

One of my approaches to ensuring reliability was through the pilot study. By piloting the research tool with a group of professionals, I was able to obtain specific information on how to observe cultural protocols through the use of appropriate language during the field work.

Secondly, by using mixed methods such as observation and secondary sources of data, the study was able to increase reliability through multiple perspectives provided on the phenomenon of social inclusion.

Finally, I made an effort to repeat and rephrase questions to ensure that answers from participants conform to research questions and its intended meaning.

4.3.7 Validity

Validity is crucial to research design and according to Patton (2002), it determines whether the research truly measured what it was intended to measure.

Gall et all (2003) argues that, in qualitative social research, validity of a study can be achieved through approval by a panel with expertise in the field of studies. This

can also be based on the logic and reasoning of information provided by the researcher. In this study, validity was addressed through the following actions.

Firstly, I allowed my supervisor (as an expert in the filed) go through the study guide to ensure that questions being proposed were fit for the purpose. Concerns raised by my supervisor were further discussed and converging ideas were finally incorporated and accepted to be used as the guide.

Secondly, I checked for validity by comparing information generated among the two schools and between different set of parents and teachers. I paid particular attention to how participants' answered questions and I observed that there were common patterns in their experiences. By making this comparison and observation, information obtained could be considered as representative of the phenomenon at hand and its validity can be deemed appropriate.

4.3.8 Ethical Considerations

Since my intention was to investigate a taboo topic, ethical issues were central to me from the planning through to the implementation of this study. Within the field of qualitative social research, a number of ethical concerns are raised since it involves contact with people who could be harmed by revelation of what they say or do. The usual ethical procedure for dealing with this is to ensure anonymity. As part of fulfilling this, I have assigned pseudonyms to protect the anonymity of participants and confidentiality of information generated. I also tried to be creative by coming up with what I have termed *"inverse anonymity"*. By this, I tried to change biographical information in some places where I am confident that this does not have a bearing on the analysis.

A second means of maintaining ethical standards was to ensure that participants were fully informed about the study. Through the process of informed consent, participants were provided with full explanations of what the study entails and participants were given the option to opt out if needed. I ensured that all participants had copies of the consent form even if they were not willing to sign or they could not read. Consent forms were given at least a day before scheduled interview. This ensured that participation was voluntary and participants' agreed to be interviewed upon careful consideration of what the interview entails. Another idea for giving out consent forms ahead of interviews was to enable participants who couldn't read to have a familiar

person read and explain things. This was a way of ensuring openness, clarity and confirmation of what participation entails.

Thirdly, on occasions when emotions were high or participants' were tired, I mostly suggested for continuation of the interview at a different time and in agreement with participants, another schedule was fixed.

Fourthly, I respected participant's decisions not to tape or video record the interview.

Finally, I have endeavoured to show respect for people with intellectual disabilities by using people first language. This emphasizes the need to say a child with intellectual disabilities instead of intellectually disabled child.

4.3.9 My Ethical Dilemma:-Touched by a Narration

During the study, I encountered an ethical dilemma by being touched by the experiences of one of the participants and suddenly found myself crying uncontrollably with her. It was one of the longest and most emotional interviews conducted during the study. It was long because this parent was also a teacher at one of the special schools. Even though spoke in the capacity of a parent, she provided additional insights on the educational aspects. The emotional aspect was that, I could identify with every step of her journey. Firstly, she lost her husband when her son was at the same age when I also lost my father. She narrated her widowhood rites ordeal to me and how she was worried about her son with intellectual disability during the period of confinement. This narration gave me flashbacks of when my mother was not allowed to have contacts with me and my siblings during her weeks of confinement as a widow. The other aspect of this participant's narration was when she faced the reality of life after her husband's death by looking for jobs to cater for her children. In an attempt to do the latter, her son with intellectual disability was sometimes tied unto a seat and locked up in a room to enable this parent go to town and back. This aspect of our conversation reminded me of my late niece Yaayo. This was exactly how she was treated. My cousin will sometimes over feed her, tie in her to a tiny plastic chair, put stones around to give her support and just leave her. I was mostly filled with anger any time I had accidently seen my late niece fall off from the chair and sometimes lying hopelessly with flies all over her.

The conversation with this participant crushed me from within. Perhaps it was a good thing to have let out my emotions as a human being. But maybe, this might be

seen as an ethical challenge owing to my position as a researcher. The question is that, did this affect information gathered? I find the answer two fold.

Firstly, the common grounds established with this woman encouraged her to give me very detailed information which was unique to other narrations.

Secondly, my ability to identify with her story allowed me to interpret things from a natural or maybe "biased" perspective. But I see this more as an advantage because in general, I was able to capture full details which provided me with a rich text for this study.

4.4 Data analysis

The literature displays a wealth of generic approaches to analysing qualitative data. These include conversation analysis, narrative analysis, grounded theory and discourse analysis. For the purpose of this study, I have decided to use content analysis. This consists of organising data, reducing the data into themes through a process of coding and representing the data in figures, tables or a discussion (Creswell, 2007).

In my data analysis, the first step was to transcribe information from participants into an MS Word document. My perceptions on social inclusion for children with intellectual disabilities introduced the possibility of "researcher bias" so I made the conscious effort to understand data from the perspective of participants. This was achieved by bracketing personal perspectives to avoid biases and opening myself to new ideas narrated by the participants'. The new ideas were then analysed using latent content analysis. As described by Patton (1990), latent content analysis is "*the process of identifying, coding, and categorising the primary patterns in the data*" (p.22).

In my writing, participants' ideas were described in the form of notes and frequently occurring ideas were compared to see if there were any patterns. Once a pattern was established, I selected significant statements in terms of how participants' experience social inclusion and what this means to them.

Following this, I used thematic coding guideline developed by Flick (2006) to group relevant statements onto sub-themes. Precisely, information emerging from the interview were categorised into three broad topics for analysis: Cultural conceptions, Belief systems and Customary values and norms. This was of coding helped me to reduce a large amount of data contained in the field notes to provide a summary under the various categories. As a result, significant themes were merged, adjusted or sub-

divided as a structure for the analysis. The summaries were read and re-read and compared for familiar and contradictory responses. This method of presenting data allowed for triangulation between data sources for validity. I found thematic coding significant since the study focused on *"social distribution of perspectives on a phenomenon or a process in which differing beliefs or view points were expected"* (Flick, 2006, p.307).

4.5 Information on Participants and Schools

4.5.1 Meet the Parents

Aunty Akos works as a petty trader at the market selling cooking wares on weekdays and seasonal vegetables on weekends. Her child has Asperger's Syndrome and her vision included a future where her child will be a footballer by the age of 19 to solve the family's financial problems. At the time of the interview, she was living with dashed hopes as she experiences great economic difficulty in taking care of her child. In addition to her economic situation, she has been accused by family members for killing her husband through consistent nagging hence, her child's disability is seen as her punishment. As a result, she has been ignored and denied of support from family members.

Ekua left her village to settle in Accra in search of greener pastures. She is a single mother and has a seven year old son with autism. He is non-verbal and attends one of the special schools. She has observed that the demand of caring for her child does not allow her to work far away from home. At the time of the interview, she was selling basic items like gari, sugar, groundnut, tom brown, brooms and charcoal in front of the compound house where she lives. She does not feel supported by family members and expressed concerns about being neglected owing her cultural beliefs which sees children with intellectual disabilities as lazy and a burden. She was also concerned about lack of formal support in the country to help children with special needs,

Mrs. Lamptey is a well educated woman and works as a professional in the field of research. Her son has autism but with improved communication. Like her husband, she sometimes travels abroad for conferences and holidays and uses such opportunities to buy learning aides for her child. She is very happy that her son has basic communication skills which enable him to interact with other members of the community. Her husband, and immediate family as well as extended family members

are very supportive. She tries to stay on top of her son's medical issues and keeps a file with all his medical records. Among other activities, her son has a personal speech therapist, goes out to play tennis with his dad and other sibling and is a regular member of the Sunday school club at church. Mrs. Lamptey however expressed concern over lack of opportunities to make children with special needs feel part of society and lack of public funding to support families of children with special needs.

Mrs. Kyei's daughter has Down's syndrome. She has two children in addition to her daughter. Her hope was to work in an office after completing teachers' training so she took additional course in banking and finance at the university. Her husband works in another city and comes home on week ends when possible. Owing to the demands of caring for her child, Mrs. Kyei decided to forego her dream of working in the bank and now works as a teacher. She is very concerned about her daughters future and wonders what will happen when her other children are of age to marry owing to the stigma attached to having intellectual disability in the family. Also, she wonders what will happen if her husband should lose his job and they can no longer support their child owing to the high financial cost involved.

Aunty Corne is widowed and has a six year old son with autism. She is a professional special education teacher and she feels stretched by trying to manage the family's daily needs against the needs of her son. As the only boy in the family, she has anxiety about him not being able to be called a man, have a family and provide for the needs of the other family members.

Aunty Tsotsoo is a single parent. Just after her son was diagnosed with autism, her husband started behaving strangely and has disowned him saying he has not given birth to "such a child" so she should "name the father of that thing". They already have three girls and even though they yearned for a boy, her husband thinks it is worthless to have a son who cannot take over the family name. She is deeply concerned about the future of her son when she is no longer able to work to provide for him.

4.5.2 Meet the Teachers

Generally, this group was defined to include "professionals" who have direct experience with children with intellectual disabilities for at least one year. The main reason for selecting participants with this profile was to allow for a considerable amount of life experiences on the research topic. It comprised of officers within various ranks in the education of the children but the focus was those who were classroom teachers.

All the teachers who participated in this study have been teaching children with special needs who have a variety of impairments such as Autism, Down's syndrome, Fragile X and Asperger's syndrome.

4.5.3 The Schools

The study was conducted in two schools for children with special needs. One school is state owned and the other is private. These were quite distinct in that, the cost of attending a private school is very high whilst the state owned school are less expensive. In addition to this, the private school had more learning aides with fewer pupils in a class. The opposite is true for the government school.

4.5.4 Additional insights

The opportunity to conduct the interviews in three languages; English, Ga and Twi provided participants with the possibility to fully express themselves. This implied that our conversations were not only interesting but revealing and meaningful. A benefit for this study was that participants were devoted to spending a great amount of time to share their personal experiences. Even though some of the accounts were painful and difficult, the participants were prepared to speak out.

Another dynamic impacting our conversation was the level of pride with which some parents shared their experiences. Depending on their level of economic and social status, some parents emphasised their child's accomplishments in a way that seems to take off their focus on other daily struggles. The latter was minimised in order to stress the point that parents were very dedicated and proud of being able to provide "sophisticated" therapy and other learning aids to improve their child's condition. For instance, as one parent captured in her experience, "*Society would be deprived of his skills if we had not improved his ability to interact with others because he is very jovial and people enjoy his company.*"

The point is that, such a statement among others made it quite difficult to see the daily struggles of this parent in caring for a child with intellectual disabilities. The focus of this parent however changed as we spoke about another stage of social inclusion which has to do with community involvement. At this stage, the participant spoke about unpleasant attitudes in society but she suddenly "brushed" it off by saying that; *"I can't be bothered because people who look down on such children are ignorant."*

This aspect of the conversation reminded me of Goffman's ideas on face-work. Goffman explained that during interactions, people try to manage the art of face work by maintaining good feelings. However, when this good feeling is disrupted, they try to save their "face" through protocols such as avoidance. Perhaps making that statement was the parent's way to maintain that taking care of her child was indeed not a struggle. For me, I find this significant since it draws attention to the need to for researchers to take notice of under text appearing during interviews.

CHAPTER 5:- CULTURAL CONCEPTIONS

5.1 The Pre-stages

To explore present experiences of social inclusion is an attempt to take my participants back to their past lives before their children were old enough to experience the reality of community life. Becoming a parent is one of the most significant and joyous moments in the lives of most families in every part of the world. Parenting is generally stressful but being told that your child has intellectual disability could be more stressful. In Ghana, childbirth is a duty to society and the increased status children bring to their families makes it even harder for parents to know that their child has impairment.

While specifics may differ, I found it necessary to explore the feelings and reactions of my participants whose children were diagnosed with intellectual disabilities. When I asked the parents about their initial feelings and reactions, their answers were not different from what has been discussed in other studies. These included feelings of shock, grief, disappointment, adjustment and powerlessness (Oeckerman, 2001, Lessing and Strydom, 2001). Questions like, *"Oh God, why me?" "What did I do wrong?" "How could this have happened to me?" "Who is behind this*?" were asked without answers. In most cases, the mothers had uncertain expectations about the child's future and most of all; they wanted to **escape reactions**

from society. Each of the participants had a unique experience but within each family, the physical presence of having a child with disability and perceptions among community and extended family members could not be denied.

In the study of how parents react when they learn that their children have intellectual disabilities, researchers usually mention that families go through stages such as shock, sorrow and acceptance (Oeckerman, 2001, Lessing and Strydom, 2001). But I think that in the case of Ghanaian parents, "acceptance" is rarely part of their experience. As mentioned in **chapter 2**, Ghanaians have a strong belief in spirituality and this leads to perceptions that nothing happens by chance. As a result, the parents expressed ambivalence about the cause of their child's intellectual disability and they did not only seek medical remedy but explored spiritual causes and solutions to the diagnosis. In the case of one mother; she attends every religious function with the hope of finding what has caused her child's impairment as well as find healing for him: "*There is no miracle working man of God who doesn't know me in Ghana. And I don't mean these small, small ones….I mean the big ones.*"

For yet another mother, she has taken her child to all the powerful traditional healers…"*We have taken him to the North and Volta regions to see all the powerful spiritualists and [4] "mallams" just to change his fate…*"

Thus, for participants of this study, when they talk about reactions, they refer to the need to explore human and supernatural causes and not merely accept a diagnosis. Most often, the assumption is that, "something" or "someone" must be behind the cause and as one mother asked, *"Of all the people in the world, why should I be the one with such a child? I am sure someone is behind this…"*
In this situation, the cultural context of thinking about intellectual disability is emphasized and the determination to know the root causes within the supernatural realm is even stronger.

In addition to considerable feelings of lack of acceptance, a significant component of having a child with intellectual disability for the participants was the issue of cultural conceptions of impairment. It is a well known fact that no cultural heritage can fully explain how individuals think and act; yet, the culture of a people can provide an understanding of social reactions and implications of having a child with intellectual disability. More often than not, differing cultural beliefs are approached by

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[4] "Mallams" are spiritualists who are believed to have supernatural powers.

people who do not understand it in an oversimplified manner. However, for participants of this study, the cultural conceptions of intellectual disabilities in terms of beliefs systems, cultural norms and values determine attitudes, guide decisions, and affect interactions of their children with broader society. As a result of such perceptions, children with intellectual disabilities are viewed as "others" and this affects interactions with them. But what kind of belief systems and cultural values and norms are they reacting to? In order to throw more light on them, I will discuss these one by one.

5.2 Belief Systems

When discussing the pre-stages of diagnosis and how parents react, I mentioned that in the Ghanaian society, nothing happens by chance and this make parents refuse explanations that medical factors are solely responsible for their children's impairments. Here, I want to argue that the personhood of Ghanaians are influenced by belief systems which are seen as an interconnection of visible (seen) and invisible (spiritual) worlds. Regardless of the type of religion that people follow, Ghanaians continue to maintain and follow indigenous beliefs in supernatural forces (Salm and Falola, 2002, Anthony, 2009). Elegant traditional ceremonies such as festivals, and rituals performed for individuals to mark birth, puberty, marriage and death symbolise the religious and cultural values of Ghanaian society. While these rituals vary by tribe, a common feature includes paying homage to ancestors and asking for their continued protection and prosperity.

In addition to this, a belief system structured on the power of hierarchy is found across all tribes. This consists of the High God ("Nyonmo" or "Mawu"), small gods ("abosom"), ancestors, witchcraft, oracles, magic and sorcery also known as 'juju' (Nukunya, 2003, Salm and Falola, 2002). To this end, the gods give warnings when society is out of order through earthquakes, famine and individual misfortune such as disability. They however protect and watch over their people when order is restored.

To most Western readers, scientific explanations may hold a certain degree of credibility to influence their way of life. On the contrary, *"spirituality is the medium by which Ghanaians understand and make sense of their world"* (Dei, 2004, cited in Anthony, 2010, p.92). The content of these beliefs appear in folk stories, art, proverbs, and the literature. For instance, a regular character in Ghanaian folktale is the famous "anansi" which happens to be a mischievous spider. Just like the Norwegian tales of

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Asbjørnsen and Moe captured in *"askeladden som kappåt med trollet";* Ghanaian folktales teach acceptable behaviour and tell stories that frown upon unacceptable behaviours. In most of these folk stories, the life of "anansi" serves to impact the beliefs, values and history of Ghanaians to future generations. It is worth mentioning that, such stories are mostly told by well respected older people in society as a result of their elderly status. However, whether told by elders or teachers or by mothers to their children in the kitchen, such stories provide insights into beliefs systems and values of Ghanaian culture.

In writing this thesis, I have discovered that it is easy to get caught up in theoretical and other forms of debates surrounding social inclusion for children with intellectual disabilities. However, I think that the dilemmas surrounding this are complex and as intellectual disability was defined as an experience, in **Chapter 1**, I suggest that we turn to the experiences of participants to explore their realities. For this analysis, I will like to use the experience of a parent called Akos. My reason for choosing her is that her experience illuminates deeply held beliefs on spiritual forces which I find salient for this analysis. Besides, her experiences were also similar to what three mothers (Tsotsoo, Aunty Corne and Ekua) shared.

Question (Author): You mentioned that your child feels disowned by your family members and you also feel neglected because of your child's condition. Can you please tell me how you exactly experience these?

> **Answer (Akos)**…*I gave birth in the city and I remember the first time I went to the village with my son…I saw the river from which we used to gossip as village girls and after I drank water from the calabash, the flavour from the smoked pot made me realise that my spirit had returned within me. Rumours about my child's condition were rife before I got there. I used to have a small girl from the Northern Region who used to stay with me. She stole my money and I really beat her mercilessly before sacking her to her parents. You know; people say the Northerners use a lot of [5]"juju" so one of the rumours was that she used her witchcraft to make my child disabled to teach me a lesson….As tradition demands, I went to greet the "abusuapanyin" (head of family) as a way of presenting myself and my child to him. But I sensed that he didn't want to get closer to my child because he never requested to carry him; which is the norm. Rather,*

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[5] "Juju" is a fetish object of charm believed to have supernatural powers

he said that if I know I have done something wrong to bring this curse upon me and the family, I should confess so that they can pacify the gods. He did not even talk about "kusum" (customary rites) for my child. Apart from my mother, people avoided me and my child like a plague. Even my own sisters did not carry him on their back or play with him like we do with other children.

…In my culture, disability is not accepted because it is seen as a sign of laziness. As a male child, he is expected to own a farm in future and go out with his fellow men to bring food home and take care of the rest of the family. Then he has to marry and have children. But if you are disabled, you cannot do all these things. The belief is that, when you use harsh words to insult them, they will be forced to speak back and this way, they will learn to talk and fight back like a man to overcome their problem. I experienced this during our visit and I felt a lot of emotions when they used foul language to insult my child. Sometimes he just doesn't want to play or do anything and prefers to sit alone in a corner looking at others. Then they will say things like, "ei, jimi jimi, sɔ ri" (meaning, hey! Stupid boy, stand up!) or "kwaa don to, sɔ ri na mi suma wu" (lazy one, get up and let me send you). For them, it was a way of engaging with the child, but as a mother, it was heavy to hear them call my child lazy and stupid. He can't be here all the time. He needs to experience life among his family members. But what else can be done when no one wants him around just because they see him as a burden and lazy. They have just cut us from what they do and see him as a lost member of the family. What else can I do?

Ghanaian culture is grounded in harmonious relationship between the living and the dead. Any form of expressed hostility is a taboo since it disrupts the harmony in the community. When impairment is believed to be caused by witchcraft, it is typically believed to be the punishment for an offence committed against someone close to you who has used a spiritual practitioner to enact justice. Amongst other traits, suspicion of witchcraft is associated with characteristics such as "loners", those with "queer habits" and anyone "considered anti-social" (Nukunya, 2003, p. 60). Owing to this way of understanding witchcraft, its association with intellectual disability becomes logical. This is because; it is quite common to find "anti-social" traits in children with intellectual disabilities.

I think that Akos's experience presents the above way of thinking. When she told us about rumours in her village on what caused her child's impairment, we first notice that there was a belief that the young girl from the Northern region who she once beat mercilessly has used her "powers" to bewitch her son. With this basic view, we

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also see that, people tried to avoid her company as well as her son. As she said, even her own sisters avoided her child like a "plague". This is due to the belief that any close association with such a person may place others at risk for transfer of the witchcraft or "curse". The latter obviously creates a distance and when this occurs, the child becomes isolated from basic daily life activities such as playing with other kids or having the chance to feel connected with other members of the family such as aunts, uncles, grandparents and other members of the community. Here, I think we should pay attention to the fact that in Ghana, the individual is closely bonded to the family and being distanced from such relationships can be very disturbing and discriminating to its individual members. This reflects Akos feeling that her son is a lost member of the community and they have been cut off from activities owing to his impairment.

Although witchcraft and "juju" are feared in Ghana, they are not given the same effect of power such as the power associated with gods or ancestral spirits. The belief in punishment offered by spiritual powers is to serve as a social control and challenge individuals to uphold the moral code of society. It is widely held that when a sin is committed, the spiritual powers punish the offender and this can take the form of impairment such as intellectual disability. However, it is also believed that, in some cases, a spiritual man ("mallam") can make contact with the relevant high powers to "minimise" the pain of the punishment and appeal to the gods not to allow that punishment to occur again. Such appeals can however be made when the offenders makes a confession and goes through some cleansing rituals. The request by Akos's head of family (abusuapanyin) reinforces notions of belief in supernatural as explanations to causes of intellectual disabilities. By asking her to confess any wrong-doings, it becomes widely accepted that Akos has indeed caused a taboo or sinned. The salient point for this discussion is that, as a result of the belief that intellectual disability is a punishment or curse from gods, a distance is created between the child and other members of the community. Another outlook is the conclusion that individuals are ultimately accountable for their actions which have caused misfortune and this leads to their rejection. The impact of such attitudes is that Akos will be shamed and blamed in the village and together with her son; they will experience isolation which will affect their inclusion in the everyday activities of the community.

Also, when Akos talked about "kusum" (rites), she was actually referring to rites of passage performed to accept new members into the community. Akos had this expectation because she gave birth in Accra and it was the first time he was taking her

child home. Under normal circumstances, tradition demands that the head of family would hold the child, put a drop of water and "schnapps" into his mouth, mention his name three times and present him to the ancestors that their "young blood" has returned home and a new member has been added to the family. Participation in such a rite to celebrate birth highlights the cultural value attached to children as the rebirth of new life and continuation of the family's lineage and heritage (Salm and Falola, 2002)

Unfortunately, the head of the family was not concerned about this ritualistic protocol. Rather, he was focused on the "curse" brought into the family. The inability of Akos's child to participate in this significant rite of birth indicates that, he is not seen as a full member of the family and this could contribute to the possible alienation of mother and child from family and community activities. Such distancing can be viewed as a result of cultural beliefs with suggests that impairment is brought about by an individual's misdeeds and individuals must be removed from such people to avoid the calamity from spreading to them. In fact, in some societies in Ghana, (such as the Ga's and people of Volta region), it is believed that the mere mentioning of the name of someone with intellectual disability can put others at the risk of a similar impairment.

Putting these elements of beliefs and their accompanying attitudes together, we see why Akos said she and her son have been abandoned by the family. Basically, she has brought a curse to herself and the family. The effect on the latter is seen as stronger because it is not only Akos and her son who bears the blame. Rather, it trickles to the image of the bigger family as having "bad blood". The latter has a potential of preventing other members of the family from getting married owing to the belief that the curse of children with impairments runs through the family.

In Goffman's (1963) work on stigma, he discussed that stigma does not only affect the stigmatized individual but also, other people surrounding the stigmatized person. He referred to this as 'courtesy stigma' or stigma by association. In analysing Akos experience, it becomes clear that she experiences stigma by association since it is not only her son who has been isolated but she also feels neglected by her family members. Further to this, the distance being created by her family members emphasizes Goffman's (1963) idea on stigma by association since they are also trying to avoid "contamination" by associating themselves with the "cursed" child and mother.

It is worth mentioning that, it was not only Akos who experienced stigma by association. From the conversation I had with the 12 participants, it strongly came up

that they all experienced stigma by association as a result of close and regular contacts with children with intellectual disabilities.

As the rest of the thesis will demonstrate, the deeply held beliefs in supernatural and magical forces profoundly shape experiences of having intellectual disability in Ghana. It is also clear that this is linked to customary norms and values and they affect each other.

5.3 Customary Norms and Values

From the above discussion, a picture is beginning to emerge that belief systems guide understanding, attitudes and actions towards children with intellectual disabilities. As mentioned earlier, the belief in spirituality leads to the acceptance of intellectual disability as a curse and this is strong enough to create a distance between the child and other members of society. In this section, I will attempt to demonstrate that traditional values and norms affect how social inclusions for children with intellectual disabilities are understood. Most importantly, I want to stress that it is only through an exploration and appreciation of the traditional, cultural and historical context that one can really begin to understand perceptions of intellectual disabilities and the impact of these perceptions on social inclusion in society.

To make the analysis clearer, I will divide the discussion into two sections. The first section will discuss customary norms as they relate to values attached to an individual's behaviour and the second section will look at customary norms in relation to expectations of survival and expectations of social participation for children with intellectual disabilities.

5.3.1 Customary norms and values on behaviours

I proceed on the premise that Ghanaians attempt to interpret their daily experiences through a complex web of practices such as adherence to the social custom on greeting and respect to elderly members of the community. Greeting is a valued demonstration of respect and it is also a way of asking for blessings from elders. For instance, among the Krobo's of Eastern Ghana (where I come from), children greet adults by bending low and saying, "dzoor mo" (meaning, bless me) and they respond by raising their right hand with the words, "Mawu nɛ dzoormo" (meaning may God himself bless you). Basically, the custom of greeting varies with the person you are

greeting, their status and their gender. But generally, children are supposed to greet adults. With regards to respecting elders, Ghanaians attach value to seniority and old age because it is believed that an elder achieves old age by living in harmony with their families, the community and spiritual realm. Consequently, they must be respected and admired by younger generations. Any act of disrespect towards an elder is a huge offence and frowned upon. Thus, if customary norms and values are specific to a society, it follows that attitudes and actions which are seen as "abnormal" or unacceptable are also culturally bound. In this case, behaviours of an individual which are different from the norm or expectations are viewed as "disordered".

An analysis of these views and their impact on the experience of intellectual disability is the central theme in the next sections.

5.3.2 Valued and devalued social traits
5.3.2.1 Otherness

The concept of "otherness" is based on supposed difference which allows humanity to be divided into two groups: one that embodies the norms and whose identity is valued, and another which is defined by faults and susceptible to discrimination and devalued. I think that in order to help readers understand the social implication of such "otherness"; I must distinguish between the ways in which "otherness" is understood in Ghanaian society. In Ghana, "otherness" is viewed as unfamiliar characteristic of an individual. Perhaps this might be termed "uniqueness" in some Western societies. But in Ghanaian societies, "otherness" is perceived as difference from prescribed customary norms and this could be the cause for condemnation, exclusion and in extreme cases, ostracism. In order to illustrate this, I suggest that pay attention to excerpts from a conversation I had with one of the parents; aunty Corne. I have extracted specific aspects to make the illustration clearer.

Author (Question): You mentioned that people ignore your child because she cannot speak properly. How does this affect her ability to be included in social activities?

> *Aunty Corne: You know, the first time I noticed that my child had a problem was when he was not saying mummy or daddy after 6months. When the doctor told us about the problem; my greatest fear was if he was ever going to talk. You see, all the children in the neighbourhood, when they meet an adult, we expect them to at least say good*

morning or good afternoon as a sign of respect. These are all part of our way of life in the community so I have been very worried that if he can't talk, it will be difficult for him to be part of everyone. In fact, that is why I bring him to school everyday. I want the teachers to help him to talk and once he is able to do that, he will be fine. But as I said, I know that God will heal him and for me and as long as he lives long, I am ok. Even if he cannot take care of me, or marry in future or work, at least, I know that I still have a son…

I think that Aunty Corne's concern is typical for many parents and families. As children grow, they are expected to express themselves with words and a concern arises when this is not happening. But what's more, the lack of speech can be a major source of worry particularly in a country like Ghana which has an oral tradition and the ability to talk is highly valued. The ability to talk becomes necessary during the communication custom of greeting which is seen as a sign of respect. In a culture where greeting is valued children who do not demonstrate this are seen as having bad manners and this could be particularly isolating and stigmatising. Thus for Aunty Corne, her concern may be based on two issues. The first one is for the sake of the child's personal development and the second one would be to have a sense of belonging in the community by participating in daily social protocols.

However, for the child with intellectual disability, the struggle to greet may be the result of the child's failure to learn this social custom or 'aloof' personality as explained by Wing and Gould (1979) **chapter in 2**. But regardless of the impairment, failure of a child to uphold this custom of greeting is viewed as difference and this creates "otherness". Considering these factors, I think that Aunty Corne tried to imagine how her child will be treated by others if he is not able to participate in such valued social custom. Perhaps this is why she emphasized the notion of speech as important for her child. As a parent, she might also be concerned that without this skill, her child will be excluded from opportunities where people generally meet to interact with each other. In a culture where collective living is emphasized, the inability of Aunty's Corne's son to be part of such general gatherings will be accompanied by isolation and social stigma. Thus, we can say that Aunty Corne's concern extends beyond her child's personal development to include his ability to live as a member of the community by participating in simple protocols of daily life such as greeting.

In addition to the custom of greeting, children are not supposed to look into the eyes of their elders. Children who do so are seen as challenging the status and authority of their elders (Salm and Falola, 2002). Despite the many challenges associated with behaviour of children with intellectual disabilities, they are still expected to show respect by looking by standing still and looking down to the ground when talking with elders. The latter are skills which children which intellectual disabilities might struggle with but then, it is considered as a sign of misbehaviour and stubbornness if they fail to do so. Owing to the inability of some children with intellectual disabilities to take their eyes off and stand still in front of elders, they are seen as "disrespectful". Such unusual behaviour is against the status quo and it is often seen as an indication that something is wrong with the child and the child gets noticed as being different hence, "others".

From the above explanation, it becomes easier to appreciate Aunty Corne's concern for her child to be able to at least talk or say basic words. Understandably, acquiring this social skill will enable him experience socialisation and avoid the tendency of being isolated or viewed as disobedient. Further to this, children are seen as a reflection of their parents and "disrespectful" children can bring shame to their parents. Obviously, when aunty Corne thinks about her child's inability to talk, she interpreted it from the custom of greeting and she might have had this conversation with herself: *"what would others say if he is not able to greet them? Oh! They will say his parents didn't teach him good manners. No wonder he is different from the other children in the neighbourhood. Shame on her mother!"*

At this stage, it is important to acknowledge that the ability to communicate and socialise with people while maintaining expected norms of behaviour are highly valued in Ghanaian societies.

In talking about respect for elders, I mentioned that, the status of being an elder is valued because elders are believed to have lived in harmony with people and the spiritual realm. In addition to this, being an elder also means living to become very old and dying a natural death. The latter is highly cherished because an individual can then attain the status of an ancestor.

5.3.2.2 The desire to become an ancestor

Besides the need to talk, Aunty Corne also mentioned the issue of living long, marriage and work. Owing to space constraint, I will like to briefly touch on these aspects since they will be discussed in detailed in subsequent sections.

Traditionally, Ghanaian societies consider becoming an ancestor as one of the goals in life. To acquire this status, a person must fulfil certain criteria such as living to an old age, having children, supporting the lineage or community and dying a clean or natural death (Nukunya, 2003; Salm and Falola, 2002). The prestige of becoming an ancestor is that, ancestors are supposed to watch over and protect their family members in the realm of the spirits. In most cases, the traditional perception is that children with impairments do not live long (this will be discussed in details in the next section) so they cannot attain this status. In addition, Ghanaians consider suicide, lunacy and death through accident as unclean and unnatural. Even though it was not specifically mentioned in this study, it is generally reported that most people who commit suicide in Ghana have a form of impairment such as intellectual disability ([6]Ghanaian Times Newspaper, 2011). Thus, in a culture where old age and elders are valued, the belief that children with intellectual disabilities will not live to an elderly age or die an unclean death excludes them from full membership in the community.

Closely related to the value placed on attaining the status of an ancestor is the idealistic expectation to marry. Even though Aunty Corne has already imagined that her child might not be able to marry; her story still confirms that, in Ghanaian society, marrying and having children are obligations to society. Perhaps she feels that her child will not marry because of societal stigma or because, he will just not be able to do so. But regardless of where the blame is placed, there seems to be an agreement that in Ghanaian societies, children with intellectual disabilities are not likely to marry. Such perceptions do not only create barriers for full membership in community whilst alive. Rather, it also prevents one from achieving the status of being an ancestor after death since ancestors are expected to have a family and children.

So, looking at it from a bigger picture, it becomes reflected that beyond the ability to talk, Aunty Corne was also thinking about the need for continuity in the family and the honour attached to being an ancestor. The question for her might be, *"how can my son live a full life in the community especially with his speech problem?"* So according to my understanding, I think that when she talks about social inclusion, she is also referring to the inability of her child to maintain customary norms on greetings which binds society together, his inability to marry and have children to continue the family lineage and the probability that he might not die a natural death to

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[6] http://newtimes.com.gh/story/most-suicides-caused-by-mental-health-dr-akwasi-osei

become an ancestor. As a result, her child will be neglected in socialisation protocols and other forms of social activities where other children are socialised into values, customs and norms of society. The latter will be discussed in detailed in chapter 6.

In this way, I think that when participants talk about social inclusion for children with intellectual disabilities, they are also talking about customary norms which are enforced through valued and devalued traits in society. What has created this barrier between the child and family and community members according to my point of view is the emphasis placed on norms, and values attached to social customs such as greeting, the desire to become an ancestor and value placed on marriage and procreation. As I have already explained, the perception is that children with intellectual disabilities are not capable of upholding such customary norms and values and this isolates them from the rest of the community.

I therefore wish to reiterate that, by exploring traditional values and their influence on its individual members, it is possible to understand how emphasis placed on abiding by these values and norms distinguishes children with intellectual as "others" who are not full members of society.

Subsequently, while "otherness" includes a notion of unfamiliarity, it extends beyond difference. It also includes characteristics such as rejection. In most instances, children with intellectual disabilities are seen as an embarrassment and must be hidden from public view. The cumulative impact of such attitudes associate leads to feelings of rejection for children with intellectual disabilities. To illustrate this, I will precisely draw attention to the experience of Tsotsoo in the following narration:

> *Some time ago, there was an art and painting competition for 9-11 year old children at the Dansoman community center. My child is good at painting so I decided to let him participate. That morning when we got there, some parents who had known me for years asked "why are you here"? And I said I brought Nii Lante. And they were like, oh…yeah, your son. What is he coming to do? I was very hurt because it was as if my child doesn't exist or he was not supposed to be there. The hardest part is that, there is lack of social events for him to participate so it hits me real hard when we make an attempt for him to take part in activities and people treat him like air or piece of furniture in the room*

If we look at Tsotsoo's narration, she sent her child out just to enable him participate in a children's activity. If we look deeper into why she sent him out, it can be noted that she also wanted him to have the chance to interact with other children and perhaps just feel like any other child having fun with painting among his peers. In fact, it was not only Tsotsoo who mentioned the desire for her child to socialise with other children in the community. Mrs. Kyei and Akos also mentioned that they send their children out with the intention of helping them play and interact with other children, particularly, non-disabled children. In the schools were I conducted this study, I also noticed that all the schools have planned activities that involve interaction of the children with non-disabled children. It can therefore be argued that experiencing life through interaction with non-disabled members of society is important for children with intellectual disabilities.

From my informal talk with the key contact persons of the schools, I got the impression that when the children socialise with non-disabled children, the latter are able to see their disability as "unique" instead of emphasizing negative perceptions of "otherness" that exist in society. By so doing, it is expected that, the trend of "otherness" towards children with intellectual disabilities will change among the younger generation. So, generally speaking, when participants talk about social inclusion, they also have some kind of idea that through interactions with non-disabled people, rejection will be minimised and perceptions will change with time.

Contrary to such expectations, in this study, five out of six parents experienced distance between their children and non-disabled members of the community and all the six teachers agreed that the reality of being perceived as "others" limits possibilities of interaction between the children intellectual disabilities and non-disabled children.

In Tsotsoo's experience, we can see that her frustration was directed at comments which implied that her child was not supposed to be at the art and painting competition. But it was a community activity for children so why did this woman ask what Tsotsoo's son was doing there? I think we can look at this from two angles. In the first instance, it could be argued that this woman thinks children with intellectual disabilities are not capable of taking part in painting competitions since they probably have nothing to offer. On the other hand, it is possible to argue that she thinks Tsotsoo's son doesn't belong there because by virtue of his impairment, he is not part of the non-disabled children ("us") but belongs elsewhere "others". As Tsotsoo mentioned, it is rare for her child to have such opportunities to participate in social activities and it hits

her real hard when her child is treated like "a piece of furniture" or as if he doesn't exist when they try to take part in events. In this statement, there is a sense of feeling that organised activities in the communities do not make provisions for children with intellectual disabilities. The latter indeed leads to rejection and together with negative comments and attitudes; it becomes easy to understand Tsotsoo's frustrations.

From this angle, it becomes possible to argue that when participants talk about social inclusion, they are indeed referring to comments and attitudes which reinforce perceptions that children with intellectual disabilities do not belong or are not supposed to take part in the same activities as non-disabled. After all, they are not part of "us".

But then such negative comments and attitudes do not just spring up. If the law of causation is anything to go by, it can be said that, something might have happen to cause such attitudes. After all, regardless of their difference, children with intellectual disabilities are still 'humans'. So, what is it about them that make society think they are incapable? In other words, what is the history behind the perception that once born with impairment, nothing good will come out you?

5.3.3 Traditional perceptions on expectations for survival

Till now, I have discussed that emphasis placed on norms of behaviour can distance a child with intellectual disability from opportunities to be socially included in family and community socialisation processes. In addition to norms on behaviour, it is also important for readers to note accepted traditional perceptions about survival of children with intellectual disabilities. The persistent belief in Ghanaian society is that such children will not survive. As a result, it seems more reasonable for families to avoid "wasting" money on them by paying school fees or buying learning aides to improve their condition.

Currently, in Ghana, advancement in science and technology as well as medicine can help with the survival of children with intellectual disabilities and correct or improve some of their defects. However, the notion persists that such children are *"with us just for a short while"* and this strongly reflects traditional expectations of survival for the children. My argument is that, such perceptions and attitudes may compromise attempts by parents to plan for their children's future by neglecting their education. I wish to mention that this does not mean that the children are not loved. Rather, it is seen as less important to spend the already scarce family resources on them at the expense of "normal" children. The grave implication is that the child might miss

formal development of skills and the opportunity to socialise through avenues provided by the school. As one teacher stated;

> *School re-opened many weeks ago but as you can see, the class is empty. The needs of these children are last on the family list. This delays their skill development which is essential for interaction with non-disabled people…*

Concerning how values placed on expectations for survival impacts on social inclusion, I will like to refer to two experiences. The first one was shared by a teacher, Mrs. Gaisie and the second one by a parent; Tsotsoo.

> *Mrs. Gaisie: I have a pupil called Adjo who is over the moon when she hears that the school has been invited for a program outside. She has fragile X syndrome and extremely impulsive. Her biggest problem is that, she didn't get proper potty training so she still defecates on herself even though she is almost 11 years. The worst part is that, she hates diapers and no matter how had you try; she still finds a way to take it off to ease on herself. Because of this, we hardly take her out and this clearly affects her chance to participate in social events outside the school…. For a child like this, you can't blame society for not accepting or including her. Until she overcomes this attitude, it will remain very difficult to meaningfully engage her with non-disabled children.*

> Tsotsoo: *I love Kwame. He is my first born and in spite of the fact that he is a special needs child, I want him to have the same things in life like his younger siblings....But [7]sister, I have spent 6 years of sleepless nights worrying how these can happen. My son's condition needs a miracle… (Long pause with tearful eyes). He is very restless, spits in the face people and smears toilet on his body. They call him the horrible boy and any time we go out and he starts playing, it turns to hell. The last time we took him to the children's park; he spat on everyone's face and chased the other kids away. To him, he was just playing but that is not fun for the other kids or their parents…. I don't know how the people out there will make him feel part of them with his behaviour.*

When asked how the children were involved in family activities, four out of the six parents mentioned that having intellectual disability is enough burden for the children and they find it as extra work to involve them owing to their inability to do things on

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[7] It is very common for Ghanaians to call each other 'sister' or 'brother'. Sister as used here refers to me,

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their own. Precisely, one mother stated: "*But what can he do for himself? It takes too much time to get to him to eat; let alone, clean plates or tidy up. I just do everything for him.*"

In order to understand the significance of why children must take part in house hold chores and behave well, I think it is necessary to discuss some of the roles of a child in Ghanaian families. In the first instance, children are expected to contribute to daily running of the family, be hardworking and disciplined. Being disciplined here also means taking care of yourself as well as younger and older members of the family. If I can use myself as an example, at the age of nine years (primary 3), I was able to prepare porridge for breakfast, wash my own clothes as well that of my mother and older siblings. My elder sisters were responsible for preparing lunch and dinner and my big brother washed heavy items like curtains. By primary five, my older siblings were in boarding school and with the help of my mother, I started taking care of the house, going to the market, cooking, washing and cleaning. The point I am trying to make is that, for a child with intellectual disabilities, their impairment is seen as a limiting factor to contributing to such household tasks. Whether this is real or perceived, the notion is that the children are 'useless'.

Going back to the narrations for this analysis, teacher Gaisie points out that her pupil (Adjo) wasn't given proper training on using the toilet and that is why she defecates on herself. Given this feeling, teacher Gaisie thinks that unless Adjo is able to be responsible and independent, it is unlikely that she would have opportunities to socialise with other pupils outside the school. Similarly, Tsotsoo mentioned that her child is neglected by other children and referred to as 'horrible' owing to his attitude of spitting in the face of other children.

But the question is; what do these tell us about social inclusion? In this part, I will provide two arguments: First, the accepted traditional knowledge that children with intellectual disabilities will not survive must be noted. Second, investing in children who will not survive or cannot give back to society is seen as a "waste" of scarce resources. These two aspects are related to each other and I will expand on them in the course of the analysis.

Turning to my first line of argument, the choice of parents to neglect their children with intellectual disabilities reflects traditional expectations of survival. Until recent advancement in medical technologies, long term survival of children with intellectual disabilities was not the norm in Ghana. In some cases, this expectation used

to manifest itself in the notion of disposing of such children through "bloodshed". The latter refers to ways of cleansing the community from the presence of "cursed" children by leaving them in forests or rivers to hasten their return into the spirit world. In cases where the children are not disposed off through "blood shed", expectations that they will not survive translate into attitudes which compromise attempts at training them towards the future. Such attitudes are justified on the notion that, it is not worth "wasting" money on medical care since the children will definitely not make it in the long run. Rather, there is a need to pay attention to and invest in "healthy" or normal children since they will take care of the family in future.

My second argument is reflected in the feelings of teacher Gaisie. When teacher Gaisie talks about lack of training, she was implying that parents do not recognise the value of training their children to be independent since they probably see it as a waste of time. After all, they will depend on others for the rest of their lives and as one parent said, *"What can he do for himself?"* This stresses the point that right from a tender age, it is internalized that the children are "useless" and cannot do anything. As a result, a lot of effort and attention is not given to their training. The frustration of teacher Gaisie is in her shock that at age 11, Adjo still defecates on herself. Not only was she frustrated at this lack of improper training but as a professional, her reaction emphasizes the statement of the other teacher that parents do not take education of these children seriously. Thus, for teacher Gaisie, social inclusion will be enhanced when children with intellectual disabilities are given appropriate training to make them responsible during social interactions. As a professional, her feelings underscore the importance for parents to invest early in the education of their children to enable them acquire formal training and social skills needed to enable them do interact with other members of society.

The need for training was also reflected in the narration of the parent. Tsotsoo mentioned that her child's behaviour is the main reason why they cannot participate in activities. Looking at this through the lens of child training, it can be argued that if Tsostsoo had focused on training her child, his habit of spitting spiting in the face of people could be controlled to enable him take part in community events.

But if child training is a natural thing that comes with child birth, why is it that the children with intellectual disabilities are not given the appropriate training? It is likely that readers with psychological or medical minds might attribute this to biomedical conditions. In as much I agree with such arguments, I think that beyond

biomedical the argument, the expectation that children with intellectual disabilities will not survive becomes much stronger here. The belief that "such children are with us for a while" translates into attitudes of gross neglect towards their training. Also, when the children fail to be "with us for a short while", they are indeed seen as not being able to do anything for themselves. To stress this point, I will once again quote the parent: "*but what can he do for himself?*"

Thus, according to my thinking; expectations that the children will not survive leads to lack of investment towards their training (both formal and informal) and this leads to poor development of personal and social skills which excludes the children from enjoying the benefit of being involved in activities outside the home and schools.

In line with my argument and participants experiences, I think that social exclusion occurs as a result of inherent traditional perception that children with intellectual disabilities will not survive. The latter translates into poor investment in the training of children with intellectual disabilities to enable them develop needed competence for interaction. This leads to their isolation and limits their chances of enjoying the life of ordinary children in the neighbourhood.

5.4 Expectations of social participation

In Ghanaian society, problems do not end when a child with intellectual disability survives. When they beat the odds of life to survive, society sees them as a burden and this prevents them from being given any social roles, and this restricts their involvement in community life. As mentioned earlier, perceptions on causes of intellectual disability, expectations for survival and expected social roles contributes to cultural conceptions of intellectual disability in Ghana. In earlier discussions, I also mentioned that society dictates social roles for its members through kinship structures. An example of such social role is that as children grow, they are expected to return home to care for their elderly parents. As a result of this expectation, any form of investment in the child is offered on the assumption that the child will reinvest back into the family. Also, Ghanaian families emphasize the interest of the collective group and individuals are expected to sacrifice their personal interest to realise the interest of the family or group.

In order to get a clearer picture of this, I suggest that we take the analysis back to Akos's narration under the subsection, **5.2.** In Akos narration, she mentioned that in

her culture, children with intellectual disabilities are seen as a burden. The community expects its members, especially male children to have farms, grow crops to feed himself and the rest of family, marry and have children. This implies that the individual has economic responsibility towards his immediate and extended family. Also, he is supposed to have children to continue the family lineage. Based on these ideals, it becomes clear that the expectation to give back to one's family both socially and financially are valued roles. However, in a society where social stigma prevents employment opportunities for children with intellectual disabilities in their adult life, it becomes logical to think that they do not have the potential to earn monies to "give back" to the larger family. The inability of the children with intellectual disabilities to fulfil this obligation becomes a barrier for their full membership in the family and community. This is because; they are seen as non-contributory members who will feed on the hard labour of others and this is unacceptable.

Owing to the perception that children with intellectual disabilities cannot contribute towards the progress of the family, it is regarded as unnecessary and a waste to invest in them. The situation becomes worse when the child is a male child or the first born. For instance, a gender bias in favour of male children is the norm in Ghanaian societies. Principally, men command a lot of respect because they are the bread winners who protect and maintain the family name. Additionally, positions of power and authority for making community decisions reside in men. The Ga's call them **"*weku nukpa*"**; the Akans say *"abusuapanyin"* and the Ewes say *"torgbe"*. As mentioned earlier, survival of the family is dependent on mutual cooperation and supporting the extended family through regular contributions within the kin system is a duty. In effect, the inability of a man to contribute or marry as a result of having intellectual disability deprives him of being in a position of power and authority and this is very devastating for men in Ghanaian society. Thus, for participants of the study, they break the line of family authority by having a male child with intellectually disability. The consequence is that in their adult life, they are left out when 'real men' are needed to represent the family.

The feminine aspect of the above is that; Ghanaian women are expected to nurture and satisfy the needs of other family members including their husbands. The perception is that a woman with intellectual disability is burdened by her own needs and this will make it difficult for her to meet the demands of other family members. As result, a man who marries a woman with intellectual disability will end up playing the

role of nurturing family members and this is against the social conventions of the role of men in society.

Owing to this masculine position of power; the complexity of having a male child with intellectual disability could be more devastating. Frustrated and drained, one mother stated:

Ah! He was my only hope. We already have three girls and he was the one to step in for the family and protect mummy....you know what I mean

Another mother felt that:

When he grows up, people will look down on him because they will say he is a weak man... family members consider him non-existing and he is seen as a lost member...

From the above, participants' experiences speak to the point that; a key challenge for children with intellectual disabilities is how families and society define social roles of its individual members. Expectation within Ghanaian societies that children will develop towards ideal goals of supporting the family and providing for its elderly members becomes a powerful force. The inability of children with intellectual disabilities to fulfil these roles excludes them from family support and no investment is made towards their future. The latter translates into poor development of skills and in the case of Adjo (the 11 year old pupil who still defecates on herself); this means that her chances of going out to mix with non-disabled children and enjoy social activities become restricted. The effect is that, isolation becomes more and social exclusion becomes deepened.

But how about the community? If social inclusion means taking part in family life and meaningful participation in community activities; how are the children viewed through the social lens of the community? To explore this, I suggest that we turn to contexts in which participants experience this.

5.4.1 Participating in community activities

From the experiences of participants, I think that the motivation for social inclusion is based on two major reasons. The first one is in the interest of the child to make him feel like any other person. The second one is for the sake of the family and community to feel "blessed" by the presence of its members who can contribute in

various forms to its progress. For instance, when I asked participants why social inclusion is necessary for the child, they provided answers such as, *"to make him experience life like any other child", "for development of her communication and social skills", "to contribute his talents to society"* and to *"prove to society that such children are capable of contributing to national development."* By considering these factors, I think that when participants talk about social inclusion, they evaluated its benefits in relation to the interest of the child.

The second motivation was based on the interest of the family and community or society. As mentioned earlier, in Ghanaian societies, the individual's sense is closely connected to the family and community, and the survival of the self suggests that the individual must be kept close and not at a distance.

Too often, a discussion on the "community" in African societies turns into an abstraction of networks which are assumed to exist reflecting a group of people with familiar characteristics who naturally care and support its members in times of difficulties. But such descriptions of the community could be misleading and problematic. In order to understand participants' experiences, I deem it necessary to discuss the essence a being a 'person' as part of a community in the Ghanaian context.

First of all, it is worth mentioning that, whereas most Western ideas of a person is that of a "lone" individual, in Ghana, a person is defined in reference to the community. John Mbiti (1970) summarised this African view of a person by saying that, *"I am because we are, and since we are, therefore I am"* (p.141). The implication of this statement is that, for the Ghanaian, the reality of community life takes precedence over the life of an individual. In the Ghanaian view, it is the community that defines a person and without incorporation into the community, individuals are considered to be mere people who "loosely hang around" and the description "person" cannot be fully applied to them. This distinction is emphasized by the native Ga's (of southern Ghana) who use terms such as *"gbormor kɛkɛ" and "gbormor hekaalor"* to differentiate between a "mere man" and a "man of great importance" respectively. The word *"hekaalor"* includes the idea of excellence, maturity and power and the expression *"gbormor kɛkɛ"* translates into "mere man" or "not a man". In addition to such expressions, Ghanaians believe that an individual can fail in life or at worse, be ineffective. As a result, society emphasize rituals of incorporation such as "dipo" and the necessity of learning social rules by which the community lives is emphasized

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during such rituals. The essence of these initiation rituals is to show that the individual has attained the status of a full person in the eyes of the community.

Traditionally, this sort of status is attained in expectation that the individual will participate in communal life through the discharge of various obligations. It is through the discharge of these obligations that transforms the individual into a full member of the community. In this sense, in the Ghanaian understanding, emphasis and priority is given to duties which individuals owe to the collective group and the exercise of these duties is of great value.

Therefore, it can be assumed that when talking about social inclusion, the individual thinks about how he can be part of this community and how he can live as a "full" member. To some extent, this assumption can be verified by all the twelve participants in this study. All the participants mentioned that participation in rites of passage such as puberty rites (performed when children usually attained teen age to signify that they are fully grown members of the community) are significant but unfortunately, it is impossible for children with intellectual disabilities to participate. When asked why, one teacher explained that such rituals require an understanding and obedience to ritualistic protocols and because of sensory difficulties and loud nature of some children with intellectual disabilities; it becomes difficult for them to be initiated. But one of the parents had a contrary view. According to her, such rites signify that the children are now adult members of the community capable of marrying and being independent. Children with intellectual disabilities are not considered as being able to attain such status hence, their neglect in such rites. Both explanations are valid and regardless of the views, the fact still remains that the inability to participate in such significant rites contributes to alienation of children with intellectual disabilities and their families from community life.

But such elaborate ceremonies are not the only activities in the community. Participants mentioned events like clean up exercises, community durbars, football matches, drama, weddings, parties and funfairs as some activities which take place in the community. Ironically, participants in this study could not recollect a particular community activity which meaningfully involved the children. Out of the six parents, Aunty Corne and Tsotsoo told me that, clean up exercises and football matches are mostly organised in their respective communities However, their children are kept out because no one sees their worth in such activities. On occasions when they have been

out, they only end up as spectators and not active members. Tsotsoo captured this by saying, *"they don't even want my child to get near them, let alone, involve him".*

Another parent, Mrs. Kyei said, *'the community activity is not there and even if it is there, they don't care about these children'.*

For Mrs. Lamptey, her experience of community participation relates to access. According to her, no special facilities exist to accommodate the needs of children with disabilities during community activities. These include wheel chair access and playground items for children with special needs. In her view; the lack of facilities to accommodate their needs of the children makes it very inconvenient and stressful to take them out. In the long run, this limits their participation in community activities and their ability to make new friends and interact with non-disabled children. She questioned those behind the design of facilities for children at social centres by saying that,

> *Do they ever consider that there are some children out there who are disabled? But the truth is that, who really cares about these children? These are public facilities and a proof that government doesn't care about their plights or simply put, they don't even know that such children exist!*

A contrary view to the above was that, some participants decide not to participate in social activities to avoid drawing attention to their child's condition:

> *He gets very noisy and restless when a lot of people are around and people stay focusing on him. Sometimes, it's embarrassing when we go out.*

Public disgrace is however not the only possible issue. The reality of financial problems and poor health represents a real barrier for social inclusion for children with intellectual disabilities. All the parents in the study mentioned financial difficulties as a source of strain but four of them stressed that; without enough money, it is challenging to access transportation which is critical to attend social functions. Two of the four parents who are also single mothers cited their health as a reason for preventing them to be present at functions where their children will get the opportunity to mingle with other people. According to these parents, their overwhelming responsibilities make them depressed and this confirm studies by Plant and Sanders (2007) that, taking care of children with chronic disabilities such as intellectual disabilities has an impact on the

health of parents and such parents have the risk of experiencing higher rates of mental and physical problems.

It is unclear that the single status of the parents made them more impoverished. However, the combined financial problems may have contributed to putting them at risk of poor health which renders it impossible for them to take their children out for activities outside the family. Perhaps further studies on single mothers could provide additional findings concerning the overall situation of social inclusion for children with intellectual disabilities.

For some of the teachers, their experiences on community participation relate to lack of meaningful involvement,

> *It is always nice when they go out and hang out with other kids. But there is no conscious effort to involve them. They are just treated as spectators. Even we the teachers are not involved in the planning of inter-school activities. They only remember us when they see us at events and sometimes try to create something artificial for them…Teacher Quaye*

Others teachers also spoke about prevailing myths and stereotypes about people with intellectual disabilities. Mrs. Gaisie, narrated her experience by recounting an occasion when they were invited to participate in a singing and choreography competition. At the end of the program, all the participants were refreshed with drinks and biscuits. She however noted that, her pupils were served in disposable cups whilst the non-disabled children had 'proper' cups. Additionally, the drink for her pupils was over diluted and they complained to her that it was not sweet. Apparently, she approached those who were serving and asked if they could do something about the drink. But this was the response she got:

> *She looked in my face and said, madam, **shut up**! You people like complaining too much. You were initially not part of this program and the budget was approved before your school was included. So be grateful that we have managed to squeeze something to refresh your pupils.*

In the deep thinking of Ghanaian society, the use of disposal cups for the children is an indication that, their cups have been contaminated and must be disposed off after use. Even though this might not be the real meaning behind the use of the cups, the reaction of the organiser to Mrs. Gaisie's request implied that, the children were indeed not considered in the community activity meant for all children in the area. Perhaps this

stresses home the point that, they must indeed be kept out of public view. Thus for the teachers, participating in community activities means being involved in planning of activities and being treated like any other children. .

Politics viewed as a barrier to community participation

One of the teachers however viewed community participation differently. According to him:

> *The greatest barrier facing these children is the government. It is not about what our ancestors and forefathers said about disabilities. It is about giving them opportunities to meaningfully participate in community life and the government has the power and all it takes to break this barrier. If today, government should announce that it is mandatory for all public sectors to employ one percent of these children for basic jobs, I can tell you, their dream for inclusion will be fulfilled. So the issue here is the government and not stereotype or their lack of ability.*

I found the above point challenging because I never thought about social inclusion as such. Also, I have decided to separate this idea to throw more light on it. Ghana has ratified all international treaties on rights of people with disabilities and it was the **first country in the world** to commit to the United Nations Convention on Rights of the Child (UNCRC) on 5th February 1990. Also, the government's decision to distribute free copies of 'The Persons with Disability Act (2006) indicates positive steps in raising awareness on rights of people with disabilities. Yet, there was a general feeling among participants of this study that policy makers are partly to blame for barriers faced by children with intellectual disabilities to be socially included. As one parent said to me:

> *When I asked why you were interested in this topic, you told me about your experience in Norway. My daughter, if the government of Norway has not invested into that sector, maybe the story of people with special needs in Norway will be the same as Ghana. It's all about government. Who are the ones running the printing press in Ghana? Where do we get our pens from? Who is sewing government uniforms for children in public schools? These are sectors which can be reserved for people with special needs. But what is happening? Either politicians are running them or Chinese folks are in charge. Do the government even know about these children? You take them to school and train them and it's like everything is in vain because the struggle continues…*

With this inherent feeling, it can be argued that participants believe that major changes can occur if government pays attention to children with intellectual disabilities and dedicate efforts at implementing the numerous policies on their rights to enable them realise their dreams of participating in mainstream society and contributing to national development.

But the question is that, will the problem of social inclusion be solved if government decides to implement all policies for people with disabilities in a month? Perhaps, it is tempting to say yes, but I do not have the answer so let's turn to what participants have to say in chapter 6

CHAPTER 6 TRADITIONAL NOTIONS

6.1 Culturally perceived causes of intellectual disabilities

When discussing impact of belief systems for social inclusion for children with intellectual disabilities in chapter 5, I mentioned that intellectual disability is seen as a form of punishment. Here, I want to argue that, the culturally perceived causes of intellectual disability tend to shape all aspects of family and community attitudes towards the child. In most cases, people may distance themselves from those who have brought such "curses" to the family and community. It is worth mentioning that, the distance created in such cases is more than the simple distancing of family and friends often reported in the literature. In Ghana, the child is seen as a physical evidence of divine displeasure and this is accompanied by rituals

Tsotsoo remembered an incident when:

> One of the elders of my husband's family came to visit… He asked for a bottle of schnapps and went round the house pouring it and saying some incantations. Then he came back to the room, and put some white and red cloth on the wrist of my husband and me and marked the forehead of our child with white clay…. He claims they signify protection so we were supposed to be safe from future attacks.

But the "curse" of impairment does not vanish with the performance of the rituals. In most cases, the reasons for this curse become a topic for discussion in the community and any form of close association with the child or family is believed to place other members of society at risk of being "cursed"as well.. In order to throw more light on this social reality, I will like to use excerpts of my conversation with one of the mothers, Ekua to analyse this.

Question (author):- "You mentioned earlier that your child does not feel part of the family owing tensions with his grandmother. In what way (s) do you experience this?''

Aunty Ekua…*My mother in-law openly referred to my child as a "musu b" (forbidden or cursed child). She jokingly says that God must be sleeping when forming my child and she won't be surprised if he was formed on a Sunday because God must be resting. Suddenly, grandma says my child and I are the cause of all the family woes so they don't want to have anything doing with us. I lost my mother many years ago so my mother in-law is my child's only grandmother. But because she sees him as bad luck, she is physically and emotionally distanced from him. She has given him the nickname, "fa nipa" (meaning half human). The last time we visited grandma, his cousins who were around started calling him "fa nipa" and "jimi jimi" boy when they were playing. When I shouted that they should stop calling him that, my mother in law scorned me and said that if I don't want them to play with my child, I should stop bringing him around after all, he is indeed "half human." I think this is creating so much tension between us so of late, we don't go there and they also don't invite. We don't benefit from family support which is supposed to be strong and he will never get to know his cousins and other relatives well…*

In Ekua's narration, we can easily recognise how cultural perceptions about the cause of impairment can distance a child with intellectual disabilities from other family members. Her son's grandmother calls him a "cursed" or forbidden child and the belief is that close association with him can lead to the transfer of such curses. As a result, it became evident that her child's little cousins were also calling him "half-human" and gradually, the perception to be distanced from him seems to be growing. We also get a picture of the tension she talked about. For instance, she thought that she could change the perceptions about her child by asking grandma to stop calling him "half-human". Perhaps by so doing, the other children will see her son as any other child but 'unique'.

On the contrary, grandma openly rebuked her and told her not to bring her son around if she feels bad that others are calling him by his due name. In Ghana, it is common for children to be with their grandparents during school holidays and week ends. Even though such informal supports are taken for granted; they can be very helpful especially when parents are overwhelmed with child care. An additional benefit is that, grandparents are known to be the custodian of the family's history and culture and they serve as a good source for teaching younger generations about the family history.

In Ekua's case, grandma is physically and emotionally disconnected from her child owing to his impairment. The effect of this that, in addition to missing out on child care support, her son also misses out on opportunities to enjoy the benefit of learning the rich culture of his family through grandma. Most importantly, he misses the chance to establish a relationship with his cousins as well as enjoy the company of other family relations. Thus, when Ekua said that they have been cut from family support which is expected to be strong, she was actually referred to having a family life where members of her extended family will be more supportive, see her child as one of them and involve him in family gatherings and activities like any other children in the family. However, the perception that her child is "cursed" has led to negative attitudes which have created a distance between her child, grandma, his cousins and other family members. In reality, it is not only Ekua's son's who feels this disconnection. Her other children are also likely to experience this neglect from grandma and the rest of the family.

In addition to the power of cultural perceptions, upon deeper reflection, I think that one aspect worth considering is the issue of relationships. If we go back to Ekua's narration, she made use of the words, "grandma says" and expressed the desire to avoid tensions. Also, she was concerned that her son will not be able to establish a relationship with his cousins. But how about the possibility for Ekua to invite her son's cousin's to her house or take him to their houses to establish this relationship since grandma might not be there? I wish I had the chance to ask Ekua this question. But in my opinion, it will not be easy for Ekua to navigate her way through. My arguments are based on the following reasons:

Firstly, relationship between an individual and mothers-in-laws are very important in Ghanaian family life. Culturally, the opinions of mothers-in-laws are very strong and supposed to be respected. As it is commonly said in Ghana, mothers-in-laws have the power to break or bind marriages. For instance Ekua's mother-in law can bring confusion to her home by constantly nagging to her son (Ekua's husband) about the repercussions of having a child with intellectual disability in the family. In extreme cases, Ekua's mother-in-law can arrange for her husband to have another woman to prove that he is capable of giving birth to a "non-disabled" child. In most cases, tradition demands that he obeys his mother since she knows best and he also risk being cut from the family line if he refuses to obey his mother. At this stage, it is worth mentioning that, in Ghana, women get blamed for being the cause of impairment since

they naturally carry the baby in their womb. Even though men are not blamed, there are perceptions that men who give birth to children with impairment are not "real men" and this creates issues of self-confidence for them. Sometimes, under undue pressure and mocking, some men try to '"redeem" their lost confidence and image by having a child outside the family. A key person to promote the latter could be the man's mother and one repercussion is that; Ekua and her child could suffer total neglect from her husband. I'm sure Ekua might have weighed the consequences of the latter and in order to have her peace, she would rather prefer to move away from grandma than have tensions with her. The latter could lead to a disrupted relationship and grandma could further accuse Ekua of being disrespectful by bringing her child around in spite of her displeasure.

Secondly, with regards to the other in-laws (Ekua's sister's and brothers-in laws), they will also seek to maintain a good relationship with their mother in law by respecting her. As such, it is relatively easy for them to keep their children away or protect them from Ekua's child owing to the strong perception of grandma that he is capable of transferring his 'curse' to them. Most of all, as a result of grandma's attitude, the other cousins (who are I believe are young since Ekua's son is 8 years) start getting a form of socialisation or awareness that they must not interact with people who are different since they are capable of letting bad things happen to them. Perhaps to make matters worse, grandma would tell them folk stories of how "anansi" the famous character in Ghanaian folk tales avoids people with impairment to keep the community clean from disasters such as famine, earthquake and deaths.

Thus, according to my analysis, I think that in addition to cultural perceptions that Ekua's child is "cursed", she also feels obliged to respect her mother-in-law to avoid tensions with her. With regards to her child's cousin's it becomes obvious that they are being socialised into accepting that people who have impairments must be avoided. I therefore think all these factors come together to create a distant between Ekua and her son from the rest of the family and this limits their chances to participate in family activities.

6.2 Filling the Pitcher: - How do they handle it?

In order to understand how participants managed their challenges, an aspect of the conversation focused on how they manage to keep going. Looking at the answers provided, I find it important to mention the resilience of the parents.

Baskin and Fancett (2006) used the metaphor, "filling their pitcher" to refer to ways in which women who provide constant care find ways to replenish their energy to continue functioning. Following Baskin and Fancett (2006), I coined local term "εεkor sɛn" and "te oyaa nor tεε" (meaning, how do you handle it) to explore this aspect of participants experience. In fact, some participants laughed at the mention of those terms while others paused to think about what really keeps them going.

Similar to Goffman's (1963) ideas on how stigmatized people cope, participants of this study also talked about their coping strategies. One mother gave weight to her child's improvement as key component to "filling her pitcher". Whilst this mother may have difficult moments, she didn't make much reference to situations which sees her son's condition as a tragedy. On the contrary, she was inspired by her child to do more and focused on improving his condition. For me, this parent's focus on the child's ability to improve was self-empowering so it was not surprising that she was one of those who paused for long when the metaphor ''εεkor sɛn" was used.

Four parents mentioned their religious beliefs as their key means of coping. These parents had different experiences on how they exercise these beliefs. One of the parents cited her inability to go to church owing to her child's disruptive behaviour. She however said that she and her child participate in "church service in the comfort of your home" (a live church service radio program held every Sunday) and other religious programs on TV as well. Another parent mentioned that, they have family devotion at home and attend church on festive occasions like Christmas, Easter and New Year. This mother however gets frequent visits from the priest and other members of the church and she is also convinced that they pray for her child every Sunday.

Some of the parents also mentioned support from parent's associations as another way of coping. Two of the mothers spoke about their membership in an association for families with special needs. According to these parents, a key element in helping them "fill their pitcher" is knowledge and experiences at such meetings. As one of the mothers said, *At least, I know that I am not alone in this thing and we understand what each other is going through"*.

In general, many of the mothers expressed positive aspects of how they cope and many found their children as tremendous sources of inspiration. For some of them, they feel that the children care for them through simple things they do whether expressed or unexpressed. Looking back, one of the mothers said that any time she is not happy, her child is able to sense it and she comes to put her arms around her. This to her was significant to carry on in life because she sees her child to be comforting and sensitive to her feelings.

A final aspect of this section was to consider the weight carried by "silent". According to Ross (2001), the silence of women must be recognised as a language that needs to be carefully probed to understand the essence of the silence and identify gaps between fragile words to hear what they have to say. When asked, "ɛɛkor sɛn", one of the parents paused for a long time, started crying and answered "en kor yie" meaning, it *is not going well*. Her feelings were very heavy as she said,

> *I am suffering… (Paused to cry again)…it's because of attitude towards me and my child through this period of hardship. Raising a child with special needs as a single parent is difficult…because everybody, including my own blood sisters have rejected us…(another pause and tears)…that's our life…*

During this aspect of the conversation, the feelings and emotions of this parent were deep and her pauses and tears were long. Her words were very real to her situation and her tears could not be ignored. In her situation, she expects society to be more understanding and supporting because of her child's condition but this is not happening and makes it difficult for her to cope.

6.3 Positive elements of Ghanaian culture

While majority of experiences relayed by participants in study were negative, I wish to state that there are positive aspects of Ghanaian culture. I have not highlighted many aspects of Ghanaian culture because they are not salient to understanding data for this thesis. My aim is to highlight aspects of the culture which impacts on the perceptions of children with intellectual disabilities which I found during my research on this topic. On the positive side, one advantage of extended family to individual members can be found in the expectation that as children grow, they will return home to care for their elderly members. Whereas the state provides for the elderly in Western countries, in Ghana, the duty traditionally falls on grown children so such bonds of support can be helpful to its members. Also, while research by Ingstad (1999) in

Botswana suggest that devoted care for the elderly in African societies is a myth, Kuada and Chachah (1999) reported that, the responsibility to care for elderly *"is one of the cherished values of the Ghanaian society, a value which the citizens are determined to preserve"* (p. 78).

I also wish to state that, difference in terms of "others" is not always seen as negative. As mentioned in chapter two, some societies in Ghana, example the Ga's understand intellectual disability to be a connection with reincarnation. As a result, society sees such children as an obligation and opportunity to assist and care for them.

Finally, the issue of belief in the supernatural becomes positive when "faith" is emphasized as sources of healing to enable children with intellectual disabilities survive. For example, in the case of one parent, her strong affiliation to the church and hope for a miracle encourages her to reject cultural notions of survival. For this particular parent, it appears that her belief has led to greater acceptance that "her child will not die". This appears to have improved the quality of life for the child in question and during the interview, the mother seems confident that: *"one day, a miracle will change everything and my child will be normal."*

While comforting for those who believe, it seems that such expectations can encourage parents not to give up but rather, pay attention to other needs of their child with intellectual disability. Perhaps future research can examine how beliefs in "faith" allow parents to avoid self-blame and stigma associated with having a child with intellectual disability in Ghana.

With the above discussion on positive elements, I now feel that it is possible to turn my attention to how some participants have managed to "keep their heads above the waters".

6.4 Meet the exceptions

So far, I have discussed how social inclusion for children with intellectual disabilities has been interpreted by the participants'. I have specifically emphasized that cultural conceptions, values and norms influence attitudes towards the children. Even though advancement in science and technology may challenge some of the cultural values, it does not guarantee that traditional beliefs will disappear. But the question is that, are there any participants who have managed to overcome these cultural and social pressures? The answer is yes. Among the participant's I find the experiences of two

parents very unique. For these participants, it is not about cultural norms. Rather, it has more to do with the resilience of the family.

Mrs Lamptey:

> *My child is autistic with Asperges and even though it was difficult, I did my best to develop gestures and other forms of non-verbal communication with him at a tender age. We use facial expressions and body posture to express ourselves and I made sure I spoke with him a lot even though he couldn't speak back. He had delayed language development but I kept forcing and pushing him. I never insulated him from talking and the whole family made a conscious effort to bombard him with talking…Anytime we go church or the shopping mall, he seems to know everyone and says hello to them. These people also know him and they mostly stop to chat with him for a while. His best friend is not disabled and they hang out pretty well though with some difficulties. To some extent, he feels part of this community of people owing to his ability to talk with them. I believe that family members are responsible for initiating conversation with their child with special needs. I know it's not easy because the level of speech problems might vary. But I think mothers are more responsible to help their children with speech owing to their emotional bond and familiarity with these children from birth. If not, people will see them as "mumui" (dumb) and who wants to chat with a "mumui" in Ghana? You see, if we had kept my son in a situation where he never had the chance to talk, I don't think he would be having this kind of enrichment in his life…*

Mrs. Kyei

> *In my family, the love for our children is at the heart of everything we do. We try to think positively and give her the best of support to make her live a normal life. We don't accept what society offers to children with special needs. We are very regular with her health care and therapy and she has improved quite a lot. In order to increase her social skills, I sometimes sit with her in front of the house and this gives her the opportunity to interact with other neighbours. She needs a lot of supervision so when my husband is home, we take all the children out to play and have a meal. We never allow people to look down on her or treat her with disrespect.*

In accordance with the validity of findings and reliability of the analysis, I believe that it is worth analyzing the above exceptional experiences and explain them further. In order to do so, I will use a comparative approach. In comparative analysis, researchers are encouraged to pay attention to specific contexts in order to understand differences. To do this, I asked myself the question, what factors have made these participants

different in spite of the strong prevailing wind which seems to have 'suppressed' others? In answering this, I found the reasons below:

First of all, the two parents are arguably the "lucky" ones who were in a position of relative wealth. During the study, I noticed that both of them drive very "classy" cars and by Ghanaian standards, I can "confidently" categorise them as belonging to the upper class in society. Their lives are "less" affected by cultural perceptions because it seems they can afford the needed health care and learning equipments to support in the development of their children. For instance, in Mrs. Lamptey's case, her child's speech has improved, he can hang out with other people and his best friend is non-disabled. This means that for this child, isolation and exclusion is not so high and his life is contrary to societal perceptions of children with intellectual disabilities. She added that: *"we dress him well and he looks better than most people out there so you dare look down on him because of his disability."* In fact one of these parents travels with her child to USA for occasional health care and the other parent's husband buys a lot of learning materials for the child when he travels abroad.

Contrary to the above, the realities of financial difficulties, especially as experienced by other parents such as Ekua, Aunty Corne and Tsotsoo implies that, their daily life is a struggle and in addition to their child's condition, society places them on a much lower margin. As Aunty Corne said:

> *…It's all about "kudi" (jargon for money). Sometimes I wish I could buy some of those learning equipments and learning games for him but I can't afford. I have other mouths to feed and sometimes buying his medicines is even a problem… There is shop near our house. Anytime we go there, they treat us like the lowest of low because I am always asking for the cheapest items…*

Traditionally, people who are "cursed" are believed to live a life of misery and apathy and it seems the experiences of the latter group of parents (Ekua, Aunty Corne and Tsotsoo) seem to confirm perceptions that their lives are indeed affected by such cultural perceptions.

Secondly, with better economic conditions, Mrs. Kyei and Mrs. Lamptey don't have to worry so much about how to economically provide for the needs of the other children in the family. As a result, they can have a greater focus on developing their children with intellectual disabilities. This confirms studies by Ambilike and Outwater (2012) that families who experience less economic challenges are often able to develop the skills of their children with intellectual disabilities than those who live in poverty. In

other words, children from families with good economic background could have improved social skills which can enhance their chances for greater participation for social inclusion.

Finally, even though these parents acknowledge the reality of societal attitudes and perceptions, they are motivated at improving the quality of life for their children. By contrast, the other participants have internalised perceptions that their children will forever depend on them since they will not be allowed to be part of mainstream society. In this context, I think that the motivation to develop the children and get them involved in community life also depends on how parents internalize future prospects of their child.

In spite of their relative wealth and focus on positive future prospects, Mrs. Kyei and Mrs. Lamptey had other concerns. Mrs. Keyi has heard rumours that she used her child for rituals ("juju") to get rich and that is why her child is disabled. For Mrs. Lamptey, she was worried that when the siblings of her child are adults, the issue of having a disabled member in the family will surface when they have to marry. In as much they don't seem go by such comments, they seem worried and affected by such perceptions.

From the above explanation, it is evident that the exceptional cases do not entirely go against my previous conclusion that the effects of cultural perceptions are very powerful.

CHAPTER 7 CONCLUSION AND WAY FORWARD

7.1 Discussion of theoretical framework with respect to analysis

The present study is concerned with social inclusion for children with intellectual disabilities in Ghana from the experiences of parents and teachers. Theoretical perspectives were drawn from Goffman's work on stigma, Mead's self-identity theory, Brofenbrenner's family systems and my conceptualized model which looks at culture as a cross-cutting issue in all the theories. In Brofenbrenner's work on family systems, he described the micro-system as the context in which the child experiences face-to-face interactions to construct essential beliefs about reality through the acquisition and development of skills and abilities. The development of the child at the micro-level affects behaviour of the child especially during interaction processes

within the other systems. Traditionally, the significance of parental role in the child's development process becomes crucial since it is assumed that they are responsible for this learning process. From my conversation with the participants, I strongly feel that they all agree with the integral role of social and communication skills in the process of social inclusion for children with intellectual disabilities. In the analysis, it became evident that children with intellectual disabilities were viewed as dependent, "useless", unproductive and not expected to even survive. These perceptions are translated into attitudes of neglect by some parents and this leads to poor development of basic skills and abilities in the children. A typical example is the case of the 11 year old pupil (Adjo) who still defecates on herself because of improper toilet training. The effect is that this behaviour prevents her from participating in social activities outside the school. At a first glance, it can said that Brofenbrenner's interpretation is supported by this study since according to his theory, the skills and activities a child learns within the micro-system can affect interaction processes within the other systems. And in this study, we saw that children who have poor family training experience negative developmental skills which prevents them from being involved in social activities outside the family. However, in my opinion, the development of skills should be seen more in terms of traditional perceptions which believe that children with intellectual disabilities will not survive. This interpretation is supported by participants' experiences which suggest that it is not worth investing in children "who are with us just for a while". Thus, in as much as Brofenbrenner's theory is still valid; this study suggests that, in Ghanaian society, cultural traditions and values embedded in the micro-system must be critically considered when discussing how children with intellectual disabilities acquire social skills at the micro-level.

Goffman explained that stigma exists when people identify and label others as different owing to characteristics society evaluates as negative. He further explained stigma by association as stigma experienced by people who have regular or close contacts with stigmatized individuals or groups. This study identified social stigma and discrimination as some of the barriers for social inclusion for children with intellectual disabilities. Owing to their inability to uphold customary norms such as greetings, they are viewed as disrespectful. Moreover, community members believe that they are "contaminated" and must be avoided. Link and Phelan (2001) argued that when people are stigmatized, it leads to perceived negative label as being different. In this study, the children also experienced feelings of being different when family and community

members see them as being "others" owing to perceptions that they cannot uphold customary norms and values and they cannot contribute to the upkeep of the family.

Perhaps most importantly, belief in the supernatural combined with the belief in accountability for one's actions lead to increased stigma by association for family members of a child with intellectual disabilities. For instance, in analysing Ekua's case, it came up that she has also been neglected from family activities as a result of bringing a "cursed" child into the family. Further to this, her family members avoid contacts with her and she longer participates in family life. Ekua's case is similar to what other parents experienced. Four out of the six parents told me they have either been separated by family members or friends as a result of their child's impairment. In addition to stigma associated with having a difficult child, parents also expressed worry about the systemic consequence of having a child with intellectual disability within the family, particularly, how it can endanger the ability of their siblings to marry.

During this field work, all the teachers mentioned that people have nicknamed their school "jimi jimi" (stupid) school and call them "jimi jimi" teachers as well. The experience of the teachers is similar to my own experience. Being aware of the focus of my thesis, my mother advised me to be very careful with the children:

> *wɔ nii mɛ kɛɛ mumɔi ji amɛ ni ofɔ ko daŋ no hewɔ lɛ kwɛ mɔr ohe nɔ jogbaŋ' meaning…our forefathers said such children are spirits and you haven't given birth yet so be very careful with them.*

In addition to this advice, intensive family prayers were said for me on the first day of my field work. The essence was for God to protect me from any form of spiritual attack I might encounter in the cause of my work with the children.

Closely related to stigma is labelling and discrimination. This study confirmed that labels given to children with intellectual disabilities such as "jimi jimi" (stupid), "fa nipa" (half-human) and "musu bi" (forbidden child) are very derogatory and leads to stereotypes and discrimination which creates barriers between the children and other members of society. Finally, participants have adopted various coping strategies such as their belief in miracles, encouragement by their child's improvement and the feeling of love and warmth from the embrace of their children In line with this study, it can be concluded that Goffman's theoretical thinking are in fact real and supported by participants' experiences.

Mead explained in his theory of social identity that an individual forms a self-image through interaction with himself by taking on the role of the generalized other.

This study showed that participants look up to general attitudes, words and actions of people in the family and community to develop interpretations towards their "self". In this study, I think that society's perceptions on children with intellectual disabilities have been internalised into the individual in the same way that an individual interprets their own action by taking the role of the generalised others.

Firstly, it came up that, there is a general perception that children with intellectual disabilities are "useless". In addition to being seen as "curses" the children are not considered full members of the community since they cannot contribute socially and financially towards its upkeep. This perception has been internalised in the minds of people and this translates into low expectations of the children. As a result, the children are neglected and not considered during family and community activities. Following this, some parents have also internalised this perception and see their children as a burden who will depend on them for the rest of their lives. Closely related to this was the knowledge that through folk stories which present people with impairments as a sign of wrongful acts in society, younger generations internalise such perceptions and try to distant themselves from people who look or behave different. I think that this internalization is important for us to understand how isolation and social exclusion occurs for children with intellectual disabilities.

Also, some statements of participants emphasize the importance of symbols in formulating self-identity. For instance, Akos spoke about the river in her village and Tsotsoo talked about red and white cloth being tied around her wrist as a sign of protection. For me, these signs and symbols lead to the development of interpersonal relationships and serve as a symbol of identity to help Akos and Tsotsoo recognize their identity to the village where they belong.

Considering this analysis from Mead's theoretical point of view, it can be said that participants' experiences are representative of the idea that individual form a self-image through an interaction with himself by taking on the role of the generalized others and symbols and signs play a mediating role to establish self-identity.

In all of these processes, one key factor that runs through is the salient role of cultural traditions. Putting this process back to my model we can say that the meanings of family systems, social identity theory and the theory on stigma are specified, formed or altered within cultural contexts. In this way, I feel that my constructed model discussed under chapter 3 may contribute to a greater understanding on how social inclusion can be differently experienced by individuals.

7.2 Conclusion

In this thesis, I have attempted to understand how parents and teachers experience social inclusion for children with intellectual disabilities in Ghana. The beliefs surrounding intellectual disability and social inclusion uncovered in this thesis were diverse and complex and below highlight the findings:

1. Firstly, an exploration of participants' experiences revealed that; there was an imbued sense of spirituality amongst Ghanaians. Interpretations and understandings of intellectual disability are deeply rooted in systems of beliefs which attribute intellectual disability to divine punishment. Such beliefs permeate every aspect of life and an exploration of this highlighted its significant influence on social inclusion for the children with intellectual disabilities. For instance, the perception that a child with intellectual disability is "cursed" was highlighted as a barrier to social inclusion within the family and larger community. The distance created was explained as a way of preventing other members from being contaminated with the '"curse" or object of bad luck. This has led to feelings of rejection and isolation between the children and their families from participation in community life. Given the collective nature of Ghanaian society, such feelings of isolation may even have greater impact in experience of daily life for children. Thus, interpretations and understanding of intellectual disability as a punishment from ancestors informs attitudes and actions which exclude the children from participation in daily life of the family and community.

2. Secondly, interconnections in all aspects of life are translated to obligations whereby the individual is expected to contribute to the good of the family through kinship structures and the community. The cultural expectations that children will develop towards ideal goals to support the family and provide for its elderly both socially and economically was highlighted as a barrier to full membership of children with intellectual disabilities into their extended families and community. In order to understand this ideal, it is important not only to think about it in terms of cultural norms. Rather, it is also significant to consider structural meanings of dependency associated with having a child with intellectual disability. The way Ghanaians think about childhood in terms of competence and independence helps to explain why children with intellectual disability have been constructed in terms of dependence. An

exploration of this highlighted the significant influence of providing for elderly members of the community since the state does not provide for its elderly citizens in Ghana. This ideal provides a cultural script for decoding the child as an object of hard work. Thus, the exclusion of children with intellectual disabilities rests on cultural perceptions that see disability as the inability of the child to function in terms of working hard to provide for themselves and the family.

3. Thirdly, the study revealed that, in Ghana, a child's validity as a full person is denied as a result of having intellectual disability. In other words, being different means being less. Rules of social behaviour influenced by shared values and norms attribute certain behaviours as 'disordered'. As noted in the study, expectations of conformity in behaviour and respect to elders in society impacts on children with intellectual disabilities in negative ways. For instance, children who do not comply with verbal instructions due to speech problems are perceived as disrespectful and such behaviours were found to lead to "othering" in a society. The real challenge is that such identities impacts on individual achievements for the child and their inclusion in society.

4. Fourthly, a significant finding of this thesis is the knowledge of how Ghanaian culture influences understanding of social inclusion for children with intellectual disabilities. In general, findings on the need for meaningful participation in community activities for children with intellectual disabilities in Ghana resonates with studies such as those conducted by Baffoe (2013), Kassah (2007), Abbot and Mc Conkey (2006), Hall (2010) and Harris et.al., (1996).
Specifically, this study discovered that interpretations and understandings of social inclusion for children with intellectual disabilities in Ghana are deeply embedded in the culture, traditions, values, norms and systems of beliefs of Ghanaian society. Thus, in order to understand the experiences of participants, I feel that it is best to see things from the reality of their daily lives. In this way, I feel that my constructed model discussed under chapter 3 may contribute to a greater understanding on how meanings of family systems, social identity and stigma are specified, formed or altered within cultural contexts.

5. Finally, this thesis has brought out the culturally specific understanding of social inclusion for children with intellectual disability in Ghana. I have sought to further the

understandings of intellectual disability and social inclusion as an experience to broaden this view to one which allows for significance of family and community experiences. As participants have the last word with regards to their own experiences, I conclude by giving voice to one of the participants:

> *The best thing I want is for people to understand that; it is our cultural beliefs that handicap them. They are not curses and their condition can happen to anyone so people must learn to accept them to make them feel part of the community.*

In the light of this, I conclude that no meaningful understanding can be attained on social inclusion for children with intellectual disabilities in Ghana without a deep understanding of the culture of Ghanaians in terms of their belief systems, customs, values, norms and traditions. Experiences of participants in this present study indicate that, cultural elements are strong enough to make children with intellectual disabilities in Ghana **shut up!**

7.3 Way forward

Looking towards the future, further exploration on the role of beliefs systems deserves greater attention as it pertains to Ghanaian communities. Perhaps an interesting area for future study will be the role of religion in fostering social cohesion among children with intellectual disabilities and the community. It will also be interesting to investigate how religious beliefs combine with culture to enhance or inhibit social inclusion for the children with intellectual disabilities. The results of such a study would be helpful in addressing perceptions and in creating bridges between people with intellectual disabilities and non-disabled members of society.

In addition, future research could investigate the roles and responsibilities of extended kinship support in the social inclusion of their family members with intellectual disabilities especially the roles of grandmothers.

Finally, since symbols are widely used in Ghana and mostly embedded with spiritual significance, there is a potential to explore the relevance of such symbols and its meaning towards inclusion. An example to illustrate this is the *'funtunfunefu-denkyemfunefu'* symbol showed below
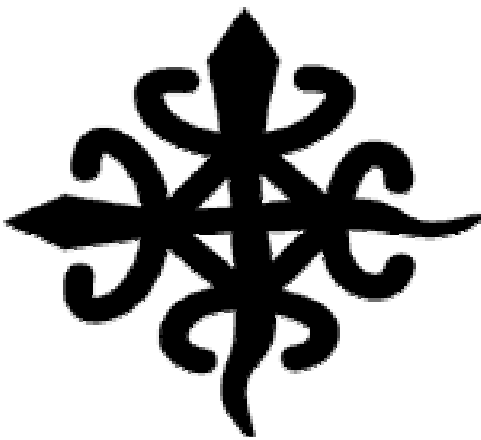
Traditionally, this symbol represents a Siamese twins crocodile. The meaning is that, even though they share a common stomach, they still fight over food but they are still joined together and live in peace as siblings. On occasions when this symbol is used in Ghana, the message sent across is that, even though people may have differences, they can still work together to achieve a common goal.

Perhaps the story behind this symbol can be used to explore how families and community members can co-exist and co-operate with children with intellectual disabilities to achieve common goals of society.

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APPENDIX 1 INTERVIEW GUIDE

Background questions for parents

To help you fully describe your experiences, I would like you to think about what happened, when, where, who was involved, how it happened and how you felt.

First, I would like to know a little about you.
- What keeps you busy during the day? Do you work? If yes, what work do you do, what are your responsibilities and what hours do you work?
- Tell me about where you live. Do you live in a compound or private house? Can you tell me what you and your child do for fun?

Involvement
Social inclusion involves taking part in activities or attending events such as games (sports), funfairs, reading clubs, cultural activities (play/drama), church and other community programs.

1. Tell me about community activities that keep your child busy after school and on week ends
   - How often does your child attend such community events?
   - How do you know about such events?
   - Who does your child play with during such activities? (Children with or without disabilities?).

2. Can you tell me about your experience of a moment when your child participated in a community event?
   - What exactly did your child do during this event?
   - Can you describe the experience of your child after taking part in this activity? Did your child say or do anything that captures how he felt?
   - Describe opportunities available for your child to be involved in community activities?

Relationships
Relationships with family, friends and people around are important aspects of social inclusion.
3. Can you tell me who your child's friends are?
   - Does your child have any close friends?
   - Can you describe an experience when your child made friends with other children who are not disabled?
   - Tell me about the relationship between your family relations and your child.
   - Describe what do they do when they meet
   - What is your experience of how they treat each other?
   - Describe the nature of interaction between your neighbours and your child.

Belonging

Having a feeling of belonging is also part of social inclusion. This can be expressed in terms of being an important member of a group, having a say or playing an active role in activities, people being nice and treating you with respect (and vice versa), and feeling comfortable and happy to be part of the group.

4. Describe an experience where you felt your child was an important member of a community activity.
   - Can you tell me what your child did during this event?
   - Tell me about an incident when you felt your child was not an important part of an event. Describe what happened.

5. What can people do differently to let your child feel s/he is an important member of a group or society?
   - What do you think should change about how society perceives children with learning disabilities?

6. Is there any other experience you would like to share?

Teachers

To help you fully describe your experiences, I would like you to think about what happened, when, where, who was involved, how it happened and how you felt.

Background questions

How long have you been working as a teacher with children with learning disabilities.
What prompted you to take up this job?
Describe the children you work with.

Involvement

Social inclusion involves taking part in activities or attending events such as games (sports), funfairs, reading clubs, cultural activities (play/drama), church and other community programs.

1. Describe your experience of a social event that involved these children.
   - How where they meaningfully involved and what was meaningful to you?

Relationships
Relationships with family, friends and people around are important aspects of social inclusion.

2. What opportunities are available to enable these children make friends outside this school?
   - Who are the friends of these children beyond the classroom?
   - Describe an experience when these children had relationships with other children who are not disabled.
   - Can you share your experience of how they made new friends and interacted?

Belonging
Having a feeling of belonging is also part of social inclusion. This can be expressed in terms of being an important member of a group, having a say or playing an active role in activities, people being nice and treating you with respect (and vice versa), and feeling comfortable and happy to be part of the group.

3. Tell me about your experience of a situation where the children were actively involved in an organised social activity with children without disabilities.
   - What did you perceive during this interaction?
4. How can society make these children feel they are important?
5. What other things should change to make these children have a sense of belonging in broader society?
6. Do you have any other experience you would like to share?

I appreciate hearing your experiences and thoughts. Thanks for your time.

APPENDIX 2 INTERVIEW PROTOCOL/INFORMED CONSENT

Social inclusion of children with intellectual disabilities

Participant name:……………………………….........................

Location:………………………………………….

Date & time of interview:……………………….

Introduction

Hello. Please, my name is Vyda Mamley Hervie. I am a student at the University of Nordland in Norway and I am doing a study on social inclusion of children with intellectual disabilities. I appreciate your time to talk with me. For the purpose of this study, social inclusion refers to being involved in activities, having relationships with others, having a feeling of belonging and hanging around.

Before we begin, I would like us to go through the informed consent form. The form describes the study and I would be happy to answer any questions you have about the study. If you agree to participate, kindly sign your name at the bottom of this page.

Read the informed consent aloud. Briefly describe what it means and answer any questions.

Signed consent form received?............

Consent

The interview may take about an hour. You are eligible to participate in this study because you have a relationship with a child or children with intellectual disabilities. I am interested in hearing your thoughts and learning about your experiences of social inclusion for the children. I will ask you about activities your child do (or activities the children do), their relationships with friends and family, how you feel that they belong and how they hang out. My aim is to have a better understanding of the experiences of

these children and understand the barriers they face towards social inclusion. Knowledge of your participation or non-participation will remain confidential

If you need a break at any time, please let me know. If there are any questions you do not want to answer, please feel free and let me know. And if at any point, you would not want to continue in this study, please let me know.

Do you agree to take part in this study?...................

Do you have any questions before we begin?................

Participant pseudonym…………………………………..

Sex:…………………..
Teacher
Parent/guardian
Your insights and first hand experiences are valuable. Thanks for your time.