

**DEPARTMENT OF PSYCHOLOGY**

**UNIVERSITY OF GHANA, LEGON**

**PERCEPTION OF STIGMA ON THE PSYCHOLOGICAL WELL-BEING  
OF SIBLINGS OF CHILDREN WITH INTELLECTUAL DISABILITY**



**A THESIS SUBMITTED TO THE DEPARTMENT OF PSYCHOLOGY,  
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**Declaration**

I hereby declare that this research is conducted by me under the supervision of Dr. Adote Anum and Dr. Araba Sefa-Dedeh. This work has never been submitted to any other institution by anyone for any award. All references cited in this work have been duly acknowledged and I take full responsibility of any shortcomings associated with this work.

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**Stella Nartey****(10169371)**

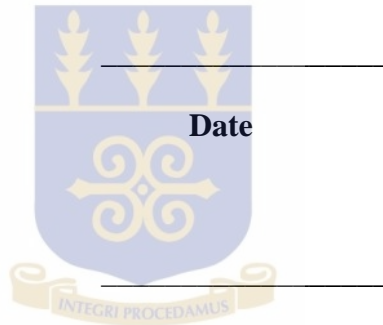
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**Dr. Adote Anum****(Principal Supervisor)**

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**Dr. Araba Sefa- Dedeh****(Co-Supervisor)**

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**Date**

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**Dedication**

I dedicate this work to the Late Robert Dornu Nartey, whose life and death inspired me to explore higher heights and to be the best that I can be.



## **Acknowledgements**

What shall I render unto the Lord for all his benefits towards me? I will take the cup of salvation, and call upon the name of the Lord. I will pay my vows unto the Lord now in the presence of all his people. Psalm 116 vs. 12-14. Lord, you were, you are and will always be.

I am ever indebted to God Almighty for all His goodness, mercy and guidance towards me throughout my life and especially during my stay on campus. Had it not been for Him, I would not have here today. Glory unto the Name of the Lord, Amen.

My sincere thanks go to my parents, Mr. and Mrs. J. L. Nartey and my siblings. Da, I am very grateful for your unswerving support and the midnight prayers you always say for me. Eno Mary, I say God bless you for your concern whenever you saw that I was discouraged. Thank you to my sisters, Doris and Becky for their unwavering support.

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**List of Abbreviations**

AACT Autism Awareness Care and Training

ADHD Attention Deficits Hyperactive Disorder

ASD Autistic Spectrum Disorders

CLAS Community Living Attitude Scale

FEIS Family Experience Interview Scale

ID Intellectual Disability

SIB Sibling Inventory of Behaviour

WBMMS Well-Being Manifest Measure Scale

**Abstract**

Siblings' relationships are one of the longest and one of the most influential relationships in the development of psychological well-being, and the formation of attitudes. The present study investigated the influence of the presence of having a brother or sister with intellectual disability and the positive and negative sibling relationship on the psychological well-being of the siblings. A sample of 69 siblings of a brother or sister with intellectual disability from four special schools in the Greater Accra Region of Ghana participated in this study. A correlational survey research design was used. Tests assessing, psychological well-being, perceived stigma and attitude towards intellectual disability, family relationship were administered to participants. Parents or guardians were asked to rate siblings' relationship with their intellectually disabled brother. Results of the study show that only positive sibling relationship one develops affects their psychological well-being. The type of intellectual disability, siblings' attitude towards intellectual disability and perceived stigma did not predict the siblings' psychological wellbeing. This study implies that developing of quality positive sibling relationship between a sibling dyad helps maintain the psychological well-being of siblings of an intellectually disabled person in spite of perceived stigma

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## CHAPTER ONE

### INTRODUCTION

#### **Background**

Intellectual disability is the most stigmatized deficit in Ghana (Agbenyega, 2005; Inclusion Ghana, 2011; Slikker, 2009). Intellectual disability, also called mental retardation, is defined based on deficits in cognitive function and social adaptive skills (Maulik & Harbour, 2010; Allison & Strydom, 2009). People with intellectual disability have deficits in their cognitive functioning; with their level of intelligence below the average level of intelligence of the normal population (DSM IV-TR, 2004). Intellectually disabled people also show significant difficulties in at least two of the following everyday adaptive skills; learning, communication, self-care and social skills (DSM IV-TR, 2004).

According to the World Health Organization, (1992) intellectual disability is also associated with most developmental disabilities such as cerebral palsy, autism spectrum disorders, foetal alcohol syndrome (FAS) and epilepsy. It is manifested in different forms with different causes such as, hydrocephalus, asphyxia, genetic defects (e.g. Down syndrome) and exposure to toxoplasmosis and drugs (including alcohol) during the neonatal period (Payne & Isaacs, 2002).

People with intellectual disability in Ghana, are given derogatory names in the local dialects among the various ethnic groups in the Ghanaian society (Agbenyega, 2005). Agbenyega stated that names given to these people by different ethnic groups in the Ghanaian society connote insults such as feeble mindedness, fools or idiots. For instance, the Ewes refer to them as “asotowo” meaning a fool or an idiot and the Gas call them “buulu”; which means reduced

mental abilities. These names are often given because of the belief systems of the Ghanaian society, and this negatively affects the individual with the disability.

Unfortunately, the impact of a disability does not end with the individual alone but extend to significant others who have some form of relationship with the disabled individual, for instance the family members and people who relate to him or her on a daily basis (Anum, 2011). Studies done in Ghana on disability and family relations have concluded that family members experience stigma from the general public, even though the family members do not necessarily have the disability (Anum, 2011; Slikker, 2009).

The goal of this study is to find out how siblings of such children are impacted; specifically how psychological well-being of siblings is influenced, the type of sibling relationship formed between the sibling dyads and their attitudes towards intellectual disability.

### **Ghanaian Culture and Intellectual Disability**

Children are seen as assets in the Ghanaian family and so a lot of measures are put in place to protect a child from being born disabled. Pregnant mothers are subjected to the adherence of various kinds of rituals and taboos, especially in rural society, in order to “curb the menace” of giving birth to a child who is disabled (Agbenyega. 2005). When children are born, the expectation is that they develop and behave normally.

A child is expected to sit, crawl, walk, talk and perform many actions as any normal child at the expected time. But a deviation from this norm is seen as a breach of such traditional belief systems (Avoke, 2010). The birth of a disabled child could lead to negative or ambivalent reactions from the society towards the family of persons with disability.

Various ethnic groups in the Ghanaian culture have the belief that children born with any form of disability especially intellectual disability are outcasts who cannot be integrated into society. Furthermore, persons with intellectual disabilities are seen as dangerous, unable to achieve anything profitable or “imperfect human beings” (Slikker, 2009).

According to Ocloo (2005), some communities in the Ghanaian society believe that people with intellectual disability are cursed because of some evil deeds done by the children themselves or a member of their family. It is also believed by the people from the Brong Ahafo Region that Down’s syndrome is caused by the expectant mother eating fish caught from a particular river in the region; hence they are called “nsuoba” meaning “water children” (Agbenyega, 2005). In the Northern parts of Ghana, their belief is also similar. It is believed that such children are spirit beings or are possessed by evil spirits who come to harm members of their family and society (Ocloo, 2005). Another belief about the cause of intellectual disability in a family especially if that family is known to be rich in the society is that the family exchanged the child’s intellect for money and riches (Slikker, 2009).

These beliefs, based on the cultural and religious views and also lack of understanding of the causes of intellectual disability (ID), have negatively affected families in which a person with intellectual disability is found (Agbenyega, 2007; Ocloo, 2005; Anthony, 2009). Such families are ostracized, labelled negatively, isolated from the rest of the society and stigmatized. Such families may not be allowed to participate in certain traditional and cultural practices; for instance, persons with any form of disability are not allowed to visit the chief’s palace because; it is believed that they will make the palace and the chief impure. They are also not able to hold a leadership role. According to Ocloo (2005), most families in the Ghanaian society, in order to avoid this disgrace and stigmatization, end up “giving back the children to the water”, abandon

the children or kill them as soon as they are born. Some of the children are locked up so that members of the society will not know of their existence. In some communities, children with disabilities are also used as clowns and jesters in the chiefs' palace during durbars (Ocloo, 2005). It is recognised that negative labels applied to social groups can lead to negative attitudes and beliefs about individuals associated with the group label (Agbenyega, 2005). One of the negative things to affect a person is stigma. When persons are stigmatized, by others in the communities in which they live, they are likely to lose their self-esteem. People, who are stigmatized, no matter what the reason, are perceived as being separated socially from people who are not stigmatized.

Perceptions of people with intellectual disability, grounded in the cultural and religious beliefs and misconceptions have also negatively affected the relationship other people may have with intellectually disabled persons (Quinn, 2007). Stigma can affect people in several ways especially their well-being. Stigma is said to have a dire impact on a person who experiences it; it affects people who are seen as „not belonging“ because of a mark or a variance that may be revealed on them sometimes due to sickness or disability (Goffman, 1963). In recent times, though the trends of attitudes are changing gradually due to an increase in awareness of individuals with intellectual disabilities, many people would not want to associate with them (Anthony, 2009). Family members are also not left out of the stigmatizing situation.

### **Impact of disability on families**

At the birth of a child, family members become eager to know the well-being of the child. Any child born with a defect is perceived as a betrayal of traditions and the family will suffer the consequence of the violation of traditions (Salm & Falola, 1999).

Most parents go through a lot of psychological turmoil on hearing the news about the condition of their child (Messer, 2005). Most people with intellectual disability live with their families (Anthony, 2009) and the burden and responsibility for their care falls on the family. Because of this, members in the family help to support the intellectually disabled.

The presence of intellectual disability in a family has been shown to have a significant impact on the family. The effects of having an intellectually disabled person in the family include physical and psychological distress due to the burden of caring for an intellectually disabled person (Anum, 2011; Sharpe & Rossiter, 2002; Seltzer, 1992). Disability in the family has also been noted to affect aspects of family functioning, causing strain on interrelationships of family members, which causes instability in such families (Anum, 2011). Studies have also found that there is likely to be a higher rate of marital discord and divorce in such families (Gupta & Singhal, 2004; Agbenyega, 2005). Further, families of children with intellectual disability undergo different emotional and psychological turmoil after the birth of such a child, which includes guilt, shame, anxiety and depression. Parents are found with unstable emotions, constant grief, psychological ill-health and poor social health (Vidyasagar & Koshy, 2010). Parents and siblings spend a lot of money and time on such a child.

Apart from the emotional adjustment and psychological changes that families of an intellectually disabled child undergo, they have to come to terms with the societal perceptions of their child and themselves, which usually are negative. In a culture where disability is perceived as a violation of taboos or a curse; stigma, exclusion and discrimination are some of the treatment meted out to families with disability (Slikker, 2009). Although families of persons with ID do not have any impairment themselves, they become sensitive to social prejudice and discrimination (Kawamura, 2009).

When family members feel that they are discriminated because of the family ties with an intellectually disabled person, this is called stigma by association (Goffman, 1963). According to Goffman, there is an important difference in the way stigma is experienced depending on whether the disability is readily and visually apparent or it can be easily perceived or not. According to Link and his colleagues there is a kind of loss associated with stigma; and as a means of defending themselves, they tend to develop forms of coping, which may include both positive and negative strategies to deal with their loss.

However, this is quite difficult for families looking after persons with disabilities. This is because family members are attached to persons with disability in a unique way and relate to them on daily basis; it then becomes necessary to think about how the wellbeing of family members is affected by exposure to discrimination. In addition, these families tend to be avoided not only by strangers but also by those close to them. Family members also avoid public places such as place of worship and community events (Anthony, 2009; Birdy & Nicholson, 2006). In addition, stigma does have an impact on relationships within family (Kawamura, 2009).

Siblings of children with intellectual disability will also face a lot of challenges that could affect their relationship and their perception of intellectual disability. Behavioural components associated with intellectual disability inherently change the relationship of siblings. For instance, there may be communication impediment because intellectually disabled children usually do not fully develop skills in communication, hence communication becomes very difficult and in the severe cases, impossible, between the affected child and his or her sibling (Smith, 2010). A child's self-injurious behaviours could be very frightening for siblings and the family in general and could make the family helpless and stressed. A sibling would not want to

be with his mentally disabled brother or sister because of these behaviours. Effect of the breakdown of sibling relations could have some impact not only on their interaction alone, but other aspects of the social and psychological development of the sibling (Volling & Blandon, 2003). Siblings become teachers and advocates and this is valuable in the family especially to persons with intellectual disability who lack acceptance in both community and educational settings (Anthony, 2009). The breakdown of sibling relationships affects this aspect of the relationship.

### **Attitudes of siblings towards disability**

One area that is limited in literature is the attitudes of siblings towards their brother or sister and persons with disability in the community. General attitudes from the society towards persons with intellectual disability and their inclusiveness in the community have been negative, with differing beliefs and perception from different communities (Anthony, 2009). One reason for this negative attitude, according to Agbenyega (2005), is because of the labels placed on individuals with intellectual disability. These labels are consistent with religious or cultural models. However, parental attitudes on the other hand, seem to be positive, especially in making decisions concerning their wards (ElZein, 2009). It has been explained that parents, because of their relations to the children with intellectual disability, are able to show positive attitudes. However, sometimes, in order to protect and shield them from societal prejudice, they keep them away from public view (Slikker, 2009).

**Statement of the problem**

There is a large body of literature on the impact of the different types of intellectual disability on the family. Notable among these studies is the adjustments and coping styles of parents, caregivers and other families to intellectual disability and the effect of intellectual disability on psychological well-being of significant others (Mbwilo, Smide & Aarts, 2010; Vidyasagar & Koshy, 2010, Anum, 2011). Nonetheless, there is a dearth of literature on how sibling relationships are impacted in families of intellectually disabled children especially in our Ghanaian culture which is collectivistic society. Sibling relationships play an important role in the total development of a person. A preponderance of research has stressed the importance of understanding the effect of sibling relationships in families (Furman & Buhrmester, 1985). This is because, unlike parental and peer relationships, sibling relationships are often long-lasting and influential in a person's life (Dunn, 2000). Sibling relationships provide an emotional as well as physical contact and support at critical stages. Siblings also serve as important agents of socialization for each other and this socialization can lay a foundation for development of conflict management, caregiving, and understanding of social processes (Hetherington, 2003). Therefore it is important to explore how sibling relationship is affected with the presence of an intellectually disabled brother or sister.

Studies of sibling relationships between typically developed siblings and those who have a disability have revealed a lot of outcomes. Early studies stated that having a sibling with a disability could lead to negative mental health outcomes for the typically developing sibling (Ostman & Kjellin, 2002; Sharpe & Rossiter, 2002; Stoneman, 2005). On the contrary, recent

studies have revealed that, typically developing siblings are not affected negatively, but may be influenced positively by the presence of a disabled sibling (Seltzer, Orsmond & Esbensen, 2009).

Research suggests that certain factors are influential in the determination of psychological well-being of siblings of children with intellectual disability. These factors include the reaction of the public towards siblings of an ID person, the type of sibling relationship developed between the typically developed sibling and the person with ID and attitudes towards intellectual disability (Bellin & Rice, 2009). Perception of stigma has been identified as a correlate of sibling psychological well-being, with higher perception of stigma correlating negatively with psychological well-being. Type of sibling relationship formed has also been noted to influence psychological well-being (Volling & Blandon, 2009), though much research has not been done where one of the sibling dyad is intellectually disabled. The question therefore is, does the presence of intellectual disability influence the outcome of the psychological well-being of siblings? Do siblings perceive stigma because of their position within the context of the disability? How does it affect their psychological well-being? How will the outcome influence their attitudes towards inclusion of intellectual disability? Given that, attitudes towards the ID have also been identified as a correlate of perceived stigma (Agbenyega, 2005), though its influence has been understudied, is it possible that negative attitudes will be influenced by higher levels of perceived stigma? Furthermore, how does the family relationship moderate between perceived stigma and psychological well-being, and what is its direct effect on psychological well-being? In line with the above, this research aims to find out how the well-being of siblings of ID children are impacted by the presence of intellectual disability, the effect

of perceived stigma on themselves and how their attitudes towards intellectual disability influences their psychological outcomes.

### **Aims of the Study**

The aim of this research is to find the impact of the presence of a sibling with ID on the other siblings in the home.

The objectives of the studies are as follows:

- To examine the effect of type of intellectual disability on the psychological well-being of siblings,
- To examine the influence of positive and negative sibling relationship on their psychological well-being of siblings,
- To examine the relationship between the type of sibling relationship, perceived stigma and attitudes towards ID children on the psychological well-being of siblings of children with ID
- To examine the relationship between stigma and the psychological well-being of siblings of ID children
- To examine the moderating effect of family relationship, on the positive and negative sibling relationship and psychological well-being.

### **Relevance of the study**

This study is relevant because of a number of reasons. Research into studies of intellectual disability has concluded that family members feel stigmatized because of their association with intellectual disability. Siblings grow together and they influence and are influenced by each

other. Studies have been conducted to find the impact of intellectual disability on psychological well-being of their siblings. Additionally, attitudes of siblings have a significant impact on how they cope with challenges they face and few studies have examined siblings' attitude towards their brother or sister's disability. Having a disabled brother or sister brings up a lot of challenges to which one must contend with especially in the face of negative societal attitudes. Secondly, individuals with intellectual disability are surviving into old age (Messer & Jones, 1999) and are outliving their parents who usually are their caregivers when they are younger. This raises the concern for families where an individual survives and outlives parents. The onus of taking care of individuals with intellectual disability would usually fall on the siblings to provide and care for their needs in those times.

Thirdly, it has also been confirmed through studies that siblings are able to assist in intervention programmes to assist children with disability (e.g. Reagon, Higbee and Endicott, 2006; Sage & Jegatheesan, 2012). Knowing the impact of intellectual disability on the psychological well-being of siblings could help in the structuring of intervention programmes to aid children with ID and their siblings.

Understanding the way siblings' view their brother or sister's disability will help gain much insight into the processes and outcome of siblings' relation with an individual with intellectual disability. Secondly it will be appropriate to conduct a study to examine the psychological well-being of siblings of intellectually disabled persons in the Ghanaian society.

Furthermore, findings from this study will aid families in which there is a person with intellectual disability to understand the ways siblings cope with their affected sibling and also to strengthen positive attitudes towards siblings with disability. Lastly, this study will help governmental institutions handling disability issues and other advocacy groups to effectively

plan and meet the needs of the intellectually disabled and their families. The findings of this research will also be vital in designing educational programmes for the public, geared towards the eradication of some of the bad cultural practices that have been associated with intellectual disability in Ghana.

## CHAPTER TWO

### REVIEW OF LITERATURE

This chapter presents a review of some theoretical underpinnings of the factors that affect sibling relationships with an intellectually disabled child. The review examined theory relating to sibling relationships and psychological well-being. Using the attribution theory, this section also explains siblings' perceived stigma and attitude of siblings towards intellectual disability. This chapter also reviews related studies in relation to the concepts mentioned earlier. Lastly the hypotheses and conceptual framework has also been presented in this section.

### THEORETICAL FRAMEWORK

#### **Sibling relationships and psychological well-being**

Sibling relationships have been seen as an opportunity for development of psychosocial and cognitive abilities, such as conflict and conflict resolutions, language development and proper behaviour of persons in a social environment (Dunn, 2000). The quality of sibling relationships have been studied within the context of having a sibling with intellectual disability, but most of these studies focus on either the negative or the positive aspects of sibling relationships (Orsmond, Kuo and Seltzer, 2009). However other studies have concluded that both negative and positive aspects of sibling relationships have an impact (Beyer, 2009; Bellin & Rice, 2009). It is therefore important to study sibling relationships considering both positive and negative aspects of sibling relationships, because every sibling relationship develops in unique ways (Dunn, 2002; McGuire, McHale & Updegraff, 1996).

**Furman and Buhrmester's quality of sibling relationship**

According to Furman and Buhrmester's (1985) model that examines the quality of sibling relationships, there are four main variables that constitute this theory and they are sibling relationships, parent-child relationships, characteristics of individual children and the family constellation variables. The sibling relationship variable includes the dimensions of warmth/closeness, relative status/power, conflict and rivalry. The parent-child relationship variable includes the quality of relationship and the management of sibling relationships. The third variable, characteristics of individual children, comprise cognitive, social, and personality variables. The variable entitled family constellation includes: relative age, age difference, sex and sibling sex pattern, family size, and birth order.

This model states that there is an interaction effect among three of the four variables and this has either direct or indirect effect on the fourth variable. Sibling relationships have an effect on the characteristics of individual children and on parent-child relationship; hence each of these variables has interactional effect on each other. Though the fourth variable, family constellation influences the parent-child relationship and sibling relationships, it indirectly affects the characteristics of individual children variable.

The quality of sibling relationships has been expressed in both positive and negative dimensions. According to Furman & Buhrmester (1985), these dimensions include warmth/closeness, relative status/power, conflict and rivalry. Sibling rivalry has been a central theme in the sibling relationship studies (Buhrmester & Furman, 1990; Furman & Buhrmester, 1985; Hetherington & Clingempeel 1992). In a study by Buhrmester and Furman (1990), they defined rivalry/conflict by the following dimensions which included quarrelling, antagonism, competition and parental

partiality for sibling. Warmth/closeness was defined by intimacy, prosocial behaviour, companionship, similarity, admiration by sibling and admiration of sibling. Relative status/power was defined by the following behaviours including nurturance of sibling, nurturance by sibling, dominance over sibling and dominance by sibling. The quality of sibling relationship has an impact on the development of a person, because of the composite of both the negatives and positives dimensions. For instance, Volling and Blandon (2003) in their review of literature made a reference to the study of Caya and Liem, (1998) to assert the fact that warm and supportive sibling relationships is likely to increase self-esteem, and perception of competence among adolescent. Likewise, the negative aspect is also confirmed to have an opposing effect on one's psychological well-being. Pope (2006) found that positive sibling relationships correlated negatively with depressive symptoms and emotional conflict, however, an aspect of negative sibling relationship would have an impact on anxiety and depression of adolescents.

For instance, a study by Pope (2006) found that there is a strong inverse significant relationship between positive sibling relationship and anxiety and depression among normative groups. This assertion confirmed other studies done previously; for instance McHale and Gamble in 1989 found evidence that the quality of sibling relationship correlated with self-esteem, anxiety and depression. In recent studies such as the one by Derkman (2011), it was confirmed that both positive and negative aspects of sibling relationship has consequential effect in times of difficulties. She stated that rivalry/conflict may increase with siblings' level of depression and anxiety, which then affects their psychological well-being.

Despite these assertions made in the context of two typically developing siblings, it may be debatable to conclude sibling relationships with intellectually disabled (ID) persons remain the same as any other sibling relationship; considering the various challenges that are associated with a sibling with disability. Having a brother or sister with a disability may also affect the type of sibling relationship. According to Taylor and her colleagues, sibling relationship was less likely to be companionate, implying that siblings may mutually show warmth, conflict, and the other aspects of the sibling relationship but suggested that the sibling relationship will be based on the care giving role that the non-disabled or typically developed siblings display (Taylor, Greenberg, Floyd & Seltzer, 2008). While siblings tend to develop more care giving kind of relationship with their siblings, Greenberg, Seltzer, Orsmond and Krauss (1999) suggest that females are able to give care more than males, because females are more likely to be brought up to give care for others.

Studying sibling relationships within the context of intellectual disability, many factors have been identified as playing major roles in the development of sibling relationship and psychological well-being (Beyer, 2009). For instance, Ross & Cuskelly (2006) noted that siblings of autistic children are at a higher risk of internalizing behaviour problems and this has an effect on the sibling relationship. One contributing factor identified by Ross and Cuskelly is genetic predispositions but they stated that there are many unknown factors. Others such as Aksoy and Yilidirim (2008) have stated that the type of disability of the sibling is important. One significant factor that is related to the studies of intellectual disability and their families is stigma.

### **Attribution theory**

Studies of attitudes towards intellectual disability, have considered societal influences such as stigma as a major factor to negative attitudes towards intellectual disability. Stigma is an important consideration, however, because of its deleterious effect on families of children with disabilities (Fong, 2005; Skinner & Weisner, 2007). Assertions have been made that exposure to social discrimination and stigma affects the well-being and attitude of a person. Stigma is defined as “any attribute that discredits or disqualifies a person from full social acceptance” (Dale, Smith, Norlin & Chess, 2006, p.81).

Attribution theory has been used to explain the stigmatization of disabilities, especially mental disabilities. According to Weiner (1993), attribution explains people reactions to disabilities; in that both negative and positive reactions towards disability are based on the causative factors. Persons, who are seen as not having control over their disabilities because of the biological or physical cause, are shown positive and more helpful behaviours as opposed to persons whose disabilities are recognised as caused by themselves and who have control over what happens to them (Boysen & Vogel, 2008). Attitudes towards disability in Ghana have suggested they are more negative (Quinn, 2007), because of the belief that intellectual disability is inflicted upon selves by their own wrong doing and curses (Slikker, 2009).

Slikker posited that family members and individuals with disability felt stigmatized in the society because most people have the belief that the causative factors were more likely to be of the traditional view. Explaining the relationship between stigma and attribution theory, Corrigan (2000) also assented to the fact that people’s reaction to disability depends on the interpretation of the symptoms of the disability. When seen as uncontrollable, the person is not deemed

responsible. This is also true for those perceived as having control over their symptoms. The general attitudes in many communities towards children with disabilities are negative because disability is generally considered an offence against gods, atonement for sins of family and ancestors. Thus, some persons with disabilities are ostracised, and excluded from the mainstream community (Avoke, 2010).

Stigma sometimes extends to other individuals or things because they have a relation with the stigmatized. This type of stigma is known as stigma by association (Mehta & Farina, 1988) or courtesy stigma (Goffman, 1963). Stigma by association or courtesy stigma is when other people are regarded “as having spoilt their identity because they share a web of affiliation with the stigmatized”. Stigma by association results from the affiliation that one has with a person already being stigmatized; and this happens through physical, biographical or relational role (Birenbaum, 2010). Courtesy stigma or stigma by association includes the emotions and beliefs of those surrounding the stigmatized person, including family members and professionals (Larson & Corrigan, 2008; Rusch, Angermeyer, & Corrigan, 2005). Stuart (2005) argue that family members who feel or experience courtesy stigma, may experience it as fear, loss, lowered family esteem, shame, secrecy, distrust, anger, hopelessness and inability to cope. Family members of people with intellectual disability feel stigmatized for the reason that, they are associated with the intellectually disabled person and secondly being associated with the cause if the cause is perceived as a curse or a punishment of evil-doing. The effects of stigma-by association are especially powerful because they are likely to persist after even a single exposure. Risen and Gilovich (2007) found that the mere association of a rare group member with a rare behaviour is sufficient to produce a link with the stigmatized and set the stage for more elaborate stereotyping. Pontikes, Negro and Rao (2010), confirmed this in their study that, the mere

association of a person to an already stigmatized or would-be stigmatized member of a group was enough to cause the third person to also be stigmatized against.

Siblings' positions place them in a unique position; in that they are associated with the disability but are not the stigmatized themselves. Whereas siblings themselves do not have any disability and are not likely to feel stigmatized against, they may suffer from the courtesy stigma. Despite this attitude from persons from outside the family, acceptance and learning to live with a disabled sibling, affects siblings attitudes towards their intellectually disabled brother or sister which in turn may have an impact on their well-being. Aksoy and Yildirim (2008) emphasized that acceptance of a brother or sister with intellectual disability in the family depended on the level of handicap and the diagnosis of the ID.

### **Summary**

Several studies have been done to understand how stigma works in families of the intellectually disabled. Cultural explanation given to stigma is based on the knowledge one has about what the norm of society is and what it is not. A combination of the above explanations gives a clearer picture of how stigma operates in the society especially against people with intellectual disability and their families, especially their siblings. Being a sibling to someone who is being stigmatized against may affect one's psychological well-being and also the attitude one will develop towards the disabled.

### **Review of Related Studies**

There is a body of literature that exist on the presence of intellectually disabled persons on the siblings and their well-being. There is still on-going research to elaborate on the states of siblings

living with their intellectually disabled brother or sister. The effect of having an intellectually disabled person on siblings' well-being has been studied. This section reviewed some of these studies.

The impact of intellectual disability on sibling relationship cannot be underestimated because sibling relationship is bound to change at the different levels of developmental stages. For instance, a meta-analysis of studies by Dew, Balandin and Llewellyn (2008) of psychosocial impact on sibling of people with lifelong disability concluded that sibling relations may be different from typical sibling relationships. This conclusion was drawn based on the different methodologies used in the various articles reviewed. Data or information gotten from mothers for instance, viewed impact of disability more negatively than siblings did.

In a study by Ross and Cuskelly (2006), 25 siblings of children with Autistic Spectrum Disorder (ASD) and their mothers completed questions assessing knowledge about autism, problems experienced with disabled sibling and coping strategies employed and behaviours of non-disabled siblings, respectively. Participants age were between 8 and 15 years, with 19 male and 6 females, 14 siblings were younger than the child with autism and 9 were older. The study revealed that out of the total classifications of problem exhibited by siblings, 53% was aggressive behaviours and siblings were more likely to respond aggressively. Aggressive behaviours exhibited as physical, verbal, destruction of properties and disruption. The study also revealed that mothers noted that siblings had significant adjustment problems, which placed them at-risk of clinical levels of internalizing behaviour problems. However, this study, inasmuch as it has identified adjustment issues and aggression as main difficulties faced by the sibling, the study did not take into consideration the siblings relationship formed when one sibling has intellectual disability. Studies have showed that positive sibling relationship has

beneficial impact on siblings. In that, positive sibling relationship serves as buffer for typically developing children.

A study by Mulroy, Robertson, Alberti, Leonard and Bower (2007) described the impact of having a sibling with either Down syndrome or Rett syndrome. The researchers employed the survey method, where parents responded to open-ended questions about impact of two intellectual disabilities. This study's findings were that a greater number of siblings from both groups reported disadvantages of having a sibling with disability. Some disadvantages reported in this study included negative experience among siblings, burden in caring for the disabled child on long-term basis, financial issues and difficult behaviours. Though having a sibling with disability had disadvantages, respondents from both groups (20.5% of Rett syndrome and 79.5% of Down syndrome) reported some benefits associated with having a sibling with disability and a greater number of siblings of children with Down syndrome report more benefit than siblings of Rett's syndrome.

Sharpe and Rossiter (2002) did a meta- analysis of studies of siblings of children with chronic illness. Reviewing 52 published studies, Sharpe and Rossiter (2002) found a statistically significant and moderately negative overall effect as a result of having a sibling with a chronic illness. Sharpe and Rossiter had a result that showed a consistent poor level of psychological functioning among siblings of children with a chronic illness.

The negative psychological functioning was exhibited as lower psychological functioning, peer activity and cognitive development scores than the siblings of children with no chronic illness. These studies highlight the emotional burden and stress that are experienced by healthy siblings

of chronically ill children. Overall, these studies suggest that severity and chronicity of an illness could be a determining factor on the well-being of the healthy siblings.

Beyer (2009) analysed studies of Autistic Spectrum Disorder (ASD) and sibling relationships. She examined birth order, family size and gender on sibling relationships among children whose siblings were diagnosed with ASD. The studies identified that both positive and negative sibling relationship were developed among the typically developing siblings of children with disability. Further, she found out that the positive and negative had an impact on their adjustment with their siblings who were diagnosed with ASD.

Positive sibling relationship was reported in some studies when siblings recognised their role in the family, less favouritism and understanding of their siblings' disability. Negative sibling relationship were reported in studies where siblings spent less time and contact with their ASD brothers or sisters, and were concerned about destructive behaviours of their ASD brothers and sisters. Unfortunately, her findings were not conclusive on the adjustments of siblings.

Siblings of children with intellectual disability with and without autism were studied by Petalas, Hastings, Nash, Lloyd and Dowey (2009) to ascertain the emotional and behavioural adjustment in such siblings. Demographic data of the siblings included: 13 females and 12 males of which 6 were younger, 18 were older and one was a twin and siblings' ages ranged from 5 years to 17years. Data was collected from mothers who rated the emotional and behavioural adjustment of the siblings. Results showed that siblings of children with both autism and ID were reported to have scored high on emotional problems than siblings of children with only ID and not autism. This study concludes that siblings with children with autism had more difficulty with emotional

challenges; however the sample size was small, so that the generalization of results has to be done with caution.

Taylor, Greenberg, Floyd and Seltzer (2008) identified 268 siblings, drawn from a longitudinal study, of adults with mild intellectual deficits (ID) and 83 siblings of adults with mental illness (MI) participants were from age 18 years to age 64 years. This study contrasted the later life sibling relationships, patterns of family formation, and psychological distress and well-being of siblings of adults with disabilities to a nondisabled normative group. Siblings of adults with mild ID had more contact with family members and were more likely to live in the same state as the sibling with the disability but reported less affective closeness. Siblings of adults with MI reported more psychological distress, less psychological well-being, and less adaptive personality characteristics compared with sibling of adults with ID. There were no differences between groups in the patterns of marriage and childbearing. This study showed favourable outcome of having a sibling with a lifelong disability than having a sibling with transient disability. They also concluded that sibling relationship was supported by the family relationship even in adulthood.

Lobato and her colleagues studied psychological and school functioning of Latino sibling of children with intellectual disability (Lobato, Kao, Plante, Seifer, Grullon, Cheas & Canino, 2011). They compared children of siblings with intellectual disability (50 Latino families and 50 non-Latino families) and children of siblings without intellectual disability (50 Latino families and 50 non-Latino families) on various psychological variables including personal adjustment, internalizing and emotional symptoms, and absence from school and academic performance. Their findings was that sibling with intellectual disability generally reported significantly more internalizing and emotional symptoms, experienced more absence from school and lower

academic performance than those without siblings with intellectual disability. But according to their study the type of intellectual disability did not influence the siblings' adjustment. These findings revealed that the presence of ID has an impact on siblings' well-being; however, there was no consideration of other family relationships because inferences have been made in other studies of the importance of family relationships.

### **Intellectual Disability and Sibling relationship**

Bellin and Rice (2009) studied the quality of sibling relationship in families of youth with Spina Bifida. They hypothesized that individual, family and peer factors would explain differences in sibling relational warmth and conflict. Secondly, it was hypothesized that individual, family and peer factors would each contribute to warmth and conflict in sibling relationships with their brother or sisters with Spina Bifida. Finally, it was hypothesized that, individual and family factors, which were classified, as proximal environmental factors to sibling relationships would be strong determinants associated with relational warmth and conflict than peer factors, classified as distal environmental factors. Using a cross-sectional sample of 224 siblings (between 11 and 18 years) of children with Spina Bifida, the following results were obtained. Siblings reported having positive interaction with their brothers and sisters. Significant bivariate relationships were reportedly observed among demographic and clinical factors and quality of sibling relationships; same gender in dyad and less condition severity of Spina Bifida had higher sibling relational warmth. Furthermore, factors associated with individual and family relationships had a more predictive effect on sibling relational warmth and conflict than peer relationships.

Orsmond, Kuo and Seltzer (2009), investigated sibling relationships and well-being in adolescents and adults with a sibling with an autism spectrum disorder (ASD).

Results from the study showed that positive qualities existed among siblings in spite of having an intellectually disabled sibling. Stability of closeness of sibling relationship existed between siblings despite distance that was experienced during adulthood. They also concluded that this pattern of closeness was not experienced when neither sibling had a disability. Another conclusion they made was that the quality of sibling relationship remained stable from adolescence through adulthood when one sibling had a disability. A finding that was contrary to their presumption was that adolescents showed symptoms of depression but not to the clinical level. Adolescents in this study used emotion-focused skills to cope with issues than adults; which is typical of adolescents generally. Another conclusion that was made was that parental support was relied on as a means of social support throughout the lives of siblings.

In a similar study in 2009 by Seltzer, Orsmond and Esbensen, they examined sibling relationships and sibling wellbeing when one sibling has Autistic Spectrum Disorder (ASD) during adolescence and adulthood and factors associated with the variability in sibling relationships at these stages of life. This study measured whether sibling relationship, well-being, coping strategies and support from parents and friends varied in any way between the two age groups. Findings from the study showed that there was no significant difference between the two age groups in positive affects or depressive symptoms of siblings with ASD children in the relationship but siblings who were closest in age to the ASD child had the highest score in depressive symptoms. Both groups reported having received social support from friends and family especially from parents. Support from friends was not associated with closer sibling relationship.

Inam and Zehra (2012) sampled 30 females between the ages of 12 and 18 years in a study to look at the effect of intellectually disabled children on the non-disabled female siblings. Their findings revealed that female siblings faced problems regarding their relationship with their parents and social adjustments due to the presence of a mentally retarded child in the family. Younger siblings were found to be having more problems in their social adjustment than the elder siblings. Positive relationships were found to moderate social adjustment and future outcomes of the respondents. This study showed that presence of mentally retarded children has impact on the siblings; their sample of females could limit the generalization of the findings. Other studies have found adjustment problems in both males and females. This study also did not consider looking at the siblings' attitude towards disability, in considering the future of caring for their siblings.

Holsen (1999) did an exploratory study on siblings of children with Down syndrome and typically developing siblings. Parents were asked to rate the siblings' general anxiety and specific worries concerning the disabled child. The results of the study indicated that siblings of children with Down syndrome showed that the siblings were more worried and showed heightened internalising behaviour than the typically developing siblings. These results indicate that siblings of Down's syndrome also face challenges as the other IDs such as ASD.

Mophosho, Widows and Gomez (2007) studied the interaction and perception of siblings with children with cerebral palsy and the impact on the life of typically developed children. They used qualitative methods and found out that siblings developed acceptance, friendship, responsibility towards their brother or sister with cerebral palsy. This, unlike the presence of some other intellectual disability, revealed that siblings' perception of their brothers' disability was positive.

Siblings of adults with mental retardation were contrasted with siblings of adults with serious mental illness in a study by Seltzer and her colleagues (Seltzer, Greenberg, Krauss, Gordon & Judge, 1997). The aim of the study was to find out how the pervasiveness of the disability would impact the sibling's life, the closeness of their current relationship and frequency of contact with the brother or sister with the disability, and the factors related to the sibling's level of psychological well-being. The sample size of siblings of person with ID were 329 and 61 siblings of persons with mental illness participated in the study. Findings from the study revealed that although siblings of adults with ID were significantly more likely to perceive a pervasive effect on their life and on their sibling relationship than siblings of adults with mental illness, the nature of the pervasiveness of the effect were more likely to be positive among siblings of adults with mental retardation than sibling of adults with mental illness.

In addition, findings related to pattern of contact; measured by frequency of contact, face to face contact and contact by phone revealed that, siblings of both adults with mental retardation and mental illness showed no difference in contact pattern. However, the findings revealed that siblings of adults with mental retardation had an approximately 15% more face to face contact with their siblings. On the appraisal of closeness of the relationships, which were measured by trust, respect, affection, fairness and understanding by both sibling participants and their siblings with MR or MI, it was hypothesized that siblings of adults with MR would have a closer relationship than siblings of adult with MI. This hypothesis was confirmed in their study. Finally, siblings of adults with mental retardation had better psychological well-being when they had a close relationship with their brother or sister. In contrast, siblings of adults with serious mental illness had more favourable psychological well-being when they perceived a less pervasive impact of the brother or sister on their life. This demonstrated that siblings' psychological well-

being is associated with the relationship they exhibited towards their brother or sister with mental retardation.

### **Relationship between stigma and the psychological well-being**

Notwithstanding that the presence of a sibling's disability can affect the sibling relationship and psychological well-being of a typically developing sibling; other factors have been identified as predicting factors of the possible negative impact on sibling relationship and their well-being. In our context as Ghanaians, stigmatization may be unavoidable among siblings of an intellectually disabled person, where disability of a person is seen as a taboo or a forbidden effect on a person and his family (Inclusion, 2011). Miller and Kaiser (2001) maintain that understanding the effect of stigma, gives room to explore its impact on psychological factors.

Chou, Pu, Lee, Lin and Kroger (2009) used a survey interview to investigate whether there would be differences in the significant predictors of female ageing family carers' quality of life between family carers of adult with intellectual disability (ID) and carers of adult with mental illness (MI), especially their perception of stigma. Interviewing 350 family carers of persons with ID and 66 carers of persons with MI, the result highlighted in both groups was that health and social support were strongly associated with the level of quality of life. Carers' perceived stigma had a strong effect on their quality of life. Another finding they made was that female family carers of adults with mental illness had a higher level of quality of life compared with the carers of adults with intellectual disability. Using hierarchical regressions, they found that there was a stronger effect of perceived stigma on the quality of life among carers of adults with mental illness than among carers of adults with intellectual disability. These findings showed that relatives of intellectually disabled perceive more stigma than carers of the mentally ill.

Horwitz (1993) interviewed 108 adult siblings of seriously mentally ill persons on factors associated with caring of their ill siblings with the aim of examining the extent of social support siblings would give to their mentally ill siblings. Contrary to the premise that, siblings will provide care for their siblings who could reciprocate their care, siblings in this study showed significant affectionate relationships. They also stated that their provision of care for their ill siblings depended on the type of help needed (household tasks (17%), giving gifts (87%), emotional support (93%), transportation (48%), lending money (45%) and support during crises (43%). The above study indicates that siblings in the adult stages of life would care for their mentally ill and intellectually disabled sibling even when they may be unable to reciprocate their gestures.

A study was conducted by Ostman and Kjellin (2002) to investigate psychological factors associated with stigma experienced by relatives of mentally ill patients. Using a semi-structured questionnaire, they interviewed 162 relatives of patients in acute wards following voluntary and compulsory admissions. Majority of relatives experienced mental health problems because they perceived stigma regardless of the characteristics of their mentally ill relatives. A majority of relatives experienced psychological distress associated with the stigma they perceived. Ten per cent had had suicidal thoughts and 18% wished death for their mentally ill relative.

A study conducted by Ngoakoana (2006) on families of disabled children and its influence on the relationship of family members have with the disabled person. Findings from the study revealed that families experienced stigma when they got inadequate information about the causes. This information usually are gotten from other family members and neighbours rather than experts, and this influences the way family members relate to the person with intellectual disability and also how they feel in the presence of the disabled child (Ngoakoana, 2006). It has been

recognised that few family members get the adequate information they need from experts such as medical doctors, psychologists and educators. As such, reliance of information from other family members and neighbours may not be effective in dealing with issues arising out of being related to a disabled person. This issue was found to be one of the causes of stigma among family members of a disabled person.

Perkins, Holburn, Deaux, Flory and Vietze (2002), investigated mother-child relationship and self-esteem of typical children of mothers with intellectual disability with the aim to examine the emotional outcomes among them. They administered questionnaires to 36 participants (18 males, 18 females) who were between the ages of 9 and 17 years. The questionnaires assessed attachment style, caregiver style, perception of maternal stigma and self-esteem of the children. Children of mothers with intellectual disability were found to feel stigma associated with their mothers' disability and also felt stigmatized themselves and this has an effect on their attachment to their mothers and their self-esteem.

Kadri, Mahmoudi, Berrada and Moussaoui (2004) did a study to explore whether family members of patients with schizophrenia suffer from stigma and its effect on their lives and also to explore family members' knowledge about the illness and their attitude towards the patients. 100 family members who accompanied the patient to seek treatment answered a questionnaire that inquired for participants and patients' socio-demographic data, participants' attitudes and knowledge about the illness, and their perception of stigma. Results showed few members had any knowledge about schizophrenia (24%) but most family members considered the illness as incurable (39%), severe (37%), chronic (80%) and handicapping (48%). Family members' beliefs of the cause included the use of drugs, stressful life events, sorcery, organic disturbance and heredity. Family members reported suffering from stigma and discrimination. The effect of

the presence of schizophrenia in the family and the perception of stigma was relational disturbances and a poor quality of life. Negative attitudes towards persons with schizophrenia by family members included distrust, rejection aggression and overprotection. This has also been recognized as having a relational disturbance between the family members and their relative suffering from schizophrenia. Though this study used relatives of schizophrenia, its importance to the current study cannot be overemphasized. This study brings to the fore some features related to mental disability in a non-western country.

A qualitative study of Ghanaian families of people with disabilities was done by Anum (2011). This study explored the experiences of Ghanaian families with a disabled child. Employing qualitative techniques such as semi-structured interviews, participant observation and narrative analysis; the researcher explored experiences of four families with disabled children in the Dangme West District. The study's findings showed that families of disabled children experience stigma, strain on family relationships and lack institutional support most likely because they experience stigma. One explanation that was given to why families, especially the mothers who are the primary caregivers, felt stigmatized was the cultural explanations of disability in the Ghanaian context. This perception of stigma was also found as one of the causes of the strains in intra-family and inter-family relationships.

### **The attitude of the typically developing sibling towards ID**

It has been recognised that the general attitude of the general public is negative towards people with intellectual disability (Agbenyega, 2005). However being siblings to these persons with ID place the siblings in a unique position. Understanding attitudes towards persons with intellectual

disability is important because negative attitudes might create barriers to the development of sibling relationships and this can affect their psychological well-being and the interactions between the sibling dyads. There are very few studies on the attitude of siblings towards their brothers or sisters with intellectual disability.

One study that investigated attitudes of parents towards inclusion of their children with disability in a mainstream school was done by Elkins, van Kraayenoord and Jobling (2003). Their study aimed at finding out parents' attitudes and opinions related to students with special needs in a regular school. Using a survey method, a sample of 354 parents was asked to give responses on a questionnaire. Results from this study found out that majority of parents showed positive attitudes towards the inclusion of their children into mainstream. This highlights the fact that parents and relatives will show positive attitudes towards inclusion of their wards.

Mbwilo, Smide and Aarts (2010) did a study to explore the factors that would influence family perspectives in providing care for persons with mental disability. The study employed qualitative methods to explore variables associated with family characteristics and factors associated with care-giving of a mentally disabled person in the family. The study was analysed using thematic content analysis to categorise the data into meaningful phenomenon. The study found that family characteristics, lack of knowledge about the mental disability and health care resources were found to be associated with caring for children and adolescents with mental disabilities. Effects of the presence of mental disability in the family brought certain challenges associated with discriminations and interpersonal relationships problems. This study concludes that the lack of knowledge of the disability and the lack of social support affected the perception of family members with children and adolescents with mental disability.

A study on attitude of siblings towards intellectual disability was done by Al-Ma'aytah, Al-Bawaliz, Al-Qamsh and Sarayreh (2012). The study was to investigate the relationship between these attitude and gender and educational level of siblings in Al-Karak governorate of Jordan. In this study, 385 siblings whose ages were above 15 years and who lived in the same house as their mentally retarded brother or sister were involved in the study. The findings of the study were that males and females differed significantly on the attitudes towards mental retardation; females showed more positive attitudes while males showed moderate attitudes. Educational level was also noted to influence the attitude towards mental retardation. Those with less than secondary school level of education scored higher on the attitude scale than those whose educational level was above secondary school level. However there was no effect of the interaction of the two variables on the attitude towards mental retardation. Despite these results, this study did not take into considerations other factors such the effect of stigma on the siblings' relationship and family factors.

Another study by Hakeem and Subathra (2013) investigated siblings' attitudes towards their mentally retarded brother or sister. In their study 60 participants related to a person with mental retardation, were interviewed. Siblings who responded to the questionnaires were between the ages of 11 and 15 years and their brothers or sisters with mental retardation were between the ages of 5 and 9 years. In this study it was revealed that siblings showed positive attitudes towards their brothers or sisters with mental retardation regardless of their age difference or their gender. Furthermore, there was mutual respect, trust and similarity between the siblings, and also siblings regarded their brothers and sisters with mental retardation as important to them.

One study that included siblings of children with different intellectual disabilities was done by Aksoy and Yildirim (2008). The study was conducted using siblings between the ages of 10 and

18 years. The disabilities included learning disability, Down syndrome, mental-motor retardation, cerebral palsy, and autism. The attitudes of the healthy siblings were examined; attitudes towards their own sibling with the disability and attitudes towards other disabled people. The results were that healthy siblings showed positive attitudes towards their own brother or sister with the ID but their attitudes toward other persons with ID were less positive. Further, it was concluded that the type of diagnosis and level of disability influenced their attitudes towards their own brother or sister but not their attitudes to others.

Although there have been some form of research done on sibling relationship within sibling dyad when one sibling is intellectually disabled and its effects on their well-being, literature available on the influence of the type of sibling relationship on psychological well-being, sibling perception of stigma and their attitude towards intellectual disability on any level is very limited especially in Ghana and Africa. This research aims to find out how both positive and negative aspects of sibling relationship will affect psychological well-being. Another aim of this study is to examine siblings' attitudes towards ID and their perception of stigma and its effects on their psychological well-being.

### **Statements of Hypotheses**

**Hypothesis 1:** Positive sibling relationship would predict psychological well-being of non-disabled sibling.

**Hypothesis 2:** Negative sibling relationship would predict psychological well-being of non-disabled sibling.

**Hypothesis 3:** Type of ID would predict psychological well-being of non-disabled sibling.

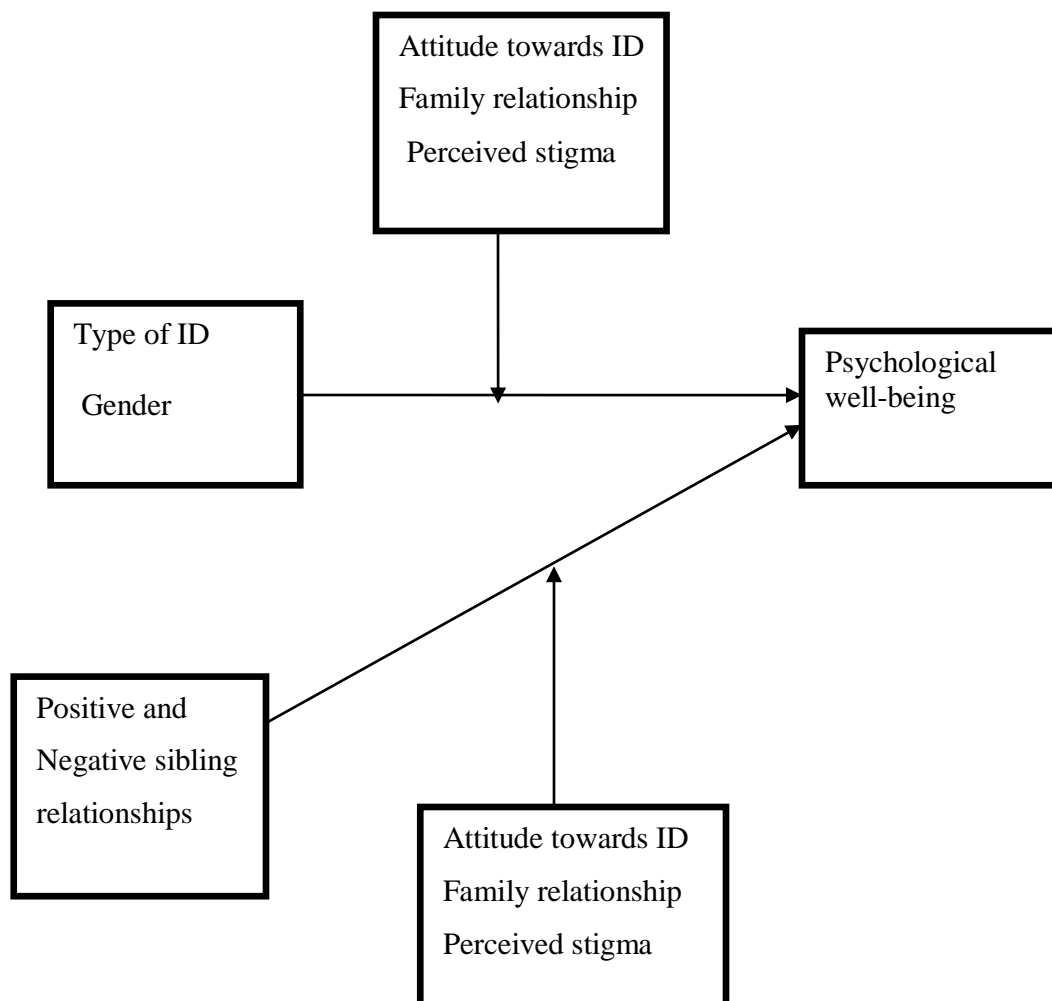
**Hypothesis 4:** Gender of siblings would predict psychological well-being.

**Hypothesis 5a:** Perceived stigma, family relationship and attitudes towards intellectual disability would moderate between positive sibling relationship and psychological well-being.

**Hypothesis 5b:** Perceived stigma, family relationship and attitudes towards intellectual disability would moderate between negative sibling relationship and psychological well-being.

**Hypothesis 5c:** Perceived stigma, family relationship and attitudes towards intellectual disability would moderate between type of intellectual disability and psychological well-being.

## Conceptual Model



In the model above, type of intellectual disability, gender, and negative and positive sibling relationship are hypothesized to be predictive factors of psychological well-being. Attitude toward ID, positive and negative sibling relationships are hypothesized to be moderating factors between the predictors on one hand and the dependent variable on the other.

### **Operational definitions of terms**

**Intellectually disabled person:** a person who is intellectually below the average intelligence level of his peer, may or may not have certain physical characteristics as measured by the ICD-10

**Sibling of an intellectually disabled person:** a brother or a sister who has lived with an intellectually disabled person.

**Sibling relationship:** any relationship that develop between siblings or a person who is regarded as a sibling. Positive and negative sibling relationships were examined.

**Psychological well-being:** this includes the six dimensions measured by the Well-Being Manifestation Measure Scale (happiness, control of self and events, social involvement, self-esteem, mental balance and sociability)

**Perceived stigma:** this is measured by the stigma scale of the family experience interview schedule.

**Attitudes towards intellectual disability:** this includes the 4 discrete subscales measured by the community living attitude scale:

- i. Shelter (SH): attitudes regarding the need to shelter people with disabilities from harm in communities.
- ii. Empowerment (EM): belief about the extent to which persons with disability should be empowered to make decisions affecting their own lives, regardless of the extent to which they are cognitively impaired.

- iii. Exclusion (EX): attitudes regarding the exclusion of persons with disabilities from community life, and
- iv. Similarity (SIM): beliefs regarding the extent to which people with disabilities share a common humanity with other persons in the society.

## **CHAPTER THREE**

### **METHODOLOGY**

This chapter discusses the research methodology that was used in investigating the perception of stigma on the psychological well-being of siblings of children with intellectual disability. The research design, population and sampling are described, followed by the materials that were used, and procedure of data collection.

#### **Research Setting and Population**

This study was conducted in the Accra metropolis, the capital of Ghana found in the Greater Accra Region. It is located in the southern part of the country. The population for the study was siblings of children with intellectual disability admitted in special schools in the Accra metropolis; namely: Dzorwulu Special School, the Special Unit of Dansoman Cluster of Schools, Autism Awareness Care and Training and New Horizon School. Persons with intellectual disability in these special institutions were diagnosed by a qualified clinical psychologist or medical officer. The participating siblings for this research were supposed to be living with their sibling during the last past year in the same house. The population also constituted people from different cultural backgrounds and religious affiliations across the country. New Horizon School and Autism Awareness Care and training (AACT) are private institutions. New Horizon admits persons with special needs of different categories ranging from Cerebral Palsy, Autism Spectrum Disorder (ASD), Learning Disabilities, Attention Deficit Hyperactive Disorder (ADHD) and mental retardation, AACT admits persons with Autistic Spectrum Disorders exclusively. The rest are public schools and they also admit from a wide range of intellectual disabilities.

**Sample/sampling technique**

The research was conducted using sixty-nine (69) participants who are currently living with their families and their intellectually disabled sibling. The convenient sampling technique was used in selecting these participants. This sampling method implies that one must be available and willing to participate in the study (Babbie, 2005). This method was the best for the study because there is no data or information on persons with intellectually disabled siblings in Ghana, and as such getting the siblings through the special school was the best option available.

Potential participants who did not live with their intellectually disabled sibling were not included in the study. Also siblings who were older than 25 years were not included in the study.

**Inclusion Criteria**

Participant must be siblings of children who have been diagnosed with intellectual disability and who are above 16 years.

**Exclusion Criteria**

The following participants were exempted from the study. These were persons with intellectual disability but had no sibling and siblings of persons with intellectual disability who are below the age of sixteen years old.

**Demographic Data**

The demographic distribution of participants indicated that their ages ranged from 16 years to 24 years ( $M= 18.72$ ,  $SD=3.06$ ). Their intellectually disabled siblings ages ranged from 8 to 22 years ( $M= 15.31$ ,  $SD=3.65$ ). The differences between their ages ranged from 0 to 10 years ( $M= 3.40$ ,  $SD= 4.21$ )

Siblings of younger children who were intellectually disabled were 52 and those of older children were 17. There were two sets of twins and so there were no differences between their ages.

Table 1: Demographic Characteristics of Participants

Variable		Male	Female	Total
<b>Whom do you live with</b>	<b>Both parents</b>	19	22	41
	<b>Single parent</b>	9	13	22
	<b>Other</b>	0	6	6
<b>Level of education</b>	<b>JHS</b>	11	5	16
	<b>SHS</b>	15	15	30
	<b>Tertiary</b>	2	21	23
<b>Number of other siblings in the family</b>	<b>0-2</b>	6	4	10
	<b>3-5</b>	20	30	50
	<b>More than 5</b>	2	7	9
<b>Age difference between siblings</b>	<b>0-2 years</b>	8	6	14
	<b>3-4 years</b>	10	10	20
	<b>5-7 years</b>	6	16	22
	<b>Above 7years</b>	4	9	13
<b>Time spent with sibling</b>	<b>Daily</b>	14	31	45
	<b>Weekly</b>	8	8	16
	<b>At least a month</b>	6	2	8
<b>Type of ID of sibling</b>	<b>Down Syndrome</b>	12	15	27
	<b>Cerebral Palsy</b>	6	12	18
	<b>Autism</b>	5	6	11
	<b>Other IDs</b>	5	8	13
<b>Belief of cause of disability</b>	<b>Spiritual causes</b>	12	15	27
	<b>Medical/ biological</b>	11	21	32
	<b>Physical cause</b>	4	5	9
<b>Where one gets information about siblings' ID</b>	<b>Parents</b>	12	17	29
	<b>Another sibling</b>	0	3	3
	<b>Other</b>	5	8	13

### Research Design

The research design for this study is a correlational survey design. This design was chosen because it sought to establish relationships between variables namely sibling relationship, perceived stigma, psychological well-being and attitudes towards intellectual disability.

### **Materials/ Instruments**

The questionnaires to be used in this study include; Sibling Inventory of Behaviour (SIB), the Family Relation Index (FRI) the well-being manifest measure scale (WBMMS), the community living attitude scale, mental retardation form (CLAS), stigma subscale of the Family Experience Interview Schedule and a self-designed demographic questionnaire.

### ***Demographic data***

This part of the questionnaire uses self-designed questions to gather information characteristics such as age, gender, and information about their family environment. Other relevant questions asked in this questionnaire are about the siblings' knowledge of their brothers or sisters' disability.

### ***Sibling Inventory of behaviour (SIB; Hetherington, Henderson & Reiss 1999)***

The Sibling Inventory of Behaviour (SIB) is a 32-item 5-point likert scale that measures the quality of sibling relationship. It contains six subscales to measure individual difference in sibling relationship quality. The response rate from the frequency of 1=never to 5=always. The subscales are Companionship (e.g., "has fun with sibling," "treats sibling as a good friend", 6 items, median alpha = .88); Empathy (e.g., "is pleased by progress sibling makes", "shows sympathy when things are hard for sibling," 5 items, median alpha = .88); Teaching/Directiveness (e.g., "teaches sibling new skills," "tries to teach sibling how to behave," 4 items, median alphas = .67); Rivalry (e.g., "is jealous of sibling," "tattles on siblings," 7 items, median alpha = .77); Avoidance (e.g., "is embarrassed to be with sibling in public," "acts ashamed of sibling," 5 items, median alpha = .85); and Aggression (e.g., "gets angry with

sibling,” “fusses and argues with sibling,” 5 items, median alpha = .80) Inter-rater reliability between mother and father’s report ranged from 0.33 (avoidance) to 0.80 (empathy) with a median of 0.64.

This questionnaire was administered to a caregiver (parent/ guardian) to ascertain a true picture from them about the sibling relationships that exist between children with intellectual disability and their sibling with no disability.

The adapted form of Sibling inventory of Behaviour (SIB, Schaefer & Edgerton, 1981) by Hetherington and her colleagues was used in a study of a Non-shared Environment of Adolescent Development (NEAD) (Hetherington, Henderson & Reiss 1999). This study was a longitudinal study designed to examine family relations across different family forms including stepfamilies and non-stepfamilies.

### ***The family Relation Index***

The family Relationship Index (FRI; Moos & Moos, 1981) was used to assess family functioning. The FRI is the short version of the family Environment Scale (FES; Moos & Moos, 1981). This scale measures three aspects of family relation that is found in the FES, namely; cohesion, expressiveness and conflict. The FRI consists of 12 items on three subscales namely; cohesion, conflict and expressiveness. Responses of each statement will be scored using a 4-point Likert scale (4 = strongly agree; 1 = strongly disagree).

The internal consistency of the scale was 0.70. Test measured at 2months interval and 4 months interval produced the following reliability; cohesion- 0.86 and 0.72 respectively, expressiveness- 0.73 and 0.70 and conflict was 0.85 and 0.66 respectively.

Validity of the test has also been predicted in various studies of families of substance abuse patients and psychiatric patients. (Moos & Moos, 1994 as cited by Staiger et al, 2006)

### ***The well-being manifest measure scale***

To measure the psychological well-being, the Well-Being Manifest Measure Scale (WBMMS; Masse, Poulin, Dassa, Lambert, Belair & Battaglini, 1998) was used. This scale was developed by Raymond Masse and his colleagues to measure the well-being of adolescents and people in early adulthood. The WBMMS contains 25 items with six factors, which are, control of self and events, happiness, social involvement, self-esteem, mental balance and sociability. Masse et al. (1998) found an overall Cronbach's alpha of 0.93 for the questionnaire, and a range of 0.71 to 0.85 on the subscales. They also found that the items explained 52% of the variance in psychological well-being. The sum of total score of the WBMMS was used to obtain the full score. The well-being Manifestation Measure Scale used in a study by De Lazzari (2000) yielded level of reliability coefficients for each subscale item. The following results were found; control of self and events ( $\alpha= 0.67$ ), happiness ( $\alpha= 0.77$ ), social involvement ( $\alpha=0.64$ ), self-esteem ( $\alpha= 0.78$ ), mental balance ( $\alpha= 0.71$ ) and sociability ( $\alpha= 0.70$ ).

### ***The Community Living Attitude Scale-Short Form; (CLAS)***

The Community Living Attitudes Scales (CLAS) were designed by Henry, Keys & Jopp (1999) to assist in measuring four dimensions of attitudes toward persons with disabilities. These include beliefs about the extent to which persons with disabilities should be empowered to make decisions affecting their own lives, regardless of the extent to which they are cognitively impaired; attitudes about the exclusion of persons with disabilities from community life, attitudes

regarding the need to shelter people with disabilities from harm in communities, and beliefs regarding the extent to which people with disabilities share a common humanity with other persons in society.

The CLAS-Short Form consists of 17 questions that are divided into 4 discrete subscales: empowerment (e.g. persons with ID should be enabled and allowed to make decisions that affect their lives), exclusion (e.g. persons with ID should not live or be supported within the community), sheltering (e.g. persons with ID need to be supervised in daily activities and protected, so they will not be harmed in the community), and similarity (e.g. persons with ID have the same rights, needs, desires, and potential as anyone else). Responses of each statement was scored using a 6-point Likert-like scale (6 = strong agreement; 1 = strong disagreement). The levels of reliability of each of the subscales of the CLAS-MR were as follows: empowerment (0.74), Exclusion (0.71), Sheltering (0.70) and similarity (0.75). The internal consistency of the each subscale is as follows: empowerment (0.67), exclusion (0.85), Sheltering (0.72) and similarity (0.79). This scale has been used in a number of studies to measure the attitude towards mental retardation including attitudes of medical clerks towards persons with intellectual disabilities (Ouellette-Kuntz, Burge, Cleaver, Isaacs, Lunskey, Jones et al, 2012) and attitudes towards intellectual disability among students, disability service professionals and the general populations in Australia (Yazbeck, McVilly & Parmenter, 2004). The composite score was used in the study; the composite score was calculated by finding the means of the total score.

#### ***The Stigma Subscale of the Family Experience Interview Schedule (SS-FEIS)***

The stigma scale is a subscale of the Family Experience Interview Schedule (Tessler & Gamache, 1993), a toolkit for evaluating family experiences with severe mental illness. The

stigma subscale measures whether the family member perceives stigma because of their relation with a person diagnosed with mental illness. This subscale contains 9 items and responses are scored on either yes or no; where yes = 1 and no = 0. An example of an item is “you worried that friends and neighbours would avoid you after they found out about it.” A higher score on the scale indicates a higher level of perceived stigma. The scale is calculated by finding the average. The items include worry about: people finding out about the illness, neighbours treating them differently, friends and neighbours avoiding them, and being treated differently by even their best friends. Other items inquire about the need to hide the illness or keep it a secret, the avoidance of social events, not seeing friends and feelings of shame or embarrassment. The “yes-no” categories for response were reformatted in this study to include response categories such as 0 = not at all, 1 = a little, 2 = some, 3 = a lot.

### **The Pilot Study**

The pilot study was done prior to the actual collection to test the reliability of the selected instruments. The pilot study was conducted with the Accra Metropolis using siblings with intellectual disability and students in the tertiary institution. 17 siblings of children with intellectual disability and 18 students who were not related to a person with any intellectual disability were conveniently selected to participate in the pilot study. The ages of the participants were between 17years to 22years. All the questionnaires were administered to both groups except the Family Experience Interview Scale, which was administered to siblings with intellectual disability.

The Family Experience Interview Schedule recorded an alpha of 0.86; the Well-Being Manifest Measure Scale had an alpha of 0.85. The subscales of Well-Being Manifest Measure Scale had

alpha of 0.71(self-esteem), 0.73 (social involvement), 0.71 (control of self and events), 0.75 (hospitality), 0.61 (mental balance) and sociability (0.76).

The level of reliability on each subscale of Sibling Inventory Behaviour was as follows: rivalry (0.611), empathy (0.66), compassion (0.91), avoidance (0.86), teach (0.68) and aggression (0.25). On the community living attitude scale, reliability on each was as follows: empowerment (0.60), exclusion (0.66), shelter (0.68) and similarity (0.63). The family relationship inventory had the following as reliability on each of the subscale: cohesion (0.65), expression (0.75) and conflict (0.56). These figures suggested that the scales were reliable enough for the study. The alpha scores were presented in table 4.1 under the fourth chapter which discusses the results.

## **Procedure**

Approval for this study was obtained from the Institutional Review Board (IRB) of the University of Ghana. Another approval was obtained from the Department of Psychology of the University of Ghana. An introductory letter was also obtained from the department introducing the researcher to the various special schools in Accra. On approval, the various special schools were used as a means of getting in touch with siblings. A consent form designed to seek consent of participants and parental consent if participants were below eighteen (18) years was sent to siblings and parents. As part of the consent form, the purpose of the study was explained. The benefits and injury were explained to the participants. It was also made clear to participants that they could decline participating in the research at any point of the data collection if they so wish. Confidentiality of their information provided was assured. When their consent was given, the questionnaires were given to participants to fill. Those who were not able to fill were given a

period of one week to complete. Afterwards, the complete questionnaires were collected for scoring and subsequent analysis.

## CHAPTER FOUR

### RESULTS

The purpose of this study was to examine the impact of having an intellectually disabled brother or sister on the psychological wellbeing of the typically developed sibling. Positive and negative sibling relationships, gender and type of intellectual disability were stated as predictors of psychological well-being and attitudes towards intellectual disability. In this study, perceived stigma, attitude towards intellectual disability and family relations were examined as moderators between the relationships above. In line with the aims, 5 hypotheses were tested using a series of regression analyses.

#### **Preliminary analyses**

The preliminary analyses were made up of four sections. These were: Analysis of the normal distribution of the variables, descriptive statistical analysis of demographic variables, reliability analysis and computing the Pearson correlations among the variables of the study. First, the normality of the data obtained for the study was verified. The analysis revealed that all the study variables were normally distributed (Table 2). According to Tabachnick and Fidell (2006), a variable is normal when, the value for skewness and kurtosis range between  $\pm 1$ . All the variables were accordingly used in the analysis.

Table 2: Means, Standard Deviation, Skewness, Kurtosis and Internal consistency (Cronbach's alpha) of the various instruments or measures used.

	Means	Std. Deviation	Skewness	Kurtosis	Alpha
Family Experience	17.01	4.38	0.33	-0.02	.91
Interview Schedule					
Family Relation	11.75	4.11	0.30	-0.74	.61
Inventory					
Sibling inventory of					
behaviour					
Positive sibling	53.11	8.41	0.67	-0.19	.86
Negative sibling	37.17	8.17	-0.16	0.43	.69
WBMMS	90.74	13.14	0.28	-0.93	.85
Community Living					
Attitude Scale (CLAS)					
CLAS...Empowerment	18.94	4.26	0.18	-0.77	.60
CLAS...Shelter	9.78	3.67	0.33	-0.42	.68
CLAS...Similarity	10.62	5.30	0.55	-0.87	.63
CLAS...Exclusion	16.28	5.62	-0.26	-0.70	.66

Table 3: Pearson-Product Moment correlations between the study variables

	1	2	3	4	5	6	7	8	9	10
1 Sex	1									
2 Age	.372**									
3 Time	-	-								
	2.99**	0.29								
4 Type of ID	.028	-	.117							
		.094								
5 P. Stigma	-.140	-	-.021	.135						
		.177								
6 Fam. R	-.057	.128	.031	-.105	-					
					.615**					
7 Pos. Sib. R	.223*	-	.287**	-.189	-	.412**				
		.119			.425**					
8 Neg. Sib. R	.094	.058	-.104	.109	.233*	-.196	-.442**			
9 Psyc WB	.214*	-	.169	.012	-	.445**	.638**	-.154		
		.007			.329**					
10 Attitudes	-.121	.150	.134	-	.022	.131	-.200*	.121	-.054	
				.270*						

Note: Psyc. WB = psychological well-being, pos. Sib. R. = positive sibling relationship, Neg. Sib. R. = negative sibling relationship, P. stig. = Perceived stigma, Fam. R. = family relationship; time = time spent with ID sibling; \* $p < .05$ , \*\* $p < .01$ .

It is observed from the correlation analysis that time spent with sibling positively correlated with positive sibling relationship ( $r = .29$ ,  $p < .01$ ), indicating that the more time one spends with the brother or sister with ID, the more they show positive sibling relationship. Attitudes towards ID correlated negatively towards type of ID. Positive sibling relationship correlated positively with psychological well-being ( $r = .69$ ,  $p < .01$ ) and family relationship correlated positively with psychological well-being ( $r = .45$ ,  $p < .01$ ). Other relationships are observed in the hypothesis stated.

### **Hypothesis testing**

The Hypotheses one to four were tested using the simple regression analysis. The fifth hypotheses were tested using the Hierarchical regression Analysis. The regression analyses were conducted to test the general model that certain independent variables accounted for variance in a dependent variable (psychological well-being). Also the hierarchical regression was conducted to test the moderation effects of some variables between the independent variables and dependent variable relationship. The Dependent variable constituted a composite score of six variables, namely: Self-esteem, Sociability, Social Involvement, Control of Self and Events, Mental balance and Hospitality. The Independent variables in this study were positive and negative scores of sibling relationship, gender and type of intellectual disability. Positive and negative sibling relationships were measured as a latent score. All siblings were measured on both positive and negative sibling relationships by their parents or guardians. Four types of intellectual disability were identified in this study and were dummy coded. The reference for the type of intellectual disability was other types of intellectual disability while those that were coded were Autism, Down syndrome and Cerebral palsy.

Gender was also dummy coded with female as the reference point.

### **Hypothesis One**

One of the major aims of this study was to examine the extent to which sibling relationship explained variance in psychological well-being. Consequently, it was predicted that “Positive sibling relationship would predict psychological well-being of siblings of children with intellectual disability.” To test this hypothesis, a simple regression was computed. Positive

relationship, negative sibling relationship, type of intellectual disability and gender were entered as predictors of psychological well-being, which is the dependent variable. The results showed that positive sibling relationship significantly predicts psychological well-being ( $\beta = .77$ ,  $p < .01$ ). The results from the simple regression showed that positive sibling relationship accounted for a significant variance in the psychological well-being, thus the hypothesis was supported. The results are presented in Table 4.

Table 4: Summary of Simple Regression for hypotheses one, two and three

Model		B	Std. Error	$\beta$	Sig.
1	(Constant)		19.70	15.20	.20
	positive sibling relationship	1.20	.172	.77	.01**
	negative sibling relationship	.214	.168	.13	.21
	Gender	.274	2.57	.01	.92
	down syndrome	4.72	3.41	.18	.17
	cerebral palsy	-3.56	3.59	-.12	.33
	Autism	-.85	4.07	-.02	.84

Note:  $R^2 = .70$ , ( $p < .05$ ), \*\* $p < .01$

### **Hypothesis Two**

The second hypothesis stated that “Negative sibling relationship would predict psychological wellbeing.” To analyze this hypothesis, a simple regression was conducted to find out if negative sibling relationship is able to predict psychological well-being, with positive sibling relationship, negative sibling relationship, type of intellectual disability and gender were entered as predictors of psychological well-being, which is the dependent variable. With reference to the table 4 above, the results show that negative sibling relationship did not significantly predict psychological well-being of siblings of children with ID ( $\beta = .13, p > .05$ ). Therefore the hypothesis that stated that negative sibling relationship would predict the psychological well-being of siblings of children with ID was not supported.

### **Hypothesis Three**

The third hypothesis was stated as “Type of intellectual disability would significantly predict psychological well-being” using the simple linear regression, three types of intellectual disability; namely, Down syndrome, cerebral palsy and autism were entered into the block. “Other types of intellectual disability” was used as point of reference for the types of intellectual disability. The results presented in Table 4 showed that none of the type of intellectual disability significantly predicted the psychological wellbeing of the siblings of children with intellectual disability [Down syndrome: ( $\beta = .18, p = .17$ ); Cerebral palsy: ( $\beta = -.12, p = .33$ ) and autism: ( $\beta = -.02, p = .84$ )]. The results from the regression analysis showed that type of intellectual disability did not account for any variance in the psychological well-being of siblings of children with ID, thus the hypothesis was not supported.

#### **Hypothesis Four**

Gender was stated to be a predictor of psychological well-being in the fourth hypothesis. The gender was dummy-coded and entered. Female was used as the reference for male.

With reference to Table 4 above, the results indicated males did not significantly predict psychological well-being ( $\beta = .10, p > .92$ ). There was no relationship between gender of the respondent and psychological well-being. The hypothesis was therefore not supported by the data in this study.

#### **Hypothesis Five (a)**

To test the hypothesis that “family relationship moderates the relationship between positive sibling relation and psychological well-being”, a hierarchical multiple regression was computed. The Dependent Variable (DV) in this analysis was psychological well-being and the independent variables (IV) were positive and negative sibling relationship, gender, and type of intellectual disability, however, in analysing the predictive influence of the DVs, it was found that positive sibling relationship was the only predictive factor of psychological wellbeing. Therefore the moderating effects of perceived stigma, attitude towards intellectual disability and family relationship, were used to moderate the relationship between positive sibling relationship and psychological wellbeing.

In the first step of the hierarchical regression, sibling relationship was entered. The results showed that there was a significant R squared,  $F(1, 67) = 45.97, R^2 = .64, p < .01$ . The moderators were then entered into the second step with a significant change,  $F(4, 64) = 13.10, \Delta R^2 = .42, p < .01$ . The moderating variables explained additional 42% variance in the psychological well-being. The interacting effects of the positive sibling relationship and the

moderating factors were entered in the third step. The results indicated that there was a significant change,  $F(1, 61) = 9.48$ ,  $R^2 = .47$ ,  $p < .05$ .

The results indicated that family relations significantly moderate the relationship between positive sibling relationship and psychological well-being ( $\beta = .25$ ,  $p < .05$ ). Perceived stigma did not significantly moderate between the positive relationship and psychological well-being ( $\beta = .06$ ,  $p < .61$ ) as shown in Table 5 below. Attitudes towards ID did not significantly moderate between the relationship between positive relationship and psychological well-being ( $\beta = .03$ ,  $p < .79$ ).

There was no interaction effect between positive sibling relationship and family relationship ( $\beta = -1.35$ ,  $p = .18$ ), there was no interaction effect between positive sibling relationship and perceived stigma ( $\beta = 1.11$ ,  $p = .27$ ), and there was no interaction between positive sibling relationship and attitudes towards intellectual disability ( $\beta = -1.63$ ,  $p = .11$ ). The hypothesis that family relationship, perceived stigma and attitudes towards intellectual disability would moderate between the sibling relationship and the psychological well-being of siblings was partially supported. The results are presented in Table 5 below.

Table 5: Summary of Hierarchical multiple regression for the moderating factor of perceived stigma, attitudes, and family relationship between positive sibling relationship and psychological well-being

Model		B	Std. Error	B	Sig.
1	positive score of sib	.996	.147	.638	.000
2	positive score of sib	.888	.170	.568	.000
	Family Relationship	.787	.396	.246	.051
	Perceived Stigma	.189	.364	.063	.606
	Attitude	.151	.573	.026	.792
3	positive score of sib	.678	.184	.434	.000
	Family relationship	.925	.384	.289	.019
	Perceived stigma	.308	.363	.103	.400
	Attitude	-.494	.597	-.084	.411
	Family relationship X PSR	-2.696	2.002	-.163	.183
	Per. Stig. X PSR	1.861	1.675	.135	.271
	Att. X PSR	-2.364	1.455	-.167	.109

Note: R2 = .64; (p<.05) for step 1;  $\Delta R^2 = .42$ , (p < .05) for step 2;  $\Delta R^2 = .47$ , (p < .05) for step 3. \*\*p<.01, \*p< .05. Per. Stig. = perceived stigma, PSR=positive sibling relationship, Att. =Attitude towards ID,

### Hypothesis Five (b)

The hypothesis stated that perceived stigma, family relationship and attitudes towards intellectual disability would moderate between negative sibling relationship and psychological well-being.

From table 3, negative sibling relationship did not significantly predict psychological well-being ( $\beta = .13$ ,  $p = .21$ ), hence the moderating effect of perceived stigma, family relationship and attitude did not influence the relationship. The hypothesis was therefore not supported.

**Hypothesis Five (c)**

The hypothesis stated that perceived stigma, family relationship and attitudes towards intellectual disability would moderate between type of intellectual disability and psychological well-being.

From Table 3, negative sibling relationship did not significantly predict psychological well-being [Down syndrome: ( $\beta = .18$ ,  $p = .17$ ); Cerebral palsy: ( $\beta = -.12$ ,  $p = .33$ ) and autism: ( $\beta = -.02$ ,  $p = .84$ )], hence the moderating effect of perceived stigma, family relationship and attitude did not influence the relationship between type of intellectual disability and psychological well-being.

The hypothesis that states that perceived stigma, family relationship and attitudes towards ID was not supported.

**Summary of the findings**

Four hypotheses were formulated to find the predictive effects of positive and negative sibling relationship, type of intellectual disability and gender on the psychological well-being of siblings of children with ID. It was also predicted that perceived stigma, family relationship and attitudes towards the ID would serve as the moderating factors of the relationship between positive and negative sibling relationship, type of intellectual disability and gender on one hand and psychological well-being on the other.

The hypothesis that was stated that positive sibling relationship will predict psychological well-being was supported while the other predictive variables of psychological well-being were not supported.

Family relationship, as a moderating factor, between the positive sibling and psychological well-being was predicted. Perceived stigma and attitude towards ID did not moderate the relationships between positive sibling relationship and psychological well-being.

## **CHAPTER FIVE**

### **DISCUSSION**

#### **Introduction**

The aim of this study was to find the impact of the presence of a sibling with ID on the other siblings in the home. Areas that were examined in this study included positive and negative sibling relationship, type of intellectual disability, and gender as the predictive factors of psychological well-being of siblings of children with intellectual disability. Further, attitudes of ID, perception of stigma and family relationship were explored as moderating factors between the above relationships. The results provided support positive relationship as a predictive variable of psychological well-being. However, the rest of the hypotheses were not supported by the results.

#### **Summary of findings of the study**

Four hypotheses were formulated to find the predictive effects of positive and negative sibling relationship, type of intellectual disability and gender on the psychological well-being of siblings of children with ID. It was also predicted that perceived stigma, family relationship and attitudes towards the ID would serve as the moderating factors of the relationship between positive and negative sibling relationship, type of intellectual disability and gender on one hand and psychological well-being on the other.

The hypothesis that was stated that positive sibling relationship will predict psychological well-being was supported while the other predictive variables of psychological well-being were not supported.

Family relationship, as a moderating factor, between the positive sibling and psychological well-being was predicted. Perceived stigma and attitude towards ID did not moderate the relationships between positive sibling relationship and psychological wellbeing.

### **Relationship between Sibling relationships and psychological well-being**

One purpose of the study was to examine whether sibling relationship predicts psychological well-being of typically developing siblings. Both positive and negative aspects of sibling relationship were examined as predictors of psychological well-being. In the findings of the study, it was revealed that siblings showed both positive and negative aspects of sibling relationship. As stated in the hypothesis, positive sibling relationship predicted some variance in the psychological well-being of siblings of children with intellectual disability. This finding suggests that siblings' exhibition of positive sibling relationship towards their brother or sister with intellectual disability can influence typically developing siblings' psychological well-being (Caya & Liem, 1998; Volling & Blandon, 2003). Positive sibling relationship portrayed positive behaviours of empathizing, teaching and companionship. Sibling relationship begins early in one's life as a second child is born into family. In the Ghanaian society older siblings are expected to care for their younger siblings, and also the sick are expected to be taken care of by the healthy. Opportunities such as these give siblings the arena to build their self-esteem, hospitality increasing the likelihood of forming a better psychological well-being (e.g. Volling & Blandon, 2003). This could be possible if the siblings show acceptance of their brothers and sisters. Looking at the correlation between positive sibling relationship and their attitude towards intellectual disability shows a positive correlation. This could be seen as an acceptance of their siblings' disability.

In this study, siblings had lived with their siblings for at least a year and this could have influenced their relationship with their disabled brother or sister. Furthermore, siblings reported spending time daily with their brother or sister with intellectual disability. Spending an amount of time could explain the exhibition of positive sibling relationship by typically developing sibling towards their brother or sister with intellectual disability.

Another explanation for the effect of positive sibling relationship on the psychological well-being of siblings could be that there is stable relationship as siblings reach the adolescent and adult stages of their lives. Therefore, their rating on positive sibling relationship could be high. In their studies, Orsmond et al. (2009) found that siblings' relationship remained stable during adolescence and adulthood even when one of the siblings was autistic. In their study, many siblings rated themselves as spending time daily with their brother or sister with intellectual disability. The quality of sibling relationship, if positive, is also said to serve as a buffer against the negative experiences such as having a disabled sibling if it is positive.

Contrary to this finding, Ross and Cuskelly (2006) found that siblings of autistic children showed aggressive behaviours, which were a reflection of typical sibling relationship among the siblings of autistic children. High levels of internalizing behaviour problems were typical and these influenced their adjustment negatively. The disparity in the two studies could be related to the ages of the siblings studied. While the age of the siblings in this study were between the age of 16 years and 25 years, Ross and Cuskelly used siblings between the ages of 8 years and 15 years. As Shulman and Avigad-Spitz (2005) pointed out, siblings within the ages of 16 years and 25 years who are in their late adolescence and are emerging into adulthood, have a more matured perception of their relationship with their siblings in spite of the challenging issues they go through particularly relating to intellectual disability.

The second hypothesis of the study stated that negative sibling relationship will predict psychological well-being. This hypothesis was not supported. Negative sibling relationship was measured as aggressive, avoidance and rivalry behaviours towards their brother or sister with intellectual disability. Parental / guardians' ratings of siblings showed that siblings showed minimal levels of these behaviours towards their brothers or sisters. Siblings' recognition of their brothers or sisters disability could have been a contributing factor towards their minimal exhibition of negative aspects of sibling relationship towards their disabled brother or sister.

### **Type of intellectual disability of sibling and psychological well-being**

The third hypothesis stated that siblings' intellectual disability would predict the psychological well-being of siblings. This hypothesis was rejected. 81% of participant siblings in this study were able to identify the type of intellectual disability their siblings have as Down syndrome, Autism Spectrum Disorder and Cerebral Palsy. However, this knowledge about the type of intellectual disability did not predict the psychological wellbeing of siblings. Siblings' psychological well-being was not influenced by the type of intellectual disability because siblings of children with intellectual disability may have accepted their disability and did not see their disability as a threat to their psychological well-being.

However, in the study of Aksoy and Yildirim (2008), they identified that diagnosis of disability of a brother or sister plays an important role in the well-being of the non-disabled sibling. The more visible the disability and the more challenging the behaviour associated with the disability, the greater the influence it is on the psychological well-being. However, it would be difficult to conclude in this study if the non-visibility of the disability had an influence on siblings' attitude towards intellectual disability because this aspect was not assessed in this study.

**Perception of stigma and its relationship to psychological well-being**

Also in this study, perception of stigma was examined as a moderating variable between the relationship between positive sibling relationship and psychological well-being. The hypothesis was stated as perceived stigma would significantly influence the sibling relationship and psychological well-being. This hypothesis was rejected as a significant moderating variable between positive sibling relationship and psychological well-being of siblings. One would have expected that perception of stigma would affect siblings' psychological well-being as it was seen in the correlation results but it did not impact on the positive sibling relationship and psychological well-being. This result negates the impact of perceived stigma on psychological well-being. The findings of this study revealed that siblings of intellectually disabled children felt minimal level of stigma. Further, siblings' level of stigma was low and a possible explanation could be the acceptance of their brothers' or sisters' disability by both themselves and their family. Another explanation to the low level of perceived stigma could be the length of stay and time spent with the intellectually disabled sibling. Siblings in this study have lived together for at least a year and may have first hand information about their intellectually disabled brother or sister. Spending time with could further explain their acceptance of their siblings, which could in turn reduce the level of stigma perceived.

**Attitudes towards ID and psychological well-being**

Attitude towards ID was hypothesized to moderate between the sibling relationship and psychological wellbeing of siblings of children with intellectual disability. This hypothesis was rejected. Attitude towards intellectual disability was measured by the community living scale. This scale contains four subscales that measure similarity of an ID person to other people,

exclusion of persons with intellectual disability from the society, sheltering persons with ID from harmful behaviours in the society and empowering persons with intellectual disability. A high score was an indication of siblings' positive attitude towards empowering their disabled brother or sister and a low score was an indication of negative attitude towards empowering their sibling with intellectual disability.

The study recorded generally low score on the siblings' attitudes towards their brothers and sisters with intellectual disability. The scores did not significantly influence the relationship between positive sibling relationship and the psychological well-being, hence its non-influencing effect on the siblings' psychological well-being. The average score of siblings of persons with Cerebral palsy was the highest on the attitude towards intellectual disability, while siblings of those with the category of other or unknown type of intellectual disability score the lowest. There was no significant difference between siblings of children with Autism Spectrum Disorder, Down syndrome and Cerebral Palsy in their expressions of attitudes towards intellectually disabled persons.

It can be explained the knowledge of the disabilities identified by the siblings influenced their attitude towards their siblings with ID. Those who did not know the type of disability showed the lowest levels of attitudes towards intellectual disability. Though siblings' knowledge about their brother or sisters' disability was not detailed, this information gives the understanding that siblings who have an idea about their brothers' or sisters' disability are able to show more of a positive attitude than those who do not know.

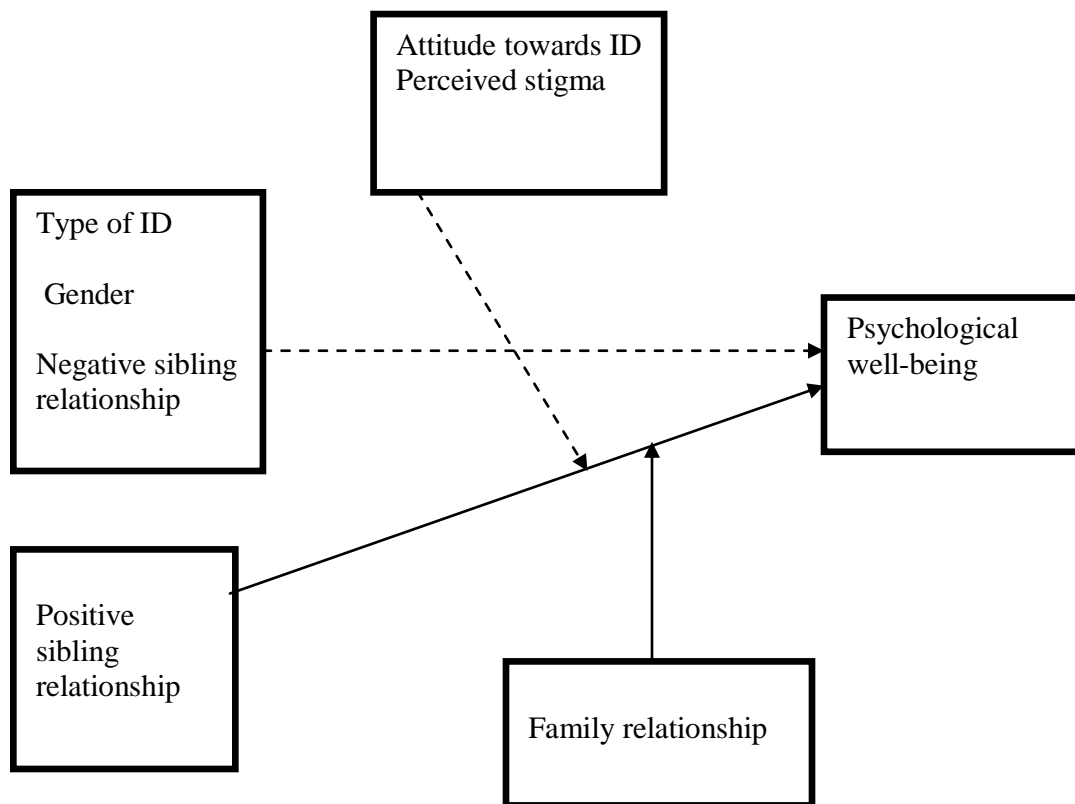
In line with the research findings, Aksoy & Yildirim's (2008) comparison of siblings of children with learning disability, autism and mental retardation indicates that siblings with autistic brothers or sisters were more negative in their views towards disabled sibling than the other

groups. Their study indicated that type of intellectual disability influenced siblings' attitude which was not in support of the findings in this study.

### **Family relationship and psychological well-being**

Family relationships moderating effect on the relationship between psychological well-being and positive sibling relationship was significant. This finding presumes that strong family relationship is important in the psychological well-being of siblings in family with an intellectually disabled member. As indicated, parental acceptance of a child with disability and positive family relationship reduces stress (Neely-Barnes & Dia, 2008); hence stabilising or increasing psychological wellbeing of other members in the family.

Family relationship was measured with the Family Relation index. The study revealed that family relationship correlated positively with positive sibling relationship and psychological well-being of the siblings. this finding suggest that an positive family atmosphere is likely to increase psychological well-being of its members in spite of the presence of a person with disability. Further positive family relationship enhances other relationship with the family, for instance sibling relationship. This was confirmed in the study by Bellin and Rice (2009) in which they confirmed that family factors were strong determinants associated with sibling relationship.

**Observed conceptual frame-work**

NB

-----> : Non-predicting effects

—————> : Predicting effects

In the model above positive sibling relationship is predictive factor of the psychological well-being. In other words, positive relationship is directly related to psychological well-being. The other predictive factors; type of intellectual disability, negative sibling relationship and gender are not predictive of the psychological well-being. Perceived stigma and attitude towards

intellectual disability does not moderate the relationship between positive sibling relationship and psychological well-being. However, family relationship moderates the relationship between positive sibling relationship and psychological well-being.

### **Implications of findings for clinical practice**

The findings from this study have several important implications for clinicians.

The knowledge gained from this study and other previous research emphasized the importance of sibling relationship and family relation as significant sources of psychological well-being (Dunn, 2003; Seltzer et al, 1997), no matter what the circumstances are. Siblings also act as caregivers when parents are no longer able to care for disabled siblings (Horwitz, 1993). Therefore helping to build a strong sibling relationship for an intellectually disabled child will have an impact on the psychological well-being of both siblings and help counter negative perception about themselves. Clinicians and other persons working with families of ID children should encourage positive and strong relationship among siblings. Families should help strengthen the bond between siblings over the years, especially during the adolescent stages. Sibling relationships frequently remain stable from adolescent stages throughout the adult stages (Nandwana & Katoch, 2009).

Siblings of children with ID get knowledge or information about siblings' disability from parents and other caregivers. Clinicians who work with parents of these children should periodically get them apprised on the progress of the child in order that siblings may also be informed properly. Further, family therapy or family psycho education can help in keeping siblings informed as to what is happening. Psycho education employs the use of psychological methods to help family gain knowledge and skills in several domains such as interpersonal interactions and self esteem

(Bergin, 2004). Family therapy creates an opportunity for siblings and families to understand evolving situations and learning coping strategies within the family.

### **Limitations of the current study**

This study has its limitations which may have affected the general outcome obtained. These limitations include a small sample size and the use of some measures.

First the number of siblings used in the study would make generalization of results to a larger population difficult. In this study the total number of siblings who participated in this study were sixty-nine (69), and it include siblings related to persons with the four types of intellectual disability identified. Due to the nature of the study, it was difficult to employ probability sampling strategies because there was no data on the number of families with persons with intellectual disabilities in Ghana or in the greater Accra Region, where the study took place. With small numbers, there is also low statistical power to detect effect especially on a survey type of study.

Questionnaires used could not give room for further responses and therefore, certain important elements of the study may have been overlooked. Future studies could make use of questionnaires that will elicit more information about the challenges of having a sibling with a particular type of disability and its effects on the general well- being of siblings. Thirdly, the researcher's inability to explain some of the terminologies on some of the scales could have affected the responses on the tests.

Finally, parental rating of the sibling relationship scale could also have had an effect on the outcome. Parents and guardians may have overrated or underrated siblings' performance on the

scale. Future studies could adapt the self-ratings by both siblings themselves as well as the ratings of parents and guardians.

### **Suggestion and Recommendations for future studies**

This research has identified the effects of stigma on the psychological well-being of siblings of persons with intellectual disability, with sibling relationship, type of intellectual disability and attitudes as serving as moderating effects. However, this study is not without limitations. The first limitation was the inadequate information gotten from the participant siblings about their knowledge of their brothers' or sisters' disability; questions about the name of the disability and the cause were the only questions asked.

Future research should consider a more detailed approach in soliciting information about siblings knowledge of their brother' or sisters' disability.

Secondly, future studies should consider a much detailed qualitative approach.

This would give room for exploration of specific details concerning the way they perceive stigma, its impact in specific areas of their lives and the way they exhibit attitudes toward intellectual disability in general.

### **Conclusions**

This research brings to fore new information about a relatively under researched area of siblings of children with intellectual disability in Ghana. Stigmatization of families is one of the stressful situations that intellectually disabled persons and their families go through. This unfortunately can affect the attitudes and psychological well-being of siblings. This study examined the perception of stigma and its effect on attitudes of intellectual disability and psychological well-

being with sibling and family relationship and intellectual disability serving as moderating variables. However, positive sibling relationship and family relationship is likely to serve as buffer against the negative perception of stigma in families of children with intellectual disability.

In contrast to what was hypothesized and previous literature, siblings' attitude toward the intellectual disability does not seem to have been affected by perceived stigma. Perception of stigma by siblings directed at themselves has a dire consequence on siblings' functioning in terms of the relationship that is formed with their intellectually disabled brother or sister (Miller and Kaiser 2001). As such helping siblings cope with stigma and its interpretation to themselves is important.

Helping build a stronger relationship between siblings and within the family makes it possible for siblings to cope with having a sibling with an intellectual disability and the challenges that come with it.

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## **Appendix 2**

### **PARENTAL CONSENT FORM**

Title: **The perception of stigma on the psychological well-being of sibling of children with intellectual disability.**

Principal Investigator: Stella Nartey

Address: Department of Psychology, University of Ghana, Legon.

#### **General Information about Research**

This study is to find out how sibling relate to their siblings with intellectual disability and its impact on their well-being. Further this study is finding out the impact of stigma on the relationship between siblings. Hence this research involves answering a questionnaire within maximum forty-five minutes to ascertain the needed information,

#### **Possible Risks and Discomforts**

The anticipated risks involved in this research will be boredom or tiredness. This might be due to the number of items on the questionnaire. Therefore, ample time will be sought so as to give enough room for recuperation. It will also be made clear to your ward that he/she is free to stop responding to the questions at any section of it and at any point in time. Further, responding to the questionnaire might rekindle some experiences they may have had as a result of their sibling's disability (for your ward) since aspects of the questionnaire finds out about their experiences of stigma. Hence, phone numbers (of the supervisor and the principal investigator) will be provided to help any child who will have problem in a free psychotherapy session. In addition, enough time will be created for questions and answers so as to allay fears and discomforts that might have occurred during the study.

#### **Possible Benefits**

This research will help give up-to-date information on sibling relation in families with an intellectual disabled child.

#### **Confidentiality**

The research will ensure absolute anonymity of your ward's responses since there would not be any tag (either name or code) to identify him/her in any way.

#### **Voluntary Participation and Right to Leave the Research**

This research will be voluntary and your ward can withdraw without any penalty.

#### **Contacts for Additional Information**

The following numbers can be contacted in case of any discomfort, explanation or further information.

Researcher: Stella Nartey (Tel: 0243-137-192)

**Your rights as a Participant**

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your ward's rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: [nirb@noguchi.mimcom.org](mailto:nirb@noguchi.mimcom.org) or [HBaidoo@noguchi.mimcom.org](mailto:HBaidoo@noguchi.mimcom.org) . You may also contact the chairman, Rev. Dr. Ayete-Nyampong through mobile number 0208152360 when necessary.

**GUARDIAN/PARENTAL AGREEMENT**

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to me (Guardian/Parent) as well as my ward. Hence, he/she can go ahead to participate in the study.

---

Date

---

Name and Signature of Guardian/Parent

### **Appendix 3**

#### **CHILD ASSENT FORM**

##### **Introduction**

My name is Stella Nartey and I am from the Psychology Department at University of Ghana. I am conducting a research study entitled the perception of stigma on the psychological well-being of siblings of children with intellectual disability. I am asking you to take part in this research study because I am trying to learn more about how one relate to their sibling with intellectual disability. This will take approximately forty- five minutes.

##### **General Information**

If you agree to be in this study, you will be asked to respond to some questions on several areas of your relation with your sibling with disability.

##### **Possible Benefits**

Your participation in this study will result in getting some knowledge about how one relates with his sibling who has intellectual disability as well as getting up-to-date information on stigma of siblings of children with intellectual disability.

##### **Possible Risks and Discomforts**

However, the risks associated are spending more time in answering the questions which can make you bored or tired. Therefore, more time will be provided to help you get better. Further, some of the questions may remind you of how you feel about having a sibling with intellectual disability and the stigma attached. In this case, feel free to contact me or my supervisor on the cell numbers provided for free psychotherapy sessions.

##### **Voluntary Participation and Right to Leave the Research**

You can stop participating at any time if you feel uncomfortable. No one will be angry with you if you do not want to participate.

##### **Confidentiality**

Your information will be kept confidential. No one will be able to know how you responded to the questions and your information will be anonymous.

##### **Contacts for Additional Information**

You may ask me any questions about this study. You can call me at any time (Stella - 0243137192).

Please talk about this study with your parents before you decide whether or not to participate. I will also ask permission from your parents before you are enrolled into the study. Even if your parents say “yes” you can still decide not to participate.

**VOLUNTARY AGREEMENT**

**By making a mark or thumb-printing below, it means that you understand and know the issues concerning this research study. If you do not want to participate in this study, please do not sign this assent form. You and your parents will be given a copy of this form after you have signed it.**

**This assent form which describes the benefits, risks and procedures for the research titled perceived stigma on the psychological well-being of siblings of children with intellectual disability has been read and or explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate.**

Child's Name: \_\_\_\_\_

Researcher's Name: \_\_\_\_\_

Child's Mark/Thumbprint \_\_\_\_\_

Researcher's Signature \_\_\_\_\_

Date: \_\_\_\_\_

Date: \_\_\_\_\_

**Appendix 4****SOCIO- DEMOGRAPHIC INFORMATION**

**Please answer all the questions as honestly as you can. Your responses will be kept in absolute confidence. Your personal information will not be associated with your responses and none of the information will be discussed with anyone.**

Date: \_\_\_\_\_

Name: \_\_\_\_\_

1. Age: \_\_\_\_\_

2. Sex: Male [ ] Female [ ]

3. Where do you live? \_\_\_\_\_

4. What is your religion?

a. Christianity [ ]

b. Muslim [ ]

c. Traditional [ ]

d. Others (specify): \_\_\_\_\_

5. Do you live with your biological parents?

Yes [ ] No [ ]

6. Whom do you live with most of the time?

Both Parents [ ] Single Parent [ ] Others (specify) [ ] \_\_\_\_\_

7. What is your highest level of education?

a. No formal education [ ] b. JHS [ ] c. SHS [ ] d. tertiary [ ] e. other, please specify [ ]

8. Do you have siblings?

Yes [ ] No [ ]

9. How many siblings do you have? \_\_\_\_\_

10. What is your birth position? (E.g. are you the first, second etc..) \_\_\_\_\_

The following are questions about **your sibling with a disability**. Please respond as honestly as possible.

11. Sibling's age: \_\_\_\_\_

12. Birth position of this sibling: \_\_\_\_\_

13. Age difference between yourself and this sibling \_\_\_\_\_

14. Siblings' gender: Male [ ] Female [ ]

15. Who does your sibling live with? \_\_\_\_\_

16. What is your relation with this sibling? Biological sibling: [ ]

- a. Twin [ ]
- b. Step sibling [ ]
- c. Half sibling [ ]
- d. Other, please specify .....

17. How much time do you spend with your sibling?

Daily [ ] Weekly [ ] At least once a month [ ] Less once in every three months [ ]

18. How do you get to know information about your sibling's disability?`

Parents: [ ] Another sibling: [ ] other family member [ ] Friends [ ] Neighbour [ ] other source [ ]  
(please specify):\_\_\_\_\_

19. What is the name of the disability?

- a. Down syndrome [ ]
- b. Cerebral Palsy [ ]
- c. Autism [ ]
- d. Attention Deficit Hyperactive Disorder [ ]
- e. Other: please specify: \_\_\_\_\_
- f. Don't know [ ]

20. What do you know think are the causes of your sibling's disability?

Choose as many as are true

- a. Spiritual cause: Curse [ ] Punishment for wrong doing [ ] Witchcraft [ ]
- b. Medical cause: Disease or illness [ ] birth defect [ ] genetic disorder [ ]
- c. Physical cause: injury [ ]
- d. Other, please specify: \_\_\_\_\_

The following are questions about your parents, guardians' education and occupation. **Please respond to either guardian or parents (Father and Mother) you live with most of your life.**

21. What is your father/ mother/ guardian's education?

	Father	Mother	Guardian
Graduate/Postgraduate			
Training College/ Polytechnic			
Secondary			
Middle school			
No formal Education			

22. What is your father or mother/ guardian's occupation? If they own a business please state the type of business, e.g. trading/ retailing, etc.

Father: \_\_\_\_\_ Mother: \_\_\_\_\_

Guardian: \_\_\_\_\_

23. Marital status of parents

Married [ ] Divorced [ ] Widowed [ ] Separated [ ] Never married/ single [ ]

**Appendix 5****SIB****(To be answered by parent or guardian)**

This questionnaire is asking you (guardian/ parents) to circle the number that shows how often a typical developing sibling behaves in that way towards child with Intellectual disability (ID).

Please answer honestly. Please answer honestly. 1= never 2=seldom 3= some 4=often 5=always.

Thank you.

The Respondent (typically developing child)

No		Never	Seldom	Someti mes	Often	Always
1	Is pleased by the progress sibling with ID makes					
2	Teases or annoy sibling with ID					
3	Gets angry with sibling with ID					
4	Accepts sibling with ID as a playmate					
5	Is embarrassed to be with sibling with ID					
6	Wants sibling with ID to succeed					
7	Stays away from sibling with ID if possible					
8	Gets ideas for things he/she can do together					
9	Argues with sibling with ID					
10	Has fun at home with sibling with ID					
11	Acts ashamed of sibling with ID					
12	Shows sympathy when things are hard for sibling with ID					
13	Frowns or pout when he/she has to be with sibling with ID					
14	Teaches sibling with ID new skills					
15	Helps sibling with ID adjust to new situation					
16	Treats sibling with ID as a friend					
17	Avoids being seen with sibling with ID					
18	Is concerned about welfare and happiness of sibling with ID					
19	Makes plans that include sibling with ID					
20	Hurts sibling with ID's feelings					
21	Tries to comfort sibling with ID when he/she is upset or unhappy					
22	Shares secret with sibling with ID					
23	Babysits and care for sibling with ID					
24	Gossips about sibling with ID					
25	Is jealous of sibling with ID					

26	Has physical fight with sibling with ID (not just for fun)					
27	Is noseey and have to know everything about sibling with ID					
28	Tries to teach sibling with ID					
29	Takes advantage of sibling with ID					
30	Blames sibling with ID when things go wrong					
31	Is very competitive against sibling with ID					
32	Resents sibling with ID					

**Appendix 6****WBMMS**

Please answer each of the following questions according to the response provided

During the Last month

No	Item	Never	Rarely	Sometimes	Frequently	Almost always
1	I had self-confidence					
2	I felt that others loved me and appreciated me					
3	I felt satisfied with what I was able to accomplish, I felt proud of myself					
4	I felt useful					
5	I felt emotionally balanced.					
6	I was true to myself, being natural at all times					
7	I lived at a normal pace not doing anything excessively					
8	My life was well-balanced between my family, personal and school activities					
9	I have goals and ambitions					
10	I was curious and interested in all sorts of things					
11	I had lots of energy, I did lots of activities					
12	I felt like having fun, doing sports and participating in all my favorite activities and past-times.					
13	I smiled easily					
14	I had a good sense of humour, easily making my friends laugh					
15	I was able to concentrate and listen to my friends					
16	I got along well with everyone around me					
17	I was able to face difficult situations in a positive way					
18	I was able to clearly sort things out when faced with complicated situations					
19	I was able to find answers to my problems without trouble					
20	I was quite calm					
21	I had the impression of really enjoying and living life to the fullest.					
22	I felt good, at peace with myself					

23	I found life exciting and I wanted to enjoy every moment of it					
24	My morale was good					
25	I felt healthy and in good shape					

**Appendix 7****FEIS-stigma****Please tick the correct response**

Was there ever a time when, because of sibling's intellectual disability problems,

No.	Items	Not at all	A little	Some	A lot
1	You worried whether people would find out about sibling's condition.				
2	You worried that your neighbours would treat you differently?				
3	You sometimes felt the need to hide your sibling's disability?				
4	You kept your sibling's disability a secret?				
5	You worried that friends and neighbours would avoid you after they found out about it?				
6	You didn't see some of your friends as often as you did before?				
7	You avoided going to large parties or social events with sibling?				
8	You worried that even your best friends would treat you differently?				
9	You felt ashamed or embarrassed about sibling's disability?				
10	You felt stigmatized because of your sibling's disability				
11	You have difficulty interacting with other people because you felt stigmatized				
12	Your experiences with stigma affected your quality of life?				

**Appendix 8****The Family Relationships Index (FRI)**

The following statements help us to understand your family. Please read each statement below and place a tick in the column marked strongly disagree, disagree, agree or strongly agree if you think the statement indicate the situation in your family.

No	Item	Strongly disagree	Disagree	Agree	Strongly agree
1	Family members really help and support one another.				
2	Family members often keep their feelings to themselves.				
3	We fight a lot in our family.				
4	We often seem to be killing time at home.				
5	We say anything we want to around home.				
6	Family members rarely become openly angry				
7	We put a lot of energy into what we do at home.				
8	It is hard to express emotions at home without upsetting somebody.				
9	Family members sometimes get so angry they throw things.				
10	There is a feeling of togetherness in our family.				
11	We tell each other about our personal problems.				
12	Family members hardly ever lose their tempers.				

**Appendix 9: Additional findings**

Cross-tabulations of type of sibling relationship and name of disability

		Type of sibling relationship				
		Companionate	Conflicted	Ambivalent	Uninvolved	Total
name of the disability	Down syndrome	12	7	4	4	27
	Cerebral palsy	6	7	4	1	18
	Autism	2	5	3	1	11
	ADHD	3	1	0	0	4
	Don't know	2	5	2	0	9
	Total	25	25	13	6	69

Cross- tabulations of type of sibling relationship and who gives them information

		Type of sibling relationship				
		Companionate	Conflicted	Ambivalent	Uninvolved	Total
Parents	16	2	11	0	0	29
Other relatives	3	0	0	0	0	3
Other people	6	3	0	4	0	13
Total	25	5	11	4	0	45

Cross- tabulations of type of sibling relationship and cause of siblings' disability

		Type of sibling relationship				
		Companionate	Conflicted	Ambivalent	Uninvolved	Total
Curse	3	5	5	0	0	13
Punishment for wrong doing	0	1	2	0	0	3
Witchcraft	2	8	1	0	0	11
Illness	3	4	2	3	0	12
Birth defect	5	0	0	2	0	7
Genetic disorder	8	3	2	0	0	13
Physical cause	3	4	1	1	0	9
Total	24	25	13	6	0	68

Correlation matrix showing relationship between perceived stigma, cause of disability and name of the disability

	Perceived stigma	Causes of disability	Name of the disability	Information
Perceived stigma				
Causes of disability	-.248			
Name of the disability	.030	-.254		
Information	.172	.155	.306	

\*. Correlation is significant at the 0.05 level (1-tailed).

Correlation Matrix showing relationship between perceived stigma and the various scales of the WBMMS

Perceived stigma	Self-esteem	Mental Balance	Social Involvement	Sociability	Control of self & event	Hospitality	
Perceived stigma	1						
Self-esteem	-.089	1					
Mental Balance	-.130	.383**	1				
Social Involvement	-.487**	.099	.304*	1			
Sociability	-.497**	.381**	.483**	.769**	1		
Control of self & event	-.034	.421**	.368**	.311**	.422**	1	
Hospitality	.003	.415**	.384**	.145	.301*	.462**	1

\*\* . Correlation is significant at the 0.01 level (2-tailed).

\*. Correlation is significant at the 0.05 level (2-tailed).