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DISABILITY LOAD ON HOUSEHOLDS HOSTING CHILDREN WITH DEAFBLINDNESS IN IGANGA, MAYUGE AND JINJA DISTRICTS, UGANDA

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DECLARATION

This is my original work and has not been presented for a degree in any other University.

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DEDICATION

This thesis is dedicated to my wife Felicitas Ojwang for her encouragement while doing this work, my late parents for laying the foundation, all my children with special regards to Deo and Sam whom I have been too busy to have time for.

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ABBREVIATIONS AND ACRONYMS

ADBC	:	Australian Deaf blind Council
CBR	:	Community Based Rehabilitation
CHARGE	:	Coloboma of the eye, Heart defects, Atrasia of the nose, Retardation of growth, Genital and Ear abnormalities.
CWDBs	:	Children with deaf blindness
CWDs	:	Children with disabilities
NGOs	:	Non-Governmental Organizations
PWDB	:	People with Deaf blindness
PWDs	:	People with Disabilities
SWDB	:	Siblings with Deaf blindness
UK	:	United Kingdom
UN	:	United Nations
UPE	:	Universal Primary Education
U.S.A	:	United States of America

ABSTRACT

Unlike in the developed world, there is little documented information about children with deafblindness (CWDB) and, virtually no research has been done in Uganda regarding all aspects of deafblindness. Therefore, little is known about the disability load borne by the household and its effect on the quality of life and the educational development of the children. The purpose of the study was to determine the nature of the disability load in the household hosting CWDB and the resulting impact on the members. The specific objectives were to dimensionalise the disability load, find the effects on the quality of life, the impact on the schooling path, investigate gender differences and generate a conceptual framework for improving schooling outcomes. The building of this conceptual framework was guided by other relevant existing theories. The approach of the inquiry was qualitative, using the Grounded Theory design which is appropriate for examining complex phenomenon. The method of inquiry was systematic, intended to carry out data collection procedure and analysis using constant questioning and comparison. A sample of five households was purposively selected. From every household, between four to five participants were selected to give a total of 23 participants. They were selected because they had borne the disability load by raising and living with CWDB. Two instruments were used, namely, in-depth interviews as well as observational guide. A pilot study to test the instruments, check the use of resources and increase familiarity with the procedure for inquiry was undertaken. Permission to carry out data collection was sought from the national and district authorities. Each interview was preceded by clarification of theaim of the interview and promise of confidentiality. Individual members of the household were interviewed in depth. The information was recorded using a tape recorder, while observing accompanying behavior. Internal and communication validity were ensured by constant questioning, comparison and theoretical sampling. Reliability in Grounded Theory approach was brought about by the development of concepts which were rigorously worked out to form categories. Concepts formed in this way last long and are therefore reliable. Immediately after each interview, the recorded information was transcribed. Data analysis included open, axial and selective coding. The study established that household members while hosting CWDB, experienced disability load of many dimensions, with the emotional one being the greatest. The disability load had a severe impact on the quality of life in the households as well as the schooling path of the children. The gender difference on the impact on the schooling path was detected but was not significant. The final outcome of the inquiry was a conceptual framework grounded in the data. The framework has been named the **Disability Load Conceptual Framework.** It is recommended that policies be developed to guide practical intervention into the socio-economic lives of household members in order to improve the schooling path of the children.

CHAPTER ONE

INTRODUCTION

1.1 Background to the Study

This introductory chapter covers the background to the study, statement of the problem, purpose and objectives of the study, research questions and significance of the study. In addition, the study's scope and limitations, assumptions, theoretical and conceptual frameworks and definition of terms are indicated.

Households hosting children with deafblindness (CWDB) experience the disability load which has impact on quality of life and the schooling path of children in the household. Before this study, the nature of the disability load was difficult to explain and there was no framework for management of the load.

Hornby (1995) defines 'load' as weight of responsibility, worry or grief, while Random House Webster Dictionary (2007) defines it as something which can be borne with difficulty. Rich (2007) supports these definitions of 'load' by admitting that disability can be a heavy load to carry. In association with disability, the words 'responsibility', 'worry', 'grief' and 'burden' – all bring to mind unpleasant images of the household. Disability load is the burden that a household has to endure in the process of looking after the CWDB. People who live in a house collectively as a family, including servants, can be referred to as a household.

Deafblindness affects a person`s ability to live an independent life (Bohrman, 2007). The loss varies in degree and has a serious effect on the individual`s ability to perform tasks that are often taken for granted. As a result, it may seriously influence the quality of life in the household and the schooling path of the children in the family, including those with deafblindness. 'Quality of life' is operationally defined as the extent to which one manages social interactions and daily living activities to a reasonable level of satisfaction. The 'schooling path' is the route followed by the child as he/she goes through the educational process. This path may be followed at varying rates depending on the decisions of parents, the child's individual potentials and the existing government policies.

Historically, deafblindness has been a serious challenge to households, community members and even to professionals (*Deafblind Children, 2008)*. A case in point is Helen Keller, who was born in the US in 1880, and soon became deafblind. Local doctors were at first convinced that her deafblindness was a result of being possessed by a demon, due to her wild and violent behavior. She was later taught, made unexpected progress and led a legendary life. In 1887 another deafblind girl moved into Oberlinhaus, Potsdam in Germany. She was joined by others and the teaching of CWDB started. By 1906, the first home for CWDB had been founded, teaching continued and the home had 20 CWDB (Biesecke, 2005). From then on, teaching of the deafblind has progressed in various countries at different paces.

In France, ultra specialized services were set up and provisions for all ages were made. It is suggested that although the prevalence might be minimal in that country, that is, 3-6 individuals per 100,000, the problem of deafblindness for service providers has been specific and complex (Cote & Cloutier, 2005). Using the

Australian experience, Steer (2005) asserted that in the past 25 years, services offered to people with deafblindness (PWDB) had rapidly improved. This suggests that even educational opportunities have been increasing over the years. In sub - Saharan Africa, the earliest educational provision for CWDB started in South Africa in the 1950s, but only for white people. In East Africa, education for CWDB started in Kenya in 1981 and spread to Uganda in 1994 (Kamau, 1998). This historical background implies that previously, the disability load was wholly borne by the households without any obvious external assistance.

Geographically, the current world situation shows that disability load caused by deafblindness continues to be widespread and therefore deserves attention. The prevalence of deafblindness in the US is said to be difficult to establish because of problems in definition. A report by Watson and Taff-Watson (1993) put the total figure of the deafblind in the US at 47,500. However, Turkington and Sussman (2000) suggest a different figure: 56,000. More recently, Hellen Keller National Center (2007) gave a figure of over 70,000 PWDB in the United States. Out of that figure, nearly 11,000 are children. This figure may not be reliable because the emphasis appears to be on the children receiving services (Chen, 2007). Although all the above figures are inconsistent, they show a steady growth in the number of individuals who have deafblindness in the US.

According to Holland (2007) there were more than 23,000 individuals who have deafblindness in the UK, but the number of CWDB was not mentioned. Japan estimates its population of individuals who have deafblindness to be 18,500, although in 1998, the National Deafblind Association quoted the figure of only 434 with no figures for CWDB. It is reported that this number differs from national figures due to problems of accessing PWDB (*Japan Deaf-Blind Association, 1998*). On the other hand, China has 83 million people with disabilities (PWDs) according to Xiaoshu and Ye (2006). Children with disabilities (CWDs) are said to receive special education, but the deafblind are not mentioned in this report. Thailand has no focused account of PWDB, no official census, and the figures extrapolated to 3,815 (Sukontharungsee, 2005). The above account shows that although the population of PWDs may often be quoted, the numbers of individuals who have deafblindness, and, in particular, CWDB, are often overlooked and, therefore, less known. Only the US, the UK and, to a small extent, Japan, that try to account for the deafblind in any meaningful way.

The US reports provision of services, including educational services for the deafblind. However, the UK has one of the clearest service reports by Sense (2007), indicating the work of education professionals. With the exception of a few countries, records on the number of CWDB are difficult to access, and the type of services provided is even more inaccessible. This presents a problem which is hidden from public view in many countries, and left only to individual households to cope with.

Developing countries often have little awareness of and virtually no services for individuals who have deafblindness (Sukontharungsee, Bourquin & Poonpit, 2006). This observation may have implications for African countries. Grandia (2006) observes that individuals who have deafblindness in Africa live in isolation and cannot access school. In South Africa, records indicate the existence of over two million PWDs, but deafblindness appears to be overlooked and viewed within the health and welfare framework, with limited emphasis on education. The situation is now changing because of favorable post-apartheid policies, but only minimal success has been achieved *(Statistics South Africa,* 2005*)*. Zimbabwe has an estimation of 1.3 million PWDs (Ingstad & Whyte, 1995) but the deafblind are not indicated.

Recent information available from the regional Sense office in Kampala reveal thatthe three East African countries put together have identified only 500 individuals who have deafblindness. The number of children is 165 for Kenya, 235 Uganda, and 100 Tanzania (Nsubuga, 2007). It is noted, however, that limited efforts have been made to reach families of the deafblind and that there are plans to improve educational services in collaboration with international Non-Governmental Organizations (NGOs).Ministry of Education records in Uganda shows that there are 182,350 CWDs at school (*Ministry of Education and Sports,* 2005). There is a breakdown of other types of disability but CWDB are not indicated.

Although there are indications that government policies in Uganda favour PWDS, in general (Mpagi, 2002), and that the constitution acknowledges an imbalance in service provision (*Republic of Uganda,* 1995), a close examination of other documents, including the National Council of Disability Act (*Republic of Uganda,* 2003) and the Disability Act (*Republic of Uganda,* 2006) only emphasize equalization of opportunities. These documents are too general and they do not focus on deafblindness (Atieli, 2003). In addition, the Universal Primary Education (UPE) policy, which is a development from some of these documents, does not readily highlight deafblindness (Bategeka, 2005).

At community level, there are two upcoming organizations for the deafblind in Uganda, one for parents of the children and the other for the adult deafblind, but there are reasons to believe that many individuals who have deafblindness are hidden away for shame and fear in remote and inaccessible villages, with limited awareness by the government (Kamau, 2005). At the moment, in Uganda, there are only 40 CWDB attending school in the whole country. There are indications that with the help of Sense International (Uganda chapter), services are being planned for over 120,000 individuals who have deafblindness in Uganda (Nsubuga, 2007).

Sintef (2007) and Phillips and Noumbissi (2007) observe that there was little data on disability in low income countries in general, including Uganda. The available data was said to be of poor quality, lack comparability, had limited applicability and was only a qualified guess. By implication, lack of reliable data on disability may affect Uganda`s ability to plan programmes for individuals who have deafblindness (*United Nations Statistical Division,* 2001). In a general efforts to address the lack of information, the first Africa Regional Workshop was hosted in Kampala, although it did not specially focus on deafblindness (*UN Statistics Division,* 2003).

To conclude, the information given in this background to the study reveals that although there are some general reports on deafblindness at the global level, little, is known about the number of CWDB in African countries, especially Uganda. Even less known, and yet fundamental, is the nature of the disability load and its influence on members of the households hosting the deafblind. This lack of information creates a need to investigate the phenomenon.

1.2 Statement of the Problem

Although mentioned by professionals and administrators, many studies seem to have overlooked the historical trends, policies, curriculum issues and teaching methods (Amaral, 2003). *Canadian Society for Deafblind* (2005) provides a hint on the lack of studies on public awareness about the needs of PWDB. Feelings and decisions of parents at identification and willingness of schools to admit these children have been neglected. Moore (2006) mentions the effects of responsibility of the siblings of deafblind children together with children`s feelings towards their parents and deafblind sibling's condition. Tarczay (2005) refers to exclusion from community activities including barriers to education which could be an area of interest for researchers. According to the United Nations Statistical Division (2001), there is generally a lack of reliable data on disability affairs in African countries.

Deafblindness in Uganda is one of the most recent types of disability to get attention. Until the early 1990's, the phenomenon was quite unknown to families and members of communities who generally viewed the condition as a curse or some form of witchcraft and the mention of its supposed causes continues to stir up negative reactions (Bwana & Kyohere 2002). At the policy level, deafblindness is not specifically addressed but just included among other disabilities. In reference to this, there has been no census for CWDB in Uganda. Equally neglected is research on policy issues relating to deafblindness and the number of CWDB at school in Uganda.

At the professional level, few teachers are trained to teach CWDB. Lack of policies, inadequate data on disability and poor service provision that may accompany it could mean accumulation of a disability load whose nature and impact is yet unknown As a result of this, households are left to deal with issues of deafblindness without adequate assistance and many give up (Kamau 2005).

As a result of the above situation and context, this study focused on the nature of the disability load on the household and its impact on the quality of life and the schooling paths of all the children in the household, including the deafblind.

1.3 Purpose of the Study

The purpose of this study was to investigate the nature of the disability load on the households hosting CWDB, its impact on the quality of life and the schooling paths of the children.

1.4 Objectives of the Study

The specific objectives of the study were to:

1. Identify the dimensions of the disability load on households hosting CWDB in Iganga District;
2. Examine the consequence of each dimension on the quality of life in each household hosting CWDB;

3. Determine how the disability load impacts on the schooling paths of children (with and without deafblindness) in the selected households;
4. Investigate gender differences on the dimensions of disability load on the schooling path of the children.
5. Generate a conceptual framework (theory) on manipulating the disability load to enhance schooling outcomes for households housing CWDB in Uganda.

1.5 Research Questions

1. What are the dimensions of the disability load on the households hosting CWDB in Iganga District?
2. What are the consequences of each dimension on the quality of life in each household hosting CWDB?
3. How does the disability load impact on the schooling paths of children in the selected households?
4. What are gender the differences on the dimensions of disability load on the schooling path of the children?
5. Which conceptual framework (theory) can assist in manipulating the disability load to enhance schooling outcomes for households hosting CWDB in Uganda?

1.6 Significance of the Study

At the policy level, the study was expected to provide information which may help policy makers and legislators make supportive policies to address disability load and improve schooling paths of the children in the households. From the findings, grass root practitioners and professionals may gain better insight into the disability load in households in an effort to reduce the burden. At the district level, policy implementers would have information to enable them carry out proper implementation, which could address the disability load and later improve schooling path of the children. The Uganda National Curriculum Development Centre and the Faculty of Special Needs and Rehabilitation at Kyambogo University, and, by extension, Kenyatta University, may have additional information to use in developing their curriculum and training personnel in special needs and rehabilitation. The conceptual framework (theory) which has been generated from the study may help to clarify and explain the effects of the disability load on the schooling path of the children in the households of CWDB. The conceptual framework (theory) developed may also stimulate further research to test, modify or extend the framework (theory) which has been formulated. This inquiry is expected to extend the use of grounded theory method into deafblindness.

1.7 Scope and Limitations of the Study

The boundaries of the study covered Iganga District and the neighboring districts of Mayuge and Jinja. The reasons for this coverage were that the study was a grounded theory approach, which uses theoretical sampling and in which selection of participants was carried out until saturation. At the same time, the numbers of CWDB and households hosting them were limited in any given district, creating the need to move to the next district. In due course, theoretical sampling was carried out and saturation of data was reached.

The study was restricted to households that were willing to take part in the inquiry and had children registered as deafblind by the rehabilitation workers and the national organization for deafblind in the district. Within each household which was included in the inquiry were parents, the CWDB and their siblings. Both girls and boys participated in the study. Parents were aged between 30 years and 45 years. The age of the children was between 4 years and 13 years.

The sample size included 5 households hosting a total of 23 participants. The sample was small because it was a qualitative in-depth study which sought to build a conceptual framework (theory). In terms of methods, this study was qualitative and non-statistical (Haig, 2001). It excluded quantitative methods whose aim would be to test, extend or modify theory (Amin, 2005; Byrne, 2011).

Theoretically, the study sought to examine the impact of disability load on households in order to fill the knowledge gap. Regarding the content, the scope was disability load and deafblindness as independent variables and quality of life and schooling path as dependent variables. This created room for better understanding of the issues and discovery of intervention points.

The study had a number of limitations. As noted by Ferioli (2003), deafblindness has had little attention as far as research is concerned. This state of affairs provided limited relevant literature for review as compared to other areas which have been extensively studied. Time was a major limitation. The study was done within 5 years. An increase in time, therefore, would have improved the validity of the results by increasing theoretical sampling even further, and, as a result, strengthening the emerging conceptual framework (theory).

Increase in the number of participants would also have improved quality of generalization of the findings. As has been stated, the scope of the methodology was qualitative, but a quantitative design done after this work would give more application to the findings. Triangulation, which would normally improve validity of the findings, was undermined because parents did not have sufficient documents related to the deafblindness of the children. Other constraints in the study included delays in obtaining resources for the various stages of the research. Money, being a limited and yet essential resource in all undertakings, was a major setback from the time of approval of the research to actual data collection. Attempts were made to accelerate the acquisition of money for the project from stage to stage by early presentation of financial requests to the financing committee.

Entering households to collect data often created many high expectations and misconceptions from household members. The expectations were often financial. Attempts were made to clarify some of the issues from the beginning. Obtaining sufficient information from a CWDB was challenging. Interpreters who usually communicated with the CWDB, especially household members, were used to obtain information, but this could have led to some loss of information.

1.8 Assumptions

It was assumed that:

1. All households were equally vulnerable to the impact of deafblindness but the level of vulnerability was not uniform from household to household.
2. Siblings of CWDB might not have been equally affected from household to household or even within each house.
3. Gender differences in the household may contribute to the variation of the impact of the disability load.
4. All households seek to find ways to reduce the disability load individually
5. Household members experience disability differently, and construct their perception of the situation individually. These constructions influence the impact deafblindness has on them with the CWDB, and significantly influence the schooling process for the children in the household.

1.9 Theoretical and Conceptual Framework

In this section, the conceptual and theoretical frameworks are presented and discussed. The theoretical framework has three theories which guided the study and increased theoretical sensitivity. The conceptual framework involves a number concepts identified early in the study. These concepts helped to direct the study.

1.9.1 Theoretical Framework

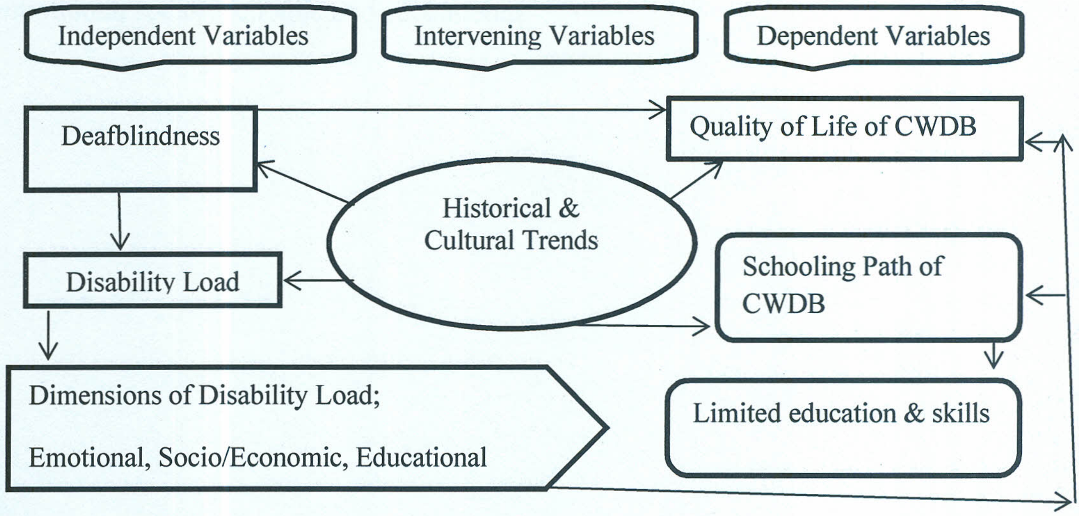
Although there were no readily available theories to provide insight and explain the relationships between these concepts and the daily reality in the household hosting CWDB, this work engaged three theories as a starting point. These included: the

Theory of Symbolic Interactionism, Festinger`s Cognitive Dissonance Theory and Family Systems Theory (Amin, 2005). Symbolic Interactionism describes the way we learn to interpret and give meaning to the world through our interaction with others. It was the lead theory and was expected to contribute to the understanding of the participating household because it views the family as a unit of interacting personalities (Plumkett, 2007). It suggests that the interaction in the household is by use of symbols which provide meanings for household members. Lack of communication in the family as a result of deafblindness may bring frustration in the household thus increasing the disability load and lowering the quality of life. Supporting the lead theory are the Cognitive Dissonance and Family Systems theories.

In 1957, Festinger put forward the Cognitive Dissonance Theory, which explains relationships among pieces of knowledge referred to as cognitions. The knowledge includes values, and in this study, it referred to the value of the CWDB as seen by members of the household. Dissonant cognition creates psychological dissonance which is an unpleasant psychological tension. The tension has to be reduced for the individual to be comfortable. However, it may, instead increase as the disability load on members of the household (Rudolph 2007). The Bowen or Family Systems Theory, developed by Dr. Bowen between 1954-1959 suggests that to understand the individual, one needs to understand the rest of the family. Individuals cannot be seen in isolation; family members are emotionally interconnected and interdependent (Genopro, 2008). In this study, individuals needed to be understood as members of the household with emotional ties to each other. Any severe change in emotion in one individual as a result of the disability load may bring about related change in emotion in the other members of the household. It can be noted that there is a possible circular flow of relationship between Symbolic Interactionism Theory → Cognitive Dissonance Theory →Bowen or Family Systems Theory feeding back to Symbolic Interaction Theory. The conceptual framework (theory) to be built is to be grounded and should relate itself to this flow.

1.9.2 Conceptual Framework

Figure 1: The Conceptual Framework



Source: The information that was used to develop the conceptual framework in Figure was from the review of literature on deafblindness.

Explanation of the Conceptual Framework

The conceptual framework in Figure 1 above indicates the concepts which helped to direct the research process. It consisted of three main sets of variables;- (1) the independent, which includes deafblindness and disability load, (2) the dependent variables which are the quality of life and schooling path and, (3) the intervening ones which are the historical / cultural trends. Deafblindness causes the disability and increases the weight of the load. Both deafblindness and the disability load, through its dimensions, have negative impact on quality of life of CWDB and their schooling path. The effect on the quality of life could be on factors such as enjoyment of life and ability to satisfactorily face day to day challenges. The schooling path could be distorted by loss of opportunities for CWDB and their siblings when they fail to go to school. The siblings could even enroll in schools but have irregular school attendance or drop out completely. These influences are mediated by historical and cultural trends. The disability load consists of several dimensions which include the emotional, socio/economic and educational.

1.10 Operational Definition of Terms

Conceptual Framework: a visual representation of theoretical constructs of interest; in Grounded Theory studies it is used in relation to theory, and in this study it is synonymous with it

Deafblindness: loss of both the sense of sight as well as hearing. The loss varies in degree and has serious effects on the individual`s ability to perform tasks that are often taken for granted. As a result, it may seriously influence the schooling path of the children in the family.

Disability Load: the burden that a household has to endure in the process of looking after the CWDB. It means reallocating family resources, including time and family labour.

Household: all individuals living in the same house. It means the same thing as family.

Interveners: people who give personal support to PWDBs

Jajas: a local word for spirits of ancestors.

Middle Range Theory: a theory with limited scope that seeks to explain social phenomena

Quality of Life: the level to which life can be said to be worthwhile and enjoyable to the individual. It is closely related to the physical and mental wellbeing of the individual. In case of deafblindness this quality of life is undermined by the severe limitations in communication. It also affects the other members of the household.

Savedees: fanatical Christians who claim spiritual perfection.

Schooling Path: the route followed by the child as he goes through the educational process. This path may be followed at varying rates, depending on the decisions of parents, the existing government policies and the child's individual potentials.

Theoretical Sampling: the process of choosing who to interview next. This choice is guided by the level of theory generation in the ongoing analysis of data which has already been collected (Strauss et al. 1990).

Theory: a set of conceptual relationships that offer explanations of the phenomenon under study Strauss & et al.(1990).

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

The literature review presented below covers the characteristics of the disability load, the consequences of each dimension on the quality of life, and the impact of disability load on the schooling path. Previous research undertakings and related gaps are mentioned. At the end of the Chapter, a summary is presented.

2.1 The Characteristics of the Dimensions of the Disability Load in Households

From the available literature, one can characterize a number of dimensions of the disability load within the household. They include communication, educational, emotional, socio- economic and public awareness. Deafblindness is one of the most challenging, but also least understood disabilities. Some people are born, or later become completely deaf-blind; this brings immense challenges in communication. For young CWDB, it is very difficult to find out about the world around them, get to know the family or have a conversation. Learning becomes challenging. It is difficult for them to know where they will live and what to do with their lives (Sense, 2013). They face great difficulty in knowing for certain what is happening around them (Sense, 2001). For the household, and even the community at large, the situation is equally challenging. For concerned parents, the realization that their child has problems with her/his sight or hearing with resulting difficulty in communication can be a daunting experience, which can create complex emotional experience (Sense, 2013) . A mother has been quoted as saying that because her daughter is deafblind, her eyes seem to be in her hands and she touches people to get clues about who they are. Sometimes this can lead to uncomfortable situations leading to rejection and, eventually, isolation of the child and household members. The mother has to explain to people they are in contact with, that the child cannot see or hear, and that this is her way of communication and of understanding the world (Sense International, 2011).

CWDB lag behind because parents are often not aware of the importance of communication (Rodbroe & Ramsing, 2005; Tap, 2003). When people lose their sight and hearing at advanced ages, they face new problems related to poor communication, and may become frustrated or distrusting if they feel excluded (Sense, 2013). In some kinds of deafblindness, a PWDB will have only reduced access to communication clues, for example, they may be unable to see body language. This should be considered by the person they are conversing with (Sense, 2013). Such consideration may not be within the household or school, creating difficulties in communication. PWDB face huge challenges with communication, getting around safely and living independently. Households members may feel stressed by having to battle for the right help for such an individual (Sense, 2013). Such stresses and battles within the household can be exhausting. As observed by Sense (2013), good communication is crucial to our relationship and membership of social groups. People’s lives are highly affected by the quality of the contact they have with other people.

According to Sense (2001), a person`s quality of life depends on communication that is clear, concise and accessible. Unfortunately, having to find a way to communicate with a PWDB can be extremely challenging, therefore, one needs to work in close partnership with families (Sense, 2013); and yet such partnership is rare. With regard to a CWDB, the beginning of a conversation is a subtle, sensitive undertaking which creates demands on households and professionals. For the household, failure of the child to develop can be frustrating (Sense, 2013).

Many of the PWDB find it difficult to communicate their desires and wishes. This can cause them stress, anxiety and leads to challenging behaviuor. These challenges have to be endured by household members and the community. Failure to come to terms with behaviours like these may lead to rejection. Buttler (2001) reported that it is difficult to know how much a PWDB understands because her/his options for communication are limited. Equally unsettling for a PWDB is being moved from one place to the next without any explanation so by introducing tactile methods of communication, the PWDB is able to exercise some control over his day to day routine (Sense International, 2011).

With increase in life expectation, it is noted that more and more people are becoming deafblind as they grow older. For these people, it can be a lonely struggle, looking after themselves, talking to friends and enjoying leisure which involves hearing and vision. Such loss of communication can make life increasingly difficult (Sense, 2013). The main barrier PWDB experience in joining social activities is poor communication (Mairs, 2011). PWDB acknowledge that communication guides are crucial (Sense, 2013). They provide a one to one support and communication with the world around PWDB including in the person's home, community, school and vocational setting (Sense, 2013). Such help is not available in many countries including Uganda.

The method of communication used by a PWDB depends on the amount of residual sight and hearing, and any additional disabilities the individual has as well as earlier learning of spoken language before becoming deafblind. Her/his needs also vary enormously and may change during her/his life time (Sense, 2013). Such changes create extra demands in communication on the household and rest of the community. Household members and communities have to cope with demands like these or they may neglect the PWDB. In this study such neglect and isolation is reported. With the support from professionals, young children start to learn to communicate with their families (Sense, 2013) & (Mold, 2011). However, Sense (2013) states that in order to improve performance, communication specialists need to meet regularly to share ideas and information about the latest development in communication with PWDB. Where such specialists do not exist, such improvements may be not possible. Sometimes PWDB who use basic signs may need an interpreter who is not always available (Patel, 2011). In such situations communication becomes very difficult. Providing support in communication gives PWDB a sense of participation and belonging and it breaks barriers (Mairs, 2011). The public is often not aware of the needs of PWDB (Sense, 2013).This lack of awareness and understanding of deafblindness affects CWDB and it has been observed that by the time they arrive at school, they are often withdrawn and they exhibit challenging behaviour (Sense International, 2011). At the social level, there is isolation from their communities, as families have to struggle to cope with their child's complex disabilities.

Wolf (2003) suggests that siblings of CWDB may have to cope with emotional complexes. Jones (2006) also observes that these children may express frustration or become withdrawn in order to spare their parents or siblings from emotional stress. It has been reported that caring for children at home can be exhausting (Cretin-Billet, 2005). While the individual child may suffer from periods of severe mental anguish (Guest, 2003), a lot of patience and love may be needed while working with the CWDB (Kamau, 2005).

School opportunities are often not available and teachers are not trained (Rodbroe & Ramsing, 2005). Cretin-Billet (2005) states that CWDB may need boarding facilities to access education and that due to the complexity of their conditions, the children may need to be attended to by a multidisciplinary team.

It is reported that at school level, a significant number of brothers and sisters to the CWDB have been suspended or suffered exclusion from mainstream schools where there may be a total lack of understanding of the negative effects of having a disabled brother or sister *(Deafblind Children, 2008).* According to Kamau (2005), in the developing world parents struggle to take the children for educational assessment but it is oftena long distance from the home. Subsequent appointments may be difficult to afford and the parents may give up on educating the child. She also mentions the presence of barriers to education because CWDB need their own school.

There are instances when schools lack proper programmes to meet the needs of the children who may be forced to leave school prematurely. Teachers often lack knowledge on new approaches and intervention methods (Hathazi, 2003). Since deafblindness is not widespread, it may be difficult for affected households and individual deafblind persons or their parents to meet and share common experiences. Experiences also suggest that individuals who have deafblindness are isolated (Vilhelmsen, 2005) and services are not developed to meet their needs (Kremneva, 2003). They are excluded from community activities (Tarczay, 2005). Grandia (2006) further argues that individuals who have deafblindness in Africa are very isolated and impoverished. An apparent reference to Uganda suggests that CWDB may be hidden from the public (Atieli, 2005). It has been observed that some parents of CWDB may believe in witchcraft as the cause of the condition, suspect neighbours and therefore increasing isolation (Kamau 2005).

CWDB may have problems interacting with the world; have difficulty in acquaintance, orientation and response to events and are not easily accepted (Jakes, 2003). Neglect, isolation and dependency on members of the household have also been reported (Leela, 2004). In a related report from Ghana, Afutu (2004:8) mentions that due to lack of awareness of the potential of PWDBs ‘many people think that people with deafblindness are unable to take an active part in life.’ As pointed out by Kumwenda (2004), it can be quite tough to live as a deafblind person in Malawi. This statement suggests that there is limited support for PWDB, including from the members of the household hosting the deafblind.

Within the household they may blame each other, get traumatized and sometimes marriages end in divorce (Kamau, 2005). Children may have difficulty learning social skills needed to interact with the others. Hartshorne(2003) states that the children may develop behaviours that may be counterproductive in social situations. Providing evidence from Spain, Lopez (2004) points out that families of CWDB have leadership and representation problems. He indicates that the parents and families are left out without capacity for any representation. Poor representation may have implications for opportunities for good quality services.

In many African countries, the cost of taking care of a CWDB is often high and not affordable compared to the income in most families and parents may experience extreme economic difficulties (Kamau 2005). In apparent reference to both Uganda and Kenya (Kamau, 2005) observes that CWDB lack funding and do not have any assistive mechanisms. They are often living an impoverished life (Grandia, 2006).

Drescher (2005) points out that in most countries deafblindness is not recognized as a distinct disability. There are oftenno specific programs for identifying newly diagnosed CWDB. In other countries, the government may claim that the number of CWDB is negligible and therefore does not warrant services provision (Hathazi, 2003; Salomie, 2006). As stated by Collins (2005) policy issues may be a major barrier to intervention, especially in developing countries including Africa where limited resources, lack of trained personnel and shortage of materials pose significant obstacles. This could partly be due to absence of relevant policies or poor interpretation and implementation of the ones already in place. In Uganda, there is lack of specific policies as well as public awareness of deafblindness to address the condition (Atieli, 2005). In some situations, there is insufficient public awareness to highlight the needs of persons who have deafblindness and to reduce the misconception among governments *(Canadian National Society for Deafblind,* 2005*)*.

2.1.1 Knowledge Base and Gap on the Dimensions of the Disability Load

It is worth noting that the reports on various dimensions of the disability load were those obtained from literature. These were views expressed by various groups including parents, pressure groups, and adults with deafblindness, NGOs and professionals. The dimensions are presented as follows:-

Emotional Dimension

Wolf (2003) states that siblings of CWDB cannot cope with emotional complexes and Jones (2006) points out that children become frustrated and withdrawn. According to Cretin-Billet (2005) caring for the children is exhausting, and Guest (2003) observes that the individual child experiences mental anguish. In Africa, particularly Uganda, Kamau (2005) suggests that CWDB need patience and love.

The findings of this study agree with the above authors. The households reported emotions which include frustration, regret, conflict, stress, disgust, desperation, apathy and rejection. The emotional dimension was a development from the other dimensions including the educational, policy, social and communication dimensions. These dimensions accumulated to increase the disability load on households.

Educational Dimension

Rodbroe and Ramsing (2005) observe that there is lack of school opportunities and trained teachers, while Cretin-Billet (2005) points to the need for boarding facilities for CWDB. *Deafblind Children* (2008) reveals that there is lack of understanding of negative effects of living with deafblindness. Hathazi (2003) states that teachers lack knowledge on new approaches and methods, while Rodbroe and Ramsing (2005) as well as Tap (2005) argue that parents do not know the importance of communication and daily life skills. In Uganda, and in Africa as a whole, Kamau (2005) notes that educational services for CWDB are limited.

The findings of the study indicate that the educational dimension is reflected by insufficient attention from teachers as was reported by parents some of whom were also experienced teachers with reliable opinions. They strengthened their opinions by saying that the teachers were too few to give enough help to CWDB assigned to them. The shortage of teachers was due to lack of opportunities for training teachers in this area of disability. The lack of training opportunity can further be associated with lack of focused policy on deafblindness as a specific area that demands a more focused attention compared to other areas of disability which now have sufficient teachers because of available training opportunities. Limited resources to keep the children at school further increased the impact of this dimension. Shortage of resources, especially in finance, is another area which can only be effectively addressed by government input and supported by NGOs. Once again this is a policy question as pointed out by some of the parents. The educational dimension was affected by economic and policy issues. This meant that the educational dimension was not independent of the economic and policy dimension but is clearly influenced by it.

Social dimension

Vilhelmsen (2005) points out that there is isolation of PWDB, while Kremneva (2003) observes that services needed by CWDB are not developed. According to Tarczay (2005) there is exclusion from community services. Jakes (2003) notes that CWDB are not easily accepted and Leela (2004) points to neglect, dependency and isolation as some of the load borne by CWDB. Hartshorne (2003) observes that CWDB may develop counterproductive behaviours and Lopez (2004) asserts that there are leadership and representation problems for PWDB. Afutu (2004) says that in Africa, there is lack of awareness of their potential and Kumwenda (2004) reckons that life is hard for PWDB. Grandia (2006) argues that they suffer isolation in the African setting. Kamau (2005) writes about marriage breakdown as well as isolation due to beliefs in witchcraft and suspicion of neighbors.

The findings of the study indicate that the social dimension exists in a number of ways including rejection, neglect, isolation and exploitation by household members, relatives and the immediate community. Rejection was evident when a sister said that she did not want a brother to be near her because he would disturb her friends when they visited her. Neglect could be seen by the way some CWDB were dressed compared to their siblings who were adequately dressed. Exploitation was reported by parents when they said that traditional healers asked them to pay a lot of money and to add extra resources they were aware that the service they provide could not benefit the CWDB.

In one of the households, a breakdown in family relations was most likely reinforced by having to look after a deafblind child. Such family tensions and the resulting negative actions could have been reduced by the availability of relevant services including guidance and counseling which is currently not available to households hosting CWDB such as these, despite the availability of many unemployed trained counselors. Rejection, neglect and isolation which are the elements of the social dimension are also linked to the emotional dimension and they reinforce the disability load.

Communication Dimension

PWDB experience severe communication challenges (Sense, 2013) & (Sense, 2001). Loss of communication due to deafblindness can occur any time in one`s life and is accompanied by emotional problems. PWDB find difficulty in communicating their desires (Sense, 2013). Limited options in communication makes understanding difficult for PWDB (Buttler, 2001); and according to Tap (2005), it is considered a setback for the development of CWDB. Increase in life expectations causes related increase in the number of people with communication difficulties due to deafblindness (Sense, 2013). PWDB experience barriers in social interaction because of limited communication (Mairs, 2011). Lack of awareness of communication of PWDB complicates the problem for the individual with deafblindness (Sense, 2013).

Communication is crucial in daily activities and lack of it is exhausting for household members.

The findings of this study indicate that the children could not see, hear and talk. Inability to receive information from the surroundings and to react appropriately to it affected their capacity to take care of themselves. Poor communication interfered with their capacity to benefit from the available programmes. They could also not participate in household activities and their mental development was slowed down. Slow mental development hindered their ability to learn and effectively participate in educational activities. They were often seen as helpless individuals whose value to the household and community was low. This perception undermined the social investment in these children, often leading to apathy and even rejection. Communication issues combined with social issues to negatively influence the educational dimension, and therefore reinforcing the disability load.

Economic Dimension

In Africa in general and also relevant to Uganda's situation, Kamau (2005) points at extreme economic difficulties and lack of funding experienced by PWDB. Grandia (2006) asserts that PWDB lead impoverished lives.

The findings show this dimension in several ways: First, concerned parents spent money looking for medical assistance which was often in faraway hospitals where specialist advanced medical care could be found. Parents desperately spent their meager resources in vain. When the children were not cured of the deafblindness, they came home and, as is often the case, sought local healing. Such expenditure was another desperate attempt to reverse the disability, likely on the advice of relatives, neighbours and other members of the social contact groups. Attempts like these lead to further poverty due to expenditure using already scarce household resources. Other costs were incurred on expensive feeding and transport costs. The feeding was expensive because the children were not willing to eat cheap locally available foods as was reported by parents. Transport costs were high because the children were often difficult to transport using cheaper regular means.

Time for productive work was also lost during this period complicating the poverty situation. The accumulation of the economic situation led to and got linked with the emotional dimension and further increased the disability load.

Policy Dimension

Drescher (2005) argues that PWDs are not recognized as a distinct group. Hathazi (2003) and later Salomie (2006) point that the number of CWDB is seen as negligible, therefore, do not warrant service provision. Collins (2005) observes that policy issues are a major barrier for intervention. Atieli (2005) states that in Africa, and specifically in Uganda, there is lack of policies that address deafblindness.

The findings of the study indicate limited support to the households, by government. Support from NGOs was also reported to be insufficient and unreliable. Limited support from these basic organizations was rooted in inadequate policies which could direct resources and specific action as needed by CWDB and their families. This lack of assistance led to an increase in the already existing level of frustration as could be heard in the words of some of the parents who questioned the level of government awareness of the existence of CWDB. The policy dimension which was another source of frustration and apparent apathy strengthened the emotional dimension which in turn increased the disability load.

There are no reports on policy issues by researchers. The scarcity of studies could be related to the views of Ferrioli (2003) that in most Universities, there is limited interest in the work of professionals dealing with deafblindness and, that of Amaral (2003) that lack of initiative in research is "due to thinking that these children can`t be taught and that they can`t learn." Therefore, knowledge gaps do exist in respect to the research on these six dimensions.

2.2 The Consequences of Each Dimension on the Quality of Life

There are a number of important dimensions of the disability load. These include the educational, emotional, communication and policy. Having identified the dimensions, it is necessary to examine the consequences of each dimension on the quality of life. The educational dimension has an influence on the quality of life. In reference to this, Potmesil (2006) suggests that one can describe quality of life by taking into account school attendance and accessibility by CWDB. It has also been stated that education improves the quality of life for CWDB *(The Canadian National Society for Deafblind,* 2005). Both attendance and accessibility are important variables in education. They increase the contact hours with teachers, other pupils and the general school environment. More contact hours provide opportunity to improve acquisition of knowledge and skills for social interaction. This, in turn, promotes the amount of social inclusion which in itself is basic to good quality of life.

Taking the two views into account, it can be argued that when education is undermined, quality of life may also be compromised. This point of view needs to be considered against the fact that CWDB are dependent on others' help and may often have to be accompanied to access education (Spring & Woodtli, 2004).

As a result of their unique needs they may require special attention to access knowledge and skills (Kumwenda, 2004). Even when put into the school setting, they may miss information from the surrounding (Palmer & Lahtinen, 2005). Cote and Cloutier (2005:7) add that deafblindness influences "life habits and may have severe psychosocial consequences because the two disabilities intensify the effects on one another creating a severe disability." The complexity of the disability may not be acceptable to some schools and the children may be rejected further, therefore, lowering the quality of life (Tap, 2005). The *Stickler Syndrome Support Group,* (2006) also emphasize that children of school age may face considerable educational difficulties because of the combination of impairments.

The emotional dimension closely relates to the educational aspect and also influences quality of life beginning from the household. In a bid to meet the special needs of the child, parents may desperately struggle to find a school for the child. Depending on the outcome, such a struggle may generate frustration in parents and they may end up hating the child because they may view the child as a burden. In support of this, Kamau (2005) also suggests that CWDB need their own special programmes, but this need is often difficult to meet. As emphasized by Rodbroe and Ramsing (2005), sometimes parents may be driven to desperation and may wish to start a school unit for their children. Such extreme difficulties in meeting the needs of the child may also have a negative effect on the individual's quality of life.

Miles (2003) observes that some parents may not accept the fact that their children have sensory loss, they may lose hope and the whole family may get affected. This effect is bound to lower the quality of life. Parents may develop anxieties about the unknown and may, therefore, need support (Lopez, 2004). However, often such support is not easily available (Poggioni, 2007). Both the need for support and lack of it may create a traumatizing situation for the parent's right from the stage of identification. According to Hartsborne (2003), having a disability can get in the way of success and feeling good on the part of the CWDB, therefore lowering quality of life.

It has been observed that a totally deafblind person is deprived of 94% of the information from the environment, (*Croatian Deafblind Association,* 2005). That is, only 6% of the information from the surrounding is available to him/her. This information is received by means of the remaining senses, mainly touch supported by smell, taste and proprioception. Their hands also serve as the voice they use to express themselves (Miles, 2005). Such a condition is unusual and demanding for the individual and frustration may accumulate as these children try to make unsuccessful efforts to interact with their environment. In support of this (Deasy & Lyddy, 2006) further point out that individuals who are congenitally deafblind are presented with significant challenges in language as well as communication and that these obstacles are arguably more complex and may cause emotional problems. It has been further argued that the children are often excluded and live in a dark silent world, (*Croatian Deafblind Association,* 2005). Exclusion, living in the dark and in silence may result in emotional problems with depressive tendencies. According to Guest (2003), the CWDB may develop periods of extreme mental anguish which could result in depression and eventually reduce his quality of life. As the children grow, they may wish to contribute to family life. Not only may deafblindness prevent them from getting in touch with the environment, but they may also fail to express themselves and end up with frustration (Vilhelmsen, 2005; Boothroyd & Hampton, 2003).

In addition to affecting the quality of life of parents and the CWDB, the emotional dimension of the disability load may continue to manifest itself within the household, affecting the quality of life of the siblings. Observations indicate that siblings of CWDB are often expected by parents to be more independent earlier in life than the peer group. They may have more responsibility compared to children in other households, while their needs may be down played, ending in frustration. The siblings may be expected to spend a great deal of time caring for their sibling with disability. In an emotional reaction to this deprivation of free time, the child may develop bitter feelings towards both the parent and the SWDB (Moore, 2006). The parents may be hated because they don't give enough attention to the sibling while giving him/her extra assignment. As emotional complexes develop, the CWDB may be a major source of frustration to the siblings and the target of their anger. Such emotional stress may have a bearing on the siblings` ability to enjoy life. Furthermore, the demands for care by their SWDB may overshadow their own need for love as well as care and they may feel neglected. Excessive responsibility of helping to care for their sibling with disability may be too much for these children and as the burden continues, the children may miss their youthful years of play and develop emotional deprivation.

Research shows that there may be many difficulties. According to Wolf (2003), the following feelings have cropped up time and again in the households ofCWDB: guilt, jealousy, fear, loneliness, sadness, embarrassment, confusion, anger, frustration and worry about their brother/ sister, their parents and the future. Another research was undertaken in the US in 1986 using surveys and interviews with 125 families. The study aimed at determining the unmet needs of families and teenagers diagnosed with Usher Syndrome. Varying responses were found: some participants indicated that receiving the news of the diagnosis was stressful; some had never heard of the condition; others had never met anyone with similar condition; still others wanted to keep the diagnosis from their children; others did not want family members to know this, while others kept the information hidden from school officials. Finally, one mother placed the child up for adoption. The study concluded that the diagnosis of Usher Syndrome is usually difficult and haunting for parents and for the child (Miles, 2003). Although these researches indicate the impact of emotion on the quality of life, such studies are yet to be carried out in Uganda. When both senses are affected, one finds it difficult to get connected to the environment, cannot manage simple tasks and ends up in isolation (Tap, 2003; Afutu, 2004).

Leela (2004) adds that there is isolation as a result of lack of communication between the CWDB and family members. Negligence by family members may occur and relationship with relatives and neighbours may deteriorate, reinforcing isolation. The CWDB, therefore, loses the chance to effectively interact with the environment and is not easily accepted by other people. He/she is cut off from his/her surrounding and misses information which is around him/her. While using his/her hands as a voice, he/she does not give out enough information to those wishing to receive it and there is insufficient self-expression (Jakes, 2003). Thismay demonstrate poor quality of life.

In a study which was meant to increase awareness of possible frustrations in CWDB, Sense International spent a year investigating the relationship between project managers of charities in the developing world and individuals who had deafblindness at their workplace. The aim of the study was to find how individuals who had deafblindness could be empowered to participate in society by taking up leadership roles within their organizations. They used survey methods for professionals and interviewed the individuals who had deafblindness. The study showed that although the individuals who had deafblindness praised the managers for the work they did, they were often frustrated by them (Simms, 2003). This study reveals general frustration and lack of inclusion of the deafblind but does not specifically focus on the children.

In another study, Steer (2005) reports that the Australian Deafblind Council (ADBC) prepared itself to undertake research to review the situation of deafblindness in Australia. Literature was to be reviewed and questionnaires to be designed. The findings of the research were to be out by July 2005.This investigation aimed at showing the situation of deafblindness in general, but did not focus on children and how their quality of life could be affected. Related studies have not yet been done in Uganda to establish the impact of emotional dimension on the quality of life.

After considering the effects of isolation on quality of life, one may need to examine, the economic and financial considerations. CWDB have special and unique needs, (Collins & Campbell, 2003). These needs may require alternative programmes with extra resources. It is generally difficult to consider quality of life without taking into account financial costs. In a similar view, (Potmesil, 2006) points out that it is important to consider economic issues while assessing the quality of life. The finding of a supplementary research by Watters, Owen and Munroe (2005) show the need for funding for improvement of services for persons who have deafblindness, implement public awareness and training programmes. The study also reveals the importance of highlighting the needs and capabilities of PWDB, and the need to reduce misconception among government sector and the public about the uniqueness of this dual disability. There is therefore need for research to establish how economic and policy issues may influence quality of life of CWDB in Uganda.

Closely related to both educational and emotional dimensions are policy issues and public awareness.There are indications that policy issues on deafblindness are often lacking (Kumwenda, 2004). In support of this point of view, Rodbroe and Ramsing (2005) point out lack of knowledge and public awareness on deafblindness in many situations. In further support, Drescher (2003) states that individuals who have deafblindness do not have rights to participate fully in society and are yet to be recognized as a separate group.

In a possible remedy to the situation, Steer (2005) suggests the need to persuade governments to focus on programmes for the deafblind. Collins and Campbell (2003) argue further that policy issues will continue to need attention. Despite the lack of clear policies in many situations, there is, however, an emerging awareness of the needs of CWDB (Salomie, 2006). On the contrary, Kamau (2005) points out that policy improvements are not enough as barriers to services may still persist. Lack of favorable policies and public awareness may have a negative impact on quality of life.

Watters, Owen and Munroe (2005) carried out a study to investigate demographic information, service needs of PWDB and their parents and to identify the barriers and successes of PWDB. They used documentary research by examining the national registry. The findings established that there were an estimated 3,306 individuals who had deafblindness in Canada. This figure was, however, criticized as an underestimate of the total deafblind population due to the difficulty of reaching individuals with this disability. The same team carried out a supplementary research using ten focus group discussions with PWDB, their parents and advocates. The aim of this additional study was to assess the quality of life of the participants. This study was general and needed to focus on the quality of life of deafblind children.

2.2.1 Knowledge Base and Gap on Consequence of Each Dimension on the Quality of Life

A review of the section on quality of life indicates that there is little information due to limited studies, Ferrioli, (2003). Most of the information provided is by parents, adults with deafblindness, NGOs and professionals. Although no research has been done regarding other dimensions, emotion and its influence on quality of life have been reported by several researchers. Cote and Cloutier (2005) while investigating the effect of emotion on quality of life concluded that deafblindness influences life habits and has severe psycho-social consequences. Hartsborne (2003) established that disability gets in the way of life and feeling good. Miles (2003) reports that parents do not always want to hear that the children have sensory loss. Simms (2003) found out that PWDB are easily frustrated and Steer (2003) reported that PWDB live in difficult situations. Watters, Owen and Munroe (2005) found that service needs of CWDB were not met and there were barriers to success which ended in frustration.

Reports which were not given by researchers but made by parents, NGOs, PWDB, and professionals which make up knowledge gaps are outlined below.

Educational Dimension

Potmesil (2006) observes that quality of life in relation to educational dimension has to do with school attendance, while the *Canadian National Society for Deafblind* (2005) argues that education increases the quality of life for CWDB by increasing their participation and inclusion is society. Spring and Woodtli (2004) state that CWDB are dependent on others and need to be accompanied to school and Palmer and Lahtinen (2005) say that they often miss information from the surrounding. Tap (2005) points out that schools may reject the children. In Africa, Kumwenda (2004) observes that CWDB need special attention to access knowledge and skills.

Emotional Dimension

Rodbroe and Ramsing (2005) argue that parents become desperate to educate their children. Lopez (2004) observes that parents develop anxieties and according to Poggioni (2007), they often do not get support. Guest (2003) observes that CWDB have periods of mental anguish. Moore (2006) suggests that siblings develop bitter feelings because of lack of free time. Wolf (1986) points out that the unmet needs of the families generate frustration. Wolf (2003) later adds that families experience many difficulties including feelings of guilt, jealousy, fear, loneliness, sadness, embarrassment, confusion, anger, frustration and worry. Miles (2003) says diagnosis haunts parents while Tap (2003) notes that the effects of deafblindness are isolation. In Africa, particularly in Uganda, Kamau (2005) asserts that CWDB need special programmes, but these are often difficult to meet. The difficulty frustrates parents.

Communication Dimension

Desy and Lyddy (2006) state that PWDB have challenges in communication, while *Croatian Deafblind Association* (2005) note that CWDB live in a dark silent world. Vilhelmsen (2005) and Boothroyd and Hampton (2003) point out that CWDB cannot express themselves. Leela (2004) points to lack of communication and Jakes (2003) refers to insufficient self-expression. Afutu (2004) also argues that deafblindness is associated with isolation.

Economic Dimension

Internationally, Collins and Campbell (2003) emphasize the need for extra resources while Potmesil (2006) asserts that economic resources are important for improved quality of life. Watters, Owen and Munroe (2005) highlight the need for funding to improve services for PWDB.

Policy Dimension

Steer (2005) suggests that there is need to persuade governments to do more for PWDB. Rodbroe and Ramsing (2005) say that there is lack of knowledge and public awareness, while Drescher (2003) argues that PWDB have no rights to social participation. Collins and Campbell (2003) note that policy issues have not yet received adequate attention. Salomie (2006) points to emerging awareness of the needs of PWDB. In Africa Kumwenda (2004) notes the lack of policy on deafblindness, and in Uganda, Kamau (2005) regrets that improvements in policies are not enough.

2.3 The Impact of Disability Load on the Schooling Path

A number of views which may influence the schooling path have been put forward.Brownell and Carriger (1998) suggest that social relationships are the context in which knowledge is formed. Meadows (1999) also points out the importance of interactions with the environment in the development of cognitive abilities. It has further been observed that communication is the foundation for both social relationship and interaction within the environment. Both knowledge and education largely depend on these factors. In addition, Zoppi (2006: 54) emphasizes that ‘communication is the foundation of an educative approach, related to quality of life.’ Communication is needed and is important at all levels and in all interactions including the school setting. It is a major contributor to development, self-determination and social inclusion. Deafblindness, however, has a serious negative effect on communication. Poor reception and expression in the communication process in turn limits exchange of information in different social settings. The schooling path may be complicated by poor acquisition of daily living skills and poor mobility both indoors and outdoors, making it difficult to access educational facilities. Jakes (2003) further suggests that deafblindness presents pedagogical, psychological and social problems. It causes serious problems for the disabled child and its effects and challenges are personal and social(Alverez, 2002; Frolova, 2003). It is a characteristic and distinct disability which has influence on aspects of development and learning.

According to Deasy and Lyddy (2006), CWDB have significant challenges when attempting to acquire communication skills and lack of communication severely diminishes interactions with the environment. Since their sensory input from the environment is reduced and motor function limited, their chances of benefiting from school programmes is greatly reduced. Spriet (2006) further states that CWDB do lack language and communication as well as daily living and locomotion skills. These are all important competency areas which enable the child access the school curriculum. Lopez (2003) also agrees and states that the first problem of CWDB may be lack of communication and that there is need for one-to-one support from trained professionals. Levy (2003) goes on to suggest that difficulties with expression or the constant experience of having their expressive communications misinterpreted can lead some children to give up, or resort to explosive behaviours that may in turn be seen as unpredictable or irrational ; therefore, placing obstacles to educational opportunities.

Dianton (2007) further observes that the most significant and yet common barrier to development of CWDB is communications or, more importantly, socializing. The children may find it very difficult to socialize in a meaningful way, thus putting limits to their educational opportunities. Lack of personal assistants, such as interveners in deafblindness, who are trained wherever there is a PWDB, including schools, as indicated by Lopez (2007), is another possible educational challenge. Mathews (2007), while raising the issue of deafblindness as a unique category of sensory impairment, also refers to the importance of availability of one to one communication support. In many circumstances the need for individualized assistance may put high demands on resources which could be scarce in the first place. Steer (2007) also makes reference to the need for daily assistance with communication. Such assistance may be difficult to access in many school settings. Drescher (2005) argues for the need to train interpreters and communicators to provide support. The opportunities for such training may not be easy to come by, therefore limiting the availability of such personnel.

Amaral (2003) observes that CWDB do not use speech or any other language form to communicate but rely on movements, smiles and manipulation of objects. Partners in the learners` environments may therefore find it difficult to discover the meanings of these means of communication and therefore not give appropriate feedback. Poor social relationship and interaction as well as lack of communication all act as barriers to the schooling path.

Available literature indicates that there are global efforts to assist CWDB to lead better lives. Research on communication needs of these children, how they learn, and how schools can meet their needs are yet to be done. Amaral (2003) argues that the lack of initiative in research in this direction is partly because it is thought that these children can neither be taught nor develop.

In addition to communication, there exists a negative attitude towards the CWDB. Kersten (2006) says that sometimes some CWDB feel forgotten by their parents as well as professionals whereas they too need services and support. Children who need education may find themselves in this situation. Afutu (2004) gave an example of poor attitudes towards individuals with deafblindness in Ghana. She says they are thought to be unable to take an active part in life. Kumwenda (2004) also recalls that having become deafblind, he was not accepted in his original school and had to be placed in another school. He goes on to suggest that in Africa, there is probably a very substantial number of CWDB who cannot access educational services. Kappan (2008) also adds that there are traditional taboos and discrimination against individuals who are deafblind. Kamau, (2005), while discussing some of the barriers to education of CWDB says that some parents have been told that their children would never be able to do anything for themselves and that they should not waste their time with them. The educational path may be limited in this way. Although some literature exists about attitudes and the schooling path, there is need for further research.

Hathazi (2005) suggests that deafblindness involves new approaches and different methods of interventions. Training of teachers in this area of skills and knowledge is a basic necessity. Citing the example of Australia, Steer (2003) reveals serious and worsening skills shortage among teachers, who increasingly find students with disabilities assigned to their classes yet they are not prepared for this experience. Alongside the shortage of teachers, the number of CWDB seeking places in established educational institutions may be excess (Tap, 2005). In the Irish Republic, households have been quoted as having to cope with lack of sufficient appropriate services for their children including education. Therefore, studies involving the role of teachers in influencing the educational path of CWDB and their siblings may need to be carried out.

Some of the most important barriers to education of the CWDB are policy issues and funding. Drescher (2003) indicates that deafblindness is yet to be recognized as a separate disability and Best (2007) states the need for financial support. It has also been reported that a group of researchers have at the University of Nijmegen Medical Centre discovered the Coloboma of the Eye, Heart Defects, Atrasia of the Nose, Retardation of Growth, Genital and Ear Abnormalities (CHARGE) gene which is related to deafblindness and has educational implications, (Brown, 2004). This research did not, however, focus on how specific issues including policy, public awareness and funding could affect the schooling path. Emotions generated within the individual child as a result of having to live with dual disability may develop into depression and moods that may hinder educational progress (Mortensen & Moller, 2007).

There have been studies by Heller, Gallangher & Frederick (1999) in Moore (2006) in which a survey of 35 parents of CWDB was done. It was found that the siblings were handed the responsibility of taking care of the CWDB. An earlier study by Banta (1979) also in Moore (2006) raises the issue of the effect on the child who has a deafblind sibling. However, this study did not address how these caretaking responsibilities and living with a deafblind sibling affect the educational opportunities of the sibling. In many universities, there has been limited interest in the work of professionals dealing with deafblindness (Ferioli, 2003). This has allowed the misconception that the child with deafblindness is not eligible for education to thrive, therefore denying the child the educational opportunities.

As shown by some of the studies, limited attempts have been made to address the impact of disability load on households. There is still need to focus on the issue of how these aspects directly affect the decision to take the child to school and how the siblings of the affected child might be disadvantaged.

2.3.1 Knowledge Base and Gap on the Impact of Disability Load on the Schoolingpath

Internationally, some reports were made by researchers and therefore constitute knowledge base. These studies were as follows:

Reporting on communication, Steer (2007) found that there was the need for daily assistance and Amaral (2003) points to the need for CWDB to rely on movements, smiles and manipulations of objects. Brown (2004) found that the CHARGE gene had negative educational implications. Heller, Gallangher and Frederick (1999) found that siblings had great responsibilities in taking care of CWDB and Tap (2005) established a link between multisensory impairment and educational development of CWDB.

Reports by parents, PWDB, NGOs and professionalsmake up the research gap which could be filled by systematic inquiry as follows:-

Education Dimension

Hathazi (2005) suggests the need for new teaching approaches and methods. Steers (2003) points to serious and worsening skills shortage among teachers. Mortensen and Muller (2007) argue that depressive moods hinder educational progress. Meadows (1999) points to the importance of interaction with the environment in cognitive development. Zoppi (2006) emphasizes the dependence of education on communication. Alverez (2002), Jakes (2003) and Frolova (2003) observe that deafblindness presents pedagogical, psychological and social problems.The study found that limited sensory input and the related lack of expression affected children`s educational development. The children were often lying or sitting helplessly or were in moody states. This state reduced their interaction with peers and undermined their opportunity to learn social skills which was basic for further acquisition of knowledge and skills.

Communication Dimension

Deasy & Lyddy (2006) argue that CWDB have challenges in acquiring communication skills and that lack of communication diminishes interactions. Spriet (2006) says that CWDB lack clear language, communication, daily living and locomotion skills and Lopez (2003) points out that they lack communication and need support from trained professionals. Levy (2003) points to the difficulties in expression which results in misinterpretation, and Dianton (2007) argues that the barrier to development of CWDB is communication and socializing. Lopez (2007) points to lack of personal assistants in communication. Mathews (2007) emphasizes the importance of one to one communication and Drescher (2005) writes about the need to train interpreters and interveners to provide support. The study revealed that the children could not see, hear, talk or sometimes even walk. This inability to communicate limited social interaction. The state of affairs also isolated them from the community and minimized their opportunity for learning.

Social Dimension

Brownell and Carriger (1998) report on importance of social relationships. Kersten (2006) observes that PWDB are neglected by their parents and professionals, while Kappan (2008) argues that there are traditional taboos and discrimination against them. With reference to Africa, Afutu (2004) says that there is poor attitude towards CWDB and Kumwenda (2004) suggests that they are unable to participate in life. The disabilities were reported to have existed since childhood. This implies that opportunities for inclusion were missed early. Playing with other children was reported to be problematic. The children could not socialize in any meaningful way placing limits to their education.

Policy Dimension

Internationally, Drescher (2003) observes that deafblindness is not recognized as a separate disability, while Best (2007) suggests the need for financial support.The government was reported to have limited focus, awareness and interest in education of CWDB. Lack of interest and therefore policies meant limited resources for the education and welfare of CWDB.

2.4 Summary

The review of literature indicates that there are six dimensions which have been identified. These dimensions include the educational, emotional, social, communication, economic and policy. The six dimensions are spread globally. The reports reflecting the dimensions are largely information given by parents of CWDB, NGOs, advocacy groups, PWDB themselves and professionals who work with them. There is a visible absence of information on dimensions from researchers, indicating a big knowledge gap.

The review also shows that low quality of life is related to poor education, lack of policy, communication difficulties, emotional and economic problems. Poor quality of life for CWDB can be seen in the areas under review as suggested earlier. Limited research has been carried out on education, emotion, and demography of CWDB. However there is a huge research gap in many areas of quality of life related to education itself, policy and demography especially in the African countries including Uganda. The information on quality life is by non-researchers for example various pressure groups. There is therefore a gap in information from researchers in the following areas which reflect quality of life; education, communication, economy and policy. This is true at global level, but particularly in the African and Ugandan setting.

The literature indicates that globally there is impact of the disability load on the schooling path and Uganda is no exception. Like those of dimensions, the reports have been made by people who are just interested in or are merely affected by deafblindness. Limited work has been done by researchers in the following areas including education and communication. However, there are significant gaps in information from researchers in areas which affect the schooling path such as methods of teaching, communication, social life and policy. These gaps are global, but they are most significant in African countries and specifically in Uganda.

CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction

This chapter presents research techniques utilized by the study which include research design, variables, location of the study, target population, sampling techniques and sample size. Also presented are research instruments, pilot study, validity, reliability, data collection techniques, data analysis, logistical and ethical considerations.

3.1. Research Design

The design was based on Grounded Theory principles which is, for this reason, a qualitative one (Creswell, 1998). The qualitative nature of Grounded Theory approach is supported by a number of writers as outlined below. It is a qualitative research method that develops a theory about a phenomenon (Chamberlain, 2007). This statement is similar to the views of (Strauss & Corbin, 1990). A series of other writers also appreciate the qualitative nature of the approach and make additional and related statements as follows; Grounded Theory approach is one of the qualitative research designs (Moghaddam, 2007); it is a qualitative research method (Pandit, 1996); based on a qualitative study (Barker, 2007) and is one of the forms of qualitative research (Oktay, 2012). Grounded Theory is a qualitative approach that generates theory from observation (Calloway, 2007). Qualitative researchers have increased their interest in Grounded Theory (Chiang, 2007).

It is further stated that in qualitative studies, one of the most popular approaches scholars tend to rely on is the non-statistical, set of procedures known as Grounded

Theory method (Larossa, 2005). The research method addresses the why and how questions rather than the frequency or incidence. It is qualitative and non-statistical (Pidgeon, Turner & Blockley, 1991). It is typically presented as an approach for doing qualitative research and its procedures are neither statistical nor quantitative (Haig, 2007). It is currently the most widely used qualitative research method across many disciplines (Bryant & Charmaz, 2007). In another point of popularity, a recent study used Grounded Theory as a qualitative study to explore how African American couples cope with breast cancer (Morgan, 2007). The writer argues that qualitative design is useful when the problem is not well defined in literature. The views cited above are many and provide sufficient basis for using qualitative method in a Grounded Theory work, including this study, and therefore makes the use of statistics insignificant.

Maxwell (1996:19) postulates that one of the strengths of qualitative research is that it enables identification of 'unanticipated phenomenon and influences, and generation of new grounded theories.' At the same time, qualitative research has also been seen as having the potential to inform practitioners in the relevant fields by creating better understanding of the phenomenon under inquiry. What exactly happens in the household of CWDB in Uganda has hardly been investigated and, therefore, the Grounded Theory approach, which is also qualitative as suggested by the writers cited above, was relevant. Until this study, there has been no known theory which pertains to deafblindness that is readily available to explain the interactions in the household of the deafblind. In yet another reference to qualitative research, Amin (2006:46) states that it has strong roots in grounded theory and that it has no strict design but progresses as an ‘emergent rather than tightly prefigured’ undertaking. The purpose of this particular study was to investigate the nature of the disability load in households hosting CWDB. A qualitative study using the Grounded Theory approach was therefore appropriate. In relation to the above observations and points of view relating to the qualitative nature of Grounded Theory, this study explored the experiences which had been built from interactions of households hosting CWDB.

Grounded Theory has also been defined as a methodology that has been used to generate theory in areas where there is little already known and an apparent lack of integrated theory in the literature (Goulding, 1998; Goulding 2002 & Samik- Ibrahim 2000). Grounded Theory methodology has been used to ‘build theory that is faithful to, and which illuminates the area under study;’ (Strauss et al.1990:24). This approach has been further described as a systematic general research method that is useful in generating, and, at the same time, verifying theory (Locke, 2001) and addressing the participants` main concerns and how they can resolve them. The method is generally applicable where the researcher has observed an interesting phenomenon without an explanation, and from which he/she seeks to discover a theory from data (Blog, 2007). Theorizing is seen as a process of creating an alternative explanation (Moghaddam, 2007); and theory building leads to development of good explanations (De Vaus, 2007). The experience of members of the household hosting CWDB were not known and an explanation was necessary and therefore the need to build theory using this approach.

Historically, Grounded Theory approach developed as a result of the extremes of qualitative and quantitative methods. It is built around principles of fit, understanding, generalizability and control. 'Fit' implies that the conceptual framework (theory) which has been generated through induction fits the data from which it was derived. 'Understanding' means that the conceptual framework(theory) is understood by both the researcher and possibly the participants, while 'generalizability' means the conceptual framework(theory) can be applied to similar phenomenon elsewhere and across time. Control is achieved because the conceptual framework (theory) can be used to initiate action to address the needs of the participants (Strauss et al.1990). The action resulting from this investigation is expected to lead to improvement of the quality of life and schooling path of the CWDB.

Central to this study is the interactions in the household, quality of life and the effect on the schooling path. This methodology seeks to generate a conceptual framework (theory) that is of direct interest to and relevance for practitioners and aims at discovering the basic social process in order to resolve the main concerns of a particular group (Jones, 2002). Grounding of the theory creates a relationship between the data and the theory (Pidgeon, Turner & Blockley, 1991). The exact influence of disability load resulting from deafblindness on quality of life and the schooling path of the siblings is comparatively unknown. There is no theory or even a conceptual framework to explain the load, but this method provides an opportunity for explanation.

3.1.1 Study Variables

According to Amin (2005), independent variables are the ones that influence or affect the dependent variables. They also help to explain the variations in the phenomenon under study. The dependent variables depend on the independent ones. They are the ones which are influenced by the manipulations and on whom the effect is felt. In this study, there were two independent variables: the level of deafblindness in the child and the resulting disability load on household members. Both of these have influence on two other variables: the quality of life of members in the household and the schooling paths of the children. This work is therefore expected to explain how both the level of deafblindness and disability load influence the quality of life in the household hosting children with deafblindness and the impact on the schooling path of the affected children (Kombo & Tromp, 2006).

3.2 Location of the Study

In theoretical sampling, cases for study are selected purposively. Data is then collected from the cases. The data which has been collected is analyzed by identification of similar concepts and formation of categories. The process of data collection and analysis continues until no new categories are found and a strong theory has been developed (Strauss & Corbin, 1990). Following this principle, this study was initially located in Iganga District, in Uganda, but was extended to the neighboring districts of Mayuge and Jinja as theoretical sampling required. All the three are newly subdivided districts which were once a single district with similar way of life. They all form a major section of Busoga region, found midway between the source of the Nile River, south western Kenya border, and north of Lake Victoria

(Appendix vii). The area is largely inhabited by the Basoga ethnic group who are engaged in peasant farming, small scale trade and the civil service. Iganga District was selected because deafblindness is more prevalent there than in other districts in the country (Sense Uganda Office 2007, Unpublished Records). The district is part of the Busoga region, which has had history of visual impairment since the colonial times. In response, it has, through the years, developed specialized services to meet the needs.

The first school unit for CWDB was started at Buckley High School in Iganga because of the comparatively high prevalence of the condition in that area as opposed to other regions. Iganga District has 9.6% of the currently known population of CWDB in the whole country and the highest prevalence rate compared to the other districts (Nsubuga, 2007). Currently, the community based rehabilitation (CBR) service in the district is well developed and its identification and assessment services are so far some of the best in the country. District service providers working together with the NGO for deafblind have been able to identify 10 CWDBs, which is the highest number in the country for any given district.

3.3 Target Population

The target population from which samples were drawn was made up of all members of households hosting CWDB living in various districts in Uganda as proposed by (Mugenda & Mugenda 2003). The members of the households, who were bringing up the CWDB, had the most relevant experiences, views and expert information to contribute to the research objectives. National records indicated that there were 165

CWDB throughout the country (Walugembe, 2007). These children were, in turn, living in an estimated 165 households.

3.4 Sampling Techniques and Sample Size

In conformity with the Grounded Theory principles, two sampling techniques were used, namely, purposive and theoretical sampling. Sample size is the number of participants drawn from the target population and used in the study to give the required information.

3.4.1 Sampling Techniques

Purposive Sampling

It has been observed that sampling in Grounded Theory is purposive (Morgan, 2007). Purposive sampling is a type of sampling which is most effective when one wishes to study an area made up of participants who know a lot about the phenomenon (Tongco, 2007). It is also argued that the selection of participants in this type of sampling is limited to individuals who have experienced the research problem first hand. Theoretically important cases are selected for the study (D`Onofrio, 2007) and therefore the researcher makes an effort to seek out those with credible and authentic experiences. Following this principle, Hansen & Kautz (2005) suggest inclusion of a number of participants with knowledge of the area to be examined. Purposive sampling is popular with qualitative research and the participants are selected because of some characteristic (Patton, 1990). The three districts which included Iganga, Mayuge and Jinja were selected purposively because they had households whose members had lived with CWDB, knew about them and were theoretically important for the study.

Theoretical Sampling

Theoretical sampling is a method of sampling which is directed by the findings of analyzed data from a previous round of data collection. It is often used in combination with purposive sampling and from the beginning the most obvious incidents and events are sampled (Chamberlain, 2007; Moghaddam, 2007). Using the findings, the researcher goes back to the field to collect data from other individuals and locations. The aim of collecting more data is to strengthen and extend the evolving theory, (Goulding, 1999); Pastra (2007) also supports the view that after initial coding of the first set of data, the researcher gathers more data and a second stage of coding is embarked upon.

Additional views have been made on theoretical sampling by other writers mentioned below. It is stated that it is a significant feature of Grounded Theory and that initially the researcher will go on to the most obvious places and the most likely informants (Goulding, 1999). In the process, the first analysis leads to further research into meanings. This in turn leads to further sampling from appropriate participants (White, 2007). Sampling of informants is not determined to begin with, but is directed by the emerging theory. Once categories begin to emerge, they are used to enhance further data collection (Sheldon, 1998). According to him, Glaser and Strauss termed this "theoretical sampling". Theoretical sampling allows for previously unforeseen lines of inquiry to be pursued, enabling closer inspection of reality. It is used to pick additional participants for the study (Morgan, 2007). In the process of theoretical sampling, additions are made to the sample. The purpose of the addition is to strengthen the emerging theory (Dick, 2000).

Theoretical sampling cannot be planned before embarking on a grounded study. The specific sampling decisions evolve during the research process (Strauss et al.1990). In theoretical sampling, data is first analyzed, and on the basis of this analysis and the theory which is emerging, additional cases are selected (Pandit, 1996). It involves interplay between observation and explanation, collection of further facts to test the explanation and refinement of the explanation and so on (De Vaus, 2007). Similar arguments are advanced by (Pidgeon, Turner & Blockley, 1991) who reaffirm that theoretical sampling is the process of collecting more data to clarify ideas. They add that one of the features of grounded theory are the changes in site selection as a result of theoretical sampling. During this type of sampling, data collection and analysis are deliberately combined and proceed simultaneously (Buckley & Waring, 2007). Following the views and principles advocated by the many writers cited above, this study started by collection of data from participants in Iganga, followed by Mayuge and finally Jinja district.

In this study, each household and its members were purposively selected from the study district. In order to obtain a sample, the researcher went to Iganga District Rehabilitation Officer and requested for the list of CWDB. The list had 11 CWDB. Using this list, he inquired from the rehabilitation worker the most appropriate households to include in the sample. Children who had been established as having deafblindness between the ages 0-18 years, living in the households were included in the research. As suggested by the cited authors, data collection and analysis were combined, in such a way that initial data collection was immediately followed by data analysis. Coding of the first set of interviews generated concepts and categories that directed the next sampling and data collection, and therefore determined which of the remaining households to go to for the next set of data. In accordance to the ideas of theoretical sampling, each time data was collected; it was followed by data analysis and further data collection. This process of sampling which is directed by analyzed categories was continued until no new categories were identified from the data obtained from the households, a process referred to as saturation.

3.4.2 Sample Size

There are certain principles about Grounded Theory that proponents more or less agree. As long as these principles are kept in mind, the details of the procedure can be modified to suit the researchers needs (Larossa, 2005). Among these are the principles governing sample size. Samples are normally fixed but in grounded theory design, this size depends on how soon the theory is generated.

It has been suggested that sample size of 12 be the minimum for a Grounded Theory study (Goulding, 1999). Most studies achieve saturation between 8-24 interviews depending on the topic of focus (Riley, 1996). Morrow & Smith (1995) used 11 women in a Grounded Theory study about the survival and coping strategies of childhood sexual abuse victims. In his Grounded Theory study, Morgan(2007) used a sample 20 African American couples. Weiss & Lynn (2007) in another Grounded

Theory study of the Hurricane Mitch interviewed 16 survivors to develop the Disaster Response Theory. In this Grounded Theory study which aimed at generating a conceptual framework (theory), a number of 23 participants were used. The use of only 23 participants in this study fits into the principles and expectations of the writers cited above. The other reason for the small number was that this was a qualitative study which sought detailed information from few participants (Amin 2005; & Kvale 2000). Among the sample of 23 participants were 10 parents, 8 siblings of the CWDB and 5 CWDB. This number provided data which was sufficient for conceptual framework (theory). The sample size increased until a framework was arrived at.

3.5 Research Instruments

The instruments used for collecting data consisted of in-depth interviews and observation guides as shown in Appendix (i-iii). They were developed according to the objectives of the study and addressed the impact of disability load on quality of life and schooling path. The effect on gender was also sought. There were three instruments; one interview guide for parents, Appendix (i), one interview guide for siblings of CWDB, Appendix (ii) and one observation guide for CWDB, Appendix (iii). The two interview guides were made up of interview questions developed to answer the research questions. Each of the guides was sub-divided into themes or topics. Each theme consisted of the major and general opening type of questions and also probe questions as suggested by Ingstad and Grut (2006). Additional consideration in the construction ofthe instrumentswas the need to start the interview by building rapport, trust and confidence with the interviewees. In order to achieve this, the interview guides were designed to address general and less sensitive issues first. Questions which were more sensitive were included in the last part. Probe questions were added to each main question to allow room for detailed questioning, which gave rise to in depth interviewing.

The advantage of in depth interviewing in this study was that it provided detailed information from the participants from which rich data was obtained to build a good conceptual framework (theory). The specific highlights of the data collection instruments included the following:-

3.5.1 The Interview Guide for Parents of CWDB (Appendix i)

This instrument covered an introductory part, which consisted of areas meant to assure the participants of confidentiality and set a conducive environment for dialogue. It consisted of biodata and general information about the participants and the household. The first part of this instrument focused on problems experienced by the child, including the various dimensions such as the emotional, social, economic, health, educational and policy. The last section thanked the participants for taking part in the interview.

3.5.2 The Interview Guide for Siblings of CWDB (Appendix ii)

This was meant to give additional information to that provided by parents using the above guide. It therefore covered the same areas except that the questions were simplified and child- friendly.

3.5.3 The Observation Guide for CWDB (Appendix iii)

The guide covered the level of deafblindness, general health, hygiene status and nutrition. The level of deafblindness depended on whether the child had deafness and blindness only or there was an associated disability for example a physical disability. Communication and interaction was also observed.

3.6 Pilot Study

A pilot study was carried out in one household of CWDB in Mukono, a district which has Kampala to the East. The selected household provided the five participants required for the study. They included the two parents of the CWDB, the CWDB herself who was 16 years old, and two siblings, a boy and a girl. The boy was 14 years and the girl 11 years. The nearby district was chosen to save time and money as well as to avoid unnecessary contact with the interview sites in Iganga, Mayuge and Jinja Districts, which might have introduced bias because of maturation of the participants.

3.7 Validity of Research Instruments

Validity is the extent to which an instrument measures what it is supposed to measure (Punch, 1998 & De Vaus, 2007). It focuses on the accuracy and truth of the data and is of several types (Kaahwa, 2008). To increase the validity of the findings in this study, as is the practice in most qualitative work, a number of measures were put in place.

The first was triangulation, which was achieved by employing several methods of data collection, including in-depth interviews which were rich in content and was expected to yield a lot of information. The interview was supplemented by observation as well as documentary evidence as proposed by (Maxwell, 1996). The second measure employed was to ensure communication validity by further questioning of participants to clarify answers and increase truthfulness. The third was through ecological validity. This was arrived at by interviewing the participants in their homes, which is also their natural environment. Working with them in their natural environment helped to build confidence in the participants, allowed volunteering of information and provided opportunity for observation to verify what was said by the participants. The fourth measure was by improving internal validity through the process of theoretical sampling, which was carried out as the building of the conceptual framework (theory) progressed. In order to ground the evolving theory, the associated hypotheses were continuously validated against the reality in the data (Strauss et al. 1990). Finally experts in validation were utilized, whereby at least three experts from the Department of Special Needs Education, Kenyatta University read through the instruments, and confirmed their validity.

3.8 Reliability of Research Instruments

Reliability is the consistency or repeatability of the measures. It is the obtaining of the same results in repeated trials and a reflection of the quality of the study. There are different types of reliability and the concept is very important in some study designs. Reliability also has a close relationship with validity and according to Amin (2005), a valid instrument is always reliable.

Enhanced reliability in this study was, therefore, achieved in two ways; first, by maximizing validity using the steps mentioned in the previous section, including triangulation, conducting interviews in the home environment of the CWDB and repeated questioning to obtain rich information. Secondly, by using the Grounded Theory approach of developing concepts from the rich data already gathered. The most important property of conceptualization for Grounded Theory is that it is abstract of time, place and people. Concepts last forever (Glaser, 2002), and this endurance is a guarantee of consistency and repeatability. In this work, concepts were rigorously generated and, once obtained, made a continuing mark on the study and therefore further addressed reliability. These concepts, in return, guided thinking and theorizing.

3.9 Data Collection Procedure

Data collection, which involved interviewing members of the households hosting CWDB and observations, lasted 8 months from 21/11/2009 to 8/7/2010. Before each set of interviews began, the researcher introduced himself to the household members and clearly explained the purpose of the interview. To reduce reactivity to the researcher by participants, and create a good environment for interaction, confidentiality was assured before beginning each interview. Members of the household, including the parents and siblings, were interviewed in depth and individually using the interview guides described in section 3.5.The CWDB could not be interviewed because their disabilities were a barrier. The observational guide was used to pick out important issues to note down. Photographs of the children were also taken. Data from interviews was recorded using a digital tape recorder. Two research assistants helped with the interview process. One of them took notes as the interview proceeded while the other worked as an interpreter and translated the questions from English to Lusoga, the language which was understood by some of the participants.

The set-up of the homestead, the economic status as reflected by the structures around and the home environment were observed and notes taken. The interactions of the members of the household were observed and taken note of right from the time the researcher entered the premises. The writing, using a pen and a notebook, was done immediately after establishing rapport with each interviewee. The observation was meant to take note of what could not be expressed verbally, but could only be observed. Photographs are useful but sometimes sensitive issues. Therefore, after each interview, permission was requested from the head of the family, to allow photographs to be taken. The photographs were later used to strengthen the information collected about the CWDB. Any existing documents that referred to the CWDB were requested for. However, the study area being a rural community, they were no documents about the children and the few that were there were said to have been misplaced.

A reasonable degree of flexibility was allowed in asking questions during the interview process and throughout the data collection exercise. This allowed exploration of new issues which arose as the study progressed.As each interview ended, the researcher acknowledged the contribution of the participants by thanking them.The eight months of data collection and analysis allowed for theoretical sampling as well as saturation of data.

3.10 Data Analysis

After transcribing the data from interviews, the whole analysis followed the grounded theory method involving open, axial and selectivecoding (Pandit, 1996 & Punch, 1998). The three stages of open, axial and selective coding were first suggested by Strauss et al. (1990). In this study, the method was modified to make it more practical.

Open coding was the first stage of this type of analysis and involved identifying, naming, categorizing and describing phenomenon grounded in the data. Before the analysis began, part of the data which was collected in English was uploaded into the computer. The portion collected in the local language, Lusoga, was translated with the help of a translator before uploading. The coding process began immediately after the data was uploaded. Each line, sentence, or paragraph in the text was read and re-read in search of the answer to the question "What is this about?" (Borgatti, 2007). Labels were attached to refer to the concepts which were discovered. Examples of such concepts were anger, rejection, fear and acceptance. The process of making notes, which is also referred to as memoing, went on throughout the data analysis process. There was also constant comparison of the concepts and the ones which were similar were used to form sub-categories or sub-themes. Larger categories were formed from the sub-categories and made into themes. Additional concepts which helped to validate the statements made by participants were obtained by examining the notes on the environment in which the household lived, and the photographs of the CWDB.

The second stage of analysis was axial coding in which the categories are related to each other using their properties and dimensions. Use of the paradigmic model facilitated this stage. It involved focusing on the phenomenon, its context, causal and intervening conditions. The actions and interactions of the participants and the consequences of these interactions were also categorized, and compared for similarities and differences. They were then grouped. Awareness of the causal and intervening conditions, actions and interactions improved understanding of the various phenomena and the dynamics of behavior in the household.

The third and final stage of analysis wasselective coding, in which one of the categories which integrated all the other categories was chosen. However, as part of the process of analysis, there was need to deconstruct the disability load in order to build the substantive conceptual framework(theory). Six dimensions which were identified in the data earlier were recalled and reviewed. Sorting was done. The emotional dimension emerged and was selected as the most frequent category. It therefore became the central phenomenon and was related to the other categories. The relationships make up the conceptual framework(Strauss et al.1990). These relationships were validated by referring to the data in order to ground the conceptual framework(theory) further. The impacts of each dimension were also assessed and conceptualized. Each impact was further evaluated and the mitigations leading to the reversals of the disability load were identified. The cycle of events is indicated in Figures 2-5. These steps allowed for the development of propositions about the central phenomenon and the writing of the storyline leading to the development of the disability load conceptual framework. It was noted, however, that although the ideas of Strausset al. (1990) appear sophisticated and systematic, they are rather theoretical and time consuming. In this thesis, they were simplified and made more practical and relevant.

3.11 Logistical and Ethical Considerations

Logistics in research refers to processes, activities or actions to be addressed to ensure successful completion of the research project (Mugenda & Mugenda, 2003). Before embarking on the study logistical work included requesting for funding for fieldwork from Kyambogo University administration, undertaking a pilot study and improving the instruments for the data collection. An application was made to the Uganda National Council for Science and Technology for permission to carry out data collection. The permission was obtained and copies are attached in appendixes (v) and (vi). The District Chief Administration Officers, through the Directors of Community Development, to the Rehabilitation Officers in the districts, were requested to allow access to participants. Two teachers were identified by the Rehabilitation Officer of Iganga District. They were requested to work as assistants to the researcher. These two were then working and continue to work with the CWDB at the local school. They knew the households well enough to allow easy access and communication. They were met and oriented in the use of the research instruments two weeks before data collection. They helped in planning the data collection exercise by making a list of the villages where the households could be found. They also went ahead to seek permission and arrange appointments for interviews with the heads of the households. During the visit, language barriers and suspicion of strangers was reduced due to the presence of the two already familiar research assistants.

To ensure that ethical standards were upheld, the following measures were observed: the researcher made introductory statements to create confidence and rapport with the informants. They were then asked if they were willing to take part in the study. The request was made, first to the fathers, who were also heads of households. Later each participant was also asked if they were willing to be interviewed. Trustworthiness was maintained by building rapport with the participants. The level of rapport was maintained by keeping calm and avoiding any questions or remarks that might have offended the participant. Truthfulness was achieved by introducing the researcher and explaining the research process (Befring, 2004). Creswell (1998) also suggests explaining to the participants the purpose of the research, maintaining anonymity and confidentiality. The researcher explained to each participant the reason for the interview before each dialogue. In each case, the researcher assured the participants of confidentiality and anonymity. It is suggested and it is equally important in ethics that acknowledgment is made of any contributions to the research process by various stakeholders (Glathorn & Joyner, 2005). This was done by maintaining a warm relationship as the interview proceeded and thanking each member of the household after each interview.

CHAPTER FOUR

PRESENTATION, ANALYSIS AND DISCUSSION OF THE FINDINGS

4.0 Introduction

In chapter three, the methodology for the research was closely examined. In this chapter, the nature of the disability load in households was explored using the process of open and axial coding. Continuous memoing and constant comparison of concepts facilitated the coding and generation of categories (themes) which were presented in dimensional form (Martin & Turner 1986). Through the chapter, comparison was also made between what was reported in literature and the findings of the study. It covered the six themes which included demographic information about the participants, dimensions of the disability load, the consequences of each dimension on quality of life, impact on the schooling path, gender differences in the schooling path and how to manipulate the dimensions to enhance the schooling outcomes.

4.1 Demographic Analysis of Study Participants

Five households hosting CWBD participated in the study. In four households five members of the family were interviewed and observed. In one of the households (the third household), only three members were found (It was a young family, separated early by the disability of the first child) and included in the study. However, because of the separation, this family provided a unique opportunity for examining an extreme negative impact of the disability load on family cohesion.

In order to maintain anonymity, the names of the villages and the household members who were interviewed were replaced with pseudo-names. The home environments which were observed have been described in order to provide a holistic picture of their quality of life. Below is the overview of the household characteristics

Household One

The first household interviewed lived in Ntindo Village in Iganga District, a remote rural setting. The home was built among some fairly decent dwellings. The CWDB was a 9-year- old girl, Liali. She was the sixth child in a family of ten and severely disabled since infancy. She could not see, hear or speak, had to be moved from place to place and looked frail. She could not walk and was almost helpless. She also appeared to be poorly nourished. In search of a cure for her ailments, the parents had desperately sought both traditional and modern medical treatment, but in vain. She had not been to school but benefited from a teacher who visited and helped her with physical exercises.

Liali`s mother was Jeloka, 36 years old and a peasant farmer. She was a mother of 10 children, 6 boys and 4 girls. These appeared too much of a burden to her. Jeloka`s level of education was lower primary. The hosting of the disabled child and having to do manual work to make up for a husband who was sickly seemed to weigh her down.

Liali`s father, Peka, was 43 years old. Being a sickly peasant, he could hardly support the family. His level of education was lower primary. Liali had a sister, Maka aged 16, with education level of primary seven. She went to school, but also had to help the household with child care and domestic work.

Her brother, Muju, was 19 years and in form three. He also helped the household a lot by gardening and looking after the cow. From his talk, he was a responsible young man. He appeared concerned and was already making efforts to compensate for his father`s shortcomings by helping his mother in raising extra income in his spare time. At the time of this interview, some other children were out of the home. The rest appeared preoccupied with simple domestic chores while others remained close to the disabled child.

The economic status of the household reflected an impoverished home. The family had limited land and seemed unable to do much cultivation. This state of affairs intensified their apparent poverty and hardship. There was only one cow tethered at the corner of the small plot of land, which, from the interview, was the economic hope of the household. Their only house was poorly built and looking incomplete, provided further evidence of their level of deprivation.

Household Two

The second household was located in Wiyaha Village. The homestead was set along the main tarmac road between Jinja and Iganga. The house was about 50 meters from the highway. The CWDB, Damia, was 13 years, the fourth child in the family and with very severe disability. He could not speak, could not walk and was confined to a wheelchair. Although he was unable to look after himself, he appeared to be well attended to by the family. His parents said that they had spent a reasonable amount of resources consulting modern and traditional healers to try and get him cured but in vain. They reported that he had dropped out of the school for the deafblind after three years.

Damias`s mother, Babilo, was 34 years old and the mother of 9 children, 6 boys and 3 girls. Although she studied only up to upper primary, she looked quite informed and the homestead looked reasonably organized with well looked after gardens.

Damia`s father, Basa, was a 44-year-old teacher with a Diploma in Special Needs Education. He was an active and resilient father, determined to look after the family. Apparently he had given his disabled child all that was possible, but the returns to his effort were too low. Even his studying special needs education was to enable him understand and manage his son`s condition better!

Kama, a sister to Damia was 18 years. She had recently sat the A-level examinations and was then helping her parents with domestic chores. Considering her level of education, she was a poor communicator, unduly shy but carefree.

Damia`s brother Josa was 14 years and in primary 7. He helped the household during his free time. He looked concerned about his disabled brother, loved and cared for him. Compared to the previous household, this family appeared to be responsive to and benefited from government agricultural programs aimed at improving their quality of life.

Household Three

The third household was made up of a separated family. The mother and the CWDB lived in a remote village named Kasuu, whereas the father of the child lived in Iganga Town close to the school he taught in. Kasuu Village was hardly accessible except by a narrow, muddy road. The mother and the child lived in a small trading centre, where they occupied two small rooms. One room served as a small drug shop while the other was a bed room. Most domestic chores, including cooking, took place on the narrow verandah. Visitors like us were offered a wooden bench under a nearby tree to sit on.

The boy with deafblindness, Presi, was 4 years and the only child to the mother. He was severely disabled with associated inability to walk. He was all the time on a wheelchair, and could not see, hear, or speak. The mother reported that they had used all available medical interventions in an effort to get him cured, but in vain. He was currently cared for by the mother, after the father gave up. He was dressed well before being brought to us. Due to limited space, he spent most of the time in the tiny bedroom. Also, because there was no one else to help take care of him, his mother often locked him in the house when going for garden work and to carry out other domestic activities.

The mother, Naci, was 32 years. She had a certificate in nursing and so ran a small drug shop, supplemented by garden work. She was living away from Presi's father and appeared lonely, depressed, and remorseful in life. She was visibly struggling to earn a living and to look after her son single handed. Her facial as well as verbal expressions showed a degree of mistrust and bitterness in her life. During the interview, she visibly struggled to hold back feelings of broken relationship and seemed to appeal for outside help in looking after the child. The two people, mother and child appeared isolated within the trading centre.

Presi's father Romu was 32 years and a teacher with a Diploma in Education. He was at the time living in Iganga town with a wife whom he talked well about, had recently formalized marriage with and they then had one child. During the interview, he revealed that he had a child who was deafblind from a previous relationship whom he reportedly helped, but was not willing to divulge more information. He appeared more concerned about his life as a teacher and with his current family. He preferred to be interviewed at the school where he taught, but not at his home like other participants. Perhaps this was to avoid misunderstandings with the other family members.

Household Four

The fourth household was in the far end of Mayuge District and at the tail end of the town center. The household lived in a rented simple two - roomed house. Living in this crowded environment was Katosi, a 6- year- old girl, the seventh born to the parents, who was severely disabled. She could neither see nor hear and lay down most of the time. She looked poorly nourished and too small for her age. Much of the meagre family resources were reportedly spent on modern and traditional medicines in attempt to get her well, but without success. Her severe disability stopped her from going to school. She lived with most members of the household, including both parents.

Katosi`s mother, Namaha, was 30 years old with 9 children: 4 girls and 5 boys. She was a peasant farmer whose plots were located far from the trading centre where they lived. Karo, Katosi`s 35- year old father was also a peasant. He did odd jobs to earn money for the family and so had to be away from home frequently. Katosi`s sister, Namshi, was 12 years old and in Primary 3. She attended school regularly, but also helped the family with domestic chores and played with the sister with deafblindness. Kuda, Katosi`s 13- years old brother was a primary 4 pupil who loved his education. He also took some time to play with and help the sister with deafblindness. Some of the other siblings lived with their relatives.

The resources in this household, including space, appeared insufficient for the family. The household seemed to live from hand to mouth. This was complicated by having to live with a CWDB. Although part of the house had been intended to be a small business premise, the parents were not engaged in any business, but went out to dig in the distant farm. It was partly the reason why Katosi`s father was not at home at the time of the first visit. He also did petty jobs outside the home for some money.

Household Five

The fifth household lived in Bugaa Village in Jinja District. It was a small settlement surrounded by a sugar plantation. The continuous flow of traffic disturbed the family environment, which was close to the main road. This location was reportedly dangerous to the CWDB; who was also quite mobile and often, could ran into the road. The family house itself was quite reasonable and the household looked well off for rural standards. The CWDB, Toka, was 12 years old and the fifth born to the parents. He was well dressed and appeared well looked after compared to the other children already observed. He could be quite hyperactive at certain times, wanting to explore the environment. He often clung to his father, who was protective of him. He had limited vision and hearing and could hardly communicate well. His level of nutrition was reasonable and he appeared loved by most family members, especially by the parents, who had done all they could to seek medical care for him, but with hardly any good returns. He had spent 4 years at the school for the deafblind, but had since left.

Toka`s mother Kasa, was a robust 41 year-old woman. She was a reasonably informed, hardworking mother of 8 children, 4 boys and 4 girls. She was a peasant farmer, who grew various crops and a part-time business woman, selling vegetables. Toka`s father, Kada, was a 45–year- old teacher in a school located near the home, and also a part-time farmer. He seemed to have struggled to bring up his family to a reasonable standard, except for the lack of progress in the son with deafblindness. He was an active member of the local Parents of Deafblind Children`s Association. Toka`s sister, Mula, was an 18- year- old O` level student, who also helped with housework. She appeared intelligent, practical and loved Toka, but regretted the possibility of Toka spoiling her relationships with her friends when they visited her. He was often hyperactive and wanted to touch them against their wishes. Mula contributed well to family chores. Toka`s brother, Mugerefa, was 9 years old. He was a school going boy, helped family members with domestic work and played with the deafblind brother.

Table 1. Summary of Characteristics of Study Participants

	Father	Mother	Boys	Girls	CWDB
Household One	Peka,43 yrs, peasant	Jeloka, 36 yrs, peasant, mother of 10	Muju,19 yrs	Maka,16 yrs	Liali, girl, 9 yrs
Household Two	Basa,44 yrs, teacher	Babilo, 34 yrs, peasant, mother of 9	Josa,14 yrs	Kama, 18 yrs	Damia, boy 13 yrs
Household Three	Romu,32 yrs, teacher	Naci, 32 yrs, nurse estranged mother of 1	No brother	No sister	Presi, boy, 4 yrs
Household Four	Karo,35 yrs, peasant	Namaha, 30 yrs, peasant, mother of 9	Kuda, 1 yr	Namshi,12 yrs	Katosi, girl, 6 yrs
Household Five	Kada, 45 yrs teacher	Kasa, 41 yrs, mother of 8, peasant/business woman	Mugerefa, 9 yrs	Mula, 18 yrs	Toka, boy, 12 yrs

4.2. Dimensions of the Disability Load on the Households Hosting Deafblind Children

4.2.1 Understanding disability load

Disability load has been defined as the burden that a household has to endure in the process of looking after the CWDB. The load often creates many demands on the family. In Chapter two, six dimensions of the disability load within the household were characterized. They included the educational, emotional, communication, social, economic and policy dimensions. Although each of the dimensions appeared negative in the findings, analysis indicates some positive aspects. In the next section, the dimensions are examined in detail. They are presented in order of emphasis by the participants. The most important dimension to them, which was the emotional dimension, is described first.

4.2.2. Emotional dimension

The emotional dimension was the most common dimension in the households as shown by the many statements made by the participants. The data collected also supports the literature which was reviewed. They included: frustrations, regrets, conflicts, stress, confusion, withdrawal, anguish, helplessness, disappointment, lack of sympathy, misunderstandings, anxiety, worry, disgust and rejection.

Frustration

In this study, frustration was the most common aspect of the emotional dimension. In most cases, on discovering that the children were deaf and blind, the parents were confused and did not know where to go. In an apparent state of panic, they sought help in various places, often beginning with modern medical care. When the children did not improve, then they went to traditional healers; and even then, ending without success.

In many instances, it was reported that the children could not see, hear, talk or play with their siblings. In most cases, these disabilities were reported to have existed since childhood, suggesting long lasting and cumulative frustration within the households. As was observed, the severe disability also interfered with the children's normal development. They could not attain the usual development milestones to be able to take care of themselves at the right time. This was frustrating for household members. In several cases, parents were disappointed not only by the children's inability to see and hear, but also by their failure to proceed from sitting to standing. Their state of helplessness created extra demands on other members of the household.

It was repeatedly reported that getting assistance under the demanding circumstances was difficult. The resulting frustration was so intense and dealing with the condition so difficult that in order to cope with the frustration, most often parents turned to God for consolation. One parent even referred to the disability of her child as 'luggage' which had to be carried all through the life of the household. The children were often vulnerable; because of their severe disability, could not be left alone and often needed to be closely watched. Keeping a close watch over them interfered with the time required for other essential domestic activities. This was a further source of frustration, as expressed by Kasa: (Mother 5) interviewed on 8/7/2010 as follows:

> "*It is we parents who face challenges because if you have a child like this one at home you can`t do any work smoothly. It means that you will sit there to look after him all the time, as well as inspecting what he might be doing.*

In a number of cases the children with severe disabilities did not want to eat the locally available foods; however the reason for this was not clear. This was a source of challenge to the parents and a possible additional source of frustration. Frustrating experiences were also reported in cases where abnormal behaviors were extreme and unbearable. Some of the children cried a lot without explanation. In some cases, parents wandered from place to place in search of help outside the home. The presence of the disabled child undermined and disorganized the family work programme and intensified the challenges of work, resulting in further frustration. The following response by Karo: (Father 4) interviewed on 1/6/2010 reflects the frustration:

> *"Like with the work I do, sometimes it needs both of us (husband and wife) to go and do some work together. I can`t leave the disabled child here alone, so it disorganizes the family programmes".*

He reported that when the other children had gone to school, the mother could not leave this disabled child at home alone and go to help the husband with work in the garden. The result of this was a double burden for the parents: providing food for the family and staying home to look after the child.

Even during play times, the siblings reported getting frustrated. Several times it was reported that though the siblings liked to play with their deafblind brother/sister, they got no response from them.

In an effort to overcome the difficulty of living with their CWDB, the parents tried to form associations with the aim of getting some assistance from the government. However, it was emphasized that this was difficult and instead ended in collective disappointment. Moreover, most of those children frequently fell sick, causing even more frustration and hopelessness, as expressed by Kada (Father 5, interviewed on 8/7/2010):

> *"OK. It is difficult and we have been facing it, as parents. We tried to form an association; thinking it will be easy for us to maneuver. But we have realized it is very, very difficult. So it is not easy to get assistance."*

Jones (2006) reports that CWDB may express frustration or become withdrawn in order to spare their parents or siblings emotional stress. Caring for these children at home is reported to be exhausting (Cretin-Billet, 2005) and the individual CWDB may suffer from periods of severe mental anguish (Guest, 2003). A lot of patience and love may be needed while working with the CWDB (Kamau, 2005).

Regret

Closely related to frustration are other highly demanding and regrettable situations created by the level of disability in the children. Wolf (2003) says that families of CWDB may have to cope with emotional complexes. Regret was felt because it was difficult to take care of the CWDB compared to the other normal siblings. For instance, they could not express themselves even when they were in pain. The degree of helplessness was reported to be high. It was lamented that the children just sat there and got wasted. They could not do any work. This was revealed by: Babilo, (Mother 2) interviewed on 10/4/2010.

> "*Yes, sometimes difficulties are met, because if that child was okay, she would fetch some water and do some other work. But you just see her there, it is you who caters for her, so it affects you. My child would at least do some work, help me do some other things and may be even get a job, but he just remains there and becomes wasted.*"

The expenditure on medical care was often high and left a trail of discontent and poverty. As they regretted the degree of inability in the children, parents anxiously looked for some help to cure the disability or improve the welfare of the CWDs. To show their deep regret of the disability situation, some said that they never wished their children were born with deaf blindness.

In addition, caring for these children, bathing, washing, dressing and feeding them took a lot of time. In many cases, because of limited communication, the caretaker could not tell when they wanted to relieve themselves. So, mothers had to continuously inspect and monitor how the CWDB were fairing and also to find out whether they were hungry or which parts of their bodies were causing them discomfort. More time was also spent with the children because they could not do anything for themselves. In visible regret, parents emphasized the fact that the children could not be left unattended.

Conflict and Stressful Memories

There was general failure to understand the causes of the disability, probably because it was so severe and intolerable. This was expressed by Basa: (Father 2) interviewed on 10/4/2010.

> *"Most parents fail to understand that it is God`s making. Others say either the neighbor charmed the boy or that there is an ancestor who is struggling to bring some 'defeats' in the family or bad spirits".*

Because most times, the disability was thought to originate from an ill-intentioned neighbour, there was mistrust, conflict and misunderstanding with the neighbors. Bitter memories and stresses were evident in some situations. For example, one mother, after introducing herself as a nursing assistant, went into long silence, a probable sign that something was wrong. She seemed to be in deep pain perhaps having some bitter memories caused by the circumstances surrounding the deafblindness.

Anxiety and Worry

Often parents could not tell what the child wanted. They therefore, used guess work to establish the children`s needs. This ignorance of the children`s problems and needs could be a further source of parents anxiety. On discovering that a child was disabled, the parents got worried. Such worries left them with little energy for productive activities. It was also reported that unlike other children, when feeding the disabled child, family members had to take extra care. For instance, one child was reported to swallow food, including maize, without chewing. This kept on worrying the mother who feared that he might be choked. This situation was worsened by these children`s inability to express their felt needs. This increased the demand on daily care. Parents` worry and anxiety is partly shown by the following response by Basa: (Father 2 interviewed on 10/4/2010).

> *"He was born with his sight, but he just got the disability. At the beginning we were very worried, took him to several hospitals thinking that he will normalize…"*

Disgust and Desperation

In addition to the continuous anxiety, households hosting CWDB also experienced disgusting situations such as when these children failed to control their bowels, especially at night. This was revealed by the following complaints by Romu: (Father 3 interviewed on 24/4/2010).

> *"…. He cannot feed himself. Even this kind of long calls, everything is done, by the parents…"*

Another expression of disgust was by Basa (Father 2 interviewed on 10/4/2010).

> *"They have the problem that if the child is sleeping, you can hardly know that he has soiled down there. So at times you find when he has got hold of the faeces so when holding him, he will also hold you with hands (disgusting voice) which are dirty. While taking care, he may smear the whole body with faecal matter in case you are not around to help him. It is also a problem."*

The caretakers emphasized that the children were filthy, even at the age of 12 years and had to be washed and cleaned. That many other things had to be done for them, for example they had to be fed and their clothes washed for them, abilities which they should have acquired by that age.

More feelings of disgust was implied by the family members` saying that it was hard to live with a disabled child that the child could start crying and yet the parents could not detect what was wrong. This disgust led to desperation shown for example, by the father who took a course in special education in the hope that it would solve his child`s problem.

Apathy and Rejection

Apathy was reported where neighbours did not see themselves as part of the disability problem, an implication that they not only stigmatized the child but also rejected him. This rejection which occurred even within the households was depicted when a sibling said she did not want her disabled brother to stay where her friends were, because he would disturb them.

4.2.3 Economic Dimension

The economic dimension was found to be a major part of the disability load and was closely linked to the emotional dimension referred to previously. It was associated with feelings that the household had for the CWDB, especially love and involved spending money and paying for services such as health and nutrition, depending on the state of deafblindness in the child. This dimension came up in discussions with members of the household, especially the fathers, most likely because they saw themselves as breadwinners.

Expenditure on Medical Care

Referring to the economic dimension, Kamau (2005) observed that CWDBs lack funding. Grandia (2006) also points out that the deafblind are often living an impoverished life. The findings of this research concur with those of Kamau (2005) and Grandia (2006) observations.

Parents told stories of persistent financial problems compounded by the disability situation. Lack of money was apparent even in the home surroundings. According to the parents, to meet the children`s medical needs e.g. drugs and surgical operations, they were forced to sell their property. These children were often treated in faraway hospitals making the costs too high for the households to meet. Below is Basa's (Father 2) response in the interview held on 10/4/2010.

> *"He was treated in Buluba Hospital and from there we were referred to Mulago Hospital. They demanded a lot of money so that they could treat the boy. They said they are going to put in conduits but we had no money. As I have told you that it is expensive. Medical care is the most expensive part of the boy. Yeah..."*

Expenditure on Traditional Healers

In this study, parents reported consulting traditional healers. However, they said they found them more exploitative than useful as explained by Basa (Father 2) during the interview held on 10/4/2010.

> *"They come and try to convince you, do this, come to me, I will do that..Ah..Ah.. They picked some foods, chicken and even money, because in the struggle you would not just look at the child. ..... they fail despite the fact that they took the money, the goat and the chicken. We just run away from them, they demanded more, saying that.... "the goat you brought is not the one we wanted; so the jajas are saying that you bring another one."*

In some cases, the traditional healers suggested the use of herbs which they said were in their possession but demanded payment first. They asked for extra resources, sometimes pretending that it was the ancestors who were demanding for them. In one case, a traditional healer, after receiving a goat turned around to say that the goat was not the correct type. The parents, who were often short of cash, instead gave chicken, goats and money, but the healer demanded more. Quite often, the parents gave whatever the traditional healers asked for, but no improvement was realized in the disability of the child. The money was lost, the healers were seen as useless and parents gave up or sometimes went back to medical doctors.

Feeding Costs

In addition to medical care, providing food that met the delicate needs of the children was another high expenditure burden experienced by the household on the disabled children. According to the parents, the children selected particular kinds of food such as tea or porridge with sugar, yet these foods were costly. Without such appetizing foods they became uncooperative and unruly leading to further stress on the households. The evidence for this was provided by Karo: (Father 4) interviewed on 1/6/2010 as shown below:

> *"It is right and expensive indeed. Because for her case to take tea or porridge, it must have sugar, without it she can`t take it. Instead she may display anti-social behaviors like cries, scratching the person as well as biting her."*

When the CWDB were sent to school, extra expenses were experienced in feeding. One child rejected the school food so the parent had to take to him food all the way from home. This became too expensive for the household and so had to be abandoned.

Transport Costs

Since in most cases the children were severely physically disabled and had to use wheel chairs, they could not use regular transport when going to school or hospital. Vehicles had to be specially hired. The cost was often too high for the family, increasing financial demand on the household. The following response by Kada: (Father 5 interviewed on 8/7/2010) reveals this situation and summarizes other parents` responses.

> *"Yes, it is actually expensive. It is expensive because when it comes to things like movement, you need may be to hire a vehicle, especially when he is sick. These children ....when they get sick, you need to spend a lot. ...before this child went to school, it was very, very expensive".*

4. 2.4 Communication Dimension

In the literature reviewed, it is observed that CWDB lag behind because parents are often not aware of the importance of communication(Tap, 2005; Rodbroe & Ramsing, 2005). Most of the participants in this study while describing the children, repeatedly emphasized their inability to see, hear and talk, and for some even to walk. From observation, indeed the children were unable to express themselves. They could only show signs when in need of something, including food and water, which had to be delivered to them. They were also reported to have problems in expressing toileting needs. So, often they relieved themselves where they were lying or sitting, to the disgust of the caretakers. This emphasizes the communication dimension of the disability load.

It was reported that playing with the other children was also problematic. While playing with the children, siblings found out that they could not see. When the children felt like playing with them, they could not join them creating disappointment within the playgroup. It was also reported that when the children felt hungry, they could not say it. Poor communication often resulted in wasteful consumption of resources including time. Romu: (Father 3) interviewed on 24/4/2010 giving evidence on the difficulty in communication.

> "*The boy cannot sit, cannot walk, ...Yeah. Even sight he cannot, if the seeing...it is partially and even hearing is kind of partially... Yeah.*"

4.2.5 Social Dimension

The social dimension of the disability load was reflected in a number of ways including rejection, neglect, isolation and exploitation by some members of the household, relatives and the wider community, including some spiritual leaders.

Rejection and Neglect

There was apparent rejection and isolation of the children even within some households. It is reported that the responsibility for their care was left to the parents alone. In one case, when other members of the household were asked to move the child around, none of them was willing to do so. Neighbours too, were reported to be unhelpful and often distanced themselves from the household.

CWDB were also excluded from community activities (Tarczay, 2005). Within the household, members may blame each other, get traumatized and sometimes the marriage ends in divorce (Kamau, 2005). Children may have difficulty learning social skills which they need to interact with the others. Hartshorne (2003) states that the children may develop behaviours that may be counterproductive in social situations. The above situations were observed in this study. Dialogue with the siblings revealed that even the peers and friends of the siblings did not easily associate with the children from the family of the CWDB. An example was when on hearing that their peer had a disabled brother, they just burst into laughter.

Isolation

The findings of this study agree with Vilhelmsen, (2005), who points out that individuals who have deafblindness are isolated, and that some of their parents may believe in witchcraft and suspect neighbours and therefore increasing isolation. Grandia (2006) further argues that individuals who have deafblindness in Africa are very isolated. As pointed out by Kumwenda (2004), it can be quite tough to live as a PWDB. These statements suggest that there is limited support for the PWDB, including from the members of the household hosting them.

CWDB may experience problems interacting with the world, difficulty in acquaintance, orientation, and response to events are not easily accepted (Jakes, 2003). Neglect, isolation and dependency on members of the household have also been reported (Leela, 2004). In another related report from Ghana, Afutu (2004) says that due to lack of awareness of the potential of PWDB, many people think that they are unable to take an active part in life. This study reveals that the severe disability in children often created negative style of perception in the community. The negative perception was clarified by Basa: (Father 2) interviewed on 10/4/2010 as indicated below:-

> *"Some family members would not like to look at CWDB.*
> *For example for us here in Busoga, when a woman is pregnant, they will say that if she looks at a dog, she might produce a child who looks like a dog. (He laughs heartily) So they would not like to look at such children".*

The nearest relatives seemed to get to the child was just by inquiring about the health of the child was. In most cases, they did not visit the family as expected or care about the CWDB. They were also reported to give no advice, financial or material assistance. The family was therefore expected to suffer alone with the children.

Blackmailing Spiritual Leaders

The role and influence of spiritual leaders does not easily occur in literature. It could be because of cultural differences or the level of desperation in the various communities being reported on. Despite these differences, the statements made by some parents suggested that there were no spiritual leaders who were interested in supporting the disabled child per se. In one case, it was emphasized that despite being made aware of the presence of the disabled child, nearby spiritual leaders did not call on the household to even come and just pray. The only religious people who went to the household were the "saved" ones, whose aim was not to help with the disability but to use the opportunity to spread their religious beliefs. They wanted members of the households to change from being Catholics to being "saved". They even blackmailed the parents by telling them that if they did not get "saved", the child would not improve. The blackmail is described below by Namaha ; (Mother 4 interviewed on 29/5/2010).

> *"Yes, I have ever but its only the "Born Agains", the "Savedees" who have ever come here to pray for her. They only say that if I continue praying, become a "Born Again", the child will be okay and normalize, but if I don`t, nothing will normalize. That is what they say".*

Exploitative Tendencies and Unhelpful Community Reactions

Other community members were said to have called on parents of CWDB with the promise of providing financial support and took photographs of the children. However, the parents complained that they never got any feedback from them. This was reported by Kada: (Father 5 interviewed on 8/7/2010).

> *"O.K. We have actually not got any of such experience, since the child was born. Apart from these other people who just come and take photographs and then they disappear, you don`t know what they have gone to do...They just come..." This is ...we are registering children who are ...what ...blind what...blind ....what..." They take photos....and they go."*

Exposure of the CWDB leads to such exploitative tendencies and negative reactions. According to Atieli (2005) CWDB may be hidden. It was also reported that people who see CWDB look at them with excessive curiosity, which may embarrass some parents and make them hide the children. Exploitative tendencies were also evident when in one case community members who passed by and noticed that the child was disabled, advised the father to take him to their traditional healers who, would give back his sight. The traditional healer took money, promising a cure but the child did not improve. It was mere trickery and extortion. This could have been one of the reasons why some parents hid their children. Another reason could have been to avoid excessive embarrassment and further exploitation. This exploitation and lack of assistance is evident from Kada's (Father 5) response to an interview on 8/7/2010 indicated,

> *"Hmmm....actually these spiritual leaders have got concerned so much.... I have been thinking maybe they are going to extend any kind of assistance ....but up to now....we...have not got anything."*

4. 2.6 Educational Dimension

The educational dimension is related to the social one in that how the society views and treats CWDB also influence the educational path. In *Deafblind Children*(2008), it is reported that at school level, a significant number of siblings have been suspended or excluded from mainstream schools owing to total lack of understanding of the negative effects of having a disabled brother or sister. Cretin-Billet (2005) states that CWDB may need boarding facilities to access education and due to the complexity of their conditions they may also need to be attended to by a multi-disciplinary team. However, according to Rodbroe and Ramsing, (2005) the community may not appreciate these needs and even school opportunities are often not available as teachers are not trained. The study findings agree with the above points of view. All the children observed needed boarding facilities. The few taken to school were not regular because of lack of extra resources needed to keep them there more permanently. In addition, at school they were reported not to get enough attention from the teachers because those appointed to help them were overworked: they taught both CWDB, regular classes where the latter`s teaching load reduced the attention the teacher would give to the CWD.

Kamau (2005) reports that in the developing world, parents struggle to take the children for educational assessment, where the assessment centres are oftena long distance away from the home. This makes subsequent appointments for assessments difficult to afford and so the parents may give up educating the child. She also mentions other barriers to education such as the deafblind needing their own school, and schools not having proper programs for the needs of the children forcing them to leave school prematurely. In this study, the only available assessment was the medical. Worse still, not only was it a long distance and parents could hardly afford subsequent appointments, but educational assessment was hardly there. As observed by Hathazi (2003) teachers who were expected to do this lacked knowledge of new approaches and methods of intervention. In addition, many nearby schools lacked programs that suit CWDB. Although the government was expected to help fund education and some other related materials, at the time of data collection they were not doing that. Even the immediate community and the local government representatives did not show interest in the education of the CWDB. Similar findings have been reported by Kamau (2005) and Hathazi (2003).

4.2.7 Policy Dimension

The policy dimension brings together all the other dimensions which have been discussed earlier and also covers the work done by Ugandan government and NGOs.

Lack of supportive government policy

As pointed out by Drescher (2005), in most countries deafblindness is not recognized as a distinct disability, so, often there are no specific programs for identification of newly diagnosed CWDB. Hathazi (2003) and Salomie (2006) state that in other countries, the government claim that the CWDB are negligible and cannot warrant special service provision. Related to the above, Collins (2005) says policy issues may be a major barrier for intervention, especially in developing countries including Africa where limited resources, lack of trained personnel and shortage of materials pose significant obstacles. He continues to suggest that this could partly be due to absence of relevant policies or poor interpretation and implementation of the ones already in place.

This study agrees with the above views. Lack of specific policies and public awareness of deafblindness to address the condition as also suggested by Atieli (2005) was observed. This was coupled with what *Canadian National Society for Deafblind, (2005)* says: that in some situations,there is insufficient public awareness to highlight the needs of persons who are deafblind, and to reduce the misconception among governments. The findings concur with Kremneva (2003): who argues that these services are not developed to meet the needs of the deafblind. This study revealed that the then existing government policy did not serve the needs of CWDB. Instead, NGOs made attempts to fill the gap left. Parents complained that the government was not putting enough efforts to get assistance for these children.

Providing evidence from Spain, Lopez (2004) points out that the families with CWDB have leadership and representation problems. He indicates that the parents and families are left out without capacity for any representation. Poor representation may have implications for improvement of opportunities and provision of better services. The strongest evidence in this study that pointed to limited concern by government was a household who lived near the local council chairman who never showed any support for the disabled child. A parent regretted by saying that the people in government did not take their responsibilities seriously. In addition, other parents pointed out that no government representative, not even the local councilors visited the household despite the awareness that they had a disabled child. It is specifically emphasized that the nearby councilor who represented the government at grassroots level did not give any advice or assistance. In another case, it is reported with disappointment that despite having a Minister for People with Disability, the family was avoided by people in government and that there were no politicians who came to visit them and help them fight for their rights. The parents pointed out that the government needed to be told, that even these kinds of children could be productive. It was emphasized by several parents that the government did not help and where it gave help, the assistance was too small to meet the specific needs. On a depressing note a parent asked an emotional question as to whether parents should kill such children if the government thought they were useless. Basa: (Father 2 interviewed on 10/4/2010) expressed his disappointment in this way:

> "(Laughter)… *The government is still not yet putting in enough effort to see that those children are helped. Actually government, I think it needs to be told that even this kind of child can produce something: even if they don`t produce, should we kill them? The*

> *government has not yet taken a visible hand as far as CWDB are concerned."*

Unreliable NGO policy

The NGO policy was on several occasions reported to be unreliable and unhelpful, as quoted below. Namaha: (Mother 4 interviewed on 29/5/2010) said this.

> *"There is nothing like help we get from NGOs though one NGO is there. Not even 5000/ - that they can give to you to cater for her. We just cater for ourselves."*

In a few cases, it was reported that there were no visits or contribution from NGOs. Other parents also said with emphasis that there was no single help or money that they had received from NGOs.

4.2.8 Emergent Disconfirming Evidence

Though the literature reviewed in Chapter 2 did not reveal any disconfirming evidence it is difficult to ignore these because they make the findings more realistic. They include positive emotions, government and NGO contributions.

4.2.8.1 Positive Emotions

The most important positive emotion was love. It was demonstrated through various actions including acceptance, play, training, visits, encouragement, and assistance. The love was interwoven and reflected in many ways.

Acceptance

The first of these positive emotions was love. The findings revealed that it was associated with the acceptance of the children. This was indicated by actions of many people including members of the household. Parents, for example, made efforts to solve their children's health problems and also contributed to their welfare by adequately dressing them. When the clothes got torn, they struggled and bought others. The children also accepted the disability status of their siblings and their feelings about them were positive. One of the siblings even said that it was not hard to live with the SWDB because he was also a human being like them. Namaha (Mother 4 interviewed on 29/5/2010) confirms this as follows:

> "Still *my other children help me with feeding her, shifting her to other places, bathing her and cooking food for her, and dressing her up. Still it takes a lot of time to cater for her. You may only identify and realize that she wants to ease herself and you take her. Afterwards you need to bathe her, wash her dresses and even change the dressing as well as organizing where to place her. Therefore it needs and takes a lot of time"*.

According to the study findings, efforts were made to provide good feeding for the children despite the numerous financial constraints encountered by the households. For instance, it was reported that they fed the child on porridge with sugar despite the high costs, while the other children in the households took care of their SWDB when they were eating.

Play with the CWDB

It was reported that despite the domestic and other school activities, the children spared time to play with their SWDB. They sat around them playing and singing songs that praised the disabled child. The play involved moving the child around or putting the child in sand. Magerefa (Brother 5 interviewed on 8/7/2010) explained this thus:

Positive Sibling Interaction

There was love for the CWDB from their siblings. This was evident in relationships within the households. Reports showed that there was close interaction between the siblings and the CWDB. For example, when the brothers and sisters returned from school, they played with the disabled child using a walking frame. Talking about sibling interaction through play, Mula (Sister 5 interviewed on 8/7/2010) said.

> *"The boys in the family play with him. When he has asked that, "I want water." ....they can bring for him. Also the girls the same. They play with him, when he feels tired he stops."*

This response shows that in addition to play, the siblings helped the children when they needed something. For example, when they cried, or were hungry, they gave them food and water. However, this interaction was rather limited because of poor response from the CWDB.

Visits and Advice by Relatives

Despite the reports of neglect by some relatives as reflected earlier, it was revealed that others played a useful role by advising and encouraging the siblings to continue caring for the disabled children. For example Karo: (Father 4 interviewed on 1/6/2010) said the following:

> *"They always pay us visits and also pray for her, greet her as well as encourage her us to endure".*

It was also reported that other relatives visited the family and, when they found the children left alone, they cared for them and advised household members how to help the children do physical exercises. This care by relatives sometimes also involved removing the children from dangerous places, including hot sunshine, to which they were normally exposed. It is also reported that other members of the extended family came to assist the disabled child and brought food and clothes for them.

Encouragement and Prayers

Despite the earlier report of isolation by spiritual leaders, one household benefited from them. For example Romu: (Father 3 interviewed on 24/4/2010) said,

> *"Like the born again, they come and pray for him. They normally say that it is Satan that brings problems and ...continues to also to tell us to be firm, to have love for God and that one day, one time the problem may try to normalize. Yeah."*

Other reports about some of these spiritual leaders revealed that some came to see and pray for the disabled children, while others came with money for buying them food and clothes. Some others guided and counseled the parents. For example, they encouraged household members to remain firm in their trust in God because one day their problem would end. When family members went to church, the priests expressed love for the child.

4.2.8.2 Contribution by Government and NGOs Government Assistance

Although government assistance was not received very frequently, in a few cases government was appreciated for providing medical care, paying salaries for the multidisciplinary team that cared for the children and giving the CWDB wheelchairs. Kada (Father 5 interviewed on 8/7/2010) acknowledged government input and limitation by saying.

> *"O.K. Generally government cares for people with disability only that this particular type of disability, people had somehow neglected it. As per now,....(thoughtful) ....government has not assisted because even this deafblind unit we are talking about, government has not put in so much."*

Contribution by NGOs

Findings also show that despite the negative reports about contribution from NGOs, there is evidence of help from them. The Uganda Parents Deafblind Children`s Association (UPDCA) gave a goat which was producing milk for one of the children while Rotary Club gave the children wheelchairs. Other donors built a school unit for the deafblind, assisted in medical care and paid teachers to help with exercises which had improved the physical ability of some of the children.

4.3 The Consequence of Each Dimension on Quality of Life in Each Household Hosting CWDB

In section 4.2, a number of important dimensions of the disability load in the household are outlined. They include the educational, emotional, communication, social, economic and policy dimensions.In this section, both the literature reviewed and the data showed that each of them influences the quality of life in the households. These influences are accounted for below:

4.3.1 Emotional Dimension

Generally, emotions are central to the level of happiness. In this study they were found to influence the quality of life. The emotions included frustration, anxiety, worry, anger, embarrassment, disgust, and desperation.

Frustration

Cote and Cloutier (2005) state that deafblindness has severe psychosocial consequences because the two disabilities intensify the effects on each other, creating a severe disability. Long before school is thought of, parents of CWDB begin to experience negative emotions following the discovery that the child has multiple and severe disabilities. The seriousness of the disability has an immediate and continuing negative influence on the parents. Watters, Owen, & Munroe (2005) reveal that the needs of PWDB are many and so are the barriers to success. In a slightly related study, Simms (2003) reveals that there is general frustration and lack of inclusion of the individuals who have deafblindness working in an organization. Steer (2005) also found that individuals who have deafblindness generally live in difficult circumstances.

The above cited studies imply that frustration is common among the deafblind and members of their household. The findings of this study too, show that frustration is common in these households and presented itself in various ways.

On discovering that the children had multiple disabilities, including inability to see, hear, talk and, most often, to sit or walk, parents became unhappy, to say the least. The unhappiness was worsened where the children were so helpless that they had to be carried from place to place. The following report by Namishi (Sister 4 interviewed on 29/5/2010) reflects the helplessness and frustration:

> *"She can`t feed herself, sit, doesn`t talk, see and the legs can`t stand so she is unable to walk. Since she was born...if it is a Saturday, the mother leaves her with us to look after her".*

The caretaking of the children was seen as a struggle with a burdensome situation which made life unpleasant. When it came to physical and emotional development, children did not follow the normal path. They could not proceed from one stage to the next as expected and parents were disappointed. Even feeding them was reported to be problematic for members of the households. Contrary to expectations, the children often had poor appetite and required appetizing food which was often difficult to get.

This finding concurs with Miles (2003) observation that some parents do not want to hear that their children have sensory loss. When they realize that the child has such a disability, they may lose hope, and the whole family may get affected. In this study, statements by parents suggest that the discovery that the children had severe disability put them in a state of panic and confusion and they did not know what to do. Hoping to get a cure, they took numerous steps but in most cases not much was achieved. The resulting and continuing helplessness required that parents watched the children closely. Quite often, they had to leave other urgent tasks. Having to be a parent in such an apparently hopeless situation may also lower the self-esteem of parents. Enduring frustration, confusion and low self-esteem result in lower quality of life. Helplessness on the part of the CWDB also implied that many things are to be done for the child, such as feeding, bathing and dressing leaving other domestic chores unattended to. Such competition for household labour and time may lead to role conflict and reduce pleasure of life within the household. The complexity of the disability made the care of the children challenging. Siblings of the CWDB too, were not happy as their siblings with disability did not usually respond to their advances to play. On the whole, the daily life of members of the household showed a low quality of life.

Anxieties and Worry

Research by Wolf (2003) shows that many negative feelings are generated in households of CWBD. In a similar study on emotions, it is reported that parents may develop anxieties about the unknown and therefore may need support (Lopez, 2004), yet often such support was not easily available (Poggioni, 2007). Both the need for support and lack of it may create a traumatizing situation for the parents right from the level of identification. Similar feelings were expressed in this study. Reports implied that because the children were helpless and could hardly care for themselves, parents were anxious when they left them alone. In one case it was feared that a child who could walk could easily run into dangerous situations or get accidents. For example, Namishi (Sister 4 interviewed on 29/5/2010) expressed the anxiety and worry in this way:

> *"She might be knocked on the way because she can`t see. It`s because she can`t see, walk and hear, can`t speak and doesn`t know that she needs to give way to vehicles".*

There were reports of limited communication between the CWDB and household members. So they could not tell what the children wanted. This lack of information caused anxiety and worry, which was bad for the household. In one incident, the parent who had a hyperactive CWDB found when he had dismantled everything in the house. Some parents reported being confused and fearful when the children had accidents. A parent also pointed out that even medical personnel feared to treat his daughter with deafblindness.

Anger and Embarrassment

According to Moore (2006), the siblings may be expected to spend a great deal of time caring for their SWDB. In an emotional reaction to this deprivation of free time, the child may develop bitter feelings towards both the parent and the SWDB. In relation to this, this study revealed that CWDB were demanding and equally needed constant care. The demands were described by Namishi (Sister 4 interviewed on 29/5/2010).

> *"Those problems with carrying her. She is not light and easy. She is heavy. I first feed her before I continue. She can`t see, sit, feed herself, walk, we just carry her, feed her. We feed her. Yes, even when she wants to drink, we give her, in case she wants to ease herself, she squeezes herself and we help her out. In case she has soiled her clothes, we change, give her others and bathe her.*

As shown above, these children needed attention whereas household members had to get on with their daily work like other members of the community. The demanding and upsetting situations were experienced in other areas such as the child`s poor communication and poor feeding habits. As part of the care, the children also required to be bathed, washed and dressed, yet communication with them was limited. This meant that some of them could relieve themselves anywhere, creating anger and embarrassment. While feeding the children, parents got worried because some of them could not chew food properly and often got choked or swallowed the food badly and vomited. This high demand for care generated anger, the frequent occurrence of which lowered the quality of life in households.

Regret and Disappointment

The situations that produce regret and disappointment are related to those which cause anger and embarrassment. According to Miles (2003), the discovery that a child had Usher Syndrome was difficult and haunting for parents, some of whom were stressed. Other parents had never heard of the condition, while others did not want to hear that their children had it. Miles (2003) also reports that one mother even rejected the child and wanted to place it for adoption. Similarly, this study revealed the frequent occurrence of such behaviors in households. The degree of helplessness, the high expenditure and the anger generated from the realization that the child was severely disabled led to disappointing and regrettable situations that reduced the worthiness of life. There was great potential for conflict as members of the household blamed each other over the disability because it was often too much for them to bear. In one case, the parents were even forced to live apart, leaving the mother to take care of the child single handedly. Reports from households indicated that there was general failure to understand the causes of the disability. The occurrence of disability created a painful and unfavourable experience and laid the foundation for regret in the households. Under the circumstances, enjoyment of life was not guaranteed. Basa (Father 2 interviewed on 10/4/2010) expressed the disappointment in this way:

> *"Most of them are challenging because when you look at the disabled child in most cases, everyone will blame the other."*

Disgust and Desperation

Guest (2003) states that CWDB may develop periods of extreme mental anguish. This is in agreement with the findings of this study. Parents reported their disgust and annoyance at children's abnormal behavior, including crying without any obvious reason. Often they could not feed themselves. The food choked them or they vomited while eating. It was reported by household members that it was hard to live with the CWDB, largely because of behavior problems. Despite their age, the children often could not control their bowels. The atmosphere which they created was not conducive to the members of the household. As a result of this, the children were rejected and excluded from various activities. This was not good for their wellbeing, yet even parents' efforts to seek assistance, hardly yielded any good results. Even community members paid only lip service to them. In addition, rejection from some family members and stigmatization from neighbours made life unpleasant for the members of the household. Their disgust and desperation were summarized by Kasa (Mother 5 interviewed on 8/7/2010) as follows;-

> *"It is really hard to get help because since that child was born, I have been confronted by over 10 people asking and advising me to write a report saying ... 'we shall give you help'. But I have never got help except at school where he is assisted for example with clothes. But this side there is nothing given to such people".*

4.3.2 Economic Dimension

Potmesil (2006) points out that it is important to consider economic issues when assessing the quality of life, while according to Collins & Campbell (2003) CWDB may have special and unique needs which may require alternative programmes which may also need extra resources.

In this study, parents admitted that caring for CWDs was expensive and that one of the challenges they met was financial. They often lacked money to buy even basic necessities such as salt. This shows that inability to meet expenses frequently lowered quality of life. Parents often hardly got financial assistance from elsewhere, thus they had to struggle to meet the needs of these children.

Expenditure on Medical Care

As already reported, parents persistent financial problems was compounded by the disability situation. They clearly pointed out that while living with the CWDB, their major problem was money. When medical care could not yield the desired results, the severity of disability and helplessness of the children forced parents to seek further remedy, including from traditional healers. Reports indicate that traditional healers proved even more exploitative than useful. This worsened the parents' situation as they had lost their hard earned money, and got nothing in return. This double deprivation made their life meaningless.

High Cost of Feeding

This study also revealed the problem of high cost of feeding. Feeding the children was reported to be expensive because the parents had to spend extra money as most often the children refused to eat home grown food. Some of them even demanded to eat when the food was not yet ready. Such food had to be bought to prevent the children crying. Some of them often wanted only soft food or selected only particular kinds of food, which involved extra costs. The high costs of feeding were revealed by Romu (Father 3 interviewed on 24/4/2010).

> *"It is very expensive because as I have said, there are some types of disabilities which are very expensive,...it is expensive. Feeding him as I have told you, all that requires much attention, financially. So it is really expensive."*

When the children were sent to special schools, extra expenses were encountered in feeding. In one case, it was reported that the child rejected the school food, so the parent had to take him food all the way from home. This was not only demanding but also caused financial stress and lowered the quality of life.

Transportation

It was reported that transporting the children was expensive. The disability was often so severe that the children could not use simpler and cheaper public means of transport when going to hospital or school. For example, they could not sit on a motor cycle, so a car had to be hired for them, which was costly and unpleasant. For some children, wheel chairs had to be included when transporting them which increased transport costs even more. Basa (Father 2 interviewed on 10/4/2010) said the following:

> *"....and most children with disability are very expensive, you cannot move without a wheelchair, which is very expensive for someone to buy. We had to move to Mbale, where we had not even gone before".*

4.3.3 Communication Dimension

Hartsborne (2003) and Miles (2005) report that communication is important for full enjoyment of life while Deasy and Lyddy (2006) point out that individuals who are congenitally deafblind have significant challenges in communication. In addition, the *Croatian Deafblind Association*, (2005) report that the children are often excluded and live in a dark silent world. Furthermore, Boothroyd & Hampton (2003), Vilhelmsen (2005) state that deafblindness may not only prevent them from getting in touch with the environment, but they may fail to express themselves. Jakes (2003) also says that CWDBs use their hands as a voice, do not give enough information and cannot express themselves sufficiently. All these may lead to misunderstanding and confusion.

In this study, parents reported that CWDBs used signs and gestures, which their siblings sometimes could not interpret. As a result, there was misunderstanding; confusion and conflict in communication as the CWDs were reported not to use the same language with their siblings. According to them, poor communication also caused problems in meeting the children`s special needs. In some cases, the children would merely cry in order to communicate their needs. Difficulty in speaking and walking implied that needs were not well expressed. This was a barrier to communication and a major challenge to parents. Even play with the siblings was limited despite the fact that the siblings were reported to involve CWDB in their games. Since the children were unable to express themselves verbally, they could only show signs when they were in need of something. Kasa (Mother 5 interviewed on 8/7/2010) pointed out the problem as indicated.

> *"Its only that they don`t use the same language. For him the way he gives out his words /language always defeats the others to understand and coordinate the words".*

Limited communication implied that food and water had to be given to the children whenever the caretaker suspected that they needed it. The caretaker also had to be continuously on a lookout for signs of both hunger and need to go to the toilet, a task which complicated caretaking and created even more demand. Regarding daily life, it was reported that playing with the other children was also problematic. While playing with their SWDB, the children found out that they could not see, hear or talk. The inability to communicate frustrated the playing process. Poor communication also prevented the children from going to school thus further affecting the quality of life.

4.3.4 Social Dimension

Social dimension is also related to the communication dimension and further makes life unpleasant. In the study this was reflected in many instances. As pointed out by Leela (2004), there is isolation as a result of poor communication between the CWDBs and family members. Furthermore, Tap (2005) and Afutu (2004) state that when both senses are affected, one finds it difficult to get connected to the environment thus ending up in isolation. Negligence by family members may occur and relationships with relatives and neighbours may deteriorate, reinforcing the isolation.

In this study, rejection of the CWD was observed at two levels: within the family, where there was also lack of cooperation by the siblings in taking care of the CWBD and outside the household where some relatives and neighbours showed no interest in the children. This was evident in statements made by parents indicating that neighbours stigmatized the child and made sarcastic remarks. Situations like these made life difficult for both the parents and the CWDBs. It was also reported that even peers of the siblings did not show enthusiasm about the CWDB. So, right from the beginning, it was problematic for parents to leave the children alone in the home.

Parents reported experiencing hard life because most people had a negative attitude towards CWDB. A parent reported that she normally stayed alone with her child because it appeared to her, that the child was not wanted. Parents were ignored whenever they approached someone for help so seeking help remained a big challenge. Interaction with the general community was not pleasant. Anxiety and discomfort was generated as some other people whom they came across looked at them with excessive curiosity. Rejection and isolation all led to poor quality of life. Romu (Father 3 interviewed on 24/4/2010) expressed the isolation faced by the household as shown below:

> *"It is very hard, because most of the people, they have what we call negative attitudes towards such people and earlier on I said that getting that somebody who can attend to such a child is very hard, it is too heavy for him...and all that, so it is very hard to get somebody to help in such situations, due to the fact that most of the people, their attitude towards such people, is not all that positive".*

4.3.5 Educational Dimension

Where there is isolation and rejection, education is also likely to get affected. Potmesil (2006) and the*Canadian National Society for Deafblind* (2005) both state that one can describe quality of life by taking into account accessibility of school by CWDBs. This point of view needs to be considered against the fact that CWDB are dependent and may often have to be accompanied to access education (Spring & Woodtli, 2004). It is further observed, that they have unique needs, and may need special attention to access knowledge (Kumwenda, 2004).

According to Palmer and Lahtinen (2005) in the school setting, CWDB miss information from the surrounding. This is clarified by Kamau (2005) who states that CWDBs need their own special programmes, though this is often difficult to meet. In support of this view, Rodbroe and Ramsing (2005) observe that parents may be driven to desperation and may wish to start a school unit for their children.

The complexity of the disability may not be acceptable to some schools (Tap 2005). The Stickler Syndrome Support Group (2006), also emphasize that children of school age may face considerable educational difficulties because of the combination of impairments. This study showed that most of the CWDBs were too disabled, even for "education" to be readily considered by the parents. It was evident that some children stayed at home and were being visited by teachers who helped with physical exercises. Meanwhile, the ones who went to school were not well attended to because the teachers were overworked. Noted was the fact that not only was relevant resources insufficient but also both local government officials and neighbours discouraged the education of the siblings. Parents who made efforts to take the children to school were often discouraged by people who were surprised and questioned why the CWDB, who could not see nor hear should be taken to school. They wondered whether these children would learn or pass any examination. Kasa: (Mother 5 interviewed on 8/7/2010) clarified this point as follows;-

> *"Some people wonder and ask, "Are you taking that one to school? What does he learn there? Because he doesn't see, hear. Now he passed and was promoted to which class? " So you find it hard to answer such questions, but at times we tell the teachers at school to train them first the way a child showers, wash hands, brushes teeth and the way he/she does things, washing clothes, step by step."*

In most cases, siblings of the CWDB were not benefiting maximally from their education because their time was taken up by caring for their siblings with deafblindness. They often had to look after the CWDB before going to school. When they came back, their homework time was taken up by the care of the sibling with disability: giving them food, preventing them from crying and so on. Lack of education therefore laid the foundation for poor quality of life.

4.3.6 Policy Dimension

Watters, Owen, & Munroe (2005) reveal that there is need for government funding to improve services for PWDB, public awareness and training programmes yet Kumwenda (2004) states that policy issues on deafblindness are often lacking. Rodbroe and Ramsing (2005) point out lack of knowledge and public awareness on deafblindness. This agrees with Drescher (2003) who states that individuals who have deafblindness do not have rights to participate fully in society and are yet to be recognized as a separate group. Steer (2005) also suggests the need to persuade governments to focus on programmes for the deafblind. Furthermore, Collins and Campbell (2003) observe that policy issues will continue to require attention while Kamau (2005) argues that improvements in policy are not enough as barriers to services may still persist. In this study, both government and NGO policies were found to be ineffective. This amounted to negligence, which affected quality of life.

Government Policy

Parents reported that they found it hard to get help from government. When they informed those people who were in position to provide government assistance, they did not get any appropriate response. It was evident that the multiplicity of disability in deafblindness and lack of specific government policy to address it made deafblindness a neglected area. It left parents desperate and confused as to what to do regarding the management of the disability of the children. Poor government policy created the atmosphere for poor quality of life. The lack of focus on CWDB by the government expressed by Karo (Father 4 interviewed on 1/6/2010) is indicated:

> **Respondent.** *"They only gave us this wheelchair."*
>
> **Interviewer.**" *Is there anything in your community that the government has done in favour of that child?"*
> **Respondent..**" *No.* "

NGO Policy

Salomie (2006) observes that despite the lack of clear policies in many situations, there is an emerging awareness of the needs of CWDB. This study showed that although NGO's were making effort to help parents, they were not consistent and widespread. For example, reports revealed that some households did not easily access the assistance NGO's gave to other parents. This lack of specific and favorable policies had a negative impact on quality of life.

4.4 How the Disability Load Impacted on the Schooling Path of Children with and without Deafblindness in selected Households

The last theme examined the consequence of each load on the quality of life on each household. This current one deals with the impact of disability load on schooling paths of all the children in the households. The disability load has been found to have impact on the schooling paths of children with and without deafblindness.

4.4.1 The Impact of the Load on CWDB Interference on Cognitive Development

According to Mortensen & Moller (2007), emotions generated within the individual child as a result of having to live with dual disability may develop into depression and moods that may hinder educational progress. This study revealed that the normal learning process in children was seriously affected by the disability. It was evident in the continuous moody states, poor peer interaction, inability to communicate clearly and limited use of opportunities to learn social skills. The children were reported to have not only just dual but multiple disabilities. It was repeated many times that the children could not see, hear, or talk and most often could not sit or even walk. In most cases these disabilities were reported to have existed since birth. The following statements from Basa (Father 2 interviewed on 10/4/10 support this point as indicated:

> **Interviewer.** " *So how has the disability affected his education?* "
> **Respondent.** " *It has affected it very much.* "
> **Interviewer.** " *How ?* "
> **Interviewer.** " *For instance at the age of 11 years he could be in P4 or P5, but he is unable to do that.* "

Brownell and Carriger (1998) argue that social relationships are the context in which knowledge is formed. Meadows(1999) also reinforces the importance of interactions with the environment in the development of cognitive abilities. It has further been observed by the writer that communication is the foundation for both social relationships and interactions with the environment. Both knowledge and education largely depend on these factors. In this study, it was reported that playing with the other children was also problematic. While playing with the CWDB, siblings found out that these children could not see or hear. For this reason they could not join in play activities as earlier pointed out. This meant that social relationships and interactions were missed out, indicating that knowledge could not be formed, and the development of cognitive abilities was interfered with as indicated by earlier studies.

Tap (2005) also found a link between the multi-sensory impairments and the cognitive development of these children. In this study, reports from household members based on their observations, indicate that the severe disability interfered with the children's normal development, such that they could not attain the usual development milestones to enable them learn self-help skills. They were often lying or sitting helplessly. In one of the instances, a father acknowledged that the education of the disabled child was seriously affected because at the age of 11, the child would be in Primary 5, but his son could not fit in that class.

Effect of Poor Communication on Learning

Lack of communication also affected learning. According to Deasy & Lyddy (2006) CWDB had significant challenges when attempting to acquire communication skills and, lack of communication severely diminished interactions with the environments. Sensory input from the environment was reduced and motor function limited. Spriet (2006) further states that CWDB may lack language and communication as well as daily living and locomotion skills. All the CWDB in the households interviewed in this study could not easily access the school curriculum because of reduced sensory functioning.

Lopez (2003) also agrees with the above position by stating that the first problem of CWDB was lack of communication, and that there was need for one to one support from trained professionals. The evidence in this study is that the children severely lacked communication skills. They needed help from trained professionals whom they could not get, except for only one teacher, who was even reported to be overworked.

Levy (2003) states that difficulties with expression or the constant experience of having their expressive communication misinterpreted can lead some children to give up, or to resort to explosive behaviours. Such behaviours could, in turn, be seen as unpredictable or irrational, therefore, placing obstacles toeducational opportunities. In this study, some children were reported to be unable to socialize. This is supported by the following statement made by Kuda (Brother 4interviewed on1/ 6/2010).

> **Interviewer.** "*What challenges do you meet in playing with her?* "
> **Respondent.** "*She cannot walk, see, talk or sit so that you can give her an object to use for playing*".

Dianton (2007) further observes that the most significant and yet common barrier to education for CWDB was communication or to a larger extent, socializing. This study found out that the children had difficulties to socialize in a meaningful way, thus putting limits to their educational opportunities. The reports by the households showed that because of poor communication, the children could not participate in normal social activities as some of their behaviors were not acceptable and difficult to explain. Consequently the children could not benefit from existing educational programs. Kuda (Brother 4 interviewed on 1/ 6/2010) testified in this way:

> **Interviewer.** *"Could you please tell me about your sister's education? What challenges does she face on going to school? "*
> **Respondent.** *"She can`t afford walking, can`t see and understand that I am going to such a school, can`t say that I am going but I will be able to bathe and even feed myself or even see a teacher writing on the black board."*

Lack of personal assistants such as interveners in deafblindness, who are trained wherever there is a PWDB, including schools, as indicated by Lopez (2007), is another possible educational challenge.

In a related argument, Mathews (2007), while raising the issue of deafblindness as a unique category of sensory impairment, also refers to the importance of availability of one-to-one communication support. As suggested by these two authors, there were no trained interveners in households or schools, and no one-to-one communication support was found in this study.

Steer (2007) further refers to the need for regular assistance with communication. Drescher (2005) also argues for the need to provide trained interpreters and communicators to give support. The evidence collected from this study showed that there were hardly any resources in the households and schools to allow for training and employment of a one-to-one communicator. For this reason, the children were poorly supported, thus severely limiting their access to school curriculum.

Zoppi (2006) emphasizes that communication is basic to education; that it is needed at all levels, and in all interactions, including the school setting. It is seen as a major contributor to development, self-determination and social inclusion. Therefore, deafblindness, has a serious negative effect on communication. Poor reception and expression in the communication process in turn limit exchange of information in different social settings, including the school. Jakes (2003) further emphasizes that deafblindness presented pedagogical, psychological and social problems. (Alverez 2002) and Frolova (2003) also argued that it causes serious problems for the disabled child and its effects and challenges are personal and social. For all the children in this study, the schooling path was complicated by limited verbal and visual communication and poor mobility both indoors and outdoors. The following discussions with Basa (Father 2 interviewed on 10/4/2010) illustrate this.

> **Interviewer.** *Some people say it is difficult to educate a deaf blind child. Please tell us about his education.*
> **Respondent.** *OK it is difficult since this child cannot see, cannot talk. I know, I am not the one teaching them, but I am sure teachers are getting problems. I know it is not easy for them, because even we here, I cannot communicate with him. I cannot talk to him, I cannot do what. Just look at him at him...I just bear with him, but there is no communication at all.*

These conditions made it difficult for the CWDB to acquire daily living skills and to access educational facilities. In agreement with such views, deafblindness has been found to be a unique and distinct disability which has influence on many aspects of development and learning.

Related to the issue of communication, Amaral (2003) observes that CWDB did not use speech or any other language form to communicate, but relied on movements, smiles and manipulation of objects. According to that report partners in the CWDB's environment could not give appropriate feedback. Lack of communication, poor social relationship as well as limited interaction was all seen as barriers to the schooling path. In this study households acknowledged that the severe lack of communication seriously affected the CWDB, and the majority did not attend school. A parent said that because of the child's inability to cope with school activities, the school administration eventually advised them to keep the child at home.

After a close look at communication, the question of skilled teachers in handling CWDB also needs some consideration. Hathazi (2005) says that deafblindness involves new approaches and different methods of interventions. Availability of specially trained teachers with communication skills and knowledge to help these children was seen as fundamental. Steer (2003) and Tap (2005), in their report, point out that there is an increasing shortage of skilled teachers who have to work with an increasing number of CWDB. Another finding of this study was that the teacher-pupil ratio was not realistic. A parent reported that one teacher was expected to teach ten CWDB. Government level of awareness of the shortage of teachers, therefore, remains questionable.

Neglect by Families, Communities and Professionals

In addition to shortage of trained personnel, there is a general negative attitude and neglect towards the CWDB by individuals and groups who are expected to support them in their educational endeavors. Raising this issue, Kersten (2006) says that sometimes some CWDB feel forgotten by their parents as well as professionals, whereas they too need services and support. In this study, a father was noted to have abandoned the child and his mother who was struggling to bring him up single-handedly.

Kumwenda (2004) recalls that, having become deafblind, he was not accepted in his original school and so had to be placed in another one. He reports that in the Africa region there is probably a substantial number of CWDB who cannot access educational services. This study indicates that the children could not easily access school, evidenced by this report from Namasha (Mother 4 interviewed on 10/4/2010).

> **Interviewer.** " *What do you say about people`s perception that it is useless to take such a child to school?* "
> **Respondent.** " *I also see it as difficult because she can`t stand, can`t walk, talk, hear and even see. So how can she really see and understand what is being taught. The sense of understanding is lost. So I also see it as difficult and she can`t study or learn.* "

There is also the existence of poor attitudes in communities which is potentially detrimental to education. For example, where parents made some effort to take these children to school, some neighbours were not sympathetic but instead made sarcastic remarks wondering why resources should be wasted to take such children to school. This is indicated in the following conversation with Kasa (Mother 5 interviewed on 8/7/2010).

> **Interviewer.** " *What do your neighbours think and say about this child?* "
> **Respondent.** " *Some of them just discourage us that... " even that one can also be taken to school ! Then others like in town where I could go, on discovering that the child is deaf blind, they would come and see the child and then go back to tell each other about the deaf blind child they have never seen.* "

Such a remark was unduly hostile and discouraged parents from taking their children to school. Further evidence of negative attitude in this study was the apparent rejection and isolation of the children, even within some families. In one instance it was reported that the responsibility for care was left to the parents alone. In another case it was recalled that when other members of the household were asked to move the child around, none of them was willing to accept the responsibility. The case for isolation within the family was emphasized when a sister said she did not want her brother with deafblindness to stay where her friends were. Rejections like these limited the opportunities for informal learning through interaction yet leaving the children in one place deprived them of a stimulating environment, which is important for cognitive development and learning.

In a related case, Kappan (2008) also adds that there are traditional taboos and discrimination against individuals who are deafblind. This study revealed that there was also fear among relatives because extended family members reported not to like looking at CWDB since they feared that if they were pregnant, they would produce children who were disabled. Such unwarranted fear intensified negative attitudes, creating avoidance and neglect of the CWDB, and also reducing their chance of learning through interaction.

Kamau, (2005) observes some of the barriers to education of CWDB, such as parents being told that the child would never be able to do anything for himself or herself and so that they should not waste their time with CWDB. In this study, a parent experienced a situation in which some people in the community asked why parents should waste time taking a CWDB to school and whether such a child could even pass examinations. This was Kada (Father 5 interviewed on 8/7/2010) who replied in this conversation thus:

> **Interviewer.** *"And what do they (community)think about his education?"*
> **Respondent.** " *They think we are wasting time...when they see us taking him to school. They...Hmmm....some of them say.... Hmmm. ..." They have money...why do they bother taking such a child to school ? " So they feel we are wasting money. We are wasting time to take Damia to school. But with our experience we realize that it is the only way we can try to keep this boy, at least in a place where he can enjoy life with other people with the same problem".*

Social opinions similar to this pose a major challenge to and could influence the educational path. It is also reported that people who see the CWDB look at them with excessive curiosity, which may embarrass some parents and make them hide the children, yet hiding children prevents interaction and creates limitations in learning.

Amaral (2003) argues that the lack of initiative in research in this direction is partly because it is thought that these children cannot be taught and cannot develop. Researchers` opinion is sometimes biased by attitudes and opinions encountered. Such attitudes may add to the assumption that research in this area is insignificant. Limited knowledge which results may add to the vicious circle of barriers to learning among CWDB.

Financial constraints

Best (2007) advocates for the need for financial support for families with CWDB. In this study, most parents reported that they were experiencing financial difficulties. In one case, Basa (Father 2 interviewed on 10/4/2010) said that the most serious problem he faced was transporting the child from home to school. He needed to transport the child in reasonable comfort together with his personal assistive devices which proved too costly. Circumstances like these made education difficult. The child could also not eat the food provided at school. The parent tried to meet the challenge of poor appetite by taking food to school through a long distance, but this was too demanding and he soon gave up, making the child's stay at school short lived. The child could not eat school meals, in addition to getting limited attention from teachers. These are his own words.

> *"It may be difficult, the child was defeated to be educated in the school. It was difficult because he could not eat the staple food in the schools. Then, the teaching itself. He could just want someone to be close to him so that he can learn something. It means one teacher to a child. So it is actually very difficult. So the administration of the school advised us to keep the child at home so that the teachers can come and visit him and at least see how he can go about it."*

Unfocused Policies

At the centre of all the other barriers to education of CWDB, is the policy issue. Drescher (2003) asserts that deafblindness is yet to be recognized as a separate disability. One parent in this study also pointed out that the government paid attention to PWDs in general, but did not focus on deafblindness. He emphasized that the government needed to be made aware that these children needed special education. Another parent even wondered whether parents should throw CWDB away if the government was not interested in them. Lack of specific policies to address education for CWDB meant shortage of resources including teachers, as had been the case in this study. In conclusion, both the literature which have been cited and the many examples in this study indicate major obstacles to the path to school for CWDB as a result of lack of focused policies. Basa (Father 2 interviewed on 10/4/2010) said the following:

> **Interviewer.** " *So how has the disability affected his education?* "
> **Respondent.** ". *It has affected it very much.* "
> **Interviewer.** " *How? For them, they say that ... ".disabled children...10 of them to a teacher". But you cannot handle 10 children with deafblindness as one teacher. Can you? That is the policy which is there. Yes, so as far as education of deafblind, the government, I don't think is aware. The government needs to be made aware that even these children need education. Hmm...whichever type of education...but they need it.* "

4.4.2 Mitigating issues on education of the CWDB

Although not mentioned in the literature reviewed, a few positive points on the education of CWD emerged during the interview. A father pointed out that the school administration welcomed the CWDB because at the school, there was a deafblind unit and there was hope that the child would learn some skills. According to this father, the teachers appeared to see the child's potential to learn. They developed plans for him to learn, including washing, dressing and self-help. He also reported that the teacher came home frequently and tried to assist him from there. This was reported by Basa (Father 2 interviewed on 10/4/2010) as follows:

> "*Yeah, the teachers have plans of making the child learn some skills for example, washing, dressing and those self-help skills. .....They started doing it here, the teacher comes here.*"

Help was also received from a few donors, for example Rotary International gave the disabled child a wheelchair and it was found out that in 2 years, the child got 2 wheelchairs. Home visits by the teachers and donations by NGOs are examples of mitigating circumstances.

4.4.3 The impact of the load on siblings of CWDB

This section reveals how the schooling paths of the siblings without disability was affected by the presence of the CWDB in the households.

Caretaking Responsibility and Time Wastage

Banta (1979) and Heller et al. (1999) in Moore (2006) raises the issue of the effect on the child of having a SWDB. In this study it was found out that caretaking responsibilities and living with such a child can be an obstacle to the educational opportunities of the sibling. It was reported that too much time was spent by the siblings in caring for the disabled child and that living with a SWDB was generally difficult. A case in point was when the boy Kada (Brother 4 interviewed on 1/6/2010) lamented that it was difficult to live with the sister with disability because he was spending much time looking after her. The difficulty was reported this way:

> **Interviewer.** " *How long does it take you to take care of her?* "
> **Interviewer.** "*Does she take long time or short time?* "
> **Respondent.** " *She takes a long time.* "
> **Respondent.**" *In case she is in bed, I wake her up, wash her face, and look for her dress and then dress her up. If there is tea in flask, I gave her and food. Q. So is that short or long time?* "**Respondent.** " *Its somehow long.* "

Karo (Father 4 interviewed on 1/ 6/2010 provided more evidence of interruption with school attendance as follows:

> **Interviewer.** "*When she is going through such conditions, how does it affect other children?* "
> **Respondent.** "*At times and on some days they don't go to school because they have to care for her as their mother also tries to prepare food and some other domestic work to see that at least we get what to eat when one of her sisters/brothers has remained to look after her*".

In relation to feeding and time wastage, one girl reported feeding the sister with disability, bathing her and washing her clothes. So, the extra time which could have been spent on school related activities was used up in caring for the sister. A parent also said that when the sibling ate, they had to serve the disabled child first. However, considering the needs of the disabled child first, may be a reflection of poor use of the siblings' time, which may also include loss of reading time.

A brother also complained that the disability of his sister affected him by reducing his time for reading books. He emphasized this by adding that the sister needed even more time when she was sick, yet this was the same time he required for doing his school work at home. So, he had to leave his books and attend to her. Another instance was when a brother said with a disappointing tone that the challenge he had was the need for a lot of time for study, but which he did not have due to caring for the sibling.

Many other examples not listed here implied that the siblings of the children with disabilities were emotionally affected by the caretaking assignments. Being unable to effectively attend to school related activities was the highest cost of the care taking responsibility for these siblings.

Parents also acknowledged the contribution of their other children. For example, Kasa (Mother 5 interviewed on 8/7/2010) recalled that she was always away and could even leave her CWDB under the care of the siblings to go to the garden and for retail business. On returning, she always found when the siblings had given the CWDB food, washed his clothes and bathed him. That they even interacted with him though he could not walk and brought him objects to play with. These were her words:

> "*They have helped me especially my children, since I am always away. I can even leave my child here and go for garden work or retail business, but I find when they have given him food, washed his clothes, bathed him up and even try to take him around since he can't see and walk, you find that they have brought objects like jericans to play with while banging so as not to be bored.*

Parents reported that the contribution by family members, especially children was considerable. However, there was no degree of limitation to this contribution, but the danger of loss of reading time, which could result in poor performance at school. Another mother Namasha (Mother 4 interviewed on10/4/2010) said the following:

> " *Still my other children help me out and very much like feeding him, shifting him to other places, bathing him and cooking food, and dressing him up.*"
> **Interviewer.** " *How long does it take her to take care of the child? The way you would look after this one is not the same way you would look after others.*"
> **Respondent.** " *Still it takes a lot of time to cater for her compared to this one. You may only identify and realize that she wants to ease herself and you take her.... Afterwards you need to bathe her, wash dresses and even change the dressing as well as organizing where to place her. Therefore it takes a lot of time.*"

It could be argued that for such a child, having to spend much time with the sister with disability at that formative stage of her own life implied giving away her opportunity for personal development, especially education. Emotional problems and time wastage in such instances may hinder successful learning.

Fulfilling Financial Demands

At financial level, one boy said with deep concern that he had tried to get some money to take the sister to the hospital whenever she was sick. The boy also contributed by working for some money to buy food for the sister. The extra time used in looking for money wasted his study time. Another boy reported that the disability of the sister affected his education by reducing the amount of money spared for his school fees. One girl complained that the disability affected her education because the money for school related expenses was spent on buying a wheelchair and other equipment for the sister with disability. Parents too agreed that the disability of their children affected the education of their other children without disabilities. Peka (Father 1 interviewed on 21/11/2009) said:

> "*In the times when we used to go to traditional healers we could spend much on her, instead of paying school fees for them. They could ask for 60,000/- others 70,000/- and we could give in, thereby making the other children sit at home and not go to school, due to lack of money spent in useless and unproductive ventures that could not even heal her. They could sit at home for some weeks and even miss studies. So since then we stopped it.*"

Another parent Babilo:(Mother 2 interviewed on 10/4/2010) added:

> "*Yes, it affects them, because when Damia was at school, we saw or met no problems.* So *it affects us especially in terms of fees for these children, instead of paying for them, you end up spending it on Damia.* "

4.4.4 Moderation of the disability load

Whereas the negative impact of the disability load on the educational path of the siblings is well highlighted, some members of the households revealed a few positive aspects associated with the load. These positive aspects provide disconfirming evidence, and are difficult to overlook. In one case it was stated that the condition of the child did not affect the other children. In another, a father pointed out that as long as he was still alive; he vowed to make sure that the disability of the son did not affect the other siblings. This shows that in some cases parents made all efforts to cushion their children from the effects of sibling's disability. Basa (Father 2 interviewed on 10/4/2010) said:

> *"We made sure it didn`t affect them. Because we are still around, the others went to school and I had to take the child there myself."*

In one household, it was reported that there was no serious effect of financial demand caused by the disability on the education of the siblings, as they were treating the children equally. The family planned for the child with disabilities in the same way as they did for the rest of the children financially. Kasa (Mother 5 interviewed on 8/7/2010) said this:

> *"No. Because in case you have some money, you prepare for him in the same way, you would plan for the rest. ...he is not like others and so you have to get him more requirements than other children. So it does not affect them so much."*

Kasa`s reason was that all the children were equal. However, despite the positive points raised by parents, there was a relatively large transfer of resources from the other children in order to care for the child with disabilities. So, the positive argument by parents may have been more of a moral issue.

4.5 Gender Differences in the Dimensions of the Disability Load on the Schooling Path of the Children in the Household

The previous section revealed how the disability load impacted on the schooling paths of children with and without disability. The following section examines gender differences in the dimensions of the disability load on the schooling path of the children.

4.5.1. Effect of disability Load on the Schooling Path of the Girls

Reports showed that the girls cared for their SWDB by feeding them, putting them in bed and playing with them, before they slept. In addition to the above duties, the sisters appeared to be responsible for giving them food. However, even this must have been frustrating and consumed their educational time, because it was done regularly. In one case, it was emphasized that the sister helped more than the brothers by cooking for and feeding the brother. Further reports that the sisters of a CWDB helped in bathing the sibling and washing her clothes reveal that their school time must have been taken away. The extra time for school related activities was used up by the care taking. In addition, the sister helped their disabled sibling to exercise to enable him walk. This was ascertained by Kasa (Mother 5 interviewed on /7/2010) as shown:

> *"They help in bathing him, getting him what to eat, laying him in bed, and to interact with him in terms of games and all the like."*

However, one account stated that the boys helped less, meaning that the burden of care was left mainly to the mother and the sisters. In such a case, a lot of the sisters' time must have been taken in caring for the sibling. For the young girls, attending school and caring for their sibling was very demanding: the care consumed the time that could be used for school work. The dimensions of the disability load for girls were emotional and social.

4.5.2 Effect of the Disability Load on the Schooling Path of the Boys

Just like the girls, in some instances boys too cared for their SWDB. It was reported that one of the boys had to sleep next to his brother with disability so as to monitor him as he slept. Sometimes the brother even soiled himself in bed at night. This boy having to watch over and change his SWDB even at night had some negative emotional impact on him as he was a pupil. He must have had disturbed sleep as he had to be alert throughout the nights. During the day the boys played with their brothers with disability, got them to stand and walk and gave them food. In one case, the boy took care of sibling with disability by ensuring that his temperature was not high. This must have robbed him of his time and energy for school work.

A lot of time spent in caring for the SWDB continues to be a common issue and adds to the emotional dimension. This was evidenced by a brother who complained that looking after the brother with disability took too much time. 'Taking too much time ' showed negative educational implication on him.

Furthermore, boys were reported to take the child with disability to relieve himself, get him water to drink and give him food that they had prepared. This was a continuous caring input which interfered with the boys' time for school related activities. In addition, taking this SWDB to ease himself whenever he was uncomfortable must have been disgusting, especially with the older CWDB. This disgust and the resulting frustration might in turn have interfered with these boys' concentration on school assignments.

Another brother was said to carry his sister when she would start crying, shift her to another place and hold her till she kept quiet. He also fed her whenever she was hungry. This meant that he took full care of her whenever the two were together. However, though this contribution was worthwhile, it was time consuming and so must have used up his time for school related activities.

Yet another brother used to put his sister on a wheel chair, moved her around slowly and took her to nearby places wherever he was going. While another helped with exercising the sister with disability. When she got tired and started crying, he consoled her and put her to rest. These were demanding tasks which must have interfered with the boys` education. Another brother reported that he prepared for the sibling with disability something to eat. However, the time used for this preparation, could have also been needed for school work.

In another report it was stated that a brother used to wake up his sister with disability, washed her face, looked for a dress for her and dressed her up. He also fed her. To him all this took a long time. Other boys reported that they related to their brothers with disability by feeding them. One boy added that he struggled to support the household financially by performing manual jobs to earn some extra money which he used to care for the sibling.

As in the case of the girls, the many contributions of the boys in caring for the sibling with disability also took time for school related work and their learning must have been affected.

Josa (Brother 2 interviewed on 20/4/2010) gave evidence as follows:

> **Interviewer.** “ *How do the boys help with looking after him?”*
> **Respondent.** “ *The boys, especially playing with him, getting him to stand and walk, giving him the food, like that”.*
> **Interviewer.** “ *Now to look after your brother, how long does it take you?”*
> **Respondent.** “ *It takes much time.”*

The dimensions of the disability load for boys were emotional, social and economic. They all affected their schooling path.

4. 5.3. The common effect of Dimensions on the Schooling Path of Girls and Boys

The previous section indicated the differences in dimensions between girls and boys. This section indicates the similarities. A number of instances indicated that both boys and girls contributed equally to the caring for the SWDB. A mother said that the time spent by various members of the family in the caring was the same between the girls and boys. She failed to break down the time spent and said that it was ‘equal’, attributing it to whoever was at home. These dimensions were both emotional and social. The equality of dimension of contribution may mean that both girls and boys shared the responsibility of caring and therefore lost equal time for learning. One reason for her saying that the time was ‘equal’ could have been because their contributions towards caring for the child depended on whoever was near the child. Another reason could be because she did not want to downplay the contribution by the other members of the family. She further reported that in the evenings, she inspected and monitored the way the CWDB had been fed by the children. She used the word ‘children’ but not ‘girls’ or ‘boys’, probably to emphasize the fact that these roles were not assigned to any specific gender. Since the roles were more or less similar, the impact could be the same.

A mother reported that she instructed the siblings to wake up the CWDB. According to her, this was their responsibility regardless of gender. She also said that each day she left the CWDB with them. Another mother reported that her children helped to clean up the place. This contribution was time consuming for both the girls and the boys, and took away school time from both sexes.

It was also confirmed that the girls did the same things as the boys such as demonstrating love and care for the SWDB. This was a strong sign of acceptance. One boy said that both girls and boys helped mainly by exercising the CWDB. This shows that both girls and boys sometimes played similar roles an indication that the impacts are difficult to distinguish.

This was evident in Kuda's (Brother 4 interviewed on 29/5/2010) response below:

> **Interviewer.** " *What about girls? How do they help her?* "
> **Respondent.** *"They also do the same activities like what the boys do".*

4.5.4 Summary

As pointed out above, a number of gender differences on dimensions of the disability load emerged. However, the differences were found to be minor because in many households the boys played similar roles as the girls. Depending on the age of either sex in any given household, roles were easily taken over by the opposite sex. Playing of roles therefore influenced the schooling path.

4.5.5 Conclusion from the Findings

The findings of the study indicate that households hosting CWDB experience the disability load. This load has five dimensions which include the emotional, educational, communication, social, economic and policy. Each of these dimensions interferes with the quality of life and the schooling path of the children in the households. There were no major differences in the way the dimensions interfere with the schooling path of the boys and girls. Before this study, there was no framework of action for intervention into the disability load. This study enabled the generation of a framework of action.

4.6 Deconstructing the Disability Load: A Conceptual Framework

Objective Five of the study was to develop a conceptual framework to enable intervention. The subsequent sections now demonstrate how this was finally achieved. In this section, sorting of categories and selective coding have been used to uncover the conceptual framework, (Strauss et al. 1990) and (Jones & Alony 2011). The various steps of how this was done are presented. The concept of theory and how it is grounded andits relationship with the conceptual framework is also reconsidered. The Disability Load Conceptual Framework which emerges from the deconstruction of the disability load is presented in a diagrammatic form (Cresswell, 1998). It is evaluated and possible application is outlined.

4.6.1 Development of Disability Load Concepts and Evolution of Theory

In much of Chapter Four, data was presented and analyzed and at this point in the study it is observed that several writers acknowledge the fact that in Grounded

Theory approach theory is linked to data. According to (Larossa, 2005); (Sheldon, 1989) and (Cockton, 2007), Grounded Theory method has a potential for generating theory and the developed theory is generated from and therefore grounded in the data. In view of the above, the purpose of any Grounded Theory research is to generate a theory which is fully grounded in data and therefore emphasis of the method is development of theory (Pickard, 2007). Categories (dimensions) are the cornerstones of developing theory (Pandit, 1996). In this study, the categories (dimensions) which were built from the various concepts in the earlier sections of Chapter Four are used in the deconstruction of the disability load and these steps allowed the framework to emerge. These steps are related to the accepted position that the conceptual framework, in this kind of approach, evolves during the research process itself (Goulding, 1999). In this study, the evolution process is displayed and explained in the subsequent table and figures.

Table 2: indicates dimensions (categories) derived from the data, the flow of events that emerge from the categories and how they relate to each other. It shows related impacts, mitigation and possible reversal.

Table 2. Development of the Disability Load Concepts

Dimension (Categories)	Impact	Mitigation	Reversal
Emotional	The household members experienced emotional complexes such as frustration, desperation, conflict, anxiety, apathy, stressful memories, disgust, rejection, isolation, and depression. There was hopelessness and disorganization of family programmes	Provision of guidance and counseling services Strengthening of NGO's that support parents Training in skills for management of deafblindness	Acceptance of the condition Better understanding in management of deafblindness Positive living and better care of CWDB's Improved capacity for productive life in households.
	Parents experienced confusion, helplessness, regrets, desperation, frustration, disappointment, lamentations, dissonant feelings, inner conflicts and disbelief	Strengthening of NGO's that support parents Training in skills for management of deafblindness Provision of guidance and counseling services	Parents are in charge of the situation
	For CWDB's the multiple and severe disability caused rejection	Employment of interveners	Better care for the children
	Siblings experienced embarrassment, regrets anxiety and frustration	Creating contact groups for the siblings Guidance and counseling	Increased confidence among siblings
Educational	The deafblind children experienced limited mobility and transport to school, poor feeding at school, limited boarding facilities and resources	Provision of suitable boarding facilities and resources	Optimum educational facilities for the CWDB
	Parents were discouraged from sending CWDB to school	Guidance and counseling of parents	Optimum education opportunities
	Teachers were scarce,	Provision of	Better attention from

	overworked and had limited skills, resulting in school dropouts	adequate trained teachers and related personnel	teachers and related personnel
	Siblingsspent a lot of time that could be used in school work caring for the CWDB and earning money for caring for them	Employment of trained personnel to take care of the CWDB and train them on basic life skills	More time dedicated to school work by the siblings at home
Communication	Parents were not aware of the importance of communication	Training of parents and teachers on communication skills	Improved communication
	Limited exchange of information by CWDB due to poor reception and reduced motor functions.	Training of residual senses of CWDBs	Maximized use of residual abilities Increased participation in daily life activities.
Social	Poor attention given from the household and the community	Inclusion and participation of CWDBs in plays with siblings	Optimum socialization for household members
	Negative social attitudes	Mounting of campaigns through public media, workshops and conferences.	Increased community awareness of CWDB and better contribution to their development
	Relatives and communities were unsympathetic	Mounting of campaigns through public media, workshops and conferences	Increased community awareness of CWDB and better contribution to their development
	Lack of normal 'give and take' relationship intensified the limited interaction with the environment	Training the CWDB to improve the give and take relationship	Better learning environment
Economic	High costs of maintenance and care interfered with economic progress	Training and involvement of parents in income generating activities	Parents in a better position to fight poverty
	Reduced energy for productive work and wastage of time	CWDB to be taken care of in special boarding schools instead of by parents alone.	Increased income and optimization of education opportunities
	Minimum financial	Persuasion of	Better government policy

	support, advice and material assistance	government to improve financial inputs	on finance
Policy	Lack of specific policies	Persuasion of government to improve education policy for CWDBs	Effective government policies that address the social, emotional, educational and financial needs of the CWDB households
Public awareness	Limited public awareness	Use of public media to increase public awareness	Increased public awareness Greater community input

Diagrammatic Flow of Events

Figures 2-5 indicate the diagrammatic flow of events which build up to the disability load. It is shown in a series of conceptually related circles, including the nature of the disability load, the impact, mitigation and reversal.

Figure 2: The Nature of the Disability Load

This figure reveals, in dimensional form, the complex nature of the disability load. It shows how the emotional dimension (category) is the most central and that it influences all the other dimensions. It also shows how each dimension not only relates to the central (emotional) dimension but also to each other.

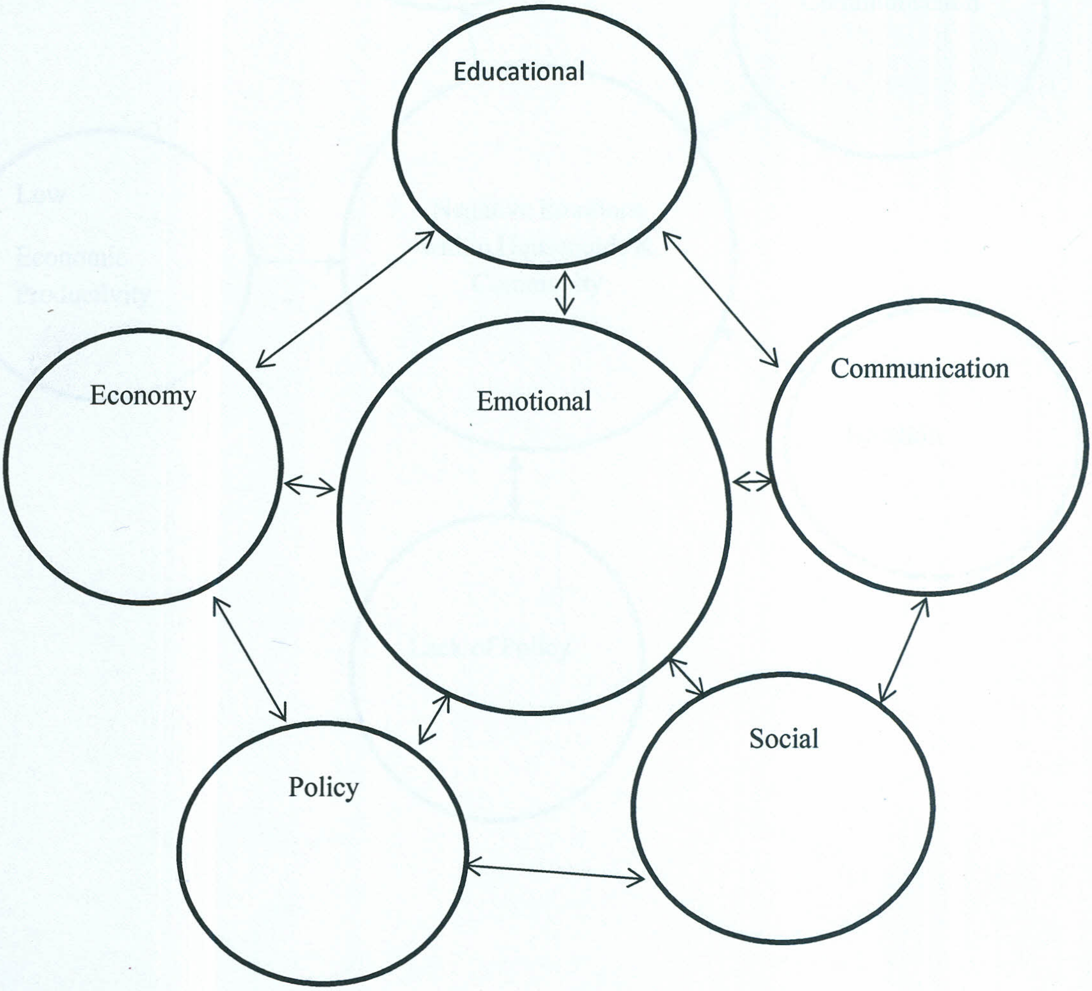


Figure 3: Impact Cycle (Independent Variables)

This figure indicates the central position of the negative emotion as reflected by the findings. Emotions are powerful and have negative impact on the other activities and aspects of life of household members. The negative emotions arise from and are created by other social, psychological, economic and political issues. There is a vicious circle of impacts creating and influencing the disability load.

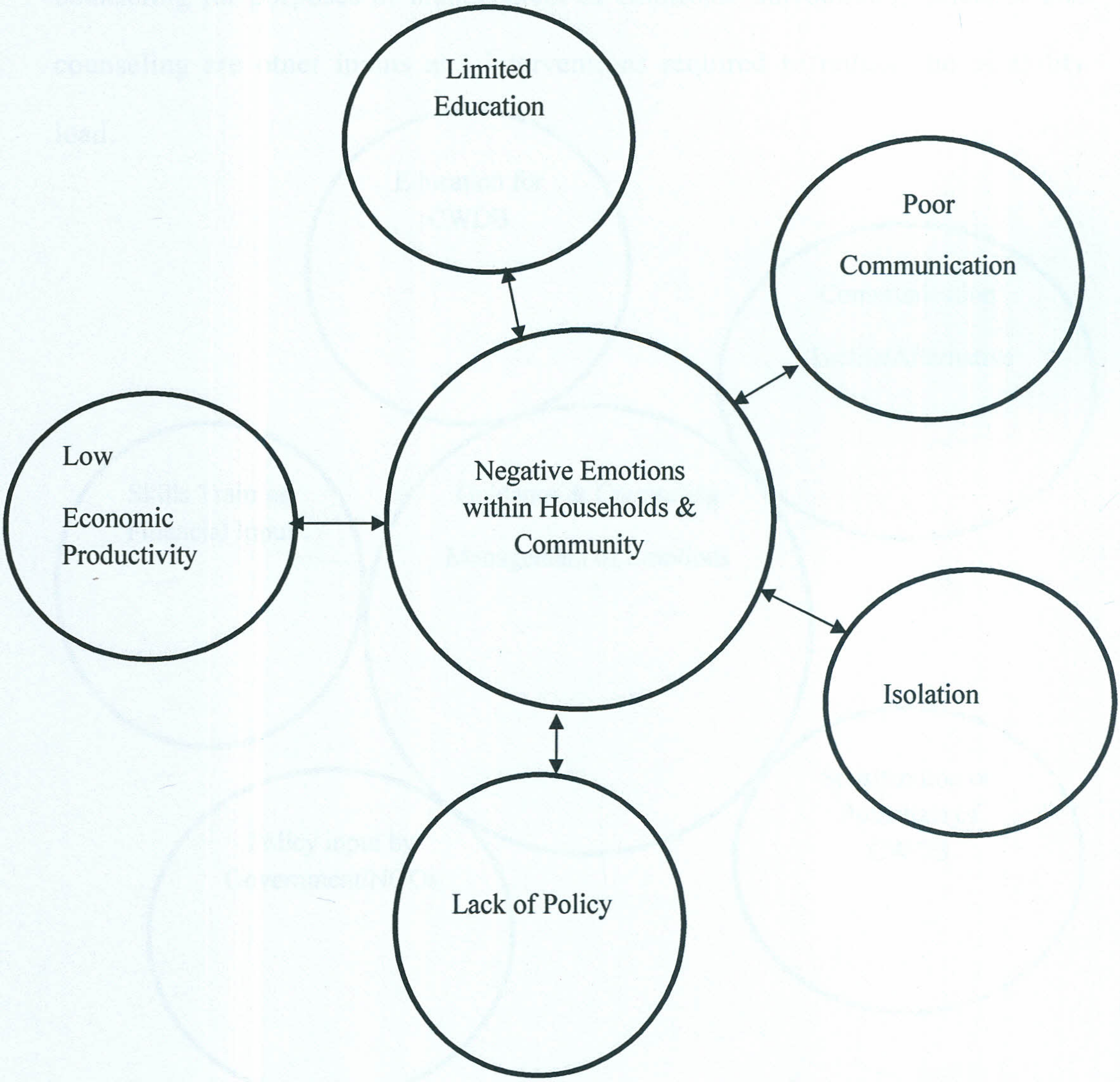


Figure 4: Mitigation Cycle (Intervening Variables)

NB. The mitigation cycle was examined and approved by two Curriculum Developers and Trainers from Faculty of Special Needs and Rehabilitation, Kyambogo University.

The Figure indicates the various interventions (mitigations) which reduce the impact of the disability load. It shows the central position of guidance and counseling for purposes of management of emotions. Surrounding guidance and counseling are other inputs and interventions required to reduce the disability load.

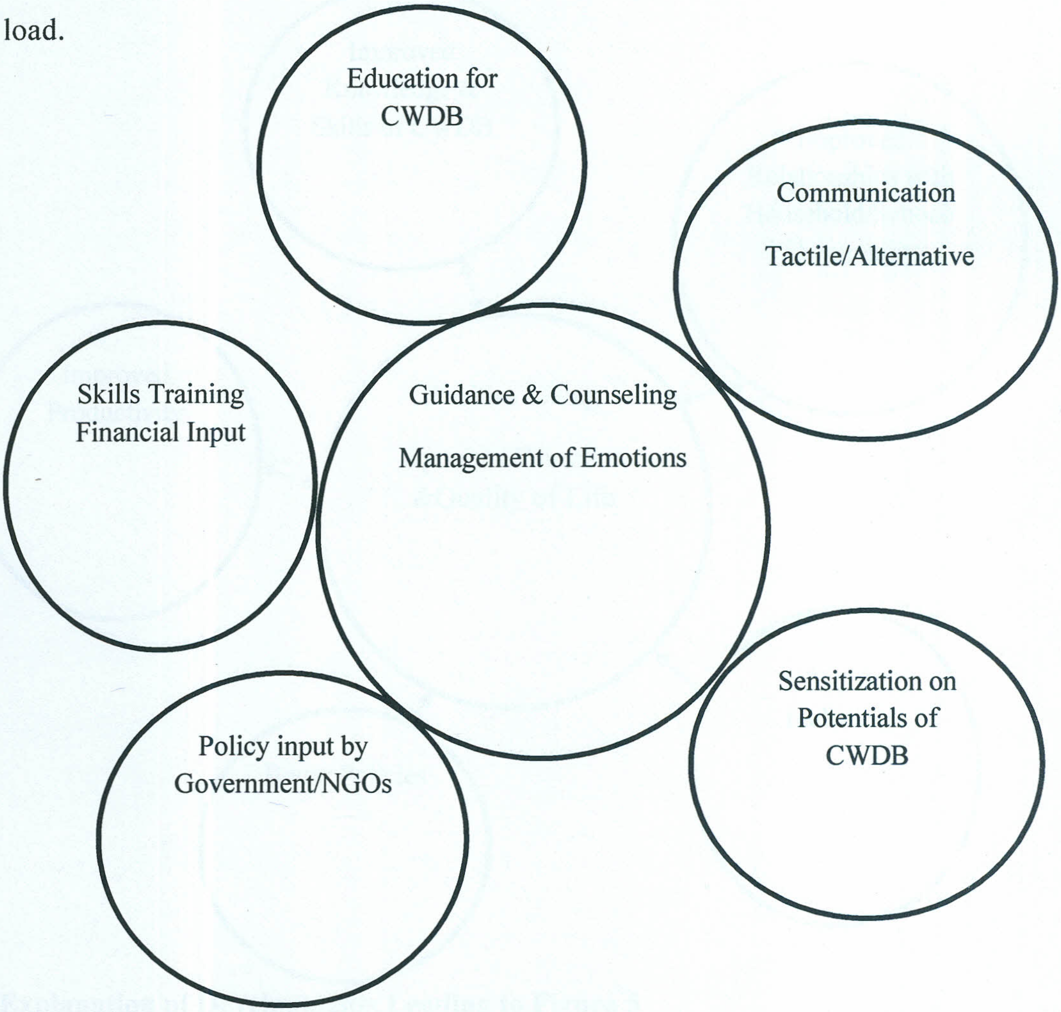
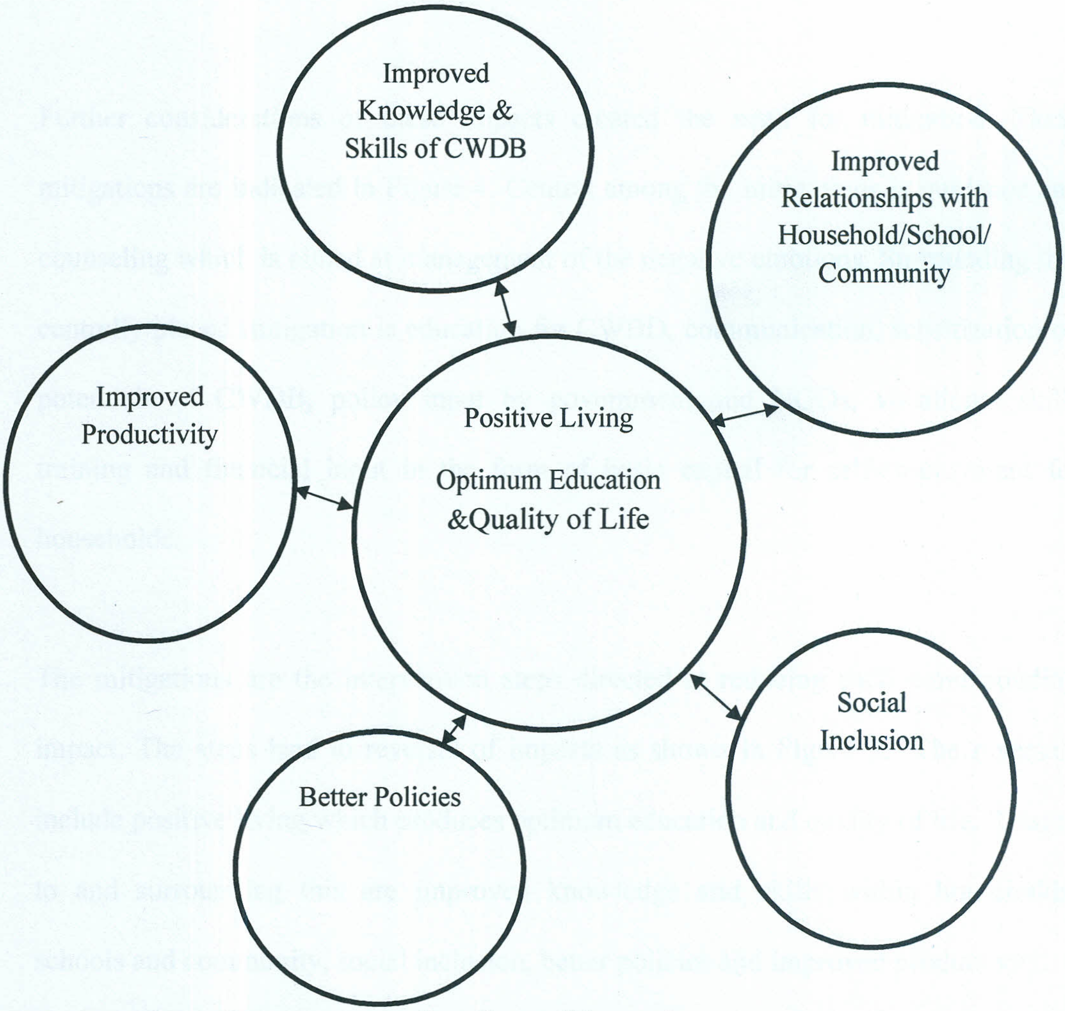


Figure 5: Reversal of Impact (Dependent Variables)

This figure indicates the reversal of impact as a result of various inputs and interventions in figure 4. Guidance and counseling supports positive living providing energy for optimum education and quality of life. The impact of the disabilty load is reversed at this point creating improved knowledge and skills in the household, better relationships, social inclusion, improved economic production and better policies. The overall effect is the reduction of the disability load.



Explanation of Developments Leading to Figure 5

Figure 5 is developed starting from Figure 2. In Figure 2 the dimensions of the disability load which were identified in Table 1 are indicated as the Nature of the Disability Load. These dimensions include the emotional, which is central and is surrounded by the educational, communication, social, policy and economic. Reflections on these dimensions allowed the impacts to emerge in Figure 3. The impacts include negative emotions within the household and community at the centre, limited education, poor communication, isolation, lack of policy and low economic productivity.

Further considerations of these impacts created the need for mitigation. These mitigations are indicated in Figure 4. Central among the mitigations is guidance and counseling which is aimed at management of the negative emotions. Surrounding this centrally placed mitigation is education for CWBD, communication, sensitization on potentials of CWDB, policy input by government and NGOs, vocational skills training and financial input in the form of basic capital for self-employment for households.

The mitigations are the intervention steps directed at reducing each corresponding impact. The steps lead to reversal of impacts as shown in Figure 5. The reversals include positive living which produces optimum education and quality of life. Related to and surrounding this are improved knowledge and skills within households, schools and community, social inclusion, better policies and improved productivity.

4.6.2 Rethinking Theory and Conceptual Framework

The previous sections have displayed the deconstruction of the various conceptual ideas which emerged from analysis of the data and which contribute to the final write up of the conceptual framework. To clarify further how a grounded theory or the associated framework can be developed, it is necessary to rethink the concept of theory, its generation and application as suggested by other writers. The revised thinking is presented in the subsequent write up.

In an earlier report (Strauss & Corbin, 1998) define theory by stating that it is a set of well-developed categories and concepts that are related. They also describe it as a set of relationships that offer explanations of the phenomenon under study (Strauss etal. 1990).

Theory which is based on observation is referred to with a number of names. Glaser and Strauss in 1967 and later Strauss and Corbin in 1990 referred to it as "Grounded Theory" because it is based on observation. Others have referred to it by other names. Merton in 1968 referred to it as Post Factum Theory or Ex Post Facto Theory because the theory comes after the observation and not before (De Vaus, 2007). In this study the "theory" is referred to as a conceptual framework because it is a lower level theory as suggested by Creswell (1998) and a "middle ranged" theory; a phrase used by other writers including Pidgeon et al.(1991). At the same time, the method which has been used more or less suits the grounded theory development approachand which depends on development of concepts. The term grounded theory derives from the word "grounded" i.e. it is faithful to the local situation. The theory does not come from the outside, but arises from the data itself (Pidgeon, et al. 1991). Grounded theory is the theory that is grounded in reality, (Sheldon, 1998). The reality in this work are the experiences of households hosting (CWDB) in the three districts. It is also suggested that, Grounded Theory refers to theory that is developed inductively from a corpus of data (Borgatti, 2007). In this case the corpus of data is the information from the households which are presented in the previous chapter.

Revisiting these terminologies indicate that meanings do change and can be contextual, allowing room for development of ideas. On the basis of this permissiveness, theory in the Grounded Theory context may be synonymous with the conceptual framework as is the case in this study.

Like other writers (Calloway, 2007) observes that the explanation of the phenomenon under investigation is the theory developed from the data. Grounded Theory methods generate conceptual framework from data and because of this the conceptual framework fits the data set (Moghaddam, 2007).

In this work concepts which explain the disability load in households were generated from the data from the three districts. These concepts were used to build dimensions (categories) that are related. These dimensions (categories) were used in the final stages of the write up of the conceptual framework (Strauss et al.1990).

The analysis of data and the subsequent write up, indicate sufficient evidence of relationships between the dimensions (categories) themselves as well as between the concepts and the dimensions which contribute to building of a conceptual framework. These relationships also further explain the phenomenon under study. The phenomena in this work are the experiences in households hosting CWDB and the resulting disability load. Bryant and Charmaz (2007) make the additional point that Grounded Theory approach is by far the most widely used research method across many disciplines and subject areas, including social sciences, nursing health care and psychology. In this particular work, it is applied to disability studies which is multidisciplinary, cutting across social, psychological and educational issues and yet has no theory or even a conceptual framework of immediate relevance to it.

4.6.3 Generation and Application of Conceptual Framework

Proponents of Grounded Theory assert that some of the theories of our predecessors, because of lack of grounding, in data, do not fit, and are not sufficiently understandable to be used in research for theoretical advance and practical application (Glaser & Strauss, 1967). By this position it is implied that theories should and can be generated from data. Generation of theory should stimulate development of a given discipline. According to them such a theory is also easy to understand and to apply to the relevant circumstances. The position of fit, understanding and application is made clearer when one reflects on the relevance of the three theories mentioned at the beginning of the study; the Family Systems, the Cognitive Dissonance Theory and the theory Symbolic Interactionism. Although these theories alert the researcher on some concepts of relevance, they do not explain some issues on deafblindness and are of limited use in disability studies.

As already stated, Grounded Theory approach is the method for theory generation. It is used to generate theories where little is already known about social phenomena

(Charmaz, 1983). When put into use theory helps to explain nursing or other phenomenon (Strauss et al. 1998). The social phenomenon in this study is the disability load in the households. Very little was known about it, creating the need for some theory and therefore explanation. The aim of using the Grounded Theory approach in a study is to understand the nature of human behaviour, by generating theories about social and psychological phenomenon (Chemitz & Swanson, 1986) in (Sheldon,1998).There were behaviours reported in the data early in Chapter Four which were difficult to understand and explain. Grounded theory analysis has made the nature of behaviour more understandable and evident.

The critical issue at this point is that the writers referred to above seem to agree that there is an observable relationship between theory and explanation. In other words theory makes issues which are not easy to understand clearer. In this study it is the experiences of members of the household and the associated disability load that lacked clarity. This study is an attempt to provide explanation using a conceptual frame work or a lower level theory (Creswell, 1998). The data which were collected from the households are used to create or build the conceptual framework.

Sheldon (1998) argues that Grounded Theory approach provides a method for examining social behaviours and enhances practice. It can influence the way practitioners do their work, and allows the gap between theory and practice to be made apparent. In this study, the conceptual framework which has been developed alerts practitioners of the need to do their work better to address the disability load in the household hosting CWDB. The various practitioners are counselors, teachers, therapists and policy makers who have up to now not included or refined their work in relation to CWDB. The conceptual framework will therefore contribute to advancement of practice.

It is further suggested that, Grounded Theory is an emergent research process with some similarities to action research (Dick, 2000) and permits action and interaction to be evident (Cresswell, 2002). The conceptual framework developed as a result of this study will add action and interaction among the various actors and professionals whose work should relate to deafblindness. In a recent study, Weiss & Lynn (2007), developed the Disaster Response Theory to explain disaster response as experienced by Honduran survivors of Hurricane Mitch. In their work the purpose was to generate a theory that explained how survivors thought about the hurricane and the help they received. The Disaster Response Theory as it was labeled is helpful for nurses providing assistance following disaster. The conceptual framework developed in this study may be used by practitioners in this area.

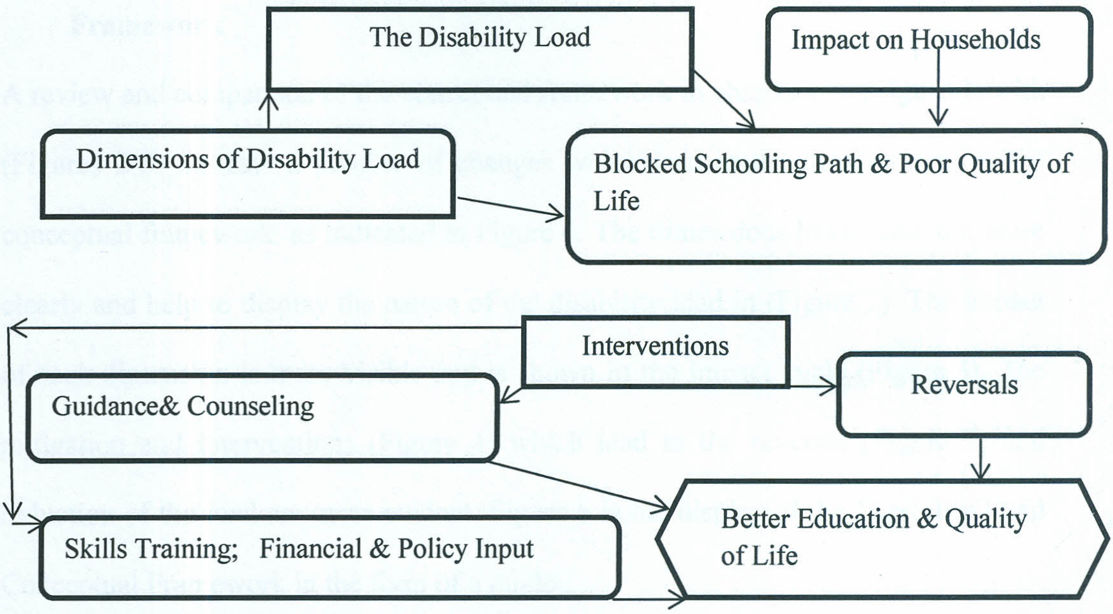
In defense of training in and use of Grounded Theory Glaser and Strauss (1967) argued that graduate students in the social sciences were being trained to confirm the ideas of early theorists, but were not being encouraged to generate theory themselves. This study has provided such an opportunity. In relation to this point of view Pidgeon, et al. (1991) suggests that Grounded Theory aims to develop middle range theories that explain behaviour and processes. The aim of such theories is to understand the associated data and the relationships within it. This argument is supported by Oktay, (2012) who reaffirms that Grounded Theory is used to develop theory and that practitioners need middle ranged theories that are neither highly abstract nor difficult to apply in real life. Using the phrase "middle ranged" they help to make a clear distinction between what has been referred to elsewhere as great man or grand theories, Haig, (2007); Strauss et al. (1990). The three theories referred to in Chapter One are the examples of grand or great man theories. They are abstract, difficult to understand, and lack relevance to disability studies. Their level of usefulness is undermined. This work provided an opportunity for generation of a new middle range theory and distinguishes this new theory from the great man theories. Dick (2000) acknowledges that a middle ranged theory can be discovered by grounded theory method and that such a theory makes a contribution to knowledge. This acknowledgement is relevant to this study and the conceptual framework which has been generated. The views expressed above should allow advancement of knowledge as suggested by Strauss et al. (1990). In this study, the conceptual framework which has been generated from data from the three districts can be associated with such a middle ranged theory. For ease of reference, theories are given names. Weiss et al. (2007) referred to their theory as the Disaster Response Theory. The conceptual framework which has been generated by this study is named the Disability Load Conceptual Framework.

Questions may arise as to how to present such a conceptual framework. Creswell (1998) and (Strauss et al. 1990) suggest that the middle range or lower level theory may be presented in a diagrammatic form. Following these suggestions, the Disability Load Conceptual Framework is presented as a diagram in Figure 6.

4.6.4 The Disability Load Conceptual Framework

Objective 5 required that the study generates a conceptual framework. Figure 6 indicates the framework which was developed as result of the findings of the study using the grounded theory approach.

Figure 6: The Disability Load Framework



Explanation of Figure 6

The Disability Load Conceptual Framework

The Disability Load Conceptual Framework indicates that households hosting CWDB experience a disability load whose central category is emotion. This core category is closely associated with the other categories including educational, communication, social, economic and policy. The disability load has various impacts which interfere with the schooling path of all the children in the households and reduces quality of life. The load can be reversed through various interventions such as guidance and counseling, formation of parents groups, training of parents and teachers, increased financial input and improvement of government policy. The reversal leads to optimization of resources, maximum possible benefits, including education and improved quality of life.

4.6.5 Changes as a Result of the Study and Evolution of the Conceptual Framework

A review and comparison of the conceptual framework in chapter one (Figure 1) with (Figures 2-5) indicate a number of changes which lead to the development of the conceptual framework as indicated in Figure 6. The dimensions have come out more clearly and help to display the nature of the disability load in (Figure 2). The impact of each dimension is more visible and is shown in the impact cycle (Figure 3). The mitigation and interventions (Figure 4) which lead to the reversal (Figure 5) and reduction of the load are more evident. Figure 6 is the display of the Disability Load Conceptual Framework in the form of a model.

The emergence of the conceptual framework has been facilitated through two steps. By reflection on the three theories which were cited in chapter one and review of literature in chapter two. These steps increased theoretical sensitivity during data analysis, strengthened and accounted further for the emerging conceptual framework (Strauss et al. 1990).

Further comparison of the two sets of conceptual frameworks also indicates some similarities as well as differences. The earlier conceptual model in (Figure 1) and the more recent ones (Figures 2-5) both have independent, intervening and dependent variables. However, the framework in chapter one is more general, while this latter model is more precise and refined. It is also more practical, action oriented and relates more easily to the findings of the study as advised by Mugenda & Mugenda (2003).

4.6.6 Putting the Disability Load Framework into Action

Objective five points out the need to use the framework to manipulate the disability load in order to enhance schooling outcome. In order to intervene into the disability load there is need to understand how the framework could be applied to improve the schooling path and quality of life. The five steps suggested clarify in detail how this framework would work in the real world.

Negative emotions emerged as the most frequent of the dimensions. Guidance and counseling services could help manage the various negative feelings common in households due to the disability load. The aim is to create a reasonably controlled emotional atmosphere with less frustration, disappointment, confusion and time wastage. Guidance and counseling could be done through peers as well as professional counselors. This would create a better atmosphere for all household members, and particularly the children, to enhance learning.

Isolation and seclusion of households complicated the negative emotions. NGO's that work with parents of CWDB and contact groups for siblings of CWDB could be established in order to reduce isolation and enable positive thinking and productive activities, including education.

Poverty was found to be a frequent occurrence in the households. There should be training in skills for survival and development of income generating activities to reduce poverty and financial distress within the households. More money would be available in the households for feeding, transport and maintenance at school.

Deafblindness brought in serious difficulties in communication. Speech and communication therapy services could be provided to improve communication of the children and all the household members. Improved communication would lead to better understanding within households, reduction of conflicts, better environment for school attendance and access to the curriculum.

During the interview some parents complained lack of attention from government. Analysis of the data indicated that government policies addressing deafblindness were not ineffective enough to deal with issues related to this particular phenomenon. Strong government policies, along with public awareness are needed to address deafblindness at economic, educational, emotional, and social levels. Using the above measures, the impact of the load on households hosting CWDB would be reduced. General improvement on quality of life would be achieved and gender differences in the schooling path would be minimized.

4.6.7 Evaluation of the Disability Load Conceptual Framework

On the basis of the Grounded Theory approach, this conceptual framework is sufficiently grounded. It obeys the four rules of Grounded Theory i.e. fit, understanding, generalizability and control, as stated by (Kara 2007). It fits the deafblindness in the households hosting the children because it was generated from data collected from such households. It can be understood by the researcher and members of the households especially, during the application. It can be generalized by application at national, regional and international levels with minor modifications (Strauss et al.1990).

CHAPTER FIVE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.0 Introduction

Chapter four presents the findings and compares the findings with the literature review. This chapter is drawn from the previous one. It presents a summary of the findings, conclusions and recommendations as suggested by Bak (2004), Glatthorn and Joyner (2005) and Kenyatta University (2005).

5.1 Summary of the Findings

This covers the research themes which were developed from the objectives of the study. The themes included the dimensions of the disability load, the consequences of the dimensions on quality of life, the impact on the schooling path of the children in the household and gender differences on the schooling path.

5.1.1 Research theme 1: Dimensions of the disability load

Many of the dimensions of the disability load emerged to include the following;

Emotional dimension

This was the most common of the dimensions. It consisted of a number of categories which were in turn built from concepts that emerged from the data (Strauss et al.1990). It was reflected in related concepts like disappointments, conflicts, regrets, anxiety and apathy. Regrets were caused by the severe level of disability and difficulty in caring for the child. Associated with the regrets was lack of sympathy from some neighbours. Conflict and stressful memories as a result of failure to understand the cause of disability also added to the frustration. Parents reported bitter memories of experiences of bringing up the children. Disgust and desperation were frequent and resulted from the inability of the children to control their bowels. They were filthy and hard to live with. Rejection of the CWDB was shown by some of the household members and apathy was evident, as neighbours didn`t feel concerned.

Economic dimension

This dimension involved spending money on the child with disability by paying for services such as health, education, transportation and nutrition. Expenditure by households on medical care involved selling anything valuable. Expenditure on traditional healers was also frequent, though it was more exploitative than useful. Feeding was reported to be expensive: it often involved special foods to meet the selective appetite of the children and at times taking food to school. Transport was expensive because the children could not use regular transport easily because of the severity of their disability. Extra money was paid to take children to hospital and to school.

Communication dimension

The children were unable to express themselves and could only show unclear signs when they were in need of something, including toileting. Poor communication caused problems in feeding, toileting, education and playing with siblings.

Social dimension

This was reflected in many ways including isolation, rejection and neglect by household members, relatives and the community. Some relatives gave no financial support, advice or material assistance. Community reactions were often unhelpful, tricky and exploitative. Some spiritual leaders did not show genuine interest in the children.

Educational dimension

The CWDB needed boarding facilities, but even in the boarding school, they did not get sufficient attention from teachers. They could not remain long at school because there were not enough resources to keep them there.

Policy dimension

There was no specific policy to address deafblindness, and the existing policies were generally weak and inadequate. NGOs filled some of the gaps where government was unable to although even then, the efforts were insufficient.

5.1.2 Research theme 2: Consequence of Each Dimension on Quality of Life

Each dimension of the disability load noted above had an impact on the quality of life of members of the household. The discovery that the children had severe disability put parents in a state of desperation. Demanding situations arose because the children were helpless and could not be left alone. They needed extra attention from the household members. Often these members did not know the needs of the CWDB. The severity of the disability created disappointment, a degree of helplessness, and high expenditure often regretted by household members. The demand for care was disgusting as the children would soil themselves anywhere and often found it difficult to feed properly. For example, food would choke some and they would even vomit while eating.

Households also experienced many financial difficulties related to medical care, feeding, transport and education of the CWDB. Communication was poor and caused misunderstanding, confusion and conflict. Poor communication caused problems in meeting the children`s needs adequately.

There was rejection and isolation of some of the CWDB by family, neighbours and the immediate community, thus good relationship with neighbours and relatives was absent. Some spiritual leaders who were expected to provide support and comfort to the households instead became exploitative of the disability situation. Also the severity of the disability interfered with access to the curriculum and the education of the children was not assured. In addition, help from Government was not sufficient and left parents in difficulties, desperation and confusion. Even help from NGOs was not widespread, proved inconsistent and limited.

5.1.3 Research theme 3: Impacts of Disability Load on Schooling Path of the Children with and without Deafblindness

The findings indicate that there was impact on the schooling path of both the children with and without disabilities and was more direct and profound on CWDB. The summary of the effects are presented:

Impact on CWDB

The disabilities which were multiple, severe and enduring grossly interfered with education. Poor oral and physical communication meant that the CWDB did not have the means of accessing and responding to the curriculum in a meaningful way. Teachers were scarce and overworked, while poor communication reduced the socialization process often required to reinforce learning. Even assistance in the development of communication was difficult owing to limited resources for employing a helper. Poor mobility limited the search for information and knowledge. At school the teacher-pupil ratio could not allow for proper attention needed by CWDB.

There were potentially poor social attitudes which were detrimental to schooling paths. Isolation of households interfered with the schooling paths. Community members had poor attitudes and questioned the expenditure on the education of CWDB. Transporting the children to school was too expensive for households, while feeding them at school was also expensive, making it difficult for the children to stay long there. Furthermore, the lack of policies to address education of CWDB translated to limited resources being allocated for their education.

Impact on children without disability

Caretaking responsibilities and living with a SWDB affected the educational path of the children without disability in the households. They abandoned reading their books in order to pay attention to their siblings. Some siblings had to participate in income generating activities at the expense of school work to look after the CWDB; while other siblings had to help with feeding and caring for them. Parents confirmed that the condition of deafblindness affected the siblings in many ways.

5.1.4 Research theme 4: Gender Differences on the Dimensions of Disability Load on the Schooling Path

Gender differences on the schooling path emerged although the differences were not significant. They are also presented in dimensional form. The major dimensions among girls were the emotional and the social. These dimensions could be seen in various activities which took time for academic work. The activities included feeding SWDB, putting them in bed and playing with them. These were regular undertakings and took more time from the girls. In addition to feeding and bathing their siblings, the sisters also washed their clothes, provided general care and assisted the children with exercises.

The dimensions of the disability load for boys was as follows:- Boys too experienced the emotional and social dimensions. The emotional and social dimension included the following activities; they slept next to the disabled siblings to monitor their wellbeing at night, woke them up, washed and dressed them. They played with, exercised their siblings and trained them to walk, fed them, helped them in toileting, cared for and calmed them. Brothers also put the siblings on the wheel chair, consoled them and moved them around. One boy experienced the economic dimension of the load which involved having to work to earn some money to assist with caring for the disabled sibling. These dimensions like those of the girls also consumed the boys time for academic work.

The common dimensions of the disability load for girls and boys were communication and economic. In some situations the responsibility for waking up the CWDB fell on both the girls and boys equally. Poor communication by the CWDB affected both girls and boys because if they could not communicate well, they all would have to put up with the difficulty arising from poor communication. The effect of poor communication was frustration which could be counterproductive in school work. The economic dimension fell on both girls and boys because money was spent on CWDB resulting to poverty in households. This implied that school expense for all the children in the household was undermined regardless of gender.

5.2. Conclusions

The conclusions are derived from the assumptions. There was a relationship between the assumptions and the findings. The findings of the study agree with the assumption that all households are equally vulnerable to the impact of deafblindness. However, the level of vulnerability was not uniform from household to household. For example, the impact of the disability load was considerably heavier in household three where there was only one child. In that household, the severity of the disability also increased the impact to the extent that the two parents were living apart. The mother of the child was left by the husband. She led a lonely and deprived life with her son with disability. However, even in household one where there were many children, the impact of the disability load was also heavy. The cost of care was more compared to the resources available. This increased the impact on that household. All in all, the severity of the disability, the number of children in the home, whether too many or too few, in addition to the poverty level, increased and made variations in the disability load.

There is further agreement between the findings and the assumption that siblings of CWDB were not uniformly affected from household to household and even within each household. The variables in this were two-fold. They included the age of the siblings and the level of deprivation of the household. Older siblings were taking greater responsibility over their siblings with disability and therefore taking a bigger share of the disability load within each household.

In poorer households, the poverty level meant the small income of the peasant households was shared out and used for medical care, education and general upkeep in the family. Household one provided a good example of the effect of poverty, whereas household, two and five, where the fathers of the children were professional teachers with better income, appeared to manage the disability load better. These two households seemed to be better cushioned against the impact of the disability load.

In all the four households that had both girls and boys as siblings, differences in sex did not create a clear difference in the impact. The possible reason for the lack of clear difference was emotional, social and age related factors. Emotionally all the children were often attached to their CWDB and took the responsibility readily. It was socially because they all felt a sense of belongingness and shared out the responsibility. It was age related because the older siblings took on the responsibility regardless of their sex.

There is another agreement between the findings and the assumption that all households sought ways to reduce the impact of the disability load individually. The individuality was enhanced by the fact that the disability occurred at different times, in different places to different households. They did not therefore have the opportunity to share experiences early. However, all the households generally sought mitigation in different ways. They sought medical care differently. The help from traditional healers and the education was at different times and places. Households two and five were active members of the National NGO for CWDB, whereas the other three households appeared more passive.

The final observation is that the findings agree with the assumption that household members experienced the disability load differently, but most often responded to their needs almost in a similar manner with the aim of meeting those needs. Household members constructed their perception of the situation individually, most likely due to personality differences and expectations of their children. The construction influenced the impact of the deafblindness on them. An example of such a construct and the resulting impact was in household two, where the father took up a course in Special Needs Education with the hope of responding better to the deafblindness of the son. The construction of perception in turn significantly influenced the schooling process of the children. In households two and five the schooling process was influenced through efforts which were made to take children to school. In household one, the teacher was welcome to do home visiting with the aim of reducing the impact of the disability load. In household three and four, education was not given the priority it deserved most likely because of the perception which was constructed by these households.

5.3. Recommendations

Objective five suggested the use of Grounded Theory approach in providing control of the phenomenon under study, (Strauss et al. 1990). Accordingly, the summary of the findings have been used to suggest recommendations that could guide policy, practice and further research.

5. 3. 1 Recommendation for Policy

It was found that the education opportunities for the CWDB were negligible, such that the CWDB could not access school easily and their quality of life was below acceptable standards. The reasons for poor educational attainment were found to be many, but largely due to poor policies and the resulting limited resource input. It is recommended that the Government, through the line Ministry of Education and Sports, and that of Local Government revisit and systematically redefine its policy towards deafblindness with a view of making tangible improvements on the education of CWDB.

The emotional dimension of load borne by the household was found to be the most common. The negative emotions were found to be so destructive that in some cases it destroyed good relationships in the families. It reduced the love that children needed for normal development and achievement including their education. The energy that households needed for development was reduced. At the worst, care for the children, including their education, was at risk. In effect, negative emotions reduced opportunities for investment in the children including in their education. It is recommended that a policy by line ministry particularly Ministry of Education and Sports on guidance and counseling be developed to cover households hosting CWDB.

The communication dimension indicated that children were largely unable to express themselves. This hampered the schooling path. Speech and communication therapy training is currently underway in Uganda. This means that communication therapists will soon be available for employment to assist with communication problems. At the same time, teacher training programmes for CWDB is being developed. Teachers for CWDB are expected to be available in the foreseeable future. The recommendation is that the national policy on development of communication for CWDB needs to be addressed by using the services of these professionals.

The financial dimension of the disability load was among the most important findings. In households, parents especially fathers talked about limited finances against expenses and high costs of caring for the children who needed money for education, medical care, and nutritional services. It is recommended that the Ministry of Gender, Labour and Social Development works out an income generating policy which clearly includes households hosting CWDB.

5.3.2 Recommendations for Practice

When the policies have been developed, there is need to implement them. The findings indicate that the schooling path of CWDB was blocked by lack of trained teachers and related human resources. It is recommended that the Government employs more teachers so that the teacher pupil ratio becomes more reasonable.

The negative emotions lowered the morale of household members hosting CWDB. Practical provision of guidance and counseling services would enable households to deal with the negative emotions and therefore improve chances for educational investment in CWDB. It is recommended that the Government, through the District Service Commission, employs counselors who are competent and knowledgeable on the needs and problems faced by households of CWDB.

The findings showed that communication was a major barrier to the social and intellectual development of the children. It therefore interfered severely with the educational paths. There is need to improve communication for CWDB. More teachers should be trained to teach communication skills to the children at school. Home visiting programmes need to be strengthened for children who cannot reach school. Speech and communication services be made available to households, through the Community Based Rehabilitation Programmes, which were already available in the districts but are not yet of great benefit to the children and households in the districts. It is hoped this will greatly improve the communication of the children, reduce their isolation and improve attachment to school programmes. Quality of life in households hosting CWDB will then be better.

The findings showed that poverty was a barrier to optimum development of the children. It prevented the CWDB from maximizing the educational opportunities and improving the quality of life. It is recommended that the Ministry of Local Government and grass root NGOs involve households hosting CWDB in activities that can help increase their income. Opportunities should be sought for CWDB with moderate disabilities for income generating skills training. At the end of it all, better income will greatly improve the chances for the children securing educational opportunities and improved nutrition.

5.3.3 Recommendation for Further Research

It is suggested that recommendations for further research be based on objectives and findings of the study. The suggestion is responded to as follows;

Dimensions of the disability load

Objective one was to identify the dimensions of the disability load. Analysis of the data found that there are six dimensions. These dimensions included the emotional, educational, communication, economic, social and policy dimensions. It is recommended that further research using different participants be undertaken to verify these dimensions and to try to uncover new dimensions.

Consequences of dimensions on quality of life

Objective two was to find out how these dimensions impact on quality of life. This objective led to the finding that the disability load has impact on quality of life of members of the household in a number of ways. Each of these consequences can be studied separately as indicated below.

Living with CWDB generated complex negative emotions. These negative emotions included frustration, regret, disgust, desperation, apathy and rejection.It is recommended that research be carried out to find out how to minimize the onset of these emotions and prevent them from becoming unmanageable.

The educational dimension showed the children could not easily access educational facilities and once in school the resources they needed including boarding facilities were insufficient. They could not get attention from teachers. It is recommended that further research be carried out to find out how to improve input from teachers.

The economic dimension indicated that households had limited income and yet expenditure on health, transport, feeding and education was too high. It is recommended that further research be carried out to find out how to improve household income for the families.

The communication dimension showed that CWDB were unable to communicate effectively. Poor communication caused misunderstanding, confusion, conflict and limited children`s opportunity for learning. It is recommended that investigation be carried out to find out ways of improving communication with these children.

The social dimension showed that at community level, households hosting CWDB were isolated by relatives and communities. Within the household there was rejection and neglect of the CWDB. It recommended that a study be made on how to minimize rejection and neglect of CWDB within the household and how to change community attitudes towards households hosting CWDB.

The policy dimension indicated that help from government was not sufficient and NGOs were not consistent with their contribution. Such situations reflected poor policies from both government and NGOs. It is recommended that research be done in this area with a view of improving policies to benefit these children. All these studies should be carried out with a different group of participants to enable verification of earlier findings.

Impact of the load on the schooling path

The third objective was to find out how the disability load impacts on the schooling path of the children in the households. The findings were that the disability load impacted on CWDB in the following ways; Poor physical and oral communication resulted in limited access to and benefit from the curriculum. Development of communication was difficult; there was need for a helper. There was poor teacher – pupil ratio and teachers were scarce and overworked. Transport to schools was expensive; community members isolated the household and questioned the expenditure on education for CWDB. Lack of specific policies on deafblindness led to limited resource input.

Impact on children without deafblindness

Caretaking responsibilities interfered with the schooling paths of siblings of

CWDB. It is recommended that further research could be conducted with another group of participants to verify these findings. The research could also be conducted to fill any gaps including improvement of communication, the most appropriate teacher pupil ratio, how to influence attitudes in favour of CWDB and development of policies that can promote education of children in the households hosting CWDB.

Gender differences the impact on the schooling path

The fourth objective was to find out any gender differences in the impact on the schooling path. The findings were that both girls and boys contributed equally to the welfare of their siblings with deafblindness. Both girls and boys cared for the CWDB and lost time for school work. Both gender experienced the emotional and social dimension which affected the educational dimension. Therefore, there were no major difference on impact of the disability load. It is recommended that further research could use different groups of participants to verify the findings.

Generation of Conceptual Framework

The fifth objective was to generate a conceptual framework (theory). The study developed a conceptual framework referred to as the Disability Load Conceptual Framework. It is recommended that further research be carried out with another group of participants to verify the framework and to check the extent to which it can be generalized. Other studies could also be carried out to confirm, extended and modify the framework.

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APPENDIX I

INTERVIEW GUIDE FOR PARENTS OF CWDB

The information obtained is kept Confidential

Theme /Topic	Question	Probes
General Information	Please, tell me about your family.	How many children do you have? How many are girls and how many are boys?
Problems in the child:	Some people say that having a child with disability in the family affects the family in many ways. What has been your experience?	Can you please tell me about the disabled child. How old is he/she? What problems does he have? (Please describe). For how long has he/she had this problem? How did you deal with this problem? What challenges did you meet in trying to handle the problem? Describe how his condition affects the other children? (Emotionally, Socially, Educationally).
Emotional Dimension	How has life changed since the birth of the child with deafblindness? Some people say that children who are disabled often have health problems, what is your experience?	(Please describe). How do you deal with the disability problem? How much time do you spend looking after the child? Describe how the disability affects the other children?

	Please describe the type of problem Tell me about the assistance you get from other people. What experience do you have on feeding the child?	How do other people assist with the problem? How do you deal with any problem that may arise?
Economic Dimension	Some people say it is expensive looking after CWD, what is your experience?	How do youmeet extra costs in looking after the child? How does the extra cost affect the education of older children?
Social Dimension	Some people say it is difficult to get help in looking after the child with deafblindness. Please tell me about your experience.	How do other members of the family assist you in dealing with the disability? What challenges do you experience in trying to get help from family members? How does looking after this child take time from family members? Who in the family spends most time with the child? Who in the family spends least time with the child? Which family members help more with looking after the child? How do the boys help with caring for their sibling with disability? How do the girls help with caring for the sibling with disability? How do other relatives help with caring for the disabled child?

	It is said that the presence of the child with deafblindness may affect the relationship within the family. Please tell me your experience.	Please describe your marital status. How has the disability in the child affected your marriage?
	Spiritual healers and traditional leaders sometimes get interested in disabled children, what is your experience?	Have you ever discussed his/her problems with spiritual leaders? What do they say about him? Have you ever discussed his/her problems with traditional healers? What do they say about the disabled child?
Educational dimension	How has the presence of the disabled child in the family affected the schooling for your other children?	How have you dealt with the situation?
	Some people say it is difficult to educate a child with deafblindness. Please, tell me about his education.	Describe how his disability affects his education.
	Tell me about his experience at school.	What problems does he/she encounter trying to go to school? How do you deal with the problem? What challenges do you meet in dealing with the problem?

		How does his/her education affect the other children? What do his/her peers say about his/her disability? What do neighbours think about the child? What do they think about his education? What does the headmaster say about his disability? What do his teachers say about his disability?
Policy and legislation	Some people say the government does not care about people who are deafblind, what experience do you have with people in government? Tell me about the work of NGO's. Is there anything else you would like to say?	What do people who work in government say about his education? How does the government assist you? How do they help you to look after the child with disability?

APPENDIX II

INTERVIEW GUIDE FOR SIBLINGS OF THE CWDB

Theme /Topic	Question	Probes
General Information **Problems in the child with deafblindness**	Can you please tell me about your brother/sister who is disabled?	How old is he/ she? What problems does he/she have? For how long has he/she had this problem? How do you help with this problem? What challenges do you meet in trying to help with the problem? How does his condition affect you as a child in the family?
Disability Problems	Please, tell me about the Disability problems.	What disability does the child have? How do you deal with the disability? What challenges do you meet in dealing with the problem?
Emotional Dimension	Some people say it is difficult to live with a disabled brother or sister. What is your experience?	How do you help in solving these problems? What challenges do you experience while dealing with the problem?
Health	Describe any health problem that your brother may have.	How do other people help you in dealing with the problem? How do you assist with the feeding the child? What problems do you encounter in helping to feed the child?

Nutrition **Self-care**	Please, tell me about the feeding of this child? Please, tell me about the dressing of the child.	How do you assist in dressing the child?
Social Dimension	Please tell me about the friends you play with. Please, tell me about your sisters/brothers interaction with other people.	What does your brother do as you are playing? How do other members of the family assist you in dealing with his/her disability? How does looking after this child take time from family members? Who spends most times with the child? Which family members help more in looking after the child? How do the boys help with caring for your disabled brother/ sister? How do the girls help with caring for your disabled brother/ sister? How do relatives help with caring for your disabled brother/ sister? Describe the challenges that you meet while playing with him/her? How do you look after your brother/sister? How do you help him/her?

	Please, tell me about the relationship in the family. Please, tell me how church leaders assist.	How does looking after him/her affect you? How does the disability in the child affect the relationship in the family? How does this happen? How does the disability of your deafblind sister/ bother affect your relationship with your friends at home? What do they tell you?
Educational dimension	Some people say that the disability of a brother /sister can affect the education of the other children in the family, what is your experience? Please, tell me about the education of your brother /sister?	How does the disability of your deafblind sister/ bother affect your relationship with your friends at school? How does the disability of your brother/sister affect your education? What problems does he/she encounter in trying to go to school? How do you deal with the problem? What challenges do you meet in dealing with the problem? Describe how that affects you? How does his/her education affect the other children in the

		family? What do the neighbours think about your bother /sister? What do they think about his/her education?
Policy	Please, tell me about your experience with people who are in government. Tell me about the work of NGOs. Is there anything else you would like to say?	What type of assistance do they give him/her? How do they help you to look after the child with disability?

APPENDIX III

OBSERVATION GUIDE FOR CWDB

(It was supported by photographs)

Health status

Nutrition status

Level of deafblindness

Level of care

Dressing

Hygiene

Communication challenges:

Communication with siblings

Communication with peers

Interaction challenges:

Interaction with siblings

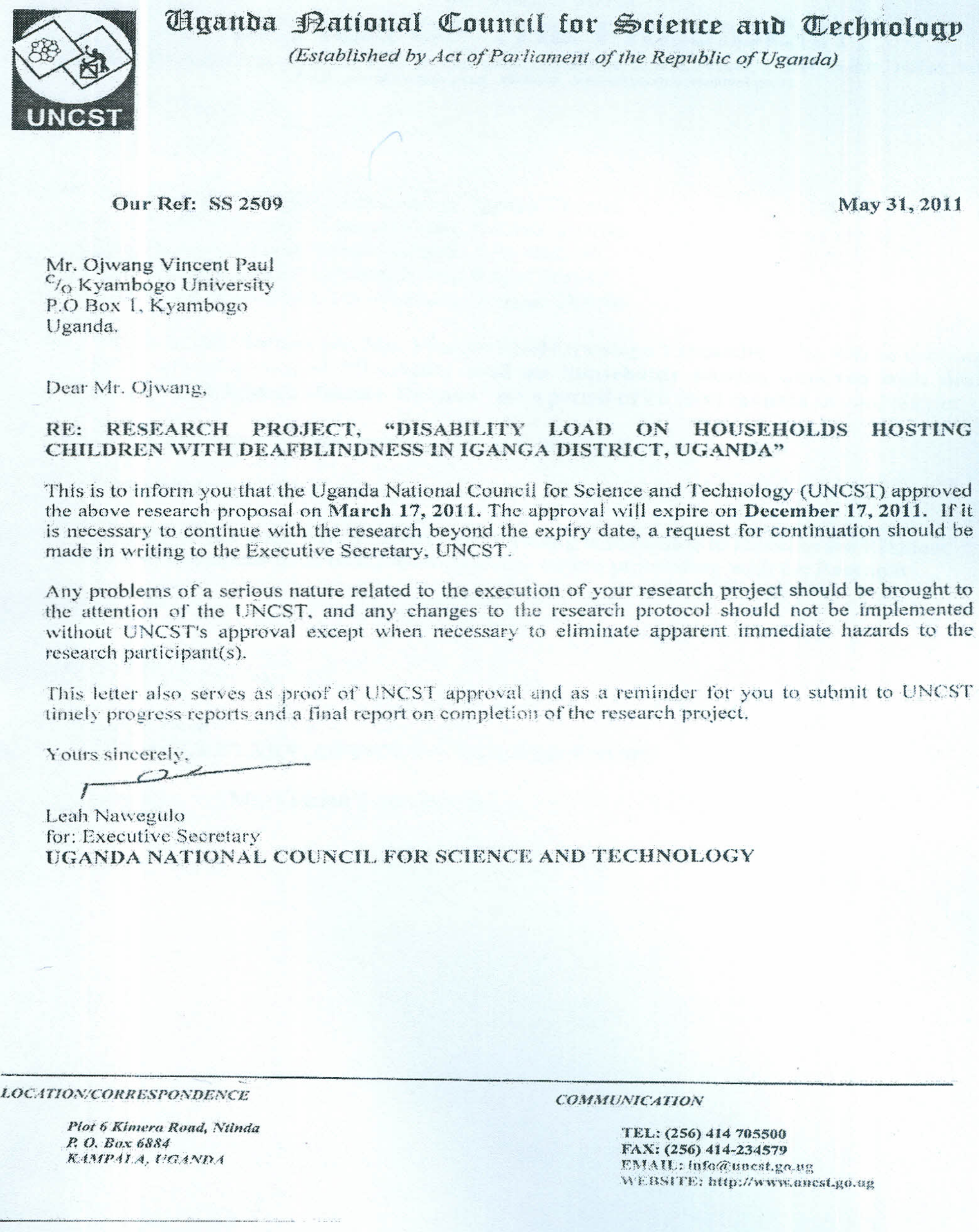
Interaction with peers

APPENDIX IV

MAP OF UGANDA SHOWING IGANGA, MAYUGE & JINJA DISTRICTS

APPENDIX V

AUTHORITY LETTER FROM UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY



Uganda National Council for Science and Technology
(Established by Act of Parliament of the Republic of Uganda)

Our Ref: SS 2509 **May 31, 2011**

Mr. Ojwang Vincent Paul
C/O Kyambogo University
P.O Box 1, Kyambogo
Uganda.

Dear Mr. Ojwang,

RE: RESEARCH PROJECT, "DISABILITY LOAD ON HOUSEHOLDS HOSTING CHILDREN WITH DEAFBLINDNESS IN IGANGA DISTRICT, UGANDA"

This is to inform you that the Uganda National Council for Science and Technology (UNCST) approved the above research proposal on **March 17, 2011.** The approval will expire on **December 17, 2011.** If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST.

Any problems of a serious nature related to the execution of your research project should be brought to the attention of the UNCST, and any changes to the research protocol should not be implemented without UNCST's approval except when necessary to eliminate apparent immediate hazards to the research participant(s).

This letter also serves as proof of UNCST approval and as a reminder for you to submit to UNCST timely progress reports and a final report on completion of the research project.

Yours sincerely,

Leah Nawegulo
for: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

LOCATION/CORRESPONDENCE

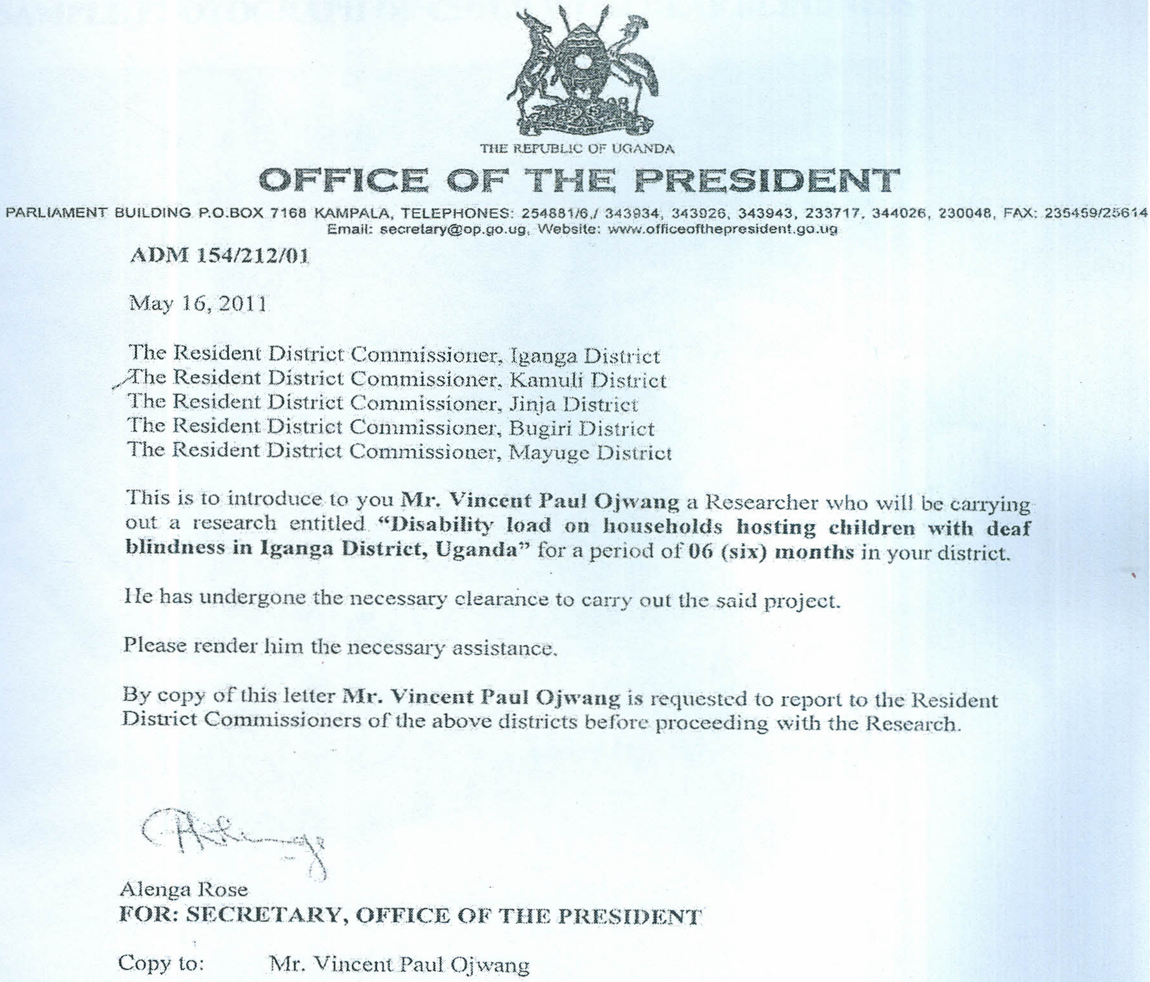
Plot 6 Kimera Road, Ntinda
P. O. Box 6884
KAMPALA, UGANDA

COMMUNICATION

TEL: (256) 414 705500
FAX: (256) 414-234579
EMAIL: info@uncst.go.ug
WEBSITE: http://www.uncst.go.ug

APPENDIX VI

AUTHORITY LETTER FROM OFFICE OF THE PRESIDENT



THE REPUBLIC OF UGANDA
OFFICE OF THE PRESIDENT
PARLIAMENT BUILDING P.O.BOX 7168 KAMPALA, TELEPHONES: 254881/6,/ 343934, 343926, 343943, 233717, 344026, 230048, FAX: 235459/25614
Email: secretary@op.go.ug, Website: www.officeofthepresident.go.ug

ADM 154/212/01

May 16, 2011

The Resident District Commissioner, Iganga District
The Resident District Commissioner, Kamuli District
The Resident District Commissioner, Jinja District
The Resident District Commissioner, Bugiri District
The Resident District Commissioner, Mayuge District

This is to introduce to you **Mr. Vincent Paul Ojwang** a Researcher who will be carrying out a research entitled **"Disability load on households hosting children with deaf blindness in Iganga District, Uganda"** for a period of **06 (six) months** in your district.

He has undergone the necessary clearance to carry out the said project.

Please render him the necessary assistance.

By copy of this letter **Mr. Vincent Paul Ojwang** is requested to report to the Resident District Commissioners of the above districts before proceeding with the Research.

Alenga Rose
FOR: SECRETARY, OFFICE OF THE PRESIDENT

Copy to: Mr. Vincent Paul Ojwang

APPENDIX VII

A SAMPLE PHOTOGRAPH OF CHILD WITH DEAF BLINDNESS