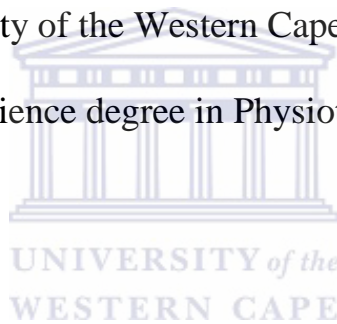


VIEWS AND EXPERIENCES OF CHILDREN WITH DISABILITIES AND THEIR PARENTS REGARDING SCHOOL ATTENDANCE

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A mini thesis submitted to the Physiotherapy Department, Faculty of Community and Health Sciences, University of the Western Cape, in partial fulfillment of the requirements for Master of Science degree in Physiotherapy



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Supervisor: Prof. P. Struthers

KEY WORDS

Education

Children with physical disabilities

Parents

Attitudes

Cultural beliefs

Education barriers



ABSTRACT

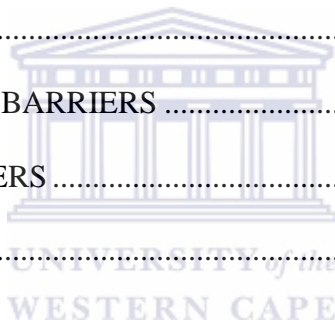
A number of children with physical disabilities are not attending school in Zambia, despite the endorsement of the 1996 by UNESCO “Education Our Future” that provides children with disabilities the right to be educated with their peers in public schools. The aim of the study was to explore the views and experiences of children with physical disabilities and their parents towards school attendance of children with disabilities. The study setting was in Mazabuka, Zambia. The study population was children with physical disabilities who were not attending school and their parents. A sample of 19 participants was purposefully selected. A qualitative approach was used to explore the participants’ attitudes, cultural beliefs, and challenges related to school attendance of children with physical disabilities. A content analysis approach was used for data analysis after translating and transcribing raw data from Tonga into English. The data were coded, categorized and themes of the content identified. Ethical procedures included, obtaining permission from the University of Western Cape, the Ministry of Community Development and Social Services in Zambia and Rural Health Centre. Signed consent from parents, consent from parents stating that their children can participate and assent from children was obtained. Anonymity and confidentiality of participants was emphasized and participants were reminded that their participation was voluntary. Participants had the freedom to withdraw without any prejudice. The results indicated positive attitudes of children and their parents towards school attendance of children with disabilities. The traditional and religious beliefs of parents did not influence or contribute to children with disabilities not attending school. The main reason why most children with physical disabilities were not attending school in Mazabuka district was due to physical and social barriers.

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ABBREVIATIONS

CHIN	Children In Need Network
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disability
CSO	Central Statistics Office
DFA	Dakar Framework for Action
EENET	Enabling Education Network
EFA	Education for All
EOF	Education Our Future
ICF	International Classification of Function
IDP	Interaction with Disabled Person
ILO	International Labour Organisation
MAD	Mazabuka Association of Disabled
MCDSS	Ministry of Community Development and Social Services
MDG	Millennium Development Goal
NGO	Non – Government Organisation
NPA	National Plan of Action
SREOPD	Standard Rules on the Equalization of Opportunities for Persons with Disabilities
UN	United Nations
UNESCO	United Nations Education, Scientific and Cultural Organisation
UNICEF	United Nations Children’s Fund

WHO World Health Organisation

ZAFOD Zambia Federation of the Disabled



DECLARATION

I hereby declare that Views and Experiences of Children with Disabilities and Their Parents Regarding School Attendance is my own work, that it has not been submitted for any degree or examination at any other university, and that all the sources used or quoted have been indicated and acknowledged by complete reference.

Signature.....

Kennedy Born Kauka



Witness.....

Professor P. Struthers

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CHAPTER ONE

INTRODUCTION

1.1 INTRODUCTION

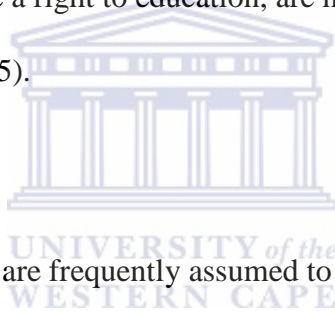
Out of all children with disabilities worldwide, only two percent of children with disabilities are attending school (UNESCO, 2003). Such discriminations of children with disabilities from school attendance hinders community and national development. It is a pity that children with disabilities are stigmatized from the time they are borne through exclusion, concealment, institutionalization, abuse and abandonment (UNESCO, 2009). It is reviewed that 98% of children with disabilities did not attend any form of education world wide by the year 2009 according to UNESCO report. Rousso in UNESCO (2003) report reviewed the lack of education among girls with disabilities as “double” discrimination for as most girls are discriminated from attending school (UNESCO, 2003). According to Rousso, negative attitudes towards women and girls compounded with negative attitudes towards disability contributed to children with disabilities not attending school (UNESCO, 2003, p. 3).

Quoting Marco Bristo in International Disability Rights Monitor (IDRM), “fundamentally, problems experienced by people with disabilities stem from the perception that they are not fully humans” (IDRM, 2003, p.1). Hence, children with disability are mostly left out of national planning and implementation of developmental programs such as healthcare and education. Meanwhile, the rights of children with disabilities to attend school are clearly stated in Article 28

and 29 of the UN CRC, which all nations have enshrined into their constitutions for development and protection for every child of that country including children with disabilities.

1.2 BACKGROUND

Literature indicates that a number of children with physical disabilities are not attending schools (Angelides, 2004; Mindes, 2007). From the researcher's experience of working with children with physical disabilities as a physiotherapist, many children with physical disabilities are not in school in Zambia. The question that arises is: how can we take steps towards ensuring that these children with disabilities, who have a right to education, are not left out of school? (Kalabula, 2000; Ahuja, 2000; UNESCO, 2005).



Children with physical disabilities, are frequently assumed to be in frail health and likely to die young. Hence, a child with a disability is referred to as a “little angel” (Groce, 1999). Sending children with disabilities to school, including them in social interactions or preparing them for participation in the adult world seems unnecessary to many as they are considered “not to be real people at all” (Albert and Harrison, 2006, p. 1). Groce (1999) continues by saying that, in many countries, families of children with a disability often anticipate their early deaths, but not their possible survival (Groce, 1999).

Although the vision of *Education For All* (EFA) in year 2000, was extremely broad, the language of “all” has overlooked the issue of children with disabilities and failed to reach the

poorest and most disadvantaged children (Miles & Singal, 2008). UNESCO (1994) estimated 113 million primary school age children are not attending school worldwide and 90% of them live in low and lower middle-income countries. Over 80 million of children with disabilities live in Africa (Ahuja, 2000). The EFA Monitoring Report (2007) estimated that 10 % of children with disabilities are in school (UNESCO, 2007). As long as children with disabilities continue to be excluded from school, the Millennium Development Goal (MDG) of universal primary education for all will not be achieved and the cycle of poverty and education exclusion will continue (Miles & Kaplan, 2005).

Despite endorsement of the “Education Our Future” (UNESCO, 1996), that provided children with disabilities the right to be educated with their peers in public schools, only one in five children with disabilities is in school in Zambia (ZAFOD, 2003). Zambia was among the 92 governments and 25 international organizations to agree on Salamanca Statement (UNESCO) in 1994, with its first declaration as:

“We, the delegates of the World Conference on Special Needs Education representing ninety-two governments and twenty-five international organizations, assembled here in Salamanca, Spain, from 7-10 June 1994, hereby reaffirm our commitment to Education for All, recognizing the necessity and urgency of providing education for children, youth and adults with special educational needs within the regular education system, and further hereby endorse the Framework for Action on Special Needs Education, that governments and organizations may be guided by the spirit of its provisions and recommendations”.

Thus, every country has a responsibility towards the education of children with disabilities as stated above.

The prevalence of physical and mental disability among school-aged children requiring active intervention and specialized services in Zambia is about 10-15%, (Kalabula, 2000). Most Zambian children with disabilities do not attend school, even when the government and local associations provide education facilities (Ahuja, 2000).

Mazabuka is one of the 72 districts of Zambia found in Southern Province, one of the nine provinces with a population of about 1,212,124 out of 11.9 million national wide (Henninger, 2009). The nearest town or city is Lusaka which is the capital city of Zambia that at approximately 147 kilometers away (CSO, 2006). The district has two special primary schools offering free education to children with disabilities with transport facilities that take children with disabilities to school and back at home after classes under the support of the Mazabuka Association of Disabled (MAD) and the Catholic Church. There are other primary as well as secondary schools in the district that accommodate school attendance of children with disabilities. The Association offers education to children on her premises and sponsorship to other children with disabilities in public schools as well as special teachers' training. Unfortunately, the majority of the children with disabilities in Mazabuka District are not attending school (Ngulube, 2008).

The support of children with disabilities 'casually' integrated into schools has become an integral part of the work of community based rehabilitation professionals in other countries (Miles, 1998), but not in Zambia. Miles (1998) suggests that there is need to advocate for the Ministry of Education to develop policy to support children with disabilities going to school, by working closely with children with disabilities, parents and teachers at community level. Miles suggests that where integrated education is considered appropriate, the role of a physiotherapist could be to: “a) raise awareness of the need to integrate children with disabilities into schools, b) identify, assess and refer children with disabilities, where appropriate, c) prepare children with disabilities for school, d) work with people with disabilities in the campaign for integrated education, and e) challenge negative or demeaning attitudes” (Oriel, Pemberton & Urfer, 2005; Miles, 1998). I have observed that, the only time children with physical disabilities meet professionals like physiotherapists is when their parents bring them to attend physiotherapy sessions at hospital or community rehabilitation centers. In Zambia, physiotherapists and community workers are involved in the rehabilitation program of the people with disabilities in conjunction with the Mazabuka Association.

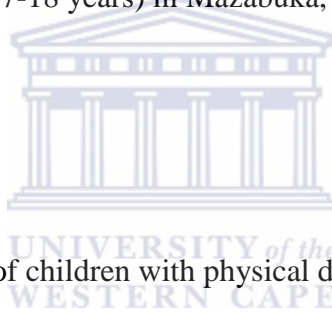
1.3 PROBLEM STATEMENT

Despite the effort and concern given towards educating children with physical disabilities by the Ministry of Education and local associations in Zambia, most children with disabilities are not attending school in Mazabuka District (Ngulube, 2008). Literature does not describe the views and experiences of children with physical disabilities and their parents towards education in

Mazabuka. Lack of views of children with disabilities and their parents towards school attending of children with disabilities contribute to failure of poverty eradication and community development among communities and nations. One of the major implications of lack of views from both children with disabilities and parents is that the policy makers, government departments and NGO's under-estimate or miss-understand the actual limitations and barriers towards school attending of children with disabilities.

1.4 RESEARCH QUESTION

Why are children with disabilities (7-18 years) in Mazabuka, Zambia not attending school?



1.5 AIM OF THE STUDY

To explore views and experiences of children with physical disabilities and their parents on school attendance.

1.6 OBJECTIVES

To explore the attitudes of children with physical disabilities and their parents towards the child attending school.

To explore the cultural beliefs of parents about children with physical disabilities and the implications for attending school.

To explore the children with disabilities' and their parents' views and experiences of barriers related to attending school.

1.7 DEFINITION OF TERMS

Activity – is an execution of a task or action by an individual, it represents the individual's perspective of functioning (WHO, 2002).

Activity limitations – are difficulties an individual experiences in executing the activity (WHO, 2002).

Barriers are factors in a person's environment. Through their absence or presence, they can limit functioning and create disability. These include physical environment that is inaccessible, lack of assistive technology, negative attitudes towards disability, as well as services, systems and policies that are either non-existent or that hinder the involvement of people with a health condition in any area of life (WHO, 2002).

Body structures – are the body structural or anatomical parts of the body, which include body organs like limbs (WHO, 2002).

Disability – it is an umbrella term for impairments, activity limitations and participation restrictions. This is the definition of the World Health Organization (WHO). Disability denotes a negative connotation of the interaction between the individual (with a health condition) and that individual's contextual factor (environmental and personal factor) (WHO, 2002). According to Edmond (2005, p. 2), "disability is the outcome of the interaction between a person with

impairment or health condition and the negative barriers of the environment. It is the way(s) in which people with impairments are excluded or discriminated against.” Therefore, it is a social and developmental issue (Edmond, 2005).

Environmental factors – these are factors that make up the physical, social and attitudinal environment in which people live and conduct their lives (Edmond, 2005)

Impairment – it is a loss or abnormality in body structure or physiological functioning (WHO, 2002). According to Edmond (2005), impairment is a “characteristic or condition of a person’s body or mind that limits an individual’s personal or social functioning in comparison with someone who has not got that characteristic or condition” (Edmond, 2005, p2). Hence, it is an individual issue. For the research purpose, impairment is refers to body structure.

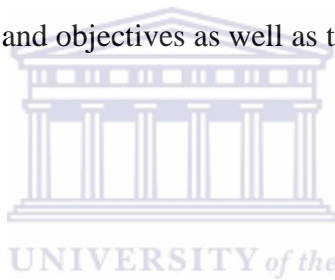
Participation – is a person’s involvement in a life situation as it represents the societal perspective of functioning (WHO, 2002).

Participation restriction – is a problem an individual experiences in involvement in life situations. The presence of a participation restriction is determined by comparing an individual’s participation to that which is expected of an individual without impairment in that culture or society (WHO, 2002).

1.8 OUTLINE OF THE THESIS

Each chapter of the research study is summarized, describing the main issues being presented.

Chapter One introduces this study on the lack of school attendance among children with physical disabilities in Zambia. It also reviews the vision of EFA which was introduced in 2000 and the endorsement of Education Our Future (EOF) that was introduced in 1996 by the Zambian Government to support the education of children with disabilities. The problem statement, research question, aim of the study and objectives as well as the significance of the study is presented.

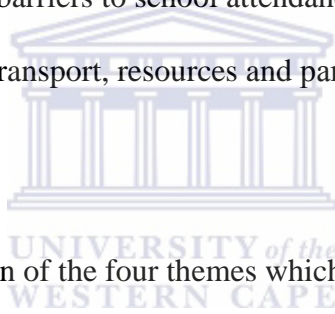


Chapter Two is an overview of the literature on disability, prevalence of disability, rights of children with disabilities, education for children with disabilities and factors that influence school attendance of children with disabilities, i.e. attitudes, cultural beliefs and barriers related to school attendance. Attitudes reviewed are those of parents with children with disabilities, children with disabilities, families of children with disabilities and the community members. The chapter also reviews literature on cultural beliefs of disability as well as barriers such as physical and social barriers towards education of children with disabilities.

Chapter Three presents an overview of the research methodology and application of the study design in order to achieve the objectives of the study. Using a qualitative approach, the chapter

consists of the research design, setting, study population, procedure of data collection, language used in data collection, data analysis, ethical considerations and self-reflection during data collection.

Chapter Four presents the results of the study after analyzing the data. It begins with the demographic characteristics of the participants and the themes that emerged from the data. It uses direct quotations of the participants. Four themes emerged, which are 1) attitudes towards disability and school attendance; 2) cultural beliefs of parents about disability of the causes and cure for physical disability; and 3) barriers to school attendance of children with disabilities such as infrastructure, distance, lack of transport, resources and parents' death.



Chapter Five presents the discussion of the four themes which emerged from the data, basing the discussion on the objectives of the research study in relation to the literature reviewed in Chapter Two. It includes attitudes of parents, children with disabilities and the effects of the family, community members and the government on school attendance of children with disabilities. It discusses cultural beliefs, including traditional, religious and Western medical beliefs of disability. Chapter Five ends with a discussion on physical and social barriers related to school attendance of children with disabilities.

Chapter Six presents the conclusion, summary, significance of the study, limitations of the study and recommendations.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

In order to obtain an overview of the research, Chapter Two will focus on a review of the literature on disability and its causes, prevalence of disability among children, rights of children with disabilities and the education for children with disabilities. The chapter also reviews literature on attitudes of children with disabilities and their parents, family and community members as well as the effects of government departments and NGOs. Cultural beliefs of disability and barriers related to school attendance of children with physical disabilities are reviewed

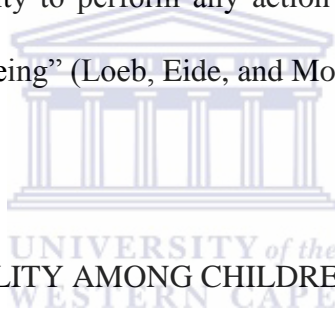


2.2 DISABILITY

According to the UNESCO Report (2007), the choice of words used to identify someone with a disability can either perpetuate negative or positive values. The term “children with disability” is often preferred to “disabled children” in order to emphasize children’s individuality before their disability (UNESCO, 2007). Any loss or limitation of physical, mental or sensory function that is permanent is called an “impairment” according to the International Classification of Functioning, Disability and Health (WHO, 2002). Practically, the World Health Organization (WHO) has classified disability into a multi-dimensional understanding which based on body function and

structure, activities and participation in respect with the level of impairments, activity limitations and participation of an individual (WHO, 2002).

Hence, Albert (2004) in Healthlink Worldwide research argues for a social model that conceptualises disability by asserting that children are disadvantaged by “limitations imposed on them by attitudes, culture, economics, social and environmental barriers instead of the impairments” (Albert, 2004, p. 3). From the Zambian context, following the Persons with Disabilities Act of 1996 which the Zambian Government adopted in 1996, “disability” is defined as “any restriction or lack of ability to perform any action in the manner or within the range considered ‘normal’ for a human being” (Loeb, Eide, and Mont, 2008)



2.2.1 PREVALENCE OF DISABILITY AMONG CHILDREN

Quoting Albery and Harrison in Lessons from the Disability Knowledge and Research Programme, “the lack of reliable statistics has been a major stumbling block to getting governments and aid agencies to understand the real significance of disability as a development issue or its link with poverty. What makes this even more difficult is the failure to agree on what is being measured – the prevalence of particular impairments or the imposition of activity limitation and social exclusion” (Albery & Harrison, 2006, p. 7).

In the meantime, the absence of data on children with disabilities, presents considerable challenges to organizations arguing for a greater political and resource commitment at an

international level to the inclusion of children with disabilities in education (Ahuja, 2001). The inclusion of children with disability remains a question of debate. According to Mont (2007), high quality, internationally comparable data on children with disability for planning, implementation, monitoring and evaluation of education policies is not accessible (Mont, 2007).

Studies done by Peter (2004) and UNESCO (2001) review some discrepancies on prevalence of disability and children with disabilities. A study done in 2001 by UNESCO indicates a worldwide total population of 600 million, with 250 million school aged children (UNESCO, 2001), whilst the 2004 Peter indicates 500 million, with 120-150 million of children with disabilities (Peter, 2004). Such inconsistencies in figures contribute to marginalization of children with disabilities attending school. Furthermore, Peter (2004) has estimated that at least 25% of the entire world population is affected by the presence of disability. The latest estimation of total population of children with disability in 2010 is 200 million (UNICEF, 2010).

UNESCO (2010) report that the prevalence of disability among children with physical and sensory impairments alone is about 2.5% leaving 7.5% with other impairments (UNESCO, 2010). Developing countries has the prevalence of disability among children of about 5%, while developed countries have an average of 10% to 20% (Loeb, et al, 2008). All the variations in reporting the prevalence of disability among children are a result of mitigation factors, which include definition of disability, different data collection methodologies and definitions a of child by different countries (Loeb, et al, 2008).

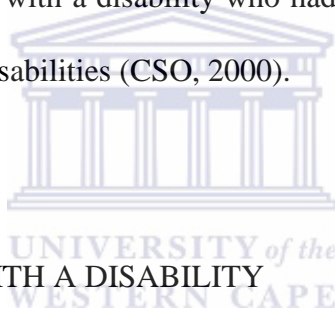
Apart from that, certain countries have reported higher rates of disability for males than for females. In Cape Verde, China, Mexico and Pakistan ratios are ranging from almost equal, one boy for every girl with disability, but two boys for every girl with disability in Egypt, and three boys for every girl with disability in Venezuela (Groce, 1999). According to the Groce (1999), the reasons for this gender disparity may include higher rates of work-related injuries and greater risk-taking behavior among males.

According to a UNESCO (2005) report and Ahuja (2001), Africa alone has 80 million of children with disabilities (UNESCO, 2005; Ahuja, 2001). In developing countries, 50% of all disabilities among children are acquired before the age of 15 years who mostly live in lower middle-income countries (Peter, 2004; UNESCO, 2005). In a World Bank commissioned study, Ahuja (2005) estimated that children with disabilities might account for as many as one in five of the world's poorest, yet they remain absent from most mainstream research, reports, policies and planning, as a result little is known about their experiences and education, except a series of assumptions (EENET, 1998).

Physical disability knows no boundary in terms of time-space, geographical location, social or economic status and age (Kisanji, 1998). Despite lack of up to date data on disability in Zambia, statistics indicate that 7 to 10% or 690, 000 to 1 million children has a disability (ILO, 2009) out of a population of 6,125 000 children (Mulenga, Mulonda and Kamanga, 2007) of which 39% comprises of children with physical disabilities only (CSO, 2000; Kalabula, 2000) out of the 50% population of persons below the age of 19 years (CHIN, 2003).The ILO report indicates

that majority of children with a disability live in remote areas where access to basic services is limited (ILO, 2009). Furthermore, there is every indication that this number is growing due to conditions of increasing poverty, child labor practices, violence and abuse, and HIV/AIDS (Peters, 2004).

These figures are very different from those described in 1990. According to the Central Statistics Office of Zambia's report on disability, in 1990, the country's disability was at 0.9% and in the last census of 2006, the disability prevalence increased to 2.7%. In the Southern Province, the proportion of people with a disability who had a physical disability was 43.5% of which 37.8% were children with disabilities (CSO, 2000).

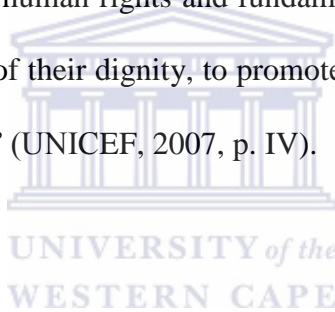


2.2.2 RIGHTS OF CHILDREN WITH A DISABILITY

According to the UNICEF Report (2010) on Promoting the Rights of Children with Disabilities, both children with disabilities and their parents face number of difficulties that stop them enjoying their basic human rights. “Their abilities are overlooked, their capacities are underestimated and their needs are given low priority” (UNICEF, 2010, p. 7). Chapter 15 of the United Nations (UN) Convention on the Rights of Persons with Disability (CRPD) reaffirms the Universal Declaration of Human Rights in Article 25, the Convention on the Rights of the Child (CRC) as well as the Standard Rules on the Equalization of Opportunities for Persons with Disabilities adopted by the UN in 1993. This Chapter 15 declares children have a right to equal access to education and allow parents the right to choose the kind of education for their child.

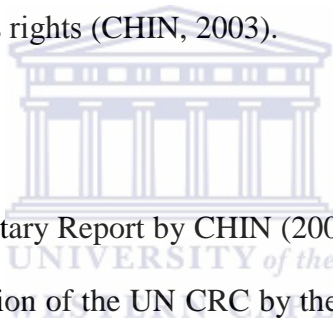
In 2007 Heads of States and Governments gathered to review the rights of the all people with disabilities, including those of children, and a new document with the CRPD was signed (UNICEF, 2007). It was a follow up of statement made by Heads of States and Governments adopted by the United Nations General Assembly held in 2002. At the Special Session on Children, Marta Santos Pais, Director of UNICEF Innocent Research Centre said:

“Each girl and boy is born free and equal in dignity and rights; therefore, all forms of discrimination affecting children must end....We will take all measures to ensure the full and equal enjoyment of all human rights and fundamental freedom, including education, to ensure their recognition of their dignity, to promote their self-reliance, and to facilitate their active participation...” (UNICEF, 2007, p. IV).



All the rights of children to education are enshrined in Articles 28 and 29 of the CRC. Article 28 indicates that all States Parties must recognize the right of the child to education, and with a view to achieving it on the basis of equal opportunity through making primary education compulsory and available free to all and taking measures to encourage regular attendance at schools and reduce the drop-out rate. Article 29 Number 1 indicates that States Parties agree that the education of children shall be directed to the development of the child’s personality, talents and mental and physical abilities to their fullest potential (UN, 2006a)

Despite signing the United Nations Convention on the Rights of the Persons with Disabilities, the Zambian parliamentarians had not yet ratified it by the year 2009 as the ILO launched an initiative on raising disability awareness (Hemminger, 2009). However, in support of children with disabilities, the Zambian government signed the UN CRC in 1990 and ratified it in 1991 (CHIN, 2003). Nevertheless, many rights of children in Zambia have not been attained leaving loopholes for deterioration, as the Children In Need Network (CHIN) Report states. Some of the factors affecting rights of children explored by CHIN were: the existence and practice of certain traditions and customs that tend to negatively affect children; an inadequate legal framework and the weak enforcement of existing laws resulting in unabated violations of children's rights; and widespread ignorance on children's rights (CHIN, 2003).



According to the NGO Complimentary Report by CHIN (2003), following the initiation and first periodic report on the implementation of the UN CRC by the Government of Zambia, only 19% of the entire population was aware of the CRC (CHIN, 2003). The report further describes that CRC, as a core component on the National Programme of Action (NPA), does exist on the District Committees as a document but there is no related action or commitment on a district level (CHIN, 2003)

There are number of factors that influence the attendance of children with physical disabilities in schools. Such factors include negative attitudes and cultural beliefs, physical and social barriers (Kalabula, 2000; Choudhuri, et al, 2005; Eide & Loeb, 2006; Higgins, 2002; Miles, 2000; Preston, 2004). Literature related to these factors is presented in Section 2.3 – 2.5

2.3 ATTITUDES TOWARDS CHILDREN'S EDUCATION

Perry, et al, (2008) define attitudes as a tripartite view, as it can be a learning disposition affecting feelings, thoughts and action. Attitudes of people with and without disabilities can be negative or positive influencing their participation in society. Attitudes are evaluative reactions directed towards a person, object, or event, exhibiting one's beliefs, feelings or intended behavior (Perry, et al, 2008, p. 5). These include the attitudes of families, the community and professionals (Kalabula, 2000; Turmusani, 2005; Kassah, 2007; Shapiro, 2001; UN, 2006b; Beresford, Rabiee, & Sloper, 2007; Choudhuri, et al, 2005; Eide & Loeb, 2006).

2.3.1 FAMILY ATTITUDES TOWARDS CHILDREN'S EDUCATION

Due to societal prejudices, children with disabilities are given less priority than their siblings when it comes to education (Choudhuri, et al, 2005; Kassah, 2007) by their families. Families without enough finance often give priority to siblings of children with disabilities when money for school fees and uniforms is tight. Perhaps the primary reason why children with disabilities are so often not in school, however, is that there is little perception by their families or their societies that they will need an education (Groce, 1999). Apart from that, children with disabilities are not sent to school so as to avoid siblings feelings of guilt, shame, and embarrassment at school or public places (Cullingworth, 2002).

2.3.2 ATTITUDES OF PARENTS OF CHILDREN WITH DISABILITIES

The stress and difficulties parents have coping with children with disabilities have been studied from both positive and negative points of view (Gupta & Singhal, 2004; Ravindranadan & Raju, 2007; Li-Tsang, Yau & Yuen, 2001; Tolor & Geller, 1988; UNICEF, 2002; Elkins, Christina,

Kraayenoord & Jobling, 2003; Masasa, Irwin-Carruthers & Faure, 2005). Unfortunately, numerous studies tend to highlight the negative aspects of having a child with disability. Due to stress, parents develop negative attitudes, which affect the family's self-esteem, burdens the family's emotional resources and coping strategies, interrupts the normal routine of the family, and depriving education opportunities for their children. All these negative effects lead parents to adopt poor coping skills including feelings of guilt, pessimism, hostility, aggression and avoidance (Li-Tsang, et al, 2001). Consequently, parents end-up hiding children with physical disabilities (Agegnehu, 2000), depriving them the right to free education (Rieser, 2008).

Although to a parent, every child is special in his or her own way, a study by Ravindranadan and Raju (2007) indicates that, the initial response of parents and the broader community to a child with birth defects is guilt and embarrassment. Ravindranadan & Raju, (2007) argues that, the birth of a child with a disability, or the discovery that a child has a disability, can have profound effects on the family, which exacerbate negative attitudes. Li-Tsang, et al, (2001) indicate that some children have special needs that challenge parents to find best ways to prepare children with physical disabilities for the future and to handle any problems that may surface. Every parent wants his or her child to be physically and developmentally perfect, including school attendance regardless of the disability the child might be having. However, some children have a temporary or permanent physical or mental disability.

Additional stress is also created due to marital conflicts associated with rearing the child with a disability. There are extra financial burdens to obtain the necessary services, and fatigue and loss of leisure time due to care-taking responsibilities. Added to these is the extent of behavior

problems exhibited by children with disabilities. Negative reactions from others can also serve as a source of stress for the families (UNICEF, 2002). The influence that parents face due to stress may affect children with disabilities and their education needs. Parenting a child with physical disability increases stress in the areas of everyday management of disruptive behaviours, heavy care giving responsibilities, and concerns about the future of the child when the parents are no longer able to care for him or her (Li-Tsang, et al, 2001). Contributory factors to stress include lack of information, mothers' lack of education and negative attitudes among extended family members (Gowramm, 2007). Many parents of children with physical disabilities exhibit negative attitudes towards their children with disabilities. "Most parents are weighed down with feelings of hostility and shame, denial, projection of blame, guilt, grief, withdrawal, rejection, and sometimes, with feelings of acceptance. Some parents also experience helplessness, feelings of inadequacy, anger, and shock whereas others go through periods of disbelief, depression, and self-blame" (Gupta & Singhal, 2004, p. 23). All the stress may result in negative attitudes of parents towards school enrollment of children with physical disabilities.

People in India still view disability in terms of a "tragedy" with a "better dead than have a disability" approach (Gupta & Singhal, 2004, p. 23). According to Gupta and Singhal (2004), Indians think that it is impossible for children with disability to be happy or enjoy a good quality of life, which incorporates education privileges. These attitudes result in children with physical disabilities not being considered for school enrollment in most cases.

Studies show that for both male and female children, those with disabilities are three times more likely to be physically or sexually abused than their sibling peers. Groce and Trasi (2004) indicate that family members, caretakers, attendants and others see children with physical disabilities as easy victims, because children with physical disabilities have trouble in defending themselves and in reporting the abuse (Groce & Trasi, 2004). As a result, families with children with physical disabilities get worried leaving their children with other people, including professionals. This might discourage families sending children with physical disabilities to school (Groce, 1999; Groce & Trasi, 2004).

In Chawama, Zambia, Chakwe (2010) reports how the husband left a mother of five after having a child with a physical disability (Chakwe, 2010). All these problems experienced by parents and their families can influence the decision to meet the education needs of the children with physical disabilities (Tolor & Geller, 1988; Gupta & Singhal, 2004).

2.3.3 ATTITUDES OF CHILDREN WITH PHYSICAL DISABILITIES

Kisanji (1998) in his study of culture and disability: an analysis of inclusive education based on African folklore, cited Miles (1983) contending that, generally, the dominant types of attitudes towards children with disability have progressively changed from “negative, stigmatizing and rejection attitudes, through to pity and compassion, towards willingness to accept children with disabilities on equal terms” (Kisanji, 1998, p. 12). “Looks or appearance” can have a significant impact on the child's perceived value (Dennis, Harper & Peterson, 2001). The stigma children with disabilities experience due to negative attitudes and labelling can have serious consequences

on their self-perception which may lead to poor attendance or performance in school. Substantial evidence suggests that children with physical disabilities often experience hostility, rejection and social uncertainty that hinders school attendance (Dennis, Harper & Peterson, 2001; Rieser, 2008).

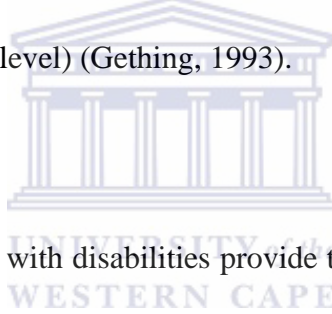
Children with physical differences receive negative social feedback, and such feedback often reduces self-esteem and limits the likelihood of the child approaching peers socially in the future (Dennis, et al, 2001). These cyclical negative peer interactions can place children with physical disabilities in the position of not attending school due to social discomfort, rejection, and potential adjustment problems throughout their life span (Dennis, et al, 2001). Sometimes, children with physical disabilities may feel segregated when they are in special class as other children without disabilities call them names and give their teacher names such as a teacher for fools (Rieser, 2008). Although these personal reactions may not reach the levels of children having psychiatric problems, they are distressing and disturb school attendance for children with physical disabilities (Dennis, et al, 2001).

Girls with physical disabilities suffer more discrimination based on both gender and disability compared to boys with physical disabilities; they are less likely to receive an education or job training (Groce & Trasi, 2004). Furthermore, girls with physical disabilities are at higher risk of physical and sexual abuse either by family members, strangers or professionals (Groce & Trasi, 2004). If they are from extremely poor families, they are also at increased risk of being forced

into prostitution and once there, may acquire additional disabling or deadly diseases, such as syphilis and AIDS preventing them from going to school (Groce, 1999).

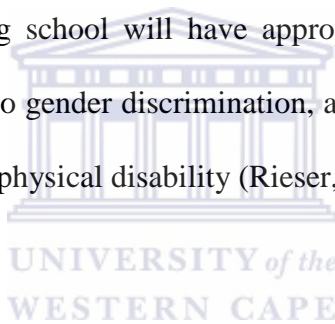
2.3.4 ATTITUDES OF THE COMMUNITY MEMBERS

According to Gething (1993), community attitudes towards children with disabilities are generally negative and devaluing. Using Interaction with Disabled Persons (IDP) Scale, developed in Australia by Community Disability and Aging Programm, Gething indicates that people express attitudes on two-levels. The first level of attitude is the reaction of contrast between the person's beliefs about the way children with disabilities should be treated by the society (society level) and the second level is their own personal reaction to interact with children with disabilities (personal level) (Gething, 1993).



Some of the contributions children with disabilities provide to the society also shape the manner in which communities respond to children with physical disabilities (Groce, 1999). Some communities are more tolerant of children with disabilities, depending on what people believe to be the cause of disability than others. Such attitudes are not always negative. For example, in northern Mexico the belief that God often gives children with disabilities to couples who are capable of caring and show special compassion influences the way parents and surrounding community responds to education needs for children with physical disabilities (Groce, 1999; Gowramm, 2007).

Community attitudes are very important as active community involvement in educating children with physical disabilities is essential for successful and sustainable communities (Rieser, 2008). The impact of community attitudes can affect the self-esteem of the child and influence the physical and social environment (Monk & Wee, 2008) . Children with disabilities value the opportunity to develop their talents by mixing with other children to develop friendships and social networks in the community. Children with physical disabilities do not perceive themselves as intrinsically different to other children without disabilities. It is rather how the community treats them or how they experience the physical environment that promotes a sense of difference (Evans & Plumridge, 2007). An effective community, with positive attitudes towards children with physical disabilities attending school will have appropriate education policies, qualified teachers, transportation facilities, no gender discrimination, and accessible school buildings with tailored furniture for children with physical disability (Rieser, 2008).



2.4. CULTURAL BELIEFS

Cultural beliefs of disability are described in two levels. There are certain beliefs that are accepted at an international level and there other disability beliefs that are accepted locally by a community or a nation without any common international beliefs.

2.4.1 INTERNATIONAL CULTURAL BELIEFS RELATED TO DISABILITY

Quoting a medical anthropologist Nora Groce (1999) of the meaning of disability in various cultures, she suggests that cultures view disability in three ways: by its cause, by its effect on valued attributes, and by the status of the person with disability as an adult (Higgins, 2002).

Cultural belief provides a major framework for understanding the cause of various forms of disabilities. With regard to this, children with physical disabilities are treated well or badly depending on cultural beliefs about how and why they have such disability. For instance, some cultures explain disability by witchcraft, reincarnation, divine displeasure, and genetics (Higgins, 2002).

On the other hand, disability may have a positive association. Countries like Mexico and Botswana have beliefs that the birth of a child with disability is evidence of God's trust in a parent's ability to care for that child (Higgins, 2002). With such beliefs, children with physical disabilities are considered no different from children without disabilities, hence, children with physical disabilities have equal rights and opportunities to attend school.



In Ghana some people still perceive disability to be a punishment or a curse (Kassah, 2007). In Ethiopia, it is considered by some as a sin to have a child with a disability (Shapiro, 2001). Therefore, Ethiopian communities prefer to hide children with physical disabilities or send them to places where their origin cannot be traced easily. The parents will allow children with disabilities to live by begging rather than sending them to schools (Agegnehu, 2000).

Other societies believe that disability is caused by religious and cultural sanctions, and therefore, children with disabilities, particularly girls with physical disabilities are often kept at home in fear of stigma (Tara, et al, 2008). Consequently, a girl with a disability does not have access to education services, information, health service, and social interaction (Hailemariam, 2006). These kind of beliefs result in the majority of children with physical disabilities not attending

school (Gowramm, 2007) unless the parents and communities are sensitized to matters related to disability and the importance of education (Rieser, 2008). According to Turmusani (2005), in Afghanistan, culture blames women for having children with disabilities. As a result, women are entrusted with a responsibility of taking care of children with disabilities (Turmusani, 2005). In many countries, children with disabilities are considered incapable of learning, no matter what their disability is. Often a child with disability is considered a distraction to other students in class, and simply sent home (Groce, 1999).

Parents, especially fathers, give first priority to other siblings without disabilities when it comes to education due to social prejudice, leaving children with physical disabilities not attending school (Choudhuri, et al, 2005). A belief that still prevails very strongly in some communities is that disability is a punishment for past karmas. “Any form of disability is looked upon as a curse that has been bestowed upon the family to atone for the sins committed by the person or the family members in their previous lifetimes” (Gupta & Singhal, 2004, p. 24). In Indian culture, children are future investments (Shapiro, 2001). When children are born with disabilities, they do not see the children as a source of support or income in the future. Hence, they would rather spend their income on the children without disabilities, especially if they are male (Shapiro, 2001). Consequently, over 94% of children with disabilities in India do not receive any educational services (Gowramm, 2007).

Some cultures believe that sex with a child with a disability can rid one of a sexually transmitted disease (Groce & Trasi, 2004). Some communities in sub-Saharan Africa, Asia, Europe and

America believe in virgin cleansing. Consequently, people with venereal diseases, believe they can liberate themselves of the condition by transferring the virus through sexual intercourse with a virgin. A disparity of this practice warrants attention of “virgin rape” of children with physical disability, since they are assumed to be sexually inactive, hence virgins, and they are easy targets by people who are HIV positive (Groce, 1999; Groce & Trasi, 2004).

2.4.2 ZAMBIAN CULTURAL BELIEFS RELATED TO DISABILITY

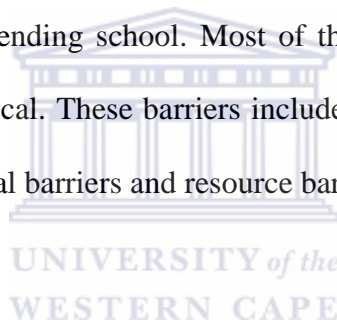
In Zambia, 40% of the population resides in the rural regions, and the vast majority of rural people are subsistence farmers. This environment of poverty with high rates of disease and disability, and limited formal education is fertile ground for misinterpretation and misunderstanding regarding disability (Atadzhanov, Chomba, Haworth, Mbewe and Birbeck, 2006). The myths and misconceptions surrounding disability have continued to exist in some sectors of the Zambian society despite the change of attitude towards children with disabilities in other parts of the world (Mwale, 2009).

In the past, in Zambia, disability was perceived as either God's punishment to individuals who did not obey His commandments or a consequence of someone's evil deeds that had manifested themselves (Mpundu, 2005). Children with disabilities were considered unholy and were kept away from able-bodied persons to avoid contact because it was believed that such children could infect others. In some extreme instances, a child with a disability was ordered to always give a signal that there was an unclean person coming to an able-bodied by shouting "unclean, unclean" (Mwale, 2009).

According to Zambian tradition, children are not allowed to come to the forefront (Rieser, 2008). They are told not to speak without the permission of the elders, even when children with disabilities have educational needs (Rieser, 2008).

2.5. BARRIERS TO SCHOOL ATTENDANCE OF CHILDREN WITH PHYSICAL DISABILITIES

Apart from negative attitudes and cultural beliefs, there are other barriers that hinder children with physical disabilities from attending school. Most of the barriers encountered by children with physical disabilities are physical. These barriers include structural barriers, barriers related to the social services, environmental barriers and resource barriers.



2.5.1 STRUCTURAL BARRIERS

Children with physical disabilities encounter many obstacles in trying to gain access to services and in obtaining assistance in order to meet their education needs. Infrastructure and public-vehicle design are often not accessible to children with physical disabilities (ZAFOD, 2003). Most of the school buildings are non-accessible to children with physical disabilities despite Zambia scoring success in the education system, there is still difficulty in infrastructure, especially in rural areas (Mpundu, 2009). School buildings are usually built with stairs, no ramps and automatic doors or far from community centers, making them inaccessible to children with physical disabilities (Gal, Schreur & Engel-Yeger, 2010). Apart from that, school furniture and

toilets is not user friendly taking into account the needs of children with physical disabilities (Ahuja, 2001; Miles, 2000; Miles & Kaplan, 2005).

2.5.2 SOCIAL BARRIERS

Poverty among families of children with disabilities is a barrier towards school attendance (Albert, 2004). Children with disabilities are more likely to come from single parents, who are not working, unskilled, and unable to own their own homes. There is a cycle of poverty experienced by parents of children with physical disabilities caused by different factors such as discrimination, extra medical costs, inflexible employers, inflexible school hours, frequent shifts in quest of appropriate housing or schools and lack of government support (Preston, 2004).



Literature indicates that the Millennium Development Goals (MDGs) that represents the policy directions for targeting poverty reduction, good health, environment as well as education, does not mention the needs of children with disabilities that relates to social services (Yeo, 2005; Edmonds, 2005). The majority of people with disabilities live in absolute poverty due to a lack of community based services (Edmonds, 2005). Edmonds (2005) suggest that a significant focus by government to ensure prevention, early intervention, rehabilitation, access to education and social integration will promote social development of parents and their children with disabilities. In 2000 the Zambia Association of Parents of Children with Disabilities (ZAPCD) was formed with the vision to ensure that all children with disabilities can access social services like education and health (Mpundu, 2005).

One of the barriers related to social services for children with disabilities in Zambia is the small proportion of the budget devoted to social expenditure for children by the government (CHIN, 2005). The CHIN report indicates that the budget allocations to the health, education and water and sanitation sectors have not registered impressive results. In addition, there is lack of implementation of National Child Policy guidelines for the welfare of children with disability (CHIN, 2005). If Zambia's economy has to grow to reach the 2015 goals and eradicate poverty, much emphasis is needed towards enhancing education for children with disabilities through inter-professional participation support programmes.

2.5.3 ENVIRONMENTAL BARRIERS

Environmental barriers to attending school for children with physical disabilities include the political environment such as undemocratic politics of a country, the economic environment the such as fragile economics, and geographical environment such as mountainous terrain (Miles, 2000; Gal, Scherue & Angel-Yeger, 2010).

Miles (2000) describes how in some countries, governments, NGOs and the communities do not prioritize access to education for children with physical disabilities. Policy and legislation that support children with physical disability to attend school is not effective (Miles, 2000).

Physical environment barriers can stop the child going to school. Distance is also one of the major challenges to attending school for children with physical disabilities (Miles, 2009; Gal et al, 2010). Most of the schools in rural areas are located far from villages where children with physical disabilities live, especially in rural areas making it difficult for children with physical disability to attend school (World Bank, 2003).

Transport can also be a barrier. Masasa et al (2005) conducted a study on the problems encountered by persons with disabilities in using public transport and found that children with physical disabilities, especially children using wheelchairs, pay more because they occupy extra space in public taxis, (Masasa, et al, 2005).

2.5.4 RESOURCE BARRIERS

Apart from lack of material resources, the lack of human resources is a barrier to children with disabilities attending school. A number of primary schools in rural areas do not have a required number of trained teachers and physiotherapists. As a result, schools fail to teach children with disabilities (Miles, 2000). Majority of the teacher training institutions in Zambia do not include information on children with disabilities.

2.6 SUMMARY

The literature indicates that there are many children with physical disabilities not attending school despite the support of the United Nations for the education of children with disabilities. There are many factors that affect school attendance of these children around the world. This includes attitudes, cultural beliefs, lack of social services, environmental barriers and a lack of resources.

CHAPTER THREE

METHODOLOGY

3.1 INTRODUCTION

This chapter will describe the research design, the research setting, study population, sample, inclusion criteria, procedure of data collection, language used in data collection, data analysis, ethical consideration and self reflection during data collection.

3.2 RESEARCH DESIGN

This study used a qualitative method, which focused on the exploring the subjective experiences or views of children with disabilities and their parents regarding attending school. The qualitative approach was used because of its advantages. It places emphasis on understanding the individual's life experiences through closely examining peoples' words and actions and it describes the situation as experienced by the participants (Denzin & Lincoln, 1994). The qualitative approach was thus used to describe the attitudes of children with disabilities and their parents to disability and attending school, parents' cultural beliefs related to disability of their children, and the barriers encountered by the parents and children with disabilities regarding school attendance.

3.3. RESEARCH SETTING

The research was conducted in Mazabuka District, which has a population of about 203,219, in the Southern Province of Zambia (CSO, 2000). Mazabuka District is about 147km from Lusaka the capital city. The district consists of three constituencies: Chikankata, Magoye and Mazabuka. In terms of development, Mazabuka constituency has two secondary, six basic schools besides private ones. In terms of health facilities, the constituency has a district hospital and two rural health centers. Its road network is well done. Socially, the constituency has three big shops such as shoprite and pep stores. Chikankata constituency has a mission hospital and a nursing as well as paramedical training institution despite its poor road network. In terms of schools, the constituency has one basic and three primary schools. It is one of the mountainous areas making transportation difficult for children with physical disabilities. Out of all the three constituencies, Magoye is the less developed constituency. It has one rural health center and two primary schools. It is dominated by farming activities.

The district was chosen as the research setting as the researcher had experience of the district while working with Mazabuka Association for Disabled and the Mazabuka District Hospital. Most of the activities and programmes of Mazabuka Association for Disabled are concerned with rehabilitation and education for children with disabilities. A number of children with disabilities benefit from the facilities and opportunities that the association offers i.e. the community

outreach rehabilitation programme, organized surgical intervention for corrections, sponsorship to education, and transportation to community schools.

3.4 STUDY POPULATION

The research population consisted of children with physical disabilities who were not attending local schools and their parents/caregivers.

3.4.1 SAMPLE

In order to have different to views and experiences of the respondents, the sample consisted of participants selected from three constituencies: Mazabuka, Magoye and Chikankata. From a developmental point of view, Mazabuka constituency is more developed than the Magoye and Chikankata constituencies. These constituencies are located approximately 45 km and 90 km respectively from Mazabuka constituency, which is a town.

The sample consisted of 19 participants who were identified purposefully. There were eight children with disabilities (three boys and five girls) who matched the inclusion criteria out of 18 children with disabilities who were identified. Among the parent participants (four men and seven women), some children were orphans hence, the elder sister, an aunty, and grand father were included as caregiver. As such, parent participants included fathers, mothers, an elder sister, an auntie and a grandfather.

3.4.2 INCLUSION CRITERIA

- The sample included children with different types of physical disabilities including paraplegia, cerebral palsy including hemiplegia and athetosis. Some of these children had other impairments, such as not being able to speak.
- All the children with disabilities were not attending school.
- These children with disabilities were between ages 7 - 19 years old.
- The parents or caregivers had child/children with physical disabilities who were not attending school.

3.4.3 INTERVIEW GUIDE

The interview guide (Appendix 1), was designed with open ended questions to allow participants to share their views and experiences freely. As indicated by Breakwell et al (1998), an interview guide is necessary to guide the researcher for relevant questions and pursue unanticipated issues during the interview using prompts without the researcher being suggestive. The parents' interview guide started with questions that covered attitudes towards school attendance of children with disabilities, followed by barriers related to school attendance and the beliefs about disability at the end. With children's interview guide, questions on attitudes towards school were covered first then followed by beliefs about disability and ended with questions on related barriers to school attendance. The distinction between the parents' interview guide and children's interview guide lied in the types of prompts during the discussion.

3.5 PROCEDURE OF DATA COLLECTION

After ethical approval had been given (See Section 3.8), the first thing that the researcher did was to recruit three research assistants from the three constituencies. In Magoye and Mazabuka constituency, the research assistants were community social workers and in Chikankata constituency, the research assistant was a community health nurse.

In Magoye constituency, the social workers identify participants from the community. Because it was a cultivating season, most of the community members were not around as they relocated themselves to temporary homes, in the villages on their farms far from their original homes. The roads and bridges were in bad shape and the only way to reach them was by using a motor bike. Out of the few villages the researcher and research assistant travelled to, two children with physical disabilities were included in the study after meeting their parents. As these two families were from two separate villages the interviews were conducted on two different days. The first interview was with the child's grandfather and his auntie. Afterwards, the child was interviewed. With the second family, the interview was conducted with the father, while the child with a physical disability was present, however, she was not interviewed since she was unable to speak.

In Mazabuka constituency, being a town and more densely populated than the other constituencies, the research assistant identified a number of children with physical disabilities. Parents and their children with disabilities gathered at the research assistant's home where four children with physical disabilities and their parents were selected to participate in the study. The researcher and the research assistant took time to explain the nature and the purpose of the study

to the participants. The appointment time to conduct the interviews was arranged. These were conducted at the home of the research assistant as it suited both the research assistant and the participants. These interviews were conducted on two separate days. In every interview with the parent or caregiver, the child was present and interviewed immediately after interviewing the parent or caregiver. Each family interview session lasted for about 2 to 3 hours. At the end of each interview, the participants were given a bottle of orange drink and some biscuits.

In Chikankata constituency, the nurse, as the research assistant, identified a number of children with disabilities through a community chairperson, and the physiotherapist at the mission hospital. In this constituency some of the people live traditionally in the mountains and valleys to raise cattle and farm maize. The researcher and research assistant went around the villages meeting the families and the children with disabilities. Out of the six families identified, three families with children with physical disabilities met the inclusion criteria. From these three, two families each having a child with physical disabilities were recruited for the study. Arrangements were made to conduct interview at a convenient time and venue. The first interview was conducted at the mission hospital in physiotherapy department, interviewing both the father and the mother at the same time in the presence of their daughter who was interviewed on finishing interviewing the parents. The second family was interviewed at their home the next day. The child was interviewed in the presence of her father and mother who were interviewed first. At the end of each family interview, participants were given some powdered milk provided by 'the sergeant', a community social welfare officer for the Salvation Army.

With the permission of the participants all interviews were audio-recorded.

3.6 LANGUAGE USED IN DATA COLLECTION

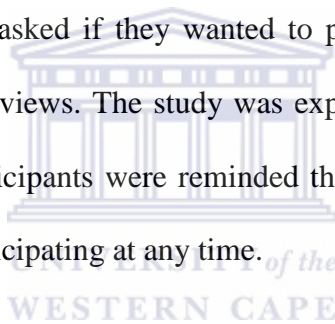
Most of the interviews were done in Nyanja and Tonga (for participants who could not understand English) by the professional nurse and the community social worker and translated into English. The researcher understands and speaks Nyanja but does not speak Tonga despite understanding it. An independent professional translator translated and transcribed the Tonga and Nyanja data into English. The data were analyzed in English

3.7 DATA ANALYSIS

Data analysis was done using a content analysis method following a systematic approach (Denzin & Lincoln, 1994). First, data was transcribed verbatim from the original recording. The transcriptions and translation (from Tonga and Nyanja to English) were done soon after finishing all the interviews. To check the English translations of recordings were accurate reflection of the responses in Tonga, an independent translator was involved in listening to each recording. Secondly, using the method described by Denzin & Lincoln (1994), data was coded to identify key factors, such as words, sentences or meaning. Some of these codes were collapsed to create sub-categories. The relationship among these sub-categories was further refined and reduced in number by grouping them together, producing themes. Lastly, the main themes were further synthesized which resulted into sub-themes. .

3.8 ETHICAL CONSIDERATIONS

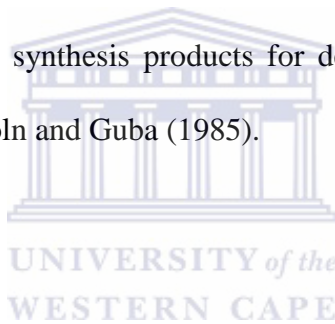
Written permission to conduct the research was obtained from Senate Ethics Committee of the University of Western Cape. In Zambia, written permission was obtained from Biomedical Research Ethics Committee from the University of Zambia, the Ministry of Community Development and Social Services through the District Community Development and Social Services and verbal permission was obtained from the constituency leaders as well as Constituency Community Development and Social Services. In addition, signed consent from parents/guardians was obtained stating that they were willing to participate in a interview and that their children could participate. Older children were asked to sign an assent form. Prior to each interview, all children were asked if they wanted to participate and if they wanted their parents/guardians to sit in on interviews. The study was explained to the participants using the participant information sheet. Participants were reminded that their participation was voluntary and they could withdraw from participating at any time.



As mentioned in Section 3.5, participants were introduced to the topic of the research study prior to the in-depth interview. Thus, the participants were informed about the study process, research duration and schedule and how the results would be used. The researcher assured the participants that their anonymity would be maintained and that it would not be possible to identify individuals from the report. Privacy was ensured. Interviews were conducted in the environment of the participants' choice, generally at home except for one interview which was conducted in a physiotherapy department. This particular interview session was conducted at that time when there were no other patients for physiotherapy treatment. The researcher ensured that the participants' self-respect and dignity was maintained.

3.9 TRUSTWORTHINESS

Trustworthiness of the research study was indicated in its credibility by through a) triangulation i.e. collecting data from different sources; children with disabilities and their parents using different questions, b) referential adequacy i.e. study findings was documented by taking field notes and audio-tape recording during the interviews. Secondly, transferability was exercised through purposeful sampling i.e. selected informants that had different physical disabilities and from different locations and a thick description, extensive quotes of participants are used as word verbatim (quoting word by word). Thirdly, the study supervisor went through the raw data, data reduction, data reconstruction and synthesis products for dependability and conformability as stated by Mouton (1998) and Lincoln and Guba (1985).



3.9.1 SELF- REFLECTION DURING DATA COLLECTION

Looking at the nature of the qualitative methodology, using an in-depth interview which is flexible in nature as has been explained above, it is common in qualitative interview to find the interview proceeding in a manner which was unexpected (Jonathan, 2004). Self-reflection during data collection helped me in deciding how to respond to and deal with unexpected reactions or irrelevant material that may have emerged.

During the in-depth interviews I found that some interviews took longer and others shorter time than expected. Due to the nature of the study investigating people's experience with disability,

participants felt a need to retell the story of their children's disabilities and experiences in detail. As the researcher, I intended to proceed from more open-ended exploration to more specific areas of the study topic. However, I often had to first listen to a long and involved account of the life of the parent participant. Often, information was mentioned that bore no significance to the objective of the research topic under investigation.

On the other hand, during the in-depth interviews some participants were not comfortable talking of their children's disability and traumatic experiences. Hence, due to the nature of the qualitative interview, these participants decided not to answer in detail or simply not to answer particular questions. This was common with girl-child participants, which might have been as a result of Zambian tradition. In Zambian culture, a child is considered respectful, humble and wise when that child remains silent in the presence of elders. Consequently, most of children failed to express themselves in detail during interviews.

Self-reflectivity includes sensitivity not only to ways in which the research process may have shaped the data collected but also to how the researcher may have impacted on the process and outcome. These factors could include personal characteristics such as race, class or professional status. I think that my personal characteristics (stature, race and profession) had quite an important effect on the outcome of the data collection after telling them that am a physiotherapist. In reality we are known to be working in hospitals but not in schools or education matters by the majority of Zambians. In most of the interviews with parents/guardians, I was asked what I was going to do for them in return for them giving the interview. This made

me wonder what impact this could have had in the interview. I did feel uneasy and uncomfortable seeing that I could not meet the expectations of the participants (i.e. provide medications and education sponsorship).

3.10 SUMMARY

In this chapter, the methodology used to achieve the aims and objectives of the study has been described. A qualitative approach, using individual interviews as the method of data collection was used. The various aspects of the methodology as well as the ethical considerations were described. The next chapter presents the results of the study.



CHAPTER FOUR

RESULTS

4.1 INTRODUCTION

The focus of this chapter will be the presentation of the results. The demographic characteristics of the study sample will be described and the main themes that emerged during the study will be presented.

4.2 DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

The study sample consisted of 19 participants. There were eight children with physical disabilities (three boys and five girls) and 11 parents/guardians, as some children had lost their parents (four men and seven women) who included fathers, mothers, an elder sister, an auntie and a grandfather. The children's age ranged from 7 – 19 years.

Table 4.1 Participants' demographic characteristics

Name of child *	Age years	Sex	Diagnosis	Parents/Caregivers*	Relationship	Child's school attendance
Pezo	13	F	Cerebral palsy Hemiplegia	Mr Mudenda Mrs Mudenda	Father Mother	Previously attended school
Chisengo	15	F	Cerebral palsy Hemiplegia	Mr Sondoyi Mrs Sondoyi	Father Mother	Previously attended school
Muzala	13	F	Cerebral palsy Ataxic/unable to speak	Blackson	Father	Never attended school
Luka	10	M	Cerebral palsy Athetosis	Headman Muloogo	Grandfather Auntie	Never attended school
Chich	10	F	Cerebral palsy Spastic diplegia	Rosina	Mother	Previously attended school
Banda	10	M	Hydrocephalus/ Epilepsy	Chopeza	Mother	Previously attended school
Momo	18	M	Epilepsy	Kam	Elder sister	Previously attended school
Munya	7	F	Cerebral palsy Spastic quadriplegia	Rosia	Mother	Never attended school

*All names have been changed to protect participant's identity

*M = Male F = Female

4.3 THEMES

The following themes were identified:

1. Attitudes towards disability and school attendance
2. Cultural beliefs towards disability
3. Barriers to school attendance

Table 4.2 Themes and sub-themes

Theme	Sub – themes
1. Attitudes	<ul style="list-style-type: none">• Parents’ attitudes• Parents’ hopes and dreams for children with disability• Effects of the community on parents’ attitudes• Effects of the family on parents’ attitudes• Effects of the community on children with disabilities’ attitudes• Attitudes of children towards school attendance
2. Cultural beliefs	<ul style="list-style-type: none">• Parents’ beliefs of the causes of disability• Parents’ understanding about disability• Parents’ beliefs about a cure for disability
3. Barriers	<ul style="list-style-type: none">• Lack of transport• Type of schools• Lack of resources/poverty

4.3.1 ATTITUDES TOWARDS DISABILITY AND SCHOOL ATTENDANCE

The attitudes of the participants that are described emerged from their actions and their words. Attitudes towards children with a physical disability and their school attendance were both positive and negative. These attitudes are divided into individual attitudes and community attitudes. The individual attitudes are those of the participants themselves, comprising the attitudes of parents and children with physical disabilities towards physical disability and school attendance. Secondly, institutions and the community's responses or actions that influenced both parents and children with disabilities, resulting in children with physical disability not attending school.

4.3.1.1 Parents/caregivers' attitudes

Parents of children with physical disabilities had positive attitudes towards their children with physical disabilities. Parents demonstrated their positive attitudes to their children through their positive behaviour in providing appropriate support to their children. Parents knew that their children had some needs that went beyond those of children without disabilities. They understood that they must provide for their children to be able to survive, since their children had limited ability to perform some activities that were necessary for daily living. At such moments, parents took care of their children. Parents gave examples of how they demonstrate their positive attitudes towards their children through physical assistance.

We do support her by giving her her needs,,we always support her when she wants to move. (Mr Mudenda, Father)

A single mother said:

I do feed her, dressing, I do dress her... I still wash and bath her. In short, I do everything for her. (Rosina, Mother)

Additionally, parents took their children to hospital, clinics, or traditional healers for appointments and treatment, to assist their children to get well. They hoped this would enable their children to perform functional movements and activities for daily living such as bathing, dressing and going to the toilet on their own and, in time, become independent.

I took her to the hospital to do some exercises. (Rosina, Mother)

Yes, he takes the medicine I collect from the hospital. (Chopeza, Mother)

These examples of the behaviour of the parents demonstrate their positive attitudes to having children with a disability.



4.3.1.2 Parent's hopes and dreams for the child with physical disability

Parents described their hopes of a cure for their children with disabilities and for them to receive an education in the future. Parents indicated that nobody had explained the children's disability to them and they did not understand the management by the health workers. Some parents thought there were drugs that could cure their children's condition. These parents did not understand that impairment was permanent. Parents were hoping the government would assist them with providing drugs to cure their children.

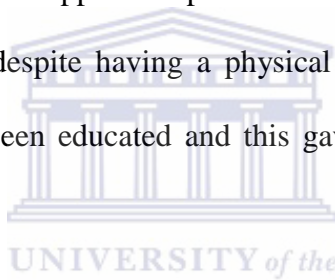
I hope that the government or any other organization can assist her. By giving her medicine maybe she can get better and help her to go to school. (Mr. Mudenda, father)

Other parents hoped the medicine from the traditional healers would cure their children of the disability.

Despite any barriers children with physical disability were facing in attending school, all parents wanted their children to receive education:

What I want is to take him to school. (Chopeza, father)

They indicated that they believed that education was the only way to enable their children to become self-reliant and to be able to support the parents in the future. The parents felt that their children had the ability to learn despite having a physical disability. Some parents had seen adults with disabilities who had been educated and this gave them hope of getting their own children educated.



We really want him to learn...because there are other people with disabilities in Monze (Town) who are learning. They get educated in order to enable them do what they want on their own. We want him to get educated so that he will learn how to do some of the things on his own. (Headman, grandfather)

He must be educated to be able to look after himself properly. (Kam, elder sister)

Another reason why parents wanted to educate their children was that parents wanted their children to learn different things in life as they grow up. Some parents decided to start teaching their own children, for example how to count and read. One mother hired a private teacher to

come to her home to teach her daughter. Her daughter had previously received some education while living in Lusaka.

School is good in order for her to know ...things, which she does not know. ... In Lusaka, a teacher used to come to teach her every Monday and that is how she knew how to read from 1-13. She is able to sing very well and is capable of mastering things she hears on the radio.
(Rosia, mother)

Parents believed in their children's ability to learn more if they were given the chance. One father did not want to keep his daughter at home without going to school as he considered her intelligent.

I did not want the child to be just home as the girl has been proven to be intelligent. (Mr Mudenda, father)



Some parents believed that once their children were educated, the children would, one day, be able to support the parents, as they grew old.

I really want my child to learn and take care of me when I grow old... Now I want to register her this year (Rosia, mother)

These words of the parents demonstrate their positive attitudes towards the children to attend school.

4.3.1.3 Community attitudes towards child disability

As a sign of positive attitudes, some people from the community would extend a helping hand to the parents of children with disabilities. For example, when the child fell sick or needed something.

In times of difficulties when the child's condition is severe, neighbours always come to our aid by helping us lift the child to take her to clinic. (Mr. Mudenda, Father)

However, majority of the communities' attitude were negative. Community members gave no support to children with disabilities and their parents. The neighbours told one parent about how they would kill the child if they had a child with a disability.

Some say that they feel pity on me. However, others say 'If it was me with this child, I could have killed her'. (Rosia, mother)

We only leave him with somebody (relative) who knows him. There is no one who says bring him here, when you come back you will find him with me. (Headman, grandfather)

Parents of children with disabilities spoke of how they needed psychological support from their communities. Such psychological support was also dependant on whether the parent was involved in one of the local clubs like a women's group or a church group. As mothers, and, wives, women needed advice on home and family management although they said there was nothing related to the child's educational needs in these groups.

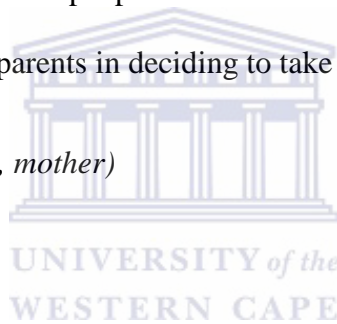
They don't offer any financial support, we just talk about family or home management. (Mrs Mudenda, mother)

Despite being in need of support, some groups had chased away one parent when she tried to join a queue with them. Parents said this behavior by the community made them feel they were being segregated due having a child with disability.

Whenever I try to go somewhere [seeking help], I am chased. (Chopeza, mother)

In addition, some parents indicated that people in the community were laughing at their children with disabilities. This did not help parents in deciding to take their children to school.

Others laugh at her [child]. (Rosia, mother)



Parents expected to receive assistance from their church. Even after telling the church members about their child's disability, the parents said they had been given nothing.

Yes, I go to New Apostolic church and I cannot cheat that they have helped and the church is aware of my problems but they have done nothing. (Rosina, mother)

Parents said that the church prioritized orphans rather than children with disabilities.

Not yet... they are about to start looking after the orphans like him. (Kam, elder sister)

There is no problem with us and we do not receive any support from them. (Headman, grandfather)

Among the parents who participated in church groups, only one mother who received some prams for her disabled child from the church.

I have received help from Sister Andrea who gives me prams whenever it becomes small. This is the third time to give me another one. (Rosia, mother).

When it came to NGOs, the parents did not seem to know which organizations or government departments were dealing with issues that concerned children with disabilities and their education. When questions were asked about NGOs, and if parents knew of them or had registered their children with these sorts of organizations or clubs, parents seemed to have no idea about the local organizations.



These actions, words and behaviour demonstrate negative attitudes of the community towards children with disabilities and parents that promoted lack of education among children with disabilities.

When it came to children playing with other children from the community, every parent wanted their children to have friends to play with. Parents realized that children needed to express their feelings by playing around with their friends. Parents allowed other children with or without disabilities to visit their children in their homes and allowed children to play outside. Even though some children who visited were teasing some of children with disabilities, some parents

did not feel offended, as they said it was not done unkindly, but in a good way to make the child feel part of the community family. However, sometimes parents did not like the teasing.

They like playing with her. They feel happy about her....teasing and entertain her. (Blackson, father)

He plays with his friends. (Headman, grandfather)

The child has got friends whom she plays with. (Mr Mudenda, father)

She does not walk unless her friends come nearby where you have sit her and play with her. (Rosia, mother)

Despite parents allowing their children to have friends to play around with, not every child from the community liked playing with the children with disabilities. Some parents spoke of other children without disabilities running away from the children with physical disabilities.

Children in this place run away when they see her. (Rosia, mother)

This behaviour demonstrates the negative attitudes of the community towards children with disabilities.

4.3.1.4 Effect of the family attitudes on child disability

Most of the parents indicated the support given by the immediate and the extended families was important. Most parents indicated that when they were away from home, the siblings of the child with a disability took care of their brother or sister.

His young brothers and sisters. (Kam, elder sister)

She remains with her elder. However, if she is at school, she usually remains alone. (Rosia, mother)

There is no support from extended family members apart from her brothers and sisters. (Headman, grandfather)

Some parents were concerned about leaving their children with others, particularly the parents of the child with epilepsy. They said that many people would not come close to the child, believing that they would also “catch epilepsy” once there was body contact. When the child had a seizure, people would run away leaving the child alone without anyone to protect or prevent further injury to the child in fear of “becoming sick”. For safety reasons, they said that a family member must be always present with the child in case the child had a seizure when the parents were not present.

It is not easy. Because when he falls down and start fitting, they all run away from him. They say that they might end-up having it as well. Except if there is somebody, a family member who comes to pick him up.....They fear that they can also become sick (Kam, elder sister)

This demonstrates the positive actions of the immediate family members towards parents and children with a disability but also the negative attitudes from some extended families.

Unfortunately, not every parent received all the financial support they needed from the immediate and extended families.

I have my elder brother who drives. However, there has been no support from him. All I do is find a piece of work somewhere and support myself. (Chopeza, mother)

One mother and the child were abandoned when a father realized he had a child with a disability. Out of fear that people may associate the father with the child, the father ran away leaving the mother and child without any support, including no financial support for school attendance.

We separated because of the same child. (Rosina, mother)

These examples demonstrate the negative attitudes of family members towards both the parents and children with disability.



4.3.1.5 Effect of community on children with disabilities' attitudes

Childrens' attitudes to their disability were a little different to those of the parents. All except one of the children indicated they had friends from the community to play with. At times, their friendships with the other children appeared to be free of stigma and discrimination towards having a disability.

At other times children without physical disabilities laughed at them. One child indicated he was discriminated against by other children in the community. This type of behaviour left a question

in one child's mind. The boy with hydrocephalus and epilepsy wondered why other children were running away from him.

When they [children without disability] see me around they run away from me for unknown reasons. (Banda, child)

The same boy suggested that he felt some sort of discrimination by his siblings. He expected his siblings to help him crush stones at home sometimes but they did not, even if they were able to do so. Some of children with physical disabilities had attended school in the past before their parents stopped them. One girl spoke of going to school alone and coming back home alone without anybody associating with her. Even at school, she had no friends.

I used to go alone and come back home alone. (Chich, child)

This unfriendliness could affect the childrens' and parents' attitudes to school attendance. Some children with physical disabilities indicated that they wanted to participate during sports and games periods at school. Despite her physical limitations, the child (Pezo) did not consider herself unable to play some sport. This was a positive attitude the child had towards herself among other children without disabilities that suggested that the child did not feel ashamed or stigmatized by other children.

I can take part [in games]. (Pezo, child)

The unfriendly behaviours from children without disability demonstrate negative attitudes towards children with disability towards attending school.

4.3.1.6 Attitudes of children towards school attendance

All the children with disabilities indicated that they wanted to go to school. Children who had never attended school indicated that their parents had asked or told them about taking them to school, which they all wanted to do. The children who had been to school before but were no longer attending school indicated positive thoughts about school. One of the responses of one child who had attended school before was:

We want the very thing (school) you are talking about that I become educated. (Momo, child)

Some children (particularly those who had been in school before) wanted to attend school because they did not like remaining at home while seeing other children going to school.

I want to go to school because I admire my friends who go to school. (Chisengo, child)

Other children wanted to attend school as they had already made up their minds about which professionals they would become at the end of finishing their studies.

I want to be a teacher. (Chich, child)

Parents and children appeared sad that the children were not attending school. One child (Pezo) had developed a habit of watching her friends from the community going to school everyday.

I am really saddened that my child is unable to go to school. Everyday she always watches her friends go to school but she is helpless as she cannot walk, but I hope that she can learn one thing in her life that is going to help her. (Mrs Mudenda, mother)

I do not feel good [about not going to school]. (Banda, child)

The children's words and desires indicate the positive attitudes towards school attendance.

4.3.2 CULTURAL BELIEFS

The participants' beliefs about disability were related to the causes of the disability, their understanding of disability and the belief of a cure for the disability.

4.3.2.1 Parents' beliefs of the causes of disability

Despite being a population of one common religious background of Christianity, there were differences in beliefs related to physical disability among parents. The three cultural beliefs that were related to parents' understanding of the causes of their children's disabilities that parents spoke about were religious beliefs, traditional beliefs and Western medical beliefs. Over time, some parents seemed to have swung between traditional beliefs, medical beliefs and religious beliefs in the process of seeking for a cure for their children. Sometimes parents could believe in more than one cultural belief. These beliefs did not appear to influence the parents' attitudes to their children getting an education but did influence their views about whether the disability could be cured.

All participants were Christians, though some of them, particularly fathers, were not active or attending church as frequently as others. Many of them believed that it was God's will for them to have a child with a physical disability despite some believing witchcraft practice among the community still existed. These participants believed that either the child or during her pregnancy, the mother stepped on traditional poison (mankhwala).

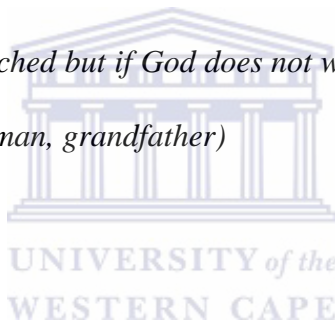
The traditional leaders we used to go to told us that she stepped on some poison (mankhwala) which made her disabled. (Mr Mudenda, father)

People tell me to go to fortune tellers (Nganga) to find out who bewitched my child. (Rosia, mother)

According to some parents, the traditional poison will only work or lead to the person having a disability if God permits this. Without God's permission, there will be no disability.

I think it is God's will. (Blackson, father)

We believe that God is the one who has caused this person to be disabled. There are other people who are bewitched but if God does not want that person to be disabled, they will not be disabled. (Headman, grandfather)



Some parents believed that people who did wrong things such as stealing, killing somebody or insulting elderly people resulted in a disability through witchcraft. In certain circumstances where the person became disabled without doing anything wrong or did not step on some poison [mankhwala] (particularly children, whom they believed to be innocent), it was perceived to be the will of God.

Other people are disabled even when they have not done wrong things or stepped on anything. All what we can say, is that it is the will of God. For this child to be ill [disabled] as this is because God decided already that she will end up with a disability at this age in her life. (Headman, grandfather)

Only one parent indicated that physical disability was caused by a natural illness. Her view was that either the mother may become sick during pregnancy and the disease affects the unborn baby or the child might become ill or get involved in an accident causing her to have a physical disability.

What causes people to be disabled? Some get sick, others accidents. (Rosia, mother)

4.3.2.2 Parents' understanding of disability

Parents explained that there is a certain period in a child's life as the child is growing up when the child is expected to be able to complete special tasks. When that child does not manage to achieve these tasks or activities, then that child is considered to have a disability. These activities included cooking, washing, lifting or talking.

We just know that this person has disability when that individual fails to do certain things or work. (Mr. Sendoyi, father)

Any part of the body that does not function properly. (Kam, elder sister)

The disability that we are talking about is that the person is not capable of bathing as an adult. He does not manage to cook food as grown up person. He has no strength. Even when you send him to lift something, he is not able...disability as the name refers itself...that particular person is unable to do work or things. She is not able to talk, wash, cook and walk properly...it means that, a person has disability to carry out or do certain things as other people will do. (Headman, grandfather)

4.3.2.3 Parents' beliefs about a cure for disability

Traditional beliefs appear to have a strong influence in the lives of parents as they first went to traditional healers to cure the disability first before consulting the Western health services. These beliefs were present regardless of whether the participants were of Christian faith or not. The parents believed that physical disability could be treated using traditional medicine since it was linked to the belief that the physical disability was caused by witchcraft. Sometimes family members or other members of the public influenced parents so they would seek for a cure from traditional healers (Nganga). To hide their fears of not coping, parents took the child to the traditional healers. Some parents took their children from one traditional healer to another to get help and a cure for their child's disability before considering Western medical help.

When we saw that there was no improvement, my family decided that we seek traditional medicine to cure the child.....we have gone to so many different witch doctors (Nganga) but so far there has not been any change. (Mr Mudenda, father)

Other parents hoped the medicine from the traditional healers would cure their children of the disability. When parents saw that there was no physical improvement in their children's disability following physiotherapy sessions at hospitals or clinics, they stopped taking their children to hospitals and again started taking them to traditional doctor (Nganga) believing that the traditional medicine would cure their children.

When we saw that there was no improvement, my family decided that we seek traditional medicine to cure the kid. (Mr. Mudenda, father)

Some parents ended up combining the traditional medicines and the Western medicine.

I take both. I use African medicine and what I collect from the hospital. (Kam, elder sister)

Only one parent, a father, indicated he believed that there was no cure for physical disability for his child. He had taken his child to traditional healers and to the hospital and he was not satisfied with the results. This father believed that only God could cure the child.

There is no treatment for this disease (disability) apart from God. (Headman, grandfather)



4.3.3 BARRIERS TO SCHOOL ATTENDANCE OF CHILDREN WITH DISABILITIES

Barriers to children with physical disabilities attending school included a lack of transport, the type of schools, the child's impairment, and a lack of resources.

4.3.3.1 Lack of transport

Transport was the barrier that most hindered children with physical disabilities from attending school. Parents indicated that in every constituency, there was a community school that accommodated every child regardless of physical ability. The distance from the home to the school seemed to be a hindrance for them.

Its very far (Mr Mudenda, father)

Hence, both parents and children themselves wanted some sort of transportation in order for the children to attend school.

If there could be some transport to take her to school. (Rosia, mother)

My appeal is to all well-wishers to come to our aid and offer us a bicycle so that I am able to take the child to and from school. (Mr Mudenda, father)

One child appealed for some assistance in terms of transport in order for her to be taken to school by her parents.

I would want to be given a bicycle so that I can be taken to school. (Pezo, child)

4.3.3.2 Type of school

Another barrier to attending school was the type of schools found in the communities. Though parents wanted their children to be educated, some parents did not want to take their children to local schools that were ordinary schools. When parents were asked at which schools they would like to enroll their children, many of them wanted to register their children at special schools.

I would like to take her to a school that is for children with disabilities. (Mr. Mudenda, father)

I want to take her to a school where there are children with disabilities only. (Rosia, mother)

4.3.3.3 Children's impairment

One of the reasons why parents did not enroll their children at local ordinary schools was that their children could not talk or communicate as well as other children without disabilities while another reason was that the child could not stand or walk on her own.

She does not talk and she cannot communicate with teachers, unless experts teach her.

(Blackson, father)

Some parents thought that their children needed to be taught by teachers who had specialized in teaching children with disabilities and not just ordinary teachers.

I thought the teachers would not manage to teach her for she requires specialist to teach

her. (Blackson, father)



Parents whose children had physical disabilities before the age of school did not try to register their children, thinking that the school administration would not register their children.

We are just thinking....they will refuse...because these (children) have their own expert teachers who teach people who have disabilities. At this school, they will not accept.

(Headman, grandfather)

However, parents whose children's disabilities were less apparent until they were older let the children start school and later decided to stop the child from attending school.

The school authorities had no problem with the child. Its me who had to go there to seek permission that the child should stop attending school until such a time when the child was able to be on her feet again. (Mr Mudenda, father)

The parents stopped one of the children from attending school because the child did not show improvement from the time she started attending school. Hence, parents concluded that teachers in ordinary schools have difficulties in teaching children with physical disabilities.

They have some difficulties to teach the child, there is no improvement since the child started learning. (Rosina, mother)

One parent did not allow her child to attend school as the child had epilepsy. The child had seizures in class making it difficult for the child to perform well. Consequently, the mother decided to stop the child attending school.

He was in school and each time he wanted to write he was attacked by fits. Therefore, this disturbed him in a way that he could not concentrate in school in order for him to write exams and pass. (Chopeza, mother)

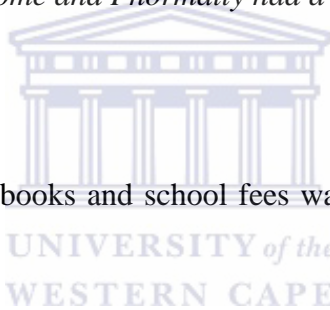
Parents indicated that they did not know their rights or rights of their children to education.

No, we do not know. (Mrs. Sendoyi, mother)

4.3.3.4 Lack of resources/poverty

Parents spoke of how a lack of financial means to buy material things contributed to children not attending school. Many parents could not afford to send their children to schools. Sometimes children would go to school on an empty stomach and without carrying any food to eat during break time. When the child reached home after school, the parents could not afford to secure food to prepare for the child. Therefore, the child ended up having a glass of water without any meal that day.

I felt hungry when I came home and I normally had a headache. (Chich, child)



Paying for school uniform, shoes, books and school fees was a problem for parents in order to send their children to school.

Support like shoes, school fees and books..., until we just stopped him. (Kam, elder sister)

If parents did not have family members who could assist with them financially to send the child to school, the child would just remain at home without attending school.

I cannot manage because my late brother was the one helping me. (Rosina, mother)

What I want is to take him to school, but everything I need is not enough. (Chopeza, mother)

None of the parents said they got any financial support from the government.

The lack of permanent accommodation was also a factor contributing to children not attending school. Many parents had no regular income to buy or build a house of their own. The majority of the parents who were interviewed were living in rented houses, and they indicated that the owners of the houses would not usually allow the tenant to have a child with a physical disability living on the property. Consequently, the family with a child with a disability may need to move frequently from one area to other in search of accommodation instead of settling at one place and finding a school to enroll the child.

Things are still hard....At the moment things are hard. House for rent is difficult. Wherever we stay, we are told to leave and look elsewhere. Where we are staying, we are also told to stay only for one month. (Rosia, mother)



4.4 SUMMARY

Despite the negative actions and words of the families and communities, most children with disabilities indicated a positive attitude towards school attendance. Some parents indicated positive attitudes and others negative attitudes towards school attendance. Parents demonstrated positive attitudes towards their children through physically caring for them and in their attempts at finding a cure for the child's disability by seeking help from traditional healers or physiotherapy. Some of the factors contributing to parents' negative attitudes were the lack of education support from the government, local organizations, communities and poverty. Cultural beliefs like traditional beliefs and religious beliefs had strong impact on parents' beliefs of the cause of the disability. Some parents indicated that disability is due to witchcraft hence they

consulted the traditional healers before taking the child to the hospitals. Nevertheless, some parents believed it was God's will to have a child with a disability.

The discussion of the findings will be presented in Chapter Five



CHAPTER FIVE

DISCUSSION

5.1 INTRODUCTION

In this chapter, the focus will be on the discussion of the results of the research study according to themes that emerged. The discussion is based on the three objectives of the research study which were: (1) to explore the attitudes of children with physical disabilities and their parents towards the child attending school, (2) to explore the cultural beliefs of parents about children with physical disabilities and the implications for attending school, and (3) to explore the children with disabilities' and their parents' views and experiences of barriers related to attending school.



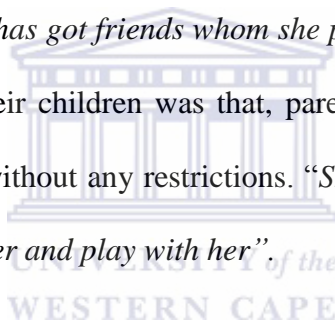
5.2 ATTITUDES TOWARDS THE CHILDREN WITH DISABILITIES AND SCHOOL ATTENDANCE

According to the participants' responses and reactions, both parents and children with disabilities had positive attitudes towards school attendance of children with disability.

5.2.1 PARENTS' ATTITUDES TO DISABILITY

The attitudes of parents to their own children who had physical disabilities were generally positive. These positive attitudes were demonstrated in different ways regardless of the stress

and burdens parents were facing. Some of the activities parents were doing for their children included bathing, washing, and cooking as well as taking children to clinics and teaching them at home. One parent said “*We do support her by giving her her needs*”. This was different to studies done by Li-Tsang, et al, (2001) and Agegnehu, (2000) where parents were hiding their children with disabilities. It was also different to the parents of the Ethiopian children who were described as having maladapted feelings of guilt, pessimism, hostility, aggression and avoidance, which resulted in the parents hiding their children (Li-Tsang, et al, 2001; Agegnehu, 2000). To try to break the stigma towards children with disability, the Zambian parents in this study allowed their children with disability to play outside the house with other children without disability. A father said “*the child has got friends whom she plays with* “. Another demonstration of a positive attitude shown to their children was that, parents allowed other children without disabilities to visit their children without any restrictions. “*She does not walk unless her friends come nearby where you have sat her and play with her*”.



The study done by Ravindranadan & Raju, (2007) indicates that parents develop negative attitudes at the discovery of their child having a disability that affects the child’s life (Ravindranadan & Raju, 2007). This was not apparent in this study, where most parents demonstrated positive attitudes towards their children upon discovering that their child had a disability. All parents wanted their children to become well and not to have the disability. The first step that most parents took was to look for cure for their child:”*we have gone to so many different.... doctors*”. Despite the financial hardship parents experienced and the great distances to the health centers, parents had found time to take their children to some sort of treatment. Literature suggests that every parent wants their child to be both physically and developmentally

perfect (Ravindranadan & Raju, 2007). According to the findings of the study, some parents were using Western medicine as treatment *“I took her to the hospital to do some exercises”* and at the same time as seeking advice from traditional healers. One of the response was *“when we saw that there was no improvement, my family decided that we seek traditional medicine”* although a few of the parents used Western health care services as the first place they went to for help upon noticing that their child had a disability. Most parents first went to the traditional healer and later to the Western health care services exception of one parent who said *“I take both. African medicine and what I collect from the hospital”*.

Otherwise, the discovery of the child’s disability did not affect the positive attitudes of parents towards the child with disability, unlike the negative attitudes described in literature (Beresford, et al, 2007; Deal, 2003). Other parents have said upon knowing or seeing the disability of their child, they experienced feelings of shame, anger, helplessness and denial or disbelief. With Zambian parents, it was believed to be the will of God as a grandfather said *“all we can say is that it is the will of God for this child to be ill [disabled] ... because God decided already that she will end up with a disability at this age in her life”*.

Out of all parent participants, only one parent indicated that her husband left her due to the child having a disability, which as a rear case. According to his wife, he did not want to be part of this family anymore; hence, he decided to abandon his family. Quoting the wife’s response: *“we separated because of the same child”*. This confirmed the experience described by Chakwe (2010) and Gupta and Singhal (2004). In the literature, parents in other studies have been found

to experience negative outcomes like depression, social isolation and marital discord (Chakwe, 2010; Gupta & Singhal, 2004). According to Ravindranadan and Raju (2007) the major reasons why break-ups among couples with children with disabilities happened are due stigma and poverty as raising a child with disability demands extra costs. Deserting the mother is similar to hiding the child as other parents do (Agegnehu, 2000) but in this case, by running away, the parent hides themselves from the rest of the family.

5.2.2 PARENTS' ATTITUDES TOWARDS SCHOOL ATTENDANCE FOR CHILDREN WITH DISABILITIES

Parents demonstrated a positive attitude towards school attendance for their children with disabilities. In some countries like Ethiopia and Afghanistan (Shapiro, 2001; Turmusani, 2005) children with disabilities are considered incapable of learning and a distraction to other students in class (Groce 1999). However, parents in Zambia indicated that they had seen people with disabilities who had obtained an education. One of the response got was *“we really want him to learn...because there are other people with disabilities who are learning....”* Parents had dreams and hopes of sending their children to school, as they considered them capable of being educated. Such hopes were *“...we want him to get educated so that he will learn how to do some things on his own”*. One parent hired a private teacher to come to the home to teach her child, *“a teacher used to come to teach her every Monday and that is how she knew how to read”* while other parents had started teaching the children at home. These dreams or hopes of parents demonstrate positive attitudes towards children's school attendance. Such positive attitudes of parents have also been found in Mexico and Botswana (Higgins, 2002). Parents in Mexico and Botswana demonstrated their positive attitudes by sending their children to school and they did

not neglect or abandon the children with disabilities. On the other hand, studies indicate this is different among parents in Ghana, India, Ethiopia and Afghanistan who have been found not to send children with disabilities to school (Kassah, 2007; Gupta & Singhal, 2004; Agegnehu, 2000).

A parent in this study indicated that members of the community said they would have killed the child if they had a child with a disability. Following a mother's quotation "*others say 'If it was me with this child, I could have killed her'*". Literature, including studies done by Gupata and Singhai (2004), Hailemanam (2006), Gowranmm (2007) and Groce (1999) indicates that some parents wish for their child to be dead rather than have the disability. One of the reasons why parents have negative attitude is because children are considered an investment for the future (Shapiro, 2001). Hence, a child with disability is not considered human, as the child was not an investment for the future. Disability translates into "nonhuman" in the Shona language of Zimbabwe (Loeb, et al, 2008). As a result of such notions, some parents do not pay attention to their children's education and even wish for the death of their children (Hailemariam, 2006). Parents with such negative attitudes to their children would not be interested in their children getting an education. This was not found in this Zambian study.

On the other hand, the reasons why parents in the study had positive attitudes towards school attendance of their children was because parents wanted their children to get a job and help or support them (the parents) once these children attained some education. As one parent responded "*I really want my child to learn and take care of me when I grow old*". Additionally, parents

hoped that their children would be independent once educated. Parents believed that it would be possible for children with disabilities to be happy and enjoy a good quality of life. Hence, educating their children was one of the important aspects in their children's lives.

5.2.3 EFFECTS OF GOVERNMENT AND NON-GOVERNMENTAL ORGANIZATIONS TOWARDS SCHOOL ATTENDANCE OF CHILDREN WITH DISABILITIES

From the participants' view, there was no support for the children getting education coming from the government or the local associations.

Most parents did not know about the rights of children with disabilities. It appeared that the government and local NGO's did not provide information on children's rights. One of the responses from parent participants when asked whether they knew any children's rights was "*We do not know*". According to CHIN (2003), the National Policy on Education (1996) that "recognizes the rights to education for children with disabilities under the responsibility of the Ministry of Education" (ILO, 2009), does not seem to provide sufficient school places and resources needed by the existing education institutions. Children with disabilities and their parents did not know their rights and privileges. The privilege of free education was one which the children and their parents should have enjoyed but did not (UNESCO, 2003; Rieser, 2008; Perry, Ivy, Allyson and Dawn, 2008; UN, 2006).

No NGO or government departments had communicated this information to the parents of the children with disabilities on their right to education. This did not allow parents to become involved in planning the education for their children together with the community schools. Despite the introduction of free education, designing appropriate curricula and teaching materials, providing special furniture, equipment, aids and infrastructure, rehabilitating dilapidated schools, and working with families, communities and religious organizations by the Zambian government, parents did not know the existence of programmes to include children with disabilities at school in their communities (UNESCO, 2003; UN, 2006; Rieser, 2008).

Some parents felt their children with disabilities would not be in capable hands in ordinary schools that accepted children with disabilities as one parent said “*I thought the teachers would not manage to teach her for she requires specialist to teach her*”. Other studies also indicate that parents get worried about leaving their children with disabilities with other people including professionals (Groce, 1999; Groce & Trasi, 2004). Some parents indicated that they wanted to send their children to special schools. Parents thought that teachers working in special schools were well trained on how to teach and handle pupils with physical disabilities such as their children. Another parents’ response was “*...because these (children) have their own expert teachers who teach people who have disabilities*”. In support of the parents’ concern, Govender (2002) found that teachers in special schools handle children with disabilities more favorable compared to teachers in ordinary schools.

5.2.4 ATTITUDES OF CHILDREN WITH DISABILITY TOWARDS EDUCATION

The majority of children with disabilities in this study indicated positive attitudes towards school attendance and indicated that they would have gone to school, had it not been for other barriers as said by a participant “*support like shoes, school fees and books..., until we just stopped him*”. Another parent said “*I want is to take him to school, but everything I need is not enough*”. One of the ways of showing their positive attitudes towards school attendance was that children would stand by the roadside in order to watch other children going to school. Parents expressed their grief of seeing their children watching other children attending school whilst their children could not as one mother this to, “*I am really saddened that my child is unable to go to school. Everyday she always watches her friends go to school...*”. According to Dennis et al (2001), most children with disabilities do not attend school due to social negative attitudes. However, despite other children without disability laughing at the children with disabilities, child participants in this Zambian study still had a strong desire to attend school. A children participant said “*I want to go to school because I admire my friends who go to school*”. Dennis et al (2001) points out that the stigma which children experience result in rejection and social uncertainty which hinders them in school performance

Another factor to indicate the children’s positive attitudes towards school attendance was that some children had already made up their mind on which career they would choose after finishing school, following such response as “*I want to be a teacher*” from a child participant. Not attending school had not reduced their self-esteem or limited their dreams or hopes for their future as has been found by Dennis et al (2001).

In this study only one boy did not have friends to play with as people were scared to be in contact with him as he suffered from seizures. This boy's parents indicated that people were afraid to come in contact with the child, especially when he was convulsing. People were afraid of "catching" or being "infected" of the disease according to their traditional beliefs. Apart from this boy, all the children with disabilities had friends and one girl said she was not ashamed of participating in school games once she starts attending classes. The children with disabilities did not consider themselves as different from other children without disabilities in terms of education. All children who had attended school at one time but stopped were willing to start attending school again, once they had all the necessary school material like uniforms, shoes, books, school fees and transportation facilities. Those who had never been to school before were also willing to start attending school once they were registered. According to literature, children with disabilities experience feelings of withdrawal, rejection and hostility due to stigma (Rieser, 2008; Dennis, et al, 2001; Li-Tsang, 2001). Despite lack of literature on attitudes of children with disabilities towards school attendance, according to Dennis et al (2001) and Li-Tsang (2001), most children with disability indicate poor class performance or attendance due to negative attitudes, which results in social discomfort and isolation.

5.2.4.1 Effects of family and community members on childrens's school attendance

Parents and children with disabilities relied on the family and community members' support. This support was necessary during difficult moments such as when parents were out of the home, illness of the child or financial need. However, not all parents received support from the family

members and the community according to a mother's response *"I have my elder brother who drives. However, there has been no support from him"*. When parents went to the fields, attended funerals or church services, parents entrusted their children with disabilities to the care of other older or even younger brothers and sisters of the child with the disability as indicated by a parent: *"there is no support from extended family members apart from her brothers and sisters"*. Barker (2004) states that siblings of children with disabilities can experience negative attitudes from the communities as people identify them with the child with disability. Loeb et al.'s study (2008) indicates that people feel stigmatized or ashamed at identifying themselves with people with disabilities. This kind of stigma is what Gray (2002) calls "courtesy stigma". According to Gray (2002), families of children with disabilities experience courtesy stigma because they are members of the family with a child with a disability. Consequently, parents of children with disabilities do not tell people that they need help or ask for any assistance from extended family members even in times of need, for example with the child's health or education (Gray, 2002) according to a parents' response *"they (community) say that they might end-up having it (disability) as well.They fear that they can also become sick"*. Many of these parents of children with disabilities relied on good Samaritans for any help.

According to the participants' responses, community members did not show any interest to support the attendance of children with disabilities towards school. According to literature, communities' attitudes depend on the causes of disability and contributions of children to society (Kassah, 2007; Gething, 1993; Shapiro, 2001).

5.3 CULTURAL BELIEFS ABOUT DISABILITY

A belief about disability has a different meanings and interpretations according to the cultural beliefs of a society, community or nation. From the participants' responses, physical disability was understood through three different belief systems: traditional beliefs, religious beliefs and Western beliefs.

Some parents described the disability of their children as inability to fulfill activities of daily living. For example, one of the participants said, *“the disability which we are talking about is that, the person is not capable of bathing... cook food as grown up person.Even when you send him to lift something, he is not able”* (Grandfather). Parents' interpretation of disability was similar to that of WHO. According to the ICF, by the WHO established in 2001, “disability was conceived as the outcome of the interaction between impairments and negative environmental impacts” (UNICEF, 2007). Disability can be interpreted in various unspoken cultural standards of what was considered normal according to functional abilities. Even when there was no terms explanation by parents similar to that of ICF (WHO, 2002), most parents understood disability on a functional level.

5.3.1 TRADITIONAL BELIEFS OF DISABILITY

Some parents believed that disability could be caused by witchcraft. According to the Zambian traditional beliefs, disability was a result of doing something wrong against someone or as a

punishment from God (Peter, 2009). As such, in the past, children with disabilities were considered unholy and the families excluded them from other persons without a disability to prevent “infection” as people believed that disability could be transferred through contact (Smith, Murray, Yousafzai and Kasonka, 2004). The myth still seemed to be in existence among the community members according to parents’ responses in this study.

However, most parents were no longer holding onto traditional beliefs towards the school attendances of their children. They considered children with disability as equal to other children. In China, according to Yang (2001), all human beings are considered good when they are born. Consequently, the people of China consider children with disabilities as equals to children without disability. Chinese traditions do not consider the birth of a child with disability as sin or that it results from something bad that the family had done in the past (Yang, 2001). These traditional beliefs promote positive attitudes of parents and the community towards school attendance of children with disabilities.

Traditional beliefs about disability vary from one group of people or community to another and this can explain the beliefs of the causes of the disability (Groce, 1999). People in Ghana and Ethiopia believe disability to be a curse or sin in a family (Kassah, 2007; Shapiro, 2001). With such beliefs, children with disabilities are not considered as equal human beings, hence, they are not sent to school. On the contrary, disability has a positive connotation in other countries like Botswana and Mexico where they believe that the birth of child with a disability is evidence of God’s trust in a parent’s ability to care for the child and not as result of witchcraft (Higgins, 2002).

The study shows that parents in Zambia believe their children are investments for the future. Such belief also exists among some parents in India, according to a study done by Shapiro (2001). Some parents in Zambia indicated that sending the child to school would enable the child to support them in the future once the child obtained the necessary education. Following this belief, children were allowed the freedom to speak to their parents about school matters in a way that was not possible in the past (Rieser, 2008).

5.3.1.1 Beliefs of cure for disability

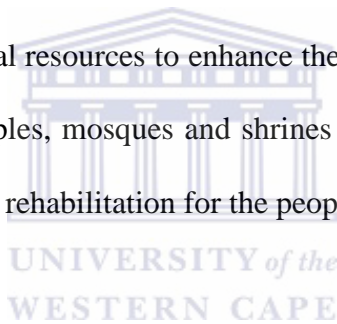
According to traditional beliefs, from the participants' perspective, beliefs such as the child stepping on "traditional poison" as reported "*the traditional leaders we used to go to told us that she stepped on some poison (mankwala) which made her disabled*" or the mother stepping on "traditional poison" while pregnant. This propelled parents to consult with traditional healers in their need to find the answer to their question: who caused this disability? Why did it happen? Or how did it happen as said by a parent "*people tell me to go to fortune tellers (Nganga) to find out who bewitched my child*". As a result, some parents used traditional medicine from different traditional healers in an attempt to cure the child of the disability. However, after seeing that the children's impairment was not cured with traditional treatment, some parents stopped going to the traditional healers and took the children to the hospital or clinic. Other parents chose to combine traditional treatment with Western medicine.

In some cases, parents went from one traditional healer to another, seeking for a cure for their children before taking the child to hospital as reviewed by a response as “.....*we have gone to so many different witch doctors*”. Others went direct to hospitals and registered the child for physiotherapy treatment. Parents did not feel any guilt or embarrassment by seeking for a traditional cure for their children. This is similar to findings from the studies done by Ravindranadan & Raju, (2007) and Groce (1999) as most parents of children with disabilities try to find ways and means in order to care and raise their children with disability for them to acquire education in life (Ravindranadan & Raju, 2007; and Groce, 1999).

5.3.2 RELIGIOUS BELIEFS OF DISABILITY

Despite the belief that disability was caused by God, as parents indicated: “*we believe that God is the one who has caused this person to be disabled. There are other people who are bewitched but if God does not want that person to be disabled, they will not be disabled*”, parents did not perceive it to be a punishment from God or sin to have a child with a disability as has been found among parents in Ghana and Ethiopia (Kassah, 2007; Shapiro, 2001). The results indicate that none of the children were hidden or sent away by their parents as has been described by Higgins (2002). All the participants in the study were Christians, and most of them believed that God allowed their children to have such disabilities. As such, some parents did not seek traditional healers for the cure of disability. Most parents would say “*God knows why He gave me this child*”. The parents of the children with disabilities in the study said they would just keep quiet, even when other people would say bad things about their children, such as “*if it was me with this child, I could have killed the child*”.

Despite acceptance of the children's disability being as a result of God's will, the belief did not influence the communities' including churches attitudes towards children's education needs. Parents indicated that none of the local community associations or groups offered any support towards school attendance of their children: *"they don't offer any educational support"*. As a result, some parents did not discuss or inform the community, in particular, the religious communities about their children. However, not all parents were closed about their children with other members of the community. It seemed that the local community groups did not take any interest in the education matters of children with disabilities in the district, unlike Indian communities who could utilize local resources to enhance the welfare of people with disabilities. In India religious centers like temples, mosques and shrines act as agencies in mobilizing local resources to empower and promote rehabilitation for the people with disabilities (Dalal, 2002).

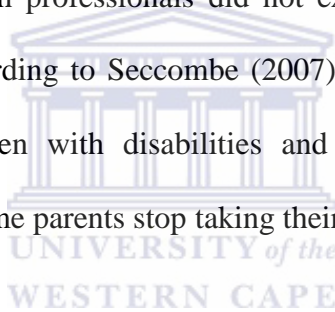


5.3.3 BELIEFS OF DISABILITY IN WESTERN MEDICINE

The use of Western medicine by most parents of children with physical disabilities was their second choice, though a few parents considered it in the first place immediately after noticing the disability of the children. One grandfather said *"there are people when they become disabled they start taking Western medicine and they become healed"*. According to parent's responses, though each parent had a different way of finding medicine, they all believed that there was a certain drug to treat the physical disability, with the exception of one parent who concluded that there is no medicine for physical disability. Such misunderstanding of treatment of physical disability was due to lack of knowledge of the disability as literature indicates that majority of

Zambians live in rural areas with limited education, which incubates misunderstanding about disability (Atadzhanov, et al, 2006).

Most parents indicated that health professionals did not explain or inform parents of their child's condition. The majority of parents did not understand what was wrong with their children. When parents were asked of their understanding of the meaning of disability, they all explained disability in terms of functional or participation limitations. Even when parents expected more from Western health services after seeing that traditional healers could not treat physical disability, doctors and other health professionals did not explain so parents could understand their children's conditions. According to Seccombe (2007), some health professionals exhibit negative attitudes towards children with disabilities and their parents during clinic visits (Seccombe, 2007). As a result, some parents stop taking their children to hospitals or clinics.



5.4 BARRIERS RELATED TO SCHOOL ATTENDENCE OF CHILDREN WITH DISABILITIES

The study showed that children with physical disabilities face a number of barriers towards school attendance. Under physical barriers: structural barriers, school accessibility and distance to school premises contribute to many children with disabilities not attending classes. Apart from that, social barriers included the lack of resources, administration barriers, poor transport facilities and the loss of parents which had an impact on lack of education for children with disabilities.

5.4.1 STRUCTURAL BARRIERS AND POOR SCHOOL ACCESSIBILITY

Parents of children with disability indicated that most of the local school buildings were not built taking into consideration children with physical disabilities in the architectural design. Most of the schools in Zambia do not have ramps, elevators or wide passages for children with disabilities. Small classroom, toilet doors, furniture and stairs made the functional disability of children worse since classrooms were not accessible to children with physical disabilities. With this in mind, some parents' response was *"I would like to take her to a school that is for children with disabilities"*. According to literature (Thorburn, 1998; Eide & Loed, 2006; Ahuja, 2001; Mile, 2000; Miles & Kaplan, 2005), structural barriers hinder many children from school attending as they are unable to access the services without difficult. Phiri (2008) indicated that most roads in Zambia are constructed for car users only (Phiri, 2008). Since there are no pavements it is difficult for wheelchair users. Thus, children with disabilities face more challenges going to school using the same roads and parents fear their children will develop further disabilities.

5.4.2 DISTANCE TO SCHOOL

The distance from home to rural centres where community schools were based was far for children with disabilities. Parents and children complained of the long distances for the child to walk to school as parents did not have any transport, such as a car or bicycle to take the children to school. One of the consistent responses that parents and some children elicited was *"it's very far"*, followed with request: *"if there could be some transport"*. As the World Bank (2003) found most children with disabilities are in remote areas. They are dispersed around the village

with one community school. The child who cannot walk due to a physical disability is unable to cover the distance to school and go back home. Long distances to school premises contributed to lack of education among children with disability.

5.4.3 SOCIAL BARRIERS

The social barriers that parents experienced indicated transport, lack of resources, poor administration support and the loss of a parent. These hindered children from school attendance.

5.4.3.1 Transport

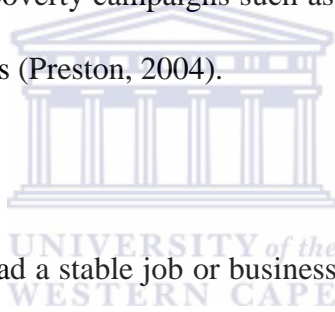
Out of all the problems parents experienced, transport was one of the greatest barriers and most needed for school attendance for children with disabilities. Almost every parent had something to say about transport for the child to attend school. Such response were *“my appeal is to all well-wishers to come to our aid and offer us a bicycle so that the child is taken to school”* from a parent participant and *“I would want to be given a bicycle so that I can be taken to school”* by a child participant. One of the reasons why transport was necessary was that in each community there was one primary school, which was located at some distance for the child with a disability.

Children with disabilities in rural areas are common victims of transport barriers to school attendance as most schools are far from the villages (World Bank, 2003). According to Masasa (2003), children with disabilities encounter difficulties or pay more for transport if they used a wheelchair (Masasa, et al, 2003). Another study done in Cambodia also indicated that lack of/or

inaccessibility of transportation contributed to most children with physical disability not attending school in Cambodia (VanLeit, Channa & Rithy, 2007).

5.4.3.2 Lack of resource

The poor social status of most parents had a negative impact on the school attendance for children with disabilities. According to Preston (2004), parents of children with disabilities incur extra costs in raising and educating their child. Consequently, some countries (United Kingdom, United States of America) have recognized such extra costs encountered by the parents and the governments have introduced antipoverty campaigns such as a disability grant and low taxes for families of children with disabilities (Preston, 2004).



None of the parents in this study had a stable job or businesses to support the family and child's education and most of them depended on subsistence farming for a living. Thus, they were poor people as one parent said *"things are still hard....At the moment things are hard"*. According to McKay and Atkinson (2007), couples with children with disabilities are less likely to work in formal employment compared to parents with children without disabilities (McKay & Atkinson, 2007). Thus, parents could not afford to meet the demand of their children's education despite the introduction of free education for children with disabilities by the Zambian government (ZAFOD, 2003; Rieser, 2008). Parents and children indicated that they found a lack of food, school uniform, and shoes hindered children from school attendance. As a confirmation, another parent said *"I cannot manage because..... everything I need is not enough, though I want to take him to school"*.

Another reasons why parents did not register their children in local schools was that, parents wanted a specialized teacher to teach their children, which the local schools did not have. The Zambian government has not been able to ensure that schools in rural areas have specialized teachers as stipulated by the Ministry of Education (Rieser, 2008; ZAFOD, 2003).

5.4.3.3 Lack of administration

Apart from that, government departments do not give administrative support to parents with children with disabilities to facilitate the education of their children. This had an impact on the school attendance in Mazabuka. From the participants' view, there was no government or NGO working in partnership with parents ensuring that children with disabilities attend school.

The Zambia Federation of the Disabled (ZAFOD), which is the umbrella of the organizations that are concerned with people with disabilities, has not monitored any progress on support for these organizations for school attendance of children. In addition, according to parents, the local organizations and the Ministry of Community Development and Social Services (MCDSS) considered children with physical disabilities last priority along with other vulnerable children like orphans. Such responses from government departments and NGOs made parents feel or think that the government does not support children with disabilities attending school. A study done by Evans and Plumridge (2007) found that the government and/or organizations usually under service children with disabilities and their parents (Evans & Plumridge, 2007). According to the 2003 NGO Complimentary Report by CHIN, most of district administrations in Zambia have not implemented the National Plan for Action (NPA).

5.4.3.4 Loss of parents

Some children had lost either a father or a mother. Death of one parent leaves the children with disabilities in a difficult position. In Zambian culture, when a husband dies, the family members of the deceased confiscate the property as benefits for the loss of their son. Such practice leaves children of the deceased poor without educational support. As most women in Zambia are not employed, both the mother and children including a child with disabilities experience total poverty. As a result, the children with disability remained at home without education.

5.5 SUMMARY

The school attendance of children with physical disabilities in Zambia was not hindered by the attitudes of children themselves or their parents, nor their parents' traditional beliefs, but by the physical and social barriers. Both children and their parents had positive attitudes towards school attendance of children with disabilities. The lack of government support towards the implementation of the wheelchair user roads, ramps, elevators in school buildings and accessibility of classrooms and other facilities prevented children with physical disabilities from attending school. Poor communication between the Government and NGOs and the parents about the education programmes for children with disabilities contributed to children with disabilities staying out of school. The lack of resources, transport and distance were additional barriers to school attendance for children with disability in Zambia. Unlike the results of other studies reviewed that indicated that the majority of children with disabilities did not attend school due to parents' and family stigma as a main reason. In addition to this, children with

disabilities were not considered to be productive as they were non humans. Zambian parents consider children with disabilities as normal human beings who are capable to be productive for development as long as the environment is accessible.



CHAPTER SIX

CONCLUSION

6.1 INTRODUCTION

This chapter focuses on the summary, conclusion, significance, limitations and recommendations of the study. Some of the components under recommendation are advocacy, community participation, infrastructure development and resource allocation.

6.2 SUMMARY

Despite the number of children with disabilities increasing every day, the majority of them are left out of school in developing countries. The United Nations and other organizations like UNICEF and UNESCO introduced Programmes, Standard Rules and Policies to enable children with disabilities to reach their full potential in life by acquiring an education. “Children with disabilities hold the key to the successful realization of the goals and the spirit of the global campaign to achieve education for all. Decades of research and practice have proven that children with disabilities can thrive in a learning environment, and that families, schools, and communities benefit when educational systems invest not only in their inclusion, but in their development and potential” (Mindes, 2007, p. 1). Unfortunately, children with physical disabilities are not attending school in developing countries like Zambia, regardless of the government adopting the UN Standard Rules and the support of UNICEF and UNESCO.

The current study aimed at exploring views and experiences of children with physical disabilities and their parents on school attendance in order to establish why most children with physical disabilities are not attending school in Zambia. The participants of the research study were children with disabilities and their parents.

The researcher reviewed relevant literature, which included studies on the disability, prevalence of childhood disability, education, children's rights and barriers towards school attendance. Some of the studies that were reviewed under barriers were studies on attitudes, cultural beliefs of disability and other related barriers towards school attendance. Generally, literature indicated that majority of children with disability are excluded from school and majority of them are in developing countries like Zambia. The findings of this study showed that the commonly contributing factors to a lack of education among children with disabilities were physical and social barriers. The negative effects of attitudes of community members also contributed towards a lack of school attendance of children with disabilities in Zambia. The study found that all children and their parents had positive attitudes towards school attendance of children with disability.

6.3 CONCLUSION

In order to achieve the Millennium Development Goals of 2015, particularly the second goal that aims at “achieving universal primary education” (UNICEF, 2007, p. 13), there is need to promote positive attitudes among community members, organization and government departments towards school attendance of children with disabilities.

Children with disabilities were willing to attend school had it not been for some physical and social barriers. If the government departments in collaboration with local organizations (NGOs), through community participation provide accessible schools, transport facilities and resources, there could be less percentage or number of child with disabilities out of school in Zambia. Such actions would demonstrate positive attitudes of the communities, NGOs and government departments towards school attendance of children with disabilities.

Though the literature indicates that parents considered children with disabilities to die young as they are in a frail health, the result of the research study contradicts such beliefs. Consequently, parents had positive hopes and dreams about their children towards school attendance since parents wanted their children to support them when they grow up as adults. None of the cultural beliefs affected the parents' positive attitudes towards school attendance of their children. Every parent believed that his or her child would be somebody or accomplish something some day. Such notion encouraged Zambian parents to have positive attitudes towards education of their children regardless of their disabilities.

From the results of the research study, parents lacked administrative and physical support from the government as well as the local community. If the local communities acted as the Indian communities (i.e. through the shrines, churches and charitable organizations) in Mumbai (UNESCO, 2009) did by organizing the local resources to support the programmes for people with disabilities, all children with disability would have been in school in Zambia.

6.4 SIGNIFICANCE

Amongst all the health professionals, a physiotherapist spends more time with the child than other health professionals. The knowledge of the barriers that affect the school attendance of a child with physical disabilities is important. Hence, the findings of the study will be valuable in informing the physiotherapists to work in collaboration with the Zambian education authorities, charitable organizations, communities and parents to develop and promote programmes that will meet the education needs of children with disabilities to attend school.

Physiotherapists can play a role explaining the rights of the child to education. There is no collaboration with pediatricians and physiotherapists at the moment in Zambian primary schools to promote social participation of children with disabilities. Both children and parents felt segregated and/or ignored by the society. In line with the UN CRC (2007) early identification of disabilities, for appropriate interventions to prevent further complications of the impairments, physiotherapists need to work hand-in-hand with other professionals, communities and the parents. The link between physiotherapists and schools will help the transition of children to attend classes smoothly.

6.5 LIMITATIONS

Despite choosing qualitative methodology to explore the views and experiences of the informants, the researcher encountered unexpected limitations during data collection.

6.5.1 TIMING OF THE DATA COLLECTION

The data collection was only done from December 2008 to February, 2009. Prior to this period most of the government offices were on Christmas and New Year Holiday. Nevertheless, during this seasonal (rain) period, most of the participants were all occupied with their domestic farming. As literature review indicates, 40% of Zambian population resides in the rural areas, and the vast majority of rural people are subsistence farmers (Atadzhanov, et al, 2006). Hence, some of participants move from their usual homes to temporary homes in the valley at the farm. The effect to this was seen in Magoye Constituency where the majority of families with children with disabilities could not be accessed. This made it difficult to find children with different types of disabilities to include.



6.5.2 TRANSPORTATION USED DURING DATA COLLECTION

Mazabuka district is occupied with both commercial and small-scale farming in the Southern Province. Being the rainy season of the year, when collection of the data was done, most of the feeder roads were in bad condition. Consequently, the participants in Magoye and Chikankata could only be reached through a motor bike and four-by-four land-cruisers respectively. The expenditure was high in following up participants at their respective homes.

6.6 RECOMMENDATIONS

As a result of the findings, some recommendations are needed in order to promote school attendance of children with disabilities in Zambia. These include advocacy, community participation, school infrastructure development and resource allocation.

6.6.1 ADVOCACY

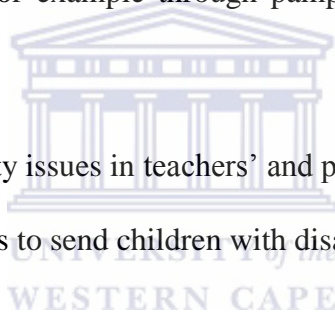
There is need to promote the rights of the children with disabilities in Zambia to education.

The government should involve all the departments and encourage NGOs to inform parents of the educational rights and privileges of children with disabilities.

The government needs to advocate for the implementation of the education policies.

Disability awareness campaigns to sensitize and educate people and communities about disability need to be introduced for example through pamphlets, booklets, seminars, banners, posters.

There is need to introduce disability issues in teachers' and physiotherapists' training curriculum to enable them to encourage parents to send children with disabilities to school.



6.6.2 COMMUNITY PARTICIPATION

- Parents need to be encouraged to participate in local school programmes to empower the parents of children with disabilities to be responsible for their children's education.
- Parents of children with disabilities need to feel respected and motivated to take responsibility.
- Parents of children with disabilities need to be involved in decision-making, voluntary work, advocacy and monitoring school activities.
- Parents of children with disabilities need to be encouraged by the local communities to send their children to school.

- Each community needs to feel the responsibility for its members and the necessity to organize the local resources and the services for development including education. This will bring unity of the community as local organizations, churches and clubs come together to participate in the community programmes.

6.6.3 INFRASTRUCTURE DEVELOPMENT

The few schools in rural areas of Zambia are dilapidated and not designed for children with physical disabilities.

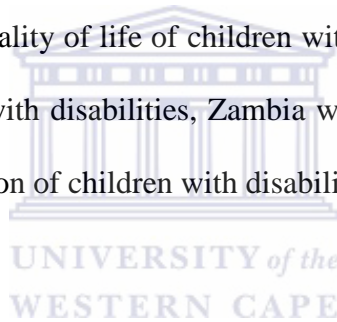
- The government must build more primary schools in rural areas to accommodate all children with physical disabilities with wide doors, passages for wheelchairs, classrooms and toilets to accommodate children in order to use the facilities.
- There must be slopes and ramps instead of stairs at schools.
- All local community organizations, business houses, churches and government departments through the Ministry of Education must be involved to promote accessible and conducive education to children with physical disabilities.
- The government needs to construct good and safe roads in rural areas and provide transport facilities to promote accessibility to education.

6.6.4 RESOURCE ALLOCATION

The government must not just develop policies and programmes for children with disabilities.

- The government needs to train more special teachers to ensure that every community ordinary school in rural areas has a qualified special teacher to teach and handle the children with disabilities.

- The government and any other donors (NGOs that are specialized in education) must support all teachers' training institutions to provide appropriate training on child disability. This includes adequate funding, expertise, infrastructure and books.
- Training schools or colleges must include people with physical disabilities themselves as member of staff or lecturers so children with disabilities can have role models.
- The government should introduce allowances and grants for children with disabilities and their parents in order for children to attend school.
- The government should channel enough resources towards research on disability, children with disabilities and their education. Without the understanding of the disability, prevalence of disability, quality of life of children with disabilities and their families and the education of children with disabilities, Zambia will not manage to eradicate poverty as a nation with the exclusion of children with disabilities.



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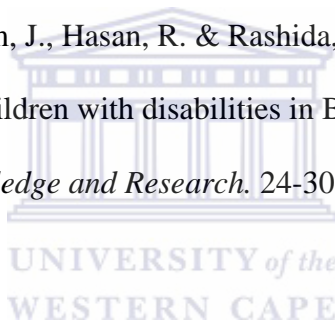
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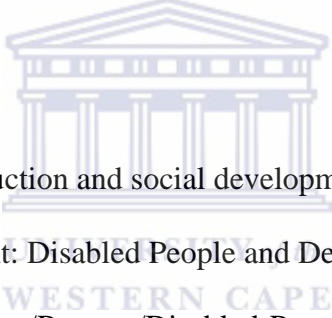
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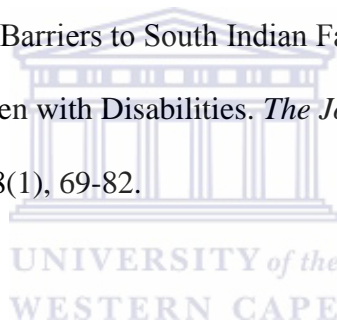
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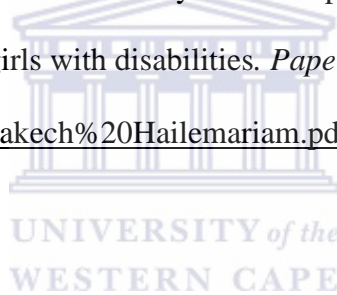
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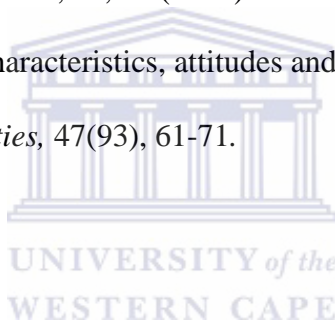
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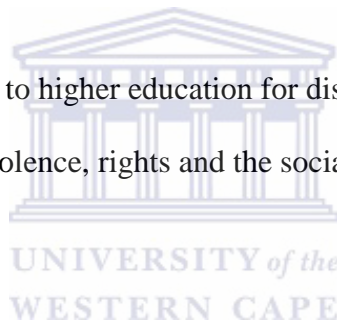
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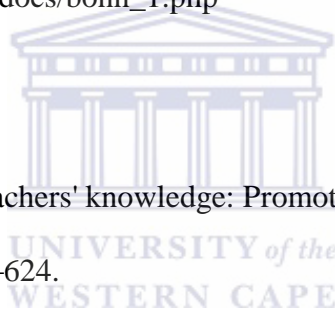
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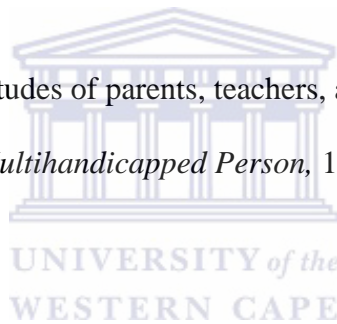
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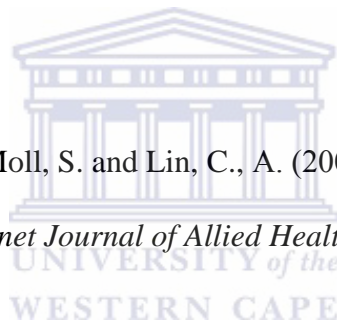
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