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## **DECLARATION**

Emmah Nashon Tembo Mutoloki, declare that this thesis is a result of my research investigations and findings. Sources of information other than my own have been acknowledged and a reference list has been appended. This work has not been previously submitted to any other university for award of any type of academic degree.

Signature.....

Date.....

## **DEDICATION**

It's a great honour for me to dedicate this thesis to four people that mean so much in my life. My beautiful daughters; Joy, Chikondi and little Nicole for supporting and believing in me even when you could not fully understand why I failed to give you time that you deserved with me, you were always there when I needed someone to talk to. I love you more than you will ever know!!

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## **ABSTRACT**

Zambia is a signatory to the United Nations Convention on the Rights of People with Disabilities (UNCRPD) and as such is expected to provide for people with disabilities. There are at present very few reports on the status of the lives and welfare of people with disabilities in Zambia. The purpose of this study was to identify the socio-cultural barriers that women living with disabilities in Kazungula and Livingstone districts experience in order to enjoy a full social life, placing emphasis on the status of their human rights.

The CBR approach was used since it is a WHO approved method of rehabilitating and integrating people with disabilities into society. Livingstone and Kazungula districts were chosen as study areas to represent urban and rural areas. The study was performed qualitatively, and the data was collected through observations as well as individual interviews and focus group discussions.

Barriers preventing women with disabilities from enjoying full social lives in these areas were physical, such as the lack of aids for the blind, interpreters or translators for the deaf, infrastructure to facilitate movement or access to buildings for the physically handicapped. In addition, poverty, dependence and negative attitudes were also identified as barriers. Poor education meant that the women could not compete favorably for formal employment and this made them unable to provide for their families especially that they did not receive any form of financial support from the government.

On the cultural influence on families and relationship, the women in Kazungula were of the opinion that this was a significant barrier to social inclusion while their Livingstone counterparts responded otherwise. The respondents in Livingstone also had a much better knowledge of human rights and UNCRPD, than those in Kazungula who almost had no idea. In both districts, the respondents felt that government was not doing enough to provide for them or to protect their human rights.

The findings of this study suggest that women with disabilities in rural areas are at more disadvantaged than those in urban areas and therefore interventions should take into account this fact. The strongest basis for the barriers observed in this study was negative attitudes. In order to remove barriers, awareness campaigns aimed at changing people's attitudes towards women with disabilities will be important. Secondly, having a job was found to be positively related to a satisfactory life style for the women with disabilities yet their educational

backgrounds disadvantaged them from acquiring employment. Introduction of programs that empower the women and encourage them to be self-reliant will be essential in removing some of the barriers faced by these women.

Finally, CBR has the potential of turning things around because it's social strategies allow different players to enter and offer different forms of support to the same community. This is important as it does not over-stretch the resources of one organization while maximizing the overall results.

## **ABBREVIATIONS**

CBR	Community-Based Rehabilitation
DPO	Disabled People’s Organization
MMD	Movement for Multiparty Democracy
GRZ	Government of the Republic of Zambia
NAD	Norwegian Association of the Handicapped
OP	Opportunity Zambia
ILO	International Labour Organisation
PWD	People living with Disabilities
UNCRPD	United Nations Convention on the Rights of People with Disabilities
UDHR	Universal Declaration of Human Rights
ZAFOD	Zambia Federation of the Disabled
ZAPD	Zambia Agency for people with Disabilities
ZHRC	Zambia Human Rights Commissioner
ZNAD	Zambia National Association of the Deaf
ZNADW	Zambia National Association of Disabled Women



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# CHAPTER ONE

## INTRODUCTION

### 1.1 Background of the study

In every society, different groups of people face different challenges. People living with disabilities have been shown to have more than their fair share of challenges and this has attracted the attention of the international community (Armstrong and Barton 1999). According to a report of the United Nations Convention on Rights for People with Disabilities (UNCRPD), about 10 percent of the World's population is disabled, reflecting approximately 650 million people. A big proportion of these people live in developing countries (U.N.enable 2012). These people represent the biggest number of disadvantaged people in the whole world and are discriminated against in many countries.

Originally, disability was defined more from a medical point of view as anything that limits a person from performing certain duties. Following some reactions from representatives of organization that represented persons with disabilities and also professionals in the field during the 70's, the definition of disabilities was viewed with a close relationship between the limitations experienced by the individuals, the environment as well as the general attitude of the society in which they live (Eide and Loed 2006). At the end of last century, the disability concept was changed from that of a medical-based model on impairments to a new one focusing on limitation of activities and social participation (WHO 2001).

The United Nation Convention emphasizes on the recognition of people living with disabilities and to ensure that the world understands what disability is; it came up with a simple definition, that disability is an interaction between society, environment and the person (Francescuitt et al. 2011). Impairment of the mind, senses, physical and mental-being can be considered forms of disability depending on how the societies are organized (Ingstad and Whyte 2007). However, disability is a very complex phenomenon and according to Ingstad and Whyte (Ingstad and Whyte 2007), it varies depending on the cultural values, political, social and economic aspects which influence what is considered and acknowledged as a disability within each country or society.

While willing to be productive members of the society and also seeking recognition, people with disabilities face obstacles that put them at a disadvantage in attaining this goal. In order to address these obstacles and also in recognition of the fact that the Universal declaration of Human Rights did not adequately protect the rights of this group of people, the United Nations convened a convention on the right of people living with disabilities. Accordingly, disability rights are not based on enjoyment in specific areas but these are equal human rights that everyone has without being discriminated because of their incapability to perform certain duties (Quinn et al. 2002). It however, acknowledges that this process of inclusion will definitely take some time especially in areas such as economics and even social sector just because people living with disabilities are usually the poorest in most parts of the world (Quinn et al. 2002).

One of the approaches that has taken center stage in addressing the obstacles faced by people living with disabilities is the so-called community based rehabilitation (CBR). Community Based Rehabilitation is a developmental strategy that focuses on addressing and improving the living standards of people living with different forms of disabilities and their families. Initiated in the 1970s and 1980s, the strategy promotes collaboration among community leaders, people with disabilities, their families, and other concerned citizens in order to provide equal opportunities for all people with disabilities in the community and also aims to strengthen the role of DPOs (WHO 2004). Key in the CBR strategy is the promotion of multi-sectoral collaboration to support community needs and activities, and collaboration between all groups that can contribute to meeting its goals (WHO 2004). Its objective on one hand is to make sure that people with disabilities maximize their abilities, both physical and mental and are able to access regular services and opportunities as well as become active players in the community and society at the same time as protect the human rights of people with disabilities through changing the way society perceives them (WHO 2004).

Zambia has a total population of about 13 million people (Zambian economist 2011). Out of these, the latest figure of people with disabilities has not yet been released although according to the previous census (2000), there were 256 690 people out of about 9.9 million, representing 2.7% (CSO 2011). The most frequent forms of disability were physical, followed by vision-related disabilities, hearing-related disabilities and then other disabilities (CSO 2011). The Zambian government together with the community recognizes the importance of

empowering persons with disabilities as reflected by the fact that the country is party to the signing the UNCRPD in 2008. On January 2010, the UNCRPD was ratified by the Zambian government with a commitment to ensure that people with disability are given equal human rights in Zambia (Mung'omba 2008).

In Zambia, there is no CBR policy that is supported by a comprehensive strategic plan (Hartley and Okune 2008;Sightsavers 2010). Implementation is largely fragmented as pilot projects spread across the country while there are no reports of any programs in some places. In order for CBR to be implemented in any area, a good understanding of the culture and social barriers is required. In Kazungula and Livingstone districts, there were no records available on the cultural understanding or social barriers that people with disabilities face except for one author whose focus was on the use of health care in childhood disabilities (Magnussen 2011).

## **1.2 Research question and objectives**

The social component is a well-known factor influencing the development, well-being and status of all people in different societies. It also contributes to the way that people living with disabilities view themselves and are treated in their societies. The present study was aimed at examining the socio-cultural barriers that stood in the way of women with disabilities in Livingstone and Kazungula districts from getting fully integrated into society and also their human rights. The choice of the target group was done against the background that women with disabilities are among the people with the least access to CBR programs (WHO 2004). Most of them are not aware of their human rights because not much has been done to sensitize them. Depending on the disability, they rely on other people especially parents or close family to perform duties for them mostly in the early days of their lives (Ingstad and Whyte 1995).

The central question was:

*What are the socio-cultural barriers that prevent women with disabilities in Kazungula and Livingstone districts from participating and contributing fully to society and to what extent are their human rights affected?*

Of interest was to view the central question from a CBR point of view since the CBR approach is at present the most desired approach of intervention. Specifically, the objective was:

*To identify, within the social components of the CBR Matrix, what kind of cultural barriers these women were experiencing in order to establish a full social life*

In order to address problems affecting women with disabilities it is necessary to gain knowledge around their life situations, how they perceive the environment and how they manage to make meaningful life, how they experience social relationships, and how/if they control their own lives. A focused research identifying the barriers and challenges that women with disabilities face would contribute with knowledge and form a basis for CBR programs designed to address these women's needs and how DPOs and government incorporate their life situations into such programs.

### **1.3 Methodology**

A Norwegian non-governmental organization Norges Handikapforbund (Norwegian Association of the Disabled (NAD) offered to partly support this study. NAD has offices internationally including Zambia where they run a branch under the name Opportunity Zambia (OP). This NGO operates mainly by supporting other non-governmental organizations (NGOs) that deal directly with the handicapped. Their central goal is to fight for equal rights and opportunities for people with disabilities, primarily the physically handicapped. It was through this link that access to target groups was obtained.

Women with disabilities and of different ages from Livingstone and Kazungula districts of Zambia were targeted. The Disabled People's Organization (DPO) and a number of other organizations that have a focus on disability in Zambia and operate in these areas were chosen purposively in order to make contacts with women with disabilities. As these DPO's have been working with the women with disabilities for some time, it was easy to gain access to their records in order to purposefully make a selection of the women to include in the research project. An inclusion criterion was the willingness to participate in the study and to this effect, a consent form explaining the purpose of the study, what the information obtained



would be used for and that it would be kept confidentially as well as the fact that participation was voluntary was signed by all respondents.

The qualitative research method was used in this study and data was collected by conducting individual and focus group interviews in these areas. Questionnaires and a tape recorder were used as instruments of data collection during these interviews. Approximately 10 purposefully selected women of age 15- 60 years were interviewed while interviews were conducted with the help of two research assistants who were familiar with the local settings and understood the local languages.

Focus group discussions (FGD) were done with the targeted women selected for the interviews and focus group questionnaires were used as guides for the discussions. Here, questions of the women's experiences and lives as women with disabilities were outlined. Pertinent questions regarding the social barriers that they faced, their understanding of their rights and different concepts of the UNCRPD were also covered while the context of their living conditions surveys was used as background information.

Leaders of DPOs were in addition interviewed; key persons in government departments who have the responsibility of implementing the UN Convention as well as those responsible of Community Based Rehabilitation (CBR) guidelines were interviewed. In order to ensure that the research results were reliable, the analysis was further discussed with persons with disabilities so that their point of view was included. The interviews were done by the researcher in order to ensure the results were valid (Bryman 2008).

Zambia has few experts in the field of disability and when available they are at a very high cost such that most of people with disabilities cannot not afford. Based on this, it was of great interest to find out what provisions were in place for people with disabilities to access the expert help and how NGO's, other societies and government facilitated this. Another focus was to investigate the opportunities of women with disabilities in different fields like the education, marriages, health and the social settings. Issues like how the Government policies, NGO's and the CBR tried to integrate these women were other also examined.

The UN Convention emphasizes strong government policies to strengthen the Convention's objectives in programs as well as in every development policies in order support and

encourage women with disabilities (Gilbert 2008). Kazungula and Livingstone districts were selected because of their differences in social landscapes as is outlined below.

#### **1.4 Research Methods**

The focus on women in the present study was chosen in order to raise awareness about the difficult experiences that women with disabilities faced and what strategies would give room for improvement of the situation (Kothari 1990). Since Zambia is a poor country and has no proper records on disabled people, it is difficult to locate the people with disabilities without the help of non-governmental organizations. The choice of the place to do the research was therefore motivated by the availability of logistical arrangements including organizations willing to avail information and also able to facilitate the location of respondents.

During the time of research it was necessary to develop a sense of trust which always had a positive effect on accessing valuable information. According to Bryman, emphasis should be placed on winning the confidence of the people involved (Bryman 2006). It was also a big challenge just to start interviewing women without going through some DPO's that they were familiar with. The Norwegian Association of the handicapped (NAD) through its offices in Zambia played a very significant role in introducing me to the DPO's that direct work with people with disabilities such as the Welfare Organization which is focusing on empowering children with disabilities through education support and educative programs such as HIV preventions lessons.

The Network organization was another DPO that helped in identifying the respondents and finally ZAPD had its share of identifying the respondents both in Livingstone and Kazungula districts. Contacting the respondents was not such a big challenge because ZAPD had mobile telephone numbers for most of the women with disabilities living in Livingstone district. In Kazungula district, Welfare organization identified the respondents for me and asked the school headmaster to help, and he was a great help. Fortunately enough all the women showed up at the agreed place and on time. The discussion started right away and as the researcher, I initiated the discussion by introducing myself to the respondents, telling them what the study was about and my interests. This made them feel free and one by one they also started introducing themselves and explaining how their disabilities developed and when it happened. I also made them aware that I would record the discussion for my use and that the two

research assistants would be taking notes as the discussion went on. During the discussion I had an opportunity to identify who I felt had information that was useful for the study. At the end I asked them if it was possible to have individual interviews with them in order to learn more from them.

At the end of the interviews I thanked them for their time and cooperation during the whole process. As for the Livingstone respondents, I thought it was reasonable for me to refund their money for the use of their telephones to get in touch with the coordinator at the DPO. The needs of respondents at Kazungula district were different from those from Livingstone. Therefore, these respondents were compensated for their time by giving them each a bar of washing soap. Furthermore, at the end of the discussions at each focus group, we had lunch together.

The theoretical framework used in this study was the social component of CBR. CBR is presently the most widely used approach in many countries where integration of people with disabilities into society is concerned and its social component adequately addressed the questions that this study was looking at such as families, culture and human rights to name a few. As already mentioned, the qualitative approach was used and data was collected through face-to-face interviews with the women with disabilities and other key players in the field. Targeted women were interviewed in order to understand the situation of being a woman with disability. The focus groups were done first where women in similar situations opened up to talk about their different experiences and challenges in their lives. The focus group made it easy to select women for individual interviews both in Kazungula and Livingstone districts. In both these districts, the researcher conducted the interviews by asking the women questions while the two research assistants took notes as a backup in case the recording did not come out clearly.

### **1.5 Research ethics**

The research project was carried out in a private and confidential manner and all the important research ethics were observed. During the entire period of the research one of the key focuses was to maintain respect, honesty and morals which helped in gathering more information on the women's experiences. It was necessary to assure them that whatever was discussed would remain confidential. Acting with respect and with right morals is one way of ensuring that the research is based on honesty, care, accountability etc (Walliman N. 2006). The researcher

created an atmosphere in which she was perceived as a participant and not a judge, with the intention to share their experiences. It was also very important to draw a line on what to ask the participants or not, since limits need to be closely observed while paying attention to legal orders of the community (Chair and Iphofen 2003).

Keeping order in form of research diary which acts as a guiding tool so that some things or topics are not overlooked is another essential issue. Research diary does on the other hand help in documenting change of decisions throughout the project and even how to access the different selected research areas (Walliman N. 2006). Posing a series of different questions (e.g. will the results of the research benefit society, or at least not harm it?) is another route the researcher took in order to ensure the ethical issues are properly handled. The use of language could distort the research project if not handled well as the aim was to be as neutral as possible in terminologies (Walliman N. 2006) that involves the description of people such as who are they, what they are as well as what they do for their living? During research it's necessary to observe that some activities are not engaged between the participants and researcher (Bryman 2008).

## **1.6 Overview of chapters**

The following chapter (Two) is a briefly literature review on Zambia as a country, its geographical location, political and economic situation. Thereafter the human rights situation and the related UNCRPD, the CBR and cultural aspects are also reviewed. Chapter three is mainly addresses how different theories relate to each other with the main focus on the definition of disability and the convention on the human rights of people with disabilities. Chapter four will bring out the results of the whole project, describing the observation as well as the findings obtained during the research study. Chapter five will be discussion on the research findings including interpretations, the author's views as well as recommendations. The final chapter (Six) is a summary of the whole work.

# CHAPTER TWO

## ZAMBIA

### 2.1 Overview

Zambia is a country of approximately 752 000 square kilometers in area and is situated south of the equator in sub-Saharan Africa. It is land locked and is divided into ten provinces. The country has a population of approximately 13 million people (CSO 2011) and has 72 tribes distributed geographically and to a large extent in line with provinces. Each province has a “dominant” tribe. English is the official language while in each province, the so called dominant tribe’s native language serves as a regional language taught and spoken in schools and to some extent substitutes English as the official language in that area. The languages include Nyanja, Bemba, Lozi, Luvale, Luanda, Tumbuka and Tonga (Ojkowski 2012).

### 2.2 Politics

Politics contribute significantly to the civilization of a people as it directly affects education, economy, human rights and other factor associated with the well-being of the people. Because of this, a brief overview of Zambian politics is presented here.

Zambia is a former colony of Great Britain. It gained its independence on 24<sup>th</sup> October 1964 under the leadership of Dr. Kenneth Kaunda. Kaunda will be remembered in Zambian politics not only for being the first republican president, but also for uniting the country ethnically and regionally through deliberate policies aimed at discouraging tribalism, nepotism or racism. He introduced the philosophy of humanism that discouraged exploitation of people by people and instead encouraged co-operation. However, Kaunda will also be remembered for the dictatorial tendencies that characterized the last two thirds of his rule (Phiri 2006). During this period, the one party state whereby only the United National Independence Party (UNIP) was allowed to exist as a political party was introduced by a constitutional change in 1973. Thereafter, he consolidated his rule by ensuring that nobody contested the presidential elections but him. He also applied the state of emergency for almost the whole duration of his reign, and used it to curb the freedom of association and expression as well as other human rights of his subjects.

In 1991, a wind of change blew across Zambia forcing Kaunda to succumb to the pressure of re-introducing multiparty politics in Zambia. He lost the presidential elections to a trade unionist, Fredrick Jacob Chiluba and his Movement of Multiparty Democracy party. During Chiluba's reign, the constitution was changed to allow a maximum of only two terms of 5 years rule for any president. Chiluba's tenure ended in 2001 and with the hope to continue ruling in the background, he hand-picked a successor who stood on his party's ticket and won. His name was Levy Mwanawasa. Mwanawasa ruled until his death in 2008 when he was succeeded by his vice, Rupiah Bwezani Banda (ECZ 2012). Banda lost the elections after a brief 2 and a half years rule to the incumbent president Micheal Sata (ECZ 2012).

### **2.3 Economics**

At independence, Zambia was a wealthy country propelled mainly by its mineral reserves especially copper, but the economy was in the hands of foreigners. The government nationalized most of the big companies including those connected to the mining sector (Osei-Hwedie 2003) and instituted some development programs some of which worked well such as the building of infrastructure e.g. schools and hospitals around the country. In the early 1970s, the prices of copper (accounting for about 95% of Zambian exports then) fell on the world market (Bized 2001). This pushed the country into heavy borrowing from the international monetary fund (IMF). By the 1980s Zambia had been transformed to become one of the most heavily indebted countries in the world, with the IMF insisting that the country follows programs to stabilize its economy. The structural adjustment programs as they were known, did not work out well and Zambia's economy continued to nose-dive (Osei-Hwedie 2003). Today, Zambia remains one of the poorest countries in the world with the average citizen living on less than a dollar a day. Basic services such as education are poor for the average Zambian while health care is almost non-existent.

When it comes to sharing the country's wealth/development, the country can literally be divided into two: urban and rural, with most wealth- goods and services being more available in the former compared to the latter. Secondly, the country's development is concentrated around the line of rail, built in the 20<sup>th</sup> century by the British South African Company to transport copper from the copper belt (Northern Rhodesia as Zambia was known before independence), through Southern Rhodesia (now Zimbabwe) to South Africa. All towns situated along this rail developed more than the towns situated away, probably because more

activity in terms of trade took place in these areas. Livingstone, one of the sites where the research was conducted is situated on the line of rail.

Poverty can be defined as something that deprives a person from certain opportunities such as a long healthy life accompanied by having access to education, resources for decent living standards (Schubert 2003). Poverty is usually categorized into two, namely; internal and external poverty. Internal poverty is something that the nation has control over while the external version is caused by a natural disaster, for example, drought or floods. Internal poverty is Zambia's main problem as a big number of Zambians lack proper housing with no running water, sanitation, income and to sum it up one would say they have no freedom to exercise as well as participate in society (Schubert 2003).

## **2.4 Research area**

As stated in chapter 1, this study was undertaken in Kazungula and Livingstone districts (Figure 1) of Southern province. The communities in these districts differ significantly both socially and culturally. Livingstone the tourist capital of Zambia is urban and therefore fairly well-developed and inhabited by many immigrants both from within and outside Zambia. It was established as a district since independence and beyond and its local government is well established and is administered by the central government which means more budgetary allocations for goods and services.

Kazungula district on the other hand is a rural area largely inhabited by the Toka-leya people. Until recently, the people in this district were administered by a local chief, Musokotwane. The attainment of district status means that more goods and services will likely become available as the local government administration will be done within the district itself.

Relevant to the present study is the fact that the average standard of living is partly dependent on where the people live, with those in urban areas being generally better than those in rural areas. For people with disabilities as well, those living in urban areas were generally better-off compared to those in rural areas. The selection of Kazungula and Livingstone as the study site was done purely on the basis of convenience since this is the operational area of NAD which was instrumental in the identification of participants of this study through their network

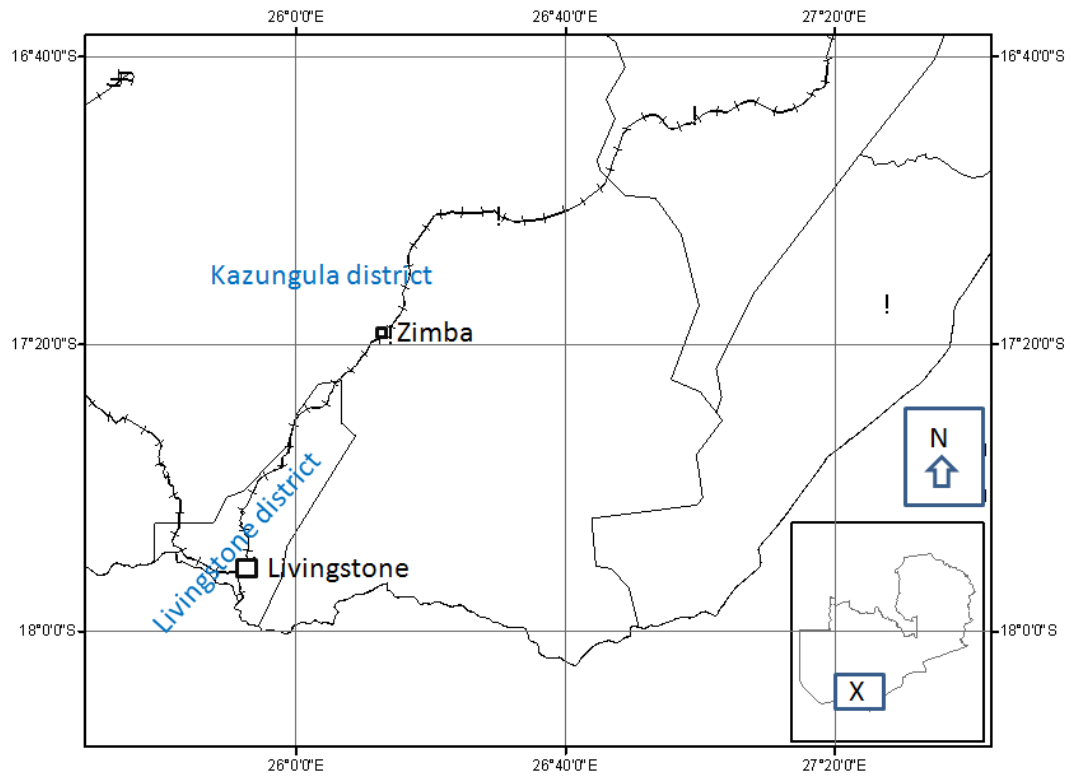


Figure1. Map of Kazungula and Livingstone districts. X represents the location of the two districts relative to the rest of Zambia.



## **CHAPTER THREE**

### **DISABILITY, HUMAN RIGHTS, UNCRPD AND CBR**

#### **3.1 Disabilities**

Disability is a social concept that is used in many different societies with a high discriminatory attitude to describe people with impairments. As much as it is complex, disability is not just an amputation, deafness, blindness (impairment) but surrounds all the barriers in the society that hinder people with disabilities from having access and full enjoyment of life. It is generally a concept that is used to describe who are different able-bodied while sometimes this description is based on criticism of another definition such as social model of disability (Gronvik 2008).

The convention does not really give one concrete definition of disability although it states that “disability could be an evolvement concept and that sometimes this concept results from the interaction between persons with impairments and attitudinal as well as environmental barriers that often hinders them from having a full and effective participation in societies on an equal basis with other members” (UNCRPD 2010). According to article 1 of the convention, one would describe persons with disabilities as people who have some long-term physical, mental, intellectual or sensory impairment which in interaction plays a role in hindering someone from having a full and effective participation in society. In Zambia, a person with disabilities means, “a person with a physical, mental or sensory disability, including a visual, hearing or speech functional disability” (Schulze 2010).

Disability as earlier mentioned is a complex phenomenon because it could also be viewed as a result of an interaction between non-inclusive societies and individuals. An example of the interaction would be when persons using wheelchairs cannot access most of the facilities because of environmental barriers such as buildings with staircases only, making it inaccessible to them. States should ensure that architects, construction engineers have the consideration of designing buildings which are friendly and easy accessibility to every person (Schulze 2010).

### **3.2 Human rights**

Human rights are rights that every person is entitled to irrespective of sex, race, nationality, shape, age and religion, to mention a few. Every human being deserves to have equal rights. The universal declaration of human rights is guaranteed by UN laws which are present in form of treaties (Uvin 2004). All nations that subscribe or ratify the treaties have an obligation to ensure that the international laws are fully respected, followed and fulfilled. According to article 1 of the universal human rights declaration, “All human beings are born free and equal in dignity and rights” (Schubert 2003). The term “human rights” is something that has a special meaning with a universal attachment to it and is protected by bodies such as United Nation and governments. According to Andreassen and Sano, human rights are an intervention that focus on things that improve the conduct of public authorities such as respect as well as ways of protecting people’s rights (Andreassen and Sano 2004).

The UN General Assembly decided to adopt the declaration on human rights in 1948 with the view of seeking to give equal rights to every human being. The declaration emphasizes that every human being needs to be given total freedom of achieving what they want by having equal rights without any form of discrimination of any kind due to race, sex, religious, nationality, ethnic group or even political grounds. The declaration in article 25 claims that “every human being deserves the right to security in case of loss of employment, sickness or maybe accident, disability, widow-hood, old age or livelihood in situations where man has no control” (Quinn et al. 2002). Since then the focus has remained the same; to empower the disadvantaged by ensuring that the world is aware that every human being deserves equal opportunities of enjoying the freedom of speech, belief as well as the freedom from fear. The UN Convention on the rights of a child adopted in 1989 shook the world as it was a big relief, a good thing which focused on the future leaders and was making the world a much better place (Gabel and Danforth 2008) .

This anti-discrimination subject has opened many doors to other rights-enforcement instruments which have played a big role in making the world a better place to live in. Following the declaration the international covenant on Civil and Political Rights came into force followed by the international Covenant on Economic, Social and Cultural Rights which was acted on in 1966. The combinations of these instruments have helped to strengthen the international code of the Legal binding provisions in the field of people’s rights (Quinn et al.

2002). The combination of two strong Covenants develops and supplements provisions of the universal declaration while putting the three rights instruments forms the international bill of human rights.

The UN has continued working hard in the interest of all human beings and realized that as much as a big percentage of world's people live in poverty, people living with disability are the most vulnerable of all around the world. The human rights commitments does emphasize that a member states must ensure that they protect, promote and fulfill human rights by even explaining each of them in clear terms. The human rights goals can only be achieved if all states adopt and ensure that policies are implemented in different activities that allow women to avoid unpleasant situation of violence (Schulze 2010).

### **3.3 Rights of persons with disabilities in Zambia**

The international bill of rights has an emphasis the promotion and encouraging human respect which includes all types of freedom despite any background, Article 1 of the universal declaration does emphasis on the equal opportunities.

*“All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood”* (UN 1996).

The Zambian government has committed itself by ratifying the convention on rights of the persons with disabilities and to ensure that the goals are achieved, it has adopted a number of different laws as well as policies in relation with persons with disabilities (U.N. 1996). At the moment it would be fair to say that the government has not formulated strong remedies or avenues to directly address specifically women rights (Zimba and Kaseketi 2011).

### **3.4 United Nations Convention on the Rights of Persons with disabilities (UNCRPD)**

UNCRPD was first negotiated and drafted between 2002-2006 and was adopted on the 13 December 2006 at the UN headquarters in New York. It was opened for signing on the 30 March 2007 (Quinn et al. 2002) and broke the world record for the number of signatories (82) on the first day with 44 others signing for the optional protocol and one ratification. Louise Arbour, the UN High Commissioner for human rights realized that there was great need and potential for the convention which would not create new human rights but add a set of new features (Schulze M 2010) but most importantly, the main aim of the convention was;

*“to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, based on the holistic approach in the work done in the fields of social development, human rights and non-discrimination and taking into account recommendations of the Commission on Human Rights and the Commission for Social Development” (Schulze 2010).*

The UNCRPD acts as a manual which explains all the articles and ensures that they are linked to both the universal declaration of human rights and the core of human rights treaties. By 2010, at least 87 countries had ratified the convention while 145 were signatories. According to Louise Arbour, the convention was not only going to be a treasure trove for the people with disabilities but also for the good of all human beings (Schulze M 2010). The convention which finally came into effect on the 13 may 2008 has become a powerful instrument of ensuring that people change attitudes and approaches towards people with disabilities. It has been a big challenge to change the mentality of people who viewed those with disabilities as just objects, rather than human beings. People with disabilities have been treated unfairly for so long in different circles of life such as medical care where they could hardly receive medical attention, a right that they are entitled to.

The social protection is another area that people with disabilities have been neglected. The UNCRPD ensures that people with disabilities claim their rights and are able to make their own decisions (UNCRPD 2010). During the recent years the discussion of disabilities has been one of the topics that has captured the world’s attention (Armstrong and Barton 1999). Indeed, numerous research projects have been carried out on how people with disabilities would be integrated into societies. However, the UN Convention has pushed things further by coming up with different mechanisms that accommodate the inclusion of people with disabilities in different circles such as by stressing its goal as explained in Article1.

The convention is a unique instrument in both development and human rights with a clear focus on promoting, protection and ensuring that every person with disabilities has full and equal opportunities. Through promoting equal rights, people are able to stand on their own and make decisions that are productive to them as well as the society. It has in many ways given universal recognition in a way that has changed lives of people with disabilities especially in the area of full inclusion and effective participation in their daily activities. As

mentioned earlier that 80% of the people with disabilities live in developing countries, UNCRPD emphasizes on focusing on protecting the poorest and the worst-off in order to make particular relevance in the advancement of the rights. Article 1 (Declaration on the rights of Development) of the declaration clearly states that every person is entitled to development. This is an inalienable human right which comes through participating, contributing to, as well as given the opportunity to enjoy economic, and social, cultural and political development.

Article 6 emphasizes that states shall by all means ensure that full development, advancement together with empowerment of women must be given priority in order to guarantee the positive impact of the convention. Just like any other person, the convention argues that women with disabilities must exercise and enjoy their rights and freedom. People with disabilities have experienced violations such as rape, forced marriages, forced sterilization due to being women with disabilities (Schulze M 2010). These women have limited chances of getting married and in cases where they have children their children are often taken away from them against their will.

The UNCRPD argues that redressing such violation is in most cases harder as these women are dependent on the care-giver who would be family, friends and institutions. Few places except them and treat them equally as it has been observed from the UN statistics that the discrimination is wide-spread such that only 25% of women with disabilities are in workforce (Schulze 2010).

### **3.5 To what extent has the adoption of UNCRPD influenced the lives of Zambia's WWD?**

Zambia, like many other countries has been keen in recognizing the human rights guidelines in order to dismantle the barriers. According to the 2009 report from the International Labour Organization (ILO), 7 to 10 percent of the Zambian population lives with disabilities and out of this number most of them live in rural areas. In the year 2000, the Zambian population and housing census on people living with disabilities showed that more than 80 percent were self-employed and dependent on small scale farming. As a result the poverty level among them was very high. Street vending and begging as a means of survival were common and literacy levels were extremely high (Mubita 2009). It was for this reason that the government together with different organizations and NGO's adopted a number of laws and policies in support of the people with disabilities. Different organizations including NGO's and the government

have included the right to decent productive work which would help to provide for basic needs. A lot of effort has been put towards implementing the Action-Plan which was established for the African decade of Persons with disabilities with the target to 2019 (Mubita 2009).

The International Labour Organization (ILO) has offices in Zambia with the goal of achieving decent work for all including people with disabilities through promoting labour standards, advocacy, knowledge building. It has some cooperating partners focusing on sufficient and effective decent work programs. Promoting the employment of the people with disabilities through effective legislation is another strategy that is being used to identify the priorities and needs of the people with disabilities mainly through representatives such as PAPD.

### **3.6 Community Based Rehabilitation (CBR)**

As briefly mentioned in Chapter one, CBR is a development strategy that focuses on addressing and improving the living standards of people living with different forms of disabilities and their families. This strategy emphasizes empowerment of people with disabilities so that they have easy access to all necessary and basic needs to overcome barriers that they face in all aspects of human life and development such as education, employment, health as well as the social services. CBR is a combined effort from people living disabilities' families, communities, organizations including DPOs and governments. Below is a schematic representation of the CBR matrix showing the different components This CBR theoretical framework is the approach that was used in the present study.

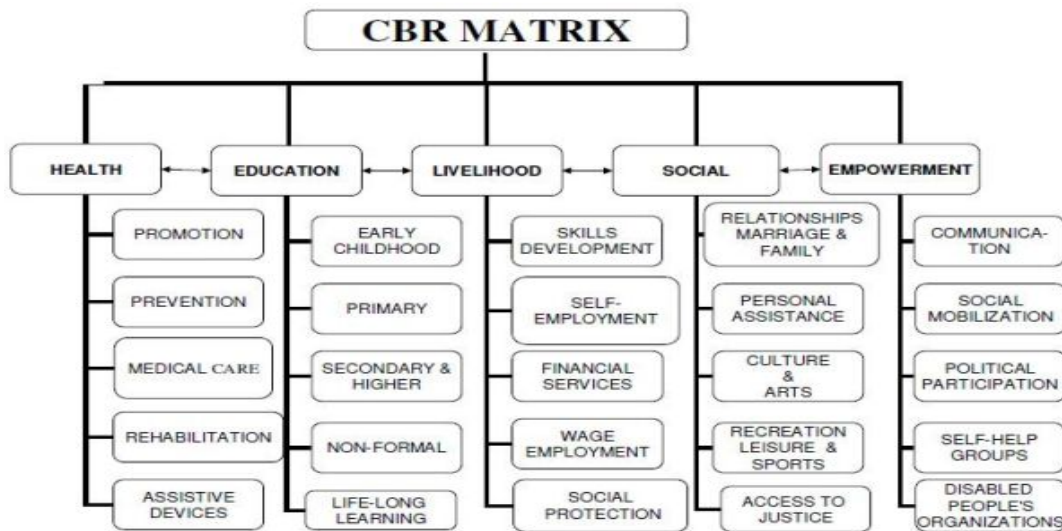


Figure 2. WHO approved CBR theoretical framework (adapted from (WHO 2010)).

CBR is basically interpreted differently depending on the local content where as some communities use already existing policies while others formulate their own in order to suit their needs. These policies have a huge influence and play constructive roles (Cornielje 2009) on the lives of people living with disabilities and their families. CBR has had a great impact on the implementation of different policies because it is interpreted differently depending on the country and community within as it means different things to different people. Some communities view CBR as an empowerment strategy while others view is as something like a service provider (Cornielje 2009).

According to Cornielje, implementing and developing CBR is in most cases dependent on the socio-economic status of any given community (Cornielje 2009). It is not a strategy that has strict rules to be followed as it also differs in the way it is organized, structural framework or philosophic beliefs. It has certain programs that only focus on health services, while others focus on empowering activities of people with disability, human rights issue is also another area that is being focused, socio-political issues as well as programs that just focus on working within the social disability model (Hartley and Okune 2008). The present study was mainly centered on the social component (second but last column to the right in figure 2). This component addresses relationships including family and marriage, personal assistance, culture and arts, recreation as well as access to justice.

CBR as a strategy has focused on addressing the needs and demand of the people with disabilities particularly in less-developed countries. Most of its attention is to ensure that equal rights are being practiced and to finding various programs that would help eradicate poverty (Hartley and Okune 2008). After a long struggle of achieving UNCRPD as a driving tool to the equal rights for the people with disability, it opens doors to opportunities that would change their lives. The adoption of CRPD is a powerful tool to ensure that CBR developments take place with an emphasis in (Article 26) which states that;

*“Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas”* (Cornielje 2009)

The adoption of CBR as an approach is definitely expected to close the gaps between people with disabilities and their communities. The equal rights and poverty reduction targets can only be achieved if the policy makers and different organizations focus on proper implementation and enforcement programs.

### **3.7 What has been done to ensure that CBR is incorporated within Zambian Policies?**

A number of organizations work with a view of changing the situation of people living with disabilities. Most of these organizations have one concept which is community development through integrating and empowering targeting programs that would allow people with disabilities become contributors in changing their own lives. One of the organizations was formed by a special group of women living with disabilities to directly deal with women in their own situation. The Zambia National Association of Disabled Women (ZNADW) was founded in 1990 with the aim of improving the lives of women throughout the country. The organization’s goal is to encourage women to accept themselves using programs that would help integrate them into communities. The other goals is to promote education, training and employment opportunities by sensitizing the public about what these women needed in order to live a normal and meaningful life. Publishing journals or newsletters which mainly focused on the human rights of a woman living with a disability is one way by which they reach out (ILO 2007).

Zambia National Association of the Deaf (ZNAD) is another organization that was established as far back as 1981 with the view of demanding the rights of people with



disabilities through having qualified interpreters and teachers who would be in a position to teach deaf children, their families, communities and service providers (Hurst 1995). The organization argued that deaf people were not recognized and demanded recognition. It later launched a sign language program after the return of two teachers from world federation of the deaf headquarters in Helsinki and as at now it has published a first sign language dictionary in Zambia (Hurst 1995). Furthermore, it aims to establish a sign language department at the University of Zambia, arguing that sign language should be recognized as an official language. Other organizations working in this field and focusing on the CBR programs include Opportunity Zambia, which is collaborating with the Norwegian Association of the Handicapped. However the convention on the rights of persons with disabilities and the protocol has and still is marking a shift in thinking about people with disabilities.

## **CHAPTER FOUR**

### **PRESENTING THE FINDINGS**

#### **4.1 Introduction**

Data collection in this study involved personal observations as well as interviewing women living with disabilities either individually or through focus groups. In Livingstone district, three key persons including one blind man heading an organization that works with the people living with disabilities were interviewed. Although not originally planned, the man was interviewed with the anticipation that his inclusion would bring out a balanced view from a man's perspective as well as a wealth of experiences about the other people living with disabilities that he interacted with and represented in the organization that he chaired. In addition, a government official, the Provincial Special Education Standards Officer (SESO) in the Ministry of Education was also interviewed in order to get a balanced view especially on questions related to the government provisions. In Kazungula district, two women living with disabilities were interviewed. In addition, an independent female social worker aged 41 years was also interviewed because she works with girls and women with disabilities in the district.

It became eminent during interviews that the level of education and employment status of individual respondents strongly influenced the responses, with those in Livingstone at a better advantage than respondent from Kazungula district. Brief backgrounds of the respondents are reported below.

#### **4.2 Stigma**

One of the strongest basis for discrimination against people living with disabilities in developing countries is stigma. The type and form of stigma varies from place to place or between ethnicities or other groupings. In both Livingstone districts and Kazungula districts, this issue also came out eminently although with different degrees from family to family or even between communities. The issue was discussed more in focus groups than during individual interviews. In general, it was believed that having a disabled child brought shame to the family. The communities and families regarded disabled people not as "full" human beings. As an example, when such families were visited, they would hide the disabled child so that other people do not see him or her. Disability was regarded as some form of contagious

disease that the rest of the community was afraid to come in contact with. Furthermore, the community treated people with disabilities as if they were not normal, were mad. Disabled people were believed or expected to produce disabled off-springs, a fact that influenced their chances of getting married as further discussed below. These issues are further discussed in respective components below where they arose.

### **4.3 Livingstone district Individual Interviews**

The first person to be interviewed (Respondent 1) was a 35 year old lady with a physical disability. She had received education up to, at least, high school level and was a head of one the non-governmental organizations related to people living with disabilities. The second respondent (Respondent 2) was a man who was approximately 48 years old, blind and had received education equivalent to college level. He was in regular government employment and also chairperson of a non-governmental organization. Respondent 3 was a woman in her sixties, also blind and had received education equivalent to high school level. Interestingly, all respondents reported that they acquired their disabilities early in their ages after suffering from one disease or another. Respondent 4 was a senior government official dealing with people living with disabilities.

#### **4.3.1 Physical barriers and empowerment**

The greatest barrier preventing women living with disabilities in Livingstone district from enjoying full social inclusion and participation in their respective families and societies are physical barriers. The blind for example, depend on other people to lead them wherever they would like to go. There is very little, if any, personal empowerment so that they may be able to go about their business without the physical help of another person as reported by respondents 2 and 3. When it comes to reading for example, very few of them have the training in Braille or else the documents were not available in the language. Respondent 2 whose job was to operate the telephone reported that he was unable to use the telephone directory because it was not translated to Braille even though this was integral for his job. On the other hand, to get the physical help that they need was a problem since such people would be required to give up their personal responsibilities in order to dedicate themselves to this service. The government did not provide this service, if it did then the service delivery was inefficient, so the responsibility rested squarely on the shoulders of relatives and friends. The lucky ones had children to lead them. For the deaf, personal assistants to interpret for help them in day to day communication were required but not available. There were very few

people trained in sign language to help out. Respondent 1, 2 and 3 attested to this problem giving examples of hospitals where it was difficult to communicate with medical personnel. These sentiments were echoed by focus groups as reported below.

For the physically handicapped, for example those that could not walk, they needed wheelchairs. Although several organizations have helped to make available wheelchairs to the needy in many areas of Zambia including Kazungula and Livingstone districts, only the basic types were available irrespective of the degree of disability. During the investigator's period in the study area, no motorized wheel chair was observed. The road infrastructure was poor making it hard to use wheelchairs while most of the buildings were inaccessible to the use of wheelchairs. As pointed out by respondent 2, it was impossible for someone on a wheelchair to visit the provincial administrative head (Permanent Secretary) whose office required that you go upstairs.

Another barrier that came out prominently was the lack of education as a means of empowerment for women living with disabilities in research areas. This was evident first and foremost by the average levels of education of the respondents, with most of them not having education beyond high school. One of the contributing problems to this was the lack of schools specialized for people living with disabilities.

Lack of employment for women living with disabilities was yet another barrier that was identified in this study. This response was given as a priority for almost all respondents interviewed. Respondent 2 said that he was largely satisfied with his life mainly because he had a job and could provide for his family.

Women living with disabilities in Zambia do not receive any disability allowances. This was viewed as a barrier to the empowerment of women living with disabilities especially those that are not in employment and have no source of income and virtually all respondents attested to this. Respondent 4 was a single mother and received no support to care for her children.

The final barrier reported in the individual interviews was loneliness. Respondent 3 said she had to relocate from some of the places where she lived before because of loneliness. Partnership means a family to share intimate issues as well as a possibility to share joy as well as difficulties.

### **4.3.2 Cultural influences on families and relationships**

In general, the respondents did not feel segregated or discriminated upon by society on the basis of their disabilities. When it came to relationships, all respondents said that it was not a problem for them to get involved in a love relationship. Respondent 1 had a boyfriend while Respondents 2 and 3 were married and had children and grand-children. Responded 3 had got married in 1981 and had met her husband through other people. None of them felt that their disabilities were having any influence on their relationships or their marriages. As for family planning, none of the female respondents expressed any difficulties in obtaining information or medicine for use in family planning. However for Respondent 2, being a blind person found it difficult to obtain information on family planning as none of the information had been translated into Braille. All the information he had on the subject had been told to him by people who had read books or had seen pictures in books. However, he felt fortunate enough to have had a wife who could see and whom he could depend on to practice family planning with.

Despite her disabilities, Respondent 3 was looking after an extended family since she was the bread-winner of her family and most of her siblings had died. She felt that she was participating adequately in the family.

### **4.3.3 Awareness and perception of WWD of their human rights and UNCRPD**

According to respondent 1, the government did not ensure the protection of human rights of people living with disabilities. She gave examples of people that were deaf saying that when they fell ill and went to hospitals, there were no trained personnel in sign language that could assist them explain their complaints or translate what the health providers were saying. It was incumbent upon the person living with disabilities to provide themselves with solutions to this effect. She also added that there were not granted any privacy and also the infrastructure provision in the country was designed for able-bodied. She mentioned that for her, she needed help to get onto public buses and usually had to be lifted and for this she depended on the crews of the buses. Even people on wheel chairs, there was no infrastructure for them. In public offices where there were no lifts and these are the majority, there was no alternative to stairs made for them. All these amounted to the failure by the government to provide them with basic services and in her understanding in violation of their basic human rights.

Respondents 2 and 3 complained that government was not doing enough for the blind and their families. For the blind trained to use Braille, it took a long time before important documents could be translated into the language.

When asked about where to report in case of violations of human rights, most of the respondents said they were aware of the human rights commission of Zambia. Some, like respondent 1 said their knowledge was however limited and if aggrieved would depend on organizations to fight for them. Respondent 2 recalled a situation where one of his colleagues' merchandise was confiscated by the local authority for street vending. They reported the matter to the Zambian Human rights commission (ZHRC) which helped to retrieve the merchandise. He also narrated an incident where a child was denied a school place on account of disability, and how the ZHRC helped to force the school authorities to rescind their decision and offer the child the place. Respondent 2 also said that he was aware of a program in Lusaka abbreviated ZAFOD which availed legal aid to people living with disabilities if their rights were violated.

On UNCRPD, almost all of the respondents said that they had heard about it although their knowledge of it was very limited. Respondent 3 said she had heard about it in the news while respondent 2 hoped more information would become available when the documents were translated into Braille

#### **4.3.4 Expectations from GRZ by WWD**

The top most expectation of women living with disabilities from the government was social security in terms of financial empowerment. This was not surprising as most of them were poor. Respondent 2 who had a job said life for him was easier because of the employment. He stated that if his colleagues were also employed, this would help a lot to make their lives better.

#### **4.3.5 Interview with GRZ employee**

The government official (respondent 4) reported that government had a policy of education for all. He pointed out that the government had built 4 boarding schools in Choma, St Mulumba, Maamba, Monze and Mazabuka within the province for people with special needs while several other centers were also opened for children. There was however no specific mention of special schools for people with disabilities in Livingstone or Kazungula districts.

On the issue of the communities' interaction with people living with disabilities, he stated that for exposed or educated communities or families, it was not a problem; otherwise it was hard for families to accept that their relative had a handicap. He had this to say about the previous consultative forum that he had attended, "It is clear that people feel embarrassed to parade disabled children. If one has 6 children, they will say I have 5 children and the other one nchilema (disabled)."

Government had embarked on a set of policies starting with educational reforms, the focus on learning and then education our future. All these were focused on disability. Thus in the opinion of respondent 4, government was doing a lot to improve the lives of disabled people.

On human rights, respondent 4 admitted that in his opinion, law enforcement officers needed sensitization on issue of disability; he gave an example where if there was need to put a wheel chair in a minibus that had no provision for this, and there no minibuses in Livingstone have such provisions, the police would impound the bus. Meanwhile he did not know anything about UNCRPD, probably since his field of expertise was education.

Asked what areas he thought should be prioritized, the respondent said education should be free, and there should be provision of health care, empowerment and recreation facilities.

#### **4.3.6 Involvement of WWD in community activities**

Most of the respondents interviewed were involved in different activities. Respondent 1 said she participated in sports for the disabled that were held in Livingstone. Respondent 2 was involved in politics at ward level, was a chairperson for the Parent teacher association at the school where his child went and was also a member of the Press club.

#### **4.4 Kazungula district individual Interviews**

The first respondent to be interviewed in this district (Respondent 5) was a woman who had become deaf at the age of 7 following an illness. She was living with her friends. The second respondent (Respondent 6) was physically disabled and had 30 years of age. She had one child, was single and was still living with her parents. She had become disabled at the age of 1 and a half years and had a humble educational background. The last person to be interviewed (Respondent 7) was a female social worker aged 41 years who was not disabled but worked with girls and women with disabilities in Kazungula district.

#### **4.4.1 Physical barriers and empowerment**

One of the biggest barriers that women living with disabilities in this district had was the lack of education and also financial support. The people in these communities were very poor and could barely afford to pay for education. As one respondent 5 put it, “My mother said there was no money to send me to college. I have no support from my family and not even the community can accept me.”

Employment was another issue. Respondent 5 said that she had no employment and life for her was very hard. Respondent 6 however said she had worked as a cook for World Food Program where she worked as a cook; thereafter she started selling doormats which she ferried to Lusaka. To her life was not that hard and the community was ok as far as she was concerned.

#### **4.4.2 Cultural influence on families and relationships**

Unlike the respondents in Livingstone, the women with disabilities in Kazungula were of the opinion that their culture discriminated encouraged against them. Respondent 6 felt that her situation prevented her from getting a husband. “My disability is affecting me from getting married. But some men would want to marry you because of the money you have and when the money is finished, they leave you.” In contrast, respondent 5 did not think disability had any influence on her getting a boyfriend. She said, “I have a boyfriend although we have not formalized the relationship.”

When it came to family planning, respondent 6 said she had previously practiced it without any problems although she was not doing it at the time of the interview probably because she had no partner.

#### **4.4.3 Awareness and perception of WWD of their human rights and UNCRPD**

Respondent 5 reported that she was aware of UNCRPD while respondent 6 expressed ignorance. The latter however added that her impression was that the courts were not treating able-bodied and people with disabilities unequally.



#### **4.4.4 Expectations from GRZ by WWD**

The priority for respondent 5 was employment and that the government needed to be more involved into the activities of the disabled people which at the moment was lacking. Both respondents however agreed that they also needed access to loans, more availability of educational centers and well as health care.

#### **4.4.5 Interview with social worker**

This respondent reported that the community in Kazungula had stigma against people living with disabilities. She mentioned the issue of some families hiding their children. She further went on... “Even the community it is the same, when they see a disabled person they say he is mad, they don’t think it is a disability.” She however added that with the government having officers open to the public and helping to protect the human rights of the disabled people, supported by the help of NGOs over the last ten years, the situation was improving. There was more interaction between the community and people living with disabilities. She further stated that government had opened up offices where children were taken for complaints and the courts differentiated cases related to disability. According to her, the self- sustainability and loans for starting or building businesses are areas that need to be given priority in order to improve lives of people living with disabilities.

On strategies of CBR, not much had been done to follow the approach. She said that they used to have games for the disabled but not any more since they lacked funding.

#### **4.5 Focus Group interviews**

Three focus group interviews were held in this study, one in Livingstone and two in Kazungula district. The women interviewed ranged from approximately 25 to about 60 years old with only three below the age of thirty. Despite the age differences the women were very free to express themselves. A detailed description of the women interviewed is provided in the appendix.

##### **4.5.1 Livingstone focus group interviews**

In Livingstone district, a total of 7 women living with disabilities were interviewed. One of the seven respondents was married and two were divorced. Three of the women had babies

outside marriage with one of them not knowing the father of her child as he or she was conceived following being raped. The other two were not yet married.

All of the Respondents in this focus group had attended school at least up to primary education while three of the women completed their secondary school. The married respondent finished school and got herself a job in the ministry of education where she worked as a telephone operator until her retirement in April 2011.

The respondents had different forms of disabilities (appendix 1) with four physically disabled, two deaf and one was blind. Only one of the physical disabled respondents was born with a disability while most of them just acquired disabilities between the ages of 2 to 12 years old. The rest of the physical challenged respondents acquired the disability either through polio, measles and accident. One of the Respondents became deaf after a serious sickness which she said almost took her life but could not get treatment due to distance from where she and her family lived. The blind respondent used a personal assistant in helping her find the way and further explained that her children have helped her in that area. The deaf respondents also used assistants in cases like when they go to hospital and places where they require explanations.

#### **4.5.1.1 Physical barriers and empowerment**

The participants in this study valued their culture which is the driving factor of their daily lives through interaction and communication. When asked if culture had a big influence in their lives, most of the women said they did not feel like their culture had a negative impact on them living with disabilities. The people around them did not treat them different. Livingstone focus group respondents 1 (Lfg1-1) and Lfg1-7 had their own views about the cultural influence on their lives. Below are the views of Respondent 1.

“When people see me they make judgments about me because they think that since I have a disability that means even my brain is disabled. I remember the experience I had when giving birth to my first born child. It was such a terrible experience that I will never forget how they decided to separate us from the rest of the patients and put me aside for unknown reasons and I really felt discriminated”.

In agreement to Lfg1-1 on the issue of hospital discrimination, Lfg1-7; expressed her views saying that people with disabilities have many different challenges such as...

“When the hospital staff sees people with disabilities, they judge them badly. We have challenges in our lives because when it is time for us to get married, men fear that maybe when they marry a woman with a disability they might end up giving birth to child with a disability which will bring shame to the whole family, although on the other hand she confessed that it does not matter what other people think of her because she has accepted her disability and life seem normal right now.”

Another note of attention raised was of one respondent (Lfg1-3) who reported that she had a neighbor who ignored her and what she had to say:

“I have a neighbor who overlooks me, when she wants to ask for something from me she asks my children and not directly from me.”

#### **4.5.1.2 Cultural influences on families and relationships**

The biggest challenge according to Lfg1-4 was the community which discriminated them because they did not understand their situation. She wondered if it was the cultural influence or maybe lack of knowledge that caused the communities to mistreat people who are disabled. Below is the statement on her experience...

“Some communities are very difficult to live in, like in my case I had to move because where I used to stay at first people would stay away from me because they thought that my disability was contagious. This really made me feel bad about myself. But now the community I moved to is very good and I am given support and encouragement.”

She further touched the issue of how the majority of the people misunderstand disability by citing an example of their marriage situation where she says that most of the time:-

...“A man may like you but your own parent not like him,

...so I discovered that problems of getting married are

... sometimes caused by parents”.

Lfg1-4 felt discriminated because of her physical appearance and therefore discrimination does in this case qualify to be not only actions but also offensive remarks which end up creating unpleasant situation for the discriminated person to handle it.

Challenges faced vary depending on the form of disability whereas respondent 5 explains that her biggest challenge had been her love life because women with disabilities are discriminated when it comes to marriage. She narrated her love story as follows...

“Men have come to me asking for a hand in marriage but what I discovered is that men think that women who are deaf are easy to sleep with, so in that case it makes me wonder if they come for genuine reasons or they just want to use me as a sex object. But sometimes I get the feeling of wanting to get married but the problem is that it is difficult for us deaf people (women) to perform in marriage because we are not taught anything about marriage and that is a disadvantaging issue in marriage for us.”

According to Lfg1-4 she mentioned that, “Going to church is the easiest way to find men although I do not greet married men”. All women seemed to agree with that statement and Respondent 1 brought in another interesting observation which she said is very common...

“Some men believe that women with disabilities are AIDS/HIV free so they come to us and because of that some married women in the neighborhood would not greet us for fear that we might grab their husbands.”

Adding to this interesting conversation Lfg1-4 condemned the women for their weakness of allowing men to entice them as little as 5,000 kwacha (\$1 dollar) for sex.

Lfg1-5 was willing to share her experience about men who are just interested in sex with women with disabilities saying that; Its very dangerous for those who come only in the night (darkness) and they have no idea if you are beautiful or not but they just have sex with you. It happened to me and the next morning when he discovered that I have a disability he immediately dumped me.”

Finalizing the contribution, Lfg1-6 had to share a very touching story when she said that the community around knew her very well and they were several occasions when unknown men entered her room and raped her. She went on saying that these people knew that she was deaf and could not scream for help, the next morning when she tried to tell her parents they totally disregarded the whole story and told her to keep quite because no one would want to sleep with a deaf person like her. But unfortunately the respondent had a child whose father she did not know at least up to the time the study was done.

Listening to these horrifying testimonies made the researcher wonder whether to go to police on her behalf or keep her promise that whatever discussed would be kept confidential?

#### **4.5.1.3 Family planning**

All the women did not think obtaining information or practicing family planning was a problem to them because if they needed it, they could easily go the hospital where they were given for free. On the other hand Lfg1-1 and Lfg1-5 said they did not need family planning because they stay without men (abstain).

#### **4.5.1.4 Awareness and perception of WWD of human rights and UNCRPD**

Even after the ratification of the convention, most of the respondents said there was very little the government was doing in terms of helping them because even hospitals have no facilities for the people in their situation. One respondent expressed concerned on how they were laughed at when at the hospital just because there were deaf. She further said that the government had made people with disabilities even poorer because of being discriminatory policies against their basic needs. Respondent 5 agreed with this saying it was the government's duty to ensure that people were given proper training skills.

Nevertheless not all respondents felt that the government had failed them, respondent 4 shared that the government assisted her in accessing health care. She recalled a situation when she had been ill and her neighbors were discouraging her parents from taking her to the hospital encouraging them to take her to tradition herbalists. Her father however insisted that she had to be taken to the hospital. She says her parents do not regret that because the government hospital has been helpful to her. She also commended the government for the new accessible building facilities for physical challenged people such as at the museum and new Shoprite supermarket.

Adding to what Lfg1-4 said, Lfg1-7 agreed that the government has introduced a system where they were given identity cards for hospital use and with that card they were able to receive free medical treatment. Lfg1-2 also commented that the government was working in the right direction because right now there were many laws that protected people in their situation and all that one needed to do was to report the complaint. Lfg1-7 however still believed that there was need for the government to build more schools which would accommodate children with disabilities citing an example that children with disabilities were

often rejected in regular schools. Women said that the government had not done much in ensuring that Zambians had an equal opportunity in all areas, discrimination had made women with disabilities to be more vulnerable.

#### **4.5.1.5 Involvement of WWD in community activities and CBR**

Respondent 4 reported knowledge about CBR and that she was actively involved in attending church meetings and made a lot of small items like ear rings, doormats, baskets etc for sale. She also commented on the wonderful job done by different DPOs saying that they helped them a lot especially with financial loans. She added that recently, some of the DPOs just get their details and never give them any feedback. She further stated that they had information that in Lusaka, people with disabilities were looked after and helped well by DPOs unlike in Livingstone.

Lfg1-5 was of the opinion that DPOs were not trusted. “There are many organizations using people with disabilities these days. People with disabilities are robbed of money. They tell us to form groups and that when we do they will give us money and buy cars, after the groups are formed, we keep waiting and waiting until our parents become frustrated because our lives are not change even after joining these groups,” she said;

“I do not go to school and I feel so violated by these organizations. My greatest wish is to work and become someone in life”.

#### **4.5.2 Kazungula focus group interviews**

Two focus groups were held in Kazungula district. In the first one, most of the respondents were not very young as compared to the one held in Livingstone district. A total of 11 women took part in this focus group discussion. The composition of respondents included one deaf, five physically challenges and five blind (see also appendix 1). Unlike the focus group in Livingstone, the respondents in this group had humble educational backgrounds and this was reflected in their contributions. They lived in surrounding villages but had no contact and did not know each another. Some of the respondents were not active in the discussion and only answered when asked while others were very active in the discussion. One could see that these women were struggling with their lives and presence of the researcher gave them some kind of high hopes.

The second focus group comprised ten women, seven of which were blind and three were physically challenged. Trying to find out their actual age was not a straight forward because some of them did not remember when they were born. When the respondents were asked what caused their disability all of the blind respondents said they were born with normal eye sight but got sick and eventually lost their sights. Respondent 5 remembered that it was when she suffered from measles that ended up being blind even though it had been treated.

The findings of both focus groups from Kazungula district are reported together as they are essentially from one community and their responses were similar. The language used in the focus groups was Tonga and there was need to use an interpreter.

#### **4.5.2.1 Physical barriers, empowerment and cultural influences**

In both focus groups, the respondents reported that their communities looked down on them. According to the respondents of the second focus group, the community was very negative about people with disabilities in general and they viewed them as if they were not normal people. Some respondents however had different views, for example respondent 1 from the first focus group (Kfg1-1) whose disability was as a result of a car accident said she personally had no big challenges because the community had never discriminated against her before and even at the hospital the staff treated her just like any other person. She further described her community as a family because it had accepted her as one of them. Her complaint surprisingly was that her father did not accept her disability as he was more concerned with her contribution to the household chores. Respondent Kfg1-11 argued and seemed puzzled why people should treat them the same as able bodied people meanwhile they had disabilities. The respondents did not take active parts in the activities in their communities although others did say that they felt like they were part of the community members and participated fully.

When it came to barriers preventing the respondents from participating fully in their families and communities, almost all the respondents had similar answers with lack of jobs or income topping them all. Respondent 5 from the second focus group (Kfg2-5) had a lot of challenges in her life being a woman living with a disability but more especially because she lost her husband and all her sisters and brothers. Her children were the only source of help who assisted her with money to buy maize meal (the staple food in Zambia). This respondent also

mentioned that it was difficult for a woman with a disability to do much without finances. She continued saying that

“Life is not good for me because there is very little I can do, I cannot walk, I don’t take part in social activities and that makes me feel bad although I thank god for giving me children who are now helping me”.

Most of the respondents agreed with her that the biggest challenge they had was financial and that made their lives unpleasant.

There was strong feeling in both groups that government was not doing enough to support them financially. They expected government to give them loans for business, school fees, health facilities, fertilizers and finally skills so that they could equip themselves. They wished that the government would help them to change their lives by even providing them with farming inputs such as fertilizer, seeds and many more. The physical challenged respondents wished for mobility because it was a big challenge to go from one area to the other without any means of assistance.

#### **4.5.2.2 Cultural influences on families and relationships**

Most the respondent at focus group 1 were not married and it was their belief that their disabilities had something to do with their status. However, one respondent Kfg1-3 argued that disability was not the reason for not getting married because she had seen other women with disabilities getting married. In her case disability did not have any effect on her marriage although she met her husband in Mulobezi before her disability.

At focus group 2, only two out of ten respondents were married and their argument was that men wanted women that were able-bodied. The two married women said their husbands were very helpful in whatever they could not manage to do.

When it came to family planning, the respondents did not want to say much it that although one respondent Kfg1-9 said she did not know anything about family planning.



#### **4.5.2.3 Awareness and perception of WWD of human rights and UNCRPD**

Apparently these women are aware of the legal systems which they pointed out is in existence. Respondent Kfg1-9 who is physically challenged gave an example of what goes on in cases where “Someone comes to you and obtains money by false pretense from me I can definitely take that person to court.” However Kfg1-7 complained about how people violated their rights just because they had disabilities but even then she said; “We are able to take them to the chief to help settle the case and I should say that the law does help us so much because the violators are always reported.”

The respondents from the second focus group condemned the government for not protecting their rights as human beings and unlike the other focus groups, this group made it very clear how difficult it was for them to seek legal help in case their rights are violated. They said that every time there was need for legal help the community would make fools of them and that made them feel terrible. They wished that the government would set up something or organization that would help them fight for their human rights. A blind respondent said that...

“... People who mistreat us just do it because we are disabled.

...each time there is a quarrel between me and the other person.

... They always say that is why I am blind.”

One of the respondent Kfg2-10 said in a doubtful way that maybe if they tried to go to police their complaints would be solved, it’s a question of trying she said which meant that the women have never tried seeking legal help. Most women interviewed expressed no knowledge of human rights and wondered what human rights were and what its purpose was. It is however true that for many years disability has been viewed as an issue of the family members in Zambia while the state intervention is in most cases channeled through the welfare institutions with minimum attention.

#### **4.5.2.4 Involvement of women living with disabilities in communal activities and CBR**

In focus group 1, one of the respondents Kfg1-7 confirmed that in her community they had clubs which at one point were given some financial assistance of about 4 million Zambian Kwacha (approx. 4 000 Nok). She said she belonged to one of the clubs called Mungogo Club and at that time of the interview the club had bought pigs and buying feed. Most of the

respondents seemed to have heard of different clubs but were not very sure if they would participate.

# CHAPTER FIVE

## DISCUSSION

### 5.1 Introduction

The social well-being of persons with disabilities is one of the components of the CBR program whose goal is to provide these people with meaningful social roles and responsibilities as well as equitable treatment in the families and communities that they belong (WHO 2010). According to the CBR theoretical framework, the social component includes personal assistance, relationships, marriage and family, culture and arts as well as access to justice (Fig. 2). The main objective of the present study was to identify barriers preventing women with disabilities from enjoying full social lives. The findings are discussed in the context of the CBR theoretical framework and according to the social subcomponents.

### 5.2 Stigma, physical barriers and personal assistance

Most of the barriers identified in the present study were common to both Livingstone and Kazungula districts, and included negative attitudes or stigma, physical access, dependence, poverty, lack of self-esteem and invisibility. These findings are consistent with what has previously been reported elsewhere and in also other parts of this country (Omolayo 2009; Save the Children 2002) and demonstrate how side-lined the groups of women with disabilities are.

#### 5.2.1 Negative attitudes

Negative attitudes towards people with disabilities include shame, fear, taboo, misinformation, psychodynamic, and even religious influences (Livneh 1982; Save the Children 2002). These arguably account for the main reason why these people are discrimination against. The fact that most people are not acquainted with the problems of the disabled, interaction with them may generate anxiety, or pose a threat to the nondisabled person's perceived body-image integrity (Livneh 1982). Negative attitudes are found at all levels of society, be it parents, community members, government workers etc (Save the Children 2002). In the present study, although there was a mixed response as to whether negative attitudes existed or not, the views of respondents in Livingstone district to a large extent contrasted those of the respondents from Kazungula, All individual respondents in Livingstone district denied experiencing any negative attitudes towards them. However, in the

Livingstone focus group interview, three of the seven respondents attested to being discriminated against on the basis of their disabilities, mainly at health care institutions by health care providers. In Kazungula district on the other hand, negative attitudes were reported by one of the two women in individual interviews and almost all the respondents of both focus groups. The women reported that they were treated dis-respectfully in their community just because they were disabled, or that their disabilities were used as a tool to mock them for example, when involved in a quarrel they were told, “You are quarrelsome that is why you are blind.” This is consistent with the views of Loeb et al. (Loeb, Eide, and Mont 2008) who reports that in some communities, disability is viewed as punishment for transgressions committed in a previous life. These results suggest that both the Kazungula and Livingstone communities believe that disability is something to be looked down upon and that there is lack of knowledge about disabilities (Wonani 2010).

The difference between the degrees to which negative attitudes were expressed in Livingstone compared to Kazungula may be related to the levels of education of the respondents, employment and consequently their financial positions in society, with those in Livingstone being at an advantage. The fact that Livingstone is more multicultural and also more westernized compared to Kazungula may also be a contributing factor to the difference, with multi-cultural encouraging changes in attitudes towards disabilities. For people’s attitudes to change, education needs to play a key role, for example by setting up training programs in villages by various stake holders in forms of what is most appreciated in a given society. Since some of the complaints relate to the health Ministry, it would be of interest to include this Ministry in such programs, as well as the key ministry which is the Ministry of education. Increased education and interaction between the community and people with disabilities has been shown to remove stigma and yield positive results (Save the Children 2002). It is necessary to integrate women with disabilities into the mainstream as much as possible by providing more and clear information that disability is not contagious (Kent and Quinlan 1997).

### **5.2.2 Physical Access**

The most noticeable physical barrier to social inclusion in Zambia, as with most other poor countries, is the lack of infrastructure to support the accessibility of services by people living with disabilities (Fleming, Kiessel, and Mindes 2010). Starting with mobility, it is often difficult for the physically disabled people to travel from one place to another, and for school-going children , it is often an excuse not to send them to school (Fleming, Kiessel, and

Mindes 2010). There are other physical difficulties such as entering buildings and other necessary areas (Fleming, Kiessel, and Mindes 2010). In the present study, Kazungula district had no modern buildings as its transformation into district status is just gaining momentum. The road network, like in most parts of rural Zambia, was very poor. In Livingstone, support infrastructure was equally poor, for example, most multi storey buildings had only stair ways with no alternative access for wheel chair users- they had to be carried! As one responded reported,

“When I am boarding a minibus it’s so embarrassing to be lifted to that level, even for big buses... sometimes I make jokes then the conductors come and lift me.”

This is consistent with a previous report that more than 90% of the buildings and roads, includes health centers and churches are inaccessible to disabled people in Zambia (ILO 2007). Article 19 of UNCRPD living independently and being included in the community states that:

*State parties to the present Convention recognize the equal rights of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:*

*(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*

*(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*

*c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs (U.N. 1996).*

As a signatory and having ratified the Convention, the Zambian government is obliged to remove these physical barriers and ensure accessibility of all places by the people with disabilities. To achieve this from a CBR point of view, it is necessary to view the problem

from a personal empowerment point of view where barriers affecting individuals are solved to suit them without disregarding those occurring at community level.

### **5.2.3 Dependence**

People with disabilities are often dependent on others for practical help owing to the barriers they face (Save the Children 2002). In the present study, both respondents from Livingstone and Kazungula expressed different degrees of dependence. For example, the blind depended on other people or their children to lead them to different places; one physically disabled lady depended on bus crews to lift her onto the buses while the deaf depended on assistants to interpret for them. Dependence is a norm of humanity for which everyone falls back on. Over dependence makes one a liability to the helper and predisposes the one who is dependent to vulnerability.

The more dependent one becomes the more prone to disappointment they get. The right of people with disabilities to live independently is covered by Article 19 (above) while Article 20 provides them with the right to mobility (U.N. 1996). States that ratified the UNCRPD convention are expected to create an environment that will encourage independence of people with disabilities. An example of this can be empowering an individual to overcome a disability like providing a wheel chair to a physically disabled person so that he or she can move from place to place unaided.

### **5.2.4 Poverty**

In developing countries like Zambia, people with disabilities constitute the bulk of the poorest largely because development program have overlooked them (World Bank 2010) since these programs are drawn by the non-disabled people. Poverty results in poor living conditions, malnutrition and predisposes to disease, thereby causing disabilities and at the same time, secondary disabilities to the disabled (World Bank 2010).

### **5.2.5 Self-esteem**

Self-esteem involves the evaluation of one's image progressively or regressively (Roessler, 1978 in (Omolayo 2009) and as it relates to disabilities, it refers to their own evaluation of their capacity to function in the society (Omolayo 2009). A mixed response was observed on this question in the present study, with those that had at least high school education and in

employment (Livingstone individual respondents 1, 2 and 3) typically being more confident in themselves compared to those with humble education and also unemployed (Kazungula respondents 5 and 6). These findings suggest that there is a link between education/employment and self-esteem and is in agreement with a previous report (Burns 1982). This is logical since women with disabilities that are educated are able to compete for jobs with able-bodied persons and therefore have a better chance to be more confident and participate more in society.

### **5.2.6 Invisibility**

“I have a neighbour who overlooks me, when she wants to ask for something from me she asks my children and not directly from me.”

These are the words of a mother with disability who felt that she was treated as though she was invisible. Furthermore, the government worker interviewed in Livingstone also reported that it had come up at one of the meetings he had attended that some parents were ashamed of their disabled children such that they did not include them in the count of their children. This is consistent with previous reports (Save the Children 2002) and demonstrates the problem of insensitivity on the part of family and the communities, respectively. It also highlights the need to sensitize families and communities on the issues of disabilities thereby breaking the barriers that exist between the communities and the women with disabilities

### **5.3 Relationships, marriage and family**

Families are a source of comfort for individuals and are therefore an important component of personal development (U.N. 1996). Society’s view of disability differs, with some accepting it while others reject it. The findings of the present study demonstrate that the issues of discrimination of the disabled on the subject of marriage are well known. Most respondents of individual interviews in Livingstone were married with families and were satisfied with the relationships they had in their communities. Even in the group interview, one of the respondents shared that the community where she lived before moving to Livingstone had been abusive, but now she was getting encouragement and was happy. On the other hand, some women within this focus group expressed dissatisfaction saying sometimes parents were responsible for their failure to get married. They also stated that they did not receive sufficient information about relationships and marriages because of their disabilities. In the Kazungula

focus group, most of the women were not married and their understanding was that men preferred women who were not disabled, who could help out with household duties.

It is unfortunate that because of people's negative judgmental attitudes towards women with disabilities some communities believe that it is alright to treat WWD as sexual objects with no sexual feelings, that they do not deserve to be loved (Hassan 1991). In some cases where a woman becomes disabled whilst in marriage, she is divorced or left alone to fend for herself and her man re-marries an able-bodied woman. If the woman with disabilities bears children, they are taken away from her and given to grandparents for their care saying she is incapable to cook and take care of them (Hassan 1991). Rajah argues that lack of women organizations has influenced the level of discrimination and the degree of judgments which based on physical appearance has also become important (Rajah 1989). She further says that if only WWD would be loved and accepted just like any ordinary woman it would definitely change their lives for the better (Rajah 1989). The government needs to formulate policies which will be strong enough and in line with the convention.

Article 23 of UNCRPD states that;

*“Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all manners relating to marriage, family, parenthood and relationships, on an equal basis with others” (U.N. 1996).*

This article highlights the need to facilitate and support the people with disabilities to establish relationships, get married and form their own families. The role of CBR in this case shall be to help remove these barriers so that women with disabilities get empowered so that they become self-reliant, independent and are able function like their non-disabled counterparts. This should also be accompanied by sensitization of the families and communities so that they realize that these women also are entitled to relationships and should be supported.

#### **5.4 Culture and recreation**

Culture is a central key in the well-being of every community which should be recognized through sustainable development as well as how healthy the community is (Torjman 2004). Recreation is an important fact in the lives of WWD because it promotes independent functioning of individuals through restoring their physical, mental as well as their social capacities. Recreation is one of the solutions that reduces emotional and social problems



while at the same time it boosting self-concept and self-esteem of people with disabilities (Torjman 2004). As observed some of the respondents suffered from self-acceptance which in the end might lead to losing hope for the future (Sherri 2004). It is worth noting that culture and recreation would help change individuals and the face of the community for the better through the promotion of social connectedness. It also opens different doors to building strong social capital through communal events which constantly keep neighbors' in touch with each other at all time (Torjman 2004).

The WWD expressed concerned on the issue of not taking part in any activities, but one wonders if they do not just want to take part or there are no activities in their communities. It is clear that the Zambian government together with different organizations have not paid much attention in the area of culture and recreation although its benefits are extremely extensive. Culture and recreation glue different communities together strengthening the neighborhood bond while at the same time keeping individuals alive and happy (Torjman 2004). There is also great need for CBR to come up with clear and simple activities that would promote WWD to take up active roles in order to boost their self-concept and self-esteem.

*“I never laughed so much as during this one week of self-defence training. Most of the time I live isolated in the house of my family, who are ashamed of my circumstances. But this week I have met so many other women in the same circumstances as myself. We could talk about so many things: marrying, the ability to get babies, work, studying, but also how to cope with the prejudices because we are disabled. I feel so powerful and aware of my abilities. Also the respect that the teachers gave me, and the role model of the teacher who is in a wheelchair too, has taught me that I can do many more things with my impairment than I ever thought”* (Aafjes and Coltman 2010).

Culture plays a big role on a person's self-identity when it comes to where they belong and the things that define them as a person. But extra attention needs to be given to WWD so that they have the opportunity to learn more about themselves and what is important to them (Smith 1995). Therefore the DPO's have the responsibility of coming up workable strategies that will encourage WWD to participant in the recreational activities and facilities which should include accessible infrastructure (Smate and Zimba 2010).

## 5.5 Human rights and Justice

Every human being is born free and equal in dignity and rights (U.N 1948) and everyone is entitled to equal access to justice when their dignity and rights are violated (UNDP 2005). The access to justice is defined as the ability for people to access the systems, procedures, information and locations that are used in the administration of justice (Stein and Lord 2007). While the universal declaration of human rights (U.N 1948) caters for the rights of every human being, people with disabilities face barriers in accessing these rights compared to non-disabled counterparts including making decisions about their lives, getting a job, obtaining an adequate standard of living, getting around and being included in society (UNCRC 2010) It is for this reason that the Convention on the Rights of people with disabilities was established with the purpose to bridge the gap. The article of the Convention that specifically deals with justice is Article 13 which states that:

- 1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.*
- 2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff (U.N. 1996).*

The results of the present study show that in both Livingstone and Kazungula districts, the rights of the people with disabilities and women in particular were being violated. For example, in Livingstone, their right to privacy at the hospital, access to most building and access to information for the blind was being denied. While these women were aware of their rights being violated, they seemingly were not sure of the right system to recourse. It would seem that according to them, the only violations that they thought they could complain about were what was perceived to be direct infringements, for example, the confiscation of merchandise by council officials from a disabled vendor or refusal of a school place to a disabled child. The situation in Kazungula district was even worse with most women not being aware of some of their rights. Furthermore, no system for judicial help seemed to be in place for the women to access.

CBR programs that will create awareness of the rights of the disabled should be introduced in these target areas, especially Kazungula district. In line with this the families and communities should also be sensitized so that they respect these rights. A workable system of accessing justice should be clearly defined with support structures or organizations. In the end, various stake holders should be sensitive to the needs of the people with disabilities so that discrimination is avoided.

## **5.6 Recommendations**

### **5.6.1 Accessibility**

Article 9 of the convention states that people with disabilities are entitled to a life of independence. It states that:

*“To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility” (U.N-GAID 2010).*

As pointed out by respondent 2, it was impossible for someone on a wheelchair to visit the provincial administrative head (Permanent Secretary) whose office required that you go upstairs. There is need to empower people living with disabilities in both Livingstone and Kazungula districts so that they can participate in day-to-day activities of communities. One way to achieve this is to “raise their voices” so that they are included in developmental programs and also so that their plight is not ignored. To include the people in developmental programs is even better because then they will be there to stand for their own interests. DPO on the other hand have a duty to ensure that government does not ignore or forget about these people.

### **5.6.2 Education**

*“Inclusion is about genuine relationships. Inclusion is about the intentional building of relationships where difference is welcomed and all benefit” (Miles 2000).*

The findings of this study demonstrate that there is a difference in the well-being of people with disabilities in Livingstone compared to those in Kazungula, with the latter being at a disadvantage and also education as the major contributor to the difference. Communication skills are an essential part of daily life as it act as a tool in explaining someone's own need which people can understand if addressed (Smith et al. 1995). Women with disabilities are double disadvantaged and that is why special effort is required to provide education and proper training which will be based on special educational needs. Acquiring proper education will pave a clear way for WWD to access information and guidance which they can use to make realistic choices and be able to prepare for their future plans (Miles 2000) . CBR programs in the area focusing on education should include education for adults as well as that for the children. There is no better strategy of promoting inclusive education than using CBR because it offers a sustainable options especially where educational resources are scarce like in Kazungula and Livingstone districts (Miles 2000). Inclusive education for these two districts is more appropriate in the sense that it is totally based on the social model of CBR matrix which emphasizes on removing community barriers that hider People with disabilities to participant in their societies fully (Miles 2000). WWD in the areas of research could not get jobs especially due to lack of education and this has to a large extent contributed to poverty.

According to the 2000 report released by the International Special Education congress, education can only be effective and meaningful if there is equal participation of pupils, teachers and even the community members (Peters 2003). He further says that this can only be achieved through introduction of human rights and empowerment. It is however necessary for the government together with different organization to work on awareness-raising at all levels such as administrators, teachers, parents, DPO's, the community, ministry of health, as well as setting up of different committees which would comprise of all key players (Miles 2000). The local community and organization of people with disabilities need to work hand-in hand in all education processes to ensure sustainability while the government has to encourage and facilitate in planning and making certain strong decisions for education (Mumba 2000). Finally the government has a duty to making education mandatory by formulation strong policies because it's a right for everyone (Armstrong, Armstrong, and Barton 2000).

### **5.6.3 Justice**

*“Are there laws that specifically address or discriminate women with disabilities? Are there laws protecting the rights of women? Are there criminal laws to ensure that all forms of violence against women, including assault, rape, domestic violence, discrimination, sexual violence, human trafficking, sexual harassment, harmful traditional practices, including female genital mutilation, are criminalized? Is rape clearly defined in the law?”* (UNODC 2010).

All these questions need to be addressed in order to ensure that WWD are part of the communities they live in. The Zambian government has for a long time neglected WWD in so many ways, it is however its obligation to address any type of injustice. Grassroots programs will help empower women as it will help them voice out their needs and build their confidence in reporting any type of violence against them. There is great need to empower them to the level where they are able to participate in the country-decision making (IPU 2008).

The policy makers have to ensure that there is a proper framework which is effective and has strong laws that criminalizes those that violate WWD. Ending injustice will open doors for the women although it requires a collective response from every citizen, however the policy makers still has the responsibility of overseeing that the laws are correctly implemented and that all the programs designed meet the standards and goals that have been set (IPU 2008). . As observed during the study most of the respondents were not aware of what to do when violated, it is of great importance for the government to ensure that WWD are educated on different procedures of how to seek legal justice in case there are violated. According to Young (Young et al. 2004) teaching women with disabilities how to recognize abuse and even different ways of protecting themselves in abusive situation is a very important strategy that would a big change (Young et al. 2004).

### **5.6.4 Empowerment**

The findings of the present study demonstrate that there is a connection between having a job or an income and satisfaction for the WWD. Furthermore, the project that was set up in Kazungula district for WWD with an initial capital of 4.000Nok was also well recommended. Similar schemes are encouraged and will form a basis not only sources of income for WWD but also a tool or point of inter-mixing between these women and also their unchallenged

counterparts. This will in turn remove the stigma that the community has for the women as the interaction will result in increased awareness.

More information is desperately needed which would be through awareness programs not only to those in the urban but even in the rural areas. Women with disabilities need to be involved in the decision making of the strategies, its goal should be understood, mutual support is necessary and focusing on vocational skills as most women have very low levels of education (Enns 2011). According to UNESCO, a person who receives quality skills-based health education has a great chance of developing skills such as communication, negotiation and even refusal skills in case of a unpleasant situation.

It gives an individual the ability to think critically, helps in solving problems as well as influencing the capability of independent decisions that are positive especially in the development of attitudes and values (IPU 2008). WWD have the potential of experiencing a better life through empowerment which would be in different forms. They deserve to start a business of their own choices if that is what one desires while those who want to work for organization need to have the opportunities as well. There are not empowered socially and it makes everything else difficult, social empowerment open doors to interact with different people gives an opportunities of learning new ideas of surviving while at the same time building strong and sustainable social networks outside their homes (IPU 2008).

## **CHAPTER SIX:**

### **SUMMARY**

People living with disabilities represent the most disadvantaged population in many if not all countries the world over. They are treated unfairly and also meet unfair competition from unchallenged people in almost everything including job-seeking and in the standard of living hence the adoption of the Convention on the Rights of People with Disabilities by the United Nations. Zambia is a signatory of this convention and as such, its government is expected to make significant steps towards the improvement of the welfare of people with disabilities.

It is necessary to recognize the good job done by international organization although it would create a big impact if they would get more support from the government. During the research project it was revealed that most of the women failed to get jobs simply because they did not have required levels of qualification to allow them compete in the job market. There is need for the government introduce/strengthen deliberate policies to favour inclusion of these women into educational programs.

Awareness campaigns have not been considered as an important aspect of eradicating discrimination. The Zambian government needs to work hand-in-hand with the communities, NGOs, different organizations to change negative attitudes of people towards WWD and ensure that equal rights is emphasized. It is impossible to build schools and manage campaigns without proper road network, during the research it was extremely difficult to reach some places because the road network is bad that cars could not pass. Roads are one of the most important targets when planning any project because they make mobility easy.

The respondents expressed that they were not involved in any activities; recreation is an important strategy of inclusion because it influences communication and boosts up people's self-esteem. Some respondents were suffering from acceptance which would be overcome by socializing meanwhile realizing that one could do more despite living with a disability.

CBR has the potential of turning the wheel around because its social strategies allow different methods of knowledge in order to discover what is appropriate for a particular society. The strategies would help eradicate discrimination against people with disabilities in different communities without really making huge changes at once. Building schools as it was observed to be one of the most needed things during the interview would not have made much

difference unless training centers for the special teachers were made available. There is great need for the government to put emphasis on the recognition of sign language as an official language for the deaf while for the blind, Braille should be the their main tool of their main literature which would help them throughout their lives.

As observed during research it was clear that WWD had no women representatives who spoke on their behalf and that made the government to sort of brush them aside all the time policies were been formulated. The Zambian government needs to establish a proper structured dialogue involving the public sector, different organizations, local communities and DPOs in order to ensure that the implemented projects are being monitored. It would be no point of implementing all the projects if they cannot be monitored. Changing the lives of WWD is a challenging assignment but can only be achieved with team work from all sectors families included.

## **Future Research**

The present study focused on women living with disabilities because they are the most vulnerable. Interviewing policy makers is envisaged as it will explain the hold back in effecting the provisions of the ratified UNCRPD. The NGOs together as well as the DPOs who deal directly with people with disabilities should also be targeted to get a balanced view from their perspective.

It is of interest to include men with disabilities in future studies in order to get their views especially on the questions of marriage and discrimination. This would supplement the findings of the present study.



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## APPENDICES

### Focus group 1 (Kazungula)

Respondent	Date of birth	Disability	Chief
1	1939	Deaf	Sekute
2	1950	Physical	Sekute
3	-	Physical	Musokotwane
4	1936	Blind	Musokotwane
5	-	Blind	Musokotwane
6	1945	Blind	Musokotwane
7	-	Physical	Musokotwane
8	1942	Physical	Sekute
9	1946	Physical	Sekute
10	1933	Blind	Musokotwane
11	1936	Blind	Musokotwane

### Focus group 2 (Livingstone district)

Respondent	Date of birth	Disability	Area
1	-	Physical	Maramba
2	-	Physical	Libuyu
3	-	Deaf	Linda
4	-	Physical	Dambwa
5	-	Deaf	Dambwa
6	-	Deaf	Dambwa
7	-	Physical	Maramba

### Focus group 3 (Kazungula)

Respondent	Date of birth	Disability	Chief
1	1947	Blind	Musokotwane
2	1948	Blind	Musokotwane
3	1935	Blind	Sekute
4	1954	Blind	Sekute
5	1951	Blind	Musokotwane
6	1961	Blind	Musokotwane
7	1950	Blind	Musokotwane
8	1941	Blind	Musokotwane
9	1931	Blind	Musokotwane
10	-	Blind	Musokotwane

## Individual interview guide

1. What can you tell me about your life in general?
2. Could you please explain to me if you were you born like this or something happened to you?
3. What opportunities and challenges have you faced in your social life as a person living with a disability? (a) Tell me more about your feelings on the difficult challenges faced?
4. Please explain your level of interaction or participation with others
  - (a) Among other person with disabilities ( it could be same or different form of disability)
  - (b) Within the family
  - (c) In the communities
5. Do you feel like the government has or is protecting your rights as an equal person?
6. What do you think about your rights and their protection by (Government; Disabled Peoples Organizations, Family Community, Society, Self?)
7. What do you expect government, as a duty bearer, to do to uphold your disability rights and/ or enable you to enjoy your human rights on an equal basis with others?
8. What do you think about the CBR strategies and their effect on your life and your social status in society?
9. Would you explain to me your participation in daily activities? e.g Home, Community, School, Workplace?
10. How does your being a person with disability affect your relationships, marriage and love Life? If I may ask, how did you find your partner or spouse?
11. Could you explain the use of family planning?
12. What role has culture played in your life as a person with a disability?
13. Please give us an example of how you followed through your challenge to seek legal redress when felt that your rights were being violated?
14. Which court(s) of law or level of assistance did you require?
15. How do you feel about being assisted to enable you be mobile and access various services?
16. Please explain to us what you know about the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
17. The Zambia Government has signed the UNCRPD, to enable it start the process of



Including its agreed terms into local Zambian laws.

18. What are the four priority areas of need you feel should not be left out?
19. Tell me your past experiences in life, when you were involved in sports activities,  
Undertook a leisure activity or recreation?

## **Focus group interview guide**

1. What can you tell me about your situations?
2. Tell me more about your experiences living with a disability?
3. How would explain your daily social lives?
4. To what extent do you think the government has incorporated human rights with the national policies?
5. How has the community realized that you deserve equal rights and to what are the changes if any, would you explain?
6. How would you explain what changes CBR has created in your lives?
7. As a women with disabilities, how would explain the difference between you and an ordinary women in terms of financial status?

## **Tokaleya Interview guide**

1. Chinzi chonga wandambila abumi bwako mubulanfwu?
2. Wakazyaligwa mbonya namu nakulizyakachitika? Pandulula.
3. Zinzi zibotu abuyumuyumu ziwabonamubumi bwako kukala bumi bwabulema?
  - (a) Twambile mbonvwa abuyumuyumu mboyinda mwadeni?
4. Mbututi mbumunwana abantu bamwi batayinsi bachilema, ape mubeleke buti ambabo.
  - (a) Mubeleke buti abamwi bantu bajesi bulema mubumibwabo?
  - (b) Ino mubeleka buti abamukowa wenu?
  - (c) Mubeleka buti abantu mbo mukala amwi mumunzi?
5. Nfulumwende (government) mubona buti, ilamukwabilila mubube bwenu nobachilema mbuli muntu uli onse ulikabotu?
6. Muyeya buti abube bwana, a kukwabililwa. Muliku abililidwe anfulumende, tubunga tubona bachilema, mikwashi yenu na mulalikwabililwa nobamukamwini?
7. Mukuyeya kwenu chinzi ziomuyanda kuti nfulumende, ichite kutenga bachilema belane abamwi bantu mubukale bwabo? Muzezo ulibutu ngomujisi ali ba CBR amibeleko yabo mubuni bwenu amumunzi wenu?
8. Amundambile lubazundomulalo muzintu zichitika buzuba abuzuba? (ang'anda, mumunzi. na-kuchito, kuchikolo?)

9. Mubulema, mbuyumu nzi mbomujana mumakwatwa, na muluyando chindi nomuyanda muntu okumukwata?
10. Ndiyanda kuziba, Mwakabajane buti bamukwete na bayanda kwata?
11. Amupandulule musebezi wa family planning?
12. Chizo chenu, chamugwasya buti mubulemabwenu?
13. Amutupe mukozyano, ninzilanzi njimutola namwalyatililwa kambo muli bachilema?
14. Njili nkuta, namulawo ngumwakainka kuyandola lungwosyo.
15. Sena inga mwayanda lugwasyo lunga lwapanga zintu kukba mubumi mwenu?
16. Amutwambile nchomuzi amilawo yakabikwa aba (UNCRPD) naba United Nations Convention yamba abulema bwabantu?
17. Nfulumende ya Zambia yakasaina asepalya UNCRPD, kuti italike kubelesya eyi milawo. Zibela zilibuti zyone ziomuyeya kuti zitakasyali zyamba alibachilema?
18. Amutwambile, ndelili nimwa kasobana zyakudisya mibili nazinonezya muntu, mbulibbola.

### **Tokaleya focus group interview guide**

1. Zinzi ziomungu mwatwambila mubulema bwenu?
2. Amundambile zinzi ziomuyinda mwadeni kambo kabulema.
3. Mbubuti mbomunga mubumi bwenu.
4. Mbubuti mbomunga mwamba kuti nfulumende yachita, nakutobela milawo yikwabilila bantu?
5. Sena mumunzi momukala bantu balizi kuti bachilema bali mbulimuntu uli onse?
  - (a) Nabalazumina kunchincha kulibuti nkomwabona?
6. Ba CBR beta kuchincha kuli buti mubumi bwenu?
7. Nobanakazi, mwindene buti kukujata mali ama chembele?

## **Tokaleya Informed Consent form**

### **Kwambilwa zijanika mulwiyo olu**

Eli pepala bandibalila ndilyo alimwi danvwa zilembidwe mukati omu, nkabela ndalibalila ndemukamwini. Ndawvwisisisya zijanika mulwiyoulu, alimwindazumina kuti ndiyo-bamba mumasisike zyonse zindiyoziba. Ndaziba kuteti ndilangulukide kutola nakutatola busena mulwiyo olu inga ndaleka kwiya kufumbwa chindi kataamba nchondilekela. Ndanvwa kuti inga ndallizima tape indidabbing'a, chindi chamibuzyo nakufuta zindamboola. Kuleka kutola busenna takuchinchi bumi bwangu munzila iliyonse. Ndabuzya mibuzyo akatabigwa.

Ndasaina

awa.....

Elipepa lyabalwa

kuli.....

(Amulembe mazina abantu batola busena)

Muchishobo chobanvwa, ndashoma kuti banvwa bupanuluzi alimwi balisalila kutola lubazumukwiya oku.

Kusaina azina lyamugwashi mulwiyo

olu.....

Izina lyamukamwini

lyiyo.....

Lilalembegwa ayisigwa mugwashi walwiyo ohu.

Year and

Date.....

## **Informed Consent form**

The information sheet has been read to me and I understand it or I have personally read and understood the information sheet.

I understand the purpose of the study and I also understand that the information collected on this study will remain confidential. I understand that I am free to take part on the study or refuse, and that I can withdraw from the study at any time without giving any reason. I understand that I have the right to stop the tape recorder during the interview or erase taped materials afterwards. Deciding not to take part or to withdraw from the study will not affect my life in anyway. I have the opportunity to ask questions and have them answered.

Signature or thumb-print of  
participate.....

This form has been read to  
.....

(Write name of participant)

Consent form should be in a language that she/he understands. I believe that she /he has understood what I explained and that she/he has freely agreed to take part in the study.

Signature and names of research  
assistant.....

Name of  
researcher.....

Year and  
date.....