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The challenges experienced by persons with physical disabilities who live in Chifubu Township in Zambia.

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Key words

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Declaration

I hereby declare that this thesis entitled “The challenges experienced by persons with physical disabilities who live in Chifubu Township in Zambia” is my own work and that it has not submitted or any part of it for any degree or examination at any other university. All the sources used or quoted have been acknowledged by means of complete references.

Mary S. Sakala

Signature______________________________Dated 31st May 2010

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Abbreviations

AD: assistive devices

ADL: activities of daily living

CSO: central statistics office

HIV/AIDS: Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome.

ICF: International Classification of functioning Disability and Health

UN: United Nations

PWD: People with disabilities

PWPD: People with physical disabilities

WHO: World Health Organisation

ZESCO: Zambia Electricity Supply Company

Definition of Terms

Abuse: the physical, psychological, or sexual maltreatment of a person (Webster, 1998).

Accessibility: the attribute of being easy to meet or deal with (Webster, 1913).

Activity limitation: are difficulties an individual may have in executing activities. An activity limitation may range from a slight to a severe deviation in terms of quality or quantity in executing the activity in a manner or to the extent that is expected of people without the health condition (WHO, 2001).

Barriers: are factors in a person's environment that, through their absence or presence, limit functioning and create disability. These include aspects such as a physical environment that is inaccessible, lack of relevant assistive technology, and negative attitudes of people towards disability, as well as services, systems and policies that are either non-existent or that hinder the involvement of all people with a health condition in any area of life (WHO, 2001).

Disability: is an umbrella term for impairments, activity limitations, and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that of individual's contextual factors (environmental and personal factors) (WHO, 2001).

Discrimination: treating people differently through prejudice (Wendell, 1996).

Environmental challenges/ Barriers: constitute a component of ICF, and refer to all aspects of the external or extrinsic world that form the context of an individual's life and, as such, have an impact on that person's functioning. Environmental factors include the physical world and its features, the human-made physical world, other people in different relationships and roles, attitudes and values, social systems and services, and policies, rules and laws (WHO, 2001).

Impairment: impairments are the occurrences of problematic bodily functions or structures. Impairments can also be described as the loss or damage of body organ that affect physiological or psychological functioning (WHO, 2001; Kielhofner, 2005).

Participation restriction: are problems an individual may experience in involvement in life situations. The presence of a participation restriction is determined by comparing an individual's participation to that which is expected of an individual without disability in that culture or society (WHO, 2001).

Physical disability: physical in the context of physical disability, refers specifically to bodily impairments resulting to the restriction towards functional activities (WHO, 2001, 2006).

Rejection: It is the denial of the very humanity of the person, especially so of people with disabilities arising from illnesses such as leprosy, epilepsy and mental impairment (Schaefer & Lamm, 2008).

Social interaction: are the acts, actions, or practices of two or more people mutually oriented towards each other's selves. That is, any behaviour that tries to affect or take account of each other's subjective experiences or intentions. This means that the parties to the social interaction must be aware of each other and have each other's self in mind (Schaefer & Lamm, 2008).

Stigma: (a sign of social unacceptability) an "attribute that is deeply discrediting" and that reduces the bearer "from a whole and usual person to a tainted, discounted one" (Goffman, 1963).

NOTE: In this document the terms disabled, persons with disabilities and people with disabilities have been used interchangeably been used in many instances referring to persons with physical disabilities.

CONTENTS

Abstract

People with physical disability experience various challenges which include physical, social and attitudinal challenges. These challenges which limit the inclusion of persons with physical disabilities in society are a result of barriers and the physical impairment itself. These factors also cause activity limitations and participation restrictions. Despite the United Nations declaration of 1993 for equalisation of opportunities for people with disabilities, not much has changed. It is with this background that the researcher aimed to explore the challenges experienced by people with physical disabilities living in a low cost location of Zambia.

Qualitative research methods were employed using a phenomenological approach to gain an in-depth insight of these challenges from participants' lived experiences. Twenty participants were purposively selected for three focus group discussions, and eight of the twenty participants took part in the in depth interviews. The data was organised and analysed using the thematic method.

Results of the study showed that participants in this study were challenged with architectural barriers due to designs, they lacked formal education, specialised skills, and most of them were unemployed and financially dependent on others. The negative attitudes of families, service providers, and the community in general resulted in discrimination and limited the participation and involvement of people with disabilities in the mainstream activities. The cultural beliefs of the participants in the research influence the manner in which society perceives persons with disability and treat them.

Limited access to information about HIV/AIDS and the myths about the cure of the pandemic makes people with disabilities more vulnerable and at risk of being infected. The information regarding challenges experienced by people with disabilities gained in the study could be used by the policy makers for implementation of the UN declaration of equalisation of opportunities for people with disabilities.

CHAPTER ONE

1.1 Background of the Study

Disability can be said to be the outcome of complex interactions between the functional limitations arising from a physical, mental or intellectual conditions, and the social and physical environment (WHO, 2001). There are various types of disabilities, this include sensory (blind; partially sighted; hearing and speech impaired), physical (paralysis; amputation; pain; stiffness and /or congenital deformities), and intellectual (mental retardation and mental illness) (Nagi, 1969; WHO, 2001 & 2006). Physical disability is the restriction towards mobility and functional activities caused by impairments such as an amputation or paralysis of a limb (WHO, 2006).

The United Nations(UN) (2007) estimates that some 650 million persons have a disability, and that the majority of persons with disabilities (around 80% of them) live in developing countries, and are among the poorest of the poor. The United Nations population information network estimates that of the 800 million people living in Africa, 50 million of these are disabled. Of the 50 million, 6% of Africans form the highest proportion of the disadvantaged population: only 2% have access to any form of rehabilitation and 70% of disabled adults are unemployed and live in poverty (UN, 2007).

Zambia's population is 11,798,678 (Zambia's central statistics office (CSO), 2002a) of which according to WHO estimates, 10 to 20% are possibly people with disabilities. However, according to the census of population and housing of 2000, Zambia's defacto population then stood at 9,337,425 of which 256,690 were people with disabilities, representing 2.7% of the total population of which 53% were male and 47% females. The census also revealed that physical disability was the most common disability in Zambia comprising 35.2% followed by partially sighted with 27.4% and others follow in descending order with the least common being ex-mental clients at 3.3% (CSO-Zambia, 2002a)

In 1993, the United Nations General Assembly proposed the standard rules on equalization of opportunities for persons with disabilities which was approved in 1994 (resolution 48/96) (UN, 1994). Resolution 48/96 (UN1994) set specific targets and implying a strong moral and political commitment on behalf of states to action for equalization of opportunities for PWD. This is aimed at decreasing the challenges faced by PWD and facilitating re-integration into mainstream and society as stated in the *Convention on the rights of persons with disabilities* (UN, 2006).

1.2 Challenges experienced by persons with disabilities

Persons with disabilities face a number of challenges in their day to day lives. These may include physical environmental, social and attitudinal barriers (Siriwardane, 1997; May-Teerink, 1999; Miles, 1999; Bosch *et al*, 2001; NORAD, 2002; & Unnikrishnan, 2002). Physical challenges are divided into individual limitations (intrinsic) and the physical environment (extrinsic). The individual limitations may arise from lack of mobility because of physical weakness due to impairment (for example: pain, weakness, stiffness, amputation or congenital anatomical malformation). The individual limitations cause the person to be dependent on others (Van der Kroft, 2002).

The physical environmental challenges experienced by people with disabilities include physical barriers which may cause a person with physical disability to be unable to access the infrastructure or any physical facility because of the design. These include inaccessible buildings, transport and roads.

The Social challenges include lack of social interaction; change of roles; unavailability or inadequacy of social structures; a lack of social support, unemploymetand poverty. Employment is a social right which brings about economic empowerments hence unemployment among people with disability may perpetuate social and economic dependence and poverty.

Attitudinal challenges **prejudice** against people with disabilities exists globally in different cultures and religions (Helander, 1999). In some cultures, beliefs about the origins of disability are particularly useful and necessary when searching for therapy; while in other cultures the mere presence of a disability determines whether one is going to be accepted by society or not (Ingstad &Whyte, 1995; White, & Oloson, 1998).

Like in many other developing countries, people with physical disabilities living in Zambia, face a lot of challenges that range from physical, to social and attitudinal. A study conducted by Smith, Murry, Yousafzai and Kasonka (2004), in Lusaka, revealed that women with disabilities encounter various social, attitudinal and physical barriers to accessing safe motherhood and reproductive health services in this particular setting. Among these challenges were the attitudes of reproductive health service providers towards the women with disabilities such as, generalized assumptions that women with disabilities will not be sexually active, and not require reproductive health services.

The researcher thus, found it imperative to look at the experiences of persons living with physical disabilities in a low cost but high density locality of Zambia which may produce representative data for similar settings in Zambia as well as other low cost and high density locations in developing/low income countries.

1.3 Statement of the Problem

In 1993, the United Nations General Assembly proposed the standard rules on equalisation of opportunities for persons with disabilities which was later passed in 1994 (resolution 48/96) (UN, 1994). Furthermore, the goal of inclusive development is to enable all people to have equal opportunities within the economic and social lives of their communities (as stated in the *Convention on the rights of persons with disabilities* (UN, 2006). Although Zambia has ratified the UN convention of 2006, not much has changed in terms of the environment and the social arena for persons with disabilities.

Persons with disabilities often still live in deplorable conditions due to the presence of environmental and social barriers. Persons with physical disabilities suffer the consequences of discriminatory social policies that deprive them of physical rehabilitation services which are not available in their communities. The above mentioned problems may contribute largely to discrimination and exclusion, failure of rehabilitation and re-integration into mainstream services. These challenges may result into the persons with physical disabilities to perpetually wallow in poverty (Yeo & Moore, 2003; Palmer, MacInnes, & Kenway, 2007)

1.4 Motivation

As a physiotherapist and prominent member of the rehabilitation team, working in a hospital which provides services to this setting (Chifubu), the researcher observed that clients with physical disabilities only attended physiotherapy rehabilitation sessions as in-patients. Once they were discharged they seldom came back as out-patients. With basic background knowledge of challenges that people with disabilities may face, the researcher was keen to follow up and find out what had become of these clients in their community.

The researcher wanted to bring to light and document the lived experiences of these clients. The researcher is compelled by the ethical responsibilities as a global citizen, health professional and physiotherapist to get involved in addressing disability which is a mediating factor to poverty and human development. It is therefore one's moral imperative to mobilise and contribute to the awareness of challenges and lived experiences of people with physical disabilities at the global level by contributing through research in a local setting.

In addition the nonavailability of published data describing the challenges experienced by people with physical disabilities of Chifubu township in Zambia led to the conception of this study.

The findings of this study will add to the body of information on the challenges that persons with disabilities face in Zambia. This information will provide a base for planning and inclusion of persons with disabilities in the provision of basic services.

1.5 Research Aim

To describe the challenges experienced by the persons with physical disabilities living in Chifubu Township.

Objectives

i. To establish the physical challenges experienced by persons with physical disabilities in Chifubu Township.

ii. To ascertain the social challenges experienced by persons with physical disabilities in Chifubu Township.

iii. To explore the attitudinal challenges experienced by persons with physical disabilities in Chifubu Township.

1.6 Outline of Chapters

The aim of the first chapter is to provide background information that will provide an insight on the challenges that are experienced by people with physical disabilities. The chapter will further provide the statement of the problem to justify why this study is essential. Finally the aim and the objectives are laid down.

Chapter two reviews literature sources concerning challenges that persons with physical disabilities experience in their everyday lives with special emphasis on those living in the third world or low income countries. This includes literature based on disability, and the models of disability to start with, then literature on the framework of the challenges that persons with physical disabilities experience with regards the environmental barriers, social barriers and social limitations and attitudinal challenges. This chapter will also review the literature concerning the role that cultural and traditional beliefs and myths play on the challenges that PWPD experience in their societies.

Chapter three will endeavour to describe the research setting in which the research was based. It will also examine the methods used to collect data. The research design, the research population, sampling method and instruments will be well described and motivated. The data collection procedure and analysis will be explained. Finally, ethical issues relating to the research will be presented before the researcher gives her brief reflexivity. The chapter will provide an inclusive description of the research process.

Chapter four is dedicated to giving meaning to the data in a very comprehensive manner. The researcher presents the data in a narrative report writing style. Roberts (2002) suggested that the narrative study of lives 'has become a substantial area for analysis of life experience and identity as connected to social groupings, situations and events'. This prompted Denzin (2003) to suggest that: we live in narrative's moments. Everything we study is contained within a storied or narrative representation. Indeed as scholars we are storytellers, telling stories about other people's stories. In this case, the researcher tells stories about the persons with physical disabilities living in Chifubu Township. The chapter starts by presenting social demographic data of participants, followed by presentation of their stories about the challenges that they experience in their daily lives.

Chapter five focuses on the main findings of the study. These findings will be discussed in relation to the aim and objectives of the study and explained where possible in relation to the findings of other similar studies. The study elicited some informative first hand insights from individuals living with a physical disability. These insights formed categories from which four main aspects of challenges emerged; one of these themes; the cultural beliefs and myths about disability was not among the predetermined themes, it is therefore treated as an emerging theme. The discussion is therefore based on the four major themes. The summery of the findings is presented.

This last chapter (6) will present the summary of the research, the researcher's conclusions from the findings, and discussion on the implications of the findings, possibility of any further research for the unanswered questions, and make necessary recommendations for the next course of action.

CHAPTER TWO

Literature Review

2.1 Introduction

This chapter reviews the literature sources concerning challenges that people with physical disabilities experience in their everyday lives with special emphasis on those living in the third world or low income countries. This includes literature based on definition and the models of disability. It discusses the challenges that people with disabilities experience with regards to the environmental, social barriers and attitudinal challenges. This chapter will also review the literature concerning the role that cultural beliefs and myths play on the challenges that PWPD experience in their society.

2.2 Disability defined

Disability is an intricate expression that has undergone many interpretations. It has been defined as:

(i) "The loss of the ability to perform in the range considered normal for a human being" (Hagedorn, 2001).

(ii) "...an illness or impairment in biomedical approach, with most emphasis falling on curing the disabled individual" (Wade & halligan, 2004).

(iii) "...a tragedy or object of sympathy and charity," (Wade & halligan, 2004) (IV) "...a form of human indifference or deviation from the social norms of acceptable levels of activity performance" (Wade & halligan, 2004).

According to the International Classification of functioning Disability and Health (ICF) (WHO, 2001) "disability is an umbrella term for impairments, activity limitation and participation restrictions" (WHO, 2001). The ICF defines disability as the negative aspects of the interaction between an individual, (with a health condition) and that individual's contextual factors (personal and environmental factors). Though disability is defined within the context of health; a person's experience of disability is also a function of features of the environment in which they live. Leonardi, Bickenbach, Ustun, Kostanjsek & Chatterji (2006), reported that the definition based on the ICF conceptualisation include all aspects of disability, and highlight the interactive dynamic nature of disability. It also acknowledges the equally important roles of the person's state of health and environmental factors in the production and mediation of the disability experience. Understanding both the health and the environmental aspects of disability allows for the examination of health interventions that could improve functioning as well as change the environment for better participation of people with disabilities (Leonardi *et al,* 2006).

2.3 Disability Legislation and Policy

2.3.1Globally

Metts (2000) narrates that in the 1950s, in keeping with the predictable understanding at the time, the United Nations assisted governments to prevent disabilities and to provide traditional rehabilitation services to people with disabilities. Metts (2000) further observes that the United Nations assistance typically took the form of support for advisory missions, workshops for the training of technical personnel, seminars, study groups, scholarships and fellowships for trainers, and the establishing of rehabilitation centres.

① – Metts (2000) gives a background on how pressure from national and international disability rights movements mounted in the 1960s and 70s, which prompted the United Nations to alter its approach to disability to promote "a fuller participation by disabled persons in one integrated society." This philosophy, initially expressed in the 1971 *Declaration on the Rights of Mentally Retarded Persons* and the 1975 *Declaration on the Rights of Disabled Persons,* was fully articulated in 1982 in the *World Program of Action Concerning Disabled Persons (WPA)* Metts (2000).

The objective of the *World Program of Action Concerning Disabled Persons was (and is)* "to promote efficient process for prevention of disability, rehabilitation and the comprehension of the goals of 'full participation' of persons with disabilities, in social life and development, and of 'equality'. This means opportunities equal to those of the whole population and an equal share in the improvement in living conditions as a result of social and economic development. These concepts should apply with the same scope and with the same urgency to all countries, regardless of their level of development (UN, 2004). In order to allow adequate time for Governments and organizations to implement the activities recommended in the World Programme of Action, the General Assembly proclaimed 1983-1992 the United Nations Decade of Disabled Persons (UN, 2004).

2.3.2 Africa region

"The Organisation of the African Unity Labour and Social Affairs Commission at its 22nd Ordinary session which was held in Windhoek, Namibia in April 1999 proposed the period 1999 – 2009 the African Decade of Disabled Persons. The recommendation was adopted by the 23rd Session of the Labour and Social Affairs Commission sitting in Algiers, Algeria, in April 2000; it was then endorsed by the 72nd Session of the OAU Council of Ministers and 36th Assembly of Heads of State and Government respectively, sitting in Lome, Togo in July 2000 (ILO, 2010).

Gumede (2007), says that the approval and launching of the African Decade of the Disabled Persons was in a bid to reinforces the commitment of the African Rehabilitation Institute to work together in the spirit of 'Pan Africanise' with all the stakeholders and at the same time open equal opportunities for Disabled People in Africa to positively contribute to the development of the African continent, alongside with the "able bodied persons" Gumede (2007).

2.3.3 Zambia

The Government of the Republic of Zambia ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in January 2010; this is after having signed it in May 2008. It is the citizen's hope that the ratification will strengthen the inclusive approach to disability issues in all aspects of society. In addition to the ratification of the UNCRPD the Government also ratified the ILO Convention No.111 concerning Discrimination in Employment and Occupation (1979), and Convention No. 159 concerning Vocational Rehabilitation and Employment of Disabled Persons (1983) (ILO, 2010). It has been noted however, that despite ratifying so many conventions, implementation has been a challenge. Nowicki, (2006) noted that, since the enactment of the previous Act there hasn't been full enforcement and its violations are rarely recognised due to mainly ignorance, among the various stakeholders, of what it entails. Nowicki, (2006) is of the view that for as long as negative attitudes persist; the full rightful acceptance of people with disabilities is unlikely. Kafwabulula (2010) a journalist living with a disability observes that there is need of political will from the powers that be for the enactment of the UNCRPD to succeed. They further add to say "It is worth noting however that although the government has now ratified the Convention, unless and until government begins to go by the tenets and principles of the Convention, disabled people in Zambia are far from being liberated.

The Convention marks the dawn of a new era in the long history and fight for the emancipation of persons with disabilities the world over observes Kafwabulula (2010). The Convention is the first human rights treaty of the twenty-first century adopted by the United Nations on 13th December 2006 (Kafwabulula, 2010). The implications of the ratification of these conventions, is that the nations concerned are obliged to observe the principles of equal opportunities, equal dealings in laws, policies and activities of available programmes, including those that concern people with disabilities. The signatory nations are expected to take a consultative approach to developing laws, policies and programmes with the Organisations of people with disabilities.

Organizations for people with disabilities (DPOs) in Zambia

It was in 1952 when a group of non-disabled people who were concerned about the social plight of the Blind volunteered to form the first organization to deal with persons with disabilities in Zambia then known as Northern Rhodesia Society for the Blind(not operational). Since then to date, a number of stakeholders have emerged to provide a service to persons with disabilities. The umbrella organization, the Zambian Federation of the Disabled (ZAFOD), is a grouping of Zambian DPOs. The Zambian Federation of the Disabled was founded in 1985 and is a member organisation of the Southern Africa Federation of the Disabled (SAFOD). Its main functions are to advocate for people with disabilities and carry out disability awareness campaigns, and also provide small loans to people with disabilities and training in small-scale business management in the bid to empower them economically.

Although disability issues are inter ministerial with all government ministries expected to play their respective roles, the Ministry of Community Development and Social Services (MCDSS), is implicitly responsible for disability issues supported by the Zambia Agency for Persons with Disabilities (ZAPD).

2.4 Physical disability

Physical disability is defined as a limitation in one or more activities of daily living such as moving around, eating and dressing (Schneider, Classens, Kimmie, Morgan, Naicker & Roberts, 1999). Venter, Rickert, and Maunder (2004) defines ‘physical disability’ as the outcome of complex interactions, arising from a person’s physical condition and their social and physical environment. This implies that, like other disabilities, physical disability has multiple dimensions, and encompasses more than an individual's health and/or medical problem.

2.5 Models of Disability

Models of disability provide a framework for understanding the way in which people with impairments experience disability, they also provide a reference for society as laws, regulations and structures are developed that impact on the lives of people with disabilities. The three main models that have influenced modern thinking about disability are: the medical model, the social model and the bio-psychosocial model.

2.5.1 The Medical Model of disability

This model is based on health care delivery systems and structures created and based on the biological cause of disease which result into disability as viewed by the medical professionals' assumptions and beliefs (Glenton, 2002). The model is of the belief that disability results from an individual person's physical or mental limitations, and is largely unconnected to the social or geographical environments. It is sometimes referred to as the Biological-Inferiority or Functional-Limitation Model. The medical model is sometimes known as the 'individual model' because it promotes the notion that it is the individual disabled person who must adapt to the way in which society is constructed and organised.

The Medical model identifies disability in terms of impairment; explaining disability as the result of physical, mental or sensory impairments that prevent a person from living, working and being part of society in the same way as non-disabled people. The model is perhaps the most widespread theory that is consciously or unconsciously used to rationalise disability. The model focuses on impairment and loss of functionality: it encourages the idea that disability is only a condition affecting the individual. Therefore it might seem that the disadvantages and challenges faced by disabled people are the result of their own personal condition rather than any failings in society or barriers in the built environment (Wendell, 1996; Glenton, 2002).

Initiatives based on the medical model focuses on finding a cure or medical intervention to help the person lead a 'normal' life. These interventions might involve surgery, prosthetic limbs, and assistive devices provision as need arise (Oliver, 1990; Wendell, 1996). From the view point of the medical model, it is easy to conceptualise how people with disabilities might become stigmatized as "lacking" or "abnormal". The medical model places the source of the problem within a single impaired person, and concludes that solutions are found by focusing on the individual (Wendell, 1996; Glenton, 2002).

2.5.2 The Social Model

The social model was inspired by an understanding that impairments are not the main cause of the problems facing people with disabilities, but that it is the way society responds to them as an oppressed minority (Shakespeare, 1996; Disabled People South Africa (DPSA), 2001). The social model conceptualises disability as 'arising from the interaction of a person's functional status, with physical, cultural, and policy environments' (Oliver, 1993; Shakespeare &Watson, 1997; Hughes & Paterson, 1997). When the environment is designed for the full range of human functioning and incorporates appropriate accommodations and supports, then people with functional limitations would not be "disabled" in the sense that they would be able to fully participate in society. Thus, the social model emerged as a new interpretation that generated a new approach to disability. The social model was a way of getting people with disabilities to think about the things they have in common and the challenges they all face, while bearing in mind that some of these challenges are impairment-specific (Oliver, 1993; Shakespeare &Watson, 1997; Hughes & Paterson, 1997).

Some of the strengths of the social model are; firstly, its recognition that disability is not the major barrier that stops people with disabilities from leading fulfilling social lives, and secondly, the social model advocates inclusion and integration of people with disabilities in mainstream activities (DPSA, 2001). Interventions are thus not only at the individual level such as medical rehabilitation, but also at the societal level which include the introduction of universal design to make infrastructure more accessible, inclusive education systems, and community awareness programs to combat stigma (Oliver, 1993; Shakespeare &Watson, 1997; Hughes & Paterson, 1997).

Critics of the social model point to the importance of the subjective nature of disability, arguing that social services alone cannot meet the needs of this population (McConkey & O'Toole, 1995). Although the social model had made remarkable gains in advocating services for people with disabilities, disability activists realised that this model was inadequate in driving political will for the creation of disability policies and legislation (DPSA, 2001).

2.5.3 The Bio-psychosocial Model

The bio-psychosocial model is a general model or approach suggesting that biological, psychological (which entails thoughts, emotions, and behaviours), and social factors, all play a significant role in human functioning in the context of disease or illness. Health is best understood when there is a combination of biological, psychological, and social factors rather than purely biological aspect alone (Santrock, 2007). This is in contrast to the traditional, medical model of medicine that suggests every disease process can be explained in terms of an underlying deviation from normal function such as a pathogen, genetic or developmental abnormality, or injury. The Bio-psychosocial model is used in fields such as medicine, nursing, health psychology and sociology, and particularly in more specialist fields such as psychiatry, health psychology, chiropractic, clinical social work, and clinical psychology. This model is also a technical term for the popular concept of the mind–body connection, which addresses more philosophical arguments between the bio-psychosocial and biomedical models, rather than their pragmatic exploration and clinical application (Sarno, 1998).

According to Santrock, (2007), the biological component of the bio-psychosocial model seeks to understand how the cause of the illness stems from the functioning of the individual's body. The psychological component of the bio-psychosocial model looks for potential psychological causes for a health problem such as lack of self-control, emotional turmoil, and negative thinking. They further elaborate that the social part of the bio-psychosocial model investigates how different social factors such as socioeconomic status, culture, poverty, technology, and religion can influence one's wellbeing.

Halligan and Aylward (2006) described their understanding of the model in a philosophical sense. They understand the bio-psychosocial model as one which states that the workings of the body can affect the mind, and the workings of the mind can affect the body. This means both a direct interaction between mind and body as well as indirect effects through intermediate factors. The bio-psychosocial model presumes that it is important to handle the body, mind and intermediate factors together. A growing body of empirical literature suggests that clients' perceptions of health and threat of disease, as well as barriers in a client's social or cultural environment, appear to influence the likelihood that a client will engage in health-promoting or treatment behaviours, such as medication, proper diet, and engaging in activity of the society (Haskard, Kelly & Dimatteo, 2009).

The adoption of the Bio-psychosocial model in health practice has led to the development of a systematic approach to understanding the clinical presentations found in many treatment settings (Santrock, 2007). This research is therefore informed by the bio-psychosocial model of understanding disability on which the International Classification of functioning Disability and Health (ICF) framework is based.

2.6 Challenges Experienced by People with Disabilities

It is known that participation in activities of daily life by people with physical disabilities is limited not only by their individual impairments, but equally by external barriers, which include: environmental, socio-political and attitudinal (United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP), 1995a; Barnes & Mercer, 1997; Miles, 1999; Craddock & McCormack, 2002). In developing countries, this is more exaggerated by poverty. People with disabilities often live in deplorable conditions, owing to the presence of environmental, social and attitudinal barriers which prevent their integration and full participation in the community. As a result, millions of children and adults throughout the world are segregated and deprived of virtually all their rights and lead a wretched, marginal life (Despouy, 1993).

2.6.1 Physical challenges

Physical challenges are the difficulties that people with disabilities encounter when trying to access the physical natural environment, and/or the built environment (McLaren, & Philpott 1997; Kulkhanchit, 2002). The physical challenges may be intrinsic; which are individual limitations (the body impairment,) or extrinsic which are environmental (the physical environment).

2.6.1.1 Activity limitations

The physical individual limitations are referred to as the inability to carry out activities of daily living for example, inability to dress oneself due to paralysed arms) (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963; WHO, 2001). The term "activities of daily living" (ADLs) refers to a basic set of everyday activities or tasks that an individual should be able to perform in order to live independently (Katz, *et al.*, 1963; Wiener, Hanley, Clark , & Van Nostrand, 1990). These activities include bathing, dressing, transferring, using the toilet, continence, and eating (Katz *et al.* 1963). Since the ability to walk inside the house is an important criterion that enhances the performance of the daily activities (WHO, 2001) it has been added to the list of ADLs. Activities of daily living are not a measure of health status, but of the functional capabilities of an individual (Kane & Kane, 1981).

The most detailed information in studies of problems faced by people with disabilities tends to be about the physical limitations of individuals. The inability to carry out activities of daily living is a common focus. Mulholland, Packer, Laschinger, Olney, and Panchal (1998) studied a group of ten disabled women with physical impairments in India with the aim of understanding their daily mobility needs. Nine of the ten reported varying degrees of difficulty in accessing toilets and bathing facilities, as well as having difficulty in fetching water and transporting objects. Among a group of physically disabled children in Nepal, Boyce, Malakar, Millman,and Bhattarai (2000) reported limitations of functional activities such as mobility, household chores and self-care due to pain. Another study in Nepal of people with impairments resulting from leprosy reported that the most commonly affected activities included washing clothes and dishes, carrying water-pots, watering the land and pouring water (Van Brakel & Anderson, 1998).

Physical weakness means that disabled people have to rely on stronger household members for support in activities of daily living which in turn increases the burden on care givers (Hollingsworth, 2001; Van der Kroft, 2002). Among the elderly with physical impairments, functional limitations become increasingly common with age. A study conducted in South Africa in people older than 65 years reported that 11 % had difficulty washing, bathing or showering, while 5 % had difficulty using the toilet (Taunyane & Hirschowitz, 1995)

2.6.1.2 Physical environmental/or architectural barriers

Physical environmental barriers are physical features that make it difficult for people with disabilities to access facilities or places. In a research project carried out by Newton Ormerod, and Lewis (2002) in England, they observed that workers who want to work and are in employment still experience accessibility challenges in their workplaces. They further reported that barriers in built environment may be a problem for employers who want to employ people with disabilities. They are hindered by accessibility issues related to the design and construction of structures and facilities in the workplace. Most of these buildings are not easily accessible by people with disabilities.

In a 2006 study conducted by Grut and Ingstad in Yemen, it was reported that the design of the houses was a challenge to people with physical disabilities. They reported that most houses for those who can afford it are quite large, providing space for a large family of unmarried daughters and married sons. On the ground floor however, there are only usually storage rooms, and it is only after ascending a steep stairway, does one get up to the living quarters one or more floors up. This of course creates a problem for people with physical impairments. Although many of the houses of poor people had the same layout, they were on a much smaller scale and more crowded. This makes mobility for people with physical disabilities more challenging.

This study conducted in Yemen also reported that official buildings as well as designs of roads did not seem to be made accessible for wheelchair users, and on the whole there seems to be much left to do in order to accommodate the needs of people with disabilities into physical planning. Leonardi (2006) write about a visit to the office of the Disability Fund and illustrated this: "the courtyard is overcrowded with disabled people, many of them in wheelchairs or with crutches, waiting while the person who assists them is attending the office inside the building that is only accessible for those who can climb the stairs".

A study conducted in Gisoo Ghaem in Iran by Habibi and Mirfatah (1991) reported that architectural and urban barriers prevent persons with disabilities from participating in social activities. In spite of their capabilities and potentials, these persons with disabilities have many difficulties due to accessibility challenging environments. The society is subsequently deprived of their abilities and talents. Newton *et al.*, (2002) reported that the physical environment of developing countries has changed over the years which they attributed to the changed infrastructure of the countries. Skyscrapers, fascinating interior, ultra modern usage of machines amongst others have made the lives more convenient and fanciful for the city or metro dweller. Although this has made the lives of non-disabled individuals easier, it has made the lives of disabled individuals difficult. The progress in infrastructure has not added any freedom for people with disabilities, as built environments have added inaccessibility, uncertainties, anxieties and dangers.

A report from Zambia on a study of the living conditions of people with disabilities revealed that a community development programme in which pit latrines were built to improve sanitation, it was clear that although this was a community development programme people with disabilities were not considered. People with disabilities could not use these latrines, as no sitting pans or wide doorways were incorporated into the plan, and as such, people on wheelchairs were excluded. The same toilets were used as bathrooms and similarly that improvement was still not benefiting persons with disabilities. A woman with a disability confessed to bathing only at night and using bushes as toilets (Leob *et al.,* 2006).

2.6.2 Social Challenges

Social challenges are difficulties that people with disabilities face to gain social freedom and exercise their human rights to the maximum. These include limited access to education, reduced opportunities to be employed, poverty, poor housing, water and sanitation, limited access to public transport, limited access to health care and rehabilitation services, and other public social services (Komardjaja, 2001; Leob *et al.,* 2006).

2.6.2.1 Challenges Experienced With Social Interactions

Improving access and mobility for people with disabilities is crucial to alleviating poverty. A three year research programme was carried out by Venter *et al* (2004) in South Africa, India, Malawi, Mozambique and Mexico to assess the access needs of people with various disabilities. The results showed remarkable similarities across countries. The small mini-buses in general provide better physical access (excluding wheelchair access) than large buses, because of their smaller size and availability at all times. However, the attitude and driving behaviour of drivers, as well as overcrowding, are major barriers to their use by people with disabilities. Sidewalks that are unpaved, poorly maintained, or crowded by vendors are common across the cities studied, and limit pedestrian mobility. In India, the road surface prevents some wheelchair users from leaving their home for all but essential trips. Geographical features such as sandy roads in Maputo and steep slopes in Blantyre limit the mobility of people with disabilities, including those with wheelchairs. Most bus drivers in India for instance do not allow sufficient time for people to board and disembark in comfort and safety, and transport personnel in general are lacking in disability awareness and training in assisting people into vehicles.

Vehicle and infrastructure design creates barriers for all types of disability. Heavy traffic prohibits people from making journeys by foot. In India, disabled women suffer more, and there is a common perception that disability is the result of a curse for sins committed in the past life. The large fleet of Volkswagen "bugs" operating as taxis in Mexico City provide relatively good curb-to-curb mobility to those who can afford them, but exclude even wheelchair users who can transfer to a regular seat due to the absence of a front seat in these vehicles (Venter et al. 2004).

Mony, (2002) reported that access to natural water sources can be difficult because of long distances and a lack in nearby areas. People with disability have to walk long distances to fetch water. The concept of social role provides a way of identifying and naming people's interdependencies. Roles are said to identify the ways that people belong to each other, participate in exchanges with each other, and expect reciprocal responsibility from each other. They are also said to identify the contexts in which people learn skills and perform skilfully, and the areas of life where people can experience satisfaction and earn status. Studies of service practice show that performance of a variety of social roles in community settings correlates strongly with measures of other valued outcomes (Flynn & Aubury, 1999; Gardner & Carran, 2005; Lemay, 2005).

2.6.2.2 Challenges Related to Provision of Services

Persons with physical disabilities struggle with the consequences of discriminatory social policies that deprive them of physical rehabilitation services, which are unavailable in their communities. This situation perpetuates functional limitation which leads to continued dependence of the physically disabled on others for personal hygiene and ambulation.

A study conducted in Yemen by Radda-Barnen (1998) revealed that lack of specialized facilities or systems of support, aids and equipment for disabled people and their families constitute a challenge to people with physical disability. Lack of training and expertise is another factor reported by Hanko (1999) in a study conducted in Vietnam where therapists are scarce and inexperienced. Trained therapists in India form part of the brain drain to the countries of the North (Payne, 2002). In many African countries, there is no clear policy for provision of assistive devices; long waiting periods and transport costs, particularly for those in rural areas, make it difficult to get access to a rehabilitation service and to obtain assistive devices (McLaren *et al.,* 1996; Philpott & McLaren, 1997). Where these assistive devices are available, they are not always appropriate to the disabled persons' living environment. More so, most equipment is imported into the country which is inappropriate for local use and conditions (McLaren *et al,* 1996).

Professionals tend to take an overly narrow view of people with physical disabilities' independence as in improved physical functioning, whereas the disabled person's view is often broader and related to social and personal freedoms (Scherer, 2002). Van Brakel and Anderson (1998) noted a similarly narrow focus among professionals working in Nepal for people with leprosy. They acknowledge the 'quite widespread' use of certain assistive device to hold spoons, pens and other tools, but point out that little attention is paid to assessing or alleviating the difficulties experienced by clients in carrying out daily activities.

The cost of assistive devices is prohibitive for most people with physical disabilities. Taunyane and Hirschowitz (1995) observed that more than 50% of the African disabled respondents in a study did not have the appliances they needed because of poverty. Lack of consumer involvement in selection of assistive devices is apparently the single most important reason they are not used. Research shows people with physical disabilities sometimes reject or abandon what seem to be well-designed and functional devices for psychosocial reasons. Examples of reasons given are that the 'assistive device will make me feel more dehumanised' or 'will turn off' other people', or will appear 'freaky' or 'comical' (Day, Jutai, & Campbell, 2002).

Lack of training, support and follow-up by assistive device service providers is reportedly the reason that one in three users in high-income countries abandon the devices (Craddock & McCormack, 2002). Community workers in low-income communities may be inadequately trained in socially sensitive areas of peoples' lives. Most of the servicing and maintenance of assistive devices is done by hospitals, but again, long waits, long distances and transportation costs cause problems for people with physical disability (McLaren *et al,* 1996). Non-disabled people often make decisions about and for people with disabilities (Ahsan, 2002).

In a study carried out by Singleton, Breslin, and Lewis (2001), on Gender and Disability in international development organisations, it emerged that the 'attitudes and beliefs of organisation members were not based on accurate information, but on commonly accepted assumptions and stereotypes (Singleton *et al.,* 2001). Lack of information about low-cost solutions perpetuates the perception that accessibility is costly. At the same time, representatives of disabled people may lack expertise in defining and articulating the needs of their members and may be unsure of the range of practicable technical solutions which they could request and which could be provided at low, or no cost (Parker, 2001).

HIV and AIDS are among the challenges that people with disabilities experience. In recent years, research has identified HIV and AIDS as a significant and relatively unrecognised problem among disabled populations worldwide. The research has demonstrated that people with disabilities are at risk of HIV infection; women with disability, disabled members of ethnic and minority communities, disabled adolescents, and disabled people who live in institutions are particularly at risk. In addition, HIV and AIDS educational, testing and clinical programmes remain largely inaccessible to people with disabilities (Abhay, Quazi Syed, Lalit, Sanjay, Goyal, & Johrapurkar, 2008). There is also very little information available on the relationship between disability and HIV/AIDS in low income communities (Jones, *et al.*, 2002). Wazakile (2006), in her study among female adolescents with physical disabilities in Nyanga (Cape Town), asserts that disabled people are at particular risk of contracting HIV/AIDS due to lack of access to health information. This view is also supported by Save the Children (2000).

2.6.2.3 Challenges Related to Education, Employment and Poverty

The people with disabilities' inability to cope with the workplace environment suggests failure to have income of their own, and being incapable of attending social gatherings independently. The above challenges would make a person lose self-esteem. The dependence on their immediate families and care-givers when not available, may lead to psychological trauma such as social exclusion, loss of self-respect and degradation of self-worth (Helander, 1999).

The link between poverty and disability is now widely recognised. This is a global phenomenon which is applicable to the developed (Oliver, 1998) as much as the developing countries (UNESCAP, 1995a; Bonnet, 1997; Elwan, 1999). Poverty increases the likelihood of being disabled as shown in South Africa, where poor living conditions and difficulties with activities of daily living were found to be related (Taunyane & Hirschowitz, 1995). Poverty makes it increasingly difficult for families to minimize the impact of impairment due to lack of resources to access care and rehabilitation including assistive devices that disabled family members need (Taunyane & Hirschowitz, 1995; Radda Barnen, 1998; May-Teerink, 1999).

Disability and poverty are closely linked in many developing countries. The incidence of disability is more than twice as high among the lowest income groups in South Africa compared to the others (Venter *et al.*, 2004). Poverty and disability reinforce each other.

Disability often leads to exclusion from education and employment opportunities, thereby causing economic hardship. In developing societies, strong social and cultural attitudes persist in isolating and excluding people with disabilities from mainstream society. People with disabilities, who are denied education, are frequently unable to find employment, driving them deeper into poverty. The consequences of this vicious cycle are evident in many developing countries. In India, nearly 50% of people with disabilities have never been to school, while only 5% of children with disabilities regularly attend school (Venter et al., 2004). Ninety-five per cent (95%) of Mozambicans with disabilities are illiterate, as compared to 60% in the overall population (Venter et al., 2004). Employment is very low: in India, for instance, the rate of employment of disabled people in the top 100 companies is only 0.4%, while the share of disabled women in employment is less than 0.3% (Venter *et al.*, 2004).

2.6.3 Attitudinal Challenges

Often the greatest barriers for disabled people are the negative attitudes and behaviours of family, community, or/and service providers (Seeley, 2001). A complex of cultural, social and political rules (UNESCAP, 1995a) can often be an even greater problem for the disabled person than the impairment itself (Gunnarson, 1998). Attitudinal and social barriers are often less easy to identify than physical barriers, and therefore less easy to change (Komardjaja, 2001). Stephen (2003), opined that attitudes are learned responses and they are the manifestations of what we had experienced in the past. He goes on to say that an unpleasant encounter or information will contribute to the formation of negative attitudes. There has been a lot of focus in research and intervention programmes on disability attitudes, beliefs, and discriminatory practices in the disability sector yet people with disabilities still struggle with the negative attitudes from society, family or/and service providers (Miles, 2000). Stephen (2003) suggests that the perpetual negative attitudes may be rooted in socio-religious belief system and are less liable to change. Dalar (2006) claims that disability policies, programmes and practices of any country are manifestations of the attitudes that people in different cultures share. It is therefore, easy to assume that in developing countries where basic life conditions are hard to maintain, such prejudices would have far more dehumanizing consequences. People in their struggle to survive and feed their dependents go through all kinds of exploitations and degrading experiences. There is poverty, illness, illiteracy and massive unemployment, leading to severe competition for diminishing resources. Under such conditions, persons with disabilities are one of the most vulnerable groups, which struggle more due to societal prejudices than due to their disabling physical condition (Dalar, 2006).

Other researchers (Chen, Brodwin, Cardoso & Chan, 2002; White, Jackson, & Gordon, 2006; Rosenthal, Chan & Livenh, 2006) review the extensive range of barriers faced by people with disabilities, that demonstrate how negative social attitudes block the integration of people with disabilities into society.

Globally, prejudice against disabled people exists in different cultures and religions. Due to prevailing attitudes, superstition and ignorance, it is common for families to hide their disabled children either because of shame, or to protect the child and themselves from negative social stigma (Helander, 1999). This is described in Nepal (Schofield-Gurung, 2000), in Yemen (Radda Barnen *et al.*, 1998), and in Bangladesh (Zaman &Munir, 1990) among many accounts. Disabled children are frequently over-protected by their families, resulting in limited interaction with their peers (Hanko, 1999; Pal, Chaudhury, Sengupta, & Das, 2002). This may be from a misplaced sense of guilt on the part of families, combined with a lack of knowledge about the child's potential.

Negative stereotypes are common, resulting in low expectations of persons with disabilities, preventing them from achieving their full potential (UN, 2002b). In Cambodia, disabled people are often excluded from society because they are thought incapable of contributing to family or community life (Hanko, 1999). As a result, disabled children tend not to be sent to school and to play with other children. In adulthood they become victims of ignorance, poverty, disease, discrimination and a whole range of negative attitudes due to their being isolated from the general social systems (Longshaw, 1997).

Negative attitudes of service personnel and bureaucracy of the systems are a problem (Bang, 1996; Philpott and McLaren, 1997). Craddock and McCormack, (2002) in their study in Ireland revealed that the way disabled people are treated when seeking information about a service can be a major cause of distress.

This is supported by a study conducted by Smith, Murry, Yousafzai and Kasonka (2004) in Lusaka which reported barriers to accessing safe motherhood and reproductive health services: the study further revealed that women with disabilities encounter various social, attitudinal and physical barriers to accessing safe motherhood and reproductive health services in this particular setting. Among the many challenges that were reported, the attitudes of reproductive health service providers towards the women with disabilities was the main obstacle to their (women with disabilities) accessing reproductive health services. The service providers' generalised assumptions that women with disabilities will not be sexually active; and that they would not require reproductive health services, lead to increased vulnerability to sexually transmitted infection including HIV. Genesi (2000) indicated that realising that persons with disabilities are still exposed to and oppressed by prejudice and discrimination may be the first step in reducing prejudice. Nowicki, (2006) further commented that "for as long as negative attitudes persist, the full rightful acceptance of people with disabilities is unlikely".

The question is: in what ways are attitudes towards disability changing in developing countries? There is no simple answer to this question, as there is a real dearth of research on this issue. Mallory (1993) observed that in developing countries, traditional attitudes of pity and charity are changing slowly. Miles (1999), on the basis of his study in Pakistan and other studies in 30 countries, noted that the progressive development is from negative, stigmatizing and rejecting attitudes, through pity and compassion, towards willingness to accept the physically challenged persons on equal terms. However, any such general conclusion needs to be tested with some standardized measures of attitudes and beliefs.

Persons with physical disabilities suffer the consequences of discriminatory social policies that deprive them of physical rehabilitation services which are not available in their communities. This situation perpetuates functional limitation which leads to continued dependence of the people with physical disabilities on others for their livelihood. Their inability to cope with the workplace environment suggests failure to have income of their own, and being incapable of attending social gatherings independently. The above challenges would make someone lose self-esteem, and the dependence on their immediate families and care-givers when not available, may lead to psychological trauma such as social exclusion, loss of self-respect and degradation of self-worth (Helandar, 1999).

2.6.4 Traditional /Cultural Beliefs and Myths of Disability

In most African cultures, explanations related to divine displeasure, evil spirits and reincarnation have been advanced as causes of disability (Ingstad & Whyte, 1995). While the concept of disability is universal, there is marked variation in how cultures interpret and understand it, and how disabled people themselves experience it. According to Schoepf (1997), disability among Africans is closely linked to the concept of illness or misfortune where it is considered only one of the outcomes when one is struck by illness, accident or bad luck. It may thus be thought that much of the discrimination experienced by people with disabilities in Africa is related to the suspicion and fear of witchcraft.

Most suspicion often manifests after the birth of a disabled child. Fathers of disabled children will accuse their wives of promiscuity because of the belief that there is no way that men could have contributed towards the 'creation' of a disabled child (Nkabinde, 1994). Children with disabilities are considered a burden to the family and to the community. It is believed that such children are unnaturally conceived, bewitched and therefore, neither fully human nor productive members of the community (Kabzems & Chimedza, 2002). Such beliefs are reflected and reinforced by vocabulary employed to refer to individuals with disabilities. Devlieger (1998) outlines how many 'Bantu' speaking people use prefixes designated for noun classes referring to objects or animals when referring to individuals with disabilities, thus reminding them of their place in society. For example Bemba noun classes referring to people usually begin with prefix *um-* in the singular to refer to *umuntu*, meaning a person. There are commonly used nouns referring to people with disabilities use the prefix i*ci-* in the singular to refer to *icilema*, meaning "handicapped" and "cripple" person. These noun classes (*ici*) are normally used for objects and when used with humans are considered negative (derogatory).

All societies have explanations as to why some individuals and not others are disabled, how individuals with disabilities are to be treated, and what roles are appropriate or inappropriate for such individuals. This includes decisions about rights and responsibilities individuals with disabilities are either entitled to or denied (Groce & Zola, 1993). Ingstad and Whyte (1995) agree with White and Olson (1998) who suggest that in some cultures, beliefs about the origins of disability are particularly useful and necessary when searching for therapy; while in other cultures, the mere presence of a disability determines whether one is going to be accepted by society or not. When families in societies where disability is accepted are unable to cope with the care of a disabled relative, it is as a result of poverty, lack of support and lack of knowledge about what can be done to improve the situation rather than a result of lack of love or negative attitudes towards a person with disability (Ingstad, 1997). Individuals with disabilities are therefore treated well or poorly, based on cultural beliefs about how and why they become disabled (Groce, 2004).

2.7 Summary of chapter two

Persons with disabilities are challenged by the physical environments such as buildings, roads and public transport because of the unfavourable designs. They are also challenged by the social factors that do not favour their social development such as limited access to education, unemployment, limited access to quality health and rehabilitation care, lack of information and the resultant perpetual dependence on others resulting into poverty. The attitudes of society, service providers and immediate families towards people with disabilities contribute to limitation of participation in the activities of the main stream.

CHAPTER THREE

Methods

3.1 Introduction

This chapter describes the research setting; it also examines the methods used to collect data. The research design, the research population, sampling method and instruments are described. The data collection procedure and analysis are explained. Finally, ethical issues relating to the research are presented before the researcher gives her brief reflexivity.

3.2 Research Setting

The study was undertaken in Chifubu which is one of the oldest but fastest growing low cost high density townships of Ndola City on the Copperbelt Province of Zambia. It has a population of 37,299 from 6312 households, which forms 10 % of Ndola's population. The Copperbelt Province has a population of 1,581,221; of this 2.2% are persons with disabilities (35,422) whose unemployment rate is 60% in the province (Central Statistical Office (CSO), 2003). In Chifubu, many people are unemployed following the closure, collapse and retrenchments at the time of the liberalisation and privatisation programme of most parastatal companies by the government of Zambia between 1991 and 2001. Ndola having been the host to most of the big Parastatal companies was affected the most (Rakner, 2003).

The township is situated approximately ten kilometres North West of the town centre, and eight kilometres from Ndola Central Hospital. Means of transportations to and from Chifubu is by mini-buses and taxis. Roads within and those leading outside the township are in deplorable states. Transport is also quite expensive. Houses are very old and small, with ablution facilities located between six to thirty metres outside the house. Though water-borne, the toilets are squat type with no special designs. The bathroom and toilet are combined in the same room which is quite small. All the housing units were electrified in the 1998 and 1999 electrification programme by the government of Zambia (CSO, 2002b).

Health services are provided by a local primary health centre known as Chipokota Mayamba. Besides the routine primary health care services, the health centre provides mother and child health which includes ante/post natal services, under-five clinics and HIV/AIDS counselling, treatment and care. The clinic operates on out-clients basis except for the maternity which is the only service with bed space where mothers are admitted to a labour ward. The primary health centre does not offer rehabilitation services of any kind. However, the township has a community based rehabilitation (CBR) programme, which caters for children with intellectual impairments. This CBR programme does not have qualified rehabilitation staff. Moreover, professional rehabilitation services are only available at the Ndola Central (for adults) and Arthur Davison Children's hospitals. The township has five (5) basic schools and one (1) high school. The only high school has double storey buildings and the only way to get to the classrooms on the top floors is by climbing a flight of stairs (CSO, 2002b).

The environmental constraints and the lack of rehabilitation services in the setting motivated the researcher to explore the challenges experienced by persons with physical disabilities living in this locality.

3.3 Research Design

A qualitative design was adopted, using phenomenological approach which employs the thematic method of data analysis. The use of qualitative research is advocated when the researcher seeks to understand meanings people attach to actions, decisions, beliefs and values (Bless, & Higson-Smith, 2000). It is also concerned with understanding the mental mapping process that respondents use to make sense of, and interpret the world around them (Ritchie & Lewis, 2003). Qualitative research relies less on scales and scores, but involves the gathering of facts that reflect experiences, focusing on perceptions and opinions of individuals taking part in the research or as observed on the scene (Todres & Holloway, (2004).

A qualitative approach was chosen to allow for exploration of challenges of participants' context that they experienced in their daily lives in their community as well as to gain an insight into their perceptions (Bless & Higson-Smith, 2000; Mouton, 2001). The advantage of this approach is the ability to place the participants' challenges in a specified perspective. However, whereas qualitative research methodology has been criticised by many for the intrinsic subjectivity, it is this exceptional subjectivity that is the core focus of the study. The strength of qualitative research lies in its ability to access the subjectivities and to so express a sense of the individual within the participants (Hammell, 2000). In this case, the researcher does not attempt to deny this subjectivity, but instead sees it as a contribution to this research. The inherent influence of the researcher's subjective experience on physical disability as a physiotherapist will be acknowledged in the reflexivity section. Furthermore, the validity in qualitative research is not as a result of indifference, but of the researcher's honesty.

3.4 Study Population Sampling

The sampling frame for the study consisted of all people with physical disabilities who responded to the advertisement about the study. A convenient method of sampling was used to delineate the primary population of interest which is persons with physical disabilities. The researcher purposively selected members for the focus groups from the available sample. Convenient sampling is the practice of including whoever is handy or available and willing to participate (Dale, 2006; O'Connor (2006). O'Connor (2006) also defines purposive sampling as one where the researcher targets a group of people believed to be typical or average; a group of people specifically picked for a unique purpose. Halling (2002) opined that purposive sampling is designed to gather a depth and richness of the experience. Thirty people responded to the advertisements and attended the meeting, however only twenty were willing to participate in the study. As the final sample consisted of 20, the researcher purposively selected members for each focus group representing all the characteristics mentioned in the sampling procedure. Thus two groups had seven members each, and one had six members.

3.4.1 Inclusion Criteria

Inclusion criteria for the study were that, individuals should be at least eighteen years of age or older at the time of the research. The participants should be able to express themselves in either of the two major dialects (chinyanja or icibemba), commonly used in Chifubu township or in English. They ought to be residents of Chifubu Township at the time of the research with only physical disability, and no other disabilities (such as, sight, hearing, or intellectually impaired).

3.4.2 Exclusion criteria

All persons with any other disabilities other than physical disabilities were excluded.

3.5 Methods of data collection

Focus group discussions and in depth interviews were used because this approach aims at describing, interpreting and understanding the meaning of experiences at both general and unique level (Todres & Holloway, 2004). The focus group discussion was for the purpose of getting a general overview of challenges experienced by persons with physical disabilities living in Chifubu Township. Mitchell (1999) reported that interviews combined with focus groups gain access to different aspects of people's experience (Green & Thorogood, 2004; Mitchell, 1999). They further mentioned that one cannot assume that people are more 'honest' from interviews alone or just from group discussions, but they may talk in different ways or reveal different aspects of their experience if the two are combined.

3.6.1 Focus group discussions

Focus groups are a form of group interviews that capitalises on communication between research participants in order to generate data. According to Kitzinger (1994) as well as Fontana and Frey (1994), focus groups are advantageous for researchers in the field of health and medicine. This method does not discriminate against people, who cannot read or write, and people who are reluctant to be interviewed may be encouraged to participate in the focus group discussion Although group interviews are often used simply as a quick and convenient way to collect data from several people simultaneously, focus groups explicitly use group interaction as part of the method. This means that instead of the researcher asking each person to respond to a question in turn, people are encouraged to talk to one another: asking questions, exchanging accounts and commenting on each others' experiences and points of view.

The method is particularly useful for exploring people's knowledge and experiences and can be used to examine not only what people think but how they think and why they think that way (Fontana & Frey, 1994). Focus group discussions are also appropriate for comparing among participants who have similar experiences and the same phenomena under study (Robinson 1999). In the focus group discussions, an interview guide with probes was employed outlining the phenomena that were being explored. The aim of the outlined questions and probes were to form a loose guide to the conversation, to allow the participants to explore things that are pertinent to them rather than discuss aspects that may reinforce the researcher's preconceptions. To ensure confidentiality of information discussed in the focus groups participants signed the disclosure statements.

3.6.2 Interviews

Taylor (2006) defined qualitative interview as 'a conversation with a purpose', while Todres and Holloway (2004) stressed the flexibility and adaptability of in depth interviews. These definitions sum up the essence of qualitative research interviewing. The aim of the interview as with any qualitative data collection tool was to explore the 'insider perspective'. To capture, in the participants' own words, their thoughts, perceptions, feelings and experiences. The researcher employed the face-to-face format in an informal two way process where both the researcher and the participants engaged in a dialogue to explore the topic at hand. During the interviews, participants were asked one open question aimed at exploring their experiences. Participants were encouraged to tell their own story about their physical disability and the challenges they faced in their day to day lives. The question the researcher asked was: "tell me about your life experiences as a person living with a physical disability".

3.7 Procedure

Advertisements which were written in English, Icibemba and Cinyanja were put in local churches in form of posters and announcements, as well as at the local primary health centre and the local market square. A meeting was arranged by the researcher to explain in details the purpose of the study and matters of ethics using the information sheet and consent form. All those that accepted to participate in the study signed an informed consent form. The researcher and participants decided on the suitable date for the focus group discussions. After each focus group discussion participants for the in depth interviews were selected.

3.7.1 Focus group discussion

The researcher introduced herself to the participants as a student physiotherapist and that; the study was part of the requirements for the master's degree in physiotherapy. All the twenty participants signed an informed consent each. They were also informed that each participant was free to withdraw from the study at any time if they felt like not continuing for whatever reason and that it would not affect them in any way.

For each group the information sheet which was written in the local dialect was read aloud by the researcher for the sake of those that were not able to read. Clarifications were made as soon as a query arose from the information sheet. When all the participants were satisfied with the explanations on the information sheet, they were made to sign a disclosure statement regarding their participation and confidentiality in the group they belonged to.

The focus group discussions took place at one of the local churches which was a very secure, central and convenient place for participants. The venue was an isolated hall free from interruption of the noise and unnecessary visits. The interview guide was used to guide the focus group discussions. All the discussions were tape recorded, with the consent of the participants. The researcher trained a research assistant by giving an orientation on ethical issues and how to take notes. The research assistant was only involved in taking notes of the discussions to enhance the richness of the data in terms of capturing some of the data which could be not audio recorded such as the emotions accompanying the verbal expressions. The researcher assumed the role of moderator for the discussion. Each group discussion took approximately one and half to two hours, within which break and refreshment periods were included. After each focus group discussion, the tape was back played and participants listened for the purpose of members checking for the correctness of the data.

3.7.2 In-depth interviews

Appointments were made with participants' who were purposively selected for in-depth interviews at mutually arranged times and places (mostly at the participant's home environment). Eight participants were interviewed, with each interview lasting forty-five minutes to one hour. The researcher conducted all the interviews, which were audio-recorded. This open unstructured style allowed the participants to present their experiences not only in their own words but also in their own style. At intervals, the researcher probed and reflected back, allowing for both description of phenomenon and an exploration of its meaning to emerge. Clarification was sought where need arose. All the in depth one to one interviews were audio recorded.

Three interviews were conducted weekly until all the participants were interviewed. After each interview, the audiotapes were played back to the participants so as to confirm or make any necessary adjustments to clarify new ideas that may have developed. This was also done to make sure that the recorded data was clear and of good quality. The tape play back and participants' listening also served as member checking. Any changes that arose were written in the note book and later incorporated into the transcripts. A copy transcribed data, in form of a summary of analytic categories and subcategories as well as verbal explanation by the researcher of interpretations and preliminary conclusions were made and presented to the first four participants. They were in agreement that the items were reflective of the face-to-face interviews. Six of the face to face interviews were conducted at the participants' homes and two were conducted at the Catholic Church at the request of the participants who were more comfortable to have the interviews away from their home environments.

3.8 Trustworthiness and Rigour

In qualitative research, the degree to which a description truthfully represents the social experience to which it refers, and the level of uniformity with which occurrences are assigned to the same category by different observers or by the same observer on different occasions are considered under 'trustworthiness'. Avis (2005) opined that in order to meet the broader objective of trying to explain social behaviour in the perspective of the people involved, qualitative research will usually require an in depth, interactive, and naturalistic approach to the enquiry. It is further said that in the conduct of qualitative research, four methodological commitments about which there is some degree of consensus were identified: narrative data, extensive interaction with research participants, a flexible plan of enquiry and naturalistic focus on social processes. It is stated that the interactive, emergent and distinctive nature of qualitative design makes it impossible for qualitative researchers to demonstrate the same degree of reliability and detachment compared to a quantitative researcher. To ensure credibility of qualitative evidence qualitative researchers have to depend on alternative principles. Avis (2005) further suggested reflexivity, transparency, and critical examination of evidence in the light of relevant theory as essential elements of the argument that researchers put forward to audiences on the credibility of their evidence. To incorporate all the above mentioned principles to ensure rigorous qualitative evidence, alternative approaches are used to measure authenticity of the research. They are different from those used in quantitative research. Marshall and Rossman (1995); Baumgartner, Strong and Hensley (2002) have thus suggested credibility, transferability, dependability and confirmability as sufficient measures for meeting authenticity purposes, which refers to truthfulness of the research as asserted by Hamell and Carpenter (2000). The researcher observed trustworthiness by ensuring credibility, triangulation, transferability, dependability, confirmability as observed here forth.

Credibility

Credibility is defined as a quality assessment of whether the data convincingly describes the phenomenon which is being researched. It is also the researcher's ability, to demonstrate that the study accurately and fairly describes the phenomenon under research (Brink, 1999). Comprehensively identifying and describing participants in the study was one way by which credibility could be ascertained. With reference to this modality, credibility was achieved, as the researcher identified the participants using a purposive sampling method, and reported detailed descriptions of each one of them under demographic data. This idea is supported by Marshall and Rossman (1995).

Triangulation

The data was triangulated through use of field notes, transcripts, the contribution of various participants both in the focus group discussions, and the in depth interviews. Such a great variety of participants involved in the study, and member cross checking, adequately contributed to the credibility, of the findings. The member checking, an independent review on the coding process from two post graduates with experience in qualitative research and a peer review by the research supervisor further satisfied the requirements of credibility of the research (Lincoln & Guba, 1985).

Transferability

Marshall and Rossman (1995) refer to transferability as how the research findings can be extrapolated from the present representative sample to the larger population, which may pose a challenge to qualitative research. However, Polit and Hungler (1995) reported that, the researcher needs to provide sufficient descriptive data so that others can consider the applicability of the data to other settings. The researcher in this study thus endeavoured to adhere to the provision as much as possible (provide sufficient descriptive data). The researcher has produced a precise description of the research methodology and data analysis process aided by direct quotations from the interviews. This amounts to 'thick description', which is the criterion of transferability which as supported by Marshall and Rossman (1995).

The researcher has provided the reader with sufficient information (thick description; quoting verbatim), so as to make it easy for the reader to make independent conclusions. The researcher dutifully described the participants at the end of each quote, and great variety of data excerpts, this entirely sums up to thick description.

Dependability

Stability of data over time and conditions through inquiry audit that involves scrutiny of the data and relevant supporting documents by an external reviewer in qualitative research is what is referred to as dependability (Polit and Hungler, 1995). A qualitative study that establishes credibility also establishes dependability. In the current study, the researcher endeavoured at all times to achieve this by providing satisfactory facts of participants' word for word citations to allow the reader to consider its dependability. It was further fulfilled through a rigorous audit trail of all data sources and data reconstruction by an academic advisor at the University.

Confirmability

Polit and Hungler (1995) assert confirmability as signifying that data are true and reliable, with Baumgartner, Strong and Hensley (2002) further emphasising that confirmability as referring to neutrality or impartiality of the data. The issue of conformability in qualitative research therefore aims at the distinctiveness of the data. To achieve this in the current research, face-to-face interviews and focus group discussion were employed in which evidence was obtained from participants about the phenomenon under investigation.

3.9 Data Analysis

Procedure

The thematic analysis procedure was used to analyse data collected from the interviews and from the focus group discussions as advocated by Ritchie and Spencer (1994). It is advocated in a phenomenological interview because ideas that emerge can be better managed and understood under the control of thematic analysis (Aronson, 1992).

Transcribing started immediately after each interview and focus group discussion when the researcher was still familiar with the narratives (Gibbs, 2007). After each interview, the recorded audio tapes were played back, with the researcher together with the participants involved listening. Following this, the researcher would sit in a quiet place to listen to the audio tapes and transcribe word for word in the language the participant said it (Icibemba/chinyanja or English). This allowed the researcher to begin to detect and recognise recurrent ideas and patterns. After transcribing in Icibemba/chinyanja, the researcher translated the data to English and gave the tapes to an independent person who did his own transcription and translated the transcripts into English; a third party checked the translated transcripts from the researcher and the independent translator for accuracy and correctness. Comparisons were made and no major differences were noted, this was done so that the voice of the participant is not altered, a procedure supported by other researchers (Birbili, 2000; Temple &Young, 2004; Boyce &Neale, 2006; Gibbs, 2007).

Data was organised by putting together the field notes and the transcribed audio taped data in form of dialogue for the face-to-face in depth interviews with the participants labelled by number codes (for example P3: standing for face-to-face, in depth Participant number three) . In the case of focus group discussions, participants' answers to a particular question were lined up according to the code-number of the participant in that particular focus group (for example P1.2: focus group number one and participant number two). This was done in order to maintain anonymity among participants.

The researcher read through the transcribed data, field notes and continued listening to the audiotapes to familiarise with the raw data, noting patterns of experiences and highlighting them using colour codes. The preliminary analytic procedure was used to make the volume of data more manageable. In this regard, the researcher formulated a table to make the data manageable (Table 2). All the responses were put in the first column, while the colour highlighted parts of responses were extracted and pasted in the second column and the third column was about the meanings behind the highlighted extracts.

The coded data gave an overview of the setting and the participants. The data which had similar meaning were grouped together in the same categories and the categories that related to each other were grouped together to generate the sub-theme. The sub-themes that had similar characteristics were identified and put under the themes. These themes were identified by means of bringing together components, fragments of ideas, perceptions or experiences that came up as major findings with to regards the challenges experienced, their collective perceptions, needs, views and opinions. The coherence of the ideals however rested with the researcher who rigorously studied how different ideas or components fit together meaningfully when linked together.

The researcher will endeavour to present the data in as clear as possible way using a narrative report writing style. In this case, the researcher tells stories about the persons with physical disabilities living in Chifubu Township and their stories about the challenges that they experienced.

Discussions with three colleagues and peers, helped to critique and review the process of coding, categorising and arranging of the data into appropriate themes. The involvement of these peers in the review of the coding process of the data guaranteed that themes were broad and comprehensive. As mentioned earlier, on in order to maintain anonymity, participants' names were changed and cited using codes P1 and P1.3. The research analysis was planned around the understanding of these discussions and was controlled thematically in ways that endeavoured to be equally unbiased to the elements of the research questions and to the concerns of the participants.

3.10 Issues of Ethical Considerations

As required by the ethical committee of the University of the Western Cape, approval was obtained from the University of the Western Cape Research Grants and study leave committee (Appendix A), the National Biomedical Research Committee, Zambia (Appendix B), an information sheet for participants with disclosure statement was signed by each member of the focus groups for the observation of confidentiality (Appendix C). Informed approved consent forms for those willing to participate in the study, (Appendix D) and focus group interview guide (Appendix E). Recorded audiotapes, field notes and other materials pertaining to the research were kept in a lockable bag and only accessible to the researcher.

This study took ethical measures, approaches and customs in order to demonstrate the value placed on the participants and their views. At all times, the researcher preserved an attitude of transparency, not to mask any aspect of the research, and being open on the purpose of the research and what was expected to be achieved. As regards confidentiality, the researcher ensured that participants remained unidentified, changing their names and their identifying particulars to codes. The researcher accorded participant the opportunity and the freedom to withdraw their consent at any stage during the research in accordance with qualitative research principles.

3.11 Reflexivity

This refers to the conscious examination of the position of the researcher within the research. It is recognised that the biographical 'position'- gender, ethnicity, class, race, sexual orientation, age, religion, (dis)ability, professional status, education and other dimensions of social differentiations- of the researcher will affect the research relationship and the nature of data collected (Hammell & Carpenter, 2000). Respect for the principle of client-centeredness and the desire to ensure relevance and value of the research to the community I chose to research on, informed my own approach to this process.

As a physiotherapist, familiar with physical disabilities (involved in physical therapy in a hospital), the researcher gained fresh insights which added on the knowledge of challenges experienced by people with physical disabilities. The researcher learnt about the many social and the attitudinal challenges as well as how the traditional and cultural beliefs contributed to the challenges they experienced.

The research design and process made the contribution of the participants and that from the researcher relevant in the subject that affects so many individuals. The researcher considered this to be a noteworthy part of the context and credibility of the research. The use of the qualitative method on the other hand proved to be a challenging task especially during the transcription and analysis stages. In spite of the aforesaid, the richness and depth of the research materials and particularly the magnitude of insights produced through the approach made the research worthwhile.

Self-reflexivity shaped a significant constituent in the research. In this context, this meant that great reflections on the physiotherapy profession (as part of the rehabilitation team), transparency and limitations of the role of the researcher, including her own social, and professional experience. It had been difficult for the researcher to reconcile academic and professional training with the knowledge of the physical limitations and the social effect thereof. It was deemed critical to engage in a process of decisive thinking and analysis during the whole process of this research.

At the end of it all the researcher's perception of challenges experienced by persons with physical disabilities changed completely. Now the researcher understands that after all disability is not just about activities of daily living but everything else pertaining to social, culture as well as attitudes of both the persons with disabilities and the people around them.

CHAPTER FOUR

Results

4.1 Introduction

Chapter four is dedicated to giving meaning to the data in a comprehensive manner. The chapter will present the data using narrative report writing style. When giving the report of the interview, the precise language and phrases used by the participants are by all means preserved. Nonetheless, for additional clarity and smooth flow of the expressions, some slight grammatical adjustments were in some instances made. To avoid repetitions of unnecessary materials, they have been omitted and replaced by three ellipsis points (...).

This chapter presents the results of the research based on its aim. Based on the experiences, feelings, thoughts and opinions of participants during focus group discussions and in depth interviews, four main themes emerged with regard to environmental barriers, social limitations, attitudinal barriers and traditional beliefs and cultural myths. The challenges experienced by persons with physical disabilities in Chifubu Township were highlighted.

For each major theme that emerged there were also subthemes, under environmental barriers were individual limitations, physical, geographical, and architectural barriers. Under physical geographical and architectural barriers emerged further subthemes such as designs and distance. Sub themes that emerged under social limitations included the lack of social interaction, change of roles, unavailability of social structures, lack of social support, unemployment and poverty (party of socio-economical barriers). Subthemes that emerged from the attitudinal barriers were stereotype of perception of society which "resulted" into the victims feeling stigmatised, discriminated against, rejected and abused. The second subtheme under attitudinal barriers was the perceptions of the persons with physical disabilities themselves.

As noted in the methodology chapter, qualitative analytical procedures were used, of which the process involved thematic coding such that codes emerged from what was in the data, rather than from a predetermined set of categories. The researcher chose this approach so that in case of other themes emerging in addition to the predetermined ones should be captured analysed, highlighted and reported.

4.2 Social Demographic Characteristics of Profile of Participants

The social demographic characteristics of the participants are presented in table 4.1. The study population was by gender ratio at 7 to 13 (male to female), employment status: about 85% were unemployed, 5% were self employed 5% had retired and 5% employed.

Participant number	Gender	Age in years	Employment status	Cause of disability	Duration of disability In years	Part of body involved	M/ Stat.
P1.1*	F	38	unemployed	Polio	33	lower limbs	M
P1.2*	M	22	unemployed	amputation/	17	both lower limbs (below knee)	S
P1.3*	F	34	unemployed	Polio	29	lower limbs	S
P1.4*	M	53	unemployed	Stroke	<1	Left 1/2	M
P1.5*	F	56	Retired	Arthritis	10	All joints	W
P1.6	M	48	unemployed	Polyneuropathy	2	appendices	S
P1.7	F	35	Self-employed	Burns Contracture	10	Neck & right arm	S
P2.1	F	28	unemployed	Polio	24	lower limbs	S
P2.2	F	67	unemployed	Arthritis	10	All joints	M
P2.3	F	20	unemployed	Arthritis deformities	20	Thoracic Spine & hands	S
P2.4	M	39	Self-employed	Amputation/ Polyneuropathy	12/3	right leg /appendices	S
P2.5	M	38	unemployed	Polio	33	lower limbs	M
P2.6*	F	50	unemployed	Stroke	>4	Right 1/2	M
P3.1	M	24		Polio	19	lower limbs	S
P3.2*	F	73	unemployed	Stroke	4	Right 1/2	W

P3.3	F	45	unemployed	meningitis	15		W
P3.4	F	60	unemployed	Arthritis	>10	All joints	W
P3.5	M	56	unemployed	Stroke	>12	Right 1/2	M
P3.6	F	24	unemployed	Polio	20	lower limbs	S
P3.7*	F	70	unemployed	Amputation	2	Right leg	W

Total=20; *=8 in depth interviews; Male =40%; Female=60%

M/Stat. =Marital status: W= widow- 5; M= married- 6; S= single-9

Table 2. The themes, sub themes and categories

PHYSICAL CHALLENGES					
Sub-themes	**individual limitations**	**physical architectural barriers**	**Physical Geographical barriers**		
categories	*Basic activities of daily living*	*Inaccessible buildings*	*Distance of utility facilities*		
		Poor designs of public transport	*Difficult terrains*		
		Poor road net work			
SOCIAL CHALLENGES					
Sub-themes	**lack of socio interaction**	**change of roles**	**accessibility challenges of socio structures:**	**Lack of social support**	**Unemployment and poverty.**
categories	*Lack of support by society and family*	*Earning income and employment*	*Rehabilitation & health service facilities accessibility challenges*	*Social Support from society*	*Low literacy levels among people with disabilities*

	Lack of self confidence and perceived self inability	*Role in the family*	*Health Communication and information challenges*	*Social support from families*	*Lack of employment and poverty among People With Physical Disabilities*
					Lack of marketable specialised skills
			Water and sanitation		*Stereotypical behaviour among employers*
			Lack of recreation facilities		*Inability to work due to the physical impairment*
ATTITUDINAL CHALLENGES					
Sub-themes	**Attitudes of society**	***families' attitudes***	***Service providers' attitudes***		
	stigma,	*abuse*	*stigma*		
	rejection	*rejection*	*Discrimination*		
	discrimination	*Discrimi nation,*			
	Abuse	*stigma,*			
EMERGING THEMES					
CULTURAL BELIEFS/MYTHS					

Sub-themes	***society's beliefs about physical disabilities***				

HIV/AIDS CHALLENGES						
	Limited information	***Influence of culture***	***vulnerability***			

4.3 Physical Challenges

Two main aspects emerged as physical challenges experienced by persons with physical disabilities. The two aspects formed the themes on which participants expressed as their physical challenges; these were individual limitations and physical environmental barriers.

4.3.1 Individual Activity limitations

The inability to carry out activities of daily living is a common focus under this subtheme. It was obvious in both the focus group discussions and the in depth interviews that participants experienced difficulties to carry out one or more activities of daily living imposed by the impairment on the physical part of their bodies. These activities of daily living were subdivided into instrumental and basic activities of daily living

4.3.2 Basic activities of daily living

Basic activities of daily living are routine activities that people tend to do every day without needing assistance, involving functional mobility, and personal care, such as bathing, dressing, toileting, and meal preparation.

It was reported among participants that they had problems with basic activities of daily living due to reasons such as the impairment itself, lack of proper assistive devices and difficulties with mobility:

> *"Sometimes my sisters help me when they can. It is not easy because I do not have enough strength and balance is quite poor because of the numbness in my legs. Doing hand work is also difficult because of the weaknesses in my arms. As for personal hygiene I manage on my own but there was a time when I was very sick my mother*

used to look after me. She used to bath me and wash my linen"; *"I do not have a lot of strength to move around"*. **P 1.6**

"I have difficulties to use my right arm which is shortened, tight, and sometimes painful and does not stretch fully. I am a right handed person so it has not been easy to switch to being left handed and relying on one hand most of the time, as a result I take longer than usual to do whatever I am doing". **P 1.7**

The above claims were supported by the responses from the participants in the in depth interviews:

"I have never tried as you can see that I am sick, I cannot manage to scrub myself and pour water to rinse myself". **P4**

It was also found that some of the participants had difficulties to use the toilet because they did not have appropriate assistive devices:

"I have problems when it comes to the use of the toilet because of the way my legs are now". **P 3.3**

Squatting is a problem for me so I either stand or sit on the hole with my legs straight....I'm Struggling to use the toilet even without callipers it is still difficult". **P3.6**

Mobility was another problem which participants indicated was a challenge:

"...I Struggle to walk with my crutches because even my arms are very painful". ***P 2.2***

The lack of mobility also influenced the participants' ability to carry out ADLs effectively:

I get burning sensation in my legs and I feel very weak. To take a bath it is very difficult for me... not been able to go to town so much because I feel very weak" ***P 2.4***

Mobility was also cited by individuals who participated in the one to one in depth interviews as one of the challenges due to impairments experienced:

"....I manage with a stick and holding on to the wall especially in the house, but outside sometimes I slip and fall....I cannot walk from home going either to church or market firstly because my right side feels very heavy...." ***P5***

> *"I cannot do most of the things alone, like I cannot walk alone…When I just came from the hospital I could use the walker to hop around within the house but now I experience severe dizziness".* ***P6.***

The lack of running water was a major challenge experienced by the participants. A number of the participants reported that they needed to draw or fetch water from a distant place in order to take a bath. The fact that they had physical impairments made the task of bathing independently a challenge as expressed in the narrations below:

> *"The problem is with drawing water, because I cannot carry a bucket on my head neither can I carry a big container in my hands because I use both hands for crutches for walking".* ***P1.1***

> *"Each time I want to shower I need someone to help me draw water".* ***P2.5***

> *"….But I have a problem to prepare my own bath if my wife is not around, especially that I have to carry the water to the bathroom and prepare where to sit when bathing it is such a big issue for me".* ***P7***

4.3.3 Physical Barriers

It has been recognized that persons with physical disabilities' participation in activities of daily life is limited not only by their individual impairments, but equally by external physical barriers: which could be architectural or geographical. It is clear that the persons with physical disabilities living in Chifubu Township are challenged by such barriers thus preventing them from participating in the activities of the mainstream as deduced from both the focus group discussions and the in depth interviews.

4.3.3.1 Architectural barriers

Architectural barriers are those that arise due to the design of built environments which challenges persons with physical disabilities making it difficult for them to access such an environment. Participants indicated among the built environments, they faced difficulties accessing or utilising buildings, public transport among others:

Difficulties accessing and using the ablution facilities was among the challenges which participants said they faced because of the design as stated:

> *"What makes it more difficult is that our bathrooms and toilets are in the same small room and the toilets are on the ground I find it difficult to use nowadays because of the pain and stiffness in my legs".* **P 1.5**

> *"Even bathing is not easy especially that the bathroom is combined with the toilet".* ***P3.3***

> *"The main problem is the toilet. Our toilets here in Chifubu are very old fashioned where the cistern is up there near the roof and the toilet has no pan or seat; it is just a hole in the ground".* ***P7.***

In addition, it was also revealed that the design of the ablution facilities posed health hazards and security risks for persons with physical disabilities due to design of the facility:

> *"We use the same room for bathing as a toilet, so when I'm going to bath I have to leave the callipers outside because I have to sit on the floor when bathing which is not hygienic besides the facilities are used by many people".* ***P1***

> *"... Sitting is out of question because this toilet is more like a communal one".* ***P5***

Apart from difficult accessibility of the ablution facilities, the participants also disclosed that they also had problems accessing other built environments such as houses, schools, and other public utility places because of the steps /stairs:

> *"I have difficulties to move around my home with my assistive device, I opt to crawl when I'm in the house".* ***P2.5***

A participant who does not have any assistive device had this to say:

> *"I have problems to climb the two stairs at the entrance of the house such that I have to crawl to get to the veranda"* ***P 3.4***

And a wheel chair user narrated her difficulties:

> *"I have a problem with movements because I cannot take the wheel chair out because of the steps...".* ***P 3.7***

It emerged from the in depth interviews that accessing school buildings were also challenging because of the steps/stairs and narrow passages:

> *"It was not easy in the first place to be enrolled in an ordinary local school here in Chifubu because of the design of these schools; ... It was also very difficult especially that I had to climb stairs at school to get to the classroom".* ***P7***

Market places were also reported to have been difficult to access due to the narrow passages and overcrowding as reported:

> *".... I cannot go in because the market is so busy and people don't care they won't wait for me to pass slowly with my callipers and crutches in those small passage".* ***P2***

It was also observed that access to other utility buildings was a challenge as narrated:

> *Faults office for ZESCO is in town, this office is up stairs I think on the fourth floor if I am not mistaken and the elevators are not reliable most of the time they are out of order".* ***P2***
>
> *"I cannot even talk about visiting the sick friends or relative in hospital because the male ward is on the 5th floor, the female ward is on 4th floor and the elevators are forever breaking down so visitors have to climb stairs to various levels. I cannot manage with crutches and callipers to that level".* **P1**

Participants cited the state of road infrastructure as one of the problems that challenged their movements from place to place as verbalised below:

> *"I cannot walk a very long distance on these poor roads without falling or being at risk of being bashed by a vehicle. There are no sidewalks for people walking on foot which includes persons with lower limbs problems"* ***P 1.1***
>
> *".... I walk to church because it is near where I stay. I take a long time because the only path from my place to church has got big pot holes and during the rainy season there are pools of water and the path is very slippery so I have to move carefully lest I fall in the mud"* ***P 1.3;***

The problem of poor state of the road infrastructure was reported to contribute to the inability to access social services:

> *"firstly it was very difficult for me to get to school because of the bad roads and paths leading to my school they were rough with a lot of pot holes and big stones and when it rains there are pools of water collected in these roads....".* ***P7***

Difficulties to access public transport due to the design of the vehicles and stations also emerged as one of the sub-domains of architectural barriers which the participants said challenged them as outlined:

> *" On the minibuses there is no provision for persons with physical disabilities and using assistive devices"…. it is quite uncomfortable because in most of the minibuses the spaces between the seats are very small for the callipers to fit".* ***P 3.1***

> *"I go to town when it really is necessary because it is not easy to get to town on a minibus problems attached to mini-buses are many: Firstly it is not easy for me to get into the bus on my own I need someone to help me, When I get on the bus there is not enough space between the seats to put my legs it is so uncomfortable that you cannot imagine".* ***P 2.5***

4.3.3.2 Geographical barriers

Geographical barriers are related to the proximity and location of the facilities. Accessing health and education services was found to be one of the problems due to proximity and non availability locally.

Most participants cited the aforementioned reasons for giving up or not attempting to access such facilities as said:

> *"….it is expensive to go to the hospital for rehabilitation because of the distance. Both facilities are more than ten kilometres from Chifubu; to get there one requires transport and transport is not cheap".* ***P 1.5***

Another participant narrated how difficult it was to get a place at the nearest school, and how he gave up his education:

> *"I passed with a full school certificate but I was not selected to proceed to senior secondary level at the same school. Wherever a place was available, the issue of the distance was the main hindrance so I just decided to stop school".* **P7**

4.4 Social Challenges

Reporting the responses from both the focus group and the in depth interviews, it was observed that social challenges included lack of social interaction ; change of roles ;accessibility challenges of social structures; lack of social support, unemployment, and poverty.

4.4.1 Lack of Social Interaction

It was gathered from the participants that they do not take part in most of the social events because they were excluded from the activities of the community, as well as some activities of their immediate families in certain instances. They said that they felt excluded both by the society or the available systems, and also because of traditional beliefs and myths. In some cases, participants did not interact because they considered themselves unable, some lacked self confidence, and others were just isolated. This is seen as indicated by their reports.

Participants experienced a lack of social interaction due to society's exclusion as reported:

> *"They do not invite us; they think that because I have this physical disability I cannot participate in social activities in my community; sometimes we are sidelined in social activities in this community because of the disability".* ***P1.1***

In some instances, the participants said that they did not interact in a normal fashion with their families as their abilities were not recognised as observed from the quote:

> *"People no longer come for encouragement or counselling or even just for an opinion. Even at church I am no longer invited for any kind of gathering, it makes me wonder. Congregants have even stopped visiting me maybe because they are fed up because I am taking too long to recover".* ***P5***

As 22years old bilateral amputee due to leprosy said:

> *".....I feel as if I am not part of my family from the time my parents died; things have not been the same my siblings have just sidelined me...I have no position in my family such that my siblings treat me like an outsider".* ***P 1.2***

A 53 years old male with left half paralysis reported that he felt denied of a physical relationship by his wife, which he felt he was capable of managing:

> *"What bothers me most is that as a husband sometimes I feel the urge to have a physical relationship with my wife but she feels pity for me and says that I should get well first she says that she is scared that I may get sicker due to excitement and exhaustion. So now I don't know whether it is my wife being punished in the name of feeling pity or it is me because of being sick".* ***P4***

While persons with disabilities can make independent decisions, they said that they lacked support from their non disabled relatives who do not have confidence in them hence wanting to decide for them and making their social life miserable as narrated:

> *"She used to say things like: 'why did you choose to marry a man who cannot even help you after you have delivered his child? Or what is the use of having a husband? Is it just to make you pregnant? Why you were in a hurry to get married to this crippled man you are so beautiful an able-bodied man would definitely have come round'.* ***P2***

In some cases, participants did not interact because they considered themselves unable while others lacked self confidence and some just felt isolated. This is seen as indicated by their reports:

> *"I like singing very much but I cannot take part in church choir competitive singing because it involves dancing because of my status I cannot take part because if my choir loses in the competition they would blame it on me. .... The way people speak especially the members of the choir, their speeches may suggest in a way that makes me feel uncomfortable to be part of the competition for fear of being blamed for the loss".* **P1**

Participant felt cut off and isolated from the rest of the community because of his status as verbalised:

> *"I cannot even socialize with my business partners I cannot even go to the club or pub because I am sick. My friends only visit only once after a long time, so I am completely cut off from the business circles and I cannot even make business".* ***P4***

4.4.2 Change of Roles

There was change of roles among persons with physical disabilities especially among those that had the disability in their adulthood. They were not able to carry out certain functions such as working to earn income, and care for the family, because of the physical demands which they could not be met because of their physical disabilities. Some could not take certain positions which involved decision making because of the society's stereotypical attitudes towards persons with physical disabilities. It was also reported that role of parenting also suffered.

Participants expressed difficulties with the role of providing for their families as bread winners, or as people contributing to the well being of the household because of their physical status as said:

A 53year old male participant who was the sole bread winner of the family before he suffered the physical disability had this to say:

> *"...am not able to provide for my family I am no longer earning an income"* ***P 1.4***

A 56 year old male participant reported the swapping of role of breadwinner in his family:

> *"I am able to bath and dress myself now, because my wife is out most of the time, she is busy trying to make ends meet for the family... ".* **P 3.5**

It was learnt that as a member of a family, persons with disabilities roles suffered partly because they could not manage, not only because of their status, but also because of the traditional and cultural myths attached to disability as expressed by the participants.

As a single parent, a 48 year old male participant expressed fears about his upbringing of his children because he had become inactive in the activities and welfare of the family:

> *".....I am no longer active in the organization of the family and discipline wise my children know that me as a sick father I am not able to physically discipline them".*
> ***P 1.6***

Further expression of fear from a female participant who is a mother:

> *"Sometimes I feel indeed disabled because most of the things I used to do on my own I cannot do them anymore have to depend on the family member, my role as a wife has suffered because I am not managing at all. My role as a mother has also been affected because I can see that on the part of discipline among the children has gone down".*
> **P5**

Another participant who is a father lamented on his inability to contribute towards his daughter's marriage arrangements:

> *"It is difficult to make important decisions as a head of the house in my state. A lot of things I would have liked to do for my daughter's marriage that no one can do for me, I am not involved in important family discussions".* **P4**

4.4.3 Lack of social support

It was learnt through both focus group discussion and the in depth interviews that persons with physical disabilities lacked social support from immediate families, and society in some cases. Some lacked support because of their position or status in society or family, and others were not supported because of the stereotypical way society perceived disability.

Single male participants reported that they had limited assistance because of their marital status as seen in the quotations:

> *"….I do not have a wife to help me but sometimes my sisters help me when they can. Sometimes I get a feeling of regret in myself which makes me feel sicker".* **P1.6**

> *"…. since I do not have a wife to help me I really struggle that most of the time I go without bathing".* P2.4

Meanwhile a 28 year old female participant who was withdrawn from school to pave way for her non disabled sibling lamented emotionally and had this to say:

> *"Because of my disability, my mother thought I did not need the education. She withdrew me from school so that I pave way for my younger sister because she thought I had no need for education. She used to say that 'you are lame where you are going to take this education even if you are this clever?'… if she had supported me to finish my education my position would have been different".* **P 2.1**

Participants also experienced lack of social support from society:

> *"Church members have now even stopped coming to see me and to encourage me. They do not even consult me anymore over issues that I used to give expert advice. Even in the neighbourhood they no longer invite me for any social events. The treatment that my society gives me makes me feel that when you become disabled you are as good as half dead or you become useless".* **P5**

The limited supports from both families and society to persons with disabilities enhances their exclusion from the main stream and promotes social exclusion:

> *"…two or three persons with physical disabilities live together in the same house, because we get a sense of belonging among ourselves and we appreciate one another better".* **P1.1**

Amid lack of support from society in general, the church seems to have stood out to provide the much desired or missed support to people with disabilities:

> "The *church has been very supportive to my family during this time that I am suffering"* **P3.4**
>
> *"My grandparents were the only ones that accepted to look after me until the catholic sisters helped them.....but I have always had my callipers and crutches replaced by the Franciscan Sisters at St. Theresa's mission in Luanshya"*.**P3.6**

4.4.4 Unemployment

During both focus group discussions and in depth interviews, it emerged that most of the persons with physical disabilities were unemployed (demographic data table), only one among the twenty participants was in formal employment. Some have never been employed, while others could not continue in employment due to the disability. Most of them expressed the state of being poor, in destitution, indigence; scantiness, deficiency and scarcity meaning that they were living in poverty. There were various reasons that emerged for the high unemployment levels among the participants such as lack of proper education, lack of marketable specialised skills and stereotypical behaviour among employers among others.

The only employed participant attributed his stay in Chifubu Low cost /high density township to his economic status as a result of his limited skills:

> *"I'm limited in the activities I can take part in to earn an extra income and raise my standard of living because I'm limited to one job which is not good enough. This is the only training that I have had because that is what the government is currently offering (craftsmanship) to persons with physical disability. I cannot do any private jobs or any other physical jobs. Us disabled persons are most of the times restricted to crafts work while there are so many able bodied persons with the same craftsman's qualifications it is difficult for us to find the market especially here in Chifubu".* **P1**

Participants narrated that the negative attitudes and behaviours of prospective employers contributed to the unemployment:

> *'....when I go to look for piece work, the boss sometimes will come to pick those that are able bodied and leave me because I am physically challenged".* **P 1.2**

A female participant who is a mother of five, who obtained a qualification as an office administrator or personal assistant is also computer literate, explained her difficult towards employment:

> *"I have done a few part time jobs and tried to find a permanent job so many times in vain. I scored the highest marks for both oral and practical assessments and I was offered the job. When I started work the boss was not around, when he came to my office to meet me, I could see the shock in his eyes when he saw me getting up on my crutches to greet him. The boss was not willing to keep me despite my good performance".* **P2**

Meanwhile **P8** had this to say:

> *"I will do any job that will give me food on my table. Even now I do not really mind I can do any work as long as I am able and I will get something at the end of it. Some manual works that do not require very long hours of standing continuously I do manage. The problem that I face is to get such a job because when people realize that I have a physical disability they are not keen to engage me. If they happen to give me that job, after finishing and getting the payment, some people would warn me not to go back...."* **P8**

Participants also related their inability to work to their physical status as reported:

A female participant with poly arthritis which caused a physical disability making it difficult for her to work had this to say:

> *"I stopped working years ago because I could not manage because of the same problem (poly arthritis)".* **P 1.5**

A 50 years old female participant suffered a stroke; because of the nature of her job and work environment, she was laid off:

> *"I'm not working but before I became sick I was working for a private clinic in town. I spent more than one month in hospital so when I was discharged I found that I was deleted from the payroll so that is how I lost my job I am not doing anything"* **P5**

Employment brings about economic empowerment to those in it, lack of employment brings about lack of financial capacity leading to financial inadequacy and constraints and the consequences thereof as it emerged in this research. The high rates of unemployment among the participants caused them a lot of financial inadequacy and constraints. Most of the participants expressed the state of being poor, leading to perpetual dependency on others as indicated:

A 70 year old widow, who had right above-knee amputation said:

> *"I can no longer cultivate alone now I have to depend on hired labour which is expensive and may not be as good; I cannot buy my own grocery, each time I have to wait upon my grand children to bring groceries for me from Lusaka, because going to town would be very cumbersome and expensive with a wheelchair and someone to help me, we may need to hire a taxi which is very expensive".* **P6**

Some of the participants were being looked after by their friends who were also living with disabilities and are not employed and without family support.

Two of such participants had this to say:

> *"....and I am not employed I live with a friend who is also living with a disability".* **P1.2**

A female participant who is not employed was chased from home by her mother because she had become pregnant outside marriage also disclosed that:

> *"....it was difficult for me to manage alone so that is how my friend who is also living with a disability asked me to move in with her".* **1.3**

A 28 years old female participant who is a single mother revealed that:

> *"The problem that I have is, if I don't have money I cannot cultivate because I'm not able to do it myself physically, I depend on hired labour which I cannot afford"*

A male participant explained the situation of the PWPD in the township.

> *"The persons with physical disabilities (PWPD) beg on the streets and are looked down upon because they have no means of survival".* **P7**

It was also learnt that because of a lack of income, there was also overcrowding among where PWPD lived. Land lords rented out any little extra space in the already small low cost housing units to get a bit of money to survive:

> “ *It is very difficult especially that I am not the only one who uses the toilet I have tenants who also have families or visitors as a result the toilet is not up to the expected standard of cleanliness. I wish I could use it alone but it is not possible because rentals are my source of income because all my children died with the new disease called AIDS”.* **P3**

> *“This toilet is more like a communal one because we have put a tenant so that we can get a bit of money from the extra space that we had”.* **P5**

Some participants could not afford to access the rehabilitation services due to the cost of travelling to the facility which is not readily available in the community. It was clear that participants could not afford financially as revealed in the focus group discussions and the in depth interviews:

> *“....I could not continue with the rehabilitation process because I could not afford the transport costs. It was proving to be expensive for my family since we no longer have a steady source of income”.* **P 2.6**

> *“I stopped physiotherapy because I could not afford anymore. I have even given up my market stall I cannot manage to maintain the business”.* **P3**

> *“I was referred to physiotherapy as an outpatient and an appointment was made but I never fulfilled it because I could not afford transport money for myself and the person escorting me”.* **P 3.3**

4.5 Attitudinal Challenges

Attitudinal challenges are those that exposed the participants to social unacceptability (Stigma); prejudice (Discrimination); negative response and reactions from both the community and family members (Rejection); maltreatments (Abuse) physical, psychological, or sexual maltreatment.

4.5.1Attitudes of society

It emerged that persons with physical disabilities are treated with a lot of negativity by the society they live in. This was more so with the providers of various services and the community at large who discriminated, stigmatised, abused and rejected them. Participants reported being treated with a lot of negativity by provider of public services, the participants reported mainly about the negative attitudes of the public transport service providers and the primary health service providers as observed from the quotes.

Participants reported that they were also discrimination against as stated:

> *"…they would always say that disabled people are very cheeky or rude or insolent and difficult to handle and threaten not to pick disabled people; Some do not stop at all to pick a disabled person because they do not want to waste time to start waiting for this person to struggle to get in or start assisting him or her board the bus. So if you plan to go to town you have to be ready to suffer the humiliation of being disabled".* **P2**

Participants further indicated that apart from being stigmatised, the health service providers also discriminated against them as elaborated.

A 69 years old lady who felt that people with physical disabilities are judged by their disability status than their health status:

> *"As an old person with physical disability, I think that we are judged on the basis of our status not on the basis of our needs….when I went to the hospital the Dr did not bother to do any investigations or examinations he just relied on my history and complaint and said there was not much he could do because he concluded that it was old age and I think that with such presumed assumptions the doctor could easily have missed out on some important problem that could have helped him to treat me better".* **P 2.2**

Participants narrated how they were stigmatised and made fun of by the mini bus crews narrated:

> *"We are treated with a lot of hostility. It seems as if we are not entitled to these services as persons with physical disabilities for example transport the mini bus crews behave as if they own us".* **P 1.1;**
>
> *"Some of the mini bus crews are very rude they pass comments like 'hurry up get on the bus; if you know that you are HH you should not waste other people's time you should be hiring taxis to take you where you are going.' They treat us as if we board their minibuses for free and yet we pay same fair with everybody else.* **P 1.5**

> *"Mini-bus conductors make fun of me when asking the other passenger to offer the seat to me. I have heard them several times saying "please allow Haakainde to sit in front while you come and sit here". Haakailende is the name of one of the opposition political parties leaders, his full names are Haakainde Hiichilema, Hiichilema means a crippled person, so instead of calling us Hiichilema they call us by his first name so that we don't realize that they are in fact saying move out for this crippled person to sit comfortably there where there is enough space for her crippled legs".* **P2**

Participants also reported their experiences at the hands of health service providers who they said stigmatised them and contributed to specialised health services accessibility challenges:

> *"Even at health centres we are asked questions like "why do you want to attend the family planning clinic why did you become pregnant when you know very well that you are physically challenged? If you think it is easy and pleasant to deliver like it is to conceive you are in for a rude shock".* **P 1.3**

> *I was being asked questions like 'with your disability why do you want to indulge in sexual relationships, don't you feel pity for yourself; you mean you also are involved in sexual relationships why do you trouble your already troubled body by carrying that pregnancy; a person with physical disability where can you get HIV infection from; why do you need contraceptives or prevention, treatment and care information about HIV/AIDS for?"* **P 2.1**

> *"On the issue of HIV/AIDS, because of too much stigma associated with physical disability and the pandemic itself we end up not getting the proper information on prevention, care and treatment of the same. People are forever asking why a physically disabled person should seek information on HIV/AIDS they forget that we also have feelings like them apart from the physical disability everything else is very normal".* P1

Commenting on the position of persons with physical disabilities in the advent of HIV/AIDS, participants expressed vulnerability and lack of support from service providers and society which they attributed to the myths about the cure of the pandemic and the stereotypical attitudes towards persons with disabilities:

> *"The HIV/AIDS, family planning and antenatal clinics are difficult to visit because the service providers for whatever reasons think that we are not supposed to seek their services".*

The participant went further to justify the assertions

> *"....it is the treatment that I have so far received from the mentioned clinics that justifies my statement. I got similar receptions from three different clinics where the service providers were surprised that me as a person with physical disability was asking for contraceptives or HIV/AIDS prevention information or going for Ante-Natal services. Yet we are a vulnerable group of people. With the advent of HIV/AIDS there is a myth going round that if an infected person has sexual intercourse with a physically or intellectually challenged person they are cleansed of the infection which puts us at risk. It is difficult for us to tell if this person who is proposing a relationship with me is infected or not; if he is genuine or not. For me to have a partner who is not physically challenged is a plus to my life so you see how much protection I need"?*
> **P 2.1**

It was reported that participants also struggled with prejudices from society as seen in the quotes.

A female participant said that people with disabilities were excluded and discriminated against by society because of their status and their contributions were not well appreciated by many as indicated:

> *"In the community the neighbours think that because I have this physical disability I cannot participate in social activities. Some people appreciated our contributions but others take anything done by a person with a disability as disability related they would not see anything good in it. Even at church...if we become very active people will gossip about us saying that we are trying to prove that we are worth what we are not".* **P 2.5**

> *"The teachers would not allow me to sweep in the classroom meanwhile at home my mother makes me sweep like my siblings do. They underrated my abilities and capabilities... Just the idea of the teacher saying "no, give the broom to A or B you cannot sweep" was making me hate the teacher".* **P2.3**

One participant narrated how her neighbours reacted negatively to her situation of the troubles associated with the use of the ablution facility and how she felt stigmatised by the reactions of other users:

> *"....So it takes me a long time to bath or finish using the toilet, which brings problems especially that the toilet and bathroom are shared among four families. The others complain that sharing facilities with physically disabled persons is such an inconvenience because they take forever to finish".* **P2**.

Another young single male participant indicated his desire to have his own family but he was sceptical about the genuineness of the young able bodied ladies and the perception of society about disabled persons marrying an able bodied person he felt rejected as indicated:

> *"I very much want to have a family of my own, but I find it difficult to find a genuine partner who will be willing to marry me despite my physical disability. I'm saying so because I have had a number of intimate relationships which end in a same way. When I try to indicate or make known my intentions of marriage the ladies turn down my offer and they stop seeing me".* **P1**

A young single male participant lamented how people with physical disabilities especially those of male gender are rejected in intimate relationships:

> *"If I like a lady I have to think twice before I can approach her to propose friendship with her, because they think that a disabled person should love a fellow disabled person. She will either turn your offer down herself or she will be discouraged by her friends or relatives because they see it as a shameful thing to do".* **P 1.2**

A male Participant who was HIV positive shared his ordeal on how he was in addition to being stigmatised was verbally abused by a member of the public and a fellow resident of Chifubu Township:

> "*As for me it is double stigma, the fact that I am HIV positive and it has even made me live with a physical disability. one day I was going to the hospital on a minibus I sat next to a lady who wanted to keep the window closed because she did not want her hair style to be spoiled when I tried to reason with her she just told me off and said 'I did not cause your sickness neither did I cause your disability please give me peace, it is your own mischievous behaviour that you are paying for. Anyway I understand lame people are very stubborn but not at the expense of my hair' then she pulled the*

> *window closed. When I tried to insist on good ventilation on the minibus another person just commented and said 'you think you can convince him? Can't you see that he is lame you cannot reason with him'. They think that we are unreasonable and insolent"* **P 1.6**

One participant also reported how society abuse people with disabilities for their benefits otherwise they consider them as a nuisance as she narrated her experience:

> *"....for me as a physically disabled person to find a place to rent is not easy because society perceives us as very difficult lot, we are too clean, we take too long to use public convenience thereby inconveniencing other tenants and so on".* **P1.1**

P1.1 cited situations where she was used for the benefit of others and pointed out how vulnerable participants were at the hands of landlords, as she shared her own experience:

> *"But when it suits them a disabled person is handy, most land lords parade their disabled tenants as part of their families when they are served with water or electricity disconnection notices so that they are spared the disconnection. This has happened to me several times and I feel abused but there is nothing I can do otherwise the landlord will find an excuse to evict me even if I pay my rentals well".* **P1.1**

Commenting on the relationship between participants and society, one participant indicated how persons with disabilities are rejected and had this to say:

> *"....we are perceived as a bunch of troublesome dependent lot. So by all means they try to keep a distance and we are seen to be the ones pushing our way closer".* **P3.1**

4.5.2 Families' Attitudes

Discrimination, stigma, abuse and rejection are also experienced within the families of participants as was expressed with a lot of emotions.

A 67 years old widow, who at this particular moment was very emotional, narrated how she felt discriminated and mistreated by her own children and how it affected her:

> *"....they are now mistreating me with their wives, shout at me like a little child;*
> *They think I fake the pain because I do not want to be helpful I just want to eat and lie down; They have even erected a small shelter outside the main house where they*

> *have put me because they are ashamed of me when their friends from church or work come to visit. They do not allow their children to eat with me anymore....I hate to see the sun go down because I do not want to go to my son's house and be an outcast because I am old and sick".* **P 2.2**

Another Participant disclosed how she was isolated and kept away from the visitors' sights and how she was treated by her mother:

> *"...if there are visitors at home I was expected to stay out of the visitors' sight, if I by whatever reason appear I would be in trouble after the visitors left."* **P2.1**

Participant reported that the treatment from both family and society affected them negatively such that they felt guilty and degraded as seen in the verbatim:

> *"When people stare at me I feel very uncomfortable just feel uneasy sometimes they make me feel guilty that I am different as if it is my fault that I am the way I am".* **P2.3**

> *"...I feel as if I belong to second class human beings because even what is rightfully due to us we have to struggle to gain access".*
> *"Sometimes I get a feeling of regret in myself which makes me feel sicker".* **P 1.6**

A male participant with below knee right leg amputation who was also HIV positive lamented how some members of his family verbally abuse him and he had this to share:

> *"Some of my family members are sympathetic others do not care, others stigmatize me because I am positive they even say that despite having lost my leg I continued being mischievous and now I have gotten what I have been hunting for".* **P 2.4**

A female participant had this experience to share:

> *"When I became pregnant of my daughter my mother threw me out of home and When I went to the father of my child he was not willing to live with me despite his previous promises that he was intending to marry me so I feel rejected and abused".* **P1.3**

Participants revealed their families' reactions towards their disabilities and their experience of rejection as narrated:

> *"My parents were hiding me from the neighbours and my father left my mother immediately he discovered that I was going to live with the disability".* **P 1.3**

> *"My immediate family was ashamed to have me in the first place such that my parents decided to send me to the village to live with my grandparents and never visited me".* **P 3.6**

Commenting on how the disability has affected the relationship with her parents, P**3.6** had this to say:

> *"It makes me feel that this physical disability is a hurdle between me and my parents and between me and the rest of society. I feel so helpless especially that there is nothing much I can do to change my physical status. I am not very close to them as it is I live with friends who are also living with physical disabilities"* **P 3.6**

It was reported that participants suffered social segregation and unacceptability by society and immediate families and they consider it as normal which made them feel degraded as a result they developed low self esteem and lack of self confidence as observed in their reports:

> *"Somehow as a disabled person I expect people to stare at me especially those that are not familiar with me so I would say it does affect me but not so much".* **P1**

Another participant shared the same feelings and for him it was expected to be treated differently by society because of their different physical status:

> "*I am physically challenged and the treatment that I get just confirms my position I do not expect the same treatment as the able bodied persons".* **P 1.4**

A female participant who had upper limb impairment did not struggle with mobility but indicated a feeling of shame and discomfort while in public places:

> *"I have no problems getting on a mini bus or walking but it is the way people stare at me that makes me think twice before I can go to a public places. I feel so uncomfortable when they stare at me. I always wonder what they think about me because of my posture and the position of my arm".* **P 1.7**

It was also observed that participants had developed an attitude which portrayed self stigma and self discrimination.

One participant indicated a feeling of shame:

> *"I do not even think of going to town whether by taxi or by minibus because I do not want to attract people's attention because of the way I drag myself".* **P1.4**

Another Participant despite his financial constraints opted to get the Anti Retro Viral Therapy services from the hospital while the local clinic also provides the same:

> *"I am comfortable going to the hospital than to the local health facility".* **P 1.6**

While Participant 3.4 appreciated the care from the family, she also expressed a feeling of guilty that she no longer contributed towards the well being of her family:

> *"I feel cared for but at the same time I feel guilty that I can no longer give meaningful contribution".* **P 3.4**

4.6 Emerging Themes

During the interviews and focus group discussions, it emerged that cultural beliefs and myths, which was not among the pre-determined themes play a very important role on the challenges that participants experience in their everyday lives. These are folklores that may shape society's perception of physical disability.

4.6.1 Cultural Beliefs and Myths

While reporting on the results from both the focus group-discussions and in depth interviews it emerged that the traditional and cultural beliefs as well as myths played a role in the enhancement of challenges that persons with physical disabilities face in Chifubu Township: both the PWPD and the society surrounding them are influenced by the said beliefs whether they (PWPD) themselves believed in these myths or not. The other challenge came with the myths attached to the cure of HIV/AIDS &STI in relation to persons with physical disabilities as observed from the responses.

When asked what they (PWPD) thought and believed caused their disabilities, most of the participants were very much aware and acknowledged the actual causes of their disabilities, they were however also very superstitious and believed that disability was also caused by supernatural powers such as witchcraft or divine punishment as expressed in their quotes:

> *"I believe that disability can be caused by disease, injury or it can occur naturally mostly with those that are born with physical disabilities when nobody knows the cause. I also believe that it can be caused by witch craft".* **P 3.3**
>
> *"Disability can be caused by nature for example poor development when the child is not yet born like my case is; it can also be caused by accident, illnesses like polio,*

> *poison. It seems as if someone caused my physical disability through magic or curse….."* **P 2.3**

Other than believing that disability could be caused by lack of knowledge Participant 1.4 also believed that it could also be caused by witch craft:

> *"…disability can be caused by ignorance; I did not know that I had high blood pressure until the day I got a stroke, had I known I was going to take preventive measures. I also believe that witch craft can also be at work. Here in Chifubu wizards and witches exist. I am part of this community and I am one of the many that believe that witch craft exists here in our community".* **P1.4**

P1 spoke with certainty that his disability was caused by witchcraft:

> *"He (uncle) told me that it was not natural illness, it came from someone's hands both my parents `and my uncle knew this person. That person bewitched me out of jealous".* **P1**

While many people with disabilities believed that their disabilities were caused by some super natural powers such as witch craft, curse, jealous or envy, **P1.3** believed that some of the causes of disability would be prevented with conventional medicine:

> **"***Disability is caused by ignorance. Most people are ignorant about a lot of causes of physical disabilities for example in my case, if my parents knew that what I was suffering from was polio they were not going to waste money and time to go and seek the traditional healers' attention for a problem that required conventional medicine. This disability was going to be prevented".* **P1.3:**

4.6.2 Society's Beliefs about Physical Disabilities

During the focus group-discussions as well as in depth interviews, it emerged that participants reported that the community of Chifubu believed strongly in superstitions, traditional and cultural beliefs and myths towards physical disability. This was observed from the discussions and the responses from the interview:

> *"My father left my mother immediately he discovered that I was going to live with the disability for the rest of my life. He told my mother that he did not want to contaminate his clan with the spirit of physical disability. Besides there were no*

> *disabled people in his family so he said it must have been my mother's fault that I had this disability".* **P1.3**

It was learnt that the community did believe that disability was not only caused by witchcraft but many other things as narrated:

> "*Our community strongly believes that disability is caused by a misfortune caused by the anger of the ancestors and God for the wrong committed by key persons in the family tree. They also believe that witch craft out of jealous and envy is also one of the causes".* **P 3.5**

These beliefs and myths resulted into participation in rituals.

P1.1 narrated her childhood experiences on how her mother was advised to do some rituals so that she could get well:

> *"When I was young my mother was advised that she should give me back to her ancestors by digging a hole in an isolated place then burry me up to the waist and leave me there for the whole day every day until when she will see the improvement in my legs. She used to take me early in the morning to the garden bury me before saying something to her ancestors and leave some food for me for the day and left me until evening when she came to fetch me. After repeating the procedure for many months there was no improvement, she gave up and stopped. Besides this ritual, a lot of tattoos were cut around my waist and the lower limbs".* **P1.1**

While Participant **1.6** narrated how his family believed that his illness and subsequent disability was related to being possessed or haunted by a dead man's spirit as verbalised:

> "*Before I went for the test, my extended family suggested that I go to seek the traditional healer's services because it seemed to them that I had a physical relationship with a widow who was never cleansed".* **P 1.6**

Participant **2.3** shared her experiences about the comments that were being made by society about her physical disability:

> *"Some people pass very negative comments loudly. Comments like "the mother must have eaten stolen food when she was pregnant" or "she must have been conceived from another woman's husband" others comment that I must have been born of a brother and sister especially when they see my hands".* **P 2.3**

Participant **3.7** shared the information on how her friends thought that her current situation was due to other people's jealousy:

> "*Some friends were advising me to go and seek the services of a witch finder because they believed that the way I lost my leg was very mysterious and within a short time all my children died. They suspected that someone was jealous of me because all my children were educated; they were supporting me financially besides I was very hard working and never starved because I grew enough food".* **P 3.7**

A narration from a female participant expressed how society reacts to her disability because of their beliefs about her disability:

> "*It is worse with extended family because they believe that I was bewitched within the family, and for them the fact that my parents left me when they retired because I was in school made them very suspicious they accused my parents of knowing what they did, which resulted into my disability they don't even understand that it is polio which caused the paralysis. A larger section of our society believes that it is a curse that caused me to be disabled. Many people have approached me to say that they know of some spiritual healers who could help me to be cleansed of my parent's wrong doings that led to my physical disability so that it does not affect my children and my grandchildren. They believe that either my father or my mother could have done something wrong and God vented his anger on them by making me crippled".* **P2**

4.6.3 Myths about cure of HIV/AIDS&STI in relation to physical disabilities:

It emerged during the interviews that with the advent of the incurable pandemic: the HIV/AIDS and the related STIs, there were myths that purported its cure which related to persons with disabilities.

Discussing the need of information by the PWPD on HIV/AIDS & STIs a female participant pointed out the challenge of knowing who were an infected person and potential abuser:

> "*yet we are a vulnerable group of people With the advent of HIV/AIDS there is a myth going round that if an infected person has sexual intercourse with a physically or intellectually challenged person they are cleansed of the infection which puts us at risk. It is difficult for us to tell if this person who is proposing a relationship with me is infected or not; if he is genuine or not. For me to have a partner who is not physically challenged is a plus to my life so you see how much protection I need"?*

A male participant revealed a myth that was circulating around the township about the cure of HIV/AIDS:

> "*There is also a belief that if an infected person sleeps with a little child, a very old person, a mentally or physically challenged or a virgin they get healed. This myth has exposed many young disabled girls to a lot of sexual abuse".* **P1**

Another male participant expressed his fears that lack of knowledge and awareness about the cure, prevention and transmission of the deadly pandemic also affect people with disabilities:

> "*With the advent of HIV/AIDS pandemic we see girls chasing after us misinformed that if they slept with person with a disability they would be cleansed of the HIV virus and be cured. Not many of us are aware, so you see that we are an endangered species. The fact that people are now using persons with physical disabilities as sacrificial lambs for their cleansing of the infection I may be a victim one day".* **P8**

4.7 Summary of chapter four

A key finding of this research is that although different pre-determined themes of challenges experienced by persons with physical disabilities exist, namely environmental barriers, social barriers and attitudinal barriers, they should not be considered in isolation of each other. Instead these pre-determined themes need to be viewed interchangeably and in an integrated manner along with the emerging themes to fully understand the concept of challenges. The discussion that follows makes reference to the established challenges which outweighed the facilitating factors for participation of persons with physical disabilities into the main stream.

CHAPTER FIVE

Discussion

5.1 Introduction

This chapter will discuss the results in relation to the available literature as regards the findings. This study also found that participation limitations of people with disabilities in the main stream is not only due to individual limitations, but also due to physical barriers in the environment, a combination of cultural, social, economic and societal barriers. These barriers have made the physically challenged to continue being left out of developmental activities of their society thus they lag behind in most of the matters of human development (UNESCAP, 1995a; Barnes & Mercer, 1997; Miles, 1999; Craddock & McCormack, 2002; Jones, 2002; Eide & Loeb, 2006; Landry, Dyck, and Raman, 2007).

5.2 Physical Challenges

Physical challenges include activity limitations experienced by the participants as well as the inability to access the physical natural environment and/or the built environment.

5.2.1 Activity Limitations

The most detailed information in studies of problems faced by people with physical disabilities tends to be about the physical limitations of individuals. With the ability or inability to carrying out activities of daily living being a common focus (Jones, *et al.,* 2002).

The inability to carry out activities of daily living is a common focus under this subtheme. It was obvious in both the focus group discussion and the in depth interviews that participants expressed difficulties to carry out one or more activities of daily living imposed by the impairment on the physical part of their bodies. Reasons such as the impairment itself, lack of proper assistive devices, mobility, design of houses, location and proximity of house hold facilities influenced the participants' ability to perform these activities of daily living. A similar situation was reported by Mulholland *et al* (1998) in a study conducted in India of ten disabled women with physical impairments with the aim of understanding their daily mobility needs. Nine of the ten reported varying degrees of difficulty in accessing toilets and bathing facilities, as well as having difficulty in fetching water and transporting objects due to the distance involved. The results of this study confirmed this.

This was also evident in a study carried out by Boyce *et al* (2000) in Nepal, among children with physical disabilities. They reported limitations of functional activities such as mobility, household chores and self-care due to pain is identified as a limiting factor in carrying out daily activities. It was also clear from the results of this study that physical weakness among people with disabilities means that they have to depend on stronger household members to collect water for them. This means that the persons with physical disabilities continue to be dependent on others for their activities of daily living. Continued dependence on others makes people with physical disability lose self worth and hence low esteem (Van der Kroft, 2002).

5.2.2 Physical environmental challenges

People with physical disabilities experience difficulty in accessing both natural and built environment, which may be constructed in a manner accessible only by specific type of users. The United Nations Environment Program (UNEP) (2000) reported that where built latrines are available, access of people with physical disabilities are rarely taken into consideration. Squat toilet facilities are common in Asia and Africa and people with lower limb impairments struggle to use them (UNEP, 2000).

Participants in this study expressed difficulties with accessing and using the ablution facilities because of the way they are designed. The ablutions in Chifubu township were designed in such a way that the toilet and bathroom are in one small room. The bath is a shower type while the toilet is a squat type (there is no toilet pan) there is just a hole in the ground. Although these toilets are water borne, they do not function as such because of erratic water supply. These toilets are difficult to use by participants with lower limb impairments whether they use assistive devices or not because they need to squat. The participants also expressed difficulties with the use of bathroom facilities especially as they needed to bring into the bathroom a bucket of water. The room was too small to fit both the toilet and bathroom. It is more difficult for persons with lower limb impairment to manoeuvre especially if they were using wheelchair or any other assistive devices. They end up having to crawl to get around in a room that is both a toilet and a bathroom. A problem of water and sanitation was cited by participants in the current study. Participants cited erratic water supply, distance to the available source, difficulty in transporting the water, and unhygienic toilet facilities caused by overcrowding.

The above challenges experienced by the participants were also reported in other studies. Jones *et al* (2002) reported on a study conducted in Zambia which described a village 'where a community project was carried out to build pit latrines. Persons with physical disabilities did not benefit, they could not use them because they did not have sitting pans and the doors were too narrow for a wheelchair to enter. The same pit latrines were used as bathrooms. A disabled woman from the same village narrated that she could not use the facility and she resorted to bathing at night and used the bushes for the toilet. Inaccessibility of water and sanitation can force disabled people into unhygienic and inappropriate practices (Ahsan, 2002; Jones,*et al.,* 2002).

Accessing other built environments such as houses, schools, hospitals, public transport and other utility buildings has been cited by the participants of this study as being difficult because the buildings are storey buildings; skyscrapers or having steps. The only high school in the township have different two levels. This was also evident in a study conducted by Grut and Ingstad (2006) in Yemen, which reported that the lay-out of the houses was a challenge to people with physical disabilities. One needs to ascend a steep stairway to get up to the living quarters one or more floors up. The design of such important buildings and facilities make mobility for people with physical disabilities more challenging and results in certain facilities and services not being accessible.

It is known that the changing physical environment of developing countries have made lives more convenient and fancy for city and metro dwellers. In the process, the levels of difficulty the persons with physical disabilities are facing have been forgotten. The progress in infrastructure has not added any freedom for them; such built environments have added inaccessibility, uncertainties, anxieties and dangers. Participants in this study, expressed that they had problems accessing the adult hospital which is approximately ten kilometres from the township. It is an eight storey building, the lifts are rarely functional and there are no ramps. The only way to get to the wards is by climbing stairs. The market has very narrow passages. Public transport is difficult to access in Chifubu Township because of both the design of the vehicles and stations (Habibi & Mirfatah, 1991; Venter *et al.,* 2004). This implies that people with physical disabilities are not able to interact fully with the rest of the communities outside their environment and they continue lagging behind in social development due to lack of social interaction.

In this study accessing utility facilities was another challenge that emerged under the physical barriers; the participants' main problem was the difficult distance and location of these facilities. Accessing rehabilitation and health services was found to be one of the challenges which made most of the participants abandon the rehabilitation process or not attempting at all. In many African countries, long waiting periods and transport costs, particularly for those in rural areas, make it difficult to get access to a rehabilitation service and to obtain Assitive Devices (McLaren *et al,* 1996; Philpott & McLaren, 1997). Inadequate rehabilitation process leaves people with physical impairments more disabled with activity limitations causing participation restrictions and they continue being excluded from the activities of the mainstream.

5.3 Social Challenges

The social challenges comprise the problems of limitations to accessing facilities that would enhance the participants' social developments and independent living through participation in the activities of the mainstream. Social barriers are often difficult to identify than physical barriers, and therefore difficult to change (Jones, *et al.,* 2002).

5.3.1 Challenges Related to Provision of Services

Persons with physical disabilities suffer the consequences of discriminatory social policies, which deprive them of physical rehabilitation services, which are not available in their communities. Lack of specialized facilities or systems of support, aids and equipment for disabled people and their families constitutes a challenge to people with physical disability while lack of training and expertise is another factor. Scarcity of qualified therapists and brain drain from low income countries to developed nations make the rehabilitation of people with physical disabilities a big challenge (Radda-Barnen, *et al.,* 1998; Hanko 1999; Payne, 2002).

The participants in the current study needed to travel long distances to access rehabilitation services which are not available at the local health centre. The community based rehabilitation project has no qualified personnel attached to it to carry out professional rehabilitation. In addition, participants abandoned the assistive devices, and opted to do without them because it was much easier to get around than with an assistive device. Others did not have assistive devices at all, not out of choice but because the cost is prohibitive for them. Lack of clear policies for provision of assistive devices makes it difficult for people with physical disabilities to access and obtain them. Where these assistive devices are available, they are not always appropriate to the disabled persons' living environment. This is so because most of this equipment are imported and are inappropriate for local use and conditions. Much of the servicing and maintenance of assistive devices is done by hospitals, but again, long waiting times, long distances and costs of transport are a big challenge. (McLaren *et al*, 1996; Philpott & McLaren, 1997). (Taunyane and Hirschowitz, 1995). This situation perpetuates functional limitation which leads to continued dependence of the physically disabled on others for personal hygiene and ambulation. Their inability to cope with the workplace environment suggests failure to have income of their own, and being incapable of attending social gatherings independently. It has been known that such challenges make someone lose self-esteem, and the dependence on their immediate families and care-givers when not available, may lead to psychological trauma such as social exclusion, loss of self-respect and degradation of self-worth (Helander, 1999).

Another social challenge the participants experienced was limited information related to HIV/AIDS and disability. People with disabilities are at particular risk of contracting HIV/AIDS due to limited access to health information. In this study, participants reported that it was difficult to access information on HIV/AIDS which they thought put them at high risk because of their vulnerability. Some of the participants who are HIV positive also expressed lack of support from their community and depended on the old parents for care. Literature has also revealed that increasing numbers of older people (with or without disabilities) are drawn into caring roles for children whose parents have died of diseases such as HIV/AIDS. This has brought about a shift in the caring role of younger generations for the elderly to be in reverses pattern. (Save the Children, 2000; Komardjaja, 2001; Jones *et al.*, 2002; Help Age International (HAI), 2002a).

5.3.2 Challenges Related to Education, Employment and Poverty

The link between poverty and disability is now widely recognized. This is a global phenomenon which is applicable to the developed (Oliver, 1998, Seddon & Yeo, 2005) as much as the developing countries.

In the current study, it was observed that only one among the participant was in formal employment and earning a monthly wage. It was reported that most of the persons with physical disabilities were unemployed (demographic data table). Some have never been employed while others could not continue in employment due to the physical impairment. A few of them, who managed small scale businesses before they had the disability, could no longer continue. Most of them expressed the state of being poor, in destitution, indigence, and scarcity meaning that they were living in poverty. There were various reasons that emerged for high unemployment levels among persons with physical disabilities such as lack of proper education, lack of marketable specialised skills and stereotypical behaviour among employers among others. To be employed is a social right which brings about economic empowerments of which people with physical disability have been deprived.

Most of the participants were dependent on others for their financial assistance which subjected them to live in poverty. Poverty makes it more difficult for families to minimize the impact of impairment due to lack of resources to access care and rehabilitation including AD that disabled family members need. Unemployed or under-employed people with disability contribute little economically to the family. In addition, families incur costs caring for disabled family members because of their reduced opportunities for income generation (In this way their existence impoverishes the family (Taunyane & Hirschowitz, 1995; UNESCAP, 1995a. Bonnet, 1997; Radda Barnen *et al,* 1998; Elwan, 1999; May-Teerink, 1999; Metts, 2000; Holdsworth, 2001).

Social segregation from the mainstream is common among people with disabilities. In the current study participants reported being excluded from the main stream activities such as attending social gatherings by both their families as well as the community they live in. Some families would hide their disabled child when they had visitors at home. Change of roles in the family was another challenge in this study where some participants were unable to resume their role of providing for the family and making important decisions caused the participants emotional pain. The above was similarly found by Gardner and Carran, (2005); Flynn and Aubury, (1999); Lemay, (2005) Komardjaja, (2001)

5.4 Attitudinal Challenges

A complex of cultural, social and economic rules can often be an even greater problem for the disabled person than the impairment itself. One of the greatest barriers for disabled people are the negative attitudes and behaviours of family, community, or/and of service providers, both in the government and voluntary sectors (Seeley, 2001). In the study being discussed, participants reported various negative treatments from their immediate families, community, service providers and society at large. These negative treatments culminated into discrimination, stigma, abuse and rejection mainly because of various stereotypical beliefs about disability.

PWD are often stereotyped which leads to their being discriminated against. This leads to low expectations of people with disabilities, which can prevent them from achieving their full potentials (UN, 2002b). As a result of all the above, children with physical disability tend not to be sent to school, to play or mix with other children. In adulthood they become victims of ignorance, poverty, disease, discrimination and a whole range of negative attitudes due to their being isolated from the general social systems. Among the participants in this study, it was observed that there was limited support for them to attain formal education especially from their families as their families underrated their capabilities to be educated.

Most of those that had some form of formal education, it was reported that they received support from faith based organisations (FBO). Some of the participants reported being discriminated against by their immediate families one of the participants was withdrawn from school by her parents despite doing well in school. The family cited the disability as the reason for withdrawing their child from school because they thought that it was a shear waste of time and resources to educate a child who has a disability. These negative attitudes towards people with physical disability push them into perpetual exclusion which results into continued social discrimination leading to high activity limitations and participation restrictions. All the above may cause low literacy levels, high unemployment levels, hence continued economic dependence on others among people with physical disabilities.

People with disabilities are discriminated against by providers of social services because of their stereotypical practices towards disability. In the current study, it was noted that health and public transport service providers were among those that treated people with disabilities with negativity. As a result of this practice, people with disabilities are marginalised and they are not keen to access such services (Craddock & McCormack, 2002)

Negative attitudes of service personnel and bureaucracy of the systems add to the list of challenges experienced by people with disabilities (Bang, 1996; Philpott & McLaren, 1997). This study reports that participants encountered a number of hardships to access specialised services such as HIV/AIDS and STI information, and ante natal services. These encounters forced people with disabilities to shun or avoid attempting to access such services. This was so in the studies by Belker, Stuifbergen and Tinkle (1997) Craddock and McCormack, (2002). Such treatment causes people with disabilities to feel degraded, which may cause them to withdraw, not eager to participate in the activities of their society.

Another common challenge that people with physical disabilities face is abuse ranging from physical, sexual, to verbal abuse. Participants in this study reported abuse from members of society, and neighbours who they believe took advantage of their status. The abuse from the family was due to the cultural beliefs and myths about disability. This is so because people with disabilities are often more vulnerable to abuse than those without disability (Sobsey, 1992).

Persons with disabilities are sometimes rejected by their own families because of the beliefs associated with disability. Family members mostly act out of shame of having a disability in the family. In the current study, participants reported being rejected by their family members and close relatives who do not want anything to do with them. This implies that people with disabilities are forced to live in isolation (Nkabinde, 1994).

5.5 Cultural Beliefs and Myths

In some societies especially in the developing world, there are strong cultural beliefs associated with the cause and nature of impairment. Different cultures, religions and myths emphasize the disgrace of giving birth to a disabled child, or having a disability which may be perceived as the result of anger of gods, or ancestors, and a sign of the embodiment of sin in the family. Due to prevailing attitudes, superstition and ignorance, it is common for families to hide their disabled children or disabled member of the family either because of shame, or to protect the child and themselves from negative social stigma (Ahsan, 2002). This study has shown how the folklores have a very strong influence on the attitudes of people towards disability. These beliefs caused a lot of turmoil in families such as fathers deserting families, disabled children being rejected or secluded from the public and from the rest of the children. This is also described in Nepal (Schofield-Gurung, 2000), in Yemen (Radda Barnen *et al.,* 1998), and in Bangladesh (Zaman & Munir, 1990) among many accounts. Disabled children are frequently over-protected by their families, resulting in limited interaction with their peers (Hanko, 1999; Pal *et al,* 2002). This may be from a misplaced sense of guilt on the part of families, combined with a lack of knowledge about the child's potential.

The people with disability tend to believe that they are less capable than those that do not have the impairment because this is the general attitude imparted on them by the society. The myths attached to disability have a big part to play in the way people perceive disability, and their attitudes depend on these beliefs the "charity model framework". (Groce, 2004) reflects a tendency for other people to make decisions about the lives of disabled people, thereby contributing to a sense of powerlessness and hopelessness (Groce, 2004).

Various studies have been conducted relating to the influence of cultural beliefs in relation to accessibility of various mainstream services including health care services among others. They reveal how the physically challenged frequently suffer more due to societal prejudices than due to their disabling physical conditions. Thus, disability policies, programmes and practices of any country may be associated with the attitudes that people in different cultures share (Nkabinde, 1994; Ingstad & Whyte, 1995; Schoepf, 1997; Devlieger, 1998; Kabzems & Chimedza, 2002).

5.6 HIV/AIDS and Disability

Literature has established that disabled people are three times more likely to be victims of physical, sexual and emotional abuse. It is documented that a number of factors that make disabled persons "targets for abusers" have been identified (Schaller *et al,* 1998, Sobsey, 1992). In this study, participants cited their vulnerability due to limited knowledge about the pandemic. They reported that health service providers passed derogatory comments about their disabilities instead of providing them with information. Gender, poverty, culture and lack of identity were some of the factors that predisposed them to abuse and eventually being at risk of contracting HIV/AIDS and/or STIs. HIV and AIDS is perhaps one of the most stigmatised medical conditions in the world, disabled people who become HIV positive suffer "double stigma" (Groce 2004) as it was also cited by some of the participants in this study.

Disabled people are raised to believe they are less "human" due to their disabilities. They are subjected to ridicule all their lives, to an extent where they start believing what society says. This response to how society treats them is internalised, and as a result, they often begin to react as helpless objects of pity in need of care and support, not able to do anything on their own (Groce, 2003) which in turn makes them charity cases. Others react in an opposite manner by having multiple sexual partners. This was confirmed among younger (sexual active) participants in the focus groups, participants revealed some sex-related cultural beliefs and behaviour practices that place disabled people at higher risk of HIV infection. 'Virginity cleansing', a practice where an HIV infected person has sex with a virgin in the belief that he/she would be cured of the infection which has led to the rape of many people with disability especially women with disability and babies. Disabled people are victims of this practice as it is believed they are virgins and in most instances cannot protect themselves from such attacks. Wazakile (2006) claims that People with disabilities are at risk for exposure to HIV infection and are less likely to access prevention, testing and treatment. The participants of this study made similar statements concerning the same.

5.7 Summary

In this chapter, the findings were discussed based on the objectives of the study. Four main challenges experienced by people with physical disabilities that emerged from both the focus group discussions and the in depth interviews were discussed in relation to similar studies. The challenges that persons with physical disabilities living in Chifubu township experience that emerged were: physical challenges, individual limitations and physical environmental barriers which hampered their mobility and access to such environments respectively. The social challenges such as low literacy levels, unemployment, limited access to rehabilitation services, lack of information about the available social structures, poor housing, water and sanitation facilities, were discussed. It was observed that because of low literacy levels, inadequate rehabilitation and unemployment, has led to perpetual dependence on others for support and wallow in poverty.

Lack of information meant that persons with physical disabilities continued being ignorant about important aspects of their lives such as health information, human rights, roles and functions of associations for people with disabilities. The people with physical disability were found to live in small overcrowded houses with limited sanitary facilities and erratic water supply rendering the situation unhygienic.

The attitudes of family, service providers and the community in general are a big challenge that persons with physical disability experience in Chifubu Township. It was observed that these attitudes were influenced by the cultural beliefs about disability. The people with disabilities were found to be vulnerable, and at risk of contracting HIV/AIDS because of ignorance, poverty, and the myths about the cure of the pandemic.

CHAPTER SIX

Summary, Conclusion, Implications and Recommendations

6.1 Summary

This study aimed at exploring the challenges experienced by people with physical disabilities who currently live in Chifubu Township in Ndola, Zambia. The study specifically explored the physical, social, and attitudinal challenges experienced by people with physical disabilities.

The study was conducted with the assumption that there dearth of information on the physically challenged, especially adults in Zambia. As such, issues of physical, social and altitudinal challenges have not sufficiently been explored. Studies that have been done in other parts of the world, especially low income countries have reported that people with physical disabilities are not only challenged by their physical state, but more so by the environment they live in, that is physical, social and attitudinal barriers.

A qualitative approach employing both focus-groups discussions and in depth interviews methods of data collection were used to guide the study. Twenty individuals were conveniently selected for focus group discussions and eight were also purposefully selected from the twenty for the in depth interviews. The participants' ages ranged from twenty to seventy three years with the ratio of 4 to 6 of male to female representation. The same interview guide was used for all the three focus group discussions, while the one on one interviews were in depth and an open question was used.

The findings of this study indicate that people with physical disabilities living in Chifubu Township indeed experienced physical, social and attitudinal challenges which were also influenced by their cultural beliefs and myths about disability. The participants were also at a higher risk of being infected with HIV/AIDS due to lack of proper information. The study also found that these challenges were interrelated. On that basis, this study found that using one model (medical) of disability to explore the challenges experienced by people with physical disabilities would be limiting the findings to physical challenges especially those caused by the impairments. The bio-psychosocial approach from where the ICF is based is so far the best approach available for implementation in health practice.

6.2 Conclusion

The persons with physical disabilities living in Chifubu Township continue to live under these difficult circumstances and conditions which prevent their integration and full participation in the activities of the community. The findings of the study revealed that the people with disabilities in Chifubu Township had physical challenges which related to their impairments as well as the physical environment.

They also experienced social challenges which resulted in inaccessibility to services provided by the education, health and labours sectors. This exaggerated their poverty and caused them to be socially isolated. The People with disabilities experienced negative attitudes from family members, services providers and community members in the form of discrimination, stigma, abuse and rejection. The findings also revealed that in the research setting, some people view disability as being related to witchcraft and other supernatural causes. The People with disabilities who participated in the study stated that they were at risk of contracting HIV/AIDS as they were not regarded as being part of the normal population who could contract the disease. They were also vulnerable victims of abuse due to the beliefs related to the cure of HIV/AIDS.

6.3 Significance of the Study Findings

The findings of the current study present a challenge to the physiotherapists and other health service providers and the community at large. They have a mandate to present the needs of people with disabilities to policy makers so that they are included in the planning and budgeting for the activities of their community. It has been recognised that disability is a more complex phenomena than what it is thought to be. The needs for people with disabilities are diverse. Based on the narrations from the participants in this study, it is obvious that there is need for a multidisciplinary approach to rehabilitation and disability welfare. Rehabilitation is not complete with physical rehabilitation alone, hence the need for a holistic approach to rehabilitation. The environment should also be adjusted to accommodate persons with disabilities and allow for a barrier free environment and equal opportunities for them to enjoy their rights without any hindrances.

6.4 Recommendations

Based on the findings of this study the researcher would like to recommend the following:

Further action:

Other than professional ethics, health service providers' training curricula should include basic knowledge about local cultural norms relating to sensitive issues of disability, sexuality and reproductive health.

The rehabilitation of Physical Disabilities in Chifubu Township should include addressing the challenges by incorporating the Community Based Rehabilitation which is the ideal strategy for rehabilitation and clients' re-integration to the community.

At the national level, there should be political will to ensure that persons with disabilities in Zambia are able to have a good education, good housing, access to good health by adhering to the UNCRPD (2010) by including the persons with disabilities in National Development strategy from planning, implementation, monitoring and evaluation and ensure that the persons with disabilities are part and parcel of the whole process.

Further research:

This study has provided first hand information about the challenges and lived experiences of persons with physical disabilities in Chifubu Township. This study was conducted in a low cost high density location, the findings may not be representative of a high cost low density location, therefore there is need to continue with the same research topic but in a different setting.

While persons with disabilities expressed their experiences, there is need to find out what the families and society say about their every day encounters with people with physical disabilities.

In the findings of this study the research did not separate the challenges according to gender, it would be of great value to compare the challenges and support that women get as compared to the men folk both married and single.

In relation to the findings of this study there is also a need to research on the profile of disabled men and women of reproductive age with regards HIV/AIDS and reproductive health. Most of the exclusion from the mainstream is blamed on policy makers, but we do not know how much they know and understand the challenges experienced by people with disabilities. Therefore to augment the findings, there is also need to find out the knowledge level of policy makers about the needs of people with disabilities, and what prevents the full implementation of equal opportunities for people with disabilities.

6.5 Limitations of the Study

This study being qualitative using both convenient and purposive sampling to select the participants and with the kind of in depth information required a small sample. The findings of this study can therefore not be generalised to all persons with physical disabilities.

The age range in this study only included adults, the results therefore cannot be generalised to the young below the age of 18years.

Sample only included people with physical disabilities; it is not representative of all people with disabilities.

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11. What is your view over the treatment that your immediate family is giving you? Does it make you feel any different?

    Probe: Why do you say so?

12. Do you think your disability has impacted on your role in the family? (as a son, daughter, mother, wife, father, husband or bread winner).
    Probe: Why do you say so?

13. How do you think your disability has impacted on your participation in your: church, club, school, workplace, neighborhood activities?
    Probe: What is the reason for your answer?

14. What do you know about disability?

15. What do you believe caused your disability?

    Probe: Why?

16. What does this society believe disability is and the causes?

17. How do you think society perceive persons with disability?
    Probe: what is the reason for your statement?

18. When you seek any social service how is the environment/atmosphere with regards, your waiting time, reception, behaviour of people providing the sought service? Why do you say so?

19. What do you know about HIV/AIDS? How does it affect you as a person with physical disability?
    Probe: Why do you say so?

Appendix A

Higher Degrees Committee
Faculty of Community and Health Sciences

Private Bag X17, Bellville 7535
South Africa
Tel: [illegible]
Fax: [illegible]
E-mail: [illegible]
Website: www.uwc.ac.za

10th November 2008

The Permanent Secretary
Ministry of health
Ndeke House
PO BOX 30205
Lusaka
Zambia

Dear Sir

Re: Research project of *Mary Sakala Mumba: Student Number: 2862637*

This letter confirms that Ms. Sakala (student number 2862637) is a postgraduate student in the Community and Health Sciences Faculty at UWC. Her proposed research entitled *The challenges experienced by persons with physical disabilities in Chifubu Township, Ndola, Zambia* submitted in fulfilment of the requirements for Masters in Physiotherapy has been examined by the Higher Degrees Committee and found to be of high scientific value, methodologically sound and ethical.

We fully support the research and urge you to allow her access to your organisation.

Yours sincerely

Dr G. Reagon
Chairperson Higher Degrees Committee

A-B – Appendix B

THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-[illegible]
E-mail: [illegible]

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

Assurance No. FWA00000338
IRB00001131 of IORG0000774

19 January, 2009
Ref.: 002-01-09

Mrs Mary Sakala Mumba
University of Western Cape
Private Bag X17, Bellville 7535
SOUTH AFRICA

Dear Mrs Mumba,

RE: **SUBMITTED RESEARCH PROPOSAL: "THE CHALLENGES EXPERIENCED BY PERSONS WITH PHYSICAL DISABILITIES IN CHIFUBU TOWNSHIP, NDOLA, ZAMBIA"**

The above-mentioned research proposal was resubmitted to the Biomedical Research Ethics Committee Secretariat on 5 January, 2008, where changes were recommended. We would like to acknowledge receipt of the corrected version with clarifications. The proposal is now approved.

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events [illegible]
- Please note that [illegible]

Yours sincerely,

[illegible]
CHAIRPERSON

[illegible]

Appendix C

INFORMATION SHEET

Title: challenges experienced by persons with physical disabilities in Chifubu, Zambia

To participate in this research project you will be asked to:

- Feel free if you decide to withdraw
- Sign a consent that you have voluntarily agreed to participate in the research project

Purpose of the research project

This is a research project being conducted by Mary Seliya Sakala-Mumba a student in the department of physiotherapy in the faculty of community and health sciences at the University of the Western Cape in the Republic of South Africa. We are inviting you to participate in this research project because you are having met the criteria of participating in this project as a person living with a physical disability. The purpose of this study is to find out the challenges that you experience because of your status. it is part of my academic requirements and this information will also be shared with the Zambian government so that they are aware of the challenges experienced by its citizens living with physical disabilities.

- If you agree groups of other participants for focus group interviews
- Keep all the information about the other participants in the group as confidential
- Give as much details of your accounts as possible

This study will be conducted here in Chifubu, our meeting place is the Chifubu Catholic Church for focus group interviews. Each focus group will meet twice on the dates and time that will be given. Each meeting will take at least from 0900hours to 12hours. I will ask you about how you access your environment and other facilities like the workplaces; churches, markets; buses; stations etc and if there are any challenges. How your families and society has accepted you and their attitudes towards you as persons with disabilities. How this disability has impacted on your individual life, on your life in the family and society in general.

The one to one interviews I will visit you at home. The interview will take at most one hour. To each participant we shall make two visits if necessary.

Confidentiality of your participation in this research

We will do our best to keep your personal information confidential. To help protect your confidentiality,(1) tape recorded together with all the written information will be kept in this lockable bag whose key is only accessible by the researcher, (2) we shall give you code names, your names will not appear on the collected data only codes will appear, (3) through the use of an identification key, the researcher will be able to link your information to your identity; and(4) only the researcher will have access to the identification key.

If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning abuse or neglect or potential harm to you or others.

The possible risks of this research

There are no known risks for this type of study.

Benefits of this research

This research is not designed to help you personally, but the results may help the investigator learn more about the challenges that persons with physical disabilities experience. We hope that, in the future, other people might benefit from this study through improved understanding of the challenges that persons with physical disabilities face.

The benefits to science and society include (1) the information about the challenges that you face will be shared with the relevant authorities; (2) we also hope that this research may be published so that many people can broaden their understanding of disability.

Voluntary participation

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this research or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

Assistance available in case you are negatively affected by participating in this research

In case of you being negatively affected by participating in this research you will be referred for specialized care at the appropriate facilities

Disclosure Statement

Participating in a focus group discussion you are expected to treat whatever information disclosed by a member of the focus group as confidential. It is not expected to be discussed anywhere or with anyone outside or after the focus group interview

Participant sign........................ Date..............................

Researcher sign......................... Date..............................

In case you have any questions

This research is being conducted by **Mary Seliya Sakala-Mumba**, MSc physiotherapy student at the University of the Western Cape. If you have any questions about the research study itself, please contact:

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Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of department: Prof. P. Struthers

Dean of the Faculty of Community and Health Sciences: Prof. R. Mpofu

University of the Western Cape

Private Bag X17

Bellville 7535

The Chairperson

University of Zambia

Biomedical Ethics Research Committee

P.O. Box 50110

Ridgeway

Lusaka, Zambia.

This research has been approved by the University of the Western Cape's Senate Research and Ethics Committees, the approval was re-affirmed by the University of Zambia Biomedical Research Ethics Committee.

Appendix D

CONSENT FORM

Title of Research Project: Challenges experienced by persons with physical disabilities in Chifubu Township in Zambia.

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's name.

Participant's signature........................*Date*..

Researcher's Name...

Researcher's signature...........................*Date*...

Witness........................ *Date*........................

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator.

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Appendix E

RESEARCH TOPIC: CHALLEGES EXPERIENCED BY PERSONS WITH PHYSICAL DISABILITIES WHO LIVE IN CHIFUBU TOWNSHIP IN ZAMBIA.

INTERVIEW GUIDE FOR FOCUS GROUP DISCUSSIONS

1. Each one of you please tell me about yourself.
2. Tell me how your condition come into being, How long?
3. Tell me about your activities of daily living.
   Probe : If one manages, how they manage? If not, why & what is the difficult?
4. Tell me how you manage to get around your home environment (e.g.: Moving within the house, to bathroom/toilet and around the surroundings?
   Probe : If one manages, how they manage? If not, why & what is the difficult?
5. Tell me about your movements outside your house? (To school, work, market, church, club, shops, banks or town)

   Probe : If one manages, how they manage? If not, why & what is the difficult?
6. How is your relationship with your immediate families?
   Probe: why do you say so?
7. How have been your relationship with your extended family; neighbours; employers; school authority and the clergy?
   Probe: why do you say so?
8. Are you aware of any rehabilitation services or any other services that may be available for persons with physical disabilities here in Chifubu or Ndola city?
   Probe: If yes, what do you know and how did you know about it?
9. What do you know about organizations for people with disabilities?
10. How does your family treat you?
    Probe: why do you say so?

11. What is your view over the treatment that your immediate family is giving you? Does it make you feel any different?

    Probe: Why do you say so?

12. Do you think your disability has impacted on your role in the family? (as a son, daughter, mother, wife, father, husband or bread winner).
    Probe: Why do you say so?

13. How do you think your disability has impacted on your participation in your: church, club, school, workplace, neighborhood activities?
    Probe: What is the reason for your answer?

14. What do you know about disability?

15. What do you believe caused your disability?

    Probe: Why?

16. What does this society believe disability is and the causes?

17. How do you think society perceive persons with disability?
    Probe: what is the reason for your statement?

18. When you seek any social service how is the environment/atmosphere with regards, your waiting time, reception, behaviour of people providing the sought service? Why do you say so?

19. What do you know about HIV/AIDS? How does it affect you as a person with physical disability?
    Probe: Why do you say so?