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THE EXPERIENCES OF PHYSICALLY-DISABLED ADULTS IN THE VHEMBE DISTRICT OF LIMPOPO PROVINCE IN SOUTH AFRICA

BY

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Submitted in fulfilment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

In the

Department of Sociology

At the

UNIVERSITY OF VENDA

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2015

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ABSTRACT

Introduction: Physical disability encompasses a complex multi-dimensional phenomenon within the context of a person's life childhood and adulthood. Disability covers a wide and diverse range of disabling conditions.

Aim of the study: The aim of the study was to explore and describe the experiences of physicaldisability acquired in adulthood.

Methodology: The study adopted qualitative research approach, exploratory and descriptive design. Snowball sampling method was adopted to select seven participants who were interviewed by means of semi-structured face-to-face interviews. In order to analyse data, Tesch eight steps of analyzing qualitative data was employed.

Results: It was found that experiences of physical disabled adults replete with daily difficulties marked by isolation, loneliness, social disapproval and rejection. Being physical disabled was accompanied with difficulties marked with, feeling of sadness and dejection which was their daily companions. However, the participants found strength and solace from support groups and religious structures which strengthen individuals who acquired physical disability at adulthood.

Conclusion: Physical disability acquired in adulthood is accompanied with changes that bring about different difficulties in personal and social life. As a result adults with that experience are left with no choice but adopting coping strategies that assist them to continue with life positively.

Recommendation: The study recommends conducting seminars/awareness where civil society and other community based stakeholders and government departments are orientated on the rights of persons with disabilities. Through dissemination of the findings of this study, the researcher hopes that strong message can be conveyed to all stakeholders in disability to ensure mainstreaming of disability in all spheres of life.

Keywords: Adulthood, Experiences, Physical disability

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DECLARATION

I, Marubini Christinah Sadiki, hereby declare that the thesis for Doctor of Philosophy degree at the University of Venda hereby submitted by me, has not yet previously submitted for a degree as this or any other University, and that it is my own work in design and execution and that all reference contained herein has being dully acknowledged.

Signature ___________________________ **Date: _____________________**

Sadiki M.C

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DEDICATION

This thesis is dedicated to my sons Andrew, Mpho and Ndamulelo for their ongoing support. "I LOVE YOU".

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ACKNOWLEDGEMENT

I wish to express my deepest appreciation and gratitude to the following people for their invaluable contributions and support towards the completion of this thesis:

- Almighty God for giving me strength and wisdom to do this work. Thank you!
- My promoters, Dr P.S.T. Zikhali and Dr. M. Makatu, for providing professional knowledge and guidance, encouragement and expertise shared in this study. Their prompt and prudent comments expedited the completion of this thesis helped me to create a thinking structure, while allowing me to own my voice as a researcher. What I valued the most from both of them was their ability to recognise the potential contribution this work might have, and sharing their excitement genuinely.
- The physically disabled adults who participated in this study and allowed me into their homes. I learnt immensely from them and I continue to learn. Without their contributions this study would not have been possible.
- My friends Prof. M.O Maguvhe and Mrs. Thandy Mathebula for whole heartedly supporting and encouraging me; for their comments and friendship, which throughout my study were extremely invaluable.
- I remain eternally grateful to my parents, Mr. Richard Sadiki (now late) and my mother, Mrs. Ntsundeni Florah Sadiki, for their parenting and support when it mattered most in my life.
- My domestic helper, Ms Florah Magadani, for looking after my children while my focus was on this study.
- My brothers David, Pastor Moses, Mbulaheni and Khamusi Sadiki for their immeasurable encouragement and motivation.
- Mr. Livhuwani George Manzere (*Mbedzi*), for his endless love and his encouragement throughout this entire journey.
- Lastly my words of appreciation to all in my family and clan vha ha **Sadiki Muloiwanombe ano lowa dzi mafuloni, Mposiwa miseve muzungu a no bva Sena.**

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LIST OF ACRONYMS

DPI	Disabled People International
DPO	Disabled People's Organisation
DPSA	Disabled People South Africa
EENET	Enabling Education Network
ICF	International Classification of Functioning
ICIDH	International Classification of Impairments, Disabilities and Handicaps
ILO	International Labour Organisation
INDS	White Paper on an Integrated Disability Strategy
NCDPZ	National Council of Disabled Persons of Zimbambwe
UK	United Kingndom
UN	United Nations
UNDP	United Nations Development Programme
OSDP	Office of Status of Disabled People
PWD	Persons with Disabilities
UPIAS	Union of the Physically Impaired Against Segregation
WHO	World Health Organization
WPA	World Programme of Action

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TABLE OF CONTENTS

Contents **Pages**

Abstract……………………………………………………………………...…………. i

Declaration……………………………………………………………..…...……........... ii

Dedication…………………………………………………………………………........ iii

Acknowledgements………………………………………………………………….. iv

List of Acronyms…………………………………………………………….............. v Table

of contents……………………………………………………………………….. vi

List of Tables…………………………………………………………………………. xv

List of Figures……………………………………………………………….............. xvi

CHAPTER ONE: INTRODUCTION AND BACKGROUND OF THE STUDY

1.1 Introduction……………………………………………………..………………1

1.2 Background of the study………………………………………………………………1

1.2.1 Physical hardship to social isolation……………………………………..............3

1.2.2 Education needs …………………………………………………………………….3

1.2.3 Economic needs ……………………………………………………………………4

1.3 Statement of the problem……………………………………………………………..5

1.3.1 Motivation of the study……………………………………………………….…….6

1.4 Aim and objectives of the study…………………………………………………........7

1.5 Research questions…………………………………………………………………...7

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1.6 Significance of the study………………………………………………………….……7

1.7 Contribution to body of knowledge…………………………………………….……8

1.8 Full integration of adults with disabilities…………………………………….……..9

1.9 Delimitation of the study……………………………………………………………12

1.10 Conceptual and operational definitions…………………………..………..…12

1.11 Conclusion……………………………………………………………………...15

1.12 Outline of the research study……………………………………………...15

CHAPTER TWO: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

1.1 Introduction………………………………………………………….............17

2.2 The history of disability rights movements in South Africa……………………….....17

2.3 Physical and psychological concept of disability……………………………......18

2.3.1 Medical model……………………………………………………………....18

2.3.2 Disability in social model………………………………………………..….21

2.3.3 Social model of impairment………………………………………........................23

2.3.4 The affirmative model of disability…………………………………………………24

2.3.5 Charity model of disability………………………………..............................26

2.3.6 The future of disability theory towards an "affirmative" model…...........................26

2.3.7 Moral model…………………………………………………………..……….29

2.3.8 Socio-cultural model………………………………………..........................29

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2.3.9 Distinction between impairment and disability in line with medical model and social…………………………………………....................30

2.4 The role of disability movement/ organization……………………………………........30

2.4.1 'Organization of' versus 'Organizations for'……………………………………......30

2.4.2 Organization of disabled and self- representation-

"A voice of your own" ……...31

2.4.3 Disability movement in South Africa………………………………………………….31

2.4.4 The role of disabled people's organisations……………………………………….....32

2.4.5 Disability in South Africa………………………………………………………….....33

2.4.6 National Population Census 2001…………………………………………………...33

2.4.7 The global context of disability……………………………….........................35

2.4.8 Disabled people's international organisation……………………………………….36

2.5 Definitions pertaining to disability…………………………………………………..38

2.6 Relationship between beliefs and attitudes……………………………………......39

2.7 Disability and social exclusion……………………………………………………………40

2.8 Feminity and disability……………………………………………………………………41

2.9 Work, education and poverty……………………………………………...……42

2.10 The construction of personhood and the production of social stigma……………....43

2.11 Institutionalisation………………………………………………………..…..…………44

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2.12 Experiences of physically disabled……………………………………..………....45

2.12.1 Disability and physical barriers……………………………………………………45

2.12.2 Experience of disability………………………………………………….…...45

2.12.3 Dealing with disability……………………………………………………….46

2.13 Survival, disability and impairment……………………………………………….47

2.14 Impairment as inferiority…………………………………………………….49

2.15 Disability in the context of poverty………………………………………….... 50

2.16 Disability and oppression……………………………………………..…...53

2.17 Disability in history……………………………………………………..….... 53

2.18 The evolution of the international classification of impairment,

disability and handicap……………………………………………………..…..54

2.19 Disability politics…………………………………………………….....….56

2.20 Context, culture and disability……………………………………………......57

2.20.1 Disability……………………………………………………………….…......57

2.20.2 Disability and culture……………………………………………..….….58

2.20.3 Disability culture……………………………………………………….….....60

2.20.4 Disability as culture, diversity and differences……………………………..…...62

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2.20.5 Disability and victimhood…………………...…………………………………..63
2.20.6 Disabled and identity……………………………………………………….…63

2.21 Attitudes to disability of people with disabilities…………………………………64

2.22 Socio-spatial production of Disability……………………………………......…65

2.22.1 Conceptualization of the bodily experience of disability in space……………....65

2.22.2 Disability in social space…………………………………………………...66

2.22.3 Accessibility………………………………………………………………...68

2.22.4 Needs of people with disability in space……………………………………...69

2.23 Disability and accessibility…………………………………………………...71

2.23.1 Mobility limitation………………………………………………………….71

2.24 Summary……………………………………………………………….....…71

CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Introduction……………………………………………………………….....72

3.2 Research approach……………………………………………………….…….72

3.3 Research design……………………………………………………………..…74

3.4 Population of the study…………………………………………………….…..76

3.5 Sampling and sampling procedure……………………………………………..76

3.6 Instrumentation…………………………………………………………...….78

3.7 Data collection method……………………………………………………...….78

3.8 Data analysis procedures……………………………………………………...…..83

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3.9 Method of data verification……………………………………………………………….85
3.10 Ethical consideration……………………………………………………………… 87

3.11Conclusion……………………………………………………………………..…...88

CHAPTER FOUR: DATA ANALYSIS AND PRESENTATION OF RESULTS

4.1 Introduction……………………………………………………………...........89

4.2 Results…………………………………………………………………………....90

4.2.1 Theme 1: Meaning attached to physical disability acquired in adulthood…..…....90

4.2.1.1 Sub-Theme 1: Limitations………..……………………………………….…..... 90

4.2.1.2 Sub-Theme 2: Disconnection…………………………………………...........95

4.2.1.3 Sub-Theme 3: New life style……………………………………………….……101

4.2.1.4 Sub-Theme 4: Cultural beliefs…………………………………………….…….106

4.2.2 Theme 2: Experience of physical disability……………………………….…..108

4.2.2.1 Sub-Theme 1: Emotional constrain…………………………………….…109

4.2.2.2 Sub-Theme 2: From being able to being disabled..…………………….…....111

4.2.2.3 Sub-Theme 3: Societal attitudes…………………………………...........113

4.2.2.4 Sub-Theme 4: Socio- economic implications………………………...........115

4.2.3 Theme 3: Strategies that physically disabled adults employ in coping with their disability in society……………………………………………………….117

4.2.3.1 Sub-Theme 1: Spiritual Support…………………………………...........117

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4.2.3.2 Sub-Theme 2: Support groups…………………………………………...............118

4.2.3.3 Sub-Theme 3: Substance Abuse……………………………………………….....120
4.2.3.4 Sub- Theme 4: Rehabilitation Services Support………………………………...122

CHAPTER FIVE: CONCLUSION AND RECOMMENDATIONS

5.1 Introduction……………………………………………………………………124

5.2 Conclusion of the study……………………………………………………….124

5.2.1 Meaning attached to physical disability acquired in adulthood ………………….124

5.2.2 Experience of physical disability in adulthood …………………………………..125

5.2.3 Strategies that physically disabled adults employ in coping with their disabilities in society………………………………………………………………….126

5.3 Limitations of the study……………………………………………………..127

5.4 Recommendations………………………………………….………………..127

5.4.1 Government…………………………………………………………………..127

5.4.2 Health professionals……………………………………….……………….....128

5.4.3 Disability organizations………………………………………………….......129

5.4.4 Support groups……………………………………………………….….....130

5.4.5 Department of transport………………………………………………………130

5.4.6 Researchers……………………………………………………………………....130

5.5 Conclusion……………………..…………………………………………..…131

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References………………………………………………………………….................133

Appendixes

Appendix A: Information letter to respondents……………………………………….…...154

Appendix B: Data collection instrument……………………………………………….…..155

Appendix C: Consent form……………………………………………………………….…..156

Appendix D: Interview questions…………………………………………………….…157

Appendix E: Indemnity form…………………………………………………………...163

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List of tables

Table 2.1 Impairment versus disability…………………………………………………......30

Table 2.2 Disability in social space……………………………………………………....66

List of figures

Figure 2.1: Poverty and disability- a vicious cycle……………………………………...51

Figure 2.2: The process of being impaired, disabled and handicapped…………………70

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CHAPTER ONE INTRODUCTION AND BACKGROUND

1.1 Introduction

This chapter introduces the overall study by outlining the background to the research, problem statement, aim and objectives, and motivation of the study. The research questions are also presented in this chapter and they are followed by the significance of the study, delimitations, and conceptual and operational definitions.

1.2 Background of the study

Persons with disabilities in developing countries often face more acute barriers than those in developed nations. Up to 80% of the persons with disabilities in developing countries live in isolated rural areas. In some countries, 20% of persons with disabilities (World Programme of Action,1983:13). Thus, when disabled peoples' relatives are included, it can be estimated that 50% of the population is affected by disability.

In addition, persons with disabilities are extremely poor. They often do not have access to adequate medical services. As a result, disabilities are often not detected on time so as to minimise their effects. By the time the disabled people receive medical attention, if at all, impairment may have become irreversible (World Programme of Action, 1983:13-14). In addition, the number of elderly people is rising around the world, thus, disabling conditions that are not common to younger people, such as strokes, heart diseases and deteriorating vision or hearing, are becoming more prevalent (World Programme of Action, 1983:14).

Some of the disabling factors are inherited, while others are caused by wars and violence. The economic structure of society may, to a large extent, be decimated by war, leading to malnutrition, lack of housing, sanitation and other problems, all increasing the risk of acquiring or compounding the problems of disability (Heath,1984:4). Persons with disabilities, throughout the world, are now empowering themselves so as to claim greater participation, integration and equality. Such claims are not only about greater control over individual lives, but also about greater influence over the social structures within which such lives are lived. For

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this reason, it is impossible to disentangle the lived experience of disability from the context of disabling societies**.**

Uneven economic and political developments mean that impairment and disability affect children, adults and older people differently in different societies. The result is that, disability in both a medical and social model sense has been framed within a minority worldview. Consequently, it is important to have a bigger picture when thinking about disability issues. Majiet (1998:1) argues that, “if one looks at the disability agenda, we can ask who sets the agenda globally for human rights. My impression and humble opinion is that this agenda is very much set by North America and that we need to take issues with that”.

Similarly, Montero, (1998:1) observes that, “when we come to the developed countries from the underdeveloped countries we see differences. We are fighting for different issues”. Such differences can lead to differences in political emphasis between disabled people in different regions. For example, while organisations for persons with disabilities in the United Kingdom were campaigning against the principle of charitable support from the National lottery, persons with disabilities in Thailand were protesting to maintain the employment of persons with disabilities Lottery ticket sellers (Montero, 1998:1). Such differences are not necessarily conflictual, but they do illustrate some of the different societal influences at work in defining the disability agenda. There are many issues facing persons with disabilities in rich technological countries, with highly developed welfare provision. However, developed countries’ approaches to disability differ from those employed in the majority of the world.

South Africa is one of the leading countries in the world which has used its period of political transition to emphasise the relationship between poverty and disability through a human rights framework. The inclusion of social and economic rights in the South African constitution reflects an understanding by that dignity, freedom and equality are not just about the absence of civil and political violations, but that the transformation of the current society into one in which there will be human dignity, freedom and equality, lies at the heart of the new constitutional order (South African Constitution, 1996:25).

According to Oliver (1993:62), disability is seen as a tragedy and disabled people are treated as if they are victims of some tragic happenings and circumstances. The inequalities and divisions

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between South African people arise from political, social and economic systems that aimed at keeping black people subservient to white people. Basically, this ensured that black people remained in conditions of poverty, with limited opportunities to share in the country's wealth. Furthermore, this meant that lived experiences of black and white persons with disabilities under apartheid were very different and reflected in general, the inequalities between white and black people in South Africa.

This study starts with the assumption that those who acquire disabilities at adulthood handle it differently from those who are born with them or those who acquire them soon after birth. The term 'disability' is conceived differently in different societies. Some societies perceive disability as a punishment from the gods, while in others children and adults with disabilities are ostracised, left to die or indeed killed through fear and ignorance (Linton, 1998:34).

According to Jackson (1989:8), negative attitudes can lead to neglect, outright rejection, lower self-esteem, and reduced opportunities for education, skills development, family life, employment, social integration and independence. Disability, hence, has far reaching consequences on the lives of the affected individuals and their families. The disability does not affect only the persons with disabilities, but the whole families and even the community.
Problems related to disability are discussed below.

1.2.1 Physical hardship to social isolation

A major consequence of living with disability is isolation, which can occur either when the affected individual withdraws from social contact, or when friends and relatives stop visiting.
Loneliness can occur out of concern about other people's reactions or by unwittingly perpetuating one's own isolation because of a visible 'negative' trait. For example, a person afflicted by a stroke and the resultant speech impairment, might avoid an encounter with others or involvement in social activities out of embarrassment.

1.2.2 Educational needs

According to the White Paper on Integrated Disability Strategy (1997:2), the majority people with disabilities in South Africa have been excluded from the mainstream of society and have,

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thus, been prevented from accessing fundamental social, political and economic rights. The exclusion experienced by persons with disabilities and their families results in failure to access educational facilities in their communities, which are largely not disability-friendly. For example, some libraries do not have wide doors for people using wheelchairs making entry into the libraries impossible for them. There is also no brail document for blind people to read for themselves and not to depend on other people to read for them. Such an environment can restrict opportunities for the 'disabled', limit their choices for development, increase dependency and foster feelings of isolation, hopelessness and a poor self-concept.

1.2.3 Economic needs

In spite of the high levels of unemployment and economic inactivity, employees with disabilities are more likely than employees without disabilities to be in low paying and low status jobs with poor working conditions (Barnes *et al*. 1999:16). Employees with disabilities in managerial or professional work are between 32 per cent and 50 per cent lower than those without disabilities working at these same levels (Arthur and Zarb, 1995:3).

According to Quinn and Degener (2002:18), when disabled people obtain work the social security system poses a new challenge. When a person with a disability obtains a job, the social security benefits stop, and yet the wages that person would receive in the job would be mostly low or even lower than the benefits they received before getting employed.

Disability movements, for example Disabled People South Africa have argued that the central role played by professionals in service delivery has legitimised the individual model of disability, which locates the problem of disability within the individual, and sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability (Oliver, 1996:31). There has been little attempt to explore the extent or nature of the impact of this model on the lives of physically-disabled adults (Oliver, 1996:32).

Disability covers a wide and diverse range of disabling conditions, which comprise salient features of physical impairment, activity limitation and participation restrictions. Thus, disability, in this context, seems to begin with the afflicted person's awareness of significant physiological changes and awareness of a series of physical and social barriers. Robison *et al*.

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(1995:75) note that “the everyday experiences of persons with disabilities can be summarised in one word, *inaccessibility* not only to elements in the environment (site or building) that do not allow approach, but also the social environment, an approach to people”.

1.3 Statement of the problem

Most people who acquired physical disabilities at adult stage in Vhembe District Municipality experience numerous barriers. These barriers include lack of access to public transport, lack of access to built environments, unemployment, lack of self-representation, exclusion and isolation. The barriers are usually the main obstacles to the integration and full participation of physically-persons with disabilities in all aspects of life. Lack of accessible transport, which presents an important obstacle to an independent life, may segregate the lives of persons with physical disabilities, leaving them with very few opportunities for social interactions or participation in mainstream community activities (Integrated National Disability Strategy, 1997:30).

The needs, dreams and rights of adult persons with disabilities are not different from those of the rest of the population. Yet, people without disabilities tend to regard disabled people as poor and helpless objects that are to be pitied and looked after. In other words, persons with disabilities are thought of as ill and different from other people. Persons with disabilities often become outcasts from their families and society and are forced to rely on charity. In fact, very often they are not seen as people at all, sometimes even by their own families. Disability does not affect only the persons with disabilities, but the whole family and even the community. The low status or bad reputation of a family may spread to persons with disabilities. Similarly, the presence of a person with disabilities in the family may influence the way the whole family is looked upon by others (Seligman and Darling, 1989:7). The study has mainly focused on the understating the experiences of adults acquired physical disability at adulthood.

Disability is considered and treated as a medical problem, in which the social, educational and economic needs of the persons with disabilities are neglected. This makes it nearly impossible for persons with physically disabilities to become active members of society. Disability scholars have long argued that what is called physical disability is not simply an attribute of a person, but a complex collection of conditions, activities and relationships, many of which are

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created by the social environment (Bickenbach et al. 1999:1173). The Disabled People's Organisation (DPO), all over the world, has also been working hard to change people's attitudes towards the exclusion of persons with disabilities from society. In South Africa, persons with disabilities are discriminated against at two levels, firstly, by the unjust laws of apartheid, and, secondly, through restrictions imposed by their own disabilities.

1.3.1 Motivation of the study

The researcher's interest in this study stemmed from the fact that the researcher is staying with her child who was born with a physical disability. Although the researcher was motivated by her child being born with a disability, the researcher's study focuses more on those who acquired disabilities in adulthood. There is not much documented evidence on the impact of physical disabilities acquired at adulthood in Vhembe District, Limpopo Province. The researcher used an open approach to explore the experiences of such disabilities. It is hoped that the findings of this research would raise awareness on the experience of physical disabilities acquired in adulthood on the lives of persons with disabilities living in the Vhembe District, Limpopo Province. The researcher has worked for the Disabled People South Africa Organisation for five years. This has also motivated the researcher to do the study.

The study seeks to provide information which would assist in bringing about equality and dignity for all physically disabled people. It is also hoped that the awareness around physical disability and related issues, will discourage the old prejudices. Persons with physically disabilities should take control of their own lives and utilise any opportunities afforded them by government and society, for example, employment. The researcher is currently working for the Department of Agriculture in the employee's wellness and special programmes sub-branch responsible for employees with disabilities and externally persons with disabilities clients who are involved in the agricultural sector.

The researcher's experiences of interacting with people with disabilities from her previous and current employment have played an important role in motivating the researcher to do this study.

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1.4 Aim and objectives of the study

The aim of the research is to develop an in-depth understanding of the experiences of physicaldisabled acquired in adulthood. The following research objectives of the study will be realised:

- To explore the meaning attached to physical disability acquired in adulthood;
- To explore the experiences of physical disability acquired in adulthood, in order to obtain a holistic perspective of adult disability; and
- To highlight the strategies that physically disabled adults employ in coping with their disabilities in a society.

1.5 Research questions

- What are the participants' views on physical disability acquired in adulthood?
- What is the experience of physical disabilities acquired in adulthood?
- What strategies do participants employ in coping with physical disabilities acquired in adulthood?

1.6 Significance of the study

It is imperative that when one is conducting a study one should understand its significance to the body of knowledge. Firstly, not much has been done to study the impact of physical disabilities (acquired at adulthood) in Vhembe District, Limpopo Province. Secondly, the researcher hopes that the study of this nature would grant persons with physical disabilities an opportunity to use their voices to raise awareness on the experience of disability. The study will also raise awareness on the experiences of disability on communities and different organisations.

The open-minded approach of this research will raise awareness of both the positive and negative effects of being physically disabled in adulthood. The outcomes of this study will provide insights into how support structures for persons with disabilities who are living in Vhembe District, Limpopo Province, could be developed and improved.
The study will assist professionals who work with physically disabled adults to identify areas that persons with disabilities consider important and which affect them in their daily lives. Since

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the study will also highlight strategies that physically-disabled adults employ in their day to day lives, professionals will also get to know of these strategies and debate their appropriateness.

1.7 Contribution to body of knowledge

The study has the potential to make contributions to the body of knowledge concerning the experiences of adults with disabilities. The potential contributions of this study are as follows:

- A lot of studies have been conducted around disabilities in general. This study adds to the knowledge that is already there, specifically with a focus on disability that was acquired when one was already an adult. The study brought forth specific experiences for adults.
  This study stands as a contribution towards bringing about change in promoting full realisation of all human rights and fundamental freedom for all persons with disabilities;
- The qualitative method approach used in the study offered insight into the lived experiences of participants as well as the experiences and behaviours of the community and government officials;
- The study challenges all stakeholders to take on a visible role in mainstreaming persons with disabilities to end all forms of discriminating against adults with disabilities;
- The study provides evidence to potentially encourage government to introduce adults with physical disability into their programmes and planning as a core development matter;
- The study exposes the immediate challenges faced by persons with disabilities in isolated areas;
- The study promotes disability awareness of the lived experiences of adults with disability, particularly in rural area like Vhembe District where the study was conducted;
- The study contributes in connecting the voices of adults with physical disability as their shared experiences were documented;
- Although the study contributed to the body of knowledge about the experiences of adults with physically disability, one cannot conclude that these are the only experiences.

These contributions of this study will promote human dignity and are based on the idea that all human beings are equal in terms of value and importance, regardless of physical disability. The impact of the Constitution, Act 108 of 1996, Promotion of Equality and the Prevention of Unfair Discrimination Act No.4 of 2002, persons with disabilities are thus also equal to able-bodied.

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The contribution of the study will convey strong message to different stakeholders in the disability field regarding contribution of adults with physical disabilities and improving the lived experiences.

The governments have to undertake appropriate measures to ensure that persons with disabilities are able to access, on an equal basis with others, the physical environment, public transport, information and communication, as well as other facilities and services open or provided to the public, both in urban and in rural areas. These measures are aimed at enabling persons with disabilities to live independently and participate fully in all aspects of life.

Organs of civil society need to become active agents of change in fighting discriminatory attitudes and belief systems that push persons with disabilities and their families to the margins of society. Organisations of persons with disabilities, as the representative voice of persons with disabilities, need to strengthen their footprint at a local level to empower persons with disabilities, to advocate for change, and to monitor and act upon rights infringement.

1.8 Full Integration of adults with disabilities

Persons with disabilities did not have equal participation to the community activities because the environment was not disability friendly. Participation and inclusion have been important aspects of the study. Participants maintained the importance of integration of adults with disabilities. It is evident from this study that adults with disabilities could not participate in different activities e.g. entering buildings which are not accessible which result in isolation or exclusion. Poor participation appeared to create emotions and dependency most of the time. Lack of understanding and exposure to disability existing legislations framework by persons with disabilities and other stakeholders, and probable absence and poor implementation of the policies which promote integration for persons with disabilities and eradicate stereotype and stigma against adults with disabilities, all these deprive these people full integration in community activities in all spheres of life.

Historically, disability was seen as an individual's own "problem" and the focus was placed on the person with the disability and the problem was defined in individual terms. Nowadays, the challenge of disability is seen as being co-determined and created by society. Every person with a disability is affected by events and changes in society and also has an effect on the

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society. These events and changes also have a unique impact on the individual, depending on his/her life experiences (Rothman 2003:79-81).

According to the White Paper on Integrated Disability Strategy (1997:7) the majority of people with disabilities in South Africa have been excluded from the mainstream of society and this has prevented them from accessing fundamental social, political and economic rights. The most important barriers which persons with disabilities are confronted with, is a negative attitude. Attitudinal barriers lead to the social exclusion and marginalisation of persons with disabilities. Persons with disabilities are often viewed as helpless and dependent, as ill and in constant need of care and medical treatment, or as tragic victims. They are also perceived as different or "outsiders". More focus is placed on the disability than on the person. People tend to stereotype persons with disabilities INDS (1997:23). Some able-bodied people assume that physical disability automatically implies intellectual disability; some assume that persons with disabilities cannot speak for themselves and for this reason they will not address a person with a disability directly. In addition, some able-bodied people have the perception that physical disability also implies that the person has an intellectual disability (Schneider in Watermeyer et al, 2006:396).

An understanding of disability as a human rights and development issue, leads to a recognition and acknowledgement that person with disabilities are equal citizens and should therefore enjoy equal rights and responsibilities. This implies that the needs for every individual are of equal importance. It further implies that resources must be employed in such a way that every individual has equal opportunities for participation in society. In addition, integration to rights for persons with disabilities, persons with disabilities should have an equal obligation within societies and should be given the support necessary to enable them to exercise their responsibilities. This means that societies must raise their expectations of persons with disabilities.

The Constitution of the Republic of South Africa (Act No 108 of 1996) protects the rights and dignity, promotes and supports the full equalisation of opportunities and advocates for the integration in society of all persons with disabilities. The Constitution declares the founding values of our society to be human dignity, the achievement of equality and the advancement of human rights and freedoms. Human rights and development approach to disability focuses on the removal of barriers to full integration, participation and the elimination of discrimination

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based on disability. The Bill of Rights Chapter 2 of the Constitution highlights equality of all persons. It specifically mentions the right to equality and non-discrimination against persons on the ground of disability (Section 9(2-3).

It is important that the needs of persons with disabilities be integrated into all components of the society and government. Persons with disabilities are a natural and integral part of society as a whole and should have opportunities to contribute their experiences. The concept of full integration encompassing human diversity and the development of all human potential captures the spirit of human rights. Defining and translating the human rights for persons with disabilities into society and government programmes remains the major challenge. Ogarnisations of persons with disabilities should be responsible in ensuring the human rights of persons with disabilities are integrated into all spheres of government in creating an enabling environment that will lead to the full participation and equalization of opportunities for persons with disabilities at all levels of society. Recognition of disability rights in these areas would lead to improved full integration in society as well as equal and stronger participation in all facets of life by persons with disabilities.

Following the enforcement of the UNCRPD, disability has increasingly been understood as a human rights issue. The Convention was intended as a human rights instrument with an explicit, social development dimension. It adopted a broad categorization of persons with disabilities and reaffirmed that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarified and qualified how all categories of rights apply to persons with disabilities and identified areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced (UNCRPD, 2006).
It is my view that persons with disabilities should receive equal opportunities and the same opportunities as able-bodied. The experiences of persons with disabilities will ensure that the study provides a platform from which the perspectives and voices of persons with disabilities be heard and understood. The study will raise deeper understanding on how to promote integration of persons with disabilities, experiences by persons with disabilities that limit their involvement in the development of their own communities.

1.9 Delimitation of the study

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The study focused on the experiences of physically disabled acquired in adulthood in the Vhembe District, Limpopo Province. The researcher focused only on Tshivenda-speaking people who were diagnosed as physically-disabled in their adulthood. The ages of the participants ranged from 18 years to 55 years old. Only four males and three females (physically disabled) participated in this study.

1.10 Conceptual and operational definitions

Rubin and Babbie (2005:141) define conceptualisation as the process of moving from vague ideas about what the researcher wants to study, to recognising and measuring what the researcher wants to study. The researcher at this juncture, gives an exposition of the major concepts used in this study, in order to clarify their general meaning, as well as their operational meaning for the proposed study.

- **Accessibility:** This involves the ability of any individual, in spite of his/her impairments, to get into and out of any building, independently (Iwarsson and Stahl, 2003:58).

- **Adult:** According to the Longman Dictionary Contemporary English (2005), an adult is a fully-grown person or one who is considered to be legally responsible for his/her actions.

- **Attitude:** This is a relatively enduring organisation of beliefs around an object or situation predisposing one to respond in some preferential manner to such objects or situations (Sills, 1968:450).

- **Attitudes:** These are a combination of beliefs and feelings that predispose a person to behave in a certain way (Noe, 2002).

- **Attitudes transformation:** This refers to a change in thinking that offers a different view or paradigm. It helps to prompt a more progressive pattern of behavior towards the successful integration of people with disabilities into the open workplace (Silver and Koopman, 2000).

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- **Disability:** This is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers (DPI cited in Oliver, 1996a:41). In the context of health, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for human beings (WHO, 1997).

  According to Thomas (1999), a disability is a form of social oppression involving the social imposition of restrictions on activities of people with impairments and the socially engendered undermining of their psycho-emotional well-being. Furthermore, Finkelstein and French (1993) define it as the loss or limitation of opportunities that prevent people who have impairments from taking part in the normal life of the community on an equal level with others, due to physical and social barriers.

- **Disabled person**: This is an individual whose prospects of securing and retaining suitable employment are substantially reduced as a result of physical or mental impairment (INDS,1997).

- **Experience**: According to Longman Dictionary of Contemporary English (2005), experience is a knowledge or skill that you gain from doing a job or activity.

- **Handicap:** These are disadvantages experienced by an individual as a result of impairments and disabilities (WHO,1997). In the context of health, a handicap is a disadvantage for a given individual resulting from impairment or a disability. It limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual (Wood, 1980).

- **Impairment:** This is the functional limitation within the individual which is caused by physical, mental or sensory impairment (DPI cited in Oliver, 1996a).

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- **Inclusion:** This is the change from the individual-change model to a system-change model, which emphasises that society has to change to accommodate diversity is to accommodate all people (INDS, 1997).

- **Physically-disabled person:** This is an individual who is born with a physical impairment or who acquires a physical limitation, such as anatomical loss of major extremities, paralysis, physiological disorders or any other condition due to illness, injury, an accident or age, which affects the body system (Hatting *et al.*, 1987).

- **Reasonable accommodation:** Silver and Koopman (2000) define reasonable accommodation for people with disabilities as follows:

- Making sure that the toilet design is disability-friendly;
- Having a system installed in the lift that announces the various floors;
- Providing parking close to the main entrance;
- Placing lift buttons at a level easily accessible to all people with disabilities;
- Providing ramps to ensure that the building is accessible to wheelchairs; and
- Installing automatic doors to the toilets, so that any person with a disability can enter or exit the toilet easily.

Stigma: This is a sign of disgrace or discredit which sets a person apart from others (Byrne, 2000:65). Link and Phelan (2001) say that a stigma is a co-occurrence of its components that is labeling, stereotyping, separation, status loss and discrimination. Link and Phelan (2001*)* further indicate that, for stigmatisation to occur, power must be exercised.

1.11 Conclusion

In this chapter the researcher provided the general orientation and introduction to the chapter. The chapter comprised an introduction, the background of the study, statement of the problem, motivation of the study, aims and objectives of the study and the research questions. The significance of the study, delimitation and conceptual and operational terms were also discussed. The next chapter reviews related literature. The necessity of this chapter is to provide information that is fundamental and essential to the study.

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1.12 Outline of the research study

This section outlines the research framework which indicates what the researcher plans to do and how she plans to set about doing it (Mouton and Marais, 1992:176). The division of chapters is as follows:

Chapter 1

This chapter outlines the introduction, statement of the problem, motivation of the study, aim and objectives, research questions to be addressed, significance, delimitation, conceptual and operational definitions.

Chapter 2

This chapter provides a literature review from a broad frame of references through which the experiences of the physically disabled are perceived. It includes an investigation of similar studies carried out in other countries, as well as their findings.

Chapter 3

This chapter focuses on the research design. The sampling method, techniques of data collection, and the limitations of the study area are presented.

Chapter 4

The chapter presents the analysis and interpretation of data. The research findings are presented descriptively.

Chapter 5

This chapter summarises the findings so as to provide conclusions and make recommendations. It concludes with an implementation plan to actualise the recommendations made for the disability sector.

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CHAPTER TWO LITERATURE REVIEW

2.1 Introduction

This chapter reviews relevant literature on the subject of disability and its experience on persons with disabilities. Literature reviewed includes literature on the different models of disability, the role of disability movement/organisations relationships between beliefs and attitudes.

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2.2 The history of disability rights movements in South Africa

The history of the disability rights movement in South Africa is one that has been shaped by many different forces emanating from people with disabilities and different advocacy organisations of persons with disabilities. Collectively, the events and circumstances which have contributed strongly to the movement, as we know it today, arose from the experiences of persons with disabilities living under the system of apartheid. Under the apartheid system, the experiences of persons with disabilities were strongly shaped by the fact that these people lived in a deeply divided and unequal society.

According to Oliver (1993:62), disability is seen as a tragedy, and disabled people are treated as if they are victims of some tragic happenings and circumstances. The inequalities and divisions between different races arose from a political, economic and social system that aimed at keeping black people subservient to white people. Basically, black people remained in a condition of poverty, with limited opportunities to share in the country's wealth. Furthermore, this meant that lived experiences of black and white persons with disabilities under apartheid were very different, and that they reflected the general inequalities between white and black people in South Africa.

The first Congress of Disabled People International (DPI), held in Singapore in 1981, adopted a manifesto which set out the organization's philosophical base. The congress maintained that all people are of equal value. This conviction implies that persons with disabilities have a right to participate in every sphere of society. The manifesto asserted that persons with disabilities have rights, as citizens, to education, rehabilitation, employment, independent living and income security. Driedger (1989) rejects all forms of segregation and refuses to accept a lifetime of isolation in special institutions.

2.3 Physical and psychological concept of disability

Perceptions of disabilities have differed from era to era. The socio-economic and political environment, attitudes of people, institutional constructs, relationships within the family, as well as relationships amongst persons with disabilities, have determined how disability is viewed in a particular society. This has given rise to different models of disability. Although

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often in conflict, these different models of disability influence and modify each other. The next section, therefore discusses these different models of disability.

2.3.1 Medical model

It has been argued that the biomedical model of practice, in which biology is prized above all else as a basis of explanation, has failed to take account of the socio-political environments within which illness and disability are experienced (Feinstein cited in Good and DelvecchioGood, 1980). In other words, it is argued that medical responses to disability have tended to reduce the focus of attention to the 'illness' or 'impairment' of individual bodies, thereby placing full responsibility for the struggles experienced by persons with disabilities on the 'disabled' individual, rather than interrogating the social oppression of persons with impairments.

Marks (1999a:75) asserts that the medical model functions to justify the exclusion and marginalisation of persons with disabilities, via the model's tendency to explore, explain, and intervene upon disability, at a level of medical solutions to physical defects. Within this form of biomedical 'practice', the notion of 'independence' becomes central, calling, as it does, upon persons with disabilities to strive for a mode of functioning which is as "normal" as possible, thus avoiding any questioning of those social structures and facilities which are designed with the needs of only a proportion of the population -the 'non-disabled'- in mind.

According to Oliver (1993:32) the medical model, obscures the social origin of impairment. That is, it attributes the loss of physical abilities or faculties to a form of individual bodily "tragedy". Consequently, under the influence of the medical model, the 'problem' of disability is located within the individual. Further, this model sees the causes of the problem as stemming from the functional limitations or psychological losses which are assumed to arise from the disability. These two points are underpinned by 'the personal tragedy theory of disability', which suggests that 'disability is some terrible chance event which occurs at random to unfortunate individuals' (Oliver, 1993:32).

The medical profession, because of its power and dominance, has spawned a whole range of what Oliver (1993:37) terms 'pseudo professions'. He further argues that physiotherapy, occupational

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therapy, speech therapy and clinical psychology are all geared towards the same aim, the restoration of normality. The reality is that the medical model lies at the heart of clinical practice. Thus, it may be difficult for health care professionals, including physiotherapists, to consider 'changing their attitudes and behaviour' towards disability and people with disability (French, 1997:336-337). Professional education, therefore, has the potential to provide clinicians with a narrowed insight of disability, which can easily give rise to conflict or ineffective communication for persons with disabilities. Fulcher (1989:44), for example, notes that a medical view is seen as 'scientific', therefore, value-free and apolitical… 'The doctor knows best'.

The view point of the medical model is that people with disabilities are 'sick patients' who need to spend their lives trying to get well. This "sick role" deprives persons with disabilities to take responsibilities of so-called normal people in society. As Jim Derksen, a Canadian relates:

> *The 'patient' or 'sick' disabled person is allowed and even expected to behave in a childlike manner. Like a child, however, he must follow orders; in this case the orders of doctors and the agents or proxies of doctors. Full participation in social, sexual, political, economic and other forms of adult behaviours are denied or at the very least discouraged on the 'patient'* (Derksen, 1980:5).

It has been argued that the biomedical model of practice, in which biology is prized above all else as a basis of the explanation by Feinstein *et al.* (1980:165) has failed to take account of the socio-political environments within which illness and disability are experienced. In other words, it is argued that medical responses to disability have tended to reduce the focus of attention to the "illness" or "impairment" of individual bodies, thereby placing full responsibility for the struggles experienced by persons with disabilities on the "disabled" individual, rather than the socio-economic and political environment within which these persons with disabilities live.

In contemporary Western society, the dominant model through which to understand, respond, and live through disability can be termed the medical model. In this model, disability is understood as 'a defect in or failure of a bodily system that is inherently abnormal and pathological' (Olkin, 2002:133). In the dictionaries of the English language the term *"disabled"* is defined as being crippled, injured, incapacitated, inoperative, and impaired

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(Dictionary.com). In contrast, to be non-disabled is to be healthy, mobile, active, and capable of being a contributing member of society; it means being valued and esteemed over the disabled body. Medical experts are perceived as the only ones holding the answers and hopes of the disabled, a role to which the 'disabled' submit in an effort to regain a well, able-bodied, valued identity. This value system shapes the stories that emerge from living in a body identified as disabled (Olkin, 2002:134).

The medical model perceives disability as an individual concern and focuses on the self of the person and its differences from the 'normal'. Abberly 1997 (cited in Gleeson, 1999:18) argues that the medical model "locates the source of disability in the individual's supposed deficiency and her or his personal incapacities when compared to 'normal' people". Until the beginning of the 20th century, this approach dominated social organizational construct. Gleeson 1999 (cited in Imrie, 1996:28) proposed the positivistic behavioural aspect of the medical in order to theorise disability as an adaptable physiological condition. Medical care, cure, rehabilitation and treatment are the most popular activities and consequently, health and care policies should be modified or reformed for mainstreaming purposes. Whilst human beings are accepted as flexible and 'alterable', society is seen fixed and unalterable, and social welfare policies are designed to support persons with disabilities to deal with their disabilities (Barnes *et al,* 1999:21). Access policies declare that built environments are designed with most people in mind. Therefore, persons with disabilities should change their environmental behaviour according to the constraints they face.

Imrie (2000) asserts that the conceptualisation of the relationship between mobility and impairment through particular discourses claims that 'immobility problem is personal and specific to the impairment' and that there is a strong need to restore the mobility. The medical model perceives disability as an illness and, because care is a priority issue, the medical model institutions like hospitals are seen as '*containers*' which remove persons with disabilities from society (Ferguson, 1997). Lifchez (1987:1-2) also mentions how society demands the removal of 'misfits' from mainstream society through placing them in asylums, prisons and hospitals, constructed according to the manager's principles.

> *According to Mairs (2002:160-161), 'medical professionals tend to pathologise disability, assuming that people whose bodies or minds*

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> *function in abnormal ways have something wrong with them . . . from a doctor 's perspective, a disability is 'wrong' because it deviates from the ideal norm built up during years of training and practice'.*

Society, generally, accepts the authority of those designated as experts within the medical model. New knowledge that negates prior understandings is usually interpreted as a medical breakthrough and embraced by society with hopes of attaining what is understood to be a longer, better quality of life. The power and pervasiveness of the medical model stems largely from the societal acceptance of the authority of the medical diagnosis.

2.3.2 Disability in social model

After the hegemony of the medical model of disability, which viewed disabled people as people needing help, care and attention, and also as people who are dependent on others and who are victims of a personal tragedy, the social model came on to the scene and used, as the basis of its argument, the past experiences of the disabled people (Barnes et *al*., 1999:21).The 1970s and 80s were the time of protests and activities carried out by disabled activists and organisations similar to those of other minority groups. These pivoted primarily on the criticism of the medicalisation of disability. This model is also called the 'right-based model' because it came at a time when emphasis was on requesting governments and society to grant people their human rights.

The disability experiences mentioned above are listed by Barnes and Mercer 1999 (cited in Gilson and Depoy, 2000:208) as negative attitudes providing limited physical access, limited access to communication and/or resources, to the rights and privileges of a social group. This model argues that problems restrict or impede the integration of people with disabilities to social life. The impairment is not seen as the problem. Long standing unequal practices and exclusionary politics constitute the nature of the problem. Disability is not a characteristic and part of an individual, but it is a reflection of a complex social environment. Persons with disabilities achieve important rights, emerging from basic human rights in different countries, as a result of the Independent Living Movement and related activities. The United State of America, United Kindom, Canada and Australia are the countries that declared the rights of persons with disabilities by Acts, which made many statutory provisions, in order to create a

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more accessible built environment social aspect and built environment are two main rights of people with disabilities (Park *et al*. 1998:211).

Blackman *et al.* (2003:357) argue that the social or right-based model of disability demedicalises disability and politicises it as an issue of universal rights. They also argue that disability is an outcome of the exclusionary practices in society, with all its bodies and fields.

The shift in society can only happen when that society's discriminatory and insufficient access implementations to power which put persons with disabilities at a disadvantage or turn them into an oppressed minority group with an unequal and inferior social position is noticed and changed (Davies,1999). The design of the built environment, therefore, is mostly disabling, and it is necessary to pay great attention to spatial concerns.

Butler and Bowlby (1997:412-413) explain the social model of disability by discussing two features of the model. First of all, the society with its economic, political and social marginalising organisations makes physically and mentally unable people 'disabled'. In addition, the built environment is constituted in such a way that it ignores the interests of the persons with disabilities. While a person with a disability might say, according to the medical model, 'I cannot go into the museum or the cinema because my disability prevents me from climbing the stairs', the same person according to the social model, might say 'I cannot go to the museum or the cinema, because the steps prevent me from entering the building' (Davies, 1999:76). From this latter viewpoint, all persons with disabilities should be able to gain access to buildings, with no difficulty and no assistance, just like 'normal' people do.

If a person with impairment cannot enter a building, a kind of social exclusion and stigmatisation begins. Parr (1997:439) also draws people's attention to service provision and participation in decision-making process works and also points out difficulties of accessing the spatial and political public realm, as well as material and immaterial barriers produced by the supposedly 'able bodied' and 'able minded'.

The social model is based on the principle that disability is a denial of the civil rights from employment to design caused by exclusionary practices in all spheres of society. This principle separates 'impairment' caused by disease or injury from 'disability' caused by personal, social and environmental barriers that, if removed, could enable capacities to be regained. Indeed,

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impairment itself is questioned as a meaningful concept when there is so much variation in physical and cognitive characteristics across human population (Blackman *et al*., 2003:357).

Blackman *et al.* (2003:367) also emphasise that focus should shift from the disoriented, confused and distressed, private sphere of the person to the disorienting, confusing and distressing environments, of the public spheres of planning and design in social model. Freund (2001:702) adds that the social model pays attention to bodies, space and active moving bodies in space. Therefore, even though disability is created emergence of two conditions, a person with pathology or an injury and environment unsupportive of an action-environmental intervention instead of medical or surgical interventions for people with disabilities to improve performance, is one of the most vital contributions of the social model (Stark, 2001:37).

2.3.3 Social model of impairment

Whatever happens to the call for a dialogue between organisations of persons with disabilities and the World Health Organization, persons with disabilities have begun their own internal dialogue around the social model of disability. A major criticism that some persons with disabilities have made of the social model concerns the way it connects or rather does not connect with the experience of impairment. The achievement of the disability movement has been to break the link between bodies, and the social situation, and also to focus on the real cause of disability, namely discrimination and prejudice. To mention biology, to admit pain, and to confront impairment, means risking the oppressors seizing on evidence that disability is 'really' about physical limitation after all (Shakespeare,1992:40). The social model of disability appears to have been constructed for healthy physically able people.

The social model avoids mentioning pain, medication or ill-health (Humphrey, 1994:66). Other persons with disabilities have criticised the social model for its assumed denial of 'the pain of impairment', both physically and psychological. Morris (1991:10) suggests that 'there is a tendency within the social model of disability to deny the experiences of our bodies'. Crow (1996:210) has argued for a renewed social model which would allow 'a more complete recognition and understanding of the individual's experiences of their body'. Thomas (1999:47) has developed a social relation definition of disability to account for the 'socially engendered undermining of the psycho-emotional well-being of disabled people'.

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2.3.4 The affirmative model of disability

In their article, toward an affirmative model of disability, Swain and French (2000) introduced the intervention within the structural /individual, barriers/experience debate. They proposed an affirmative model to disability, which, basically, gives essentially a non-tragic view of disability and impairment. The model encompasses both individual and collective positive social identities, for persons with disabilities, which are grounded in the benefits of lifestyle of being impaired and disabled. The affirmative model is identified as a critique of the dominant personal tragedy model corresponding to the social model as a critique of the medical model.

In proposing an affirmative model, Swain and French (2000:569) drew upon the writings and experiences of disabled people, which asserted that, far from being necessarily tragic, living with impairment can be experienced as valuable, exciting interesting and satisfying. This is not to deny that there can be negative experiences resulting from impairment but that impairment is not all about tragedy. By disassociating impairment from disability, they argue that the social model leaves open the possibility that, even in an ideal world full of civil rights and participative citizenship for disabled people, impairment could be seen as a personal tragedy (Swain and French 2000:571).

The rejection of a tragic view and the establishment of an affirmative model is not a concern of the social model. The feminist position 'of admitting that there may be a negative side to impairment' is also regarded as problematic (Swain and French, 2000:571). The social model is challenged on the grounds that it ignores impairment. This argument arises from the perspective that impairment is something awful, which is characterised by pain and chronic illness (Cameron, 2008:19). In arguing for an extension of the social model, in order to include the personal, feminists are not making a claim for the recognition of the rights of disabled people to enjoy being who they are.

Swain and French's (2000) affirmation model of disability article has been developed and elaborated upon in Swain and French's 2008 book, *Disability on Equal Terms*. Outlined below is a clear statement of what the affirmative model is and what it is not about.

The affirmative model is about:

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- Being different and thinking differently about being different, both individually and collectively;
- The affirmation of unique ways of being situated in a society;
- Disabled people challenging presumptions about themselves and their lives in terms of not only how they differ from what is average or normal, but also about the assertion, on their own terms, of human embodiment, lifestyles, equality of life and identity; and Ways of being that embrace difference.

The affirmative model is not about:

- All people with impairments celebrating difference;
- Disabled people ‘coming to terms’ with disability and impairment; and
- Disabled people being ‘can do’ or ‘lovely’ people.

It is clear that what is being proposed offers ‘no clearly defined formulas for change’ and ‘no comfortable remit’. The affirmative model, itself, does not provide a different set of presumptions to replace those that characterise individual models, particularly the tragedy model (Swain and French, 2008:186).

2.3.5 Charity model of disability

The charity model originates from the religious conceptualisation of disability and, as given by Davies (1999:75-76), includes pity, embarrassment, do-gooding, dependency, sympathy and rattling collection tins. Some of these attitudes are seen in the history of the United Kingndom during periods of institutionalisation and the segregation through religious approach. It can be seen that, under the effects of this approach, categorisation of physiological functions was perpetuated, and norms of abnormality, the deviant and the worthless were equated with disability (Imrie, 1996:27).

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The remains of this approach still affect the social, cultural and spatial organisation of persons with disabilities, and this should not be forgotten. There are two mediate models; namely the rehabilitation-educational approach and the psychosocial rehabilitation approach. The former supports an independent and normalised life, and then integration into the community. The latter is about developing mastery and competence, and learning new behaviours or adapting existing ones, in order to meet needs (Ferguson, 1997).

2.3.6 The future of the disability theory as a theory towards an "affirmative" model

The social model of disability continues to evolve and develop. Building upon the intellectual work described above Swain and French (2000) have outlined an "affirmation" model of disability which seeks to 'celebrate the differences' that characterise the lives of persons with disabilities. It is, therefore, contends that persons with disabilities can be 'proud' of the fact that they are different from the majority of the population. Swain and French (2000), begin their analysis by rejecting the tragedy conception of disability as purported by the medical model. They proceeded by maintaining that it is not possible to make a stark distinction between those who are disabled and those who are not, since all people, to some extent, have a degree of impairment. However, they do not necessarily encounter the negative consequences of disability. Those who wear spectacles to compensate for low vision are a case in point. Neither can a stark distinction be maintained between those who encounter oppression and those who do not, for it is possible for persons with disabilities, themselves, to be oppressors, by having racist, homophobic or sexist attitudes.

Swain and French (2000:270) further contend that the social model of disability clearly shows how contemporary society oppresses and discriminates against persons with disabilities. However, in contrast, the majority of studies on disability maintain that the vast majority of persons with disabilities accept the analysis of the social model. The studies candidly state that the social model was borne out of the experiences of persons with disabilities and they challenge the dominant individual models espoused by non-disabled people. Nevertheless, it is because of experience that many non-disabled people readily accept the social model, albeit superficially and at a very basic conceptual level. Non-disabled people generally, accept that wheelchair users cannot enter a building because of steps. Non-disabled people are much more

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threatened and challenged by the notion that a wheelchair user could be pleased and proud of the person he or she is (Swain and French, 2000).

The notion of an affirmative model of disability questions the analysis of early variants of the social model, since it is argued that the adoption of the precepts of the latter does not necessarily result in a non-tragic view of disablement. Swain and French again state that,

> *While the social model of disability is certainly totally incompatible with the view that disability is a personal tragedy, it can be argued that the social model, in itself, underpinned a non-tragedy view. First, to be a member of an oppressed group within society does not necessarily engender a non-tragic view. There is, for instance, nothing inherently non-tragic about being denied access to buildings. Secondly, the social model disassociates impairment from disability. It thus leaves the possibility that even in an ideal world of full civil rights and participative citizenship for disabled people, impairment could be seen as a personal tragedy* (Swain and French, 2000:571).

The affirmative model of disability directly challenges presumptions of personal tragedy and the determination of identity through the value-laden presumptions of non-disabled people. It signifies the rejection of presumptions of dependency and abnormality. By embracing an affirmative model, disabled individuals assert a positive identity, not only in being disabled, but also in being impaired. By affirming a positive identity, persons with disabilities actively repudiate the dominant view of normality.

Swain and French concluded their analysis by stating that embracing an affirmative view of disablement, in fact, strengthens the political leverage of the disability movement. Persons with disabilities cannot only look towards a future society devoid of structural, environmental and attitudinal barriers, but to one that can "celebrate difference and values people irrespective of race, sexual preference, gender, age, and impairment" (Swain and French, 2000:580).

The desire to celebrate diversity and difference, as well as take pride in the positive value of living with impairments, has also been expressed by those who are deaf. Some "deaf" people are of the opinion that they are not, in fact, disabled, but that they constitute a distinct and

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coherent social minority, complete with their own culture and language. A distinction is drawn between those who can hear, and those who cannot. The implication, then, is that those who are deaf belong to the latter category. Ladd and John (1991), when investigating the relationship between the "deaf community" and 'disabled people' have stated that:

> *We do not want to mainstream society to restructure so that we can be part of it, rather, we wish for the right to exist as a linguistic minority group within the society. Labeling us as 'disabled' demonstrates a failure to understand that we are not disabled within our own community. Many persons with disabilities see deaf people as belonging outside the mainstream culture. We, on the other hand, see deaf people as 'hearing' people in that they use a different language to us, from which we are excluded, and see them as being members of society's culture* (Ladd and John, 1991:14).

However, the position outlined above has been criticised from within the deaf community itself. By claiming that they constitute their own distinctive cultural identity, Corker (1998: 30). This is invariably oppressive.

> *The allusion to withdrawal from mainstream society suggests withdrawal from something, all accounts suggests that this something is cultural and linguistic oppression. But Western society, together with the dominant human services culture and its governance and legal systems which at present control, to a large extent, how we live, still view all deaf people, including those who are blind, in terms of the individual/medical model. Hence, sign language is increasingly acknowledged as a viable means of communication, it does not follow that there is a widespread cultural acceptance within such frameworks for thinking and service development* (Corker, 1998:30).

2.3.7 Moral model

Society has looked to individuals to explain not only the experiences associated with disability, but also why certain individuals are disabled, while others are not. Anxiety compels some to

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place blame somewhere, and to find answers within the values, beliefs, lifestyles and choices of the afflicted and those close to the individual. The moral model views disability as a 'defect caused by a moral lapse or sin, failure of faith', evil and test of faith' Olkin (2002:133). One's perception of the truth and knowledge, rooted in the cause of disability, is of particular importance in the moral model. What one perceives as the known cause of a particular disability strongly influences how it emerges within the framework of the moral model.

2.3.8 Socio-cultural model

The socio-cultural model of disability argues that, the core error of the medical and moral model of disability is a failure to distinguish between impairment and disability. Impairment, from a socio-cultural perspective, is a lack of or defect in one's physical body or the movement of one's physical body or the movement of one's body, whereas disability is a "disadvantage imposed on top of one's impairment and which, therefore, excludes them from participating in the mainstream social activities" (Oliver 1990:22).

2.3.9 Distinction between impairment and disability in line with the medical model and social model.

Table 2.1: Impairment versus disability

Impairment	Disability
The biological	The social model
Impairment	Disability
The body	Society
Medicine	Politics
Therapy	Emancipation

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Pain	Oppression
The medical model	The social model

Source: (Hughes and Patterson, 1997:30)

2.4 The role of disability movements /organisations

2.4.1 'Organisation of' versus 'organisations for'

Throughout the world, non-disabled people have formed organisations which seek to provide services for persons with disabilities. These organisations operate within a framework which assumes that persons with disabilities are not capable of taking control of their lives, and that they require the services of professionals and voluntary workers, as well as charity. According to Oliver (1990:115), who was a disabled academic, these organisations work within 'the medical rather than a social model of disability, which locates the problems faced by disabled people within the individual rather than being contingent upon social organization'. Hannaford (1985:82) argues that the assumption is that disabled people are the problem, just as the poor are the problem and not the society that caused the poverty.

Organisations for persons with disabilities, however, reject charity and medical models of disability, asserting that the services they require should be provided as a civil right, and that it is the society which disables them rather than their physical condition. Organisations for persons with disabilities have their social origins in the surplus time and money of the wealthy, and the post-war development of the professions.

2.4.2 Organisation of the disabled and self-representation- "A voice of our own"

Disabled people's organisations believe that persons with disabilities are their own best spokespersons. Disabled People International's motto is, 'A voice of our own'. This premise is the backbone of the movement. For too long, medical and social work professionals, as well as extended family members, have spoken for persons with disabilities. In the words of Roberts, a disabled American 'when others speak for you, you lose' (Roberts, 1983:7).

Persons with disabilities believe that they know best the needs and aspirations of persons with disabilities. They will represent themselves to governments, service providers, the United Nations and the public. Persons with disabilities redefined themselves as citizens with rights,

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not as patients and clients of professionals, nor as beggars asking for hand-outs. The National Council of Disabled Persons of Zimbabwe (NCDPZ) states that, "Our role is to act as a voice of the persons with disability. We are a 'civil rights' organization of persons with disabilities formed to consciencetise the disabled about their rights and to fight for the rights to access to all community services" (NCPDZ, 1983:1).

To assert their rights, persons with disabilities believe that all disability groups must be united in national disabled people's organisations and, of course, DPI, an international united front. As Jim Derksen urged disabled Canadians in 1975, 'Lets us reason together, let us deliberate on our problems and needs, let us consider our abilities, and when we have agreed on the problems and solutions let us articulate our opinions and ideas in a strong and united voice' (Derkesen, 1975:1a).

2.4.3 Disability movement in South Africa

The election of the first democratic government in South Africa in 1994, led to the formation of a new Constitution, which included the recognition that persons with disabilities have been disadvantaged and discriminated against. In the early 1980's, many white persons with disabilities experienced discrimination with regards to health care and social welfare, while Africans with disabilities was further compounded by the experienced of oppression and inequality under apartheid (Howell, Chalklen, and Alberts, 2006:53).

Disabled People South Africa (DPSA) recognised by Disabled People's International (DPI) was launched in September 1984 by a group of disabled activists wanting to overcome the experience of oppression of black and white persons with disabilities in South Africa. DPSA is a cross disability organisation, comprising of a number of smaller community-based persons with disabilities organisations. The aim of the DPSA is to "mobilize and organize disabled people throughout the country through building supporting self-help organizations, with a particular emphasis on capacity building initiatives and training programmes" (Howell *et al.,* 2006:53).

2.4.4 The role of disabled people's organisations

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The role of DPO's is essentially to provide an organized voice for disabled people. DPOs are also a vehicle for self-development and empowerment at a collective and individual level. DPO's play a pivotal role in the development process and the major success of the social model of disability served primarily as a political device to revolutionise disabled people, rather than a theoretical model (Thomas, 1999a in Watermeyer, 2009:13). The social model has addressed the rights of persons with disabilities; thereby fostering equal opportunities to participate at all levels of life. Equal opportunities are defined as the process whereby all systems of society, namely activities, services, information and documentation, are made available to all (World Programme of Action 1983).

The experience of the DPOs' active participation was evident in the negotiation of the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD) (UN, 2006). The role of the DPOs has been key in the implementation and monitoring of the UNCRPD. 'Nothing about us without us served as a reminder that the definition of policies was no longer possible without the active involvement of persons with disabilities and their organisations. This position set an important precedent for civil society participation in the negotiation of a human rights treaty. Furthermore, the stance of the movement emphasized that disability policy and practice should not be developed and implemented without the involvement of persons with disabilities and their democratically elected organisations. The focus of DPOs now needs to shift towards building their capacity for monitoring the effective implementation of the UNCRPD by their respective governments.

DPOs have become increasingly instrumental in working with national governments, as well as with the bilateral and multilateral institutions, in developing policies and operational modalities for the effective social inclusion of disabled people in the societies in which they live (Majiet, 2013:5). These achievements demonstrate the strategic importance of having effective DPOs to influence development outcomes. It is necessary the DPOs are led by capable leaders to ensure the rights of persons with disabilities.

2.4.5 Disability in South Africa

Disability is not a phenomenon peculiar to the South African context. It is a global phenomenon of huge proportions, eliciting growing local, national and international concern.

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Conservative global estimates of the prevalence of disability suggest that a staggering 537 million people in the world suffer from significant disabilities (UNDP, 1998). Very few reliable statistics exist on the prevalence and nature of disability in South Africa, largely due to a historical failure to integrate disability into the mainstream government statistical processes (White Paper on an Integrated National Disability Strategy, 1997). The World Health Organization (2005) estimates that two thirds of the world's disabled population resides in developing countries, and recent estimates of the prevalence of disability in South Africa suggest that 13% of the total population are disabled, 5% of whom are severely disabled (Central Intelligence Agency, 2007).

In May 1997, the Office on Status of Disabled People was established. In 1999 was moved to the State President's office. The OSDP was established to ensure among other things the inclusion of disability issues in government policies and programmes of development and "into all sectors of society" (Matsebula *et al*., 2006:85).

2.4.6 National Population Census 2001

There is a paucity of data available as to the prevalence of disability within South Africa's population. McLaren, Solarsh and Saloojee (2004:12) argue that the lack of consensus around defining 'disability' seriously hampers the ability to identify people with disability, develop disability indicators and conduct research on disability. The authors feel that until there is consensus on definitions on disability, 'obtaining accurate disability data and the development of indicators to measure disability and rehabilitation programmes will remain problematic'.

The most recent surveys which provide some data on the prevalence of disability in South Africa, are the National Population Census of 2001 (Statistics South Africa, 2005), which provides some information about serious, largely visible disabilities, and the Community Agency for Social Enquiry (CASE) Disability Survey conducted for the Department of Health (Schneider *et al*., 1999).

Statistics South Africa conducted a census in 2001, the second national census to be carried out in democratic South Africa. In this census, respondents were asked:

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Does the person have any serious disability that prevents his/her participation in life activities? None 0; Sight 1; Hearing 2; Communication 3; Physical; Intellectual 5; Emotional 6 (Statistics South Africa, 2005:8).

From this question and the respondents' answers on other demographic questions, data on disability was included in the reported statistics.

The Census 2001 report further indicated that disabled persons had a higher percentage of persons having received no education and lower rates of employment than those who did not report a disability, with disabled women being at a greater disadvantage in this regard. Fewer persons with disabilities reported being in school, compared to the rest of the population. On the average 10% fewer disabled persons between the ages of 6 and 18 were in school than nondisabled persons.

The report cautions on the validity of the data, due to the varying definitions of disability, as well as possible constraints on the respondents willingness to report disability or even consider themselves as being disabled. Despite these limitations, the survey results do provide some useful indication on the prevalence and demographics of disability in South Africa (Statistics South Africa, 2005:14).

McLaren *et al*. (2004:25) further argue that the survey questions mainly identified people with severe disabilities, and the prevalence rates may be underestimated. Schneider and Couper, (2007:28) similarly conclude that the Census 2001 survey may have discouraged individuals from reporting themselves as disabled, because of the term "serious disability"; individuals might have self-identified as being 'disabled", but not as having a "serious disability". In their focus group discussion used to assess a series of questions of disability for possible inclusion in Census 2011, they found that some persons with visual and physical disabilities, who responded as disabled in the focus groups, did not respond as being disabled in Census 2001. The reported results in Census 2001, therefore, cannot be taken as an accurate indication of the prevalence of disability in South Africa. The only study to attend measure the prevalence of disabilities only, was conducted some time before the Census 2001. They are not as recent as the results from Census 2001, and are now 10 years old, but they perhaps provide a more inclusive measure of disability than Census 2001 does.

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2.4.7 The global context of disability

Disability is a global issue. More than half a billion-disabled people live in the world today, approximately one in ten of the population. This number is set to rise dramatically over the next twenty-five years, both in richer technological societies and in the poorer majority (International Disability Foundation, 1998). At the same time, persons with disabilities, throughout the world, are empowering themselves to claim greater participation, integration and equality. Such claims are not only about greater control over individual lives, but also about greater influence over the social structures within which such lives are lived. For this reason, it is impossible to disentangle the lived experience of disability from the context of disabling societies**.**

Uneven economic and political development means that impairment and disability affect children, adults and older people differently in different societies. According to the United Nations (UN) estimates, around 80 percent of persons with disabilities live in so-called 'developing' countries. More accurately, we might say that most of disabled people spend most of their lives in the 'majority world (Stone, 1999:7).'Yet, the academic literature of disability studies consistently privileges minority world accounts (especially, those from Western Europe and North America). The result is that disability, in both the medical and social model sense, has been framed within a minority worldview. Consequently, it is important to think about disability issues in the bigger picture. Majiet (1998:1) argues that, 'if one looks at the disability agenda, he/she can ask 'who sets the agenda globally for human rights?'. My impression and humble opinion is that this agenda is very much set by the North, and that we need to take issues with that'.

Similarly, Montero (1998:1) observes that, 'When we come to the developed countries from the underdeveloped countries we see differences. We are fighting for different issues'. Such differences can lead to differences in political emphasis among persons with disabilities in different regions. For example, while persons with disabilities organisations' in the UK were campaigning against the principle of charitable support from the National Lottery, disabled people in Thailand were protesting to maintain the employment of disabled Lottery tickets sellers. Such differences are not necessarily conflictual but they do illustrate some of the

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societal influence at work in defining the disability agenda. The issues facing persons with disabilities in rich and technologically developed countries with highly developed welfare provision are indeed different from those in the majority world.

Within the global debate about disability, South Africa is one of the leading countries in the world, which has used a transition period to emphasise the relationship between poverty and disability through a human rights framework. The inclusion of social and economic rights into the South African constitution reflects the understanding that dignity, freedom and equality are not just about the absence of civil and political violations, but that the transformation of current society into one in which there will be human dignity, freedom and equality, lies at the heart of our new constitutional order (South African Constitution: 1996: 6-25).

2.4.8 Disabled people's international organisation

The significance of persons with disabilities coming together to form an international movement cannot be underestimated. Persons with disabilities are "imprisoned" within institutions, constrained within inaccessible housing and obstacle-ridden physical environments, dependent on unpaid care by family members and discriminated against in the labour market. Such people lack power by virtue of their socio-economic circumstances. The foundation of Disabled People's International was about persons with disabilities taking control over their lives. Disabled People's International is also crucial in the struggle against organisations for disabled people. In most of the industrialised world, the richest and most prominent organisations (e.g. DPI) working on disability are controlled by non-disabled people and their activities do much to confirm the prejudices against the struggle.

Disabled People's International, itself, grew out of a conflict with Rehabilitation International, an international organization made up mainly of (non-disabled) rehabilitation professionals. Until 1980, this was the only international organisation concerned with the needs of people with varying disabilities. Very few disabled people ever participated at its congress until the protests by a handful of disabled delegates, at the 1976 congress of disabled people in Sweden and Canada, organised to increase the number of disabled delegates to the 1980 World Congress and Delegate Assembly (DPI,1981).

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The Swedish delegation forwarded a resolution that organisations of disabled people should have at least 50% of the delegates in a national delegation, and this would have meant that at least 50% of the delegate assembly would be composed of persons with disabilities. When the resolution was resoundingly defeated in a meeting of persons with disabilities delegates who were attending the congress, the 250 persons with disabilities who were participating decided to form a World Congress of Citizens with disabilities, which subsequently became persons with disabilities International. Persons with disabilities who came from all over the world had a sense of their own destiny. They wanted to proclaim their rights as citizens, to equal voice in the decision-making processes pertaining to services, policies and programmes that affected them. They were no longer willing to passively accept the control by rehabilitation professionals over their lives. They demanded dignity, equality and full participation in society. They demanded release from the yoke of paternalism and charity (Dreidger, 1989:35).

The rehabilitation professionals, at the congress, reacted either with outright hostility to the idea of disabled people forming their own international organisation or with a condescending paternalism. One non-disabled delegate gave voice to this latter reaction when he wrote,

> *To me, they are going through a developmental stage which resembles the adolescent or young adult in a family, who often becomes rebellious for a period of time. After this stage, an excellent partnership and relationship with the "family" evolves and life goes on better than ever* (Dreidger, 1989:37).

It was against such attitudes that persons with disabilities had to assert their autonomy and attempt to take power away from the professionals who controlled not only the disability organisations, but also the individual lives of persons with disabilities. Persons with disabilities International delegates from both developing and industrialised countries found that there were common elements of the struggle between organizations of and organisations for persons with disabilities. Joshua Malinga for example, recounted the story of the foundation of the Zimbabwe Council of Disabled People and how they were met with hostility. According to Malinga,

> *When news came out in the papers, we were branded with all sorts of names from all corners. We were called "rebels" and "ungrateful ones". They refused to see the difference between an organization of the*

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disabled and one that is for persons with disabilities. They refused to see the difference between a service organization and a political fighting for the human rights of the disabled (DPI, 1981*).*

Like in many other countries, the Zimbabwean organisation of disabled people allied itself with the liberation movement. According to Malinga,

*As soon as our majority government took over we started meeting all members of the parliament and reminding them that the struggle for liberation which put them into power, was a struggle for social justice and that it is accepted that the justice should permeate to all communities, including the disabled (*DPI,1981).

2.5 Definitions pertaining to disability

According to a Disabled cobbler, from Kampala, Uganda cited in Lwanga-Ntale (2003:6).

Disability is when your life is not in your hands-when your physical or mental state is such that other people have to decide for you what to do, where to go, what to eat and who to associate with. You are just an object of pity, and whatever opinion that you give can never be taken seriously. Some people will treat you as if you were a child, even when you are well over 30 years (Lwanga-Ntale, 2003:6).

The above quotation encapsulates from a first person perspective the depth of exclusion experienced in Uganda as a result of having a disability. However, the formal definition of disability is problematic. The most extreme example comes from Helander who describes a situation in Mali where 'the most 'disabling condition' for a woman is to be ugly' (Helander, 1992:11). Equally, in other countries those people who have an extra finger or who are missing an eye 'may have no functional limitations and yet be labeled 'disabled' (Helander, 1992:11). What is clear, however, is that every society has a view of its own on the concept. 'There has yet to be found a human society that does not have a complex system of beliefs and practices concerning disability' (Groce, 1999:756).

Another issue regarding formal definitions of disability is that they have been traditionally defined by non-disabled professionals from the North. One particular debate has been over the term 'impairment' versus 'disability'. As shown in Helander's example above, what some

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might term ‘disability’ others regard as ‘impairment’. Yeo (2001:3) describes impairment as ‘An individual’s condition – physical, sensory, intellectual or behavioral’.

Having impairment (for example short sight, missing finger) does not automatically mean that the person is disabled (EENET, 2004). Rather, disability is defined as ‘a complex system of social restrictions imposed on people with impairments resulting in a denial of rights and opportunities’ (Yeo, 2001:3). Mile (1999:9) regards it as “a social construction which varies across culture and through time in the same way as gender or ethnicity’. This is supported by Nganwa *et al* who stated how “many decisions and therefore the outcomes of disabled people’s lives are a result of the social environment in which their disability was born and bred” (Nganwa *et al.*, 2002:188).

2.6 Relationship between beliefs and attitudes

The relationship between beliefs and attitudes is useful, in order to keep in mind the distinction made by Arthur Kleinman between general beliefs about sickness, which belong to the health ideology of the different episodes of sickness, and explanatory models. The latter is formed on the belief system but emerges in relation to specific illness episodes and, therefore, has to be analysed in the context in which it occurs (Kleinman, 1980:106). Explanatory models, in the same case of illness or impairment, may vary according to the position of the actors involved, thus influencing attitudes such as readiness to act in different ways. In all societies, the beliefs about the cause of impairment may have consequences for action. In communities where the study was conducted, there are widespread beliefs that epilepsy is due to possession or bewitchment by evil spirits or the devil. In some other cultures, the spirit is believed to be that of the ancestors. There are also beliefs that the transmission of the disease is by physical contact, such as saliva. Therefore, attitudes towards epilepsy, and the person with epilepsy in indigenous Africa, are invariably unfavourable. They reflect mythical beliefs about the disease (Tekle and Haimanot, 1991:103).

According to (Lutz, 1988) perspective on emotions not only as an individual concern, but as culturally defined, socially enacted, and personally articulated, may also widen the understanding of the concept of attitudes. Disability is visible proof of misfortune, but also in many cases, is viewed as a bill of exemption from some of the rules and obligations that hold for normal members of the society. Emotional disabilities might call forth, in others, negative

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such as fear, contempt, or even envy when special benefits or privileges are awarded. There may be pity, charity, and other forms of special treatment. Many disabled persons struggling for normalisation have found positive emotional reactions from others as difficult to encounter as the negative ones, and even harder to overcome.

2.7 Disability and social exclusion

Social exclusion is defined as "the process through which individuals or groups are wholly or partially excluded from full participation in the society within which they live" (European Foundation, cited in Francis 2002:74). The concept 'social exclusion' emerged in the North, and there has been debate around the extent to which it is applicable in the context of the South.

According to the White Paper on an Integrated Disability Strategy (1997:2), the majority of people with disabilities in South Africa has been excluded from the mainstream of society and, thus, has been prevented from accessing fundamental social, political and economic rights.

The exclusion experienced by people with disabilities and their families is a result of the following factors:

- The political and economic inequalities of the apartheid system;
- Discriminatory and weak legislative framework which has sanctioned and reinforced exclusionary barriers; and
- Social attitudes which have perpetuate stereotypes of disabled people as dependent and in need of care.

According to the White Paper on an Integrated Disability Strategy (1997:30), there are a number of barriers in the environment which prevent people with disabilities from enjoying equal opportunities with non-disabled people. These barriers include for example, inaccessible entrance stairs which does not accommodate wheelchair users and stairs.

2.8 Feminist and disability

American college students were asked to write down whatever came to mind when they heard the phrase 'disabled woman'. Many students left their papers blank, being unable to think of

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anything when they heard the term. Those who did write something wrote words signifying passivity, weakness or dependency. They wrote words such as, 'almost lifeless', 'pity', 'lonely', 'crippled', 'wheelchair', 'grey', 'old' and 'sorry' (Owen 1987:11).

The exercise was part of a research project of disabled women. The researchers were surprised at the results, even though they had been expecting negative responses. In another experiment 145 students were asked to list what came to mind when they heard the word 'woman', they wrote down terms associated with heterosexuality and heterosexual relationships, work and motherhood. These terms were almost entirely missing from the associations with the words 'disabled woman'. This is fundamentally undermining as Thompson (1985) wrote:

> *Anger felt by women because of their disabilities is rarely accepted in their communities, or anywhere else for that matter. Disabled or not, most of them grew up with media images depicting pathetic little 'cripple' children on various telethons or blind beggars with caps in hand ('handicap') or 'brave' war heroes limping back to a home where they are promptly forgotten. Such individual's anger was never seen, and still rarely is. Instead of acknowledging the basic humanity of our often powerful emotions, able bodied persons tend to view us either as helpless things to be pitied or as super-crips, gallantly fighting to overcome insurmountable odds. Attitudes display a bizarre two-tiered mindset, it is horrible beyond imagination to be disabled, but disabled people with guts can, if they only try hard enough, make themselves almost 'normal'. The absurdity of such all-or-nothing images is obvious. So, too, is the damage these images do to disabled people by robbing them sense of reality* (Thompson, 1985: 78).

Some of this is echoed by Saxton and Howe when they wrote,

> *Disabled women are typically regarded by the culture at two extremes: on the one hand, our lives are thought to be pitiful, full of pain, the result of senseless tragedy; on the other hand, we are seen as inspirational beings, nearly raised to sainthood by those who perceive our suffering with awe* (Saxton and Howe, 1988: 105).

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2.9 Work, education and poverty

According to International Labour Organisation (1983) in the modern world, work and employment are major signifiers of independent adulthood (particularly male adulthood). Yet, disabled men and women throughout the world continue to be disproportionately unemployed, underemployed and underpaid (along with young people and women) resulting in conditions of extreme poverty for many millions of their families. In 1983, ILO adopted a convention of International Standards as follows:

- Equality of opportunity and treatment for disabled persons in relation to employment and social integration;
- Equality of opportunity and treatment for disabled men and women workers to be respected; and
- Special positive measures aimed at effective equality of opportunity and treatment between disabled workers and other workers shall not be regarded as discriminating against other workers. (ILO, 1983: Article 4).

According to Shah (1990:51), drawing from her own life experiences as a young blind woman in Pakistan, disabled females, children and girls are not considered fit for education. These barriers to education leave many young disabled women, in many countries, unemployed, poor and dependent upon their families. The experience of a young blind woman in Pakistan stated is a good example of how negative the society at large regarding persons with disability is even today. If these negative attitudes are left unattended to or unopposed, persons with disability will still be marginalised, prejudiced and oppressed. One of the greatest hurdles disabled people face when trying to access mainstreaming programmes are negative attitudes. It is these attitudes that lead to the social exclusion and marginalization of people with disabilities. Negative attitudes are continually reinforced. Apartheid and its consequences in all areas from wealth to health, education and quality of life has meant countless barriers that need to be addressed in order to overcome historical disparities and promote a more equal society for all.

Republic of South Africa Constitution (Act 108 of 1996) founded our democratic state and common citizenship on the values of human dignity, the achievement of equality and the advancement of human rights and freedoms (Section 1a). These values summon all of us to

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take up the responsibility and challenge of building a humane and caring society, not for the few, but for all South Africans. In establishing an education and training system for the 21st century, we carry a special responsibility to implement these values and to ensure that all learners, with and without disabilities, pursue their learning potential to the fullest (Department of Education, White Paper 6, 2001:11).

2.10 The construction of personhood and the production of social stigma

Since the 1980s, different concepts especially those related to concepts of normality have been debated in disability theory, A strong argument has always been that of expanding the concept of normality. The content of these arguments has centered on, (i) who defines normality, (ii) who states the content, and (iii) in whose eyes and according to whose ideology/cosmology this is done. To study the process of stigma in Vhembe District, will be especially interesting because, through the human rights framework, the concept of normality has been regarded as unacceptable and replaced by the concept of 'diversity'. Society constructs disability as a stigma, defined as an "attribute that is deeply discrediting" (Goffman, 1963).

According to Oliver cited in Tremain (2002:33) Disabled People's Organizations have discussed disability as if disabilities have nothing to do with the physical body. The main focus has been on changing society and the fact that society creates barriers which generate disabilities and not the other way round.

2.11 Institutionalisation

Throughout history persons with disabilities have attempted to insist on their rights to live and to have a decent quality of life. Even those who were institutionalised under the Third Reich and killed under the Nazi Euthanasia Programme, resisted being institutionalised. According to Gallagher' (1990:138) 'The residents of Abbey (an institution run by the Catholic Church for disabled people) refused to get on the bus and their resistance put to shame the nuns and local people's failure to help'.

In the past, the most common form of care provision made for persons with disabilities was through institutions. Institutionalisation is an experience of powerlessness which can grossly

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multiply the effects of physical limitations. Disability movements, throughout the industrialised world, view the struggle against residential care as one of the most important parts of the fight for human rights. The Union of the Physically Impaired Against Segregation (UPIAS) (1981:2) states that the reality of the disabled people's position as an oppressed group can be seen most clearly in segregated residential institutions, where they are consigned to the ultimate human scrap-heaps of society. Thousands of people are sentenced to these prison-like institutions for life. For the vast majority, there is still no alternative, no appeal, no remission of sentence for good behavior, and no escape except escape from life itself.

In their analysis of the literature on all kinds of institutions, Jones and Fowles (1984) conclude that, in spite of the disparate approaches of the major writers in this area, there were five findings common to the life of the disabled people experienced in a wide range of institutions, namely; loss of liberty, social stigma, loss of autonomy, depersonalization and low material standards (Jones and Fowels, 1984:202). Persons with disabilities argued that these features are just as much a part of modern day institutions as they were of institutions in the nineteenth century, although the degree to which they are experienced may vary.

2.12 Experiences of physically disabled people

2.12.1 Disability and physical barriers

Stairs, narrow doorways and kerbs are some obstacles that limit the quality of life for people with physical disabilities. The environment can restrict the opportunities, limit the choices available, and increase dependency. According to Johnson (1995) the inability to drive a car is one that is difficult to accept and limits an individual's participation in activities. Furthermore, the economic and financial disadvantage (price of fuel and telephone), and accessibility availability of health services (distance from urban areas) add a significant dimension to the experience of isolation for persons with disabilities.

2.12.2 Experience of disability

Disability covers a wide and diverse range of disabling conditions with salient features of physical impairment, activity limitation and participation restrictions. Thus, disability in this

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context, seems to begin with the afflicted person's awareness of significant physiological changes and awareness of a series of physical and social barriers. Robison *et al.* (1995:75) noted that 'the everyday experiences of people with disabilities can be summarised in one word, *inaccessibility* not only to elements in the environment (site or building) that do not allow approach, but also the social environment, an approach to people'.

A permanent change in an individual's physical status is followed by a period, which Lubkin (1990:93) compares to a ride on a roller coaster, constantly challenged or angered by the uphill struggles, never knowing when another curve will come, and unable to stop the motion. Individuals have a sense of instability during this period of mixed and conflicting emotions, of bewilderment, and of a sense of helplessness. It is a process that is mostly characterised by inconsistency, questioning and uncertainty.

Uncertainty relates to the 'inability to determine the meaning of events' (Royer, 1998:41), and occurs in a situation where the decision-maker is unable to assign definite values to objects and events and/or is unable to predict outcomes accurately. In their discussion on uncertainty, Strauss *et al.* (1984:64) coined the term 'illness trajectory' to describe the physiological manifestations of a person's illness, his or her perception of the situation, and his or her response to the perception. For some, it is argued that the 'illness trajectory' is predictable, yet for others there is much more ambiguity. This is true for some of the participants, particularly those who live with a neurological condition. For example, Sandy who was diagnosed with Multiple Sclerosis faces a progressive condition with an uncertain outcome. It hampers the formation of any plan of action and thus impedes effective coping (Shalitt, 1977:32-45).

Human beings do not experience life solely in physical terms, but also in psychological and social terms. Consequently, it is likely that the impact of disability also affects one's sense of independence and productivity, and, ultimately, one's sense of worth and social value. Decreased independence and productivity may involve coming to terms with loss. According to Mumma (2000:192), 'The concept of loss implies a relationship with something or someone whose removal or disappearance leaves a gap in the life of the individual concerned'.

2.12.3 Dealing with disability

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The psychological 'experience of physical disability' and deformity encompasses a myriad of emotional reactions such as, a 'call to arms' of one's coping repertoire and defenses, and a journey of personal challenge through the caveats of despair, and loss to the ultimate reclaiming of oneself' (Turner and MacLean, 1989: 225).

Loss, according to Robinson *et al*. (1995:17), '… represents a disruption of life so severe that it is likened to a kind of death to people when the loss is irreversible'. Those living with acquired disability therefore, have to deal with the following:

- Mourning the loss of the old way of functioning;
- Dealing with new definitions of independence and interdependence;
- Adapting to physical discomfort as well as loss; and
- Confronting the issue of being different, both to themselves and others

'Adaptation' and 'coping' are often treated as synonymous terms, but Royers (1998:81) points out that, although both concepts are interrelated, they are distinct from each other. Coping refers '… to the special mobilisation of effort and the drawing upon unused resources or potentials, [and] always involves some type of stress'. Adaptation refers '… to a broader concept that includes routine or atomized actions'. 'Adaptation, in a psychological sense, refers to individual survival, as well as the capacity to sustain a high quality of life and to function effectively on a social level (Royers, 1998:81-82).

This begs the question: How does one deal with functional limitations and psychosocial experiences? Much has been written about how people manage to 'carry on' despite, or in spite of their chronic disabling condition. Pacing and balancing, for example, are energy conserving tactics meant to protect individuals from experiencing the world as 'intolerably anarchic' (Royers, 1998:125). Tham *et al*. (1999:405) demonstrate the importance of an awareness of disability before a person can consciously use compensatory strategies and incorporate them in daily life. They argue that the compensatory strategies must be built on the 'unique experiences and understanding of each person who has Unilateral Neglect'.

2.13 Survival, disability and impairment

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Disability creates and exacerbates poverty by increasing isolation and economic strain, not just for the individual, but for the family. There is little doubt that disabled people are among the poorest in poor countries (Coleridge, 1993:64).

Firstly, holding onto the distinction between impairment and disability is vital when thinking about poverty and development. There are obvious ways in which impairments are created and compounded through poverty (lack of access to resources, to basic healthcare, to adequate nutrition, to appropriate support) and through conflict. Then there are less obvious ways in which impoverishment is experienced by people who are disabled by the social, state and cultural responses to the impairment, through denial of access to education, employment, training, involvement in decision-making and so on. Very different strategies are required to tackle these very different issues.

Secondly, understanding the links between poverty and disability should encompass what happens to, and within households, as well as a more structural understanding of the poverty experienced by entire communities and countries. The question how disabled people can have equal opportunities in developing countries in the face of rapid cultural change, worldwide recession, armed conflicts, continued imbalanced of trade, structural adjustment and the ongoing rapid technological advances of the modern world (Kisanji,1995:199).

Thirdly, it is widely recognised that there is a vicious cycle whereby poverty producingimpairment, in a disabling society, results in poverty. Again, there is need to emphasise that having impairment does not always, and need never, result in greater poverty than that experienced by people who do not have impairment (Beresford, 1996:553-67).

The concepts suggested within survival, disability and impairment framework are as follows:

- Powerlessness is lack of political influence or leverage, exclusion from community and national decision-making, and denial of opportunities for self-representation;
- Poverty in the basic material sense of the word; it is lack of individual and household resources, assets and income (it is often, but not always related to poverty experienced by communities and whole regions);

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- Disability is institutional, attitudinal and environmental discrimination by a society (community, culture, state) towards people with perceived impairments;
- Impairment is the culturally perceived difference in the body/mind. This might also be extended to ill-health and weaknesses that result from malnutrition and overwork in the majority of the world;
- Vulnerability is living in a situation whereby any unexpected expense (e.g. on medical treatment, a dowry, a burial) or disaster (poor harvest, loss of livestock to disease, conflict) can tip the balance from survival into extreme deprivation;
- Isolation is about lack of access to support, information, education, healthcare, markets and infrastructure; and

  The complexity of poverty in the majority world, its causes, consequences and the ways in which people become locked into deprivation, (Malinga *et al*. 1992:12-13).

2.14 Impairment as inferiority

Impairment and disability are regarded in terms of inferiority, and they can be identified in the cultural dominance of the medical or individual model of disability, which is expressed in the World Health Organization's 1981 International Classification of Impairments, Disabilities and Handicaps (ICIDH) which makes the following distinctions:

- Impairment: any loss or abnormality of psychological or anatomical structure or function;
- Disability: any restriction or lack (resulting from impairment) of ability to perform an activity in a manner or with the range considered normal for a human being (WHO, 1981);
- The terms 'loss', 'abnormality', 'restriction' or 'lack of ability' are heavily laden with cultural meaning and indicate a perception of impairment and disability as characteristics of individual deficit; and
- Disability is regarded as a consequence of impairment. Cure, care, and therapy are regarded as appropriate social responses to what is identified as a personal problem (Edward, 2005:15).

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The medical model is evident in everyday practice through a myriad of behaviours, decisions, and interactions taking place in contexts in which disabled people experience their lives. It is put into practice through the manner in which services are delivered, plans are made, words are spoken and texts are read. It is embodied in gestures and assumptions, thoughts spoken and unspoken, hopes and expectations held, in conversations people have with each other and in inner conversations they have with themselves. It is a dominant model of disability, reflecting the view of the world of the non-disabled and its character as a model, or a way of looking at things, is almost always overlooked. It is considered common sense to regard impairment as misfortune.

Disabled critics, however, argue that the medical represents an ideological position and is a particular manifestation of what Michael Oliver has termed ‘the ideology of normality’ (Oliver, 1996:104). Normality is a construct imposed on a reality where there is only difference (Oliver, 1996:88). Davis pointed out that the term normal, meaning conforming to, not deviating or differing from the common type or standard only entered the English language around 1840 (Davis, 1995:24).

Disability emerged as a social category with the advent of industrialisation, the rapid growth of manufacturing towns and cities, and the arising need for a standard, replaceable able-bodied worker who can meet the production requirements of the factory system. According to Barnes, (1997:19) people with impairments, which were excluded from employment on the grounds of being unable to keep up with these requirements, found themselves removed from the mainstream of economic and community life and placed in a range of institutional settings. This process signified the systematic individualisation and medicalisation of the body and the mind.

2.15 Disability in the context of poverty

There are many different causes of disability such as war, malnutrition, unsanitary living conditions and environmental factors. Poverty often plays a significant role, in that it can either be the cause of disability or it can further exacerbate the experience of disability. Chambers (1984:111) argues that powerlessness, vulnerability, physical weakness, poverty and isolation operate as a vicious cycle to create interlocking ‘clusters of disadvantage’. Caught within the poverty trap, the poor become weak because of insufficient food. Malnutrition further depresses

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the immune system, making the body vulnerable to infections. Poverty and isolation prevent the ill and the infirm from getting to or paying for health care. Continued ill-health prevents physical labour, and lost income-earning opportunities put households into further debt and unsustained poverty.

Examining the impact of cultural differences on people with disabilities, Whyte and Ingstad (1998) argued that sensitivity to cultural factors should not deflect attention from the different social and economic circumstances of families to provide care and rehabilitation to infirm family members. They suggested that, whilst most families with disabled members provide care and support to the best of their ability, a combination of superstition, ignorance and limited household resources, in many poorer countries, may lead to neglect and abuse. It is in situations of dire poverty that households are subjected to neglect, and people with disabilities are particularly vulnerable (Whyte and Ingstad, 1998:43). The following diagram represents a vicious cycle of poverty and disability.

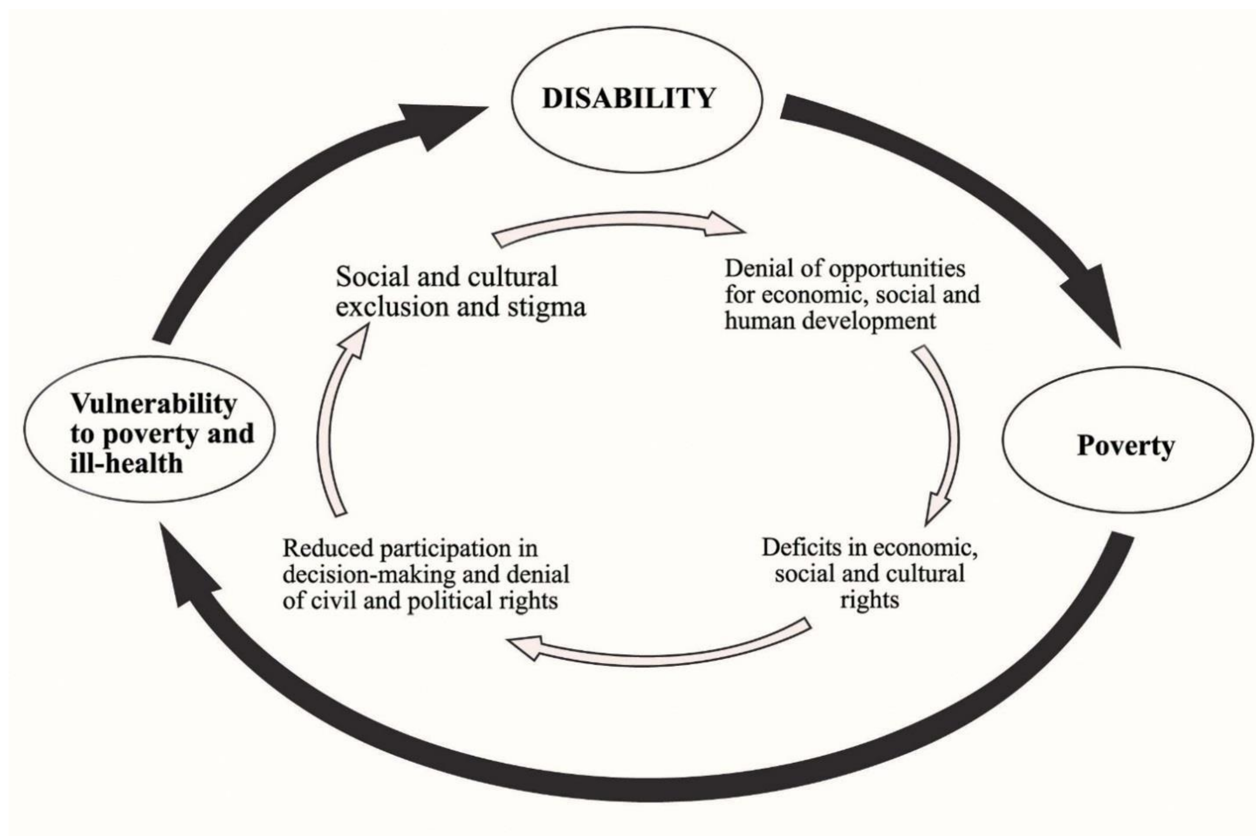

Figure 2.1 Poverty and disability – a vicious cycle (DFI, 2000)

In a review of literature related to poverty and disability, Elwan (1999:34) concluded that people with disabilities in both developed and developing countries are more likely to be

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unemployed, have lower incomes and less likely to have assets compared to the rest of the population. She further concluded that "not only does disability add to the risk of poverty, but conditions of poverty add to the risk of disability" through inadequate nutrition, sanitation and health care, resulting in an increased risk of disabling diseases. In developing countries, people with disabilities are particularly at risk of poverty, and it is estimated that disabled people make up between 15 to 20 percent of the poor in low income countries. Groce (2003a:3) reveals how 80% of the world's youth (under the age of 24) with disabilities live in the developing world, and that they are 'disproportionately represented among the poor' (Emmett, 2006:221).

Persons with disabilities in South Africa are more likely to be unemployed than the general population (Statistics South Africa, 2005). Women with disabilities may be financially dependent on men and may not have 'the freedom to prioritize their safety in sexual relationships above material needs' (Collins *et al*., 2001:163).

Throughout the world, it seems that disability is directly and strongly linked to poverty and social exclusion (Burgdorf, 1991:415). A United Nations Educational, Scientific and Cultural Organization (UNESCO) study showed that, worldwide, the most common form of employment for individuals with disabilities is begging (Helander cited in Sandhu 2001:3.8). There is a high correlation of disability with poverty, joblessness, lack of education and failure to participate in social life, shopping and recreation (Burgdorf, 1991:415). In most countries, welfare systems cannot supply sufficient income support and also they have no guiding and encouraging programmes for those with disabilities (Yilmaz, 2004a:2-3).

> *Mabubulhq (quoted in Shariff 1999:45) states that' nearly one-third of the total number of absolute poor in the world live in India. What is more distressing is that while 46 per cent of India's people survive in absolute poverty, about two thirds are "capability poor" that is, they do not receive the minimum level of education and health care necessary for functioning human capabilities'. Poverty de-individualises and alienates from the mainstream of society those affected.*

Marked by feelings of helplessness and hopelessness, poverty places limitations on the person, in terms of the personal and environmental resources to improve the equality of his or her life. As

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the most vulnerable and least vocal members of any society, poor-disabled people are often not even taken into consideration. While the unparalleled economic growth of the twentieth century is celebrated, the issues facing disabled people living in the remote villages, urban slums and tribal belts of India escape notice. While more shocking categories of violence, torture, war and sexual abuse seem manageable. The problems of inequality and injustice are so massive that they appear unmanageable (Dalal, 1998:28).

For poor families with a hand to mouth existence, the birth of a disabled child or the onset of a significant impairment in early childhood, are fates worse than death. In developing countries like India, impairment is largely caused by poverty. The prevalence of impairment, particularly polio and blindness, is at least four times higher among those who are below the poverty line than those who are above it (Dalal, 1998:29-31). This situation becomes bleak in the face of environmental barriers, which are both structural and attitudinal. For the poor, there is no allowance for disability in any area of life. Practically with no access to education or training, they are forced to live a life marked by extreme defenselessness on every score. To demand more from themselves, or what is fair and right from others, does not appear possible.

2.16 Disability and oppression

'Disability is a form of social oppression, which is circulated through prevailing ideological, social and political determinants and, as a consequence of these, disabled people are socially excluded and handicapism is constructed' (Begum, 1992:72). This is further explained by Morris (1991:166) when she asserts that, 'our society is characterised by fundamental inequalities and by ideologies which divide people against each other-the experience of disability is an integral part of this'. Clear (1999:438) states that "like the fundamental racism of apartheid, disability feeds off powerful, pernicious and persistent forms of economic and social structure, and distribution, which have not substantially been transformed, and therefore disability lives on".

Abberley (1987:17) proposes a theory of disability as oppression, which consists of five points as follows;

- It recognises and, in the present context, emphasizes the social origins of impairment;

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- It asserts the value of disabled modes of living, and at the same time, it condemns the social production of impairment;
- It recognises and opposes the social, financial, environmental and psychological disadvantages;
- It is inevitably a political perspective, in that it involves the defense and transformation, both materially and ideologically, of state's health and welfare provision as an essential condition of transforming the lives of the vast majority of disabled people; and It is historical products, not as the results of nature, human and or otherwise.

2.17 Disability in history

Since the industrial revolutions, many changes had occurred in the lives of persons with disabilities. Before the industrial revolution and urbanisation, people lived in large families and they survived on with agriculture, livestock, fishing among others. In the pre-industrial type of production, maintenance of family members with disabilities was not a problem. The existence of religions, family members and charitable persons, meant that persons with disabilities. Protected and cared for disability, was seen, from a religions perspective as warranting charity. In West Europe, in middle ages, for example protection of persons with disabilities became a duty of the church. In spite of the goodwill, these services were made far from the organization and its coordination. By the renaissance the political sovereignty of the church was displaced with that of the government. By the sixteenth century instead of protecting persons with disabilities by receiving benefits, concept of protecting by treatment, rehabilitation, training and employment began to be discussed. Work houses depending on manual labour were the initial examples of the employment of persons with disabilities.

The termination of the disabled people through death or segregation to institutions and poor houses illuminated the lack of value for the lives of disabled people amongst many cultures groups throughout human history. In addition to the customary killing of disabled infants, in historical cultures, Davis (2002:157) reminds us that disabled people have been persecuted alongside other minority groups throughout history. He argues, "let us never forget that the deaf, the feeble-minded and other 'defectives' were the first to be rounded up by the Nazi's and sent to the death camps".

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According to DePoy and Gilson, (2004:13). Historically, Western societies have stigmatised the disabled identity, stripping those who did not embody the identity of power and value. In addition, while not as overtly violent, positioning individuals, as objects of charity and denying them the opportunity to exercise their power decreases their person's options and choices. Thus, the roots of paternalism toward disabled individuals, as objects of charity, whether or not they wanted it, can be traced as far back as the Middle Ages.

2.18 The evolution of the international classification of impairment, disability and handicap

One of the most significant contributions to the rights-based disability policy and legislation was the development of the International Classification of Impairment, Disability and Handicap (ICIDH). The current dominance of the rights-based policy and legislation depended, and continues to depend greatly, on a clear system of disability terminology. Western governments have acknowledged that, in relation to legislation, "the importance of definitions has become greater as access to significant services depend upon such definitions" (Thomas, 1982:20). The framework which provides the definitions used in most worldwide disabilityrelated policies is created by the World Health Organization (WHO).

World attention towards the needs of both people with disabilities and disability policies was attracted by the WHO in 1976, when it released a preliminary set of key definitions of disability terminology. Impairment refers to a psychological or physiological condition while disability is a restriction which is a result of that condition. A handicap is a restriction placed on an individual by society. These definitions were promoted by the WHO as part of the United Nations (UN) during the International Year of Disabled Persons in 1981. The establishment of these definitions provided a welcome resolution to the issue of terminology, and they became the basis for disability-related legislative policies throughout the world. According to Richard (1982:3), although increased awareness at this time led to improvements in the areas of employment, education and social interaction, people with disabilities were still faced with a "...diminished opportunity for participation in the kind of life opened to those who are not disabled".

This criticism has resulted in the WHO keeping the definitions under constant review. Throughout the 1980s and 1990s, the WHO definitions continued to undergo minor changes.

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In recent times, however, these definitions have undergone major changes. Several new drafts of the definitions, in the International Classification of Functioning Disability and Health (International Classification International Disability Health-2), were created and trailed through the mid to the late 1990s. The result was a change of focus, finalised in 2001, and named the International Classification of Functioning, Disability and Health (ICF). The aim of the new ICF classification was to “provide a unified and standard language and framework for the description of health and health-related states" (International Classification of Functioning Disability and Health, 2004:3). The ICF indicated that, in the past, there were two main healthrelated disability models: the social model and the medical model. The social model was a combination of the charity and rights model, which defined as a social problem.

Disability could now be seen as a health issue affected by contextual factors. Kostanjsek (2004:2) has recently defined disability as 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 individual’s contextual factors (environmental and personal factors).

This definition endeavours to acknowledge the multi-dimensional nature of disability. The other associated terms within the ICF include the following critical definitions: impairment which is defined in relation to the functioning of body parts or organs; and activity which is seen in relation to the capacity of a person to do basic or complex. The aim of the new ICF classification was to “…provide a unified and standard language and framework for the description of health and health-related states" (International Classification of Functioning Disability and Health, 2004:3).

2.19 Disability politics

For as long as disability is rejected as a foundation on which to build identity, people with impairments will not be able to resist oppression. Oppression is not recognized as such but is rather treated as a natural part of the experiences, being the ordinary outcome of physical impairment. Imposed relevance’s remain ‘unclarified and incomprehensible’ (Schutz, 1970:114).

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It is not considered the role of disabled people to criticise society from a minority perspective. Disabled people are not regarded as a minority with its own distinctive way of life and traditions like women or minority ethnic groups, who, it is acknowledged, perhaps, do have reasonable grounds for viewing society from a different perspective, but are viewed by the non-disabled majority as being: just like us – but less 'disabled'…unable; defective…'failed normal'…merely that. A disabled person is nobody but our uncle who had the bad luck to be injured on the assembly line, our sister with multiple sclerosis (Johnson, 2003:124).

Pressures to discourage people with impairments from identifying collectively are embedded within everyday life practices. Those who complain about injustice are labeled as complainers…who cannot deal with the problems related to their disabilities (Murphy, 2005:161). They are identified and treated as bitter people who have just not come to terms with their limitations. Nevertheless, the past four decades have witnessed the emergence of a new social movement of disabled people who have organised around the social model and campaigned across a diverse range of areas for example through the establishment of centers for inclusive living and for the right to direct payments to meet support needs; for antidiscriminatory legislation; through the establishment of coalitions which have raised consciousness around the planning and delivery of public services; through the development of representatives national and international lobbying bodies; through the growth of Disability Arts as a cultural practice reflecting the experiences of living with impairment in a disabling society; and through the establishment of Disability Studies as an academic discipline addressing issues concerning not just the meaning of disability but the nature of society (Murphy, 2005).

Campbell and Oliver (1996:20) assert that the growth of this movement is not merely a numerical phenomenon but is also reflective of the individual and collective empowerment of disabled people through the organisations they were creating. This can be seen in the challenge to dominant social perceptions of disability, as a personal tragedy and an affirmation of positive images of disability through the development of politics of personal identity.

According to Thomas (1999:113), politics of identity are fundamentally bound up with having an impaired body (where impairment is recognised as a fixed physical characteristic), as well as being disabled (seen as socially constructed difference). These differences are affirmed and

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celebrated rather than hidden or regarded as sources of inadequacy. They become the focus for engagement with the world. Allan Sutherland sums this up as follows:

> *"We break through the idea presented to us by the medical profession and disability charities in particular, that our situations are different and unrelated, and come together not as the blind or the deaf or the epileptic, or the spastics or the arthritic, but as disabled people"* (Sutherland, 2004).

2.20 Context, culture and disability

2.20.1 Disability

In an attempt to define disability, one encounters problems of coming up with a definition that would be applicable to all cultures, and, as such, the definition is constantly evolving. The World Health Organisation, as cited by Ingstad and Whyte, has put forth a definition that has gained international acceptance. 'The concept 'disability' is usually discussed alongside its related concepts of 'impairment' and 'handicap'. Impairment is defined as, any loss or abnormality of psychological, physiological, or anatomical structure or function' (Ingstad and Whyte, 1995:5). While impairment relates to constituents of the body (the 'organ' level), disability relates to the compound or integrated activities expected of the person, that is tasks, skills and behaviours.

Disability is defined as 'any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being" (Ingstad and Whyte, 1983:5)'. A person is considered either disabled or not, depending on the extent to which he or she can function in the given society. The term, therefore, refers to a number of different functional limitations that one can observe in any population, in any society.

Handicap relates to the social consequences of deficiencies in organs and activity performance. It is defined as 'a disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfillment of a role that is normal for that individual' (Ingstad and Whyte 1983: 5-6). The meaning of handicap, therefore, focuses on the shortcomings in the environment and in many organised activities in society, which prevent persons with disabilities from participating.

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Disability, unlike impairment and handicap, is a learned social role. According to Becker (1963) and Scott (1969), disability, like all other forms of social deviance, can be viewed not as an objective, physical or mental condition, but as a role into which people are placed. People with disabilities are rewarded for behaviour that conforms to social expectations associated with the disability role and punished for behaviour that departs from these expectations. In this light, as Murphy (1990:4) points out, disability is defined by society and is given meaning by a culture. It is, therefore, clear that there are various perceptions of what disability is as there are a variety of cultures.

2.20.2 Disability and culture

The cultural understanding of the concept 'disability' is central to the determination of the position or status that the disabled individuals are given in a specific society. Cultural understanding is also shaped by the meanings attached to the concepts of human being or personhood by the social and economic organization of a given society, or by other internal cultural dynamics. Ingstad and Whyte (1983:8) note that the conceptions of disability are formed by the conceptions of the person in a culture. The 'person' refers to the evaluation of others as opposed to self-evaluation. Large and small-scale societies, perceive the concept of disability differently. According to Scheer and Groce (1988:331-332), in small-scale societies, close interactions between individual members are the norm, and each individual may have extended and multi-strand relationships with other members of the society. Individuals may interact in the course of economic production, during leisure time, or while participating in the arts or ceremonies. The social identity of the person in these small-scale societies is based on family clan and other characteristics, and not on how the individual looks. Natural integration of the disabled into family life and community activities is the norm in many small-scale societies.

In large-scale societies, however, where social relations and contexts are more impersonal, individuals are not directly related to each other in varied contexts. For example, relationships that begin at work often end at work. Based on the concepts of equality and individual rights, there is a general assumption that people are not different; difference is treated as invisible.

Large-scale societies' conceptions of disability are, therefore, formed, not from within the general society and the social processes, but "in the context of the centralist state that imposes

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a universal code through legislation" (Ingstad and Whyte, 1983:8). Legislation determines the existence and recognition of the disabled by defining what it means to be disabled, establishing criteria, and determining the classification of the disabled. Legislation also determines the establishment of medical and paramedical institutions, as well as educational services. In this way, people with infirmities become a marked group. They are given a social identity as citizens who have the same rights as others and should be integrated like ordinary people.

Disability in Europe and North America therefore exists within and is created by a framework of state, legal, economic and biomedical institutions. The concepts of personhood are also inevitably shaped by those institutions. This situation is not helped by the mass media, which according to Ferguson *et.al.* (1992:229) tend to portray the villain as associated with abnormality, either physically, psychologically, or mentally. They also note that there are usually very few positive images of the disabled in the media. The positive images displayed are mainly those of disabled children, but rarely adults. This tends to give the impression that the persons with disabilities are child-like.

2.20.3 Disability culture

Disability culture, as an emerging movement, takes pride in disability (Brown, 1994:10). The disability culture acknowledges that life with a disability is a way of life, which means that the life of disabled people is not necessarily tragic or devalued. The creation of a disability culture is the basis for the establishment and implementation of disability rights, a requirement for equality, without creating or deepening 'dilemma of difference'. This is to say, the establishment of disability as a way of life ensures disability-conscious social organisations. Within this approach, deaf people, with their distinct culture and language, could make a significant contribution to their lives. Disability Culture Institute explains disability culture as: 'to exclaim pride in the condition of disability' (Brown, 1994:10). According to Brown (1994:94),

> *The notion of disability being affirming first came to my attention several years ago when a friend exclaimed that losing his leg was the best thing that had ever happened to him. He went on to explain that prior to his accident he was unfocused, joy-seeking person who gave little thought to*

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> *what he would do with his life or how his actions might impact anyone other than himself. If I were given the choice of a new life without a disability I would not take it. My disabling condition is one of the many characteristics which has contributed to the person I have become. Without a disability I would have been different and I have no desire to be someone else. I am happy with myself* (Brown, 1994:96).

These views might be considered as 'compensation'. Similarly, sign language can be considered as an inadequate compensation for the loss of hearing loss. One woman with a disability counters this as follows:

> *Not all of us view disability as the unmitigated disaster and diminishment that seems to be expected of us. We know that what hurt, anger and distress we have felt was not generated by the condition itself but by the obstacles and offensive assumptions that society heaps upon it. If we dare express the view that it has brought spiritual, philosophical and psychological benefits, it is suggested that we are making a virtue of generally issue from those whose experiences of necessity, pain or suffering is considerably less than our own and who, above all, have no personal experience of our condition.* (Brown, 1994).

Morris (1991:187) said the emergence of a disability culture is difficult, but tremendously liberating. Such a culture enables disabled people to recognise the pressure to pretend to be normal for what it is an oppressive and impossible hurdle to achieve. Most importantly, this culture challenges our own prejudices about ourselves, as well as those of the non-disabled.

Morris adds, 'a number of the women I interviewed for the book [*Pride against Prejudice*] see disability as a positive thing to have happened to them" (Morris, 1991:187). The development of a disability culture in the history of persons with disabilities has an important role to play. History occupies a significant place in the formation of group identity. According to Morris (1990:113), we need to explore the experience of oppression common to people with all sorts of different physical and intellectual disabilities.

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The history of deaf people, obviously for their cultural and linguistic aspects, is receiving particular attention, resulting in the establishment of societies in some countries, and an international society on deaf history. Deaf History International was founded in 1991. Heroes, defined as ‘people who do something out of the ordinary’ and mythology are essential concepts for all cultures, including disability culture (Brown, 1992:227). Brown further contends that ‘almost all people with disabilities have performed heroic activities because of the pervasive discrimination encountered by each individual within a society’. Carrying the argument further promotes mythology, which is a ‘universal language’ and ‘a set of symbols placed in a context which anyone can understand’, demonstrated by heroes with disabilities (Brown, 1992:227).

2.20.4 Disability as culture, diversity and differences

Some disability theorists propose that the shared identity of physically disabled creates a minority culture and a consciousness. This is necessary in order for disabled people to unite together to resist discrimination (Barnes and Mercier, 2001). Barnes and Mercier, 2001 further argue that, while many disabled people assert that the experience of disability is unique to each individual and is not a shared cultural identity, “a shared disability consciousness and culture” needs to be actively pursued because a “vibrant disability culture is central to confronting the social exclusion of disabled people” (Barnes and Mercier, 2001).

Davis (2002) argues that identity theories seek to expand the categorical definitions of modernist discourses by questioning their construction and exposing the assumptions that surround them, as well as reinforcing the idea that people can be objectively divided into groups. Instead, he proposes that identity theories strive to transcend boundaries and join the fluid continuum of disability which can happen to anyone at any time and *will* inevitably happen to everyone on some level if he/she lives long enough. Because of the fluidity of the disabled identity, theorists should look towards disability rather than looking towards multiracial, bisexual, and transgendered identities to comprehend difference and diversity.

According to Davis (2001:543), unlike race or gender, no one is invulnerable to the onset of disability or the probability of social oppression that follows it. He proposed that disability

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should be at the center rather than the margins of diversity politics because it encompasses all forms of diversity and marginalisation. He wrote that disability, by the unstable nature of its category, asks us to redefine the very nature of identity and 'belonging to an identity group'. McRuer (2006) refers to Davis's argument as *post identity politics*. As a socio-cultural theorist, he sympathised with Davis's desire to "save all of us from the perceived failures of other progressive movements and [to extend] to queers, people of colour, feminists . . . a new and better way" (McRuer, 2006: 202). Still, he does not see the post identity disability umbrella as an answer to the shortcomings of current socio-cultural research and politics and warns that the identity groups that would join one another under one broad category of disability are "more complex and contested than Davis allows," and that the reinterpretation offered by post-identity politics would not reconcile these differences (McRuer, 2006: 202).

McRuer (2006:365) explained that, unlike hatred for people of colour, gay or female bodies, negative ascriptions based on disability can be superficially linked to real human differences. Impairment-related problems, such as pain and troubling limitation, are part of the disability experience for many individuals that cannot be linked to social construction under the sociocultural model.

2.20.5 Disability and victimhood

According to Shakespeare (2006:80), disability identity can be associated with victimhood. He explains that any problems that individuals may encounter or the failure they experience is a result 'of oppression not from any fault of their own'. Using the social model, Shakespeare argued, is a powerful way of denying both the relevance and the negativity of impairment. Activists can maintain that their problems are not due to their deficits of body or mind, but to the society, in which they live, combining with others who share the belief, their own selfimage is reinforced and they can achieve solidarity and self-respect (Shakespeare, 2006:80).

Shakespeare argues that the identity politics of the disabled people's movement has depended on strengthening the emphasis upon differences between disabled and non-disabled people, thus strengthening the coherence and separateness of the disability group and contrasting disabled and non-disabled people in a way that views the latter group as oppressive and hostile. He contended that disability identity, rather than being a means to an end, has become an end in itself. It involves an inward looking group approach rather than an approach which seeks to

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build bridges with other groups, and to achieve real inclusion for disabled people within society (Shakespeare, 2006:80).

2.20.6 Disabled and identity

According to Patterson and Elliot (2002:231), 'Identities are composites of multiple and sometimes contradictory subjectivities that materialized as a result of specific discourses. However, not all disabled people experience the same degrees of disabling barriers and discrimination'. Reeve (2002:504) further states that, "…disability is a function of both disability and impairment experiences constituted differently for each individual and will have both temporal and spatial dimensions". Taylor (1999:369) had previously noted this idea of variances in terms of identity as follows; "The extent to which individuals will identify with their communities will vary according to their circumstances".

2.21 Attitudes to disability of people with disabilities

Deal (2006), a professional with a disability, found that people with disabilities, who voluntarily met up with other people with disabilities, collectively held the most positive attitudes towards disability. Thus, the role of people with disabilities in changing attitudes to disability may be very significant. Disabled people must be at the heart of this process, influencing policy makers and service providers. Therefore, it is my opinion that disabled people must acquire greater awareness of the rights of people belonging to other impairment groups, in order to recognise discriminatory practice towards other members of the disabled in-group. This includes those disabled people who may have contact with large numbers of other disabled people, who, under other circumstances, they would not normally associate with.
As Young (1990:153) argues in relation to cultural attitudes towards minority groups, "For people to become comfortable around others whom they perceive as different, it may be necessary for them to become more comfortable with the heterogeneity within themselves".

Deal points out that collaboration between organisations of persons with disabilities and organizations for people with disabilities has been rare, with different groups often viewing each other with suspicion and even animosity. He considers that groups of people with disabilities have much to offer other people with disabilities in the general population, to

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organisations which work on behalf of people with disabilities such as the government, policy makers and major charities. Deal (2006) believes that much can be gained by working together, without compromising one's own principles. In his own word, 'If minority groups can work in unison, such coalitions based on the demand for social change can be much more powerful than working in silos'. Each minority group, whilst respecting the uniqueness of their agenda, can gain greater influence by finding those areas of commonality (Deal, 2006:453)'.

According to Voh (1993:165) 'The most effective form of cognitive coping with tough realities is engaging in political and other forms of action that can help change unsuitable social structures" (Voh, 1993:165). He further points to future research directions as follows:

> *There is a need to begin to explore the unknown, almost taboo arena of human relationships and the impact of difference. How do we shift these attitudes? How do we learn to speak differently about disability in such a way that our speaking will cause new social structures to take the place of the ones we have now? How do we all learn to tell the kind of stories that will help ameliorate differences and allow for sense of belongingness? What would it take to equip professional-in-training with a sense that learning to speak differently about disability is part of their job? How can people with disabilities themselves play a role in rehabilitating our sense of community? Self-determination and selfdefinition go hand in hand. A worthwhile inquiry might be to ask what people with disabilities need in order to define themselves newly. Even more importantly we should ask what it would take for everyone to listen with new ears. For ideas and stories that can help we need to gain exposure. Perhaps we should conduct research on the effectiveness of television as a vehicle for transforming attitudes. What more can we learn by listening to people with disabilities themselves and by using every possible medium and forum for them to tell their own stories* (Voh, 1993:165).

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2.22 Socio-spatial production of Disability

2.22.1 Conceptualisation of the bodily experience of disability in space

All changes in space affect human life in one way or the other. For disabled people, space plays a vital role in terms of its organisation and the relations emerging there. Before investigating how space should be designed to support all the activities of people with disabilities, the body, with its simple experience in space, will be discussed in this part of the study**.**

Frank cited in Butler and Bowlby, (1997:418) proposes that discourses, institutions and corporeality constitute the body, which is a statement based on Gidden's structuration theory. In this context, the body as "both medium and outcome of social 'body techniques' and society as "both medium and outcome of the sum of those techniques". Oliver cited in Freund, 2001:692) suggests that the body, as an isolated and individual body, is a limited determinant of disability, but the 'body in situ'. The body engaged in a particular socio-material structure, is highly relevant to disability. Everybody becomes a different individual according to whether the individuals very tall or short, small or large; A 'one size fits all' socio-material environment makes them disabled. According to Robins (cited in Imrie *et al.,* 1996:1257), cities contain bodies in motion, and the city life is about the experiences of, and shocks to those bodies.

2.22.2 Disability in social space

Space is permeated with social relations. It is not only supported by relations, but it is also producing and produced by social relations (Lefebvre cited in Gleeson, 1999:45). Lefebvre's discussion of social relations, which can also be derived from Massey, (cited in Imrie, 2000b:6-
7), appears mostly as oppression, exclusion, segregation and other forms of negative relations towards disabled people in space.

The first form of socio-spatial exclusion is produced through several apparent and implicit practices in urban life. When exclusionary attitudes in employment realms, unsuitable and insufficient housing combine with inappropriate accommodation, cities become 'no less than "invisible goals" for disabled people' (Gilderbloom and Rosentraub, cited in Gleeson, 1999:139).

The second form that shows four spatial dimensions of treatment for the mentally ill is explained by Dear (1981:491) who studied the mentally-ill and space. Whilst a defined place forms the

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enclosure, internal spatial organisation describes each unit as partitioning of space. Moreover, functional sites are used as integral architecturally defined space and lastly, rank is about hierarchical classification. Imrie (2000:7) further explains by giving specific examples about disability. The asylums, special schools, day care centers and other special arrangements and services are distinct places that people with disabilities are demarcated and segregated from the rest of the society by creating particular partialities in which the identities, mobility and other social interactions of people with disabilities are created.

Mathews and Vujakovic (1995:1069) note that society should not be conceived as comprising a homogeneous and unitary culture, anymore. There are broad textures, identities, and fractures which constitute the plurality of culture, and different patterns of relationships are formed with the dominant society. However, as a minority group, disabled people are subject to the negative relations dominated by the other part of the population.

Although placed in a feminist study, Butler and Bowlby (1997:416) gave the duality created by the society as follows:

Table 2.2 Disability in social space

Self	Other
Mind	Body
Culture	Nature
Human	Animal
Rationale	Irrational
Masculine	Feminine

Butler and Bowlby (1997:416)

One more category which can be added in the frame of the study is the "Able-disabled"

'Who is the other?' Golledge and Stimson (1997:490) first asked the question and then responded as follows:

> *'The other' [is] groups who are discriminated against, who face significant physical, psychological and societal barriers that produce disability. They*

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are the disenfranchised, the maltreated and the ignorant members of society. They are ethnic, religious, nationalistic, and cultural minorities who are often denied equal opportunity and equal access to the advantages and benefits of the society in which they reside.

Silbley (cited in Mathews and Vujakovic, 1995:1069) assert that social boundaries define who belongs and who does not. Consequently, some social groups are excluded through legitimisation by being defined as the 'other' or residual beyond the boundaries of the acceptable. Dear (1997:455-457) mentions the boundaries in the discussion of difference. Apart from dominant knowledge, he defines space as a factor influencing the difference phenomenon.

The distinctions between the self and surroundings, 'I' and 'not I', serve the partition and boundary maintenance process, which is also spatial. The consequences and attitudes towards people with disabilities are socially and spatially produced and 'keeping others in their place' is an explanatory statement for production.

The majority of the society does not want to see and interact with its failures. People with disability are some of people on which many unnecessary positive attitudes (pity or solicitude) and negative reactions have been developed. The body and actions may be different from the 'normal' form of the society because of their sense, or motor problems may be fearful and odd for the rest of society. Feeling of pity or hostility activates different reactions from people. The former make people give unnecessary help to disabled people as if they cannot survive without help from someone. This puts the disabled in subordinate positions. And results in people viewing them as impure, defiled, contaminated or dirty people. They should be accepted in daily life, naturally.

The attitudes towards 'disability' affect disabled people's ability to move freely within public spaces. Changing the physical environment is indeed, essential not only to improving access to public spaces for disabled people, but also to changing the social environment, and in particular, changing social attitudes and behavior towards disabled people (Butler and Bowlby, 1997:411).

According to Dear1997 (cited in Chouinard (1995:139-141), the explanation of a wheelchair user, actively marks the person as different and creates the situation of out of place. In this continuity, a non-disabled person stands distinct from the disabled person. In contrast, if the environment is designed in an appropriate way and provides easy movement for wheelchair

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users and walkers, the differentiation will disappear and a positive perception will be constituted through proximity, in contrast to separation. Moreover, this link refers to a reciprocal relation that when physical environment enables people with disabilities to be present in public spaces, attitudes of society will change positively towards them. More positive attitudes of the society should affect physical planning and address the needs of people with disabilities (Butler cited in Butler and Bowlby, 1997:412).

2.22.3 Accessibility

According to Scherrer (2001:39), an accessible building is one which allows a person with a deficiency, a wheelchair or sensory impairment to enter, circulate comfortably, exit and utilise all of the services provided there under normal conditions. Accessibility can be thought of as a chain, and if one of the rings is broken, cannot be accessible (Scherrer, 2001:42).

Blackman *et al.* (2003:357) emphasise that the relationship between the social model of disability and the issue of universal rights is tightly connected with environmental planning and design. Existing environments created by planners and designers play two fundamental roles. When they are evaluated from the point of a view of people with disabilities, they are seen as oppressive owing to the fact that they neglect needs of people with disabilities.

Kraus *et al.* (cited in Stark, 2001:38) report that one in five people in the United States of America need assistance and cannot realise actual performance while performing daily activities. Davies (1999:74) notes that, by the year 2041, nearly a quarter of the British population will be older than 65 and 9% will be over 80, and that this situation will result in a greater number of people in society being exposed to some negative effects in their environments. Therefore, the barrier-free or accessible built environment will gain more importance in the future.

Imrie (1998:133) stated that in the post-war period, the built environment has been created, in order to give priority to mobility with cars. It can be interpreted from his explanation that accessibility has been sacrificed to the perception that all people have the same ability in segregated and exclusionary built environments.

2.22.4 Needs of people with disability in space

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Before planning, designing and refurbishing built environments. It is important to understand the demands of people with disabilities and realise that they are not a homogeneous group, and that they have different body experiences. This will provide easy, independent and comfortable movement for the disabled people. Not only do different disability groups need different arrangements for mobility, but different detail requirements should also be considered under the main disability groups. Goldsmith (cited in Barnes, 1999:117) observation about building designs are for two-legged able-bodied people and not for people depending on sticks or rolling devices. Although the determination belongs to approximately thirty years ago, the picture drawn by Goldsmith still presents current conditions of people with disabilities and the built environments.

Keates and Clarkson (2003:71) find the World Health Organization's disability definition is too negative and they assert that people's 'capabilities' should be emphasised instead of their 'disabilities'. The process of impairment, disability and handicap is given in the following diagram below:

Figure 2.2 The process of impairment, disability and being handicapped

Scherrer (2001:38) gives an example of how handicap could come into being for a person:

Impairment - Spinal cord injury
Disability - Incapability in walking

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Handicap - Cannot go out alone

That is to say, if a disabled person can go outside his flat, go down in the elevator and exit the entrance door by using a ramp, he or she will not be considered a handicapped person. Scherrer (2001:38-39) adds that architecture can create or eliminate handicaps. Sürmen (2001: 44) supports this discussion and declares that, while impairment and disability are objective concepts, handicap includes an interpretation. Handicap may be hindered in an ideal urban environment. If the built environment responds to human differences such as age, health, physical and mental abilities, there would be no handicaps, at least in the spatial level. It should not be forgotten that a normal and able-bodied person cannot jump across more than a definite width either.

2.23 Disability and accessibility

2.23.1 Mobility limitation

There is one more concept concerning disability and accessibility that is "mobility" limitation. Most people in society use the built environment independently and naturally, and they are not aware of the fact that accessibility is one of the fundamental criteria's for built environments.

Since many individuals have 'deviant bodies or are out of normal criteria's, spatial arrangements are not easily accommodated in 'standard' form (Freund, 2001:692). Therefore, some people may experience certain difficulties in an unfriendly built environment when they face barriers or when they cannot use the demanded additional equipment and, accordingly, they are limited in terms of mobility. Therefore, such people can be described as 'mobilitylimited people'. From a traffic viewpoint pedestrian however, whether young or old, can be said to be disabled because of their being vulnerable and mobility-limited (Ramsay, 1990:62).

2.24 Summary

The main objective of this chapter was to review related literature. Indeed, scholars interpret the experiences of being physically disabled in adulthood from various perspectives. Key issues regarding disability and models of disability were discussed in detail. The range of disability orientations was also discussed. In summary, it is important to indicate that what has transpired

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in the literature serves as a basis for how the research will develop. The literature review will allow the researcher to examine the experiences of disabilities acquired in adulthood from a holistic perspective and that will fulfill the objective of the study. The next chapter focuses on the research methodology used to achieve the set objectives for this study.

CHAPTER THREE RESEARCH METHODOLOGY

3.1 Introduction

This chapter focuses on the research methodology used during the collection of data, and describes the processes followed as response to the specific aim and objectives of this study. The methodology and the context of the study are presented here. Le Compte and Preissle (1999:32) acknowledge that the research design can be somewhat be confusing, from one implementer of the design processes to another. They add that a number of social scientists, including a number of other authors, have failed to define and clearly differentiate between the theoretical frames, research designs and data collection methods.

The focus of the study was to gain an understanding of the experiences of physical disabilities which they acquired not at birth, but in adulthood. The study was conducted in two municipalities in Vhembe District, namely Makhado and Thulamela Municipalities. Four male's participants were from Thulamela and three females from Makhado. The researcher asked participants about the physical disabilities experience on their lives. Participants assisted the researcher to gain as much information as possible about the experience of disability on physically disabled adults acquired during adulthood, their past and present lives, especially how participants view the experience of disabilities acquired during adulthood on their lives.

The first stage of the data analysis involved the reading of the data repeatedly, in order to identify the inequalities created by the experience of disabilities on physically disabled adults. When reading the data, the researcher's objectives included comprehension, the reduction of data and

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the organisation of data into manageable material (Marshall and Rossman, 1999:153). In this chapter, the methodology for the study, guided by the research questions was introduced. First, the researcher explored the experience of disabilities on physically-disabled adults. Focus was on the categories that emerged.

3.2 Research approach

There are various approaches that may serve as guiding principles and conceptual frameworks in carrying out a desired research. The approaches cannot all be used at the same time. Bogdan and Taylor (1975:4) argue that qualitative methodology refers to research procedures which produce descriptive data. This data is the form of people's own written or spoken words and observable behaviour. The approaches used can vary considerably in any field of scientific inquiry. Before a research study even begins, a researcher should decide what approach would be the most appropriate to employ in the study. The research approach puts in place the procedures for conducting a study. The design should include when, where, from whom and under what conditions data will be gathered and analysed (Melville and Goddard 1996:30).

A qualitative approach was utilised, because the researcher was of the opinion that qualitative research would best suited to explore the experience of disability acquired in adulthood on physically disabled adults. Silverman (2005:6) concurs and postulates that when the purpose of the research is to explore people's everyday behaviour, a qualitative method is the most suitable. According to Fossey *et al* (2002:717), qualitative research is a broad umbrella term for research methodologies that explore, describe and explain people's experiences, behaviours, interactions and social contexts without the use of statistical procedures or quantification. A quantitative approach requires that experimental and quasi experimental designs and statistical techniques are used to collect numerical data from a representative population sample (Baumgartner and Strong 1998:175). Based on the aforesaid distinction, the researcher is of the opinion that qualitative research is holistic and aims mainly to understand social life and the meaning that people attach to everyday life. The researcher, therefore, employed qualitative research methods for the study as the researcher intended to explore the experience of physical disability acquired in adulthood on adults.

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A qualitative research approach is characterised by the following elements as outlined by Creswell (2009:175-176), Fossey *et al.* (2002:727), Meadows (2003:464-465) and Donalek and Soldwisch (2004: 353-356):

- Qualitative data is meaningful when understood within the context and environment in which research participants operate or live, rather than in an experimental setting. It is, therefore, important for the researcher to create an enabling environment for both researchers and research participants, in order to understand the meaning of human actions and experiences in relation to the phenomenon under investigation. For the purpose of the current study, the researcher sought to understand experience of disabilities on physically-disabled adults. Face-to-face interviews were utilised to gather qualitative data.

- Qualitative research requires the use of appropriate research participants who are affected by the phenomenon under investigation, as they will be able to describe their experiences of the phenomenon. The researcher used physically-disabled adults as participants. These participants were best able to describe the experience of disabilities on physically-disabled adults.

- Qualitative research methods are explorative and descriptive in nature. According to Creswell (2009:145), a qualitative researcher is interested in the process, meaning and understanding gained through words. The goal of the present study was to explore and describe the experience of disabilities on physically-disabled adults.

- Qualitative research methods involve field work. The researcher, personally, visited the homes of the physically disabled adults. By doing so, the researcher was afforded the opportunity of observing and recording the interviews with participants in their natural settings.

The qualitative research approach used by the researcher was very effective in that participant opened up and sharing their experiences. The researcher managed to gain an in-depth understanding of the experience of disabilities on physically disabled adults. Clarke (1999:531) considers qualitative research to be a lengthy procedure which requires creativity, imagination

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and insight on the part of the researcher, in order to produce a trustworthy, reliable and coherent account.

3.3 Research design

The research design spells out how the research study was conducted, in order to fulfill the objectives of the study (Rubin and Babbie, 2005:656). Mouton (1998:107) defines research design as a set of guidelines and instructions to be followed in addressing the research problem. He further likens a research design to a route that a research study should follow until the final product is reached. Similarly, Grinnell and Williams (1990:138) define the research design as a total plan used to answer the research questions. In a plan, decisions are made on what the research question should be, what data will be required, from whom the data will be obtained, and what exactly is the best way to gather the data.

The design is, in this way, likened to a plan that can be used when building a house. Builders use it as a map that guides them so that the structure is made purposefully and meaningfully. With this map, there is very little likelihood that one can go astray because, in such a design, data are gathered methodically and systematically, and then analysed in such a manner that the research question is answered. According to Grinnell (2001:29), "Exploratory research seeks to find out how people get along in the setting under question, what meanings they give to their actions, and what issues concern them". A descriptive strategy of inquiry was applied as part of the research design for this study because such a strategy paints a picture of the specific details of a situation, social setting or relationships (Neuman, 2006: 34-36). The researcher, in this research project, opted for the exploratory and descriptive design because of the qualitative nature of this study.

This study sought to describe the experience of disability on physically-disabled adults. Contextual studies seek to understand the social meaning and significance of an event or social action from the social context in which it appears (Neuman, 2006:158). The researcher's intention was to gain an in-depth understanding of the experience of disability on physically disabled adults. Research design includes aspects like deciding on where and when the research

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should be conducted, what information should be conducted and how the researcher would find the participants to include in the study (Yegidis and Weinbach, 2002:106).

Mouton (1998:108) stresses that the rationale for a research design is to plan and structure it in such a way that the eventual validity of the research findings is maximised through either minimising or, where possible, eliminating potential error. The descriptive researcher collects, through various specific techniques, information about conditions that exist, practices that prevail, beliefs or attitudes that are held, processes that are going on, effects that are being felt, or trends that are developing (Tucker *et al.* 1981:90). All this suggest that a research design focuses on the plan of the study, and that it is a tool or procedure to be used, in order to achieve the final product, which is the result of the study. For this to happen, the researcher needs a methodology or a research pathway through which the description can be realised. There is an axiom that is used by research scholars that the data and the problem for any research dictate the research methodology (Leedy, 1993:139).

3.4 Population of the study

In this research study, population consists of physically-disabled adults in Vhembe District, Limpopo Province. Small sample was drawn from the whole population. This is supported by DeVos and Fouche (1998:10) who point out that most of the time researchers are not able to study an entire population owing to the limitations of time and costs, thus they are obliged to draw a sample.

Rubin and Babbie (2005:238) define the population as the theoretically specified aggregation of the study. Similarly, a study population is defined as that aggregation of elements from which the sample is actually selected (Neuman, 2006:196). Arkava and Lane 1983 (in De Vos *et al.*, 2005:193) highlight the distinction between 'universe' and 'population'. *Universe,* according to them, means "…all potential subjects who possess the attributes in which the researcher is interested", while *population* "…refers to individuals in the universe who possess specific characteristics". In other words, a population is drawn from the universe as it has a narrower connotation regarding the specific and realistic characteristics that the researcher is interested in studying, in order to answer the research questions formulated for the study (Yegidis and Weinbach, 2002:180). The population of a study includes all members of a defined class of

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people, events or objects, who, for research purposes, are designated as being the focus of the investigation (Neuman, 2000:120).

3.5 Sampling and sampling procedure

Sampling is defined by Grinnell (2001:207) as a process of selecting participants from the population to take part in the research study, in order to learn about the population from which the sample is drawn. Concurrently, Becker (in Silverman 2005:136) asserts that it is not feasible for researchers to study every case which is of interest to the researcher owing to time constraints and shortage of resources.

In order to sample 'participants', purposive sampling was used. Purposive sampling has been chosen because it is regarded as central to naturalistic research. According to Patton (1990:169), the logic and power of purposive sampling lies in selecting information-rich cases for an in-depth study. Families or households known to have physically-disabled adults were sampled for participation in the study. One physically-disabled adult per family was interviewed. The researcher also utilised snowball sampling as it is relevant for hard -to- find cases (Patton, 1990: 237). All these procedures were utilised with a view to answering the research questions.

Literature does not suggest specific rules about obtaining an adequate sample size since each situation presents its own problems (Cohen and Manion, 1995:195). The target sample size was small enough for the purpose of easy management. The selected sample size of seven participants was drawn so as to reach the target set for the study.

The criteria for inclusion in the sample for the proposed study were as follows:

- Participants should be Tshivenda-speaking, and Tshivenda should be their first language. The fact that the researcher also speaks Tshivenda, enabled her to enter and understand the participant s' world and experiences;
- The age of the participants should range from 18 to 55 years; and
- Participants should be willing to participate in the study voluntarily.

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Purposive sampling was used to increase the utility of information obtained from small samples. The technique allows a researcher to select particular elements that are well-informed about the topic under investigation (MacMillan and Schumacher, 1993:378). This means that it is also possible to discover, understand and gain insight from participants regarding the topic being investigated (Coleman and Briggs, 2003:120). Purposive sampling was used because it also enabled the researcher to select information-rich cases for an in-depth analysis of the phenomenon.

Struwig and Stead (2001:122) identify the characteristics of purposive sampling as provided by Lincoln and Guba (1985) as follows:

- The sample size may change as the study progresses and, for this reason, it is not finalised before the commencement of the study;
- More sampling units are sought, as more information is required; and
- More sampling units are obtained until new information becomes redundant.

3.6 Instrumentation

The study used interviews as an instrument to collect data. According to Fossey *et al*. (2002:727), qualitative research interviews enable participants to articulate stories of their lives in an interactional and conversational manner. They also allow the researcher to gain an understanding of the participant's experiential and social worlds. For the purpose of this study, semi - structured and face to face interview were used. An interview guide with open-ended questions was the format. The semi-structured interview was digitally recorded and the participants' permission was sought to do so. The researcher used open-ended questions to interview participants to ensure probing and in order to get clarity on what the participants would have said. According to Babbie (2007:246), open-ended questions allow participants to provide their own answers to the question. They help participants to fill in gaps in their life experiences with regard to the experience of physical disabilities. According to Meadows (2003:466), open-ended questions allow the researcher to use probes to encourage participants to provide more in-depth information.

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3.7 Data collection method

The researcher obtained permission to conduct the research from the University of Venda Higher Degrees Committee of the School of Human and Social Sciences. Appointments were made with the participants before data collection and ethical procedures were followed in accordance to ensure that participants are treated well and their health and well-being are safeguarded. Data collection was done by the researcher alone. There was no need for an interpreter, since the researcher shared a home language with the participants. According to Strauss and Corbin (1990:98), all researchers need to be fully aware of their inherent biases or pre-conceived ideas about participants or respondents during a research process.

Padget (1998:7) describes the following three methods of data collection that can be used in qualitative study:

- Face-to face interviews;
- Participant observation and Review of documents

In this study, a face-to-face interview with a schedule guide was used to gain answers from disability on physically-disabled adults. According to Greef (2002:302) face to face interviews enable the researcher to gain a more detailed picture of the participants’ beliefs or perceptions or accounts of a particular topic. The face to face interview was used to obtain qualitative data regarding the impact of disability on physically disabled adults.

According to Punch (1998:174-175), this way of interviewing is a very good way of accessing people’s perceptions, meanings, definitions of situations and constructions of reality. Punch (1998:175) also cites Jones (1985:46) who writes’:

> *In order to understand other people’s construction of reality, we would do well to ask them… and ask them in such a way that they can tell us in their terms (rather than those imposed rigidly and a prior by ourselves) and a depth which addresses the rich context that is the substance of their meanings.*

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Mkhize (2006:96) asserts that certain interviewing skills and techniques are necessary for a researcher to be able to enter into the participants' experiential and social world. Such techniques will help participants to give an account of their subjective world and enable the researcher to gain an understanding of these worlds and be able to gather relevant data to answer the research questions for the study. The researcher applied the following interviewing techniques as outlined by Babbie (2007:245-268).

- Good appearance and demeanour

The researcher also dressed to acceptable standards in order to make participants feel comfortable and enable the researcher to get good cooperation and responses from them. For instance, the researcher did not wear a miniskirt when she interviewed participants as this would have been viewed as unacceptable by most of the elderly people of the community.

- Creating an enabling environment

This means a researcher creates an atmosphere of trust and builds rapport with participants to make them feel comfortable and share openly their personal experiences. The researcher informed the participants of the time set for the interviews and the estimated time it would take to conclude the session to ensure that all relevant data were gathered.

- Asking relevant questions

The researcher asked questions that were relevant to the study, in order to achieve a productive outcome. The researcher asked questions that were clear, not too long and which could be easily understood by participants. She also probed to encourage participants to generate more information on any particular aspect being discussed.

- Listening and attending skills

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The researcher listened attentively to what was being shared and attended to the shared messages by paraphrasing what had been said by the participants, by using phrases such as; “Can I check if I heard you correctly… are you saying that…?

- Listening skills

Active listening is of paramount importance when collecting qualitative data. Verbal and nonverbal cues were used by the researcher to encourage participants to speak openly, for instance, nodding of head or leaning forward as a sign that the researcher is concentrating to what is being said. The researcher, therefore, listened attentively to the words spoken by the participants, as well as paid attention to their non-verbal behaviour such as body language, facial expressions and voice-related behaviour.

- Empathy as a communication skill

The researcher sought to apply empathy to communicate her understanding of the participants’ experiential world. This was intended to assist the researcher to gather accurate information as perceived by the participants. Participants were encouraged to share their sensitive life stories when they realised that the researcher was on the same wave-length and understood them.

Following the outline given in Lofland *et al.* (2006:104), an interview guide would ensure that a number of key ethical issues (for example, informed consent, confidentiality, ownership and accountability) were discussed and clarified between the researcher and the participants prior to the commencement of their involvement in the study.

Before the start of each interview, the researcher went through the interview guide step-bystep, outlining and clarifying each point to ensure that participants were aware of what they were committing themselves to. The researcher obtained each participant’s signature as authorisation to go ahead in recording the discussions and to use data for her research. The interview schedule (see Appendix D) served as a guide.

According to Rambuda (2002:196-197), a face-to- face interview is the most effective way of enlisting the cooperation of the participants in a survey because rapport can be easily

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established during the interview. The researcher was able to clarify the meaning of the questions to the participants, and also to follow up on unclear and incomplete answers. The length of the interview varied from one hour to two hours. Various factors interrupted the interview, for example, greetings from other community members passing by.

Alston and Bowles (2003:116) maintain that conducting semi-structured interviews can be a useful method for obtaining information in an exploratory and descriptive design where there is little knowledge on the research topic. Semi-structured interviews fall between structured and unstructured interviews as they are usually conducted with the use of a schedule which allows the researcher to explore additional information which the participant has raised outside the interview schedule or interview guide. De Vos *et al*. (2005:296-297) explain that having an interview guide beforehand forces the researcher to think explicitly about what the interview should cover, to ensure that specific information required for the purpose of the research is collected.

When conducting the interviews, the researcher followed the guidelines as provided by Patton (2002:407):

- Before the commencement of the interview, the interviewer explains to the respondents the purpose of the study, the importance of the information, as well as the reason why this information is important;
- The interviewer needs to emphasise confidentiality for the respondents' data as well as voluntary participation;
- The interviewer provides clarity on the questions;
- The interviewer must be aware of the flow of the interview and provide feedback to the respondents on the progress of the interview; and
- The interviewer must have reasonable control over the interview process.

The research questions, thus, provided direction for the issues that were to be probed. Double barrelled questions were avoided and questions that were considered irrelevant were avoided. Questions that could have negative effects on people or sensitive questions were not included in the interview guide. Again those questions which could result in personal involvement of the researcher were left out in order to avoid bias.

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In crafting the questions for the interview guide, care was taken to avoid the following, based on Babbie (1992:149-152). The questionnaire thus provided clarity on the issues that were probed; double barreled questions were avoided; questions that were considered irrelevant were avoided; questions that could have negative influences were sensitively not included in the set of the questionnaire that was designed and that included personal involvement of the researcher to avoid biasness.

In addition to the digital voice-recorder, short-hand note-taking techniques were used to capture information. This was done to ensure that all words articulated by the participants were recorded. Note-taking allows the researcher to capture important aspects that need to be explored further. According to Fossey (2002:728), note-taking and digital voice-recording are useful together because they provide a holistic analysis of the information, and give details to specific components of the interview.

Digital voice-recording data was transcribed verbatim in order to have a written text of the interviews. All transcriptions were translated into English. An expert in the translation of Tshivenda was engaged to ascertain that the English translation reflected what the participants had articulated in their home language, Tshivenda. Raw data were therefore, included in the translated transcripts from the interviews, and the researcher's own reflective notes. All raw data were classified in the order in which the participants were interviewed. Participants were assigned pseudonyms, A, B, C, or D. Further classification of data was according to the date on which it was collected. The raw data, transcripts and research's own reflective notes were stored in a safe place. All transcribed interviews and reflective notes were made available for analysis.

3.8 Data analysis procedures

According to Marshall and Rossman (1999:150), data analysis is the process of bringing order, structure and interpretation to the mass of collected data. In analysing data, the desire was to transform them into meaningful findings. Similarly, Fossey *et al.* (2002:728) define qualitative data analysis as a process of reviewing, synthesising and interpreting data to describe and explain the phenomena or social worlds being studied.

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The success of data analysis depends on the thoroughness of research processes. Vaughn *et al.* (1996:99-104) give the essential steps associated with data analysis, as follows:

• Drafting of a detailed description of subjects and groups;
•Listing considerations applicable to the study prior to data analysis; and
• Determining the methods of analysis.

According to Alston and Bowles (2003:204-207), qualitative research is flexible in that, during the data collection process, important emerging themes can be identified to allow the researcher to get more information on a particular aspect until such an aspect becomes saturated and there is no more new information generated. This was confirmed by De Vos (in De Vos *et al.*, 2005:335) when he postulate that data analysis, in qualitative research does not wait until the data collection process is complete as is the case in quantitative research. Instead, it starts during the data collection process.

For the purpose of analysing the data of this study, the researcher followed the eight steps proposed by Tesch (cited in Creswell, 2009:186). These are as follows:

- The researcher reads all transcripts carefully, in order to get a sense of the whole, while jotting down some ideas that may come to mind;
- The researcher chooses one transcript which is the most interesting, shortest and the one on the top of the pile to read it and try to find underlying meanings of what she/he is reading. The researcher then writes his/her thoughts in the margin as emerged;
- After several transcripts have been read, the researcher makes a list of all topics identified. The topics are clustered according to similarities that are marked as major topics, unique topics, and left overs;
- The researcher takes the list of marked topics and reverts to the data taken. The topics are abbreviated as codes, and the codes are written next to the appropriate segments of the text. While using this preliminary organising scheme, the researcher looks for new categories and codes that are emerging;
- The researcher finds the most descriptive wording for the topics and turns them into categories. Topics that are related to each other are grouped in order to reduce the total list of categories. Interrelationships between categories are shown by lines;

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- The researcher makes a final decision on the abbreviation of each category and assigns alphabets to these codes;
- Data materials that belong to each category are assembled in one place and a preliminary analysis is then performed. Once this process is completed, the chapter in which the research findings will be presented (complemented by a literature control) commences; and
- Finally, the researcher records the existing data.

The researcher also used an independent coder in order to do a quality check of the analysis. Patton (2002:598) asserts that the aim of independent coding is to help a researcher think critically about the thematic structure he/she is developing and the coding decisions he/she has made.

The original data was safely stored after all analysis had been done, and on completion of the study, it will be destroyed. Mark (1996:48) outlined the following criteria to assist the researcher to maintain confidentiality:

- Information about participants has to be kept confidentially, unless where participants give written permission for it to be revealed;
- Information solicited and recorded should only be that which is necessary for the study to achieve its purpose;
- All participants' identifying particulars should be removed after coding; and
- Transcribed interviews should be safely stored and then destroyed after the completion of the study.

Lincoln and Guba (1985:433) indicate that there is no formula for data analysis. Potter and Wetherell (1987:168) and Patton (1990:422) argue that there are procedures which are, nevertheless, not rigid and mechanical. These scholars agree that all depends on each analyst deciding on the procedures that suit the data.

3.9 Method of data verification

According to Creswell (2003:196; 1994:157), data verification, in qualitative research means a process of checking the accuracy and credibility of research findings from the standpoint of the

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researcher, the research participants or the readers of the account. Krefting (1991:214-215) states that data verification for qualitative research differs from that in quantitative research because the nature and purpose of the two research methods are different. Qualitative research seeks to describe accurately the experiences of the phenomenon in natural settings while quantitative data requires that experimental and quasi-experimental designs and statistical techniques are used to collect numerical data from a representative population sample. The researcher sought to use trustworthiness of qualitative data, as outlined by Krefting (1991:215222), to verify the data. The model identifies four aspects that seek to ensure trustworthiness, namely: truth value, applicability, consistency and neutrality were applied as follows in this research study for the purpose of data verification:

- Truth value

Krefting (1991:214) states that truth value seeks to check how confident the researcher is with the truth of the findings based on the research design, participants and the context within which the study was conducted. It was obtained when the findings represents the human experiences as they are perceived by participants. This is termed 'credibility' which is established through a number of methodological strategies. The researcher ensures that the findings are a true reflection of the participants' experiences.

- Applicability

Applicability refers to the extent to which the findings can be applied to other contexts and settings or to other groups (Krefting 1991:216). In qualitative research, applicability does not necessarily seek to generalize findings to a larger population because the research is conducted in a natural setting of individuals with few controlling variables. Applicability is thus established through the strategy of transferability or fitness. Transferability is achieved when the research findings fit into contexts other than that of the study situation but which have some degree of similarity. As far as applicability is concerned in the present study, the researcher provided background information on the research methodology followed in exploring the impact of disability on physically disabled adults.

- Consistency

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Krefting (1991: 216) states that consistency is achieved when the study is replicated using the same participants or similar contexts and still produces the same findings. Consistency is achieved through the strategy of dependability. The researcher has provided a dense description of how the study was conducted to ensure consistency of research findings.

- Neutrality

The researcher used credibility strategies to establish the truth value of the study. Neutrality was also achieved through the guidance of the promoters. The research was conducted under the supervision of the promoters who provided guidance on decisions taken for each phase of the research process.

3.10 Ethical considerations

De Vos (1998:24) defines ethics as a set of moral principles which are suggested by an individual or group, and is subsequently widely accepted, and which offers rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students.

According to Strydom (cited by Welman, Kruger and Mitchell, 2005), ethics are a set of moral principles which are suggested by an individual or group, and are subsequently widely accepted. They offer rules and behavioural expectations about the most correct conduct towards experimental subjects and participants, employers, sponsors, other researchers, assistants, and students. Therefore, the researcher has a responsibility to ensure that those who participate in the study are not harmed. The researcher also has a responsibility to the discipline of science, to be accurate and honest when reporting the research results (Welman, Kruger and Mitchell, 2005:102).

The proposal was submitted to the University of Venda's Higher Degrees Committee of the School of Human and Social Sciences, prior to the execution of the research project, for approval. Once approved, the proposal was sent to the University's Higher Degrees Committee and then to the university's research office for ethical clearance before the study was conducted. The researcher explained the purpose and procedures of the research, and the information

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documented in the letter of request to conduct the research study with the participants. She also ascertained the participants' willingness to participate in the research study. Ethical principles, as outlined earlier, were explained to the participants.

The purpose of the digital-voice recording of the interviews was discussed and participants' permission was sought to use the recorder. The respondents were informed about team members who would have access to the tape recordings and the transcripts of the tape recorded interviews (namely the researcher, the person who will be checking the translations of transcripts from Tshivenda to English, the independent coder, and the researcher's supervisors). Participants who voluntarily agreed to participate in the research were requested to sign a consent form. All participants were requested to sign consent forms after the verbal consent (see Appendix C).

The researcher safeguarded the privacy of the participants and their identities by using pseudonyms. This ensured their anonymity and avoided information being traced back to them. Cohen *et al*., (2001:61) argue that: '… the obligation to protect the anonymity of research and to keep research data confidential is all-inclusive'. Confidential information was maintained by storing the recorded information in a locked safe place. The locked information was accessible only to the researcher and the person who was checking the translations of the transcripts from Tshivenda into English and the researcher's supervisor. After the analysis had been done, original data was stored safely, and, on completion of the study, will be destroyed.

Participants were informed of their right to withdraw from participating in the study at any stage if they felt they no longer wanted to participate. The participants were informed beforehand about the potential impact of the research, in order to ensure that they are not harmed psychologically, emotionally and physically.

3.11 Conclusion

This chapter has dealt with the research approach, research design, and population of the study, sampling, data collection methods and ethical considerations. Qualitative methodology was used to collect data from the participants. Qualitative data collection techniques and strategies enabled the researcher to describe the experiences of disability on physically-disabled adults. The researcher justified why qualitative data collection techniques and strategies were preferred

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over quantitative data collection techniques and strategies. Sampling procedures were also highlighted. Data were analysed using Tesch's eight steps. The ethical principles observed in this study are also elaborated on in this chapter. The following chapter will present the research findings and the findings will be related to existing literature.

CHAPTER FOUR DATA ANALYSIS AND PRESENTATION OF RESULTS

4.1 Introduction

The purpose of this chapter is to present the findings and to interpret the data obtained from the participants. The results are related to the objectives of the study and the implications of the results interpreted accordingly. The findings seek to answer the research questions which were as follows:

- What is the meaning attached views on physical disability acquired in adulthood?
- What is the experience of physical disabilities acquired in adulthood?
- What strategies do participants employ in coping with physical disabilities acquired in adulthood?

The content for these questions is captured within the three themes that emerged from the data. The researcher focused on the research questions in a manner that would not jeopardise the integrity of the data and the study as a whole. The participants were Tshivenda-speaking people and this enabled the researcher to fully understand the information they gave her as she is also Tshivenda- speaking. Participants were assigned alphabetical labels from A to G to safeguard their privacy and identities.

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The results of this study were presented according to the set out research objectives, namely:

- To explore the meaning attached to physical disability acquired in adulthood;
- To explore the experience of physical disability acquired in adulthood, in order to obtain a holistic perspective of adult disability; and
- To highlight the strategies that physically disabled adults employ in coping with their disabilities in society.

The main themes emerged from the participants' responses and the results of the data were processed by the researcher. The findings of this study are presented according to the three themes that were identified, are presented as follows:

Theme 1: Meaning attached to physical disability acquired in adulthood.

Theme 2: Experience of physical disability acquired in adulthood.

Theme 3: Strategies that physically disabled adults employ in coping with their disabilities in society.

4.2 Results

The above themes are presented and confirmed by providing direct quotations from the interviews conducted with physically-disabled adults in the Vhembe District. The identified themes, sub-themes and categories and the complementing excerpts from the interviews are discussed and compared with the available body of knowledge. Bolded italic- type writing will be used where the actual words of the respondents are quoted.

4.2.1 Theme 1: Meaning attached to physical disability acquired in adulthood

This section presents the meaning attached to physical disability in adults. Although this study focused on the impact of disabilities acquired during adulthood, participants often related their experiences from the period when they were not physically disabled. The gravity of the limitations experienced is mainly determined by the meaning attached to their physical

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disabilities. Participants' physical disability necessitates a change in many aspects of their lives, for example, personal change to adjust to the financial constraints, as well as the new obstacles in their lives which make it difficult for them to access the environment. Participants in this study indicated that physical disability led to a negative experience on their emotions, attitudes and socio- economic situation.

4.2.1.1 Sub-Theme 1: Limitations

According to the researcher this study limitation is any form of inability to perform some activities due to certain barriers. It could be partial or total loss of a bodily function or part of the body. Such limitations inhibit individuals' involvement in social activities, which, in turn, restrict social contacts with the society. For example, limitations can also arise because of the inaccessibility to the built environment. This can result in individuals abandoning an activity or not fully participating in community activities.

The findings of the study demonstrate that participants' physical disability impacted on their lives. Participants asserted that these limitations prevented them from performing some activities such as participating in community meetings, which they use to do independently. Participants shared their frustrations of being unable to work due to physical disability, especially disabilities associated with an inability to use their legs. The environment can restrict their opportunities to take advantage of choices available to them to do what they need to do to be independent. For example, participants indicated that accessing public facilities like community halls can be difficult for a person using a wheelchair because of stairs. The environment which is not disability-friendly hinders integration for persons with physical disabilities in everyday life. Some participants shared their frustrations of being assisted from point A to point B. Usually it is not possible for a person who uses a wheelchair to climb stairs and navigate narrow doorways. This makes physically-disabled persons dependent. Participant E indicated that he cannot even push his wheelchair, which means he is always depending on someone to move him from point A to point B.

Limitations for some participants were described in different ways, for example as feelings of guilt and fear of being a burden to the family and feelings of uncertainty. Participants' views pertaining to physical disability show that they cannot perform certain everyday tasks due to

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physical disabilities. Participants' limitations created difficulties, such as an inability to drive a car and to work. These limitations affected their social esteem and self-concept. Participants perceived themselves as a burden and as useless because they constantly need help from others. Dependency was also mentioned in relation to dressing up. Participant C, for instance, indicated that he cannot do up the buttons of his shirt. The study confirms that participants experienced limitations in different ways.

Limitation for some participants, revealed themselves through their no longer feeling that they are part of society. Some participants expressed that their limitations resulted in uselessness, embarrassment, humiliation, frustrations and being a burden to others. Participant C, for example, said he felt helpless because he has to rely on other people for the simplest things. Below are excerpts taken from participants experiences, which reveal how limiting their physical disabilities are:

I feel as if I am a burden, always asking for help. It is very difficult to deal with the new changes I have to go through in my life (Participant A).

It is challenging, I can't even drive my car anymore, I have to hire someone to take me to the hospital, of which is too expensive (Participant D).

I can't do up the buttons of my shirt; it frustrates me a lot (Participant C).

It is frustrating not being able to work and to use my legs due to my physical disability… It is so frustrating having to ask others to help constantly (Participant E).

I feel embarrassed and useless, really… I don't want to lie to you… I feel as if I do not exist in this world due to my inabilities (Participant F).

The excerpts show that the participants' limitations cause frustrations. The word used to describe the psychological experience of not being able to work or perform other duties without help from others. It was also evident from the participants' experiences that being unable to drive a car anymore and asking for constant assistance leads to their frustration.

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> *... Hey I can't push myself on this wheelchair. I need an assistant to push me from point A to point B. I spend most of my time inside the house. It bothers me a lot because I'm unable to do anything on my own. I have failed several times when I have tried to do some of the things on my own. I sometimes feel as if I am a burden because I have to rely on somebody for help (Participant E).*

The changes due to loss of physical ability created deep emotional despair, particularly when life appeared too difficult or burdensome to endure. The above excerpts from the participants show their frustrations because they are unable to do things they used to do before their disabilities, for example, driving, dressing and cooking without help from anyone. The present situation limits the participants from doing things on their own. This is because of loss of bodily functioning and the environment which is not accessible.

It was also evident from participants' views that the limitations had an impact on their lives. Often, when participants spoke about the things which they cannot do on their own due to their physical disability, emotions were expressed. These included annoyance and discontent because of their inability to walk freely in any given environment or to drive a car. It is evident in these excerpts that there are different barriers to perform certain activities. The following excerpts bears testimony to this:

> *The fact that I will never walk again and do things on my own makes me feel very sad (saying this with a hand on her cheek). I used to socialise every weekend. If there was a match at the stadium I would go with my friends to watch soccer. But now I am unable to do that anymore. Instead I spend most of my time watching soccer on TV, which I hated before. Since I have a disability, I am unable to go to the stadium due to my physical disability. My disability has disadvantaged me in so many aspects of social life, which I find difficult because I always think of things which I used to do at my own time without help or asking someone for help. Before I had my physical disability, I would just get into my car and go wherever I wanted to go. Mmmm…I can't even use the public transport, I have to get special transport to fetch me from my house to go where I want*

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to go, and somebody has to assist me to take me in and out of the car (Participant E).

... my situation is very difficult... you know what, let me tell you I don't have privacy because I have to get help for everything every day. Sometimes it makes me feel very scared of being a burden to other people. I feel like a helpless person having to rely on everyone for the simplest things like for examples shaving (Participants C).

When I think of things I can no longer do, I feel very miserable. I am not doing enough for my family. I was a breadwinner in the family before I was disabled. My mother paid for my tertiary academic fees by selling fruits and vegetables at the market. By so doing, she was investing so that I could assist my younger brothers too. Due to my physical disability, I have not full-filled my plans and I feel powerless (her voice started to tremble, eyes full of tears but she battled to hold it back...the researcher stretches her hand, to hold the participants hand, she holds the researcher's hand very firmly and cries bitterly, the researcher pulls her chair closer and holds his shoulder with another hand... then follows a moment of silence to give the participant an opportunity to assimilate the limitations of physical disability experienced) (Participants B).

Participants felt that the limitations affected every aspect of their social and emotional development. From the data analysed, it became clear that the limitations caused by physical disabilities and the emotional experiences, sometimes, lead to depression and hopelessness. It is evident that the participants' limitations and the restrictions experienced prevented the participants from fulfilling their planned goals. The study found that participants experienced limitations in trying to adjust to their new lives, trying to deal with physical, emotional, and social changes. Five participants out of seven in this study have experienced different limitations.

Participants talked about the limitations pertaining to physical activity, which affects their everyday lives. They pointed out that their inability to maintain self-sufficiency and

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independence to live a chosen life style. The responses reveal the frustrations of the participants. The following statements capture this fraction:

> *In as far as my health is concerned; my body has changed dramatically from being strong to being weak; from rapid moving to being completely immobile. I have to rely on somebody for even my most elemental functions and activities. Hey… nwana wa hashu you know (referring to the researcher) I depend on someone else to do what I want to do for myself. I lost my old self, the way I conducted my physical being. My daily routine, such as closing windows, getting out of bed, getting dressed, washing dishes and doing cooking seem nearly impossible (Participants D).*

> *From being a farmer, I am now physically disabled, always in a wheelchair. In 2010, I entered the farmers' competition in my municipality and I won a trophy plus an amount of R5 000. I again entered the district farmers' competition and won R50 000 … That was in 2010 when I was still able to do things on my own. But now, I can't do farming because of my physical disability. Now I am in a wheelchair, depending on others. Farming is now history, though I still have passion for it, my body is not functioning well anymore …Can you imagine, if I still need some more help, for me farming will be impossible. The survival of my family is in trouble because, through that business, my family was entirely looked after. Since then, I am just sitting idling at home; it is tough for me to achieve the required needs, for example paying school fees for my children. Hey... I was making good money because I was supplying my products to big companies (Participant A).*

From the above participants' excerpts, it is clear that physical disabilities lead to limitations. The participants indicated that they require assistance in managing the day to day tasks and in maintaining a sense of normality in their lives. Participants indicated that their dependency experience from being able to disabled and limitations upon their capabilities decreases selfconfidence as demonstrated by the above excerpts.

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Participants described how limitations are an extremely negative physical constraint on their lives. Participants revealed that limitations make them feel emotionally drained. Consequently if the functioning of the body indicates how participants experience life, the emotions are how they express their life with limitations. From what the participants said, the researcher deduced that life has become meaningless to them. In this study, it is evident from the participants that there are feelings of guilt, fear of being a burden and feelings of uncertainty.

4.2.1.2 Sub-Theme 2: Disconnection

Disconnection is defined as "the withdrawal from social interaction and social life, due to symptoms associated with one's condition" (Strauss, 1984:54). The findings of this study demonstrate that participants have fewer relationships. They experience, loneliness and abandonment by friends and relatives, which results in isolation. Participants' disconnection created lower levels of social activity and less involvement with other people. Such disconnection from society is like a wall being erected between the physically disabled and non-disabled people.

Participants in this study related their experiences of disconnectedness and distress caused by family and friends. Some participants regarded their lives as meaningless and felt increasingly isolated.

Disconnection for participants was associated with diminished participation in social relationships. Disconnection has resulted in social isolation due to abandonment, being less involved and withdrawal from the society. Participants viewed less social activity and less involvement with others as negative values that lead to a feeling of disconnection. Social isolation for Participant E was a result of lack of interaction with friends and relatives. Isolation was often mentioned in relation to past social activities, which participants used to do before acquiring disability. Participant B, for example, expresses his disconnection in the following excerpt:

> *...Separated with my wife five years back because I realised that she was having an affair with another man. I could not take it anymore because she used to come home late from work every time. I remember the other*

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Friday she did not come back home and when I called her, her cell phone was off. She came home on Sunday afternoon and I called her close relatives and my close relatives to meet on Sunday evening to share my disappointment with my wife to both families. During the meeting, I told them of her disrespect and that I was not receiving the love I used to receive in our relationship. She was also given an opportunity to respond after I explained my frustration. Mmmm...I am young I can't pretend as if everything is right whereas khotsi a vhana (referring to the husband) is not sexually active anymore. To be honest to you all, I can't take it anymore. Life has to go on because I am still sexually active and young (Participant B).

The above participant experiences reveal feelings of worthlessness, which are a result of his disability and being restricted from doing the activities which he used to do before becoming disabled. Participant E and F had this to say about their disconnection:

I don't attend community meetings because the community hall is not accessible to my wheelchair and it worries me. The entrance to the building is small and there are five steps before you reach the door, making it impossible for me to get in and out (Participant E).

It is difficult for me to attend different social activities (voice breaking) and this has affected me a lot. As a result, I feel as if I am living in isolation. The environment is not disability-friendly, at all, for a person on a wheelchair (Participant F).

The above extracts from participants reveal that, for example, being isolated is both demeaning and belittling. Being separated from community development meetings is sad because of an environment which is not disability-friendly. Unable to participate in social activities and being less involved with others led to a feeling of disconnection. The study has found that the major barrier is not the physical disability, reduction of a person physically, but rather the environment's inability to cater for the needs of persons with physical disabilities and the lack of integration of the physically disabled

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into the society. This is related both to fears, myths and stereotyping about the inabilities of people with disabilities, as well as lack of access to basic facilities such as community halls.

> *It was not easy for the past two years. My mother did not even allow anyone to come and visit me at home. She would tell relatives that I had been transferred from the local hospital to Pretoria hospital, whereas I was at home. Every time I asked her why she was doing that, she would tell me that...these people are not good (referring to relatives and friends), they will talk about your disability all over the villages. I started to realise that my disability would now make me not able to see my friends and relatives anymore. I told myself that my mother feels embarrassed and ashamed because of my disability. The result is that I ended up being detaching from others. I remember one Saturday morning, my cousin came to see me. I heard him greeting my mother saying Ndaa! and my mother responded. I heard her (my mother) telling him that your cousin is still in Pretoria hospital, and that she would pass the greetings to me when I came back from the hospital. My mother contributed to my limited opportunity to participate in social activities because of my physical disability. My mum felt ashamed of my physical disability (Participant E).*

The isolation, for me, generates a profound sense of loss and results in separation from friends and relatives.

I felt lonely and guilty (Participant D)

I miss my work... (Participant B).

Not having social recognition or a role to play in society was certainly, a hurtful experience for participants. The loss of functions, led to a sense of confinement and infringement on one's sense of integrity.

I have lost touch with the outside world (Participant C).

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I don't feel okay...it makes me angry for that matter (Participant F).

Some participants viewed physical disability in a negative way; as a defect that brings embarrassment and shame to the family. The family judged them through the appearance of their physical bodies. They viewed physical disabilities as an imperfect attribute that could not bring any pride to the family like other family members. The following are excerpts taken from the interview with Participant F:

> *I only stayed two months at home after I was discharged from the hospital I was then taken to an institution for the physically disabled people to stay there full time. I was not involved in the decision-making process about being placed in institutional care nor did anyone help me to deal with my physical disability either at the hospital or at home. My dad told me that he could no longer cope or assist me day and night with my disability, because I needed help constantly and he didn't have enough money to pay for a helper. Staying in an institution for physically disabled people, which was 260km from home, was not good. I felt hurt ...abandoned by my family. I missed the interaction with my brothers and sisters because I could not see them often. He (referring to his dad) will only come and fetch me during the December holidays. I felt isolated, depressed and useless because I was in a new environment and meeting strangers. I have a family, but it seems as if I am alone. Leaving my home, which I was used to, because of my physical disability, made me feel as if a part of me had died...*

Lack of contact between participants and their family members was seen as a barrier to effective integration. This resulted in poor relations with relatives. Participants perceived members who did not keep in touch with them as lacking the ability to care, love and support. This is portrayed by the above excerpt from (Participant F).

The extracts cited above showed attitudinal barriers experienced in the family, which, in turn, affected the physically-disabled persons' perceptions of their own disability. Disconnection in some cases resulted in feelings of helplessness some families and they associated physical

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disability with institutional support. Moreover, the negative experiences which came with physical disabilities made participants lose their self-esteem. Isolation was also a result of the disconnection from friends, relatives and beloved ones. The researcher found this issue difficult to deal with as it represents very real evidence of human disconnection, which is quite depressing.

A female participant, (Participant D) in this study, also confirmed that her grandmother had enormous power over her son's relationships and would make the decision with regard to her son's involvement in relationships. The following quotation testifies to this:

> *We broke up with my boyfriend after I acquired a disability. Hey...yaaa ...it was not easy for me to be separated from the person had I loved for four years. We had good future plans for our relationship. I could not believe it when I heard that I will embarrass the family of my boyfriend with my physical disability. My boyfriend confirmed that his family told him that there are lots of girls around the village for him to go for instead of having a relationship with a person who cannot even cook and fetch fire wood for the family. I was dumped unexpectedly and my life is now miserable. (Participant D).*

Participant B also had a similar experience to that of Participant D. This experience is captured in the excerpt below:

> *Jaaa...I miss the team I played soccer for in the past three years. I feel the sense of separation from my team and friends. It is very difficult to bear and adjust to this situation, which I am not used to (Participant B).*

Participant D stated that physical disability created a feeling of rejection and created tension. Disconnection for Participant B came as a result of giving up playing soccer. Playing soccer and being with friends' added value to the participant's life and, so, without it, the participant felt useless. Participants' feelings of worthlessness were mostly related to the loss of capabilities and being disconnected from social activities in which they were previously engaged and able to perform independently. The words below were uttered by Participants C and F.

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It creates a feeling of rejection and tension (Participant C).

Participant F had a similar experience to that of participants C. This experience is captured in the excerpt below:

It is bad; I have lost a number of friends due to my disability. I wish I could reverse... to my previous life (Participant F).

It is bad; I have lost a number of friends due to my disability. I wish I could reverse…to my previous life (Participant F)

Some participants indicated that discrimination impacted negatively on their relationships with their friends and family. Some of the above storylines by participants revealed these negative feelings. Disconnection for some participants made them feel that they were no longer part of the world. In this sense, disconnection relates to becoming detached from others. The findings of this study show that the participants' inability to get out easily, as they did before results in disconnection or social isolation and feelings of being cut off from everyday life. From participants' own perspectives, physical disability imposes certain demands and constraints upon an already highly compromised life style. Participants A and E expressed themselves as follows:

Oooh...you mean my friends? I don't see them any anymore (Participant A).

It's been long ...I have not communicated with him for some time. That one (referring to his friend) he used to give me a call and promise to visit, but he never came (Participant E).

Some participants felt ashamed, not because of their impairment, but because of the responses of their families and friends. This led to a reduction in social interaction. In addition, the environment can restrict the opportunities and limit choices available to the person, thus, increasing dependency.

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4.2.1.3 Sub-Theme 3: New life style

According to this study, a new life style is a reconstruction in which an individual's life story, morals, values and beliefs are reorganised, in order to account for the onset of physical disability. The process of coming to terms with physical disability poses a threat to one's identity and self-concept and the family's adaptation to the disability. The study demonstrates that participants have to face the reality that their lives have changed, and that they have to cope with the new life style. The experience of a new life style is likely to be a very personal one. Whilst there are likely to be similarities within their overall experiences, ultimately, each participant experienced the new life style in a different way.

The fact that life is not the same resulted in participants having to deal with dependency and mourning for the loss of the old way of doing things. A new life style, for example, could mean using a wheelchair for the first time and living a new life in the context of disability. Participants shared the reality of their present situation and the emotional constraints brought by their disabilities. Physical disability tended to evoke strong emotional reactions in the participants, as well as in significant others. These reactions manifest themselves in the form of mourning for the loss of an ideal and positive dream. The study revealed that participants' experiences of physical disability were characterised by the expression, "life is not the same'. Loss of physical ability created deep emotions of despair, particularly when life appeared too difficult to endure and a burden. Adjusting to a new life, Participant F, in particular, indicated that she never thought she would find herself using a wheelchair for the rest of her life.

> *Ooooh my God…I never thought that I would find myself using a wheelchair for the rest of my life. I find it difficult to participate and enjoy the same rights, privileges and responsibilities as any other citizen because I am at risk of being left out due to the fact that most of the environment is not disability- friendly for a person using a wheelchair. For your information, I have been in this wheelchair for two years as I am speaking to you. One morning I visited my daughter's school to sort-out something with the teachers. It was difficult for my wheelchair to move because of sand since I was still learning to push myself on a wheelchair. I felt embarrassed because of the stares from the learners. Modifying*

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> *one's life style to enable maximum independence in one's everyday life is upsetting (Participant F).*

Participant E also lamented the change of lifestyle because of her disability. She had this to say:

> *Hey, it is a challenge...to be physically disabled is very bad because you have to adjust to a new life style. It takes me twenty- five minutes to dress and undress myself. By the time I am done, I am exhausted. Every time when I have to travel somewhere, I have to leave very early. For example, if I have to leave at seven in the morning, I should be up by half past four, because it takes me long to prepare. My life will never be the same again…Physical disability necessitates changes to accommodate the impairments and the physical changes. My past life style has been jeopardised because of my physical disability (Participant E).*

Participants felt that physical disability can place a great deal of strain on the family due to their dependency on the family and the gradual restriction in their activities, which can adversely affect the development of healthy relationships in the family. Participant G indicated that he is not receiving the same recognition he used to receive from the family anymore and that he is no longer being involved in any family activities, the way he was before he acquired the disability. Physical disability can also place a great deal of strain on the family due to the high level of physical support needed, the emotional connotations associated with the changes in the family roles and relationships. Participants expressed how they perceive the unfamiliar life style and the status of the body in relation to the physical disability and emotional changes.

The following excerpts reveal the participants' stress and their emotions.

> *…To be physically disabled is very painful when you are not born with a disability. I wish I was born with a disability because I would have never experienced walking. As a result, I would have coped well with my disability; I would not have had any problem with it" (Participant C).*

It is evident from the excerpt that the pain which participants feel as a result of being physically disabled in adulthood is severe.

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Participant D also expressed sadness at having to use a wheelchair for the rest of her life.

> *...I felt as if I was dreaming when I was told by the doctor when I was discharged from the hospital that I will use a wheelchair permanently after I had a car accident which led to a spinal cord injury. I must tell you that there was no counselling before the doctors confirmed my disability. I was told two days before I was discharged that I would not walk anymore. I was shocked and I could not believe my ears (Participants D).*

The same pain and anger expressed by Participants C and D are captured in the following excerpt:

> *The pain I am feeling will be for the rest of my life. I acquired disability in 2005, eight years ago and I am still feeling the pain. You may not understand what I am telling you, but to be disabled is very bad because one has to adjust to a new life style which is not easy at all, nwana wa hashu (referring to the researcher). Things which just come unexpected are very painful...I had my own dreams as any individual would have and it is very painful to tell you that my dreams can no longer be fulfilled because of my disability (Participants B).*

Both Participants A and B also expressed disillusionment at the change of their life styles because of their disabilities. The following excerpts capture this disillusionment:

> *My friends are educated, employed, married and driving nice cars and I am sitting on a wheelchair depending on a disability grant. (Participants A).*

"You know what, I never thought that I would find myself using a wheelchair for the rest of my life" with tears rolling down her cheek... *"life is very tough,"* she cried bitterly...*why me? ...why me? why me?" (Participant F).*

These responses from the participants indicate that they felt disempowered to change the current situation they were experiencing.

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Participant D also expressed new life style of unable to do things which use to do before acquiring physical disabilities. The following excerpts captured bellow:

Life is not the same...It is hard for me. I sometimes feel as if it is the end of my life. [Eyes were full of tears, trying to hold them back*]. It is hard I am unable to do things which I used to do on my own. It is not easy nwana wa hashu (*referring to the researcher) *my life is just like a living hell… (Participants D).*

The following excerpts also capture the despair of the participants:

"For me it is the end of the world. My parents and relatives always tell me that I should accept my disability…you know…you know what , if one is not feeling what I am feeling, it will be forever easy to say accept your disability"(Participants C).

It is evident from the above extracts that participants felt disappointed about their physical disabilities. The depth of the participants' sense of sadness and their feelings that this was the end of life was evident in the tone of the participants' voices and their non-verbal expressions. Some of the participants were crying when expressing the experience of their physical disabilities. From what the participants said, the researcher deduced that the participants perceived life after acquiring physical disabilities as meaningless. The narratives revealed that participants felt isolated; they had negative emotional feelings and anger, as responses to this new life style. Participants were more prone to depression, mood changes as they tried to cope with the new life of physical disability.

Five of the participants revealed their new life experiences. The new life style had a negative impact on participants' morale. Some of the comments made by participants' bear testimony to this effect:

"Sometimes it makes me feel down" (Participants C).

"I am not able to do things the way I used to according to my potential (Participant E).

"My life style is not the same anymore" (Participant F).

"I am pulling too hard to survive" (Participant B).

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*"What have I done…?" (*Voice changed and became slower, while her eyes were on the wall) *(Participant D).*

Participant D exhibited an overriding sense of guilt towards his physical disability because he kept asking himself what he had done.

> *I am not receiving the recognition which I used to receive from my family anymore; I am not involved in any activities in the family. We have quarterly burial society meetings in our family of which I was the chairperson. I am told not to attend anymore because of my physical disability (Participant G).*

"I sometimes wish to be treated by a special doctor, but I can't afford payments because I am not working" (Participants F).

From the above extracts, there is clear evidence of very strong emotions attached to physical disability. Participants revealed that they had poor support from their families and were not given recognition as they were before their disabilities. The narratives highlighted that the participants require assistance to manage their day-to-day lives. In addition, the participants demonstrated a need to get support from friends and family and to access community resources, such as medical, financial and social support.

"I look at myself and say maybe I am useless" (Participant G).

"It is really hard to discover who I am now because I don't have legs" (Participant A).

"For me to adjust to a new life with this disability is not easy because it has changed my focus away from the way I used to do things" (Participant E).

The above extracts from the participants describe how their new life style of being physically disabled has impacted negatively on both their emotions and self-esteem. The new life style has led to feelings of uselessness and frustration. It has impacted negatively on participants' self-esteem. They mourn the loss of their old way of doing

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things, for example, moving from a state of independence to dependency and being different from others.

4.2.1.4 Sub-Theme 4: Cultural beliefs

This study revealed that cultural beliefs are a pervasive social variable that determine what types of behaviours, including the norms, values and knowledge held by a particular sector of society are acceptable and normal in a given society. Cultural beliefs are the commonly held norms and moral standards of a culture, the standards of right and wrong that set expectations for a behaviour. Such cultural beliefs shape people's attitudes and behaviours and, as a result, affect the way in which people view their health. The participants demonstrated that it is impossible to ignore an individual's cultural beliefs when one is trying to understand people's perceptions of physical disabilities and their reaction to the impact attached to them. Participants were concerned about the causes of their disabilities. Some consulted traditional healers to seek explanations on why they became physically disabled, and how to get a cure or to restore their physically abilities.

The findings of this study revealed that cultural beliefs played an important role in the perceptions of some participants. Some believed that physical disability is associated with evil spirits, curses, and that it was a punishment to the family or individual. Some participants consulted traditional healers with the hope that they will get answers for the cause of their physical disabilities. A common belief in the cause of disability was witchcraft which is frequently attributed to the influence of evil spirits. Participant F was told that the disability is a result of an evil spirits from his grandfather and witchcraft. Participant F stated that he decided to stop consulting traditional healers because he did not receive any help. The participants in this study stated the following during the interviews:

I was told that my disability is a result of evil spirits from my grandfather and witchcraft (Participants F).

The first day I was taken to the traditional healer by my mother, I was given two 250ml bottles of powder medicine (mushonga). I was told that I must put two table

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spoons in my soft porridge in the morning only, and then use one tablespoon to wash my body to remove bad luck (Participant A).

I was told that my neighbours are jealous of my progress at the University because soon I could be working and I would make a difference to my family (Participant E).

I have spent a lot of money consulting different traditional healers. At some stage I was told to bring two goats or to perform some spiritual ritual so that the ancestors would tell the cause of my disability (Participants B).

You are being punished… for being unable to carry out daily household activities (Participant A).

I was promised healing but I haven't seen any changes (Participant A).

I decided to stop going to the traditional healer because I was not receiving any help (participants F).

I was told that I should have bought the tombstone of my grandmother who died ten years ago with my first salary. If I had done that, I would have avoided the car accident (Participant G).

It is clear from the above extracts that the causes of the disabilities are unknown, and that consulting traditional healers to seek the causes were all in vain. This study has found that physical disability is associated with black magic (muti), evil spirits, curses and punishment. Participants received different responses from traditional healers. The above excerpts show that participants experience from the traditional healers when seeking the cause of the disability and healing. Western healthcare practitioners were consulted for assistance, for example to get wheelchairs, since the black magic could not heal them. There were different traditional healers were consulted and they all had different answers on the causes and cure of the participants' physical disabilities.

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Cultural beliefs show that participants believed that traditional healers would make a difference in their lives by providing answers to their cry. It was also clear from the participants that the goal of their lives was to know the causes of their disabilities. This is because they did not want to be treated differently forever because of their physical appearances. Being ‘normal’, therefore; meant not feeling embarrassed or humiliated, but being accepted in the society.

4.2.2 Theme 2: Experience of physical disability acquired in adulthood

This study revealed the experiences of adult with physical disability on one’s sense of independence and productivity and one’s sense of worth and social value. The study revealed that physical disability can result in emotional reactions as one has to deal with social barriers and societal attitudes. Such experience reduces one’s independence and productivity, and it involves coming to terms with the loss of one’s ability.

This study also revealed that adult with physical disability prevents one from being independent also prevents interaction between the physical and emotional constrain, and this hinders full participation in society. Social barriers in the form of inaccessibility to public transport are stated by participant C.

Participants’ physical disability in the context of this study referred to extremely negative physical constraints. The participants shared different experiences about physical disability on their lives, what it means to confront the impact of physical disability in their lives and the meaning of interacting with others as they struggle with day to day challenges.

4.2.2.1 Sub-Theme 1: Emotional constrain

According to this study, participants experience emotional turmoil, as a result of their failure to use their bodies to do what they want. The loss of ability to perform prescribed tasks and activities, as well as roles expected of them within the physical and social context due to a medically definable condition impacted on their lives and created emotional turmoil in their lives. The effect of the physical disability also placed a great deal of strain in their families, for example, participants’ need for high levels of physical care and support.

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The failure to do certain activities due to bodily impairment and the emotional turmoil expressed by participants reveal the reality of the experience of disability on physically disabled adults. For example, participants experienced various emotions such as, annoyance and discontent because of their inability to use public toilets, and for being dependent on other people for their care.

Participants reported instances of isolating themselves because of their physical disabilities. Some participants described the situations where they were made to feel self-conscious and embarrassed about needing help constantly. These feelings were evoked by instances where participants were restricted in accessing public transport and the built environment. Physical disability, largely created by the physical and social barriers within the environment, impacted negatively on the participants. Besides the inadequate public transport and exclusionary built environment, negative attitudes from the community also served to keep physically- disabled persons segregated. An environment which enables physically-disabled persons to access the public space, would result in attitudes of the society changing positively towards them. These emotions, shared by physically disabled persons, confirmed that physical disability has little appeal to public sentiments.

It is evident from participant B that if a physically-disabled person cannot access public toilets (which are a kind of social exclusion), this results in stigmatisation. It also infringes on the disabled person's dignity as this draws attention to their disabilities. Participants' experiences of physical disability revealed that the way they feel emotionally is related to the way they experience the functionality of their bodies and how they function in their everyday lives.
Participant D showed that physical disability impacted.

The following are extracts which are taken from the interviews, reveal the emotional turmoil resulting from one's physical disability.

> *I still continue taking medication due to my health condition and going to the clinic for check-ups. I remember the other day I visited my nearest local clinic to collect some medication. It happened that I had to use the toilet. When I got there it was a disaster because the door was too narrow for my wheelchair to get in and I was very pressed. I was very upset with everyone and I did not have any choice but to go back home…by the time*

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> *I arrived home, I had already mess-up…You know I won't forget that day. My sister (*Referring to the researcher)*, tell me how will you feel if it was you? (Participant B).*

Yooo!!!!!! Taxi drivers…. are problematic….one day in the morning I waited at the bus stop for two hours because taxis were just passing when I stopped them. When one happened to stop I would be told to close the door because there is no space for a wheelchair (Participant C).

My physical disability has affected me psychologically; I sometimes feel bitter and neurotic (Participant D).

My capabilities and opportunities are being restricted by an inaccessible environment (Participant E).

Some of the participants shared their stories on how they are often excluded from doing what they want to do. This is a sign of stigma and it affects their emotions and social relationships. This exclusion is a result of both a disabling environment and people's attitudes. For example, a taxi driver will decide to stop at the next bus stop, not caring about the person in a wheelchair. This situation causes participants to feel ashamed because they are being disrespected and discriminated against. Internalised emotions and low self-confidence can prevent physicallydisabled persons from accessing their fundamental rights in public facilities as clearly indicated above by participant C's extract about the behaviour of taxi drivers.

Physical obstacles and barriers are also created and perpetuated by social barriers. In addition to physically-disabling difficulties, physically-disabled people experience a combination of hostile or negative reactions in their living environment. From participant E's extract above, the main problem is not the actual disability problem but it is the society that is problem since it restricts the disabled people by making the environment inaccessible.

4.2.2.2 Sub-Theme 2: From being able to being disabled

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According to this study transition from being able to being disabled is the process of changing from one state or condition to another. The participants who participated in the study were not born with disabilities but acquired their disabilities at adulthood. The study revealed that this transition brings various barriers such as the need to establish independent social lives. The transition resulted in pain, constant need for help, feelings of worthlessness and loss of identity associated with changes in their independent status.

It is apparent in this sub-theme that participants' transition from a state of being able to a state of being disabled, did not occur suddenly, but it was characterised by slowness and pain experienced because of the prolonged period of transition. This prolonged transition created high levels of anxiety, depression and tremendous stress.

When transiting from a state of being able to a state of being disabled, participants had different experiences. The intensity of the impact experienced was mainly determined by the type of transition. Some participants felt their lives had become meaningless and they felt disempowered. Participant A in this study pointed out that her mother played a distinct role in her transition from being able to being disabled as illustrated by the following extract:

> *My mother used to take a big basin and pour water inside it every midday and put me in the basin to bath me. My sister (referring to the researcher), this situation is too stressing you know…but I appreciate the support and care from my mother because it makes my life better. I don't think that anyone can give this support I am getting from my mother, it is really appreciated … (Participant A).*

Participant A appreciated the support received from the mother and Participants B, D and E expressed pain and living hard life.

Participants B, C, D and E experiences from a state of being able to disabled is captured in the excerpt below:

This is the most painful experience for any human being. It is just unfortunate that you don't stay with me you would have seen what I am going through (Participant B).

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Jaa…living a hard life I feel disempowered about this situation (Participant D).

It has been long now …I am not sure if I will be healed one day, may be… I don't know (Participant E).

I could not assume other responsibilities as a mother of the family. My body is not functioning well like before. I cannot even lift up my legs on my own though my right hand is still active to do light things (Participant C).

The way participants shared their stories about the transition from being able to being disabled and how it impacted on their lives was emotional. The above extracts from the participants reveal the level of sadness and stress. Participant C in particular reveals a sense of despondence when she says:

"I am not sure if I will be healed one day, maybe… I don't know".

Participants expressed a sense of hopelessness as if life is not worth living anymore because of the difficult situations they are experiencing. From the above extracts on transition, it is clear that the experiences were stressing participants, and that they had no hope of improvement. The transition from being able to being disabled, therefore, has exposed participants to stressful life experiences and trauma.

Similarly, the above extract from participant A clearly shows a mixture of feelings. Firstly, the participant stressed the importance and her appreciation of the good care from her mother. Secondly, she views the transition from being able to being disabled as too stressing. It also emerged from participant C's extract that she experienced difficulty in doing basic household chores such as washing plates.

When moving from one phase to the next, participants experienced a sense of regret that they were leaving something behind. Participants indicated that the transition phase is not smooth and that it is a struggle to face the reality of being physically disabled.

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4.2.2.3 Sub-Theme 3: Societal attitudes

Society regards the disabled as 'disposable'. This evoked embarrassing compassion, as they were seen as being strikingly different, dependent and mentally incapacitated. They are also identified with disease, an attitude which is unjust for people with disabilities (Heller, 1992:250). Societal attitudes influence the way in which people interpret disability and their interactions with disabled individuals.

Participants described how societal attitudes made them feel bad about their adult physical disabilities. From participant's extracts, show that the experiences from the society of being patted on the shoulder and being pitied disempowers them. The study confirms the negative attitudes experienced by participants from their families, health practitioners and their communities. The extracts below reveal how society treats the participants:

Hey…sometimes I feel shy because I want to be like able people to escape negative attitudes (Participant B).

Being pitied made me feel dis-empowered (Participant C).

I compare myself with able bodied people (Participant D).

I am called names (Participant A).

Shame…shame…Why do you get pregnant out of marriage? You should have used prevention (Participant E). Who will take care of your baby? Where you raped? I was asked embarrassed questions by nurses at my local clinic.

Participant A related his story of being given names or labelled by the society and such experience made him feel bad. For example, *U la munna wa tshihole* "which means that disabled man" and the prefix "tshi" in Tshivenda language is usually associated with animal classes not human beings, and it sounds very derogatory. Some participants felt isolated from society due to societal attitudes. Participant A indicated that he feels different and distant from those around him, and this made him feel bad about himself.

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The shame and negative attitudes had a strong impact on how participants felt about themselves. Participants felt that they are often the recipients of stigma. Societal attitudes around disability impacted on the individual's self-esteem. It is clear that how physical disability is perceived by others is a major issue.

Some participants indicated that their families view disability in a negative way. Physicallydisabled people are viewed as defective and this embarrasses their families. Participant B's extract reveals how he was told not to worry about attending family funerals. This discrimination in the family reveals how this participant is stigmatised and his dignity devalued as a human being. It was found in this study that the most prevailing family attitudes towards physical disability were feelings of pity and embarrassment. One participant confirmed that physical disability often leads to seriously diminished contact with family members and relatives.

In this study, it was found that health practitioners stigmatised women with disabilities by disparaging their abilities to be mothers, instead of simply informing them about contraceptives. According to the findings, Participant E was not expected to be a mother and was discouraged from being one. She was told that she would be unable to get pregnant, to give birth and raise the baby. Participant E extract from above revealed the negative attitudes of health practitioners who expressed their shocked to see pregnant physically disabled women at the clinic. The participant said that she was made to feel as if she had committed a sin by becoming pregnant. Misconceptions that physically disabled woman might have been raped and beliefs that she cannot give birth to a baby caused feelings of inferiority and depression.

The stereotype that a physically disabled woman cannot get pregnant outside marriage is a serious offence because anyone can become pregnant, married or not. It has nothing to do with the service one should receive from health practitioners. Participant E felt uncomfortable and embarrassed when she was asked funny questions in front of other women at the clinic. The participant concluded that negative experiences and perceptions result in physically- disabled women distrusting health practitioners and losing confidence in their services. However, the physically disabled women should not be judged on their physical appearance. They are human too and should not be disparaged for wanting to be mothers.

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4.2.2.4 Sub-Theme 4: Socio-economic implications

The examination of socio-economic implications is a multidisciplinary approach to studying economic phenomena and the social implications and effects that result from those phenomena. Participants in this study stated that they have no income. Instead, they get financial support through the disability grant, which is not adequate to sustain their families. This is a source of stress for them. Some of the participants indicated that when there is no food in the house, they often ask their relatives to assist them with food if they have enough.

The following extracts taken from the interviews highlight the socio-economic distress of the participants in particular, lack of food for participants' households, which is a burning issue.

> *My uncle was a helping hand to my family but now he informed me last month that he is having more responsibilities of taking care of his two elder girls who have started tertiary education at the University and his last born, a boy who is doing grade 12 this year who is also expected to register with University as well next year. Due to the educational responsibilities of his children he will not be able to help me with food anymore. You know what; I don't think I would ever get a reliable person like my uncle to buy food for my family (Participant A).*

My grandmother also talks too much when I go and ask her for food. Everyone will know that I did ask her for food, so it is better not to go and ask her for food because she cannot keep it to herself. I am pulling hard and I don't want everybody to know about my difficulties (Participant B).

Yesterday I went to my cousins' house with a 10kg container to ask for mealie- mealie. His wife said bad things to me she wondered why I could not afford to buy just a mere bag of mealie-mealie when I am receiving a disability grant from the government every month (Participant C).

It is not easy; the disability grant is the only source of income for my family… (Participant D).

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My mother was a domestic worker, but due to my physical disability, she could not continue with her job (Participant E).

Lack of source of income is a challenge because I am unable to meet the family responsibilities as I used to before acquiring the physical disability (Participant F).

It is good ...my neighbour is a Christian and he has a small backyard garden. Sometimes, he provides me with vegetables which make a huge difference to my family (Participant G).

Some participants indicated that they do not get positive responses from their relatives and, because of that have decided to stop asking for assistance from them, in order to protect themselves from further discouragement and negative responses which seriously hurt them. This is evident in Participant C's extract. Similarly, participant B's extract indicated that he has stopped asking for assistance from his grandmother.

The findings of this study confirmed that all participants, in this study, had experienced severe economic stress in their families, lack of food being a major indicator of their destitution. The participants stated that it was difficult for them to survive on a disability grant, which is unable to sustain them financially and in buying just basic needs, and nothing else. The study yielded vast insights into the everyday life experiences of physically disabled people as well as the various ways in which physical disability impacted on their families and society.

4.2.3 Theme 3: Strategies that physically disabled adults employ in coping with their disabilities in society.

4.2.3.1 Sub-Theme 1: Spiritual Support

Spiritual support is divine support which serves as a consolation or as an encouragement for one to do one's best to deal with the difficulties one encounters. Some of the participants explained how they found solace in knowing that there is "God", a source from which support and strength is drawn, in whom hope is based and confidence placed.

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The findings of the study demonstrated that participants called upon spiritual support to cope with their physical disabilities. Participants have asserted that the church played an important role in their lives, and this really helped them cope with their physical disabilities. The church provided them with spiritual support through all night prayers. Participants also received prayers from the pastors. Such prayers brought confidence in to their lives and reduced their worries because they developed hope that one day they would receive miracles from God. After seeing a lady at church with a disability being prayed for and her throwing her crutches away and walking freely, Participant D believed that anything is possible. The following extracts from participants indicate that religious activities are key strategies for coping with physical disability:

My brother in-law introduced me to the local ministry which I attend every Wednesday and I believe that things will change for me and that I will be independent. I have seen other physically disabled persons receiving miracles on one of the TV channels (Participants A).

Lots of miracles are happening in that church and I hope God will also do miracles for me. I also don't miss any all-night prayer service and I am confident that one day I will be a different person. I won't lose hope because I know that with God anything is possible (Participants B).

The church has played an important role in my life. My pastor will always say to me when he prayed for me...You just need to open your heart, have faith and believe that you will stand up and walk... (Participants C).

> *Last month I saw a woman receiving healing power from the pastor. She threw away two crutches and walked on her own without any support. Though my community talk badly about that church, I won't stop going there because I don't have any problem and I enjoy being there. I am coping well with the support I am receiving from this church (Participants D).*

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It is evident that participants use coping strategies that enable them to deal effectively with their life situations. The findings of this study confirm that, despite the experiences that participants were exposed to, they are able to remain positive about their lives by attending church services. Participants' experiences of spiritual support from their churches give them wisdom to cope with their physical disabilities.

All participants testified that they drew strength from their religious values and beliefs, in order to cope with their physical disabilities. They further asserted that they have found meaning in hope and have faith in their lives. Participants' faith and religion have, therefore, played an influential role in helping them cope with their physical disabilities.

4.2.3.2 Sub-Theme 2: Support groups

A support group is a cornerstone in an intervention to prevent existing prejudice and stereotypes, and to advance the rights of individuals who have common objectives to achieve. Support groups also serve as a means of receiving support in order to strengthen the coping strategies of the physically-disabled and enable them to deal with the adjustment process. It encourages the disabled to interact with each other and also gives them an opportunity to share their distressing experiences. This has a positive effect on their self-esteem.

Support group are helpful to the participants because they enable them to cope with their physical disabilities. Participants had expressed how the support group gave comfort and enabled them to cope with their disabilities. Participant C confirmed that socialising with other physically-disabled persons gave him confidence to cope. Participant C regarded himself as better than other disabled people, especially those to those who are unable to see and do anything for themselves.

The support group has a significant advantage because it provides participants with opportunities to express their different experiences in a mutually supportive manner. It enables them to develop strategies to cope with their physical disabilities and provides a conducive atmosphere in which participants can share their experiences.

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Participants C realised that his disability is much better when compared his disability with totally blind. The following excerpt was captured as follows:

I began to realise that my disability was much better than that of others...There are others who are worse off, for example, those who are totally blind. I am lucky that I am able to see though I can't walk (Participants C).

Sharing my experiences with other physically disabled persons was helpful because I was able to open up and get assistance from other physically disabled persons. It was an opportunity for me to see how other people with disabilities are coping with their physical disabilities (Participants B).

The findings show that participants share their experiences, and that being together in various organisations for persons with disabilities makes them feel good, unlike when they are with able persons. Participant C's coping strategy involved associating with others. In the excerpt below, Participant C indicates his reason for isolating himself from the able-bodied people, as well as his coping strategy:

> *I thought of joining an advocacy organisation for persons with disability. When we are together as physically disabled persons, we are able to understand each other's disabilities better than a person without a disability. It is true…to be a member of this organisation makes me feel good because I sometimes forget that I am physically disabled, unlike when I associate with able-bodied persons who will be judging my inability to perform some activities or asking me how I acquired my physical disability. I am telling you this from my own experience. One day I was asked by another lady if I was born like this or if I had become disabled via an accident, I did not respond and I pretended as if I had not heard the question.*

We were like one family because we supported and assisted each other to overcome the challenges (Participants D).

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It was easy for me to learn other coping strategies from my colleagues (Participant E).

Participants had a good time when sharing their experiences, and they began to realise the importance of networking with other physically-disabled persons. Participant D's extract above further indicated that he has trust and confidence when he is amongst other physicallydisabled people whom he regards as a family. Support groups serve as a source of strength and they have a positive effect on the physically disabled.

4.2.3.3 Sub-Theme 3: Substance Abuse

Substance abuse is when an individual's use of alcohol or another mood-altering drug has undesired effects on that individual's life or on the lives of others. Negative effects of substance abuse may involve impairment of physiological, psychological, social or occupational functioning (Chetty, 2011:11). In this research study, substance abuse is the over indulgence, or a dependence on a drug or other chemicals, leading to effects that are detrimental to the individual's physical and mental health. It is the excessive use of a potentially addictive substance, such as alcohol and drugs, especially one that modifies body functions.

Some of the participants depended on substances to cope with their physical disabilities. Participant A indicated that alcohol and smoking dagga was a strategy he applied to cope with his physical disability. Similarly, participant B took an overdose of his medication to spend most of his time alone. The following excerpts give evidence of substance abuse:

It was not easy for me to cope with my physical disability. I would abuse alcohol and smoke dagga, because when I am always drunk I do not have time to think of my physical disability and the limitations I experience… I was fine with that (Participant A).

I do go to the hospital for check up most of the time and I receive medication from the doctors. I take a overdose of pain killers so that I can spend most of my time sleeping…When interacting with people without disabilities I feel intimidate (Participant B).

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When my two legs were amputed, I was frustrated. I made friends in the ward where I was admitted. When they smoked they would ask me if I smoked and I would refuse. After a week I joined them and started smoking dagga because I realised that I was getting bored and focusing on my disability too much. For me it was working because I continued even I got home. I am still smoking and it is working well for me. I have been approached by many people to stop smoking but I can't. If I don't make trouble for anyone I don't see the importance of pleasing other people. I have to please myself. After taking my dagga, I feel happy and I forget about all my problems. You know what my sister (referring to the researcher) I enjoy reggae music as well (Participant C).

Participant D expressed that abusing alcohol helped to cope with physical disabilities. The following excerpts give evidence of substance abuse.

I did not have any choice, it was my first experience to take alcohol… (Participant D).

Based on the participants' extracts above, it is clear that some participants deny their physical disabilities hence participant B talks about wanting to spend most of the time sleeping to avoid interacting with other people. Other participants found that using different substances such as dagga, alcohol and an overdose of pain killers helps them to cope with their disabilities. Some of the comments shared by participants demonstrate a sense of shame and embarrassment towards their disability. These are symptoms of depression. Participants reported isolation and smoking dagga as coping strategies.

4.2.3.4 Sub-Theme 4: Rehabilitation Services Support

Rehabilitation services support is defined as the combined and coordinated use of medical, social, educational and vocational measures for training a disabled person to the highest possible level of functioning ability (Frazer, 1992:11). Rehabilitation is described as a way of helping people with disabilities to become full participating members of society, with access to all benefits and opportunities in society. This means that disabled people should have access

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to benefits such as education and training, job opportunities and community development programmes.

Participants received essential medical rehabilitation, as well as appropriate assistive devices which made their lives easier. Participants also received one-on-one rehabilitation sessions for psychological and social rehabilitation, and these focused on social functioning. Such sessions brought hope and awareness for them to understand disability differently.

The findings of the study indicate that the intervention of occupational therapists, psychologists, physiotherapists and social workers plays an important role in assisting the disabled to cope with physical disability. Rehabilitation services support is holistic in approach. For example, physiotherapy provides physical exercise after factors that created the functional disability are identified. Psychologists deal with counselling to create enhanced feelings of competency, which would ease emotional stress; and occupational therapists support them with wheelchairs which enable easy movement.

Participants' extracts below indicate that participants were not aware that they can receive disability grants from the government.

> *Home visit by the social workers opened up my eyes to some other things which I was not aware of. I did not know that physically disabled people qualify for a grant. I thought I had to wait to reach sixty years (Participants A).*

> *I have learnt how to use a wheelchair. The physiotherapist assisted me lot. Without the wheelchair, I was crawling on my knees. I can now move from one point to another with very little assistance from others, and it makes my movement easy (Participant B).*

> *The Occupational therapist assisted me with a wooden table, which I use for my meals. I was in my own world, feeling helpless, discouraged and hopeless, but now I am starting to see the light through (Participant C).*

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The one-to-one sessions with psychologists and social workers brought changes to my life. I became hopeful with the support I was getting and began to understand disability in a different way (Participant D).

Indeed the findings of this study showed the value of the information provided and the important roles played by health professionals in making sure that participants adjusted to their new life styles. They gave them support in the form of self-help skills, so as to become active despite their disabilities. The information received by participants made them gain meaning about their condition and prevented them from being negative. Participant D above revealed how the one-on-one sessions with psychologists and social workers brought positive changes in his life. The interaction with health professionals restored confidence and assisted participants to gain a sense of personal control. This enabled them to cope well with their adult physical disabilities.

CHAPTER FIVE CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

The study focused on the experiences of physical disability acquired in adulthood. The study objectives sought to establish the meaning attached to physical disability, the experience of physical disability acquired in adulthood and strategies that physically disabled persons employ in coping with their disabilities in their society.

The findings of this qualitative study are in accordance with the themes, and sub-themes that emerged during the process of data analysis, and which were confirmed or underscored by extracts from the transcribed interviews. This chapter concludes this qualitative research by

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demonstrating how the objectives of the study were achieved. The study was delimited to physically-disabled adults in the Vhembe District of Limpopo Province. The researcher had a sample of seven adult respondents diagnosed with various forms of physical disabilities. The majority of the findings correlated with the literature that was reviewed.

5.2 Conclusion of the study

5.2.1 Meaning attached to physical disability acquired in adulthood

The research findings showed that there are different meanings attached to physical disability. Participants had a difficult task of resuming their new life style because of restrictions resulting from their disabilities whilst dealing with disconnection, cultural beliefs, and the social changes attached to physical disability.

Participants, in this study, considered mobility a key to quality of life. The study showed that participants were disadvantaged as they were unable to travel long distances to seek the care that they needed. Health disadvantages such as accessing health care, rehabilitation centers, to mention a few, were compounded by a lack of income.

It was clear from the participants' experiences that physical activities such as playing games are no longer possible for them and this affected their everyday life because they cannot be self-sufficient and free to live life as they choose it. Social problems that with what participants experienced and alluded to include fewer relationships, less involvement and lower levels of social activity, loneliness and isolation. In other words, participants are disconnected from others.

Feeling useless, worthless, and detached from others was related to loss of capabilities and being restricted from activities which they were previously able to perform. While participants experienced similar physical circumstances and situations, their experiences differ from one individual to the other. They attached different meanings to their physical disabilities. Physical disability is a serious assault on a person's health and wellbeing; it can also rob a person of confidence and psychological wellbeing.

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5.2.2 Experience of physical disability acquired in adulthood

Participants, in this study, identified activities lost to them due to their body impairment. Perhaps, the most serious consequence for the participants was the inability to do things which they used to do independently. The loss of the ability to work triggered a whole host of emotional responses which show that the ability to perform different activities and roles, which together constitute an individual's life and social world, has implications because of acquired disability.

Consequently, the loss of work coupled with the knowledge of one's inability to ever work again impacted on the participants negatively. Feelings of inadequacy because of being dependent on others and the need to show constant gratitude for receiving care filled the participants' lives with uncertainty and emotional constraint. Furthermore, participants realised that they have to learn to cope with their physical disabilities. It was not an easy transition to rebuild their lives from being able-bodied to being disabled.

The study showed that mobility was highly valued because it is an important element of an independent lifestyle. Loss of social networks in their communities which included loss of social contacts, were due to mobility difficulties which made it difficult for them to participate effectively in social activities. The experience of physical disabilities created a complex set of new experiences and circumstances which participants had little control over. The study revealed that the process of accommodating the impact of physical disability and change of the body was not easy.

Dependency in everyday life meant relying on others for transport from place to place, food preparation, assistance with personal self-care and other activities. Needing help and relying on others was viewed as one of the most serious drawbacks of being disabled. It is evident that the participants were genuinely concerned about the impact of their physical limitations.

5.2.3 Strategies that physically disabled adults employ in coping with their disabilities in society

The findings showed that participants resorted to both positive and negative strategies to cope with their physical disabilities. Some have not come to terms with their physical disabilities. They are not ready to face the reality that their circumstances cannot be changed some have

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over time, become reconciled to and their situation have resumed their lives by accessing spiritual support and support groups. Participants have developed strategies that would enable them to move beyond a survival mode to a way of life that is normal. They have to carry on with life in spite of their physical disabilities.

Participants have been engaged in minor and major lifestyle modifications and have adopted numerous strategies to help them adjust to their disabilities. From the participants' extracts it is clear that friendships, companionships, marriages, families, support groups which involve physically-disabled and spiritual support groups, are among the key coping strategies that participant's value. Living with a physical disability requires one to find strategies to cope with the difficulties associated with physical and emotional change.

The study showed that participants found solace in knowing that there is 'God'. This was a source from which support and strength were drawn, on which hope was based and in whom confidence was placed. Religion is a great provider of meaning and support groups play an important role in their lives.

Some participants expressed the importance of support from health professionals, whilst others were not certain about their support. Some of the participants expressed that they had adverse experiences and circumstances in their lives, whilst others testified that they were strengthened by their faith because they were able to find meaning in their lives, through the help received from support groups.

5.3 Limitations of the study

- The combination of qualitative and quantitative methods would have made a difference about how the participants view the impact of physical disability. Detailed information could have been obtained if both methods were adopted;
- The sample consisted of only seven participants who acquired physical disabled in adulthood. It would have been beneficial to include non-disabled people who were family members to add to this study, their experiences as well in caring for the disabled adults

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- Further exploration using a larger group, including those from other municipalities in the Vhembe District and their ethnic background, is warranted to determine what difference would be apparent in the experiences of adults with physical disability from different backgrounds;
- In Vhembe District no research has been documented on the experiences of physical disability acquired in adulthood. Thus, recent literature pertaining to the study population on the subject was limited; and
- Other family members were not comfortable with the research because they were afraid that the researcher might expose their disabled members to the community.

5.4 Recommendations

On the basis of the findings that have been observed by the researcher, the following recommendations are made:

5.4.1 Government

It is recommended that the government should:

- Introduce a programme for the disabled after being discharged from hospital which would ensure that there is a smooth transition from being able-bodied to being physical disability to help them to cope with the change;
- Provide training and information to caregivers and health professionals, as well as individual counseling to the physically disabled people and their families, so that they can have an understanding of disability management; and
- Develop partnerships with Non-Governmental agencies that work with persons with disabilities. The purpose of these partnerships would be to keep abreast with current legislation and this would better equip persons dealing with disabled adults to understand laws on how to assist them with their disabilities.
- The human right of the participants in this study are still not realised as espoused in the United Nations on Rights of Persons with Disabilities (2008). Human right reflects a determined effort to protect the dignity of each and every human being against abuse of power through fundamental rights.
- The right to live independently and to be included as an equal citizen in one’s community requires partnerships between all sectors of society.

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Organs of civil society need to become active agents of change in fighting discriminatory attitudes and belief systems that push persons with disabilities and their families to the margins of society.

5.4.2 Health Professionals

It is recommended that they should:

- Make sure that their programmes, in all health services, cater persons with disabilities. Health professionals should also consult with them timeously;
- Provide social service support to persons with disabilities. This service should strive to meet significant problems so that the people concerned have an opportunity to participate in social life, including participating in community activities that are meaningful to them and to live like everybody else;
- Work with diverse groups of professionals to promote and facilitate the development of what is known as "multi-agency" work that will ensure that the needs of persons with disabilities are met;
- Be attentive to detail and ensure that persons with disabilities are given emotional support because speedy recovery will be jeopardised if this is ignored. Unhappiness can become self-perpetuating and people can slip into isolation with adverse effects on their physical and psychological well-being;
- Implement awareness campaigns and rehabilitation programmes, in order to educate the public about disability issues;
- Assist with the establishment of disability forums, which will enable the physicallydisabled people to come together on a regular basis to voice their concerns with regard to equity issues pertaining to physical disability;
- Give appropriate support for physically-disabled people and their families, starting from the time of diagnosis. The quality of good health care comes from the sensitivity of the health care professionals;
- Identify and diagnose physical disability immediately to facilitate early integration into families as this will prevent physically disabled people from becoming accustomed to their dependent lifestyle; and
- Conduct therapy sessions with physically-disabled people to help them deal with the reality of having to live with a disability.

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- Public sector institutions and service organizations need to align their services at community level to provide the seamless support services required to realize this right.

5.4.3 Disability organisations

- Should encourage people with disabilities to participate in community forums, in order to be part of the decision-making processes regarding disability issues affecting them;
- Should continue to promote research in the field of disability studies and use the research to influence change to challenges experienced. The physically-disabled, themselves, should be catalysts for such change. Therefore, future research in the area of representation would provide more in-depth information about the experience of physical disability and how this could be changed;
- Should play an advocacy role as this will ensure that physically-disabled people's rights are not violated. They should promote and protect such rights;
- Should conduct seminars to provide expert knowledge on disability. The seminars should be outcome-based and should include the physically disabled in bridging the gap between physically-disabled and able-bodied people; and
- Should conduct awareness and sensitisation campaigns with regard to the rights of persons with disabilities. These campaigns should include various programmes such as participation in disability conferences. The aim, ultimately, should be to change the attitudes of society towards disability.
- Organizations of persons with disabilities, as the representative voice of persons with disabilities, need to strengthen their footprint at local level to empower persons with disabilities, to advocate for change, and to monitor and act upon rights infringements.

5.4.4 Support groups

- Support groups should be established and any physically disabled persons returning from hospitals should attend such sessions. In this way, the physically-disabled people will be made aware that support is available and they should feel comfortable discussing such confidential issues with other peers;
- Should contribute to the development of appropriate and accessible health system that would improve and maintain the general health care and well-being of the physicallydisabled people and, thus, facilitate participation in health promotions;

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- Promote reintegration into society, and interventions should focus on teaching effective coping strategies and enhancing self-efficacy and participation in a support group;
- Should be geared towards ensuring equal access and opportunities in communities; and
- Should educate organs of civil society and other community-based stakeholders on the fundamentals of being physically-disabled, in order to provide support.

5.4.5 Department of Transport

- Should make rapid progress in developing the public transport system that is flexible and accessible. Without this people with physical disabilities will continue to remain largely invisible and unable to contribute to or benefit from the services and activities available to most of their fellow citizens. It is, therefore, essential that this sector be fully integrated into the strategic plan for accessible transport.

5.4.6 Researchers

This study significantly contributes to the impact of physical disabilities. However, as with any study, it is not an answer to everything. This study indicates further research directions as follows:

- In light of the limitations mentioned above, a larger sample would be recommended for future research, as it would give greater breadth of information and would be more reflective of the population of interest. The research study could also change to include non-disabled people. This would allow direct comparisons in terms of the experiences of the physically abled. It would be of particular interest to ascertain how non-disabled people experience the impact of physical disability and how this affects their perception of physical disabilities. Furthermore, it may be beneficial to include people with different disabilities such as the blind or mentally ill-people.
- Involving physically disabled persons as equal partners in the research process, as well as discussing the results with them, will be an ideal framework within which to conduct further research.
- Research on the experience of physically disabled people in other communities within and outside Limpopo Province should be done.

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- As this study revealed that one major challenge experienced by the physically-disabled is loneliness and/or reduced social relationships with others, it is recommended that attention be given to identifying ways that can effectively break that isolation.
- Future studies with urban physically disabled people, using combined qualitative and quantitative methodologies, are suggested.

It is hoped that, if these recommendations are implemented, a new perspective will emerge and the government and other stakeholders will be able to implement the laws regarding physical disability. However the researcher will organize seminars/awareness where organs of civil society and other community based stakeholders and government departments orientated on the rights of disabled people. Through dissemination of the findings of this study, the researcher hopes that strong message can be conveyed to all stakeholders in disability to ensure mainstreaming of disability in all spheres of life.

5.5 Conclusion

This chapter concludes this qualitative research study by demonstrating how the objectives of the study were achieved. This was followed by a presentation of the summary, limitations and recommendations of the study. The qualitative research methodology employed for this study was well suited for realising the objectives of the study. The limitations of the study were also highlighted in this chapter.

This chapter also included a summary of the research findings and conclusions in the order in which the three themes that emerged during the data analysis were presented. The discussion demonstrated how the aim and objectives of this study were achieved. The chapter ends by presenting future recommendations. It is hoped that, if these recommendations are implemented, a new perspective will emerge and the government and other stakeholders will be able to implement the disability policies which are in place regarding persons with disabilities.

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APPENDIX A

INFORMATION LETTER TO RESPONDENTS

This is a study about the impact on physically disabled adults in Vhembe District of Limpopo Province. It seeks to identify strategies employed by physically disabled people in adulthood disability.

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This study aims to develop an in-depth understanding regarding the impact of disability on physically disabled adults in order to attain the goal. The study will explore the meaning attached to physical disability in adulthood in order to obtain a holistic perspective of adult disability. The findings of the study will create awareness of the positive and negative experience of being physically disabled in adulthood. The outcomes of this study will provide insights into how to develop and improve support structures for persons with disabilities within the Vhembe District, Limpopo Province.

The study will assist professionals who work with physically disabled adults to recognize areas that disabled people consider important as these affect them in their day to day lives. Since the study will highlight the strategies that physically disabled adults employ in their day to day lives, professionals will also get to know if the strategies are appropriate.

Confidentiality of information will be maintained by storing the recorded information in a locked safe place. The information will be accessible only to the researcher and the person who will be checking the translations of the transcripts from Tshivenda into English, and the researcher's supervisor. Participants in this study participated voluntary. Participants have the right to participate or to leave the study at any point with no future consequences. If participants feel uncomfortable at any point during the interview, they may discontinue the interview.

APPEDIX B

DATA COLLECTION INSTRUMENT

Topic: The experience of physically-disabled adults in the Vhembe District of Limpopo Province in South Africa.

Date of interview: __________________ Interviewer: __________________

PART A: Biographical Information

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1. How old are you?
2. What is your gender?
3. Are you attending school? If yes, please indicate the grade
4. Are you employed?
5. What is the approximate monthly income if employed?
6. If unemployed what are the reasons?
7. What is your marital status?
8. How many children do you have?

PART B: Data collection instrument

1. For how long have you been physically-disabled?
2. What was the cause of the disability and challenges experienced?

APPENDIX C

CONSENT FORM

I…………………………… (full name and surname) herby confirm that I have been informed by the researcher, M.C. Sadiki about the nature, conduct, benefits and risks of this research regarding the impact of disability on physically disabled adults. I have also received, read and understood the above written information (Participant Information Leaflet and Informed Consent) regarding the research and the processes involved.

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I am aware that the findings of the research, including personal details and comments will be anonymously processed into a research report.

I may, at any stage, without prejudice, withdraw my consent and participation in the research. I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

Participant's signature___________________ Date_________________

Researcher's name ___________________

Researchers' signature___________________

I M.C. Sadiki herewith confirm that the above participant has been informed fully about the nature, conduct and expectations regarding this research project.

Witness's signature__________________ Date __________________

APPENDIX D

INTERVIEW QUESTIONS

Researcher: What is your view pertaining to physical disability?

I feel as if I am a burden, always asking for help. It is very difficult to deal with the new changes I have to go through in my life). My experienced is that my friends don't care with me anymore, may be they are afraid of my physical disabilities. I am not sure, just assuming. Do you know that they are people who believe that if you associate yourself with disabled people you can

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also get disability? (Referring to the researcher). Disability is not good; unfortunately I am in this situation of being physical disabled (Participant A).

I am called by names (Participant A).

Researcher: What is the experience of physical disabilities acquired in adulthood?

I don't attend community meetings, because the community hall is not accessible to my wheelchair and it worries me. The entrance of the building is small and there are five steps before you reach by the door of which for me is impossible to get in and out. I am forever excluded to attend different social activities and this has affected me a lot, as a result I feel as if I am living isolation. The environment is not disability friendly at all for person on a wheelchair (Participant A).

Researcher: What strategies do participants employ to cope with physical disabilities acquired in adulthood?

It is not easy at all for me to cope with my disability, because I forever stressed with my day to day life. I spent most of my time being alone which makes me to think about so many things. If you are not interacting with others, you create your own life which will suite yourself. Alcohol and dagga is a solution to cope with my new life. When I am drunk, I will sleep and not to think too much with my present life which stops me to participate in different activities

(Participant A).

Researcher: What is your view pertaining to physical disability?

This is the most painful experience for any human being it is just unfortunate that you don't stay with me you would have seen what I am going through. When I am alone in the house I can't push myself to the toilet, you understand what I am experiencing in this situation (Participant B).

Researcher: What is the experience of physical disabilities acquired at adulthood?

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I miss my work (Participant B).

It is very painful to tell you that my dreams are no more to be fulfilled because of my disability (Participant B).

Researcher: What strategies do participants employ to cope with physical disabilities acquired in adulthood?

I did not have any choice. It is my first experience to take alcohol and for me it helps me to overcome the challenges of new life of being disabled (Participant B).

Researcher: What is your view pertaining to physical disability acquired at adulthood?

It is a serious challenge to me because I was not born with disability I find it difficult for me to leave in this situation, it is bad (Participant C).

Researcher: What is the experience of physical disabilities acquired at adulthood?

Every time I have to depend to another person for assistant, you know what it is not easy for me. It is painful I can't do things which I use to do before. My life is horrible I have to learn on how to use wheelchair, I am very frustrated I spent most of the time in house (Participant C*).*

Researcher: What strategies do participants employ to cope with physical disabilities acquired in adulthood?

I remember the other day when my friend gave me cell number of another lady who is physical disabled by a nurse to call her. I call that lady and she introduce me to a support group of physical disabled people. At one stage I was invited to attend support group meeting of which I felt good because I started to realised that I am not alone with disability. Sharing of experiences with other physical disabled to me was an eye open. When I compare my disability

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with others, mine was much better. The church has played an important role in my life. My pastor will always say to me when he prayed for me… You need to open your heart, have faith and believe that you will stand up and walk. I have confidence that things will change because I have faith that one day miracle will happen to me (Participants C).

Being pitied made me feel dis-empowered (Participants C).

Researcher: ***What is your view pertaining to physical disability?***

I am limited to lots of activities, do you see that car is mine but I cannot drive my car anymore. I have to get another person to assist me every time. I also need help for dressing, I can't do up the buttons of my shirt (Participant D).

Researcher: What is the experience of physical disabilities acquired in adulthood?

Life is tough if you are not working, I was informed about disability grant by my friend from support group. I applied for the grant and that is the only source of income in to my family. I am pulling hard because food is too expensive these days. With disability grant I can't do much and it is a stress to me (Participant D).

Researcher: ***What strategies do participants employ to cope with physical disabilities acquired in adulthood?***

Going to the church it heals me because I have witness miracles happening in front of me, I know that good things are coming and I won't stop to going to church. I also like to watch TV channels which shows church services, I even believe the touching of TV screen when pastors invite the viewers at home to touch TV screen for miracle (Participants D).

Researcher: What is your view pertaining to physical disability?

My situation is very difficult you know; let me tell you I don't have privacy because I have to get help on everything I do every day. Sometimes it makes me feel very scared of being a burden

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to other people. I feel like a helpless person having to rely on everyone for simplest things like for example shaving (Participant E).

Researcher**:** ***What is the experience of physical disabilities acquired in adulthood?***

I feel as if I am a burden, always asking for help. It is very difficult to deal with the new changes, experiencing new life. My past life style of doing things is jeopardized because of my physical disability (Participant E).

Researcher: What strategies do participants employ to cope with physical disabilities acquired in adulthood?

Sharing my experiences to support groups with other physical disabled persons was helpful because I was able to open up and get assistance from other physical disabled persons. It was an opportunity for me to see how other persons with disability are coping with their physical disabilities (Participant E).

Researcher: What is your view pertaining to physical disability?

The pain I am feeling will be for the rest of my life. I have acquired my disability in 2005, which is eight years now and I am still feeling the pain. You may not understand what I am telling you but to be disabled is very bad because you have to adjust to a new life style which is not easy at all (Participant F).

Researcher: What is the experience of physical disabilities acquired in adulthood?

Jaa…. I miss the team I played for in the past three years. I feel the sense of separation from my team and friends. In particular, it is likely being most difficult to bear and adjust to this situation which I am not used too. I feel embarrassed and useless; really I don't want to lie to you…. I feel as if I do not exist in this world due to my inabilities. It is bad I lost number of friends due to my disability. I wish if I can reverse to my previous life (Participant F).

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Researcher: ***What strategies do participants employ to cope with physical disabilities acquired in adulthood?***

Knowing the cause of my physical disability that my neighbors are jealous of my progress at the University, soon I will be working and I will make a difference to my family. I was able to know the truth and deal with the situation, because I had a serious concern that I was not born with disability (Participant F).

Researcher: What is your view pertaining to physical disability?

I am not receiving any recognition or respect from my family, some of the family activities which I was involved in were withdrawn from me because of my disability (Participant G).

Researcher: What is the experience of physical disabilities acquired in adulthood?

I feel useless (Participant G).

Loosing my basic monthly salary and depend to disability grant frustrated me because grant can't make any different to my family. I have to pay fees for my children, groceries and pay my helper. (Participant G).

It is good, my neighbor is a Christian and he is having a small backyard garden, he sometimes provide me with vegetables which made a huge different to my family. Though sometimes I feel as if I am a burger (Participant G).

Researcher: What strategies do participants employ to cope with physical disabilities acquired in adulthood?

Networking with local support groups and organizations of disabled people helped me to overcome most of challenges (Participant G).

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APPEDIX E

INDEMNITY INFORMATION

Project: The experience of disability on physically disabled adults in the Vhembe District of Limpopo Province in South Africa.

Location: -----------------------------

Date: ----------------------------------

I, --------------------------------- (name and surname, and identity number) am willing to participate in the experience of disability on physically disabled adults study. I understand that this is a research project and that my identity will not be disclosed. I also give permission that the session will be tape-recorded for research purpose.

I, ----------------------------- declare and undertake towards the research that I discard any claim of any kind that I have now or might have in the future due to any form of action or neglect

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arising from any activities within the study and which can form the basis of a civil claim that I may obtain in my personal capacity against the researcher on account of a casualty suffered by myself while involved in the study.

I hereby indemnify M.C Sadiki against any liability which might arise from any actions by me and undertake not to hold them liable for loss of any kind that I might suffer during my involvement with the mentioned study.

Thus signed at --------------------- on this --------------- day of ------------------------

Signature of applicant

Witnesses

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