

**WHAT ARE THE NEEDS OF PEOPLE WITH PHYSICAL  
DISABILITIES IN THE DISTRICT OF BUTTERWORTH, AND HOW  
ACCESSIBLE ARE AVAILABLE RESOURCES TO THEM?**

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## **DECLARATION**

I hereby declare that the work submitted on “Needs of people with physical disabilities in the district of Butterworth, and accessibility of available resources to them”, is my own work, and that it has not been submitted in its entirety, or in part for any degree or examination at any other university. All the sources I have used or quoted have been indicated and acknowledged by means of complete references.

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## ABSTRACT

This was an investigation into the needs of people with physical disabilities in the district of Butterworth, and their accessibility to available resources, conducted with the aim of improving service delivery in the area. As a physiotherapist the researcher has always been in close contact with people with physical disabilities, and could see the problems they had. The researcher then embarked on conducting this study with the aim of helping them.

The study was conducted in three areas, a rural area called Zangwa Administrative Area, Bika, a township, and Skiti, an informal settlement. The research methodology used was qualitative research. Participants in this research included people with physical disabilities, caregivers of people with physical disabilities, and service providers dealing with people with physical disabilities in the district of Butterworth. Methods of data collection used were focus group interviews for people with physical disabilities and caregivers, and questionnaires for service providers. The reason why service providers were given questionnaires, and not interviewed in focus groups, was that they were from different government departments and it was not possible for them to be part of a focus group due to the commitments they had. Questions in the questionnaires and in the interview schedules used in the focus group interviews were similar to each other, and were open ended. A total of 24 people with physical disabilities were recruited to take part in the focus group interviews in identified locations. Nine caregivers of people with physical disabilities, drawn from two of the above locations participated in this study. Focus group interviews were tape recorded, with the informed consents of the participants. The response rate to the questionnaires was 81%: 13 of the 16 service providers returned completed forms. Data analysis was done through a process of listening to the tapes, together with other students, to ensure the trustworthiness of the data, taking detailed notes, translating the interviews from Xhosa to English, coding the data and putting them into categories, with similar categories building up into themes. In the case of the questionnaires, similar responses were grouped together, and those showing the same responses from participants were prioritised.

The results of the research indicated that the primary needs of people with physical disabilities were housing, employment, skills' development - emphasising training in those skills which could bring them an income - assistance with income generating projects, suitable public transport, accessibility of buildings and facilities, driving schools catering for people with physical disabilities, and Primary Health Care. They needed Primary Health Care to not only address their basic health needs, but to include preventative care, the promotion of effective care, curative and rehabilitative care. At a personal level they required disability grants, caregivers, intimate relationships and marriage. While caregivers placed greater emphasis on assistive devices and Day Care Centres to give them some respite time, service providers emphasised on education for children with disabilities, which neither people with physical disabilities nor caregivers had mentioned. The service providers also said nothing about the need for caregivers and housing. These disparities in the needs mentioned by these three groups of participants showed that needs that may seem important to professionals and other service providers, may not be important to people with disabilities, therefore it is important to consult with the consumers first, before planning for service delivery. It was clear that services were not easily accessible, due to transport and financial problems, as travelling for people with physical disabilities meant additional expenses in terms of hiring special vehicles. Another barrier to accessing resources was lack of knowledge about the availability of those resources, and how they could be accessed.

On the basis of this study, recommendations have been made to relevant service providers for the planning and improvement of service delivery. These include more accessible buildings, good roads, and the appointment of suitable individuals to fill vacant posts in different government departments so as to be able to reach all people with physical disabilities in the district of Butterworth. Finally, the researcher emphasizes the need for outreach programmes to raise awareness about available services.

## ABSTRAK

Hierdie ondersoek ten opsigte van die behoeftes van mense met fisiese gestremdhede in die Butterworth distrik en hul toegang tot die beskikbare hulpbronne is gedoen met die oog daarop om dienslewering in die omgewing te verbeter.

Die navorser het die studie in drie areas naamlik: Zangwa Administratiewe Area, 'n landelike gebied, Bika, 'n dorp en Skiti, 'n informele nedersetting gedoen. Kwalitatiewe navorsingsmetodes is gebruik. Studie deelnemers het bestaan uit mense met fisiese gestremdhede, versorgers van mense met fisiese gestremdhede en diensverskaffers aan mense met fisiese gestremdhede in die Butterworth distrik. Fokus groep besprekings met mense met fisiese gestremdhede en hulle versorgers is gebruik om data in te samel. Voorts is data verkry vanaf vraelyste wat deur diensverskaffers voltooi is. Vier en twintig persone met fisiese gestremdhede, uit bogenoemde drie areas, is geselekteer om aan die fokusgroep besprekings deel te neem. Nege versorgers van persone met fisiese gestremdhede, uit twee van bogedoemde areas, het ook aan die studie deelgeneem. Fokusgroep besprekings is op band opgeneem, met die toestemming van die deelnemers. Dertien van die sestien diensverskaffers (81%) het voltooide vraelyste ingehandig.

Volgens die resultate het persone met fisiese gestremdhede 'n behoefte aan behuising, werk, vaardigheidsontwikkeling, projekte wat inkomste genereer, geskikte openbare vervoer, toegang tot geboue en fasiliteite, bestuurskole wat voorsiening maak vir mense met fisiese gestremdhede en primêre gesondheidsorg. Die volgende persoonlike behoeftes is geïdentifiseer: ongeskiktheidstoelae, versorgers, intieme verhoudings en huwelike. Die versorgers het meer klem geplaas op hulpmiddels en dagsorgsentrums. Die behoefte aan dagsorgsentrums kan aanduidend wees daarvan dat versorgings verligting van die sorg las nodig het.. Diensverskaffers het op hulle beurt klem gelê op 'n behoefte aan onderwys vir kinders met gestremdhede. Dit is nie deur of persone met fisiese gestremdhede of versorgers genoem nie. Die diensverskaffers het niks oor versorgers gesê nie. Die verskille tussen die behoeftes wat deur die drie groepe deelnemers uitgelig is dui daarop dat behoeftes wat as

belangrik voorkom vir proffesionele persone en ander diensverskaffers nie noodwendig belangrik is vir mense met gestremdhede nie. Dit is dus belangrik om eers die klient te raadpleeg voordat dienslewering beplan word. Vervoer en finansiele probleme het daartoe gelei dat dienste ontoeganklik was. Vervoer vir mense met fisiese gestremdhede bring addisionele onkoste mee omdat 'n spesiale voertuig gehuur moet word. 'n Verdere struikelblok met betrekking tot toegang tot hulpbronne was 'n gebrek aan kennis oor die beskikbaarheid van hulpbronne in die studie area.

Aanbevelings na aanleiding van die studie sluit in: groter toeganklikheid tot geboue, goeie paaie en die aanstelling van geskikte individue om vakante poste in die verskillende staatsdepartemente te vul om sodoende die mense met fisiese gestremdhede in die Butterworth distrik te bedien. Ten slotte, wil die navorser klem lê op die behoefte aan uitreikprogramme om mense bewus te maak van beskikbare dienste.

## KEY WORDS

- People with physical disabilities
- Caregivers of people with physical disabilities
- Service providers
- Needs of people with physical disabilities
- Accessibility of resources
- Barriers to accessing resources
- Rehabilitation
- Poverty and disability
- Rural Areas

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## ABBREVIATIONS/ ACRONYMS

PWB	PEOPLE WITH DISABILITIES
PWPD	PEOPLE WITH PHYSICAL DISABILITIES
HIV	HUMAN IMMUNO-DEFFICIENCY VIRUS
AIDS	ACQUIRED IMMUNO-DEFFICIENCY SYNDROME
ICF	INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH
WHO	WORLD HEALTH ORGANISATION
CBR	COMMUNITY BASED REHABILITATION
DPSA	DISABLED PEOPLE SOUTH AFRICA
NGO	NON-GOVERNMENTAL ORGANISATION
SAHRC	SOUTH AFRICAN HUMAN RIGHTS COMMISSION
UNCRPD	UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES
ILO	INTERNATIONAL LABOUR ORGANISATION
UNESCO	UNITED NATIONS EDUCATION, SCIENTIFIC AND CULTURAL ORGANISATION

## CHAPTER 1

### 1.1 INTRODUCTION

The aim of this study was to investigate the needs of people with physical disabilities, and the accessibility to available resources to them in the district of Butterworth, in the Eastern Cape Province. The researcher decided to do this study on people with physical disabilities, rather than on people with all types of disabilities; so as to provide an in-depth picture of their situation. Being a Physiotherapist, the researcher also has an interest and focus in working with people with physical disabilities, rather than with other types of disabilities.

All over the world, people with disabilities have always been excluded from society by decision makers, resulting in their being overly dependent on non-disabled people and state assistance (The Integrated National Disability Strategy, INDS, 1997). Services that are meant for people with disabilities are also not easily accessible to them. It is therefore necessary that needs be assessed first, then resources allocated accordingly. It must also be determined what barriers there are, preventing people with physical disabilities from accessing such available resources. This thesis therefore aims to address the above mentioned issues, in the district of Butterworth, in the Eastern Cape Province.

### 1.2 BACKGROUND OF THE STUDY

A survey done by the Community Agency for Social Enquiry (We Also Count), in 1999 to determine the prevalence of disability in South Africa indicated that there were between 2.3 to 2.5 million people with disabilities in the country. This meant that, at the time, between 5.7% and 6.1% of the total population of South Africa, were people with disabilities. The Eastern Cape Province had the highest number of people with disabilities at 8.9% of their population, followed by Kwazulu-Natal with 6.7% of their population, and then Limpopo with 6.3% of

their population. The province with the lowest prevalence of disability was found to be the North West Province, with only 3.1% of their population being people with disabilities.

It is important to note that having a low prevalence of disability does not always mean that fewer people in that area have disabilities; instead, it may be that, the concept of “disability” is construed differently, by different people. It can also mean that, although the incidence of disabilities may be high, available support for people with disabilities in that area may be insufficient; hence people with disabilities may die, keeping the prevalence of disability low. This is seen in the case of the Acquired Immune-deficiency Syndrome (AIDS), where people develop all kinds of disabilities, and die if there is not enough support. On the other hand, with good support, they may recover quickly; also resulting in a low prevalence of disability. Children with polio may not receive adequate support in the acute stage of the disease, and die, yet with good support, they survive, but are left with some form of disability.

As many as 80% of people with disabilities live in isolated, rural areas, where health and other related services are scarce, and for this reason, disabilities may not be prevented or detected in time (World Program of Action, 2002). Disabilities that can be prevented, for example, birth traumas, are estimated to give rise to as much as 20% of all disabilities. Such disabilities are not prevented because of the scarcity of services in these remote places, yet prevention programmes are less costly than to care for disabled persons (World Programme of Action, 2002).

The problem is made more complex by the fact that people with disabilities are often extremely poor, because of a link between poverty and disability. The occurrence of disability in a family often places heavy demands on the family financially, as there are increased medical and transport expenses. Therefore disability creates and exacerbates poverty by increasing economic strain (World Programme of Action, 2002).

Poverty is a serious problem for people with disabilities as many of them depend on the disability grant for their support. People who look after them, (caregivers) cannot go to work

and leave them alone, so they also depend on the same disability grant. Sometimes, if the disabled person had been the bread-winner in his family, the onset of disability means the loss of his /her income and the whole family suffers. Poverty is rife in rural areas so much that in some cases, having a disabled person in the family may be regarded as a blessing, because there will be the disability grant to support the family (Ingstad and Eide, 2011).

The Draft on Community Based Rehabilitation (CBR) guidelines (WHO, 2007), on the Evolution of the Disability Concept states that people with disabilities, because of the lack of access to opportunities, generally have lower education and income levels than the rest of the population. Subsequently, they are more likely to have incomes below the poverty level, and less likely to have savings and other assets. In this draft on community based rehabilitation guidelines, it is stated that poverty is a root cause of many disabilities, as poor people are usually not able to take advantage of prevention strategies for health, like immunisations for polio and other conditions that can be prevented. This makes those poor people vulnerable to those diseases, and in a cyclical manner; disability in turn, increases poverty.

### 1.3 THE PROBLEM

The continuing difficulties that people with disabilities face, in the context of this study can be related to five factors. These are discussed below:

- a) Lack of implementation of policies: Despite the fact that there are good policies that call for the equalisation of opportunities for people with disabilities, such as The United Nations 22 Standard Rules for the Equalisation of Opportunities for People with Disabilities, (1994), it has not been easy to actually put them into practise because of both attitudinal and environmental barriers. Many of the people with disabilities also have no idea about policies, rights and charters that are supposed to affect them and bring about positive changes in their lives. It is therefore important for the state to devise strategies that raise awareness, so that people with disabilities, their

families and their communities are made aware of these policies; and services they can benefit from (National Rehabilitation Policy, 2000). In 2009, the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD 2006) was ratified by the government of South Africa, therefore becoming law, but the challenge is the implementation of the policy, and the huge gap between policy and practice.

- b) Lack of Participation of People with Disabilities in Policy Planning: People with disabilities are also not involved in the plans to improve their own lives. The Integrated National Disability Strategy (INDS) of 1997 states that people with disabilities have always been taken for granted in that, the State and the professionals usually take important decisions that affect their lives, for them. This dis-empowers them and lowers their self-esteem (INDS 1997).
- c) Insufficient Resources Dedicated to Disabilities: Another problem is that there is a gross shortage or lack of resources, both human and financial, for rehabilitation programmes, especially in rural areas. For instance, at Butterworth Hospital, there is only one full time physiotherapist for the area. There is also one physiotherapist doing community service, and one physiotherapy assistant, and no occupational therapists or speech therapists. As a consequence of this shortage of human resources, and as Butterworth Hospital is an acute care hospital, patients are discharged early, as an example, those who have had strokes; are discharged before they are fully rehabilitated. It is not possible to do follow-ups, like home visits with these patients, after discharge because of the shortage of rehabilitation personnel and a lack of government transport. Therefore clients are given return dates for reviews. Many of these clients never come back for these reviews, mainly because of poor socio-economic conditions. Ingstad and Eide (2011), argue that the fact that patients have to travel long distances to health facilities, combined with the lack of money for transport, make it difficult for these appointments to be honoured.
- d) Poor Infrastructure in Rural Areas: There is also a problem of roads being in a state of disrepair, as well as lack of suitable public transport. Because of this lack of suitable public transport that make it necessary for patients to walk long distances. Thus people with disabilities have to hire vehicles to transport them to take advantage of services like the disability grant, to get benefits like the provision of wheelchair and walking aids, to get to the hospital or clinics, or to get identity documents (IDs). Unexpected

expenses such as this hiring of vehicles results in people with disabilities becoming more poverty stricken as vehicle owners charge exorbitant amounts for their services. Though there is an outreach programme for rehabilitation in the district of Butterworth, it is not easy to reach all the affected people, because of the poor condition of roads and the shortage of government vehicles. Kent, Chandler and Barnes, (2000), found that people with disabilities in a rural community experienced problems with the provision of services and information, provision of public transport, and with cost effective services.

- e) Changing Social Dynamics: Social circumstances including broken family units, the increased numbers of older people with no family to look after them, and broken marriages following the onset of disability, force people with disabilities to live alone. The attitudes of the community and the inaccessibility of resources have very serious effects on the lives of people with disabilities. People with disabilities are also not empowered to openly express their needs and their feelings in their communities, as they are usually not given the opportunity to do so. They must always accept decisions made by other people (INDS 1997).

An awareness of the difficulties experienced by people with disabilities experience in the rural district of Butterworth in particular, motivated the researcher felt to conduct research that would explore these difficulties and provide an opportunity for people with disabilities to express their particular needs. In addition, they were able to identify and describe the barriers preventing them from accessing available local resources. The researcher worked on the assumption that when these were identified the process of planning for services could be initiated. The process of involving people with disabilities in decision-making, would serve as a means of equalisation of opportunities and of encouraging people with disabilities to take an active part in their own rehabilitation, rather than being passive recipients in the process (WHO 1994).

Caregivers of people with physical disabilities, professionals, and other service providers that worked with people with physical disabilities had to be interviewed, in order to determine the level of understanding they had about the needs of people with physical disabilities, and their

accessibility to available resources. This process was intended to help in the development of new strategies to improve the quality of services provided. In order to help the researcher to structure her work so as to make an impact on the lives of people with physical disabilities, it was important for her to know more about their needs, and accessibility to resources. The results of this study, therefore, will indicate to service providers, including the researcher, where they are falling short with their services and what they should do; to improve service delivery in the district of Butterworth, as well as in the Eastern Cape as a whole. This will also fulfil the goals of the National Rehabilitation Policy (2000), by involving people with physical disabilities in decision making.

#### 1.4 MOTIVATION AND SIGNIFICANCE OF THE STUDY

The United Nations International Year of the Disabled Persons (WHO 1981), and the Coherent Policy for the Rehabilitation of People with Disabilities (1992) focused on full participation and equality of people with disabilities, and the United Nations 22 Standard Rules (WHO 1994) also calls for the equalisation of opportunities for them. Consequently, it is imperative that people with disabilities are fully integrated into their communities, participating fully in all spheres of life, in terms of opportunities, rights and freedom, and that their rights and dignity be respected. Such parity is not possible unless all barriers, physical and social are removed. These barriers may be removed, to create equal opportunities if service providers know what the needs of people with disabilities are, and what impediments prevent them from accessing available resources.

The miracle of our new democracy is marred by inequalities, discrimination, torture, abuse, segregation, exclusion and deprivation (INDS, 1997). Little attention has been given to the holistic development of people with disabilities, equipping them with social skills, life skills, and providing them with adequate and appropriate information to make informed decisions about their life choices (INDS, 1997). Though many of the pre-1994 apartheid barriers have been broken down and many South Africans are enjoying the new democracy, barriers do remain, particularly for people with disabilities. It is therefore clear that the breaking down of

many of these barriers requires more than just laws - it requires attitudinal shifts. The Integrated National Disability Strategy further states that; the inaccessibility of built environments is evidence of widespread ignorance of disability rights and prejudice against people with disabilities (INDS, 1997). This problem is seen in many government and private buildings, where there are steps; and no lifts.

It is disappointing and discouraging to note that, though it is more than thirteen years that the White Paper on Integrated National Disability Strategy was written; and sixteen years since the United Nations 22 Standard Rules were decided on; but very little has changed in the lives of people with disabilities. They are still experiencing almost the same in-equalities and discriminations in all spheres of their lives.

Disability is largely determined by how much the person's environment prevents him or her; from taking part in community life on an equal level with others; but it is imposed by society, when a person with impairment is denied access to full integration and social participation (SAHRC 2002). This report by the South African Human Rights Commission also states that views of people with disabilities must be recognised when legislation is revised so as to meet their requirements as citizens and to promote their rights to equality and dignity. All public sectors, in their planning and budgeting, must accommodate the needs and rights of people with disabilities. The South African Human Rights Commission report of 2002 in "Towards a Barrier-free Society" states that when developing new strategies, laws and regulations, all these sectors must include people with disabilities as equal partners.

Previous studies conducted on the needs of people with disabilities in countries like Great Britain and Australia, (Kersten et al., 2000), illustrate that community rehabilitation services did not satisfactorily address all the needs of people with disabilities, when compared to in-patient rehabilitation services. Findings were that many people with disabilities in the community, could not access services they needed, due to either financial problems, lack of suitable transport, or ignorance about available services (Kersten et al., 2000). The same applies to the situation with people with disabilities in the district of Butterworth. This situation therefore makes it imperative that needs are established first before planning; and

then allocation of resources so that rehabilitation services can be provided for according to the findings. There was also another study by the same authors, that illustrated that professionals did not know all the needs of people with disabilities (Kersten et al., 2000), and it would therefore be a disaster for the professionals to plan and decide on services to offer to people with disabilities; without consulting with them first.

In the studies mentioned above, (Kersten et al., 2000), it was only after the needs were investigated that resources were used more effectively. The researcher therefore feels that such a survey into the needs and resources of people with physical disabilities in the rural district of Butterworth will be of utmost importance. Then when the needs are identified, available resources can be better utilised.

## 1.5. THE OUTLINE OF THE CHAPTERS OF THIS THESIS

Chapters of this thesis will unfold in the following manner:

Chapter 1, as already seen, is the introduction to the study, giving the background to the study, the problem statement, the motivation and significance of the study; and how people with physical disabilities experience difficulties in accessing resources that are meant for them in this district of Butterworth. The aim and objectives, and a summary of the methodology are included in this chapter.

Chapter 2 is a literature review focussing on concepts of disability, the prevalence of disability internationally, and in South Africa, especially the Eastern Cape. This chapter also looks at other studies on the needs of people with physical disabilities in other parts of the world and what difficulties they encounter when trying to access available resources. It looks at how other studies have shown how much knowledge service providers have about the

needs of people with physical disabilities and what priorities they have regarding their needs for services.

Chapter 3 explains the research methodology of the study, looking at the study design, the study setting, study population, sampling method and how data was collected.

Chapter 4 presents the results of the study.

Chapter 5 presents a discussion and analysis of the results, focusing on how the study has identified the specific needs of people with physical disabilities, and how this knowledge can improve service delivery to people with disabilities. In addition, lessons learnt from the study are communicated and recommendations are made to different service providers in terms of improving and extending service delivery to people with physical disabilities.

## 1.6. CHAPTER SUMMARY

This chapter provides the background to the study and explores the associated problems and motivation for this study.

It has become clear that, although the objectives of the world programme of action regarding persons with disabilities are prevention of disability, rehabilitation and the realisation of the goals of full participation and equality, there are still social barriers that hamper this full participation and equality (World Programme of Action – updated in 2002)

It has therefore emerged that there is a need to know what barriers prevent people with physical disabilities from full participation, in order to address these and plan services according to needs. By discovering what people with physical disabilities feel their needs are, these may be addressed more equitably, thus, proposing the motivation for this study and the significance thereof.

## **CHAPTER 2**

### **LITERATURE REVIEW:**

#### **2.1. INTRODUCTION**

To be able to investigate the needs of people with physical disabilities in the district of Butterworth, and the availability and accessibility of resources to them, it was important to review literature on the subject critically, to establish what has been done in the field before. The researched literature was analyzed, to determine the link between those studies to the present research.

This chapter looks at the general overview of the research topic, definitions of disability and physical disabilities, needs of people with physical disabilities as discussed in previous studies. The connections in terms of HIV/AIDS, poverty and disability are also explored. It examines the impact of disabilities on people with physical disabilities themselves, and on other people, attitudes towards disabilities, rehabilitation and integration. The rights of, and policies for people with disabilities, and especially those with physical disabilities are also discussed. A review of the needs of people with physical disabilities, and the resources that are available to them round off this chapter. This discussion provides a rationale for the current study and for the methodology used.

## 2.2. GENERAL OVERVIEW

The National Rehabilitation Policy (DOH 2000), states that there is a need to find solutions to problems associated with rehabilitation. According to managers and rehabilitation professionals, this policy is structured to illustrate that part of the solution to problems, especially those of environmental and attitudinal barriers, is to involve clients in decision making. In this way, clients were made part of the process, to ensure that they owned whatever was decided upon, and to empower them at the same time. At the outset, it was therefore necessary to know from people with disabilities, what their needs were, and how accessible the available resources were, to them.

Watzlaf et al (2000), in their study on the Disability Assessment Database Model, state that there is an absolute need for people with disabilities to participate in planning for services. They argue that many well-meaning individuals think they know what people with disabilities need, yet they do not. These researchers found that programs and services are often planned, designed and implemented without any input from the people who are going to use these programs and services, (Watzlaf et al., 2000).

The South African Human Rights Commission (SAHRC, 2002), states that people with disabilities have a wide range of needs and certain circumstances affect their rights and equal access to social and economic opportunities. It is therefore important that organisations for people with disabilities must be afforded beneficial opportunities, to participate in the process of developing, implementing and enforcing the legislation. Therefore in all sectors, planning and budgeting processes must accommodate the needs and rights of people with disabilities (SAHRC, 2002). This will happen only when needs of people with disabilities acknowledged.

To be able to have a good understanding of disability and disability concepts, it is necessary to look at points such as definitions of disability, causes and prevention of disabilities, the impact of disability on the lives of people with disabilities themselves and their families.

### 2.3. DEFINITION OF DISABILITY

The definition of disability varies across health, educational, vocational and social services. Van Brackel and Officer (2008) state that “A definition of disability must be flexible enough to define disability in all aspects, must be etiologically neutral, be applicable to a range of settings, and take into consideration the environment”, (Van Brackel and Officer, 2008). Within the context of health, disability is defined as “Any restriction, (resulting from an impairment), or lack of ability to perform an activity in the manner or within the range considered normal for a human being, taking into account age and culture”, (World Health Organisation, WHO, 2001). Examples of these activities are, caring for one-self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working. An impairment, on the other hand, which the medical model of disability emphasizes on, is any loss or abnormality of psychological, physiological or anatomical structure or function (WHO, 2001)

In the context of the social model of disability, the concept is defined as the loss or limitation of opportunities to take part in the normal life activities in the community, on an equal level with others, due to physical and social barriers (Tregaskis, 2002). Also, within the social model, disability is viewed as the disadvantage or restriction or the exclusion of people with impairments from the mainstream of social activities. According to Bury, (2000), disability activists preferred to define disability as “social oppression”, brought about by discrimination and exclusion. This definition of the social model of disability contradicts the previously victim blaming medical model that saw people with disabilities as “the problem”, placing a responsibility upon them to adapt, to be able to fit into the mainstream society.

Disabled People South Africa (DPSA) state that, Disabled people internationally are effectively coming together and challenging society, those in authority and professionals to recognise that:

“Disability is not the major barrier for people with disabilities to live fulfilling lives. The external or environmental barriers, including negative attitudes, towards disability, are where disabled people’s oppression lies” (DPSA 2001:12-13).

The concept of disability therefore reflects the consequences of impairment in terms of functional performance and activity by the individual. The interaction between an individual with impairment and the social, cultural, or physical environment, within which the individual lives, can disable that individual. DPSA, also states that most of the day to day problems that people with disabilities face; are caused by the fact that they live in a hostile, disabling world that is largely designed to suit able-bodied people. They argue further that people with disabilities can actually say: “it is not me or my body that is at fault, but the society around me”, (DPSA, 2001: 14). In the South African Human Rights Commission (SAHRC, 2002) it is stated that society needs to understand how cultural, social, physical and other barriers continue to prevent people with disabilities in South Africa, from enjoying their constitutional rights to equality, freedom, and human dignity. For example, the fact that many built environments remain inaccessible is evidence of widespread ignorance of disability rights and prejudice against people with disabilities (SAHRC, 2002).

At the beginning of 2008, a memo released by the South African Department of Health and the Cabinet of South Africa came up with this definition of disability: “Disability is the loss or elimination of opportunities to take part in the life of the community equitably with others, that is encountered by persons having physical, sensory, psychological, developmental, learning, neurological or other impairments which may be permanent, temporal, or episodic in nature, thereby causing activity limitation and participation restriction with the mainstream society. These barriers may be due to economic, physical, social, attitudinal and/ or cultural factors”, (DOH 2008). This definition agrees with the social model of disability, with DPSA, and with the International Classification of Functioning, Disability and Health (ICF).

The World Health Organisation (WHO) developed ICF “to provide a scientific basis for understanding and studying health and health related states, outcomes and determinants, to establish a common language for describing health, and health related states, in order to

improve communication between different users” (ICF Short Version, WHO 2001:6).

According to the ICF (WHO, 2001), there are various interactions that come to play in the process of impairment, activity limitation and functioning as well as participation restrictions within the environment, that either make life better or worse for people with disabilities.

Disability, therefore, is not only caused by the impairments that an individual might be having, but the environment plays a major role in making the disability better, or worse. The environment therefore can either be a facilitator, or a barrier to people with disabilities. This is illustrated in figure 1 on the next page.

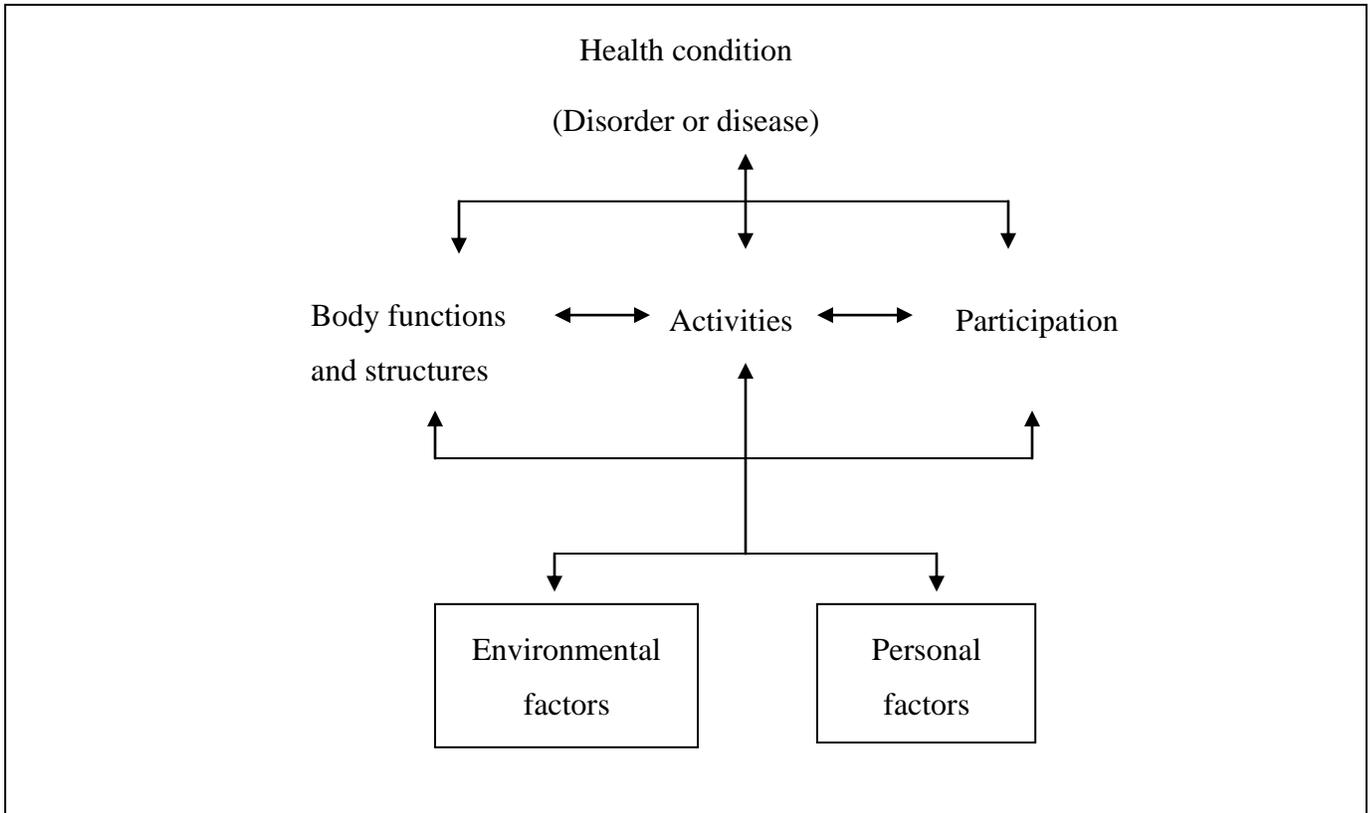


Figure 1: Interaction between the components of ICF (WHO, 2001 Short Version: 26).

This figure illustrates that an individual’s functioning in any environment is a result of a complex relationship between a health condition and contextual factors, meaning environmental factors that are extrinsic, intrinsic and personal factors, (WHO, 2001). This figure shows that the presence of impairment is not necessarily the cause of any activity limitation. On the other hand, the presence of an environment that restricts the participation in the activities in the family or the community could lead to eventual impairment, and disability, for example, mental depression. It is therefore clear that impairments do not always lead to disabilities but environmental and personal factors, on the other hand, can contribute to disabilities (WHO, 2001).

The researcher therefore, being a health professional prefers to use the definition that was decided on by the World Health Organisation (WHO, 2001) because it gives more meaning to her study, as it involves activity limitations and participation restrictions. The study requires that the researcher explores the opportunities people with disabilities are missing out on, as well as barriers that prevent them from enjoying life like everyone else.

#### 2.4. PHYSICAL DISABILITY

Physical disability is a physical limitation to perform certain activities like movement, resulting in activity limitation and participation restriction, making it difficult to integrate fully into society (WHO, 2001). Physical disability refers primarily to damage to muscles, nerves, skin or bones, resulting in paralysis or weakness of muscles, contractures or shortening of tissues, mal-union or non-union of fractures resulting in deformities and shortening of limbs, joint stiffness, and pain. Examples of people with physical disabilities include those with cerebral palsy, quadriplegia, paraplegia, hemiplegia caused by strokes and head injuries, post-polio paralysis, osteo and rheumatoid- arthritis, limb amputations, muscular dystrophy and other post-injury complications, (DPSA, 2001). Injuries resulting in fractures and burns may cause temporary or permanent disability.

Physical disability makes it difficult to move about and to perform activities of daily living such as dressing and undressing, feeding, and cleaning oneself. It is often, but not always associated with weakness of the affected part, or with pain (DPSA, 2001). People with physical disabilities experience different kinds of barriers that limit their participation in everyday activities. Some of these barriers may be present in buildings without lifts or ramps, where flights of stairs might prevent anyone who uses a wheelchair or crutches from entering.

Many people with physical disabilities need assistive devices like crutches and other walking aids, wheelchairs, splints, Orthotics and Prosthetics, specialised computers and adjustments to motor vehicles to be able to live independently. Those with severe physical disabilities often

need personal assistants, or caregivers, to constantly look after them, and help them perform those activities they need to be helped with (DPSA, 2001).

The researcher found it necessary to put forward definitions of activity limitation and participation restriction, caused by physical disabilities. The following definitions are therefore provided to show how movement, activity limitations and participation restrictions are affected by physical disabilities in day to day activities.

#### 2.4.1. MOVEMENT:

Movement is defined in the field of Physiotherapy as a means of interaction between individuals, as well as between a person and the environment, (Gardiner, 1969). It is a fundamental characteristic of all animal life, and the means by which the organism adapts itself to the demands made upon it by the environment in which it lives (Gardiner, 1969). Knott and Voss, (1968) state that purposeful movements are basic to a successful life and are co-ordinated and directed towards an ultimate goal. Different factors can affect movement either positively, or negatively. These factors include pain, muscle weakness or paralysis, joint stiffness, contractures, in-accessible environment and lack of stimulation to move. When movement is limited for any reason, it results in physical disability. Those factors that have a positive effect on movement are: assistive devices - like wheelchairs and walking aids, rehabilitation, accessible environment and a positive attitude (DPSA 2001).

When there is loss of, or decreased movement, people find it difficult to engage in income generating activities, in household work like fetching water or firewood, or any other activities that need to be done outside the home, such as going to the shops (Munyinda and Whyte, 2011).

Understanding the effects and experiences of mobility loss from the perspective of people with physical disabilities may provide insights into the provision of programmes, services, and advocacy efforts that support them (Finlayson and Van Denend, 2003).

#### 2.4.2. ACTIVITY & PARTICIPATION:

Activity is the execution of a task, or an action, by an individual, while participation is the involvement of an individual in a life situation. These tasks include, learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships (WHO, 2001). Declines in functional mobility are associated with loss of social connections, reduced participation, and altered abilities to perform self-care, productivity and leisure occupations (Finlayson and Van Denend, 2003). Kennedy et al. (2010) recognise the fundamental goal of rehabilitation as one of societal participation. However, they point that “wheelchairs have been reported as being the most frequently stated barrier to participation, preceding the actual impairment, highlighting the need for high-quality wheelchairs, to provide as little restriction as possible, to facilitate participation”. They add that environmental barriers such as transport may prevent community participation (Kennedy et al, 2010).

#### 2.5 A LINK BETWEEN HIV/AIDS PANDEMIC, POVERTY AND DISABILITIES:

There is a high incidence of disability among poor people, the reason being that poor people do not usually have the means or knowledge to access the resources that can prevent or minimize disabilities (Ingstad and Eide, 2011). According to Disabled People South Africa (DPSA 2001), poor people tend to become disabled because of their living conditions, due to malnourishment and unhealthy housing. They are also more exposed to violence, as seen in the district of Butterworth, with stick fighting causing head injuries, and stab wounds, resulting in paralysis, which lead to disabilities. This exposure to trauma resulting in brain injury is illustrated in a study by Salmon et al. (2007) explaining that the incidence of brain injury is higher in rural areas. The greater numbers of motor vehicle accidents in rural areas may be attributed to the lack of suitable transport or competent drivers during long-distance travel, or the use of cars, on roads that are in poor condition (Salmon et al., 2007).

The effects of disability deteriorate with poverty, but there is also a vicious cycle as disability in turn, causes more poverty (Ingstad and Eide, 2011). The latter may be because people with disabilities, especially physical disabilities, incur expenses like the hiring of expensive transport because they cannot access normal public transport. People with physical disabilities sometimes also need to have helpers or caregivers to help them with activities that are difficult for them to do on their own; hence they may have to hire helpers, (DPSA 2001). These helpers have to be paid from the disability grant that the person with disabilities receives. Albert (2003-2005), in the Disability Knowledge and Research Programme, said this about the association between poverty and disability:

- a) “Social factors make it more likely that poor people will contract impairments; and people with impairments are likely to become or to remain poor”.
- b) “Disabled people struggle to find employment because the impairments they have make it difficult for them to perform some manual tasks, and vocational training opportunities are limited, and tend to be in urban areas only”.
- c) “People with disabilities are denied loans to start businesses or income generating projects, because they are seen as presenting a high risk”.
- d) “Malnutrition, which contributes to a whole range of impairments, thus causing disabilities, is also closely related to poverty” (Albert 2003- 2005).

Ingstad and Eide (2011), on the vicious cycle of disability and poverty, conclude that poverty influences or creates poverty in that their being poor may delay the process of people seeking help for health problems that are normally curable. For instance, eye or ear problems may lead to permanent blindness or loss of hearing, and difficulties in labour may be brought to medical attention too late to save the baby from permanent brain damage leading to cerebral palsy, and/ or mental disability or epilepsy.

Many people have to undergo rehabilitation and sometimes need assistive devices like walking aids and wheelchairs, because of disabilities they develop, from becoming HIV positive, or having AIDS. The researcher has noticed that, in her work as a physiotherapist, people affected by AIDS may quickly respond to antiretroviral (ARV) drugs and recover, or

they may die after a short illness. It is important to note that people with disabilities are also vulnerable to HIV infection as well as other sexually transmitted infections (STIs) according to Nganwa et al. (2002), and Yousafzai et al. (2004), who quote the following reasons:

- a) Overprotection by the family: Children with disabilities are not made aware of sexual challenges, which results in adolescents being defenceless to deal with sexual demands.
- b) Sexual abuse: Sexual abuse of children and youth with disabilities by family members and members of the community is very common. Women with disabilities are more vulnerable to rape and sexual exploitation because there is a belief that they are free from HIV/AIDS and STIs as they are supposed to be sexually inactive.
- c) The need to be married and to have children: Because marriage is usually based on the ability to perform manual tasks, such as carrying water from the wells or communal taps; and working in the fields, women with physical disabilities experience difficulty in finding marriage partners. They therefore end up having many sexual partners. Another contributing factor is their desperate need to have their own children, who will look after them in old age.
- d) Access to information: Information on the prevention of HIV infection and STIs is usually not provided in languages that are understandable to the blind, the deaf or those with intellectual disabilities. Many people with disabilities therefore miss out on information promoting of behaviour change, condom use, early detection and treatment of sexually transmitted infections, and community based management of AIDS and TB.
- e) Poverty: People with disabilities have limited opportunities for participation in education and employment, leading to poverty. They are then driven by poverty to use sex as a means to meet their economic needs.
- f) Low Self Esteem: Women with disabilities usually have low self esteem because the societal concept of beauty, generally, does not include them. Their resulting lack of confidence, forces them into having many sexual partners.

The above studies demonstrate the association between HIV/AIDS and disabilities, in that it is not only about people living with HIV/AIDS who develop disabilities, but also about people with disabilities developing HIV/AIDS. Community Based Rehabilitation (CBR) is meant to improve activity and participation of people with disabilities into the community. Thus it is important to ensure that integration is accompanied by social skills that protect people with disabilities from sexual exploitation and exposure to HIV. CBR should be a vehicle of information to them, and their families, about sex and the HIV epidemic, to protect them from sexual exploitation (Nganwa et al., 2002).

Mji et al., (2009), in their paper on 'Realising the rights of disabled people in Africa', commented that, in the context of health promotion; and health protection, there is a need for rehabilitation services to address sexuality, HIV/AIDS and sexually transmitted diseases.

## 2.6. THE IMPACT OF DISABILITY:

Disability affects the lives of almost all South Africans at some stage, or in some way. This is because it does not affect only the disabled individual, but also affects the family, friends and fellow community members (SAHRC, 2002). An example of this is that of a person with disabilities who needs a full time caregiver. In most cases one member of the family, for example, a wife, a daughter, a mother, has to resign from work to be able to look after a relative with disabilities. Friends and other community members are also affected when there is someone with a disability, when there is a need to help him/her with transport, rehabilitation, or providing any kind of help.

### 2.6.1. POVERTY:

One of the major impacts of disability, as discussed before, is poverty, caused by an increased financial burden on the family. The fact that the person who becomes disabled may have been the breadwinner in the family and the fact that the caregiver may also have to stop working, may result in increased financial strain. In the district of Butterworth, as seen with clients who visit the Physiotherapy Department, there are issues around hiring expensive transport to take

someone with a disability, especially a person with severe physical disability, to see a doctor, or to get other services, because of problems with public transport. In many instances the disabled person gives up on benefiting from a service because he cannot afford it. An additional concern is that the need to provide care for the person with a disability, such as the buying of disposable napkins or other medical and surgical supplies affects the household income. These increased expenses act as barriers to people with physical disabilities receiving specific services provided for them.

#### 2.6.2. THE PSYCHOLOGICAL IMPACT:

Another effect of disability is the psychological impact. The relationship between physical disability and the occurrence of emotional and psychological problems is striking. These include difficulties in socializing, problems managing stigma, disruption in marital and family life and suicide risk (Pelletier, Rogers and Thurer, 1985). Njoki, Frantz & Mpofo (2007) found that youth with spinal cord injuries in the Western Cape used alcohol and drugs as a coping strategy due to personal struggles in adjusting to the new identity.

Kinavey (2007) found that adolescents with disabilities had problems with body image, as braces and crutches were not part of being pretty. Unplanned and ill-timed bowel and bladder evacuations resulting from spinal cord damage were a constant source of worry and shame; and prevented people with physical disabilities from socialising.

Ide (2004) found that, although the sexual functions were usually spared in limb amputees, unlike in spinal cord injury clients, the effects of the body image, and the emotional and psychological adaptations of losing a body part impacted negatively on the sexuality of amputees.

Anxiety and depression tend to affect those people with progressive conditions like multiple sclerosis and rheumatoid arthritis, caused by fears of not knowing what the future held (Finlayson and Van Denend, 2003). These people experience fears and uncertainties about what further mobility losses would mean for them, their families or caregivers. These anticipated mobility losses enhanced concerns of becoming a burden (Finlayson et al, 2003). Neville et al. (1999) found that people with arthritis also had fears about long-term side effects of taking excessive medication.

### 2.6.3. SOCIAL DEPRIVATION:

Social deprivation or the social exclusion of people with physical disabilities are experienced in the form of unemployment, poor accessibility to built environments, and barriers to utilisation of Primary Health Care (PHC) preventive services. An example of this is mentioned by Schopp et al. (2002), in their study of the impact of comprehensive gynaecologic services on health maintenance behaviours among women with spinal cord injury, where they found that many barriers existed.

These included barriers to health care services, in the form of the lack of access to care locations, health screening equipment that was not suitable for people with disabilities, and the lack of sensitivity and knowledge by health care providers about health care needs of people with disabilities. These barriers to primary health care made these services inaccessible to people with physical disabilities, therefore put them at risk of being affected by conditions like cancer that might have been detected and prevented earlier. Too often, people with disabilities are not recognised as experts, or able to understand their own conditions or disabilities (DPSA, 2001). They are usually spoken to as if they were children, or simply ignored, while the health care provider makes decisions about his/ her health care with the caregiver (Piotrowski and Snell, 2007).

Physical or attitudinal barriers prevent people with disabilities from enjoying life like other people. Such examples were the barriers to resuming work or employment after the onset of a disability that might exclude them from the advantages that people get from work. Their independence, feelings of competence, achievement and self-worth as well as feelings of being valued, making a contribution to the community and belonging are undermined. People with disabilities are usually the last group to enter the workforce, and the first out (Russell, 2002). Employers often set selection criteria that exclude people with disabilities, and workplaces are often inaccessible and inappropriate for people with disabilities, resulting in poor performance or incapacity. Employees with disabilities are sometimes encouraged or forced to apply for disability benefits or to retire earlier than other employees when reasonable accommodation of their needs would allow them to continue working as productive employees (The Code of Good Practice for Employment of People with Disabilities, 2002).

People with progressive medical conditions also faced difficulties in finding employment, or continuing to work after the onset of disability. When one has to stop working because of a disability, one is not only faced with losing a job, but also losing status. One is perceived differently; and will have a changed position in society when one is no longer working (Abma et al., 2005). People with physical disabilities therefore do not only suffer physical problems, but also suffer emotional and social losses. To them, disability means:

- Loss of function
- Loss of work or employment
- Loss of status
- Loss of social contacts

It is therefore important for employees who become disabled, to undergo vocational rehabilitation, so that they do not lose their jobs. Vocational rehabilitation is about supporting people with disabilities to help them remain in their current work, to modify their work, find new work or to give up work in a planned and co-ordinated manner (Sweetland et al., 2007).

#### 2.6.4. PEOPLE'S MISCONCEPTIONS:

There are also misconceptions, the community assuming that disability spreads out into all areas of a person's life that if the person is disabled in one way, he or she is disabled in all ways (Chance, 2002). People with disabilities are viewed by society as lacking the capacity for normal and satisfying sexual relationships. They are seen as asexual beings, without the same desires and needs for sexual and romantic intimacy that non-disabled people have (Chance, 2002). Parents tend to believe that their disabled adolescent and young adult offspring are permanently dependent on them and, like small children, should be shielded from adverse social situations. This can result in a lack of social skills on how to react to sexual advances (Chance, 2002).

#### 2.6.5. HEALTH PROBLEMS:

Pain and discomfort, associated with movement or certain postures, in people suffering from arthritis and other conditions that result in pain, like atherosclerosis, have been reported as causing disruption in sleep patterns of the people with disabilities, and their caregivers

(Wright et al., 2006). Back pain is the most common symptom in those people aged under 65 and knee pain in those aged more than 65, with the highest prevalence of knee pain among women aged 75 and above (Urwin et al., 1998). Brekke, Hjortdahl and Kvien (2002), in their study on musculoskeletal pain found that psychological factors like depression or stress contributed to the perception of pain, which explains why the burden of pain is greater in deprived populations than in more affluent ones. The difficult part about pain is that it is not visible; it is privately experienced and demonstrable to others only through the individual's narrative or non-verbal pain behaviour (Douglas, Windsor and Wolin, 2008).

#### 2.6.6. IMPACT ON FAMILY:

Another impact of disability is dependency. The inability to perform key activities like mobility, feeding, personal hygiene and safety awareness leads to a person with disabilities being dependent on other people. This care-giving is generally executed by family; that is parents, children, spouses or employed care-givers. An investigation by Harwood, Sayer and Hirschfield (2004) on the prevalence of dependency indicated that a number of people worldwide require daily assistance from other people in carrying out health, domestic or personal tasks. Findings in this study were that the greatest burden of dependency currently falls in Sub-Saharan Africa, where the dependency ratio is more or less 10% of the population, compared to 7 – 8% elsewhere. Therefore, the implications were that there was more dependency in Sub-Saharan Africa than in other parts of the world (Harwood et al., 2004). Dependency is one of the causes of poverty, because the person doing the care-giving has to quit his job, so as to be able to look after the disabled relative.

Harwood et al. (2004) estimated large increases in the population of people with disabilities in most parts of the world, therefore an increase in dependency. This necessitates development of an infrastructure for Health and Social care, with substantial capacity to support this population of dependent people and their carers. These estimated increases in dependency were due to the increase in infectious diseases and trauma prevalent in the developing world, as well as degenerative diseases in the economically developed nations.

Another impact of disability on the family is the strain on caregivers. Murphy et al., (2006), found the stress of care-giving to have a negative impact on care-giver health. Parents of older children with disabilities, especially those with cerebral palsy, report having back and

shoulder pain, chronic fatigue, migraine headaches, sleep deprivation, stomach/intestinal ulcers and distress, (Murphy et al., 2006). Parents of children who are technology dependent report anxiety, anger, guilt, frustration, sorrow, social isolation, sleep deprivation and depression. Spending all their time and funds in care-giving tasks and care-giving demands are indicative of poor caregiver health and wellbeing. Parents reported worrying about the future of their children with disabilities when they, the parents, were gone. They reported lack of time for their own health and financial consequences as well, as mothers of children with disabilities were unable to enter or maintain paid employment (Murphy et al., 2006).

A study by Wright et al. (2006) showed that parents and caregivers of children with physical disabilities were concerned about their children's sleeping positions. Most of these concerns were due to pain, abnormal muscle tone, respiratory and digestive problems. Many parents indicated that their children needed help to change position during the night. Therefore, the overall quantity and quality of sleep in children with physical disabilities and their parents or caregivers was greatly affected. This resulted in sleep-related stresses and problems with daytime functioning and safety.

It appears that the needs of carers of people with disabilities are often forgotten by the health and social care professionals whereas van Teijlingen, Friend and Kamal (2001) found that caregivers also needed help with housework, freedom to go out (respite care) and knowing that someone was available to help when required. Some carers found it difficult to cope with the physical and emotional stress of care-giving and also ended up having a longstanding illness or some form of disability, themselves.

## 2.7 PEOPLE'S ATTITUDES TOWARDS DISABILITIES

Attitudes of people can determine whether a person with disabilities will be able to access resources or not. For example, if the mother of a disabled child is afraid of what her neighbours will say when they see her child, then she will keep her child indoors, and not take the child for rehabilitation. Different reactions and attitudes of the society towards people with disabilities can either encourage or discourage people with disabilities to access

resources. These reactions and attitudes vary for different types of disabilities, (Auslander and Gold, 1999).

People from different cultures react differently towards disabilities. In some cultures and religions, disability is seen as punishment from God for transgressions committed in previous lives, it represents “Divine” justice (Mont, 2007). This can be seen in the Bible reading from John 9: 1-2, where Jesus healed a man who was born blind. Jesus’ disciples asked Him, saying, “Rabbi, who sinned, this man or his parents, that he was born blind?” This is a negative attitude that still exists even in our days, that when a child is born with a disability, for instance, then it is assumed that the parents are punished for their wrongs. Within the Xhosa tradition, if people of the same clan marry or have sexual relationships, it is believed that they will be punished and have children with disabilities. Xhosa people also have a belief that if you laugh at someone who was born with a disability, (*isidalwa*) - maybe at the way he/she walks, or looks like - then you will be punished and give birth to a child with a disability. Another belief among Xhosa people is, when it comes to head injuries and strokes that cause hemiplegia, that the person was bewitched. They believe that if someone becomes hemiplegic after being hit on the head with a stick, as in stick fighting, then that stick must have been tampered with using bad traditional medicine (*isitolom*), and should therefore be treated with traditional medicine. The researcher knows about these beliefs as she is a Xhosa herself, and she grew up hearing about them, and as a Physiotherapist, the clients she treats still have these beliefs, and even report to her when they go for traditional medicine.

One of the attitudes to disability is discrimination against people with disabilities. Discrimination includes any act, practise or conduct which has the effect of unfairly hindering or precluding any person, or persons, who have, or who are perceived to have disabilities, from conducting their activities freely. This discrimination undermines their sense of human dignity and self worth, and prevents their full and equal participation in society (DPSA, 2001:31).

There are also family reactions when it comes to relationships with people with disabilities. Couples consisting of one disabled person and a non-disabled partner often face opposition from family and friends. The non-disabled partner receives negative messages that he/she is involved with the disabled person merely out of pity, and not out of love. The non-disabled partner is even admired and treated like a saint for the sacrifice, being willing to be involved in a relationship with someone with a disability. On the other hand, the relatives and friends

of the disabled person may oppose the relationship between him/her, and a non-disabled partner, thinking that their friend/family member is more likely to find understanding about the disability with someone who shares similar challenges (Chance, 2002). On the contrary, it was also demonstrated that there are negative reactions from the society even when people with disabilities have relationships with other people with disabilities (Campbell, 2002).

In cases where disability progresses gradually, as in Multiple Sclerosis and arthritis, people's reaction is such that friends and family do not accept that their relative or friend has really got a disability. They do not expect that their friend or relative can also be in that category of people with disabilities. Finlayson and Denend (2003) showed that when people with progressive conditions started using assistive devices like wheelchairs or scooters, they were discouraged by those close to them from using these. They were seen as "giving up", or "not trying" enough. They were also said to be "losing hope".

Because of the different forms of discrimination that people with disabilities experienced, they responded by forming their own organisations. These will be discussed in the following section.

## 2.8 ORGANISATIONS OF AND FOR PEOPLE WITH DISABILITIES

There are organisations in South Africa and all over the world that are meant to protect and empower people with disabilities in all the difficulties they may encounter in their lives. It is important to note the difference between organisations *for* people with disabilities, and those *of* people with disabilities. Organisations *of* Disabled Persons (DPOs) are controlled by people with disabilities themselves. This means that the constitution of a DPO protects disabled members' decision making powers, for example, by ensuring that at least two thirds of the members of the executive committees are made up of people with disabilities. Those *for* disabled people on the other hand are usually controlled by concerned community members and service providers, with little or no active participation in decision making by people with disabilities.

The most significant organisations *of* and *for* people with disabilities in the context of this study are listed below:

- Disabled People International (DPI), formed in 1983. Its aim is to promote the human rights of people with disabilities, through full participation, equalisation of opportunities and development.
- Disabled People South Africa (DPSA) is the South African affiliation of DPI.
- Rehabilitation International (RI) is a federation of national and international organisations working for the prevention of disabilities, the rehabilitation of people with disabilities, and equalisation of opportunities within society on behalf of people with disabilities and their families throughout the world, and the
- National Council for People with Physical Disabilities in South Africa (NCPPD)

It is largely through the work of organisations such as these, that policies have been developed to protect and promote the rights of people with disabilities. Some of these policies and their implications are discussed in the next section.

## 2.9 POLICIES AND RIGHTS OF PEOPLE WITH DISABILITIES:

The United Nations (UN) has a long history of promoting the rights of people with disabilities, focussing mainly, during the 1940s to the 1960s on prevention of disabilities, and rehabilitation. The 1970s saw a shift towards the promotion of the human rights of people with disabilities (DPSA 2001). In 1981, the International year of the Disabled Persons was celebrated. The theme for those celebrations called for a plan of action at national, regional and international levels, with an emphasis on the equalisation of opportunities, prevention of disabilities, and rehabilitation (DPSA 2001). The World Programme of Action Concerning Disabled Persons (2002) has objectives like the prevention of disabilities, rehabilitation and equalisation of opportunities. In planning for rehabilitation and supportive programmes, it is

essential to take into account the customs and structures of the family and the community; and to promote their abilities to respond to the needs of the disabled individual. Services for disabled persons should be provided whenever possible within the existing social, health, education, and labour structures of the society.

The policies and rights most relevant to people with disabilities in the South African context are:

a) The United Nations 22 Standard Rules on Equalisation of Opportunities for People with Disabilities (1994), which imply a strong moral and political commitment on the part of states to take action to ensure the equalisation of opportunities for persons with disabilities. Areas to be targeted to be able to achieve this equalisation of opportunities include:

- Awareness raising
- Medical care
- Rehabilitation
- Support services
- Accessibility
- Education
- Employment
- Income maintenance and social security
- Family life and personal integrity
- Culture
- Recreation and sports
- Religion
- Information and research
- Policy-making and planning
- Legislation

- Economic policies
- Co-ordination of work
- Organisations of persons with disabilities
- Personal training
- National monitoring and evaluation of disability programmes in the implementation of the rules
- Technical and economic cooperation
- International cooperation

The above mentioned are the 22 standard rules and together they emphasize the right of persons with disabilities to the same opportunities as other citizens and to an equal share in those improvement in living conditions resulting from economic and social development.

- b) The United Nations Convention on the Rights of Persons with Disabilities (2006), the purpose of which was to promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. It called for societies to view people with disabilities as key decision makers in matters that affect their own lives
- c) The Integrated National Disability Strategy (INDS SA, 1997) is South Africa's commitment to the promotion of rights of people with disabilities. It is South Africa's response to the United Nations 22 standard rules on equalisation of opportunities and it was endorsed by the then Deputy president of South Africa, Mr Thabo Mbeki.
- d) The Constitution of South Africa (1996), in section 9 calls for the prevention or prohibition of unfair discrimination and for the promotion of equality with regard to race, gender and disability. Sections 10 and 11 are about the right to dignity, and the right to life. Section 29 is about the right to basic education. This calls for equality of opportunities of all citizens of South Africa, including people with disabilities.
- e) The Employment Equity Act (1998) calls for affirmative employment opportunities for people with disabilities in the public and private sectors. Its terms are that all legal entities that employ more than 50 people must submit their employment equity plans

to the Department of Labour, showing how many people with disabilities are employed in their organisations, and what positions they hold

- f) The Code of Good Practise on the employment of people with disabilities (2002) calls for reasonable accommodation for people with disabilities so that unfair discrimination can be avoided from recruitment to termination of employment. Selection criteria, workplaces and training facilities must be accessible, and appropriate for people with disabilities
- g) The National Rehabilitation Policy (2000) is the commitment of the South African government to bringing health services closer to the people by adopting the Primary Health Care (PHC) approach, of which Rehabilitation is an important component. It is an attempt to create the right environment for quality rehabilitation services
- h) Free Health Care Policy for people with disabilities at hospital level (2003), for people with moderate to severe difficulties in mobility, self care or activities of daily living, communication, seeing, hearing, involvement in major psychosocial life situations e.g. interpersonal interactions, including mental disabilities
- i) The Education White Paper 6 (2001) provides a framework for the government's long term goal to achieve an inclusive education and training system. This policy calls for children with disabilities, especially physical disability, to attend local schools, and to discourage sending them to special schools, that are very few. It is important to note that schools are accessible to all children, and educators must be orientated on how to help pupils with disabilities. Educators from special schools can be used as a resource to orientate other educators on how to help children with disabilities.

Since the United Nations and the World Programme of Action concerning Disabled Persons had objectives such as the prevention of disabilities, rehabilitation and equalisation of opportunities, the researcher finds it necessary to discuss rehabilitation as it is one of the important needs of people with physical disabilities, and it is used to improve disabilities.

## 2.10. REHABILITATION:

Rehabilitation is defined as a process that assists People with Disabilities to develop or strengthen their physical, mental or social skills (WHO 1994). It is the process of helping an individual to achieve the highest level of independence and quality of life possible, physically, and emotionally. The ultimate goals of rehabilitation are; minimizing disability, by ensuring equalization of opportunities, full participation, independent living and economic self-sufficiency.

Rehabilitation can be provided, using three different methods, these being:

- Institution based Rehabilitation
- Outreach Rehabilitation
- Community Based Rehabilitation

Each of these methods of rehabilitation will be discussed briefly, below to show how each strategy can be used to improve the lives of people with disabilities:

- a) Institution Based Rehabilitation: This kind of rehabilitation focuses on specialized short-term intensive therapy. It is an important part of the referral system for the provision of special assessments, surgical interventions, skilled treatment and specialized equipment. Intensive rehabilitation is also available in the institution, as most rehabilitation personnel are found in institutions. Unfortunately, this kind of rehabilitation does not always give lasting results because of the lack of continuity, partly due, to irregular attendance of clients for rehabilitation. It also focuses on clients only, and gives very little attention to the client's family and the community (WHO 1994). In Butterworth, this is the only kind of rehabilitation that is available, as people with disabilities are only rehabilitated at the hospital. It is offered only in the form of Physiotherapy. These clients are seen as both in-patients, and out-patients.

- b) Outreach Rehabilitation Service: This program provides for visits by rehabilitation personnel to the homes of people with disabilities. The focus here is on the disabled person and the family, but it does not involve the community. Not much social change is achieved because of this lack of community involvement. The problem with this kind of rehabilitation is the cost, as it requires vehicles; which are usually in short supply. This program is useful in special situations, like delivery of services to extremely remote areas (WHO 1994). The shortage of vehicles is the main barrier to outreach rehabilitation services in the district of Butterworth. The shortage of rehabilitation personnel is also a problem in doing outreach programs. This is more so in the district of Butterworth where there is only one Physiotherapist employed fulltime at Butterworth Hospital, no Occupational Therapists or Speech Therapists in a 250 bed hospital. The problem of the shortage of vehicles also applies, as the Rehabilitation Manager finds it difficult to do outreach programmes because of this shortage.
- c) Community Based Rehabilitation Services (CBR): This program is characterized by the active role in the rehabilitation process, of people with disabilities, their families and the community in which they live (WHO 1994). In this program, people with disabilities, with the support of their families and the community, play an active role in their own rehabilitation, in the management of services and in policy-making. CBR aims to provide rehabilitation, reduce poverty, equalise opportunities and promote inclusion of persons with disabilities. The new CBR guidelines were launched on the 27-10-2010 in Abuja, Nigeria. These guidelines focus on four key development areas: health, education, livelihood and social wellbeing.

CBR services aim to promote mainstreaming and empowerment of persons with disabilities and their family members. It focuses on enhancing the quality of life of people with disabilities and their families, meeting basic needs and ensuring inclusion and participation. It is a strategy that empowers people with disabilities to access and benefit from education, employment, health and social inclusion. It aims to provide rehabilitation, reduce poverty, equalise opportunities and promote inclusion of people with disabilities in their communities.

It is therefore clear that CBR is the strategy of rehabilitation best suited to solving the rehabilitation problems of people with disabilities, and if the Department of Health in the Eastern Cape could employ more rehabilitation personnel, then CBR can be introduced to

people with disabilities, their families and their communities, and its benefits can then be realised in the district of Butterworth and in the Eastern Cape as a whole.

The United Nation's Convention on the Rights of Persons with Disabilities (2006) aimed to promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities; and to promote respect for their inherent dignity. It called for societies to view people with disabilities as key decision makers in matters that affected their own lives. CBR does exactly that.

Because one of the main goals of rehabilitation is integration, it is important to note the meaning of integration:

#### 2.10.1 INTEGRATION:

Van de Ven et al. (2005:312), define community integration as “the acquiring of age, gender and culture appropriate roles, statuses and activities including inter-dependence in decision making and productive behaviours, as part of multivariate relationships with family, friends and the community”(van de Ven et al., 2005). It occurs through a process of interaction between a person with a disability, and others in society. Integration into society initially follows from the disabled person's choice, to be part of that society, with both the disabled person and those in the society contributing to the interaction. This means that the person with a disability should have an open and interested attitude towards integrating into society, and a willingness to interact with others, as well as the willingness by people from the society to accept him. According to the people with disabilities, the concept of integration as an outcome of rehabilitation appears to consist of five elements, these being:

- Functioning in an ordinary way without receiving special attention
- Mixing with others without being ignored
- Taking part in, and contributing to society
- Trying to realise one's potential

- Being the director of one's own life (van de Ven et al., 2005)

For rehabilitation to be executed effectively, and integration of people with physical disabilities to take place, it is necessary to know what needs, people with disabilities have. Hence, it is important to look at the needs of people with disabilities, as discussed in previous studies.

## 2.11. NEEDS

To be able to use the existing resources effectively and to motivate for more, to benefit people with disabilities, it is important that service providers should keep in mind that there are different kinds of needs:

- a) There are felt needs that can only be discovered by asking people with disabilities and their families, what they felt is needed.
- b) There are expressed needs, as represented by demands for services. This type of need must be considered with caution, because people may not seek, or demand services if they are unaware that such services exist.
- c) There are also needs identified by professionals. In a study by Kersten et al (2000) the disabled people were asked to choose professionals that they felt, knew them better to identify what priorities they had in their needs. The result of this study showed that people with disabilities identified more needs and priorities, than their respective professionals. This clearly showed that professionals should not plan and decide alone, on services to offer to people with disabilities without finding out their needs from them, first (Kersten et al., 2000). The following are the needs of people with physical disabilities, as discussed in previous studies:

2.11.1 Social Inclusion: People with physical disabilities want social inclusion just like everyone else. They want to be part of the society. In a study by Kennedy et al (2010), on the

needs of people with spinal cord injuries, they found that answers to open-ended questions highlighted in delays getting accommodation, adaptations and the availability of equipment. They also said that their independence and activity was limited by pain, and nearly all of them were dissatisfied with their sexual life; and these were making it difficult for them to integrate fully.

2.11.2 Economic Independence: People with physical disabilities need to be financially independent. They want to be employed, and those who cannot manage to get employed, need to get a disability grant. People with physical disabilities also need to be trained in skill's development, and to start income generating projects. Vila, Pallisera and Fullana (2007), in their study on how to improve work integration of people with disabilities in the regular work market, found that the worker's family, and not just the worker, becomes the focus of attention. Lack of knowledge about this work integration could mean that families may not be in a position to maximize the potential for independence of their child, or family member, with a disability. Family involvement is therefore very important when doing vocational rehabilitation.

It is unfortunate that, even after the introduction of the Employment Equity policy of 1998, the employment of people with disabilities is still very low. In South Africa, in 2001, the statistics of employment of people with disabilities was found to be 19%.

2.11.3 Need for Primary Health Care: In a study by Burns et al (1990) it was found that very little was done about Primary Health Care (PHC) needs of people with physical disabilities after they have been discharged from hospitals or rehabilitation centres. This is of great concern, because people with severe physical disabilities are prone to a large range of acute health problems like pressure sores, urinary and respiratory tract infections, and pain. These contribute to a high rate of re-hospitalization, yet these problems could be prevented or treated at home if diagnosed early. PHC is also important when people with disabilities reach old age, as they also experience the same chronic health conditions faced by the rest of the population, like hypertension, diabetes, and arthritis. Primary health care providers and physicians who are unfamiliar with disability tend to focus on the disability of the client, rather than on the health problems they present with, at the time (Burns et al., 1990). Mott et al. (2007) noted

that nurses with general nursing training only, often do not have an understanding of disability health needs. Because PHC is done mostly by nurses, it is important that they should be encouraged to do further training on disability studies, or should be given in-service education on disability issues.

A study by Schopp et al. (2002) showed that women with spinal cord injury (SCI) often lacked access to appropriate gynaecological health care; and might therefore be at a higher risk of getting preventable diseases or health problems. This study showed that, despite the importance of comprehensive reproductive health care for all women, such as screening for breast cancers or taking Pap smears, for women with SCI and other disabilities many barriers to undergoing these procedures still existed.

In a study by Jelsma et al., (2007:119), it was stressed that, “There is a need to manage symptoms, particularly pain and depression, as these have a severe negative impact on health related quality of life”. PHC personnel should therefore be aware of these problems, in order to address them.

2.11.4 Need for Assistive Devices: Assistive devices like wheelchairs, walking frames, crutches, Orthotics and prosthetics, are important tools that are used by people with physical disabilities to overcome barriers, (DPSA 2001:20). Assistive devices open doors to learning, employment and social participation. They are key mechanisms by which disabled people can participate as equal citizens of the society. (Standardization of Provision of Assistive Devices in South Africa, Department of Health)

2.11.5 Need for Love and Intimacy: Sexuality is an integral part of what it is to be a human being. Although love relationships for people with disabilities are often discouraged by family, friends, physicians and the community in general, people with disabilities have discovered that physical limitations need not keep them from enjoying great sexual satisfaction (Chance, 2002). In addressing sexuality and relationship issues of clients with disabilities, clinicians can help their clients to attain a higher degree of wholeness, and to

come closer to realizing their potential for love and intimacy. As discussed before, it is important to note that people with disabilities also have a need for marriage, and to have their own children who, in turn will look after them in old age (Nganwa et al 2002).

#### 2.11.6 Need for Access to Knowledge about Policies and Rights for People with Disabilities.

It is important that people with disabilities should be made aware of those rights and policies that concern them. It is of no use having rights for this group if these people do not know of their existence.

2.11.7 Need for accessibility of Housing: All the people of South Africa need to have a house to call home. People with physical disabilities need accessibility within their homes and to public places such as government buildings and facilities and to shops. The new Housing Policy and Strategy for South Africa (1994) has the following to say in its preamble: “Housing a nation is one of the greatest challenges facing the Government of National Unity. The extent of the challenges derives not only from the enormous size of the housing backlog, and the desperation and impatience of the homeless, but stems also from the extremely complicated bureaucratic administrative, financial and institutional framework, inherited from the previous government.”

A housing programme cannot be limited to housing only, but needs to be promoted in such a manner as to give meaning to the goal of creating viable communities, (The new Housing Policy and Strategy for South Africa 1994).

This promise by the government to build houses for the people of South Africa has been met with the problem of having too many houses to build, and insufficient finances to do it. Because of this, there are still many people, including people with physical disabilities, who have not benefited yet from the housing scheme, and they are still in need of houses.

People with physical disabilities, especially those living in informal settlements, such as those seen in Butterworth, are desperately in need of houses.

2.11.8 A Need for Accessible Transportation and Good Roads: The people of South Africa need good roads. People in Butterworth have a problem of bad roads, especially in the rural areas. This is apparent in many rural locations, where one cannot reach some homes by car. The car is left far from where people want to go, and they have to walk the distance to reach the homes they want to visit. This is a very difficult situation for people with physical disabilities who cannot walk distances.

2.11.9 A need for Caregivers: Disabled People South Africa (DPSA 2001) argue that people with severe physical disabilities often require assistance in the form of personal assistants, or caregivers. This is the case with many people with physical disabilities, especially those who find it difficult to perform activities of daily living.

## 2.12 ACCESSIBILITY OF RESOURCES TO PEOPLE WITH PHYSICAL DISABILITIES:

Resources for people with disabilities in South Africa differ from place to place. Rural places are more disadvantaged than urban places. There is a gross shortage of rehabilitation personnel, especially in rural areas, as well as employment opportunities, not only for people with disabilities, but for everybody. Provision of public transport is also a major problem, as there are no regular buses or taxis in rural areas as in urban areas. A service such as “Dial a Ride”; for people with disabilities, available in the Western Cape, has never been heard of in the mostly rural Eastern Cape.

Iezzoni, Killeen and O’Day (2006), pointed out that there are limited numbers of primary health care and specialist physicians in rural areas. In addition, there is an absence of sophisticated diagnostic equipment, inadequate or absent health insurance coverage, compounded by poverty, low rates of employment and a fragile socio-economic infrastructure. The physical access to Health Care Centres was hindered by barriers in the

form of inaccessible entrances and lack of equipment such as adjustable examining tables and mammography machines, amongst others.

These problems are common in the district of Butterworth where there are not enough clinics to cover all the locations, so that all the people can access health services. This scarcity of resources includes shortages of health professionals, especially rehabilitation personnel. These shortages pose a difficulty in that it is not easy to do outreach programs, as well as establishing CBR programmes, which would be very beneficial to people in the community.

Jelsma et al. (2007) compared the general quality of life of people with disabilities living in the more rural Eastern Cape, to that of the more urban Western Cape. They looked at the household members and the income of participants. The study showed that living in urban areas, even with poor resources like in informal settlements was better than living in rural places when it came to the availability of services. Therefore, living in rural areas can be a barrier to receiving resources. The district of Butterworth is a good example of a rural area, with no proper roads, high rates of unemployment and poverty, not only affecting people with disabilities, but also those without.

The above discussion uncovers some of the barriers that prevent people with physical disabilities to receiving resources. In a study by Kroll et al. (2006), it was found that there were structural-environmental barriers, and process barriers that prevented people with physical disabilities, from receiving primary preventive services to maintain their health and prevent major health threats such as diabetes, cancer, and heart disease. Structural-environmental barriers included the physical, social and economic environment in which primary preventive services are being offered, such as provider offices, diagnostic equipment, and insurance coverage. Process barriers relate to features of the transactions between service providers and patients in the course of the actual service delivery. Examples of this included provider knowledge and skill set.

## 2.13 CHAPTER SUMMARY:

This chapter highlighted various issues on disability, such as the definitions of disability and issues related to disability. These issues included different definitions of disability, the impact of disability, the rehabilitation as well as the needs of people with physical disabilities, and accessibility of resources. Previous studies showed how disability affected the lives of people with disabilities and their caregivers in different parts of the world, and similarities as well as differences to the situation of people with disabilities in South Africa, and especially the Eastern Cape.

This chapter has brought to light problems faced by people with disabilities living in rural areas, the lack of inclusion of disability issues in the curriculum of health professionals, the relationship between HIV/AIDS and disabilities. It also brought to the researcher's notice important issues she had to include in the interview schedules and questionnaires in the research.

## CHAPTER 3

### RESEARCH METHODOLOGY

#### 3.1. INTRODUCTION

This chapter is based on the methodology of the study. The aim of this chapter therefore was to demonstrate what steps the researcher took, to do the study, from the beginning to the end. It includes the discussion of the pilot study, the study setting, the study population, the research design, sampling methods, ethical considerations, and data collection. This chapter also presents the data collection strategies that were used, and how data was analysed, after the transcription and interpretation from Xhosa to English was completed.

#### 3. 2. AIM OF THE STUDY

The aim of this study was to investigate the needs of people with physical disabilities in the district of Butterworth, and the accessibility of resources that are provided for them.

#### 3.3. OBJECTIVES OF THE STUDY

The objectives of this study were to:

- Determine the demographic details of the people with physical disabilities and of their caregivers.
- Explore the needs of people with physical disabilities and of their caregivers in the district of Butterworth.

- Explore the accessibility to resources of people with physical disabilities in the district of Butterworth, as well as the barriers that prevent them and their caregivers from accessing these resources.
- Explore the perceptions of professionals and service providers regarding the needs and priorities in terms of resources for people with physical disabilities.
- Note the similarities and differences between the needs and priorities as revealed by people with physical disabilities and their caregivers, and those mentioned by professionals and other service providers.
- Make the necessary recommendations to service providers so as to help improve service delivery in the district of Butterworth.

This was a descriptive qualitative study. Data was collected by means of focus group interviews and questionnaires from the three different groups of participants. These groups were people with physical disabilities, caregivers of people with physical disabilities and service providers serving people with disabilities. It was intended that by utilizing such a methodology, the findings of the research might explicitly reveal the needs people with physical disabilities in the district of Butterworth, and if they were able to access resources that were available, at the time. The study was also structured to ascertain if professionals and other service providers were aware of the needs and priorities of people with physical disabilities.

#### 3.4. THE STUDY SETTING:

This study was conducted in the district of Butterworth, in both the rural and urban areas. Butterworth is a small town, situated along the N2, the main road from Cape Town to Durban, South Africa. It is about 120 kilometres from East London and about 130 kilometres from Mthatha. The urban area is very small, with few shops for groceries, clothing, hardware and furniture. There are also government department offices, such as the Department of Education, Health, Justice, Social Welfare, Home Affairs and the department of Labour.

There is one hospital, the Butterworth Hospital that serves the entire community within the district of Butterworth, getting referrals from clinics situated in rural and urban locations around Butterworth. Referrals also come from clinics and doctors from neighbouring districts, like Centane, Dutywa, Willowvale and Ngqamakwe, with referrals from Ngqamakwe Health Centre and Tafalofefe Hospital, a smaller hospital in Centane.

Butterworth Hospital, a general hospital that caters for all kinds of ailments, including trauma, medical, surgical, orthopaedic, psychiatric, and paediatric sections, is situated at the entrance to the town, as one comes into Butterworth, from East London. It has two hundred and fifty beds, nine doctors that are employed fulltime, and five that work part-time, doing calls after hours.

Rehabilitation personnel consist of one full-time physiotherapist, one physiotherapist doing community service, one physiotherapy assistant and one social worker. An orthotist from the Orthotic and Prosthetic Centre at Frere Hospital in East London visits Butterworth Hospital once every two months, to do assessments and measurements for those people with physical disabilities who need pylons, prosthesis, surgical boots, callipers and other devices. Once a month, a paediatrician visits this hospital to look at problems affecting children with cerebral palsy, meningitis and other conditions that affect children physically, mentally and intellectually. An Ear Nose and Throat (ENT) Specialist and an Audiologist from Frere Hospital also visit the hospital monthly. The Provincial Department of Health provides a service to make available wheelchairs to people with physical disabilities, as well as providing walking aids like crutches, walking frames and walking sticks.

It was important for the researcher to note that the number of doctors and rehabilitation personnel working at Butterworth Hospital varied from time to time. There were times when there were only four doctors to serve the hospital's in-patients and out-patients. This hospital therefore has serious problems in retaining doctors and rehabilitation personnel.

The following physical description of Butterworth is crucial to a reader's understanding of the hierarchy within this area that had an impact on the resources available to the people with disabilities. The district of Butterworth is made up of 25 rural villages that are spread in

different directions from closer to town, to as far as fifty to sixty kilometres away. The area is thus bordered by the Kei River in the West, Ngqamakwe on the North, Dutywa on the East and Centane on the South. There are also three suburbs, seven townships and eight informal settlements. Each rural village has its own headman, with a number of headmen reporting to a chief in charge of those villages. Chiefs who report to a king are traditional leaders in charge of different clans. Each clan, like Amazizi, Amabhele or Amahlubi, have their own chief, and these areas are called Tribal Authorities. Chieftaincy runs in families, inherited from father to son, and therefore rural residents do not have the rights to choose who their chief should be. Headmen on the other hand are elected by the chief, together with rural residents, to help chiefs with the administration. With the new democracy, councillors are elected as individuals, or according to the political parties they belong to, to be in charge of every ward. These democratically elected councillors are present in both the urban and rural areas in Butterworth. In rural villages, traditional leaders are responsible, mainly, for land administration, whereas democratically elected councillors are responsible for service delivery like the supply of water, electricity and roads. Democratically elected councillors are accountable to the local government, whereas traditional leaders, especially the kings, are accountable directly to the president of the country (Ntsebeza, 2004).

Unemployment and poverty are rife in this district, affecting people with disabilities and those without. As a result, rural people find it difficult to go to town to access necessary services; and there are still people without identity documents (IDs), because travelling to town is too expensive for them. Consequently, these people are not able to make applications for disability grants, child support grants and wheelchairs, which require identity documents.

The following are some of the resources available to people with disabilities in the district of Butterworth:

- a) Butterworth Hospital: This is a referral hospital, receiving patients from clinics in Butterworth and neighbouring districts like Centane, Dutywa, Willowvale, Ngqamakwe and Tsomo. At this hospital, the Free Health Policy (DOH 2003) for people with disabilities is applicable.

- b) Primary Health Care: The district of Butterworth has 10 clinics, providing primary health care throughout the district, and the Mobile Clinic Services conduct monthly visits to 35 points.
- c) The Department of Social Development: This department is important to people with physical disabilities to help them resolve their social problems, including counselling.
- d) The South African Social Security Agency (SASSA): This agency helps people with disabilities to obtain disability grants.
- e) The Department of Home Affairs: All the people in the Butterworth district, including people with disabilities register here for their identity documents, so as to be able to apply for social benefits
- f) The Department of Labour: This department ensures that people with disabilities can be trained to acquire skills, and register as Job Seekers
- g) NGO'S: There are two non-governmental organisations that care for people with disabilities in Butterworth, they are, "Rehab" and "We Care". "Rehab" provides counselling to clients, and rents out wheelchairs. "We Care" workers visit people with physical disabilities at their homes, offering assistance with activities such as washing up, dressing up, and hospital visits, where necessary.

### 3.5. THE STUDY POPULATION:

The study population was divided into three groups, these are described below:

- a) People with physical disabilities in the district of Butterworth, irrespective of the types of physical disabilities: This research group included clients with musculo-skeletal conditions like fractures and amputations, neurological conditions like head injuries, strokes, spinal cord injuries and peripheral nerve injuries. It also included congenital conditions like spina-bifida and cerebral palsies, and medical and degenerative conditions like arthritis. Only adults, 18 years and above, were included in the focus group discussions. Forms were filled in to give their personal details. Participants in

this group had to have some activity limitation due to either muscle weakness or paralysis, stiffness of joints, contractures, amputations, or limb shortening.

- b) Caregivers of people with physical disabilities: Caregivers were also interviewed in their focus groups; and they also answered questionnaires in terms of their personal details. Caregivers were not necessarily those of the people with physical disabilities taking part in the focus group interviews, but were even those caregivers of people with physical disabilities who had other disabilities, and therefore did not fit into the inclusion criteria.
- c) Professionals and other service providers who provide services to people with disabilities: These professionals included health professionals like physiotherapists, nurses, social workers, and doctors as well as personnel from Non-Governmental Organisations (NGOs) dealing with people with disabilities. Nurses from the clinics and the hospital were included, as well as staff from the Orthotic & Prosthetic Centre at Frere Hospital, in East London, as they do outreach at Butterworth Hospital. Personnel from other government departments like the Department of Labour, the Department of Home Affairs, the South African Social Security Agency and the Department of Social Development were also included. They completed a questionnaire with open ended questions, in writing.

### 3.5.1 INCLUSION CRITERIA

- a) Participants in the physically disabled group had to have a physical disability. They had to be able to communicate meaningfully verbally, either in English or Xhosa. They had to be adults or elderly people above the age of 18.
- b) Participants in the caregiver group had to be taking care of people with physical disabilities, from 18 years of age upwards.
- c) Participants in the service provider group had to be those that provide services to people with disabilities.

### 3.5.2 EXCLUSION CRITERIA

- a) People with physical disabilities, who could not participate in meaningful conversation, because they had other types of disabilities, were excluded, but caregivers of these people were included in the focus group of caregivers.
- b) There were no exclusion criteria for service providers and caregivers as long as they were providing service to people with physical disabilities above the age of 18.

### 3.6. RESEARCH DESIGN:

The main approach to this qualitative research was interpretivism, whereby the researcher aimed to explore the view of the participants within a context of the needs and resources of people with physical disabilities. This research methodology allowed the researcher to obtain in-depth information about the research participants by talking to them, or by observing them. The qualitative research methodology is subjective in that the focus is on how the respondents experienced and understood the selected research situation (Katzenellenbogen, Joubert & Abdool Karim, 2002). As a consequence, the researcher worked with responses to open-ended questions, as these were meant to provide rich descriptions of how the participants experienced the themes.

Qualitative research required that the researcher took note of the responses of the participants within their natural settings, and attempted to make sense of the research phenomena in terms of the meanings they attributed to them (Denzin & Lincoln, 1994).

The advantages, of an interpretivist approach to the study are that the results directly represented how people felt. Results that were obtained were more understandable as they were descriptions of the real situations within the context of the disabled person (Katzenellenbogen et al., 2002).

The disadvantages of this method of data collection were that there were problems with the process of analysis of information, as data collection and analysis went hand in hand. The process of analysing data was also time consuming, (Marshall & Rossman, 1995).

Although the literature readings proved that there were some disadvantages to qualitative research, the researcher preferred to use it, in order to get the actual feelings of people with physical disabilities about their needs and accessibility to available resources.

### 3.7. THE STUDY SAMPLE AND SAMPLING METHOD:

The study sample consisted of people with physical disabilities, caregivers of people with physical disabilities from the randomly selected areas, and service providers. Generally, disabled people are a minority of the population, and it is not easy to find many types of disability in one area. The researcher, therefore, included all available participants that could fit into the inclusion criteria in those chosen areas, using snowball sampling to identify them, as well as caregivers of people with physical disabilities. Purposive sampling was used to select service providers that served people with disabilities in Butterworth. All the government departments that deal with people with physical disabilities were therefore included in the sample of service providers.

#### 3.7.1 SELECTION OF STUDY AREAS

The following format was used in selecting the study areas:

- One rural village was selected
- One informal settlement
- One township

The residential areas were randomly selected to be represented in the study. This was done by writing names of all townships on small pieces of paper, putting them into a container, and randomly choosing one. The same procedure was then used to choose the informal settlement.

The rural area was chosen because people from that area had come, enquiring about the provision of assistive devices, so the researcher took advantage of the situation, and visited the area to help give the service and to conduct the research. The reason for having interviews at different locations was that living conditions were not the same at different locations.

### 3.7.2 RECRUITING THE PARTICIPANTS:

Community leaders were consulted to help identify people with physical disabilities in the areas they came from. Those people with physical disabilities in turn referred the researcher to other people with physical disabilities that they knew in their area. Therefore snowball sampling within the network was used to recruit the participants with physical disabilities. The researcher then did home visits, to explain to people with physical disabilities and their caregivers what the study was about, and to have informed consents signed by the participants before doing the focus group interviews. Caregivers of adults with physical disabilities were interviewed in separate focus groups, in specific setting.

## 3.8. DATA COLLECTION

Data was collected from people with physical disabilities, caregivers of people with physical disabilities, and service providers who worked with people with disabilities. The following methods of data collection were used:

### 3.8.1 FOCUS GROUP INTERVIEWS:

Some focus group interviews were held with people with physical disabilities from three different locations and other focus group interviews were arranged with groups of caregivers of people with physical disabilities from two different locations. The reason for using the focus group interviews was to get the in-depth feelings from the people in those groups.

Focus group interviews are defined as a “carefully planned discussion designed to obtain perceptions in a defined area of interest, in a permissive, non-threatening environment” (Kreuger, 1988:18 cited by Lewis, 1995). The researcher believed that since the key element of focus group interviews was the involvement of participants in a nurturing environment – their disclosures would be encouraged through interaction with other people (Lewis, 1995). Unstructured open-ended questions were used, as such questions allowed the participants to answer from a variety of dimensions (Lewis, 1995). Furthermore, the researcher chose to avoid “why” questions during the focus group interviews as such questions generally forced participants to provide quick answers that seem rational or appropriate to the situation (Kreuger, 1988:62 cited by Lewis, 1995).

There are advantages as well as disadvantages to using focus group interviews:

#### 3.8.1.1 ADVANTAGES:

According to Marshal and Rossman (1995) this method of interviewing makes the participants aware of the needs that are common to all of them, and of those that are unique to each individual. It also helps them to understand how other people overcome some difficulties. Being in focus groups allows people to identify with one another and in that way be healed emotionally. It is socially orientated, without the strain of a one - on - one interview. It allows the researcher the flexibility to explore unanticipated issues as they arise in the discussions, and it is relatively low in cost because a large number of people can be interviewed at one time. People are often stimulated by the discussion, revealing facts and opinions that they might not otherwise have chosen to reveal. It can help to build community involvement in the research. Participants get to know about other people who have the same problems as they do, therefore learning how to cope with those problems.

#### 3.8.1.2 DISADVANTAGES:

With this method, participants are not free to talk about things that are personal and private, such as information pertaining to sexuality. Sensitive subjects like this cannot be discussed in mixed groups, thus interviewing men and women separately might be preferable in such situations. Some people are shy and will not speak up when there are other people around, and

possible peer pressure within the group may prevent members from saying what they believe in, hence they go with the views of the majority.

The interviewer may have less control over a group, than an individual, which can result in lost time, as irrelevant issues may be discussed. It is therefore important that the interviewer should stay in control and try to keep to the interview schedule as much as possible.

Though there are some disadvantages to using focus group interviews, the researcher preferred to use them so as to be able to get people with physical disabilities to understand that they were not alone in experiencing the problems that they experienced. The researcher also preferred to use focus group interviews, despite the disadvantages, because the strategy was more economical in that more people were interviewed at the same time, saving on time and money.

In order to address some of the disadvantages, the following precautions were taken, in focus groups:

- The interviewer ensured that the group remained focussed and that discussions on irrelevant issues were avoided.
- It was important for the interviewer to work towards a sense of balance within the group and argumentative people were not allowed to dominate over those who were shy.
- The interviewer guarded against biasing the group in his/her powerful role by making sure she did not influence the participants to say what she believed in.
- The interviewer, at times, had to use probes such as direct questions to elicit additional information. It was important not to overdo the probing, as it would have limited the discussions (Katzenellenbogen et al., 2002).

### 3.8.2 QUESTIONNAIRES

Questionnaires were given to selected service providers to read through and for them have the opportunity to request explanations from the researcher where questions were not clear. The researcher returned two to three days later to respond to the questions of these participants, to provide clarification and to discuss the answers they had written, so as to avoid ambiguity. The reason the researcher used questionnaires for this group of participants was that the service providers that took part in the study were from different government departments, and some of them were working as far away as Bisho and East London, while at the same time being involved in outreach services at Butterworth Hospital. It was therefore not easy to form a focus group of service providers.

The use of questionnaires in the collection of data has advantages as well as disadvantages. The advantage of using questionnaires for this study was that they made the process economical in terms of time and could allow the data collection process to take place over a short period of time. On the other hand, the participants sometimes did not understand certain questions, so the researcher had to take more time to clarify those points to the participants. Some of the participants' responses were also not clearly understood by the researcher, who had to go through completed questionnaires with the participants. However, the researcher later realized that participants might have been restricted by the nature of the questions, and not discussed matters that they felt were important.

Despite the disadvantages, the researcher decided to use questionnaires for data collection with the service providers because she was aware that it would be difficult to secure focus group interviews with them, as they are extremely busy, and were also working at different government departments. It was also considered a cost-effective approach.

### 3.9. METHODS OF DATA COLLECTION:

The researcher used two methods of data collection, focus group interviews for people with physical disabilities and caregivers, and a questionnaire for service providers to complete. People with physical disabilities and caregivers, were also asked to fill in forms with their demographic details.

Focus group interviews were conducted at three locations, with participants including adults with different types of physical disabilities. Caregivers were also interviewed in their own focus groups. The size of these focus groups ranged from four to ten people, depending on the availability of participants in those areas. There was a total of five focus groups, three groups of people with physical disabilities and two groups of caregivers. The two interviewing schedules, one for people with physical disabilities (Appendix 5), and one for caregivers (Appendix 7), were used to obtain different opinions and views. The researcher encouraged discussions within the group by asking open – ended questions, and avoiding leading questions. Interviews were tape recorded to facilitate data collection after the procedure was explained to the participants, and the necessary consent obtained from them.

### 3.10. THE PILOT STUDY

A pilot study was done to support the researcher's motives for wanting to conduct the study and to confirm the need for such a study. It was also essential to determine the effectiveness of the data collection strategy chosen in the research methodology, together with the interview schedules and questionnaires for service providers, so that changes could be made if necessary.

The pilot study was done in two stages. Firstly, the researcher interviewed a group of people with physical disabilities and their caregivers in one focus group. Secondly, she gave questionnaires to service providers to answer individually.

A focus group interview of people with physical disabilities and caregivers was held at Ndabakazi, a rural village, 12-15 km from the town of Butterworth. Service providers were randomly chosen among those who dealt with people with physical disabilities.

An appointment with the chief of the Ndabakazi Administrative Area resulted in a formal request to him, that the researcher is allowed to meet with people with physical disabilities in that location. The aims and objectives of the research were explained to the chief, and he was also told how the project was going to help people with physical disabilities. The chief then referred the researcher to one lady who uses a wheelchair for mobility. After the researcher explained everything to the lady, she was willing to participate. This participant, in turn, referred her to other people with physical disabilities in the area. A date, time, and venue were set for the focus group interview.

The following is the sample of people with physical disabilities and caregivers that the researcher had at Ndabakazi:

- One 60 year old woman with traumatic paraplegia
- One 69 year old man, also with traumatic paraplegia
- One 43 year old woman with a through knee amputation
- One 17 year old boy with congenital impairments of lower limbs and facial disfigurement
- One 15 year old boy with cerebral palsy, resulting in left hemi-paresis.
- The mothers of both boys and that of the 43 year old lady were also present.

The pilot study sample therefore comprised of five people with physical disabilities; and three care-givers. Suitable transport was arranged for those participants who lived far from the venue, to participate in the interviews.

After introducing herself, the researcher explained to the participants the reason for calling them to the meeting, stating that this was a study that was aimed at improving services. She also explained to the participants that they should not expect any financial gains from the study. She then asked for their consent to participate, and requested their permission to record their conversation, and they all agreed.

Once a friendly and relaxing atmosphere was established, the discussions were initiated with an open - ended question, and all participants were requested to respond. The interview schedule was used so that its effectiveness could be determined, and changes might be made where necessary (see Appendix 5).

The focus group interview with these participants with physical disabilities and their caregivers took the form of open-ended, broad and non-directive questions. The interviews were conducted in isiXhosa, the mother tongue of all the participants who were interviewed and they were recorded. Participants who were all from the same area, and knew each other very well, felt free to discuss their views. Sometimes, when one answered a question, someone else added a point, or even reminded the other of how and when an incident had happened. The three participants with disabilities, who had their care-givers with them, did not say much, but the care-givers were the ones who contributed most. Only the 17 year old boy would now and again chip in and answer for himself. The 15 year old boy and the 43 year old lady did not say much, and when asked specifically to say something, they said that they did not have anything to say.

There were many useful lessons that were learnt from the pilot study. Looking at the original methodology for the research, the researcher noticed that there was a tendency for people with disabilities to know each other in their localities, so it's difficult to have a group of people with disabilities from one area, not knowing each other. Focus groups therefore were made up of people who knew each other. This was in contrast to the original plan, which was to have a sample of people who were not familiar with one another in the hope that they would not influence each other, as suggested by Marshall and Rossman, (1995), in "Designing Qualitative Research". The researcher discovered that, because the participants knew one another well, they talked freely.

The researcher then decided that it would be necessary to change to focus group interviews with those people, who knew one another, for the main research. This seemed to make members of the focus group more comfortable with one another, and therefore free to participate. The researcher also concluded that sensitive topics, such as those involving sexuality, might be better discussed in groups of men and women separately, if it became necessary to do so (Katzenellenbogen et al., 2002).

The researcher also noticed that, those participants who had their caregivers with them did not take an active part in the discussions. Their caregivers were the ones who actively participated, providing responses on behalf of those they took care of. The researcher therefore decided to have focus groups of people with physical disabilities, 18 years and above, who could take part in meaningful discussions, separate from those of caregivers. This necessitated the development of a separate interview schedule for caregivers.

A questionnaire was prepared for service providers, (Appendix 8) whose work involves people with disabilities. This questionnaire comprised of questions that were similar to those in the interview schedules for the focus group interviews with people with physical disabilities and their caregivers. The four service providers who were given the questionnaire included:

- One nurse from the local clinic
- One doctor from Butterworth who is visited a lot by People with Physical Disabilities
- One social worker from Butterworth Hospital
- A field worker from a Non Governmental Organization, dealing with People with Disabilities, with a branch in Butterworth

Three questionnaires out of the four were returned by the selected service providers. The researcher realised from the responses that some of the questions in the questionnaire were difficult for participants to understand. A few changes were therefore made to the wording of the questionnaire, and the researcher also made sure that in the main study service providers understood the questionnaire before completing it. It was also important to ensure that questions in the interview schedules for people with physical disabilities and caregivers, and

questionnaires for service providers were similar to each other. However, there had to be some differences in that caregivers were also interviewed about their experiences of living with people with disabilities. The questionnaire prepared for the pilot study did not include spaces for the participants to write their answers, so they had to write their answers on separate pages. In the main study this was changed, and the questionnaires provided spaces for the participants' responses. This made it easier for the researcher to read and make sense of the responses.

The findings of the pilot study, found that it was necessary for the researcher to remove questions that related to children from the interview schedule that was used in the focus group interview for people with physical disabilities, and the questionnaire for service providers. This was due to the fact that participants in the main study would be adults from the age 18 and above. The reason for this was that children under the age of 18 could not be interviewed without their caregivers, hence it was decided that there would be separate focus groups of people with physical disabilities and those of caregivers. It was therefore necessary to have another interview schedule for the focus groups of caregivers of people with physical disabilities, as well as forms for personal details of people with physical disabilities and caregivers, to get their demographic details (See Appendices 4, 5, 6, & 7).

### 3.11. DATA COLLECTION

During the main research data was collected from three areas. These areas are:

A – Bika Township, a township 8-9 km from the town of Butterworth

B - Zangwa Administrative Area, a rural village 30-35 km away from Butterworth

C – Skiti, an informal settlement close to town

For easy reference, these areas are called A, B, and C; while participants are identified as, A1, A2, B4, and so forth. The caregivers are referred to as AC1, BC3, and so forth, according to the areas where they came from. The interview schedules used for people with physical disabilities and caregivers during the focus group interviews were aimed at getting responses from them about the needs of and services for people with physical disabilities in the district

of Butterworth. All interviews were conducted in isiXhosa, the language in which the researcher and participants were most comfortably. The total number of people interviewed in the focus groups was 33 and out of these, 24 were people with physical disabilities and 9 were caregivers of people with physical disabilities.

The researcher will give a brief description of each area where the study was conducted, so that the reader may have an understanding of the living conditions of the participants.

### 3.11.1. BIKA TOWNSHIP, AREA A

The first area visited was Bika Township, an area that used to be a very busy industrial area in the past, with many factories. Those factories are now closed down, so most people in this area, who used to work there are now unemployed. This area is situated about 8 kilometres from the town of Butterworth along the N2 route to Mthatha. The main road going through Bika is tarred, but the side streets are all gravel. Houses are typical township houses, with two bedrooms, but they are built differently, with fewer steps and smaller passages, in comparison to houses at other townships. The population at Bika is estimated at 9643 and people with physical disabilities above the age of 18 are estimated at 15. The researcher obtained this information from the nurses at Bika Clinic, which is the only clinic serving this population. There are four primary schools, and one high school. Integration of children with disabilities is not common, as two young women who were included in the project were attending a special school in East London.

An appointment was made with the Ward Councillor who was informed of the intention to conduct the research project in her area, and was given a letter requesting permission to do so. The Ward Councillor seemed to know almost everybody in the township. She gave the researcher the names of people whom she knew had physical disabilities; even accompanied the researcher, to explain to them what the research project was about; and to ask them to participate. It was agreed that the focus group interviews would be held at a local church hall; and permission to use this venue was obtained. Eight people with physical disabilities agreed to participate in the focus group interview. After a brief explanation about how the interview was going to take place, consent forms and questionnaires about personal information of

participants were completed. The two younger women A9 and A10 could not join the group as they were attending school. They were seen together a week later, but their responses are added to those of the focus group.

A focus group of caregivers of people with physical disabilities was also interviewed at Bika Township. Collecting a group of caregivers of People with Physical Disabilities was not easy, as some of them could not leave the people they were looking after, unattended; while some of the people with physical disabilities who had been identified, did not have caregivers. Four caregivers were finally obtained - all females - three of them were mothers of the people they were taking care of; and one was a grandmother

### 3.11.2. ZANGWA ADMINISTRATIVE AREA – AREA B

The second area to be visited was Zangwa Administrative Area. This is a rural village that is situated between thirty and thirty five kilometres from the town of Butterworth, in the direction of East London, but away from the N2 route. Two locations that are close to each other, Zangwa and Thongwana Administrative Areas were targeted. These are typical rural villages, with mainly mud houses, no developed roads between the homes, no electricity and no tap water. The main road that goes through these villages is made of gravel, but well developed. The population of these two locations is around 3300 according to the ward councillor of this area.

A delegation of three caregivers working for a community project called Nontsebenziswano Community Project, situated at this area, that served these two locations, visited the Physiotherapy Department at Butterworth Hospital, in need of information on how to get wheelchairs for people who could not walk in their area. The researcher took advantage of this and told the delegation that she would visit the area and see those clients, so as to make her own assessments. As such, purposive sampling was used in choosing this area for research, not random sampling as in other areas, with the aim of rendering the service that was requested by the community workers, as well as doing the research.

Having met and introduced herself to the Director of the Nontsebenziswano Community Project, the researcher was taken to the Headman, representing the Chief of the area, whom she had to request permission from, to do the research in his area. Permission was then granted, and the researcher, with two community workers visited the homes of people with physical disabilities at Zangwa and Thongwana Administrative Areas.

On doing the home visits, the researcher found that there were many people at both locations who were bed-ridden, mainly because of old age, and illnesses like stroke. The researcher asked those who could manage to go to Nontsebenziswano Community Project Centre; the following day, to do so, so as to take part in the focus group interviews. Nine people with physical disabilities participated in the focus group interviews. Some participants managed to fill in the consent forms and personal information questionnaires themselves, but many had to be helped by the researcher and caregivers.

A group of caregivers who were able to come to Nontsebenziswano centre were also interviewed. As seen at Bika, it was not easy to bring together many caregivers, as some of them could not leave the people they were looking after, unattended to, to be able to join the focus group. Five caregivers participated - they were mothers, daughters and wives to the people with physical disabilities they were taking care of.

### 3.11.3. SKITI INFORMAL SETTLEMENT – AREA C

This informal settlement was randomly chosen above other informal settlements in Butterworth. It is very close to town, and people who are able to walk do not need any form of transport to go to town. There is a regular taxi service from this area to town; therefore people with physical disability make use of it, when they need transport. The community worker whom the researcher talked to did not succeed in organising a group of people with physical disabilities. As a result, the researcher then asked a teacher from the local school to help her organise this group of people for the following day. The focus group interviews took place in a classroom at the local school. Five people took part in the interviews.

There was no focus group with caregivers brought together at Skiti Informal Settlement. The reason for this was that most of the people with physical disabilities in this area lived on their own, especially during the day. Even those who had caregivers, those caregivers who were supposed to take care of them were too occupied, selling things like fruit in town, with the aim of generating some income, leaving the people with disabilities alone during the day.

#### 3.11.4. DATA COLLECTION FROM SERVICE PROVIDERS:

Data was also collected from service providers who provided services to people with disabilities. Questionnaires were given to selected service providers, mainly from the government departments, these including the Department of Health, the Department of Social Development, the Department of Home Affairs, the Department of Labour and the Agency for Social Security. The questions in these questionnaires matched those asked in the interview schedules for people with physical disabilities and their caregivers. One representative from each government department was given a questionnaire to answer on behalf of that department, as well from each section of the Department of Health. Sixteen questionnaires were given to the following service providers:

- The Hospital Manager at Butterworth Hospital
- One Physiotherapist doing community service at Butterworth Hospital
- One Professional Nurse from the clinic in one of the selected areas
- One Professional Nurse in charge of Mobile Clinics in the district of Butterworth
- One Professional Nurse from each of the Hospital Wards dealing with adults with Physical Disabilities, giving questionnaires to three wards
- Two Doctors from Butterworth Hospital
- One Technician from the Orthotic & Prosthetic centre at Frere Hospital, who conducts an outreach clinic our Hospital once every two months
- The Rehabilitation Manager from Mnquma sub-district, Department of Health
- The Co-ordinator of the Eastern Cape Provincial Rehabilitation Section, in the Provincial Department of Health

- One senior employee from the Department of Social Development, dealing specifically with people with disabilities
- One senior employee from the Department of Social Security
- One senior employee from the Department of Home Affairs
- One senior employee from the Department of Labour

### 3.12 DATA ANALYSIS

After doing the focus group interviews, the researcher and fellow students listened to the tapes for peer debriefing in order to maintain the trustworthiness of the results, and transcribed the focus group interviews word for word. Prior to this the students were given a data analysis workshop by the lecturers in order to be able to conduct the analysis correctly. It was important to read and re-read the data, noting down initial ideas and observations, as the researcher familiarised himself / herself with the data. She then translated all the responses into English. Thereafter the entire data set was coded according to specific features in a systematic fashion within categories. The researcher then considered the potential themes that were applicable to the codes and categories, with the help of the supervisor. She then reviewed the themes, checking if they worked in relation to the coded extracts, and did ongoing analysis, by looking at the specifics of each theme, and the overall story the analysis tells; generating clear definitions, and names for each theme (Braun and Clarke, 2006). She was then able to present the results of the research, according to those categories and themes.

Data analysis for open ended questions in the questionnaires for service providers was done by reading all the responses, and determining how many times each response was mentioned, and the more it was mentioned, the more it was taken as a priority.

### 3.13. ETHICAL CONSIDERATIONS:

Before this study was initiated, it was ensured that:

- The ethical committee of the University of Stellenbosch had endorsed this study, and given permission for it to be done. The reference number for this project is N04/10/179.
- Participants were provided with accurate information about the study so that they would participate willingly.
- Participants were asked to sign an informed consent (Appendix 1).
- The rights and welfare of the participants were protected in that they were given the choice not to respond to any interview questions that they were not comfortable with.
- Identities and interests of those involved were protected in that, they were assured that their identities would not be publicised.
- All personal information given to the researcher would therefore remain confidential.
- One of the conditions of this study was that the participants would be given feed back regarding the results of the study.
- Participants were asked to consent to the tape recording of interviews to facilitate data collection, (Appendix 1).

If confidential information emerged during the focus group interviews, that aspect of the interview was stopped immediately, and the matter was discussed afterwards with that individual alone.

### 3.14 CHAPTER SUMMARY

This chapter covered the methodology of the study and explained how the study was done. The objectives of the study provided guidelines of what needed to be done to achieve the aim. The study design, study area and the study population were defined. Different study areas were described and similarities and differences in the situations of the study areas and within the participants groups were illustrated. Inclusion and exclusion criteria were given and the

process whereby the participants were selected, as well as how data was collected, was described.

The pilot study was done, and it displayed the need to do the study, but also resulted in changes made to the methodology and measuring instruments. A brief description of data analysis was given. The results of this study are given in Chapter 4.

## CHAPTER 4

### RESULTS OF THE RESEARCH

#### 4.1 INTRODUCTION

This chapter is on presentation of results of the research. Results pertaining to the objectives of the study, as set out in the research methodology in Chapter 3 are discussed in this chapter. Quotes from the interviews, building up into categories and then into themes, are included in this chapter. This analysis gives findings of the study, which are then discussed further in chapter 5.

#### 4.2 PRESENTATION OF RESULTS

Results are presented under different headings, according to the objectives of the study. These headings are:

- Needs
- Knowledge about; and accessibility of resources
- Barriers to accessing resources
- Perception of caregivers about needs and accessibility for resources of people with physical disabilities
- Perception of service providers about needs and resources of people with physical disabilities
- Suggestions for additional resources

Responses from participants in the focus group interviews included those of people with physical disabilities, and caregivers of people with physical disabilities. As discussed in Chapter 3, there were focus group interviews of people with physical disabilities, and those of

their caregivers, conducted separately. Responses from service providers dealing with people with physical disabilities to the questionnaires that they were given are also included.

#### 4.3 RESULTS FROM PEOPLE WITH PHYSICAL DISABILITIES:

The following are responses from the focus group interviews of people with physical disabilities at Bika Township, Zangwa Administrative Area, and at Skiti Informal Settlement. These responses are presented under headings as stated above. Demographic details of people with physical disabilities that took part in the research are presented in tables below:

<b>Participants</b>	<b>Age</b>	<b>Sex</b>	<b>Marital Status</b>	<b>Highest Level of Education</b>	<b>Physical Disability</b>	<b>Cause</b>	<b>Duration of Disability</b>	<b>Assistive Device Used</b>
A1	58	M	Married	Matric + Diploma	Left Hemiplegia	Stroke	2 Years	None
A2	32	M	Single	Matric + Diploma	Weakness & Shortening (L) Leg	Polio	+ - 30 Years	Crutches
A3	38	M	Single	Matric	Paraplegia	M V A	10 Years	Wheelchair
A4	35	M	Single	Std 5	Left Hemiplegia	Epilepsy	+ - 34 Years	None
A5	50	M	Married	Std 4	Right Hemiplegia	Stroke	8 Years	None
A6	34	F	Single	Std 8	Weakness & Shortening (L) Leg	Polio	+ - 33 Years	Crutches
A7	47	F	Single	Std 3	Paraplegia	AIDS	2 Years	Wheelchair
A8	49	F	Married	Std 8	B/E Amputation (L) Arm	Gangrene from Diabetes	9 Months	None
A9	25	F	Single	Matric	Paraplegia	Spina-Bifida	From Birth	Wheelchair
A10	21	F	Single	Std 7	Para paresis	Spina-Bifida	From Birth	Crutches

TABLE 1, DEMOGRAPHIC DETAILS OF THE FOCUS GROUP OF PEOPLE WITH PHISICAL DISABILITIES AT BIKA TOWNSHIP

<b>Participants</b>	<b>Age</b>	<b>Sex</b>	<b>Marital Status</b>	<b>Highest Level of Education</b>	<b>Physical Disability</b>	<b>Cause of Disability</b>	<b>Duration of Disability</b>	<b>Assistive Device Used</b>
B1	21	M	Single	Std 8	Paralysis of Right side	Head Injury	3 Years	1 Elbow Crutch
B2	69	M	Married	Std 5	Stiffness Hips & Knees	Arthritis	5Years	Crutches
B3	63	M	Married	Std 3	Weakness Lower Limbs	Spinal cord	32 Years	Elbow Crutches
B4	64	F	Widowed	Std 6	Stiff Knees	Arthritis	3-4 Years	Walking Stick
B5	53	F	Widowed	Std 6	Contractures &	Injury	40 Years	Walking Stick
B6	80	F	Widowed	Std 6	Stiffness Hips & Knees	Arthritis	5 Years	Walking Frame
B7	58	F	Single	Std 6	Contractures both Legs	Assaulted	25 Years	Walking frame
B8	54	F	Single	Std 5	Shortening 1 Leg	Polio	50-52 Years	Crutches
B9	88	F	Widowed	Std 6	Stiffness both legs	Arthritis	2 Years	Walking stick

TABLE 2, DEMOGRAPHIC DETAILS OF THE FOCUS GROUP OF PEOPLE WITH PHYSICAL DISABILITIES AT ZANGWA RURAL AREA

<b>Participant</b>	<b>Age</b>	<b>Sex</b>	<b>Marital Status</b>	<b>Highest Level of Education</b>	<b>Physical Disability</b>	<b>Cause of Disability</b>	<b>Duration of Disability</b>	<b>Assistive Device Used</b>
C1	56	M	Single	Std 4	Contractures (L) Shoulder & Elbow	Severe Burns	15 Years	None
C2	57	M	Divorced	Std 2	Hemiplegia	Head Injury	20 Years	Elbow Crutch
C3	55	M	Single	Not Educated	Short Leg with Foot Drop	Polio	Since 1 Year Of Age	Walking Stick
C4	33	F	Single	Std 8	Paralysis Left Arm	Cerebral Palsy	From Birth	None
C5	43	F	Single	Not Educated	Short Weak Legs & weak ® Arm	Congenital disability	Since 3 Years Of Age	Wheelchair

TABLE 3, DEMOGRAPHIC DETAILS OF THE FOCUS GROUP OF PEOPLE WITH PHYSICAL DISABILITIES AT SKITI INFORMAL SETTLEMENT

Looking at the above demographic details of people with physical disabilities who took part in the research, it can be seen that the average age differed from place to place. At Bika the average age was 38.9 at Zangwa it was 61.1, and at Skiti it was 48.8. This showed that people with physical disabilities at the rural area were mostly older people, when compared to those at the township and at the informal settlement. The types of disabilities also varied.

#### 4.3.1 NEEDS

Results on the needs of people with physical disabilities as perceived by people with physical disabilities themselves are presented in Table 4 below:

THEMES	CATEGORIES
Family Life	To have own family Integration, marriage and co-habiting Family ties Meeting Dependency Needs
Economic Independence and survival	Employment Losing Jobs Disability grant Income generating projects Skills development
Health and Medical Supplies	Primary Health Care Reassurance and Advice Orthotic and Prosthetic Equipment Experiences of using Medical Equipment
Housing	Needs of People living in Informal Settlements

	Needs of People living in inaccessible Houses
Roads and Transport	Need for proper roads Need for suitable public transport facilities Need for positive attitudes of taxi drivers Driving Schools Parking bays
Caregivers	A Need for Caregivers Extra Grant for Caregivers

TABLE 4, FINDINGS ON THE NEEDS OF PEOPLE WITH PHYSICAL DISABILITIES, AS PERCEIVED BY PEOPLE WITH PHYSICAL DISABILITIES THEMSELVES

#### 4.3.1.1 Family Life:

Families of people with disabilities determine and influence their integration into society. This process of integration involves people with disabilities being perceived as part of the community and not as a separate group of people, and this process must begin with family. People with disabilities also have to see themselves as part of the community, and not isolate themselves. The categories relating to this theme are presented and discussed below:

- a) To have their own families and raise their own children: Young adults with physical disabilities expressed a wish that they wanted to start families, and have their own children. These young women felt that their families, as well as the society did not expect them to have love relationships, yet they expressed their hopes and wishes that they would also get married and have children.

*I would like to get married, and have my own children. (Participant A10)*

- b) Integration, marriage and co-habiting: Participants living in Area C responded to the question of integration and marriage, stating that, the majority of people living in their area were not married, but only co-habiting; that is, living together; without the commitments of marriage. So; the same was happening with people with disabilities living in that area. Co-habiting is different from being married, in that it involves only the couple, unlike marriage that involves both their families in the relationship, and when cohabiting, no *lobola*<sup>1</sup> is paid to the wife's family.

*Yes, we mix with other people, but I can't say that we are married, because mainly, in this area, people are just co-habiting. (Participant C3)*

People with physical disabilities, living in Area C, were also encouraging each other to integrate, and not to isolate themselves. They were surprised to find out that participant C5 was also living at the informal settlement, because they were only seeing her for the first time.

*I'm asking you my sister, don't take me wrongly, I'm also a disabled woman like you, but I move around. I don't stay in one place. Even Maam met me on the way, yet I walk with difficulty because one of my legs is limping, and I use only one arm. I'm therefore begging you, my sister, don't stay in one place, mix with other people. (Participant C4, addressing participant C5)*

- c) Family ties: People with physical disabilities who need to have caregivers are cared for, mainly, by close family. Some are cared for by their mothers, some by their grandmothers some by their daughters, some by their wives, and some by their sisters. Mostly, care-giving is done by women. When a woman becomes disabled, if there is no daughter to take care of her, her sister has to come and live with her, so as to take care of her. It is very rare to find a woman being cared for by her husband; as care-giving is regarded as woman's work.

*No, I never had a husband, I live with my sister and her children, and I never had a child of my own. (Participant C5)*

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<sup>1</sup> Bride price paid by the groom's family, to the bride's family to seal a relationship between the families.

Participant C2, who suffered a head injury, resulting in complete paralysis of his left upper limb, and stiffness of his left lower limb, whose wife had left him, had his two daughters to live with. This shows the dependence on female caregivers of people with disabilities.

*At home I live with my children. (Participant C2)*

- d) Meeting Dependency Needs: Dependency was seen as a serious problem by people with physical disabilities at Areas B and C. Participant C5, in particular, who had congenital malformations of both her lower limbs, as well as paralysis of her right upper limb, and therefore could not move around, depended on other people for everything. She had to be helped from the bed, to the wheelchair. Someone else had to prepare food for her, and give her water to wash, get her disability grant for her, and buy things for her.

*Well, I never go to the bank; my sister handles all my finances. My sister also buys clothes for me. (Participant C5)*

Another participant, Participant B6, was old, and had severe arthritis of both knees and hips, and she was living alone. Many elderly people in the rural areas live alone, because their children are grown up, either living at their own places, or living in urban areas where they usually go to find employment. These elderly people then cannot do some of the household chores, and therefore have to depend on neighbours.

*I have to hire someone to fetch water for me, from the well, or from the tap, when the taps have water, because I cannot manage to go there. I also have to hire someone to do the washing for me. (Participant B6)*

Talking about a shop in Butterworth, where one had to go up a flight of stairs, almost all of the participants from different areas found it impossible to climb those stairs. Inaccessibility of buildings, or environments, is therefore one of the causes of dependency.

*If I want anything up there, I ask someone else to get it for me. I can't even try to climb those stairs! (Participant B9)*

#### 4.3.1.2 Economic Independence and Survival:

This section on needs includes employment, losing jobs, disability grant, income generating projects and skills development.

- a) Employment: There is generally a high rate of unemployment, affecting everybody in the study communities. Despite the Employment Equity legislation that calls for all companies that employ more than 50 people to have people with disabilities employed in their companies; disabled people are still struggling to find jobs.

*If the government could enforce a certain percentage of people with disabilities to be employed in each company, or facility, employment opportunities for us would be better. (Participant A2)*

Participant A2, who had graduated from the local University of Technology with a Diploma in Administration four years before, was finding it difficult to get employed.

*You come to a company looking for work, showing your educational qualifications, and what kind of work you can do, then you are asked to leave your CV, and you are promised you'll be phoned. You'll wait forever! (Participant A2)*

- b) Losing Jobs: Due to the poor economic conditions, many people lose their jobs through retrenchments and other evictions and this affects the community as a whole. People with physical disabilities also experience such situations.

*I used to work in East London, then I lost my job, then I got injured after I lost my job (Participant C1)*

It also came up that inaccessibility of buildings and environments was also causing job losses and unemployment.

*I also worked for a short period at the clothes factory that is situated above Savell's, and because there were a lot of steps there, I had to quit. (Participant A2)*

- c) Disability Grant: Participants had different things to say about the disability grant. Some felt that the grant was not enough; others felt that the process for applying for it took a very long time. There are also problems of rejection of applications for disability grants, where one finds that there are people with disabilities, whose applications are rejected, and other people with disabilities have had their disability grant suspended. Participants had the following comments;

*I have a problem with the disability grant; the doctor signed the forms long ago, it's more than six months now that I've been waiting for it. (Participant A7)*

One 21 year old man who had a head injury resulting in hemiplegia, had applied for a disability grant, but it was rejected. This rejection of applications for disability grants causes a lot of concern, because you find people who have serious disabilities, having no disability grants.

*My problem is that I don't have a disability grant. My application was rejected. What can I do? (Participant B1)*

The problem of unemployment and poverty in the community of Butterworth, results in old people and people with disability supporting their families with the disability grant.

*The problem with our disability grant is that it is not only for us. We have grown up children, some of them married, yet not working. On top of that they also have children, and they all depend on this grant. (Participant B7)*

*Yes, I do have a disability grant; it's just that it's not enough, with children attending school. It is not enough even after it was increased to above R1000, it's not enough. (Participant C1)*

Suspension of disability grant also causes a lot of concern for people with disabilities, because it happens without any prior warning, even if the doctor had made it clear that the disability was permanent.

*One of the problems with the disability grant is that sometimes it gets suspended, leaving the person with disabilities without money. Mine was suspended in 1995, and I got it again in 1996, after a year and five months, and I never received any back-pay for the period that it was suspended. (Participant C4)*

- d) Income generating projects: Participants in Area A, and Area C, showed a lot of interest in starting income generating projects. They felt that they needed some guidance to be able to start projects. They had the following ideas about projects they would like to start:

*If we could come together as a group, and sell paraffin, have a paraffin tank, and put it in a safe place, all the people from the township can buy from us. (Participant A1)*

Other participants were interested in this project, and they wondered if there was perhaps any possibility that the government could support it.

*Is it not possible that the government could buy us the first tank of paraffin, then after that, refills can be made from the profit made? (Participant A5)*

Participants from Area C had the following suggestion about income generating projects:

*What I'm thinking of is that, since our disability grant is not enough, if there could be some projects for us to do, maybe men do shoemaking, and we, women, do some sewing, then that could improve our finances. (Participant C4)*

Regarding supplementing the disability grant, participants had different ideas:

*I have these chickens, they help me a little. Sometimes I sell chickens, and sometimes eggs. (Participant C1)*

- e) Skills Development: Participants at Areas A and C felt that it was necessary to have skills development projects, in order to help them develop skills they could use to be more independent, as well as to supplement their disability grant. Participants felt that there was a need for a centre for skills development.

*Another way of supplementing the disability grant is to make things with your hands. The problem is that there are very few places that train people on skills. Even those that are available are difficult to get. I got help from a lady I sat next to in a taxi, who asked me what I did with my hands, and I said; nothing. She advised me to go to a place that was sponsored by the Department of Social Development in Mthatha. That is where I learnt how to sew. I was the only one from Butterworth doing training there at that time. There were many different skills that were done there, besides sewing. (Participant A6)*

Participants showed a lot of interest in the subject of getting training for different skills.

*What I'm thinking of is that we, who can manage to do some work, should be trained to do skills like sewing. Maybe men could be trained to do shoe making, or even sewing as well. (Participant C4)*

#### 4.3.1.3 Health and Medical Supplies:

This theme relates to medical and health needs of people with physical disabilities in the study. The categories of responses are presented below:

- a) Primary Health Care: Participants at Area B do not have a local clinic. They only have Mobile Services, so they felt that they were in need of a local clinic, so that they could have health services all the time. The problem with the Mobile Health Services is that they visit a point only once a month and sometimes once in two months. To be seen by the doctors at the hospital's Out-patient's Department, patients had to have a referral from the clinic or from another doctor. It was not easy to get a referral from the clinic when there was no resident clinic. Participants had the following comments, regarding primary health care:

*I don't know how this can be done, for a clinic to be built at this location. At the mobile clinic they do not check our conditions, nurses only give medicines, and the clinic is not there when we need it. (Participant B3)*

*It was going to be better if there was a clinic locally, and not just a mobile clinic, because we could come and have check ups for blood pressure and diabetes anytime. (Participant B3)*

This problem of not having a local clinic was causing concerns in that it made people end up going to private practitioners, and this cost a lot of money.

*Sometimes the mobile clinic does not come for more than a month, so we decide to go to private doctors. (Participant B6)*

- b) Reassurance and Advice: Participants from all areas needed reassurance and advice in some problems that they were experiencing.

One participant who had a below elbow amputation of her left arm needed advice on how to use her arm, and what help she could possibly get, on doing household chores.

*I have a problem of having one arm. When I want to chop vegetables or peel potatoes at home, I can't, because I don't have anything to hold things with, when using the other hand. I think it would be better if there could be some gadget that could be fitted onto this short arm, to help me hold things with, when using the other hand. (Participant A8)*

Another participant was worried that he was getting cramps at the lower parts of his body. This man had been involved in a mine injury, and his back was affected. He recovered almost fully; from using a wheelchair, to walking independently. The problem now was that the cramps that he used to have at the lower parts of his body when his injuries were new, and had stopped with time were now coming back.

*I don't want to stay with something that I don't know, that is why I have to ask about it, before it's too late. (Participant B3)*

Some participants acted as resources, giving advice to each other on how to overcome some problems.

*So you see that you really need to have someone to stay with, at home, and look after you when your sister is at work, and the children at school. You are not supposed to stay alone, that could be dangerous to you. You can be a victim to criminals, and they can do anything to you. (Participant C4)*

Further advice was given to participant A2, who had problems getting a driving school that was catering for people with disabilities. This young man had been to all the driving schools in Butterworth, and even went to as far as away as Stutterheim, where he had been told there was a driving school that was catering for people with physical disabilities, but on arrival there, he was told that the car had broken down.

*You can ask anyone with a car that has automatic gears, to teach you how to drive, and practise in that car till you get your driver's licence. (Participant A1)*

Participant B4 needed some advice on the symptoms she was having; she feared that she could be getting a stroke, but because there was no local clinic in Area B, she could not have regular monitoring of her blood pressure and blood sugar.

*With me Maam, I don't know whether I'm going to have a stroke or not. I have a side that feels numb, even when I talk I mumble. I don't know whether I'm going to have a stroke or not. I was once told that I had high blood pressure. (Participant B4)*

- c) Orthotic and Prosthetic Equipment: Some of the participants needed to have some Orthotic and Prosthetic equipment in all the areas of the interviews. In area A, participant A8 had a below elbow amputation, and she was experiencing problems when preparing meals at home. She needed something to hold the vegetables with, when chopping or peeling them.

*I think it would be better if there could be some gadget that could be fitted onto this short arm, to help me hold things with, when using the other hand. (Participant A8)*

Some participants did not know how to access some services. One participant from Area B had a prosthesis that was very old, which he got from Johannesburg more than 15 years before, and he did not know how he could have it repaired, or how he could get a new one.

*What worries me is this leg, it is old, and it's difficult even to put it on. I don't know if it's possible for it to be repaired. (Participant B2)*

One of the participants who had surgical boots, needed to have them changed, the ones that he had, had been made five years before.

*I got them from Frere Hospital, five years ago, and I was told that I must go and get new ones when these are worn out. (Participant C3)*

- d) Experiences of using Medical Equipment: Some of the participants were either using medical equipment, like Orthotics, or had used them before, and stopped for various reasons. The following are their experiences on using the equipment:

*I do have a raise on my shoe, to compensate for my short leg, but I only use that special shoe when going out, and I wear takkies at home. (Participant A2)*

Other participants had stopped wearing callipers because they were either too heavy for them, or the iron rods were irritating them when they were walking, or both.

*I found that it was more comfortable for me to walk without the callipers, as they were heavy, and they irritated me at the thighs when walking on steep road. (Participant A6)*

*I also stopped using callipers because they were too heavy. (Participant A10)*

*I also used to have this type of boots, because of this short leg, but I stopped using them because they were too heavy for me. (Participant C4)*

Participant C3 had no problems wearing his boots; he wore them everyday.

*I do not have any problems, I go everywhere. I only get tired if I walk a long distance. (Participant C3)*

#### 4.3.1.4 Housing

The need for houses was expressed more by participants who lived in the informal settlement, but there was also a problem of inaccessibility of houses in the township. Housing is a problem for all residents of Butterworth, but it affects people with disabilities in particular ways. The need for housing is therefore discussed below:

- a) Needs of People Living in Informal Settlements: People with physical disabilities who lived at the informal settlement expressed their greatest need to be that of obtaining houses. Although they felt that living conditions in the informal settlement were not suitable for people with physical disabilities, they had nowhere else to go. People with physical disabilities living at the informal settlement needed basic houses and needed to own a house in order to have stability and better living conditions.. They were renting the shacks they lived in.

*What I need most and what worries me is the fact that I don't have a house; I'm renting a shack (Participant C3)*

*I also live uncomfortable, in a rented shack, and my life is a torture, because of the living conditions. (Participant C1)*

*If you make a mistake and you do not pay rent, you are told that you have to get out of the shack. (Participant C3)*

According to people with physical disabilities, living in informal settlements was not easy, and was also very unhealthy. For instance, at this informal settlement there were old toilets

that were not working, that is, they could not flush, so people living there had to go to the bushes to relieve themselves, which is not easy for people with physical disabilities.

*Here, when people want to go and relieve themselves, they go to wrong places, at the bushes, because the toilets are not working. (Participant C3)*

Some of the people with physical disabilities cannot manage to squat, due to the fact that they have stiffness of joints, and they cannot walk on uneven ground in the bushes. Those using wheelchairs definitely cannot manage to go and relieve themselves in the bushes. This is an awkward situation for people with physical disabilities.

*It is very difficult for us to squat, to relieve ourselves. (Participant C3)*

Living in an informal settlement is also dangerous, with the possibility of fire erupting anytime. Participants at Area C remarked that this situation is more dangerous for them, as they were not able to run when this happens

*It is not a joke that fire is very frequent at the informal settlement, so it is just not safe for a person with disabilities to live alone. (Participant C3)*

- b) Needs of People Living in Inaccessible Houses: Participants from Area A, a township, expressed a need for accessible housing. Some of the houses were inaccessible due to the fact that the place where they are situated was not easy to reach. Inaccessibility was also due to steps at entrances, houses with small passages, and not allowing much movement of wheelchairs, or the toilets were also too small for the wheelchairs to enter.

*I find it difficult to get in and out at my home. It is better at the front door, but even there, someone has to help me, as there is one step. It is worse at the kitchen door, where there are many steps. (Participant A3)*

#### 4.3.1.5 Roads and Transport

- a) A need for Proper Roads: Participants from Area B, a rural area, needed to have proper roads within their locations. The one single road that came through this location from Ndabakazi to the Kei River was fine, though it was made of gravel, but these participants needed roads that lead to their homes. They had to walk a long

distance to be able to reach the road, to get transport, and this was not easy for them as they walked with difficulty.

*The main problem in this location is that there are no proper roads; it is difficult for cars to come to our homes. It is worse when it is raining. Even if I could die, my body would have to be carried all the way from my home, to a car waiting on the road. (Participant B6)*

- b) A need for suitable public transport: The normal public transport that was used in Butterworth was not suitable to be used by people with physical disabilities. Taxis used were mainly kombis, with steps at the doors, and vans, (Stallions), that were so high that a step had to be made to help the passengers to climb in. This climbing into the vehicles was not possible for some people with physical disabilities, so they had to be lifted into the taxis.

*One has to be lifted up and helped into the taxi by other people. (Participant A3)*

*In some taxis, chairs are so close to each other that there is no space for a wheelchair. (Participant A9)*

- c) Negative Attitudes of Taxi Drivers: Participants from Areas A and B, complained about negative attitudes of taxi drivers. They pointed out that taxi drivers were always in a hurry, and they were impatient with people with physical disabilities as they could not walk fast. They said that taxi drivers also had an attitude that people with disabilities should stay at home, unless they were going to the hospital. The following are quotes from some of the participants;

*Sometimes the taxi leaves me because I cannot walk fast. (Participant A4)*

*Another thing we are always taken as sick people. When you want to get into a taxi, maybe going to town, you are told that the taxi is not going to the hospital. (Participant A10)*

Participants from Area B also complained about taxis;

*Yhoo, taxis are always in a hurry! When you want to catch one, you are told, 'No, I'm in a hurry, wait for the next one'. Even the following one will not take you because you take time even to get into the taxi. (Participant B9)*

- d) A need for Driving Schools suitable for People with Physical Disabilities: One participant from Area A pointed out that he needed a driving school that catered for

people with physical disabilities. He was in desperate need for this, as his learner's licence was soon going to expire, and he had not yet got a driving school where he could learn to drive. This young man had been to all the driving schools in Butterworth, and even went to Stutterheim; a town not very close to Butterworth, trying to get a suitable driving school for him, without success. He even tried to learn driving using a car with normal manual gears, but could not manage, because of his disabilities.

*I've been to all the driving schools in Butterworth, not even one caters for people with physical disabilities. (Participant A2)*

- e) Parking Bays for People with Physical Disabilities: One of the participants at Area A had a car. He pointed out problems with parking areas for people with physical disabilities in Butterworth, as only a few parking bays were reserved for people with physical disabilities.

*There are very few parking bays for people with physical disabilities in Butterworth. The other day I parked my car next to the library, on a parking bay reserved for the library staff, and I went inside to get a book. When I came out, there was a traffic ticket on my car. I talked to the traffic officers about having more reserved parking bays for people with physical disabilities next to all public buildings, but up to now, nothing has happened. (Participant A1)*

#### 4.3.1.6 Caregivers

People with severe physical disabilities usually need to have caregivers. These caregivers help them with those activities that they cannot manage on their own, like washing them, dressing them, making food for them; and even feeding them where necessary. This theme on caregivers is discussed in the categories below:

- a) A Need for Caregivers: Participants in the primary group from all three areas saw a need for caregivers for those of them who needed assistance. Some of the participants from Area B had to have caregivers to fetch water for them from the well or from a communal tap, to do their washing, and to help them with other activities. The following are quotes from participants regarding the need for caregivers;

*I have youngsters from my area, who usually accompany me and help me into the taxi. (Participant A3)*

*I live alone at home, and I have no-one to help me with anything. I cannot fetch water from the well, so I have to hire someone to fetch water for me every day. Sometimes I have to hire someone to do my washing. (Participant B6)*

*So you see that you really need to have someone to stay with, at home, and look after you when your sister is at work, and the children are at school. You are not supposed to stay alone, that can be dangerous to you. You can be a victim to criminals, and they can do anything to you. (Participant C4)*

- b) Extra Grant for Caregivers: In most cases, care giving for people with disabilities is done by close family, and these caregivers usually have to stop working, or being involved in anything else other than care giving duties. This means that there is loss of income for the caregiver, and in most cases, the caregiver depends on the grant of the person with disabilities. This was the reason why participants felt that there was a need for an extra grant for people with physical disabilities, to give to their caregivers. The following are quotes from the participants on this subject;

*Really, this special grant should be there, because there are people who really need to have someone to look after them, like old people who cannot do anything for themselves. Someone has to wash them, and do everything for them. (Participant C4)*

This is the end of the section on needs of people with physical disabilities, as perceived by people with disabilities, themselves. The next section is on accessibility of resources to people with physical disabilities, as perceived by people with physical disabilities themselves.

#### 4.3.2 ACCESSIBILITY OF RESOURCES

The following were responses from people with physical disabilities, when asked about the accessibility of available resources to them, and barriers preventing them from accessing them. They are shown as categories, building up into themes, in Table 5, below:

THEMES	CATEGORIES
<p>Knowledge about Resources, and how they can be Accessed</p>	<p>Orthotics and Prosthetics</p> <p>Physiotherapy and other rehabilitation services</p> <p>Discounts for people with physical disabilities</p> <p>Grant – in - Aid</p> <p>Disability Grant</p> <p>Skills Development</p> <p>Registering as Job-seekers</p>
<p>Barriers to Accessing Resources</p>	<p>Inaccessibility of facilities</p> <p>Scarcity of resources</p> <p>Rejection of applications for resources</p> <p>In-efficiency/delays in the processing of applications for resources</p>
<p>Suggestions about more Resources</p>	<p>More pay points for the disability grant</p> <p>Primary health care</p> <p>Awareness raising campaigns about available resources</p> <p>Employment for people with physical disabilities</p>

TABLE 5, RESULTS INDICATING THE AMOUNT OF KNOWLEDGE PEOPLE WITH PHYSICAL DISABILITIES HAVE ABOUT RESOURCES AND HOW TO ACCESS THEM

#### 4.3.2.1 Knowledge about Resources and How to Access Them

People with physical disabilities in the district of Butterworth knew about some available resources that they could benefit from, like the disability grant, but they did not have any knowledge about other important resources they could benefit from. The following categories describe resources that they did not know about and those that they knew about, but did not know how to access:

- a) Orthotics and Prosthetics: Many participants knew about this service, but they did not know about the outreach service that comes from Frere Hospital to assess clients at Butterworth Hospital. Those participants who had prosthesis and special shoes were either not wearing them all the time, or did not know how to have them repaired, or to have new ones made. Some of the participants had stopped using callipers because they were too heavy for them. The researcher advised these participants on how to have this service, according to their needs. As seen in the needs' section, one participant who had a below elbow amputation, was wondering if there could be any help for her, to help hold vegetables for her, when preparing meals at home, Another participant who had a below knee prosthesis had had it for 15 years, and he didn't know where to take it for repairs, or to get a new one. He had got the old one from Johannesburg, where he was working at the time. So now that he had come back home, he did not know where to go.

*I think it would be better if there could be some gadget that could be fitted onto this short arm, to help me hold things with, when using the other hand. (Participant A8)*

*What worries me is this leg, it is old, and it's difficult even to put it on. I don't know if it's possible for it to be repaired. (Participant B2)*

- b) Physiotherapy and other Rehabilitation Services: Participants, mainly from Area B did not know that there were rehabilitation services like Physiotherapy at Butterworth Hospital. One of the participants who had suffered a stroke, and had a stiff left upper limb, wanted to know if going for Physiotherapy would make his arm work again. The researcher explained to him that Physiotherapy might not make his arm work again,

but it could make it better than it was, and he would also be given advice on home management. There were also clients who did not know how to access these rehabilitation services.

*I have a problem with this hand that is not functioning on the affected side, I don't know if it's possible for it to get healed if I go for Physio. (Participant A1)*

One participant was worried about people in the locations, who had suffered strokes and other conditions, but who were never referred for Physiotherapy.

*There's something that I don't know how to deal with, you find that there are many people who had strokes, or other conditions in the location, who were seen by doctors, and not referred for Physiotherapy. What are these people supposed to do to get Physiotherapy and other health services? (Participant A6)*

- c) Discounts for People with Disabilities: When asked about discounts for people with disabilities, some of the participants from Area A knew about this discount, but those from other areas did not know anything about it. One of the participants said that one shop in East London had a notice that people on disability grant and those on old age pension could fill in forms, to get this discount. Participants did not know of any shop with these discounts in Butterworth, and none of them knew how they could access it. The following quotes are responses from the participating people with physical disabilities:

*I will talk about groceries. There's supposed to be a discount that we, as people with disabilities should get, like elderly people. Look at Game, there are forms there that are given to people on old age pension, to fill in so as to get discounts. I believe the same applies to people with disabilities. (Participant A1)*

*I once heard that Spar also has this discount, but I'm not sure. (Participants A5)*

*No I don't know anything about discounts, what I know of is paraffin that is sometimes given to everyone who lives at the informal settlement. (Participant C3)*

- d) Grant for Caregivers, (Grant-in-Aid): All the people with physical disabilities who took part in the research did not know about the grant for caregivers. When asked about it they all said that they had never heard about it. The researcher also said that

she had only heard about this grant, but she did not know who should apply for it, or how it could be accessed, so she promised the participants that she would visit the SASSA offices to enquire about it. These participants, therefore, did not know about this resource, as well as how to access it.

- e) Disability Grant: The procedure on how to get a disability grant was not clear to some of the participants. This was because some participants' applications had been rejected, so they did not know what else to do. There were also delays in the processing of resources, like disability grant as well as identity documents. Some participants were really discouraged by this rejection, as well as the delays. They did not know who to turn to.

*You see, I only got the disability grant a few years ago, though I'm having this short, small leg since I was a child. The Doctors were saying that I was not disabled because I had both legs, and I could walk, not considering how I walked. (Participant C3)*

- f) Skills Development: Participants from Areas A and C wanted to be trained in skills that could help them to have an income that could supplement their disability grant. They did not know how they could get this training.

*The problem is that there are very few places that train people on skills. Even those that are available are difficult to get. (Participant A6)*

- g) Registering as Job-seekers: Many participants needed employment; they were not satisfied with the disability grant only, but they were not aware that they could register at the Department of Labour as job seekers, so they did not register.

*What should one do to register? (Participant C4)*

#### 4.3.2.2 Barriers to Accessing Resources

Lack of knowledge is a major barrier, preventing people with physical disabilities from accessing resources. Besides lack of knowledge on how to access resources, people with physical disabilities experience the following barriers:

- a) Inaccessibility of Facilities: Participants from all the areas pointed out that it was not possible for them to access some public places, because they were inaccessible to them. Some of these facilities were inaccessible because of where they were situated, or because of the inaccessibility of buildings, or because of other reasons. Participants had the following to say:

*Places with steps cannot easily be accessed by people with difficulty in walking, it is worse with those who use wheelchairs. (Participant A1)*

When asked about going to facilities that were far from the taxi ranks, like Butterworth Hospital, the Department of Home Affairs, SASSA, and others, participants had the following to say:

*Of course, if we want to go there, we have to hire special transport, and there are extra costs for that. (Participant B6)*

- b) Scarcity of resources: Participants complained about scarcity of resources like Housing, Primary Health Care, etc. At Area B there was no local clinic, they only had a mobile clinic that visited only once a month and sometimes once in two months, and in Area C, what they needed most was housing.

*Sometimes the mobile clinic does not come for more than a month, so we decide to go to private doctors, and this is expensive. (Participant B6)*

- c) Rejection of Applications for Resources: Some participants with physical disabilities were worried that their applications for disability grant had been rejected, yet they could not be employed, due to their disabilities.

*My problem is that I don't have a disability grant. My application was rejected. What can I do? (Participant B1)*

- d) Inefficiency/Delays in the Processing of applications for Resources: Participants complained of delays in the processing of applications for identity documents and disability grants. Having no identity document is a big problem, because without it, one cannot access any social benefits. This inefficiency therefore caused a lot of suffering, not only to people with disabilities, but also to the community as a whole.

*This man has two daughters who have their own children; all are dependent on this man's disability grant. There is no child support grant for these children, because their mothers have no identity documents (Participant C3)*

*These girls have been trying to get these IDs for a very long time, now they are not able to apply for birth certificates for their children. (Participant C2)*

*This is not happening in Butterworth only. My sister, who lives at home, in Tsomo, is also having a child, and no ID, so she is having the same problem. (Participant C4)*

#### 4.3.2.3 Suggestions about more resources

People with physical disabilities who participated in the focus group interviews had some suggestions about more resources that they felt they needed. These included more pay-points for the disability grant, more primary health care facilities, and awareness raising campaigns about available resources, and employment opportunities for people with physical disabilities.

The above are results of the study on needs and accessibility of resources for people with physical disabilities, in the district of Butterworth, as perceived by people with physical disabilities themselves. The following section is on the needs of people with physical disabilities and accessibility of resources to them, as perceived by their caregivers.

#### 4.4. RESULTS FROM INTERVIEWS WITH CAREGIVERS OF PEOPLE WITH PHYSICAL DISABILITIES

Caregivers of people with physical disabilities were interviewed in two focus groups, one at Bika Township, and the other at Zangwa Administrative Area. All the caregivers were females, and they were all mothers, grandmothers, daughters, and wives of people with physical disabilities they were taking care of. The researcher found it difficult to collect caregivers of people with physical disabilities, as most physically disabled people do not need to have caregivers. Many people with physical disabilities who actually needed to have caregivers, could not be left alone, therefore their caregivers were not able to join the focus group interviews for caregivers. Other caregivers of people with physical disabilities, especially in Area C, were not available during the day, as they were busy generating income by selling fruit in the town of Butterworth. Because of this, the researcher did not manage to have a focus group of caregivers at Skiti Informal Settlement; that is Area C.

Demographic details of caregivers of people with physical disabilities at Bika Township and at Zangwa Administrative Area are shown in Tables 6 and 7 below:

Caregiver	Gender of Caregiver	Age	Marital Status	Highest Level of Education	Disability of Person Caring For	Age of Disabled Person	Cause of Disability	Duration of Disability	Relationship to Disabled Person	Assistive Device Used
AC1	Female	58	Divorced	Std 8	Cerebral Palsy	18	Birth Trauma	Since Birth	Grandmother	Wheel-chair
AC2	Female	52	Married	Std 9	Cerebral Palsy	19	Birth Trauma	Since Birth	Mother	None
AC3	Female	53	Married	Std 4	Spina Bifida	21	Congenital	Since Birth	Mother	Elbow Crutches
AC4	Female	66	Widowed	None	Paraplegia	38	MVA	10 Years	Mother	Wheel-chair

TABLE 6, DEMOGRAPHIC DETAILS OF CAREGIVERS OF PEOPLE WITH PHYSICAL DISABILITIES AT BIKA TOWNSHIP

Caregiver	Gender of Caregiver	Age	Marital Status	Highest Level of Education	Physical Disability of Person Taking Care Of	Age of Disabled Person	Cause of Disability	Duration of Disability	Relation to Disabled Person	Assistive Device Used
BC1	Female	52	Widowed	Std 4	Inability to use All Limbs	33	Birth Trauma	From Birth	Mother	None
BC2	Female	29	Single	Std 9	Inability to Stand and Walk	78	Arthritis	6 Years	Daughter	Walking Frame
BC3	Female	47	Single	Std 7	Bedridden	80	Stroke	5 Years	Daughter	None
BC4	Female	37	Single	Std 7	Bedridden	84	Severe Arthritis	6 Years	Daughter	None
BC5	Female	44	Married	Std 7	Hemiplegia	49	Stroke	3 Years	Wife	1 Elbow Crutch

TABLE 7, DEMOGRAPHIC DETAILS OF CAREGIVERS OF PEOPLE WITH PHYSICAL DISABILITIES AT ZANGWA ADMINISTRATIVE AREA

The above demographic details of caregivers of people with physical disabilities show that all caregivers were females, this confirming that care-giving is done mostly by women. The average age of caregivers of people with physical disabilities at Zangwa Administrative Area was 41.8, and the average age of caregivers at Bika Township was 57.25. This was because caregivers at Zangwa were mostly looking after their parents, whereas those at Bika were looking after their children and grandchildren.

#### 4.4.1 NEEDS OF PEOPLE WITH PHYSICAL DISABILITIES

The following table shows responses on needs of people with physical disabilities, in the district of Butterworth, as perceived by their caregivers:

THEMES	CATEGORIES
Financial Security	Disability Grant Employment
Rehabilitation	Exercise Assistive Devices Family and Community Involvement Tensions around Independence
Independence	Accessibility at Their Homes Training for Skills
Consultation	To be Treated like Adults Financial Matters Attention

Transport Needs	A Need for Suitable Public Transport A Need to have Own Car
Personal Needs of Caregivers	Assistive Devices Respite Care, or Extra Help A Need for Day Care Centres Feeling Appreciated Need for advice on some issues

TABLE 8, RESULTS FROM INTERVIEWS WITH CAREGIVERS REGARDING THE NEEDS OF PEOPLE WITH PHYSICAL ABILITIES AS PERCEIVED BY THEIR CAREGIVERS

4.4.1.1 Financial Security:

Caregivers of people with physical disabilities felt that there was a need for financial security for people with physical disabilities. They felt that people with physical disabilities needed money for transport, for medical supplies, for buying clothes and food, and for paying their caregivers.

- a) Disability Grant: When asked about needs of people with physical disabilities, caregivers mentioned the need for care dependency grant and disability grant as important to them. They felt that people with physical disabilities were mostly unemployed, yet they had a lot of financial needs, especially transport needs, so they needed these grants.

*They need disability grant and care dependency grant. (Participant AC2)*

- b) Employment: One of the caregivers had a son who was paraplegic due to a car accident when he was a student at the local university. She felt that if her son could get employed, then his quality of life could be better.

*I think my son needs employment; maybe he would stop spending his days at the shebeen. (Participant AC4)*

#### 4.4.1.2 Rehabilitation:

Caregivers felt that people with physical disabilities needed rehabilitation to help them cope with activities of daily living, so as to gain independence. These included the following categories:

- a) Exercises: Some caregivers felt that it would be better if some exercises could be given to their children; maybe they could gain some independence.

*My daughter needs some exercises that could maybe help her to use her arms and hands better. I think that maybe there is some treatment that she could get to make her stronger. (Participant AC2)*

- b) Assistive Devices: Some caregivers felt that they needed assistive devices for the people with physical disabilities that they took care of. They had the following comments:

*I wish that my mother could get a walking aid; then she could walk better. (Participant BC4)*

*If my daughter could have something like a wheelchair; then she could be moved around easier (Participant BC1)*

*I think that a commode could help relieve us from lifting, because I find it difficult to lift my granddaughter to the toilet and back. (Participant AC1)*

*I wish there was some special equipment to help me lift my granddaughter. She is so heavy for me that I have to ask other people to help me whenever I have to lift her. (Participant AC1)*

- c) Family and Community Involvement: Some caregivers felt that there was a need for family and community involvement in the care-giving of people with physical disabilities.

*I cannot do this lifting on my own, because she is too heavy, so when my youngest son is there, he is the one who does the lifting, then when he is at school, I have to ask my neighbour to help me. (Participant AC1)*

#### 4.4.1.3 Independence:

Caregivers of people with physical disabilities felt that the relatives that they were looking after needed to be more independent than they were. Some environmental factors caused these clients to be dependent on their caregivers in many ways.

- a) Accessibility at their Homes: Caregivers from Bika Township felt that passages at their homes were too small for wheelchairs to be able to turn around. They needed more accessible houses.

*My son cannot reach up and take his clothes from the wardrobe, or take things from the upper parts of the kitchen cupboards, he has to be helped. Even getting in and out of the house is not easy. (Participant AC4)*

*My granddaughter only sits in her wheelchair in the bedroom. She cannot be pushed around in the passage at our home, as it is too small to allow that. To be able to go outside, she has to be lifted. She also has to be lifted onto the toilet seat, as the toilet at our home is too small for the wheelchair. (Participant AC1)*

- b) Training for Skills: Some caregivers felt that people with physical disabilities that they were looking after, needed to be trained for skills, so as to gain some independence.

*My daughter failed grade 9 for the third time, so she does not want to go to school anymore. Now she wants to learn computer skills. (Participant AC3)*

#### 4.4.1.4 Consultation:

Caregivers of people with physical disabilities felt that people with physical disabilities they were looking after, needed to be consulted about things that mattered to them, especially those about financial matters. The following are needs for consultation of people with physical disabilities as perceived by their caregivers:

- a) To be Treated like Adults: Caregivers of people with physical disabilities realised that people with physical disabilities did not want to be treated like children, they wanted to be treated like adults.

*My daughter does not like to be treated like a child, like I usually do; she wants to be treated like an adult. (Participant AC3)*

- b) Financial Matters: Caregivers of people with physical disabilities said that they could not do anything with the money that belonged to the people with physical disabilities that they looked after, without consulting with them first.

*When my husband gets his disability grant, I have to give him R300 for him to buy petrol and parts for his old car. If I don't give him, he will not be happy the whole week. (Participant BC5)*

*My mother wants to know all the details of what I did with her pension money. (Participant BC4)*

- c) Attention: Caregivers also mentioned that people with physical disabilities needed a lot of attention. They did not like to be ignored.

*What I've noticed is that my husband needs a lot of attention, he wants to be cared for, and does not want to be ignored. (Participant BC5)*

*My daughter also wants to see to it that she gets all the attention she can get. If she feels neglected, she makes noises, so as to draw attention to her. (Participant BC1)*

- d) Tensions around Independence: There were some tensions over excessive independence of some people with physical disabilities, according to their caregivers. Caregivers were not very comfortable about this independence:

*My daughter goes out with friends, and even has a boyfriend, and this really shocked me. (Participant AC3)*

*My son is stubborn, he won't stay at home like I would have liked, but he goes out drinking with friends till late at night. (Participant AC4)*

*My husband drives around the location, to his parents' place, or to his brother's place, or visiting friends. This is not safe! (Participant BC5)*

#### 4.4.1.5 Transport Needs

Caregivers of people with physical disabilities found that there were needs pertaining to transport facilities for people with physical disabilities. It was not possible for many people with physical disabilities to use the public transport, as they could not easily reach the main road, where they could get the public transport.

- a) A Need for Suitable Public Transport: Caregivers of people with physical disabilities felt that the people they looked after could not use the normal public transport that other people use.

*It is not easy for them to travel, when they have to go to the doctor, or anywhere else, we have to hire special transport. (Participant BC3)*

- b) A Need to Have Own Car: One of the caregivers of people with physical disabilities was worried that her husband was driving his old car, and this was a risk, because he used only one hand. This car was also using a lot of money on repairs, as it was breaking down frequently.

*When my husband gets his disability grant, I have to give him around R300, for him to buy petrol and parts for his old car. This car gets repaired everyday, and it does not really become right for long, because he does the repairs himself. (Participant BC5)*

#### 4.4.1.6 Personal Needs of Caregivers:

Caregivers of people with physical disabilities felt that they also had their own needs. They felt that care-giving took a lot of their time; in so much that they did not have enough time to look after their own health needs.

- a) Assistive Devices: Caregivers of people with physical disabilities felt that assistive devices would make their care-giving tasks easier. These have been discussed above, under needs of people with physical disabilities as perceived by their caregivers.
- b) Respite Care, or Extra Help: Caregivers of people with physical disabilities felt that they needed time for themselves. They needed extra help to help them with care-giving tasks.

*You know what, when our children were younger, it was easy to carry them on our backs, and go and do whatever we wanted to do, but now that they are grown up, we can't do that anymore. (Participant AC2)*

- c) A need for Day Care Centres: Some caregivers felt that if there were a place where they could take their disabled people to during the day and fetch them in the afternoons they would have time to do other things, such as looking after their own health.

*It would be better if there was a place where I could take my granddaughter to; something like a day care centre, so that I could have time to attend to other things. (Participant AC1)*

- d) Feeling Appreciated: Some caregivers felt that they were appreciated by people with physical disabilities that they were looking after, but there were a few that felt that they were not appreciated.

*Yes, my husband recognises the role I play in his life. He even says; 'I don't know who would look after me so well, if you were not there.' (Participant BC5)*

*My daughter also appreciates me. She does not want to see me worried about anything. If the younger children worry me in anyway, she makes noises, and becomes angry with them. (Participant BC1)*

*My granddaughter is very loving; she does not want anything or anyone to worry me. (Participant AC1)*

- e) Need for Advice on Some Issues: Some caregivers felt that they had some problems that they needed advice on. One of the caregivers had this to say:

*My problem is that my disabled daughter menstruates. It becomes very difficult for me when she is having a period because it is very difficult for her even to put a pad on. Can anything be done to stop her from menstruating? (Participant BC1)*

The above are responses from caregivers of people with physical disabilities when asked about needs of people with physical disabilities. We are now going look at accessibility of resources to people with physical disabilities, as perceived by their caregivers. The following table shows this accessibility of resources.

#### 4.4.2 ACCESSIBILITY OF RESOURCES AS PERCEIVED BY CAREGIVERS OF PEOPLE WITH PHYSICAL DISABILITIES

Table 9 below shows the findings on the accessibility of resources for people with physical disabilities in the district of Butterworth, as perceived by their caregivers.

THEMES	CATEGORIES
Knowledge about Resources and how to access them	Assistive Devices Rehabilitation Services
Barriers to Accessing Resources	Lack of Knowledge about some Resources

	Shortage of Human Resources Problems with inaccessibility of Transport and Facilities
Suggestions about more resources	Special Equipment for Lifting Special Schools, or Day-care Centres

TABLE 9, FINDINGS ON ACCESSIBILITY OF RESOURCES TO PEOPLE WITH PHYSICAL DISABILITIES AS PERCEIVED BY THEIR CAREGIVERS

4.4.2.1 Knowledge about Resources; and how these can be accessed:

In this section, the knowledge that caregivers have of available resources, and how they can access them, is presented under the categories relating to this theme.

- a) Assistive Devices: Caregivers of people with physical disabilities had some knowledge about some resources, like assistive devices, but some of them did not know where to go to access them. For example, one of the caregivers, who had a daughter who could not walk, having contractures of all her limbs, was using a wheelbarrow to take her anywhere she had to go. She knew that she needed a wheelchair, but she did not know how she could get one.

*As I live with my mother who has painful and unstable knees, I think that a bandage could help keep her knees stable. I also wish she could get a walking aid, and then she could walk better. (Participant BC4)*

*The problem with my daughter is that she cannot walk, she crawls. If she could have something like a wheelchair; then she could be moved easier. (Participant BC1)*

Caregivers of people with physical disabilities wished for some equipment that could help them in their daily lives. They had some imagination that there had to be something that could help, though they could not say what it was.

*I wish there was some special equipment to help me lift my granddaughter. She is so heavy for me that I have to ask other people to help me whenever I have to lift her. (Participant AC1)*

- b) Rehabilitation Services: Caregivers of people with physical disabilities knew about rehabilitation services. They knew about what type of rehabilitation their children, parents, or husbands needed, but they did not know how to access this service.

*My daughter needs exercises that could, maybe help her to use her arms and hands, better. She cannot do activities like washing herself, she also has a speech problem, and drooling saliva. I think that maybe there is some treatment that could make her stronger. (Participant AC2)*

Caregivers of people with physical disabilities did not know how to access some of the resources that their people needed. They knew that their people needed resources like assistive devices, like wheelchairs and walking aids, special schools and skills' training centres, but the problem is that they did not know how to access them. One of the caregivers wished for a day care centre where she could take her granddaughter to, during the day. Another caregiver had a problem of how her daughter could get training in computer skills. Her daughter had failed grade 9 three times, and she did not want to repeat the same class for the fourth time. The computer schools they had made enquiries from, only accepted people who had passed grade 10, so this mother knew about the resource, but she had problems accessing it.

#### 4.4.2.2 Barriers to Accessing Resources:

- a) Lack of Knowledge about some Resources: Some caregivers of people with physical disabilities had no knowledge at all about some available resources. For instance one of them had a daughter with Cerebral Palsy, who was menstruating, from the time she was a teenager. The mother had problems with this, as it was difficult even to put a pad on, because of contractures, so she wanted advice on how these periods could be stopped. The mother was then advised to come to the hospital, to discuss the problem with the Gynaecologist.

*My problem is that my disabled daughter menstruates. It becomes very difficult for me when she is having a period because it is very difficult for her even to put a pad on. Can anything be done to stop her from menstruating? (Participant BC1)*

- b) Shortage of Human Resources: Some caregivers felt that it would be better if therapists could visit them at home, as it was difficult for them to carry their children to the hospital for therapy. This was not possible at Butterworth because of shortage of therapists.

*You know what, when our children were younger, it was easy to carry them on our backs, and go and do whatever we wanted to do, but now that they are grown up, we can't do that anymore. (Participant AC2)*

- c) Problems with Inaccessibility of Transport and Facilities: Caregivers of people with physical disabilities felt that it was not easy for the people they looked after to travel, because public transport was inaccessible, they had to hire special transport for them. If they manage to use public transport, they still have to pay more for that transport to deliver them to the facilities they want to visit.

*It is not easy for them to travel, when they have to go to the doctor, or anywhere else, we have to hire special transport. (Participant BC3)*

#### 4.4.2.3 Suggestions about more Resources:

Caregivers of people with physical disabilities had some suggestions about services that they felt could improve their lives.

- a) Special Equipment for Lifting: Caregivers of people with physical disabilities felt that some special equipment could help make their care-giving duties easier, like lifting.

*If my daughter could have something like a wheelchair; then she could be moved around easier (Participant BC1)*

*I think that a commode could help relieve us from lifting, because I find it difficult to lift my granddaughter to the toilet and back. (Participant AC1)*

*I wish there was some special equipment to help me lift my granddaughter. She is so heavy for me that I have to ask other people to help me whenever I have to lift her. (Participant AC1)*

- b) Respite Care – Day Care Centres: Some caregivers wished that there could be extra help, to help relieve them from the strain of care-giving. They felt that they did not have time to do what they wanted to do, or to take care of their own needs, but they spent all their time doing care-giving duties. They wished to have day care centres, where they could take their grown up children to. They felt that they also needed family and community involvement in the care-giving.

*It would be better if there was a place where I could take my granddaughter to; something like a day care centre, so that I could have time to attend to other things. (Participant AC1)*

- c) The above are the responses of caregivers of people with physical disabilities when they were asked about the needs of people with physical disabilities in the district of Butterworth, and accessibility of resources to them. Discussion of these results will follow in Chapter 5.

#### 4.5 RESULTS FROM QUESTIONNAIRES COMPLETED BY SERVICE PROVIDERS

The response rate to the questionnaires returned was 13 out of 16, so it was 81%. Some of the service providers did not complete all the questions in the questionnaires. The following government departments returned completed questionnaires:

- The Department of Labour
- The Department of Social Security
- The Department of Home Affairs
- The Department of Social Development
- The following sections of the Department of Health returned completed questionnaires:

- The Section for Rehabilitation Services at the Provincial Offices
- The Section for Rehabilitation Services at the Mquma Sub-District of the Amathole District
- The Clinic at Bika Township
- The Mobile Clinic from Butterworth Department of Health
- The Male Orthopaedic and Surgical Ward of Butterworth Hospital
- The Female Orthopaedic and Surgical Ward of Butterworth Hospital
- The Male Medical Ward of Butterworth Hospital
- The Physiotherapy Section at Butterworth Hospital
- The Orthotic and Prosthetic centre at Frere Hospital

#### 4.5.1 NEEDS OF PEOPLE WITH PHYSICAL DISABILITIES

The following are all the needs of people with physical disabilities in the district of Butterworth, as perceived by different service providers that took part in the research.

A big number of service providers put education as the most important need for people with physical disabilities. This was followed by a need for assistive devices, rehabilitation, and accessibility of buildings, then the disability grant. Accessibility of public transport then came, followed by special schools and centres for disabled people, social support, employment, housing and skills' development. One mentioned integration; another one mentioned raising awareness about available services, another one, outreach, and one, independence. They mentioned education, assistive devices and disability grant as priorities in the needs of people with physical disabilities.

On the question of needs that were met by available resources, and particularly by participating facilities, service providers put assistive devices and rehabilitation as resources that were met the most, followed by disability grant, education on management of their disabilities, then only one each mentioned assisting with employment, training for skills, and Orthotics and Prosthesis.

Education about the clients' conditions, giving health education on how to take care of themselves, involving people with disabilities in the Community Health Committee, Orthosis and Prosthesis, Community Health Workers who look after people with disabilities, social grants, training for skills, assisting with employments and starting projects, advocacy and serving people with disabilities first, and not making them wait in queues, were mentioned as resources available in different departments.

Needs that were not met by available resources, or were poorly met by available resources were; accessibility of public transport, employment of people with disabilities, education of children with disabilities, sport for people with disabilities, special schools for children with disabilities, skills' development and accessibility of facilities.

When responding to the question whether they were able to reach all people with physical disabilities in the district of Butterworth, or not, only one participating service provider answered "yes". All the others either said that they were not able to reach all of them, or they were not sure if they reached all of them or not. Barriers that prevented them from reaching all people with physical disabilities, service providers replied that shortage of transport and shortage of staff were the main barriers. Others wrote that it was problems with roads, attitudes of families, lack of intersectoral collaboration and shortage of resources.

When it came to the accessibility of facilities of participating service providers to people with physical disabilities, many facilities were said to be inaccessible, as some had steps, and no ramps or lifts, and many of these facilities were far from taxi ranks. These problems caused inaccessibility of these facilities to people with physical disabilities. Only one facility was completely accessible to people with physical disabilities; it was close to the taxi rank, had ramps, and even had toilets that were accessible to wheelchair users.

#### 4.5.2 ACCESSIBILITY OF RESOURCES

Service providers were asked what resources that were meant for people with physical disabilities in the district of Butterworth were available at different facilities of service providers that took part in the research, and the awareness of people with physical disabilities about such resources, and how to access them. They replied that all people with physical

disabilities were aware of doctors, nurses and social workers, and they were all aware of how to access these, but when it came to rehabilitation personnel, assistive devices, Orthotics and prosthetics, it was said that most were aware, but some were not aware how to access them. As regards the disability grant and obtaining Identity Documents, they said that all people with disabilities were aware of these, but a few had problems accessing them. Further more, they felt that, very few, if any people with disabilities were aware of the resources of training for skills and assisting with employment; and therefore they were not aware how to access these resources.

Participating service providers felt that resources for people with disabilities that were available in Butterworth were not enough. They felt that the shortage of human resources made it difficult to do outreach programmes, and rehabilitation personnel could not be allocated in clinics because of this shortage.

Other resources that were necessary to benefit people with physical disabilities, according to service providers were skills' development, more Primary Health Care services, Day Care Centres, Protective Workshops. Outreach Services, Mental Health Counselling Services, Crisis Intervention, Specialists, More Rehabilitation Personnel and Special Schools.

Development of life skills for people with physical disabilities was encouraged in different facilities, by encouraging community integration, and training for skills, others said that they encouraged development of life skills by personal hygiene, advising on diet, giving exercises, educating the clients to improve their quality of life, giving advice on starting projects, giving health education on life style modification, through the rehabilitation process and by giving workshops. They also promoted independence by giving health education and general advice, and educating clients on issues that affect them, by giving advice on how to start projects, and by giving rehabilitation and assistive devices.

Service providers who were health providers were asked if they included people with physical disabilities in their health education and health promotion programmes, including sex education. Four said yes. One of them said that people with physical disabilities have feelings like normal people, so they were included. Another one said that they educate both the individual and the family. The other one said that they involve people with physical disabilities in health talks like sexually transmitted infections, teenage pregnancy and screening for cancers. Two said that they give advice about the use of condoms, and that they keep condoms on their counters so that everyone can have them.

Regarding the number of people with physical disabilities that were employed in their facilities, some service providers replied they had one, two, three or four people with physical disabilities employed in their facilities. Two facilities did not have any people with physical disabilities employed.

When it came to modifications that had been made to accommodate employees with physical disabilities in the work situation, nine service providers replied that these had been made. They included suitable working areas, like, when one man who used to work at the workshop at Butterworth Hospital became blind; he was allocated to work at the switchboard after training. Ramps are present at all entrances, and there are accessible toilets. Three service providers replied that in their facilities, no modifications had been made.

#### 4.6. CHAPTER SUMMARY

This chapter has given the results, starting with the demographic details of the participants. It has shown what needs are, that people with physical disabilities have, in the district of Butterworth, what the barriers are that prevent them from accessing available resources, as perceived by people with physical disabilities, their caregivers, and service providers. It showed where service providers fall short with their services to people with physical disabilities. These results of the research will be discussed further in Chapter 5, and recommendations will be made to relevant service providers, so as to improve service delivery.

## **CHAPTER 5**

### **DISCUSSION OF RESULTS**

#### **5.1 INTRODUCTION**

In this chapter, results of the study, as presented in chapter 4, are discussed, in relation to the research questions. These results are discussed according to the needs of people with physical disabilities, their accessibility to available resources and barriers preventing people with physical disabilities from accessing resources in the district of Butterworth. In these discussions, comparisons are made regarding the manner in which these needs and accessibilities are perceived by people with physical disabilities, their caregivers and service providers. The results are also discussed according to the literature of previous studies in South Africa and all over the world. This chapter is concluded with recommendations made by the researcher from the findings of the study, to different service providers and different facilities, as seen fit.

#### **5.2 NEEDS**

The following are the needs of people with physical disabilities in the district of Butterworth according to how these were perceived by them, their caregivers and service providers:

##### **5.2.1 Accessibility of Buildings:**

Their access to buildings and other facilities is something that concerned people with physical disabilities. The problem of accessibility began in the homes, where buildings were constructed without considering the needs of people with physical disabilities. At Bika, a township, disabled people needed accessible housing. At this township, people with physical disabilities had houses, but they were inaccessible. There were problems, like that of a grandmother who had to lift her 18 year old granddaughter out of her wheelchair and carry her to the bathroom because the passage in their home was too narrow.

People with physical disabilities who lived at Skiti, the informal settlement, were in need of Reconstruction and Development Programme (RDP) houses, as they had expressed their

concerns about their inability to escape quickly, should there be a fire. In addition, the lack of toilets at the informal settlement presented a huge problem, as they were unable to walk distances or to squat in order to relieve themselves. Those people with physical disabilities who lived in the rural areas of Zangwa and Thongwana had a problem with the fact that there were no roads leading to their homes. Often the paths that lead to their homes were impossible to negotiate with a wheelchair or other mobility devices.

Housing a nation is one of the greatest challenges facing the Government of National Unity. The extent of the challenges derives not only from the enormous size of the housing backlog and the desperation and impatience of the homeless, but stems also from the extremely complicated bureaucratic, administrative, financial and institutional framework, inherited from the previous government. A housing programme cannot be limited to housing, but needs to be promoted in such a manner so as to give meaning to the goal of creating viable communities (The New Housing Policy and Strategy for South Africa 1994). RDP houses are meant for the low income group of South Africans, and they are offered to their owners free.

The Housing Code (National Department of Housing, NdoH 2008), calls for a comprehensive plan for the development of sustainable human settlements. The People's Housing Process (PHP) is the ongoing process of self provision of human settlement needs. It is the participation of communities in the process of deciding, organising and managing and, being directly involved in the development of their communities. PHP enables/encourages communities to actively contribute and participate in the housing development process, so that communities take ownership of the process, and not just act as passive recipients of housing (NdoH 2008). People with physical disabilities are part of these communities and should be consulted in developments like housing.

This calls for planning by the municipality to build houses that are more accessible to people with physical disabilities and build proper roads within the rural villages. People with physical disabilities should not have to be carried by other people to the road and those who use wheelchairs should be able to push themselves not depending on other people because there were no roads. It is clear that people with physical disabilities needed accessible housing and proper roads, whether they lived in rural villages, townships or in informal settlements. It is therefore imperative that people with disabilities and their organisations be

consulted about their housing needs. The fact that they were not able to enter some public buildings and some shops makes them dependent on other people for a numerous needs.

### 5.2.2 Accessibility of Transport:

Whenever people with physical disabilities had to travel, for any purpose, they struggled to get accessible transport. The results section illustrated that taxis, on their normal routes, did not want to stop for a person in a wheelchair or one who needed to be helped into the taxi. Therefore people with disabilities needed to find alternative transport. Hiring special means of transport implied that people with physical disabilities had to pay around ten times, or more, of the amount they would pay if they were making use of public transport. Vehicle owners took advantage of this situation that people with physical disabilities were in by charging them exorbitant amounts resulting in further poverty among people with physical disabilities. The problem with public transport does not just concern the attitudes of taxi drivers or vehicle owners, but also the way public transport was designed. Whether it was a taxi or a bus, it was not designed to be accessible to people with physical disabilities because of the way one had to climb in. As a result people with physical disabilities had no other way but to be lifted into such vehicles. Iezzoni, Killeen and O'Day (2006) in their study highlighted the problem with transport as a barrier to obtaining primary health care. In this study it was pointed out that available public transport is often inaccessible and unreliable. The upshot of the problems with public transport was that people with physical disabilities in that study missed out on appointments for routine check-ups at primary health care centres (Iezzoni et al., 2006).

Because of the problems with transportation, people with physical disabilities in Butterworth usually made arrangements for caregivers to collect their disability grants for them and buy everything they needed. They also depended on their caregivers to fetch their medication for chronic conditions like diabetes and hypertension, which meant that their chronic illnesses might not be monitored as these should have been thus putting the individuals' lives at risk. It was also noted in the findings that people with physical disabilities found it difficult to visit some institutions, because there was no regular public transport running between the town of Butterworth and facilities like Butterworth Hospital, SASSA offices and the Department of

Social Development. Arrangements with the local branch of the Taxi Association were therefore necessary to address this problem.

### 5.2.3 Assistive Devices:

In the findings of the research, it was revealed that people with physical disabilities needed assistive devices like wheelchairs and walking aids. Caregivers also saw the need for assistive devices, though some of them did not know what they were supposed to do to get them. For instance, one of the caregivers, as well as one of the service providers felt that some special equipment that could be used for lifting people was necessary, as lifting an adult was too difficult for some caregivers. Lifting an adult was not only a burden and causing ill-health to the caregiver, but it was also embarrassing, humiliating and degrading to the person with disabilities. Caregivers felt that assistive devices would make their care-giving tasks easier.

Assistive devices are supplied by the government under the Free Health Policy of the National Department of Health (2003) to the general public, but there are usually insufficient funds to respond to all the demands for assistive devices. Because of this, clients sometimes wait for 6 months and more for wheelchairs and some clients pass away before they receive their long awaited devices. Problems relating to government funds have at times created the situation when there have been no crutches or other walking aids to distribute at Butterworth Hospital. The lack of such devices could lead to simple fractures of lower limbs complicating to permanent disabilities.

People with physical disabilities, their caregivers and service providers all felt that Orthotics and Prosthesis were essential for people who needed these. The problem, according to some of the people with physical disabilities who took part in the study, was that they had stopped using Orthotic devices because the heavy materials they were manufactured from made these devices uncomfortable. The researcher got the impression that, the women participants felt that the weight of the materials from which boots and callipers were made was not only cumbersome, but also that the device was not aesthetically appealing. It was found that only women participants had this complaint as they might have felt that the device made them less attractive.

The shortage of Orthotics and Prosthetics employed by the Eastern Cape Government together with the shortage of funds to buy materials caused concern. This resulted in long

periods that clients had to wait for their Orthotists and Prosthetists devices. One of the participants in this study was measured for a prosthesis due to a below elbow amputation more than two years before, and had up to the time of the study not received it. This situation, called for more Orthotists and Prosthetists to be employed.

#### 5.2.4 Rehabilitation:

People with physical disabilities mentioned rehabilitation as one of their needs. Caregivers and service providers also mentioned the importance of rehabilitation. Some of the people who took part in the focus group interviews had undergone rehabilitation before, especially physiotherapy, but they were not attending anymore. They were not sure if continuing with rehabilitation would have improved their conditions any further. The researcher re-assured them that as long as they had functional independence, they did not have to continue attending physiotherapy.

Clients who accepted rehabilitation services often did not have the same understanding of rehabilitation as the service providers. They imagined that they ought to be completely healed, which did not always happen. These clients went on refusing to be discharged, because, as they believed, they were not completely healed. This is quite a difficult situation for rehabilitation officers, as there were too few of them to handle the workload. Matsika, Rhoda and Mlenzana (2009) concluded that service providers should encourage and allow more involvement of clients and their caregivers in their own rehabilitation and educate clients on their rights. This approach might help to overcome some of the misunderstandings that currently occur.

The goal of the National Rehabilitation Policy (2000) is to improve accessibility to all rehabilitation services in order to facilitate the realisation of every citizen's constitutional right to have access to health care services. This policy forms part of the strategy to improve the quality of life of people with disabilities. Rehabilitation includes not only the training of disabled people, but also interventions in the general system of society, adaptations of the environment and protection of human rights. In order to make rehabilitation accessible to all who need it, irrespective of their location or economic circumstances, Community Based Rehabilitation (CBR) was introduced. CBR helps families and the community to understand

the causes of disabilities and what they can do to improve the quality of lives of people with disabilities (Velema, Ebenso & Fuzikawa, 2008).

A Community Based Rehabilitation (CBR) program starts with a stimulus or motivation from outside the community then develops within the community. It is therefore not realistic to expect the community to start the CBR programme on their own, without any guidance from the rehabilitation personnel (WHO 1994). If there were more rehabilitation professionals working in government institutions, more outreach programmes could be arranged, so as to reach those people with disabilities who needed help in the community. They could even help people with disabilities and the community start Community Based Rehabilitation (CBR) programmes.

For CBR to be started and to be successful, the following conditions have to be present:

- Community leaders and organisations who are willing to support and participate in the rehabilitation program
- Community rehabilitation workers who are willing to assist people disabilities in the community
- Rehabilitation personnel who will train, guide and support the community rehabilitation workers
- Rehabilitation personnel who are available for referral
- Referral services that will provide basic appliances and assistive devices (WHO 1994).

The shortage of rehabilitation personnel at the Department of Health in Butterworth makes it difficult to start CBR programmes. It is therefore important for Butterworth Hospital management to motivate for the filling of unfunded posts, so as to employ more rehabilitation personnel. That may be considered as the first step to realising the need to start CBR programmes in Butterworth.

#### 5.2.5 Employment, Skills' Training and Income Generation:

People with physical disabilities need employment, just like everybody else. Unfortunately since there is a very high degree of unemployment within the South African population, the degree of unemployment among people with disabilities is even worse. According to the Employment Equity Act No 55 (Department of Labour, 1998) people with disabilities have a

right to be employed and should not be discriminated against. Affirmative action has to be practised by all designated employers who employ more than 50 employees in their establishments. They are required to ensure that suitably qualified people from designated groups have equal employment opportunities, and are equitably represented in all occupational categories and levels in the workforce of the designated employer. This means that measures must be taken to identify and eliminate employment barriers, including unfair discrimination which adversely affects people from designated groups. Another barrier to decent work for people with physical disabilities is that many of them are not educated lacking skills to make them employable. Employers should also accommodate people from designated groups in order to ensure that they enjoy equal opportunities.

Though there is such a good Act (Department of Labour, 1998) in favour of people with disabilities to be employed, there are still very few people with disabilities who are employed. According to Statistics South Africa (2001), the employment of people with disabilities was standing at 19% of people with disabilities, as opposed to 35% of the whole population of South Africa. This report was released in the Employment and Disabled Persons, Information Sheet, ILO, in 2003. This is substantiated by the fact that the service providers, who took part in this research, responded that there were very few or no employees with physical disabilities employed in their facilities. In addition, some of those facilities that were represented in the research had not implemented any modifications to accommodate people with physical disabilities. It is therefore crucial that the government commits itself to monitoring that the Employment Equity Act is carried out, starting with the government facilities. When the Employment Equity Act was released, the then Minister of Labour, Mr Membathisi Mdladlana, had given employers up to 2005 to establish that people with disabilities formed at least 2% of their workforce, but this has not yet happened.

People with physical disabilities in the district of Butterworth displayed keen interest in income generation during the present research. The fact that the group at Bika had an idea that they could sell paraffin, as a group of people with physical disabilities, to generate income, meant that people with physical disabilities were willing to work. This was demonstrated by the fact that one participant had attained a sewing skill that allowed her to generate an income. They were interested in skills training and were keen to register at the Department of Labour for jobs. A participant, who had a National Diploma in Administration from the Eastern Cape University of Technology, was still not employed four years after

qualifying. Generally, people with physical disabilities in the district of Butterworth were not satisfied with just getting a disability grant and doing nothing else - they wanted more.

To be enrolled in a skills training centre is not easy for people with physical disabilities in Butterworth, as the only department that claimed to provide skills training, the Department of Labour, required people to come together as a group to decide which skills they would like to be trained in. The process was not easy for people with physical disabilities - to be able to form a group, they had to be mobile and be able to move from their home to a meeting place or to the training centre.

#### 5.2.6 Education of Children with Disabilities:

It is important to note that children with disabilities have to be educated. A number of service providers who took part in the research placed education as an important need for people with physical disabilities with some caregivers also including it as a need. However, people with physical disabilities themselves were more interested in skills training to help them supplement their disability grant. The reason they preferred skills training can be attributed to the fact that those people with physical disabilities who took part in the research were all adults, over the age of 21 and not attending school anymore.

The Education White Paper 6 on Special Needs (Department of Education, 2001) mandates an inclusive education and training system. In the past education regime, children with disabilities were labelled according to their disabilities, and had to go to a centre of learning that provided for that disability, thus blind learners had to go to schools for the blind, deaf learners, to a school for the deaf and those with multiple or progressive disabilities did not go to school at all. Within this divided system of education, children with disabilities were isolated from able-bodied children, as well as from children with other disabilities.

With the introduction of inclusive education, it is now possible for a learner with physical disabilities to attend a local school with other children, as long as the environment is accessible. A child who is blind might prefer to learn with sighted learners but will require special equipment. Learners must receive the right kind of support to be able to cope in any environment and educators need to be helped with knowledge on how to help learners with disabilities to cope. Those specialist educators in special schools can be used as a resource, to

help educators who need advice. That is what is meant by inclusive education (Department of Education 2001).

In Butterworth there is still a problem of educators who refer many children to special schools. It is just not acceptable that one school can refer more than five learners in one year, to special schools because, they say that they have learning difficulties. There are very few special schools in the Eastern Cape while there is not even one in Butterworth. It is not possible for all these learners to be admitted to special schools. Consequently, if they cannot be educated at mainstream schools, then it means that they will just remain at home and not be educated at all. These children will therefore not be employable when they grow up, because they will not have skills to make them independent. It is therefore important that inclusive education should be encouraged in the Eastern Cape Department of Education, so as to accommodate children with disabilities in mainstream schools.

#### 5.2.7 Independence:

Independence is one of the milestones of all children as they grow up. Children with physical disabilities also grow up to be adults, but may be less equipped to solve problems and make decisions. As a result, many people with physical disabilities live with their parents or other relatives like sisters because they are unable to live independent lives. They become dependent on others for everything.

There is a paradox that, though this kind of dependence is not constructive, those people with physical disabilities who are more independent are not accepted well by their caregivers who prefer it when the disabled youth depend on them. Young et al. (2009) found that adolescents and young adults with chronic and complex physical disabilities of childhood face multiple challenges in transition to adulthood, including those associated with leaving school, finding meaningful occupation and achieving independent living. It is usually those people with physical disabilities who are educated and highly qualified who usually manage to gain considerable independence, as depicted in another study by Riley Jr., de Anda, and Blackaller (2007).

The reasons that caregivers are afraid of the independence are probably multiple. One example was apparent in the focus group interviews of caregivers of people with physical

disabilities, where the caregiver was not happy that her daughter, who had spina-bifida, was independent; going out with friends and even had a boyfriend. This mother felt that her daughter was not well equipped with life-skills to successfully manage the life demands of adulthood – an attitude also described in a study by Kingsnorth, Healy and Macarthur (2007). The caregiver in the present study probably wanted to protect her daughter from sexual exploitation, and possible HIV, as seen in a study by Nganwa et al. (2002). Another mother was also not happy that her son, who was paraplegic, was going out with friends and drinking until late at night. This drinking and the use of drugs by paraplegics, is evident in a study by Njoki, Frantz and Mpofu (2007), where they explored health related behaviours and factors that influenced the behaviour of physically disabled youth with spinal cord injury. This study illustrated that, as a result of the difficult process to a new identity after the injury, many participants had resorted to substance abuse as a coping strategy (Njoki et al., 2007). This therefore gives us some understanding as to why people with disabilities sometimes behave in a totally unacceptable manner as they find it difficult to adjust to their new identity. This reasoning does not stop the mother from worrying about her child, but it requires a lot of patience and understanding on the part of the caregivers of people with physical disabilities. It could also help if these caregivers could talk to social workers about these problems and maybe some counselling could help both the mothers and the people with physical disabilities they looked after. Peer group counselling by other disabled people and involvement in organisations of disabled people can also help

#### 5.2.8 Social Integration:

People with physical disabilities who were interviewed were eager to integrate. They wanted to be part of the society. In a study by van de Ven et al. (2005), it was noted that people with disabilities wanted to be part of society, just like those without disabilities. They want to be seen as full citizens and to be treated with respect. This is clear in my study in that one of the participants with physical disabilities wanted to attend parents' meetings at his daughter's school, but could not manage because of the steps. This man wanted to integrate and be a part of his daughter's school life but there were barriers. This man was excluded from the parenting role that he wanted to play because of inaccessible buildings.

In the current study, we see that the younger participants wanted to be involved in love relationships and maybe get married and have children. The caregivers on the other hand did

not expect people with physical disabilities to have such relationships. This is in contrast with a study by Chance (2002) in which she wanted to show that people with disabilities are not asexual, and they must be perceived as complete and well-rounded human beings with the same needs, desires, and capacity for romantic and sexual relationships as everyone else. Some service providers agreed that people with physical disabilities should be included in sex education because they also had normal feelings like everyone else. However, this belief was not always reflected in practice. For example, at the Butterworth Hospital, where some representatives in the service provider group were working, an incident was reported to the researcher by a husband of a disabled woman. That man's wife had polio that had left her with paralysis and muscle wasting of one leg. So she had orthopaedic boots and callipers and needed a pair of crutches to assist her to walk. This lady was shouted at by nurses in the maternity ward when she went to have her first child. According to those nurses, she was not supposed to have children because she was disabled. In fact, according to them she was not even supposed to marry. Because of the way this young woman was treated at the hospital, she signed consent that a tubal ligation be performed, without even consulting with her husband - and it was done. This was a clear demonstration of discrimination against people with physical disabilities by health professionals. This is a clear indication for rehabilitation studies to be included in the curriculum of all health professionals.

#### 5.2.9 A Need for Caregivers:

There was a need for caregivers to support people with physical disabilities who could not perform activities of daily living, such as fetching water from a well or the communal tap or doing washing. This was said to be important according to people with physical disabilities, as some of them could not do anything for themselves. They were completely dependent on their caregivers.

Having caregivers meant that people with physical disabilities had to pay them from their little disability grant. This was one of the reasons why people with physical disabilities declared that their disability grants were not enough for their needs and this was one of causes for poverty among people with disabilities. With the onset of disability in the family, it is common that one member of the family has to resign from work to look after the disabled person. This is usually a female member of the family as it is more common for caregivers to be females. Society expects females and not males, to do the care-giving duties. Even if there

was a male member of the family who was not working, he would not be expected to do the care-giving. However, a female member of the family will have to even resign from work, to take care of a person with disabilities at home resulting in further poverty. This is one of the ways women are discriminated against by society.

Service providers who participated in this study did not mention caregivers as a need in their replies to the questionnaires they were given and this indicated that they took the role played by caregivers of people with physical disabilities for granted and did not consider them as important. This means that service providers do not involve caregivers when dealing with people with disabilities, yet it is very important that caregivers should be empowered with knowledge on how to deal with people with disabilities and how to cope with care-giving tasks. People with physical disabilities were also not informed about the Grant-in-aid that is supposed to be paid by the South African Social Security Agency (SASSA), to those people with disabilities who constantly need caregivers. This serves as a confirmation that service providers do not attach any importance to care-giving.

Care-giving is not an easy task. Caregivers also have their needs and sufferings. This is demonstrated in a study by Murphy et al. (2006), where caregivers reported having back and shoulder pain, chronic fatigue, and migraine headaches, resulting from care-giving. In this study it was shown that care-giving had its stresses and a negative impact on the health of caregivers so much so that they had no time to look after their own health. This need for respite care for caregivers was also apparent in a study by Teijlingen et al. in (2001). They found that some caregivers found it difficult to cope with the physical and emotional stress of care-giving, and also ended up having longstanding illnesses and some form of disability themselves.

The researcher has the necessary experience to verify that caregivers develop illnesses when care-giving. She found that, in the past year, three people with physical disabilities attending treatment at the department where she worked had lost their wives who were taking care of them. The fact is that caregivers have to give up a lot when they look after people who cannot do anything for themselves. They wash them, dress them and clean them when they've messed that they forget to take care of their own health. Another study by Wright et al. (2006) noted that caregivers of children with physical disabilities had sleep deprivation as well. This indicated how much caregivers needed respite care. Caregivers needed help, a

place they could take their people to or someone to offer some help so that they will have time to do other things. Some of the participants needed day care centres where they could take the people they cared for, during the day and fetch them in the afternoon to allow them time to themselves and to do other things.

Caregivers of people with physical disabilities who participated in the research were usually happy about the care-giving duties they were doing. They felt that they were appreciated by the people they took care of. One of the caregivers said that her husband was always grateful to her, saying that if she had not been there, he did not know who would have looked after him. The other caregivers also told stories that proved how much they were appreciated by people they looked after. This meant that caregivers of people with physical disabilities did not only feel the pain of care-giving, but there were also rewards of care-giving. It would therefore be important for Government Departments to assist caregivers in their duties by providing assistive devices to make their care-giving duties easier and by providing financial support like the Grant-in-Aid.

#### 5.2.10 Primary Health Care:

People with physical disabilities had problems visiting primary health care centres, because of the inaccessibility to the centres. They knew about the existence of the clinics, but did not know what they were supposed to do to be able to get their chronic medication from the clinic, rather than waste money at private practitioners for things they could get free from the clinic. There was widespread ignorance about health promotion. The reason for this ignorance could be attributed to the fact that there was no permanent clinic in this location which meant that there were no educational talks that usually given by health professionals to the community.

A document on free health care for people with disabilities was issued by the Department of Health of South Africa in December 2003 (DOH 2003). It applies to all people with permanent disabilities, or disabilities that will last for more than a year. To qualify for this free health, an income based classification test will be the entry point. Frail older persons also qualify for this free health care service. This means that those people who earn good salaries do not qualify for free health for people with disabilities. Primary Health Care on the other hand offers free health to all clients.

Health for all was introduced to global health planners and practitioners by the World Health Organisation (WHO) at the International Conference on Primary Health Care in Alma Ata in 1978. The conference declared that health is a fundamental human-right. Primary health care as envisioned at Alma Alta had strong socio-political implications. It aimed to look at underlying social, economic and political causes of poor health, with emphasis on disease prevention and health promotion, community participation, self reliance and intersectoral collaboration. It acknowledged that poverty, social unrest and instability in the environment and lack of basic resources contributed to poor health. It called for the promotion of food supply and proper nutrition, an adequate supply of safe water and basic sanitation, maternal and child health care, including family planning, immunisations against major infectious diseases, control of locally endemic diseases, appropriate treatment of common diseases and injuries and the provision of essential drugs (Magnussen, Ehiri & Jolly, 2004).

The assertion meant healthcare for all and if the Department of Health could really take it seriously and have primary health care at all locations, then health for all will be a reality. The managers in the Easter Cape Department of Health need to make plans on how more clinics can be built.

#### 5.2.11 Need for Disability Grant and other Social Services:

All the participants of the research agreed that the disability grant was a need for people with disabilities, as many of them could not be employed. It is clear that with the onset of disability, there are more financial needs such as the need for caregivers and for hired transport as well as for medical supplies like disposable napkins. Many people with physical disabilities find that the disability grant they got was not enough for their increased financial needs.

Some people with physical disabilities sometimes encounter problems with their applications for the disability grant that are rejected. There was also the problem of the suspension of the disability grant and that of the slow processing of the disability grant applications. This lack of adequate funds caused people with disabilities to become depressed. The Department of Social Development could intervene to try to solve these problems so that there might be better delivery of social benefits.

### 5.3 KNOWLEDGE ABOUT, AND ACCESSIBILITY OF RESOURCES

During the focus group interviews of people with physical disabilities and those of caregivers, the researcher found that many did not know that some resources were available. On the other hand, some who knew that they existed did not know how they could be accessed. It came up in the study that they did not know enough about the resources available to them, such as acquiring new Prosthetics and Orthotic equipment or getting old ones repaired. This ignorance was worse in the rural location. People in these rural areas did not know how they could benefit from resources like medication for chronic conditions and assistive devices. Constructive education is necessary to make people from these locations aware of these services.

Further, on this issue of knowledge and accessibility to resources, people with physical disabilities did not know about the Department of Labour registering job seekers and helping them find jobs. They also did not know that they could be trained in terms of skills or how that could be done. This also applied to the Grant-in-aid, from SASSA, which may be applied for by people with disabilities who needed constant care-giving in order to pay their caregivers. People with physical disabilities also did not know that the Department of Home Affairs had a service for people who could not come to their offices that allowed their representatives to go to their homes if they were notified. Most people with physical disabilities did not know about these resources and almost all the departments concerned said that the reason for not raising awareness about available services was staff shortage as well as the un-availability of government vehicles. All government departments therefore needed to do everything in their power to increase staff in their establishments and apply for more vehicles.

Accessibility of services is also affected by poverty and the individual's access to facilities. Some people were not accessing services because they could not afford to travel to the places where the services were provided. For example, one 43 year old man who had amputations of both lower limbs because of gangrene in 2003, and who had to apply for a disability grant and a wheelchair, could not do so because he did not have an identity document. His wife also did not have it, so she could not apply for the child support grant for their four young children. She could not afford to travel to town to apply for the ID and pay for the photographs. The husband had been the only bread winner in the family as a self-employed

builder. As a consequence of the husband's disability and this problem with IDs, this family had no finances at all. This is definitely not an isolated case as there are probably other families with similar problems in Butterworth.

#### 5.4 LESSONS LEARNT FROM THE STUDY

The following are lessons that the researcher learnt from this study:

- a) Relationship between Disability and Poverty: Increased financial needs of people with disabilities stems from the fact that people with physical disabilities have to pay more for transportation, because they cannot use public transport. They also have to pay, or support their caregivers and in most cases, because of unemployment, they have to support the whole family. In some families, because of poverty, it's a blessing to have someone with a disability, as it provides an income to the family.
- b) Need for Caregivers: It was demonstrated clearly that some people with physical disabilities needed to have constant caregivers, depending on the severity of their disabilities. The burden as well as the rewards of care-giving was obvious, as well as the need for respite care, for caregivers. The fact that all service providers did not mention caregivers as a need indicated that they did not attach any importance to this need. If we look at the dependence of people with physical disabilities, and the importance of caregivers, we can see that service providers did not consider them as important. This has made the researcher decide that there may be other important avenues in the lives of people with physical disabilities that are overlooked by service providers.
- c) Need for Independence and Integration: It was verified that people with physical disabilities tried to be as independent as possible. Striving to be independent, was noted when they did all they could to continue with house-work, or to do everything to maintain their responsibilities as parents. Young people with disabilities also want independence to choose friends and particular social lives. It was also demonstrated that not all caregivers were in favour of this integration, as there were consequences that could affect both the person with disabilities as well as the caregiver. The researcher learned from this study that the perceptions of people with physical disabilities are not always the same as those of caregivers and service providers.

There are similarities as well as differences. She learnt that there were needs that were more important to people with physical disabilities, than they were to caregivers and to service providers. These were the need to be employed, to obtain drivers' licences and to be independent.

- d) Difficulties with Parenthood: The researcher also learned that parents of children with physical disabilities undergo the same difficulties that parents of able-bodied children experience. There was peer pressure to take part in undesirable behaviour like abusing alcohol and drugs, smoking and indulging in unprotected sex. Every parent does not want his/her child doing any of these activities thus it is worse if the child is disabled.
- e) Staff Shortage: All government departments that were represented in the study had gross shortages of staff. This was caused by the many posts in all the departments that were not filled. Motivations must be made by all these departments to have more staff so that there can be improved service delivery. This shortage of staff was the main reason that people with physical disabilities and their caregivers lacked knowledge about issues that were important to them, like health issues. This emphasised the seriousness of staff shortages in all the government departments in Butterworth, resulting in unsatisfactory service delivery.

## 5.5 RECOMMENDATIONS

- a) Awareness Raising: All government departments that deal with people with disabilities must do everything they can to raise awareness among the public about the services they have in their departments. All departments must address the problems of staff shortage and look at ways of maximising human resources by applying for more vehicles so as to reach all communities they serve.
- b) The Municipality: Recommendations for accessible RDP houses needs to be made, so that people with physical disabilities can live in those houses. People with physical disabilities living in informal settlements must be given first preference, due to obvious reasons discussed before. Recommendations must be made to the municipality about roads in the rural areas. It must be recommended that there should be roads that run within the locations, in-between homes, so that vehicles can travel as close to the homes as possible.

- c) The Department of Health: The Department of Health in Butterworth must do everything in their power to have clinics in all rural areas, so that there can be sufficient time to do health promotion, so as to enlighten people in the community about health issues. Motivations must be made, for the employment of rehabilitation personnel, including Therapists, Orthotists and Prosthetists. The Department of health should also have more funds allocated for assistive devices and rehabilitation equipment.
- d) The Orthotic and Prosthetic Centre: This centre, situated at Frere Hospital in East London does outreach at Butterworth Hospital and other hospitals throughout the whole of the Central Region of the Eastern Cape. Recommendations are made to this centre so that boots and callipers are made from materials that are lighter and more attractive.
- e) The Department of Home Affairs: The Department of Home Affairs needs to be made aware of the problems facing all people, disabled and non-disabled in terms of delays in processing identity documents. People suffer in that they cannot get employment, they cannot register the births of their children and they also cannot get social benefits without IDs. The Department of Home Affairs has to look at strategies on how to improve service delivery.
- f) The Traffic Department: It is important that the Traffic Department must be approached to get clarity on what can be done to have one or two driving schools in Butterworth to cater for people with physical disabilities. A recommendation will also be made to the Traffic Department about having more parking bays reserved for people with physical disabilities. Awareness must also be created in terms of where and how people with physical disabilities can get stickers for their cars for parking purposes.
- g) More Pay-points for Social Grants: It is important to discuss with the chief of Zangwa and Thongwana Administrative Areas about what can be done to have more pay-points for disability grants and old age pensions. This will mean that people with disabilities do not have to travel to other locations to get their pensions, as they are doing at the moment.
- h) The Department of Labour: Recommendations need to be made to the Department of Labour, to conduct outreach programmes, so as to help people with physical disabilities to start projects

- i) Taxi Service from Taxi ranks to Facilities: People with physical disabilities, as an association, must approach the Taxi Association, to make arrangements for a taxi service to run from the taxi ranks to the different facilities.
- j) Education of Children with Disabilities: Educators in mainstream schools need to be orientated to teach children with disabilities, as there are not many special schools in the Eastern Cape.
- k) Community Based Rehabilitation: People with physical disabilities and their communities have to be helped to start CBR in their communities, so that rehabilitation of people with physical disabilities can be taken to the community, and not only be done in the institutions.
- l) Day-care Centres: The feasibility of a day-care centre has to be discussed with the Department of Social Development. This was seen as a need by caregivers of people with physical disabilities.

## 5.6 WHAT THIS RESEARCH CAN DO FOR PEOPLE WITH PHYSICAL DISABILITIES IN BUTTERWORTH

This study has brought to light the needs of people with physical disabilities living in rural areas, in townships and in informal settlements. There were needs that were specifically associated with people from the townships, like those of driving schools that catered for people with physical disabilities and accessible housing. People from the rural areas were more concerned about having proper roads within the villages and also the need for resident clinics and more pay-points for social grants. Those who lived in informal settlements were more concerned about moving into RDP houses.

It also emerged that people living in more rural areas lacked adequate knowledge about resources. It has become necessary for all government departments to employ more staff, so as to be able to go out to the people to raise awareness about available resources. The role played by caregivers of people with physical disabilities has been clearly demonstrated, and the difficulties that caregivers experienced when performing their care-giving duties were noted. The discrimination against women who were generally expected to do care-giving was also been emphasized.

This completed study is intended to allow the researcher to do everything in her power to follow up on all the recommendations that have been made. She needs to work together with the association of people with physical disabilities that will be formed to see to it that these recommendations are carried through. When the recommendations have been carried through, then the needs of people with physical disabilities in the district of Butterworth, and their accessibility to resources will be realised.

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**APPENDICES**

APPENDIX 1A

CONSENT FORM – ENGLISH VERSION

Title of the research project:

What are the needs of people with physical disabilities in the district of Butterworth, and how accessible are available resources to them?

Reference number : 14207095  
Principal Investigator : Mrs C.J.N. Dingana  
Address : 6086 Vuli Valley  
: Butterworth  
: 4960

DECLARATION BY OR ON BEHALF OF PARTICIPANT:

I The undersigned .....participant and /or proxy.

ID NO....., the participant, or in my capacity as proxy of the participant.

.....of.....Address.

Hereby confirm that

I/ the participant was invited to participate in the above mentioned research project which the Centre for Rehabilitation studies, Faculty, of Health Sciences, University of Stellenbosch, is undertaking.

The following aspects were explained to me /the participant:

AIM: The aim of the study is to investigate the needs of people with physical disabilities in the district of Butterworth, and accessibility of available resources to them, so as to improve services.

I will be interviewed on needs of people with physical disabilities, and accessibility of resources to them.

The interviews will be tape recorded, so as to facilitate data collection.

There are no risks, side effects or discomfort that I/the participant may experience.

The information given will be treated as confidential and my identity as participant will not be disclosed.

Benefits from participating in the project will be that those needs that I feel are of importance to me will be known. I will not be paid for participating.

After completion of the study, the results of the study will be given to the participants.

Participation is voluntary and I/ the participant may refuse to participate, or may decide to discontinue at any time during the study; and that refusal will not in anyway negatively influence my receiving of services.

The above information was explained to me/ the participant by ....., in isiXhosa and I am/ the participant is in command of this language

I was given the opportunity to ask questions and these questions were answered satisfactorily.

There has been no pressure exerted on me/ the participant in this project and I realise that I may stop at any time without being penalised.

Participation in this study will not result in any additional costs to me / the Participant, and I/the participant will not benefit from it financially.

I hereby consent voluntarily to participate in the above-mentioned study.

Signed at .....on.....20.....

.....

Signature of participant/proxy

Signature of witness

STATEMENT BY THE RESEARCHER: I ....., declare that I explained the information in this document to ..... Or his representative..... He was encouraged to ask me questions in case of uncertainty. This conversation was conducted in isiXhosa.

Signed at .....on..... 20.....

.....

.....

Signature of researcher or research assistant

Signature of witness

#### IMPORTANT MESSAGE TO PARTICIPANT /REPRESENTATIVE

Dear Participant/Representative,

Thank you for participation in this study. Should you have questions at anytime during the study regarding:

More information about the project

More needs/problems in accessing resources, you thought of, please contact Mrs Dingana on telephone number: 084 5489227

Thank you,

Carol J.N. Dingana

APPENDIX 1B

IFOMU YEMVUMELWANO; CONSENT FORM – XHOSA VERSION

ISIHLOKO SEPROJEKTHI YOPHANDO: What are the needs of people with physical disabilities in the district of Butterworth, and how accessible are resources to them?

INOMBOLO YONXULUMANO (REFERENSI): 14207095

UMPHANDI OYINTLOKO: Carol Joyce Nomalungelo Dingana

IDILESI: 6086 Vuli Valley

Butterworth

4960

INOMBOLO YOQHAGAMSHELWANO: 047 4914161 Ext. 2216 (W)

084 548 9227 (Cell)

Uyamenywa ukuba uthathe inxaxheba kule projekthi yophando. Nceda thatha ixesha lokufunda oku kulandelayo okuzakuthi kukunike iinkcukacha zale projekthi. Nceda buza nayiphina indawo ongayiqondiyo, ukuze uacelwe kakuhle malunga nale projekthi.

Kwakhona kubalulekile ukuba uacelwe kukuba ukuthatha kwakho inxaxheba kolu phando kungentando yakho ngokupheleleyo, kwaye ukhululekile ukuba ungangavumi, okanye ungarhoxa xa kukho ongakuthandiyo.

Olu phando luvunywe lwaza lwarejistarishwa ziinkqubo ezisesikweni zeKomiti yoPhando Lomtu, kwiYunivesithi yase Stellenbosch, lwaye luzakwenziwa ngokwemigaqo esesikweni yophando olwamkelekileyo kwihlabathi, nakuMzantsi Afrika

IINJONGO ZOLU PHANDO: Kukufumanisa ukuba ziyintoni iingxaki, nezidingo zabantu abakhubazeke ngamalungu omzimba, nokufikeleleka keenkonzo zoncedo ezikhoyo, okanye ezifunekayo kubo, kwisithili saseGcuwa.

INGABA UZA KUZUZA NTONI NGOKUTHATHA INXAXHEBA?

Ngokwaziwa kweegxaki nezidingo zabantu abakhubazeke ngamalungu omzimba kwisithili saseGcuwa, kuyakutsho kuziswe ezo nkonzo ziyimfuneko kubo, ngolo hlobo ke uya kuzuza.

INGABA UZA KUHLAWULWA NGOKUTHATHA INXAXHEBA?

Hayi akukho ntlawulo, ngaphandle kokuba kukho iindleko ongene kuzo, zona ke uyakubuyekwezwa ngazo.

LUYINTONI UXANDUVA LWAKHO XA UTHATHA INXAXHEBA?

Kufuneka uzimisele ukuba ufike ngexesha elibekiweyo lokudibana nabanye abathatha inxaxheba, ukuze nithabathe inxaxheba kunye ezingxoxweni.

NGUBANI OZA KWAZISWA UKUBA UTHETHE NTONI?

Akuzukupapashwa ukuba ngubani othethe ntoni, kuphela nje ingxelo eya kwenziwa iyakwaziwa njengegxelo yabathathi-nxaxheba. Amagama abathathe inxaxheba aya kuba yimfihlo.

UKUBA AWUVUMANGA UKUTHATHA INXAXHEBA AKUKHO SOHLWAYO?

Hayi akukho sohlwayo; unalo ilungelo lokwala, yaye loo nto ayithethi ukuba awuzukuxhamla kwiinkonzo eziyakufumaneka ngenxa yolu phando.

Ngawo nawuphina umbuzo onokuba unawo malunga noluphando, qhagamshelana no Mama u Nomalungelo Dingana kule nombolo yocingo: 0845489227 (Cell), okanye ku 047 4914161, Extension 2216 (w).

Ngokunye ongakuqondi kakuhle malunga nolu phando, qhagamshelana neKomiti yoPhando Lomntu kwi Yunivesithi yase Stellenbosch kule nombolo: 021 9389090 ngamaxesha omsebenzi.

ISILUMKISO: Xa kuqhutywa ezi ngxoxo zoluphando, iintetho zabantu ziyaku rekhodwa okanye ziyaku teyitshwa, ukuze umphandi akwazi ukuthi sele eyedwa amamele iteyiphu. Ngolo hlobo ke kuya kuba lula kuye ukufumana umxholo weengxoxo.

ISIFUNGO SOMTHATHI- NXAXHEBA:

Mna..... ndiyavuma ukuthatha inxaxheba kuphando olunesihloko esithi: “What are the needs of people with physical disabilities in the district of Butterworth, and how accessible are available resources to them?”

Ndazisa nokuba:

Ndiyifundile ifomu yemvumelwano, kwaye ibhalwe ngolwimi endilwazi kakuhle nendikhululekileyo kulo.

Bendinalo ithuba lokubuza imibuzo, kwaye yonke imibuzo yam iphendulwe ngokwanelisayo.

Ndiyaqonda ukuba ukuthatha inxaxheba kolu phando kube kukuzithandela kwam, kwaye andikhange ndinyanzelwe ukuba ndithathe inxaxheba.

Ndiyaqonda ukuba xa kukho endingakholwayo kuko ndingayeka naninina kolu phando, kwaye andisayi kohlwaywa nangayiphina indlela.

Kusayinwe e-(indawo).....nge.....20

.....

.....

Umtyikityo womthathi-nxaxheba

Umtyikityo wengqina

ISIFUNGO SOMPHANDI:

Mna Carol Joyce Nomalungelo Dingana, ndiyafunga ukuba:

Ndilucacisile ulwazi olukule fomu ku .....

Ndimkhuthazile ukuba abuze imibuzo, kwaye athathe ixesha lakhe elifanelekileyo; ade aziqonde iimpendulo zemibuzo yakhe.

Ndiyaneliseka kukuba uyakuqonda konke okumalunga nolu phando aza kuthatha inxaxheba kulo.

Andisebenzisanga toliki, kuba bonke abazakuthatha inxaxheba bathetha isiXhosa.

Kusayinwe e-(indawo).....nge.....20

.....

Utyikityo Lomphandi

Utyikityo Lwengqina

UMYALEZO KUMTHATHI NXAXHEBA:

Mthathi-nxaxheba obekekileyo, ndigqithisa ilizwi lommbulelo ongazenzisiyo kuwe, ngokuba uthe wavuma ukuthatha inxaxheba kolu phando. Ndinethemba ke lokuba kukhona okuya kuba yinzuzo kuwe ngenxa yalo.

Ukuba kusekho omnye umbuzo onawo, okanye enye into oyikhumbuleyo ongakhange uyithethe, nceda undifonele kule nombolo yefoni: 0845489227

Enkosi

Owenu Ozithobileyo

C. J. N. Dingana.

APPENDIX 2A

LETTER TO THE WARD COUNCILLOR IN BIKA, REQUESTING PERMISSION TO  
CONDUCT THE RESEARCH

The Department of Physiotherapy

Butterworth Hospital

Butterworth

4960

2009-02-12

The Ward Councillor,

Bika Township,

Butterworth

Dear Sir / Madam

Request for Permission to do a Research on Needs of People with Physical Disabilities in the District of Butterworth, and the accessibility of available resources, to them

I, Carol J. N Dingana, would like to make a request for your permission to do a research project in the district of Butterworth. I am a Physiotherapist, in charge of the Physiotherapy Department at Butterworth Hospital.

I am a student, registered with the University of Stellenbosch, doing M.S.C. Medical Sciences, majoring in Rehabilitation. My research project is registered at the Centre for Rehabilitation Studies, in the Faculty of Health Sciences at the University of Stellenbosch.

The aim of my study is to investigate needs and resources of People with Physical Disabilities in the district of Butterworth. It will also make us find out how much these people know about available services they could benefit from.

The results of this research will help improve service delivery both in the community and at the hospital. The results of this research will be made available to you once the research is completed in your area.

For clarity on the matter, here are my contact details:

Cell No. 0845489227

Work 0474914161

Thanking you in advance

Yours faithfully

Carol J. N. Dingana (Student No. 14207095)

G. Mji (Research Supervisor)

APPENDIX 2B

LETTER TO THE WARD COUNCILLOR AT SKITI, REQUESTING PERMISSION TO  
CONDUCT THE RESEARCH

The Department of Physiotherapy  
Butterworth Hospital  
Butterworth  
4960  
2009-02-12

The Ward Councillor,  
Skiti Informal Settlement,  
Butterworth

Dear Sir / Madam

Request for Permission to do a Research on Needs of People with Physical Disabilities in the District of Butterworth, and the accessibility of available resources, to them

I, Carol J. N Dingana, would like to make a request for your permission to do a research project in the district of Butterworth. I am a Physiotherapist, in charge of the Physiotherapy Department at Butterworth Hospital.

I am a student, registered with the University of Stellenbosch, doing M.S.C. Medical Sciences, majoring in Rehabilitation. My research project is registered at the Centre for Rehabilitation Studies, in the Faculty of Health Sciences at the University of Stellenbosch.

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The results of this research will help improve service delivery both in the community and at the hospital. The results of this research will be made available to you once the research is completed in your area.

For clarity on the matter, here are my contact details:

Cell No.       0845489227

Work           0474914161

Thanking you in advance

Yours faithfully

Carol J. N. Dingana   (Student No. 14207095)

G. Mji               (Research Supervisor)

APPENDIX 2C

LETTER TO THE CHIEF AT ZANGWA ADMINISTRATIVE AREA, REQUESTING  
PERMISSION TO CONDUCT THE RESEARCH

The Department of Physiotherapy  
Butterworth Hospital  
Butterworth  
4960  
2009-02-12

The Chief / Headman,  
Zangwa Administrative Area,  
Butterworth

Dear Sir / Madam

Request for Permission to do a Research on Needs of People with Physical Disabilities in the District of Butterworth, and the accessibility of available resources, to them

I, Carol J. N Dingana, would like to make a request for your permission to do a research project in the district of Butterworth. I am a Physiotherapist, in charge of the Physiotherapy Department at Butterworth Hospital.

I am a student, registered with the University of Stellenbosch, doing M.S.C. Medical Sciences, majoring in Rehabilitation. My research project is registered at the Centre for Rehabilitation Studies, in the Faculty of Health Sciences at the University of Stellenbosch.

The aim of my study is to investigate needs and resources of People with Physical Disabilities in the district of Butterworth. It will also make us find out how much these people know about available services they could benefit from.

The results of this research will help improve service delivery both in the community and at the hospital. The results of this research will be made available to you once the research is completed in your area.

For clarity on the matter, here are my contact details:

Cell No.       0845489227

Work           0474914161

Thanking you in advance

Yours faithfully

Carol J. N. Dingana   (Student No. 14207095)

G. Mji               (Research Supervisor)

APPENDIX 2D

LETTER TO THE DEPARTMENT OF HEALTH IN THE EASTERN CAPE,  
REQUESTING PERMISSION TO CONDUCT THE RESEARCH

Department of Physiotherapy

Butterworth Hospital

Butterworth

20-05-2009

The Manager

The Epidemiological Research Directorate

Department of Health

Bisho

Dear Sir/ Madam,

Request for Permission to do a research on Needs of People with Physical Disabilities in the District of Butterworth, and Accessibility of available Resources to them

I, Carol J. N. Dingana, would like to make a request for your permission to do the above mentioned research in Butterworth. I am a Physiotherapist, in charge of the Physiotherapy Unit at Butterworth Hospital.

I am currently registered with the University of Stellenbosch, doing a Master of Science degree in Medical Sciences, majoring in Rehabilitation. My research project is registered at the Centre for Rehabilitation Studies, in the Faculty for Health Sciences, at the University of Stellenbosch.

The aim of my study is to investigate the Needs and Resources of People with Physical Disabilities in the District of Butterworth. Interviews will be done with focus groups of People with Physical Disabilities and their Caregivers, as well as Service Providers that cater for People with Disabilities.

The results of this study will not be of benefit to People with Physical Disabilities in the District of Butterworth only, but will bring about improved service delivery for the Eastern Cape Province as a whole. These results will be made available to you once the research is completed.

For clarity on this matter, here are my contact details:

Cell Phone: 0845489227, Work: 047 4914161 Ext 2216

Thanking you in advance

Yours truly,

Carol J. N. Dingana. (Student No. 14207095)

G. Mji (Research Supervisor)

APPENDIX 2E

LETTER TO THE DISTRICT MANAGER AT MNQUMA L. S. A., REQUESTING PERMISSION TO CONDUCT THE RESEARCH

Department of Physiotherapy  
Butterworth Hospital  
Butterworth  
06-07-2009

The District Manager  
Mnquma L. S. A.  
Department of Health  
Butterworth

Dear Madam,

Request for Permission to do a research on Needs of People with Physical Disabilities in the District of Butterworth, and Accessibility of available Resources to them

I, Carol J. N. Dingana, would like to make a request for your permission to do the above mentioned research in Butterworth. I am a Physiotherapist, in charge of the Physiotherapy Unit at Butterworth Hospital.

I am currently registered with the University of Stellenbosch, doing a Master of Science degree in Medical Sciences, majoring in Rehabilitation. My research project is registered at the Centre for Rehabilitation Studies, in the Faculty for Health Sciences, at the University of Stellenbosch.

The aim of my study is to investigate the Needs and Resources of People with Physical Disabilities in the District of Butterworth. Interviews will be done with focus groups of People with Physical Disabilities and their Caregivers, as well as Service Providers that cater for People with Disabilities.

The results of this study will not be of benefit to People with Physical Disabilities in the District of Butterworth only, but will bring about improved service delivery for the Eastern Cape Province as a whole. These results will be made available to you once the research is completed.

For clarity on this matter, here are my contact details:

Cell Phone: 0845489227, Work: 047 4914161 Ext 2216

Yours truly,

Carol J. N. Dingana. (Student No. 14207095)

G. Mji (Research Supervisor)

APPENDIX 2F

LETTER TO THE MEDICAL SUPERINTENDENT AT BUTTERWORTH HOSPITAL,  
REQUESTING PERMISSION TO CONDUCT THE RESEARCH

Department of Physiotherapy

Butterworth Hospital

Butterworth

4960

2009-07-06

The Medical Superintendent

Butterworth Hospital

Butterworth

Dear Sir,

Request for Permission to do a research on Needs of People with Physical Disabilities in the District of Butterworth; and the accessibility of available resources to them.

I, Carol J. N. Dingana, would like to make a request for your permission to do a research project in the district of Butterworth. I am making this request because I may need time off to be able to conduct the necessary interviews, but those periods will be as short as possible.

I am a student, registered with the University of Stellenbosch, doing MSc in Medical Sciences, majoring in Rehabilitation. My research project is registered at the Centre for Rehabilitation Studies, in the Faculty of Health Sciences at the University of Stellenbosch.

The aim of my study is to investigate needs and resources of People with Physical Disabilities in the district of Butterworth. In this study, we will not only find out what needs People with Physical Disabilities have, but we will also find out how much they or their caregivers know about resources that are available for them. It will also give us reasons why some of these people cannot access these resources.

The results of this research will help improve service delivery both in the community and in Butterworth Hospital. These results will be made available to you once the research is complete.

For clarity on this matter, please don't hesitate to call me.

Yours faithfully

Carol J. N. Dingana (Student No. 14207095)

G. Mji (Research Supervisor)

APPENDIX 3

LETTER TO PARTICIPANTS, REQUESTING THEM TO TAKE PART IN THE RESEARCH

Department of Physiotherapy  
Butterworth Hospital  
Butterworth  
4960  
2009-07-06

.....  
.....  
.....

Dear Sir/ Madam,

Request for Participants to take part in a research on Needs of People with Physical Disabilities in the District of Butterworth; and the accessibility of available resources to them.

I, Carol J. N. Dingana, would like to make a request for you to take part in a research that I am doing on needs and resources of people with physical disabilities in the district of Butterworth.

I am a student, registered with the University of Stellenbosch, doing MSc in Medical Sciences, majoring in Rehabilitation. My research project is registered at the Centre for Rehabilitation Studies, in the Faculty of Health Sciences at the University of Stellenbosch.

The aim of my study is to investigate needs and resources of People with Physical Disabilities in the district of Butterworth. In this study, we will not only find out what needs People with Physical Disabilities have, but we will also find out how much they or their caregivers know about resources that are available for them. It will also give us reasons why some of these people cannot access these resources.

The results of this research will help improve service delivery in the community of Butterworth, and in Butterworth Hospital, as well as in the Eastern Cape as a whole. These results will be made available to you once the research is complete.

For clarity on this matter, please don't hesitate to call me. My cell number is 0845489227.

Thanking you in advance

Yours faithfully

Carol J. N. Dingana (Student No. 14207095)

G. Mji (Research Supervisor)

## APPENDIX 4

### DEMOGRAPHIC DETAILS OF PEOPLE WITH PHYSICAL DISABILITIES

#### PERSONAL INFORMATION

Sex

Age

Marital Status

Next of Kin

Religion

Dependants

Are you working?

Type of work

What is your highest level of education?

Are you a student?

At what level of education are you?

#### DEMOGRAPHIC INFORMATION:

Residential area

Type of residence

Availability of transport

Type of available transport

Are there developed roads in your residential area?

Are the roads tarred or gravel?

Who do you stay with?

Do you need a caregiver to look after you?

## FINANCIAL INFORMATION

Are you employed?

If not what is your source of income?

Do you have a workman's compensation?

Do you have a disability grant?

What other source of income do you have?

## HEALTH PROFILE

Type of disability

Year disability occurred

What caused your disability?

Are you currently on treatment?

What is the treatment for? Is it for pain, spasms, hypertension, or diabetes?

What type of assistive device do you use?

## APPENDIX 5

### INTERVIEW SCHEDULE USED IN FOCUS GROUP INTERVIEWS OF PEOPLE WITH PHYSICAL DISABILITIES

1. As a Person with Physical Disabilities, what do you consider as your needs?
2. What resources or services are you aware of, that can be of benefit to People with Physical Disabilities in your area?
3. What are your accessibility needs regarding: School, Work, Your Home, The Community where you live, Healthcare Facilities, other resources like Shops, Banks, The Post Office and other government departments?
4. What barriers do you experience when trying to access the above resources?
5. What are your suggestions for improvements in the services that could improve the lives of People with Physical Disabilities?
6. Do you consider your finances to be enough for your needs, including things like transport, groceries, medical care, clothes, etc?
7. Do you know of available services meant for People with Disabilities, which could help you save on your finances?
8. Would you like to start support groups for People with Disabilities in your area?

APPENDIX 6

DEMOGRAPHIC DETAILS OF CAREGIVERS OF PEOPLE WITH DISABILITIES

PERSONAL INFORMATION

Sex

Age

Marital Status

Relationship with disabled person you are caring for

What disability does this person have?

With what activities do you need to assist this person?

Religion

Dependants

Are you working?

Type of work

What is your highest level of education?

DEMOGRAPHIC INFORMATION:

Residential area

Type of residence

Availability of transport

Type of available transport

Are there developed roads in your residential area?

Are the roads tarred or gravel?

Who do you stay with, other than the person you are taking care of?

## FINANCIAL INFORMATION

Are you employed?

If not what is your source of income?

What other source of income do you have?

## HEALTH PROFILE

Do you have any chronic conditions (E.g. diabetes, TB, Hypertension)?

Do you receive regular medical treatment?

Do you get time to take care of your own health?

APPENDIX 7

INTERVIEW SCHEDULE USED IN FOCUS GROUP INTERVIEWS OF CAREGIVERS

1. What is your experience of living with people with disabilities?
2. What needs do you think the person you are caring of, has, and what do you consider as needs of People with Physical Disabilities in your area?
3. To what extent do you think these needs are met, and what resources or services are you aware of, that can be of benefit to People with Physical Disabilities?
4. What resources do you think are necessary to meet the needs of the Person with Disabilities that you take care of?
5. What barriers does the person you take care of, experience, when trying to access resources to meet his needs?
6. What are your suggestions for improvements in the services that could help improve the lives of People with Physical Disabilities, including the one you are taking care of?
7. Do you consider the finances of the person you are looking after to be enough for his needs including transport, groceries, clothes, medical care, etc?
8. Do you know of available services meant for People with Disabilities that could help you and the person you are looking after, save on finances?
9. Would you like to start a support group for People with Physical Disabilities and their caregivers in your area?

**APPENDIX 8**

**QUESTIONNAIRE FOR SERVICE PROVIDERS**

Please answer the following questions:

**1. PERSONAL INFORMATION**

1. Name of your facility:  
.....
2. Is your facility involved in working with People with Disabilities?  
.....
3. In what capacity are you working?  
.....
4. How long have you been working at this facility, or with People with Disabilities?  
.....

**2. NEEDS OF PEOPLE WITH PHYSICAL DISABILITIES**

According To You:

1. What are the needs of People with Physical Disabilities in the District of Butterworth?  
.....  
.....
2. Which of these needs do you consider as priorities?  
.....  
.....
3. Which of these needs are met by available services?  
.....  
.....
4. Which of these needs are met by your facility?  
.....  
.....
5. Which needs are not met?  
.....  
.....
6. Are all service providers able to reach all People with Physical Disabilities in the district of Butterworth?  
.....
7. If not, what are the barriers that prevent them from reaching them?  
.....
8. Is your facility accessible to People with Physical Disabilities? Explain:  
.....  
.....

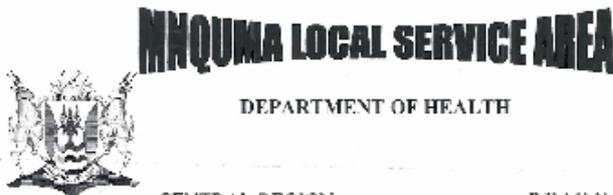
9. What form of transport do they use to come to your facility, is there public transport coming to your facility?  
.....
10. Are there taxis that bring people close to your facility? That is, less than 200 metres  
.....

### **3. RESOURCES OR SERVICES**

1. What resources or services that are meant for People with Disabilities are available in your facility?  
.....
2. Are People with Physical Disabilities aware of these services?  
.....
3. Are People with Physical Disabilities aware of how to access these services?  
.....
4. Do you think these services are enough? Explain:  
.....
5. If not, what other services do you feel would be of benefit to People with Physical Disabilities?  
.....
6. In your facility, how do you encourage development of life skills for People with Physical Disabilities?  
.....
7. In your capacity as a service provider, how do you promote independence for People with Physical Disabilities?  
.....
8. If you are a health care provider, do you include people with disabilities in your health education and promotion programmes (e.g. giving advice on how to prevent conditions like sexually transmitted infections and unplanned pregnancies, and screening for breast and cervix cancers, etc)? Explain:  
.....
9. How many People with Physical Disabilities are employed in your facility?  
.....
10. Have any modifications been made to accommodate these employees in the work situation? Explain:  
.....

APPENDIX 9

LETTER FROM THE DISTRICT MANAGER AT MNQUMA LSA, GIVING PERMISSION FOR THE RESEARCH TO BE CONDUCTED



# MNQUMA LOCAL SERVICE AREA

DEPARTMENT OF HEALTH

CENTRAL REGION

P/BAG X 3080  
BUTTERWORTH  
4960

PROVINCE OF THE EASTERN CAPE

TEL: 047-4910740/1/2/52  
FAX: 047 - 4910771

**ENQUIRIES: T.A NYANGA**

**REF: 2009/07/08**

Dear Mrs Dingana

**RE: YOUR REQUEST TO DO A RESEARCH ON NEEDS AND RESOURCES OF PEOPLE WITH PHYSICAL DISABILITIES IN THE DISTRICT OF BUTTERWORTH**

I'm pleased to let you know that permission to conduct the above named research in the Butterworth District is granted. I also wish to take this opportunity to wish you success in your studies.

Yours truly

T.A NYANGA



APPENDIX 10

LETTER GIVING PERMISSION FOR CONDUCTING RESEARCH FROM THE  
EASTERN CAPE DEPARTMENT OF HEALTH

SEE NEXT PAGE