PEOPLE WITH DISABILITIES AND SERVICE PROVIDERS’ EXPERIENCES OF COMMUNITY BASED REHABILITATION IN RWANDA.

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ABSTRACT

Background: Globally the number of people with disabilities (PWDs) is escalating especially in developing countries. Different approaches and strategies have been used to care for PWDs but could not meet their expectations. Community Based Rehabilitation (CBR) is recognised by the World Health Organisation (WHO) as the strategy to address their needs using both the medical and social model. CBR was established and implemented in two areas of Rwanda ten years ago with overall objectives that aim to facilitate accessibility to CBR service and full participation of PWDs in the community. However, the number of PWDs accessing rehabilitation services in Rwanda is still limited. Since the CBR programme started in Rwanda, there has been a lack of information on whether the CBR services provided by these two programmes are meeting the needs of PWDs and whether they facilitated the service providers to deliver the services more easily as intended. The aim of this study was to determine the experiences of PWDs and service providers of the Inkurunziza and Gahini CBR programmes in Rwanda. A qualitative method of data collection used in the study included focus group discussions with the selected PWDs. In-depth interviews were conducted with a purposively selected sample of service providers. This study was carried out at two day centers one from the Inkurunziza CBR programme and the other from Gahini CBR programme. The results revealed that the CBR programmes have increased the number of PWDs accessing CBR services. Services provided at these centres addressed some of the needs of PWDs, which included provision of assistive devices, and rehabilitation services, which were accessible. Most of the participants claimed that the programme is not doing anything to help them with activities that can assist to generate income and facilitate accessibility to schools or vocational training. The study findings indicated that services delivered in both CBR programmes only addressed some of the needs of the PWDs accessing the two CBR programmes. The service providers reported that they found it difficult to reach certain areas to provide CBR services to PWD due to geographical constraints. It is recommended that the CBR services provided by the two programmes need to focus more on education, training and employment of PWDs.

DECLARATION

I declare that “**People with disabilities and services providers’ experience of community based rehabilitation programmes in Rwanda**” is my own work, which it has never been submitted for any degree or examination in any other university, and all other sources I have used or quoted have been indicated and acknowledged by complete references.

Mr. Dieudonne Dusaberurema November 2008

Signed ……………

Witnesses: Mrs. Nondwe Mlenzana…………………...................

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List of abbreviations

CBR: Community Based Rehabilitation

PWDs: People with Disabilities

Minisante: Ministry of Health

Minaloc: Ministry of Local Government

NGO: Non-Governmental Organisation

PHC: Primary Health Care

UNESCO: United Nations Education, Scientific, and Cultural Organization

UNICEF: United Nations International Children's Emergency Fund

WHO: World Health Organization

SHIA: Swedish Organisations of Disabled International Aid Association

UN: Unites Nations

SIDA: Swedish International Development Cooperation Agency.

KMH : Kanombe Military Hospital

CBM : Christophel Blinden Mission

CHUK : Centre Hospital University of Kigali

CHUB : Centre Hospital University of Butare

DPO : Disabled People Organisation

AIFO: Italian Friends of Raoul Follereau

Key words

Experience

Community based rehabilitation

People with disability

Service providers

Rwanda

CHAPTER ONE

INTRODUCTION

1. INTRODUCTION

In this chapter, the background of the study is presented, including the prevalence of disability worldwide and specifically in Rwanda. It will include the motivation for the study, statement of the problem, significance of the study, research questions and the aim of the study.

1.1 Background

Approximately 600 million people in the world experience disabilities of various types and degrees (Italian Association Amici di Friends of Raoul Follereau: AIFO, 2003). This represents 10 % of the world's population (WHO, 2004). Helander (1999) stated that an estimated 70% of the disabled people live in developing countries. He further indicated that there were about 234 million moderately or severely disabled people living in developing countries and that this number was expected to increase to about 525 million by the year 2000.

In South Africa, the 2001 Census reported that out of its population of 40.5 million**,** an estimated 1.7 million (4.3 %) had different forms of disability (Lehohla, 2005). Rwanda is a country located in Central Africa; it has a population of almost 9 million people, an area of 26,338 square kilometers and has five provinces (National Institute of Statistics, 2002). According to the 2002 Rwanda national census, 5 % of the general population is disabled. In developing countries, less than 3 % of the people with disabilities (PWDs) receive rehabilitation of any kind (Helander, 1999). Several factors account for the inability of PWDs to receive rehabilitation and to be integrated into the mainstream society. The United Nations (2002) provided some of the following reasons: first, weakness of infrastructure or related services for social assistance, health, education, vocational training and second, constraints that include lack of resources or geographical features and physical and social barriers that make it impossible for many people to take advantage of the available services.

The general pattern of care and rehabilitation of people with disabilities in most developing countries is left in the hands of the family members and their immediate communities. There are a number of reasons for this situation in general. First is the unavailability of adequate rehabilitation services. Second is the inaccessibility of rehabilitation services in the rural areas as a large proportion of people with disabilities (PWDs) live in the rural areas, far away from these services. PWDs are also said to be among the poorest, especially in developing countries, and therefore cannot afford medical and rehabilitation services. In a survey of PWDs in five villages in the Nandi district of Kenya (Hutcherson, 1991) and another study done in Rwanda in 2003 (Thomas, 2005), the results showed a correlation between poverty, education level, poor nutrition, and gender and the prevalence of disability. This is the reason why the United Nations (UN) researchers concluded that there is a strong relationship between disability and socio-economic status (UN, 1998). In addition, the infrastructure available does not allow PWDs to access services as easily as their peers do (Penchansky & Thomas, 1981).

In Rwanda, as in most developing countries, rehabilitation services are still limited, and in most cases, the facilities are located in urban areas and not in the rural areas. Furthermore, services are unlikely to develop in rural areas where disability is so closely related to poverty (Minaloc, 2003). Most services and programmes of rehabilitation for PWDs in Rwanda have been developed by different institutions. However, since their inception, there has been no effort to establish how much they have contributed to improving the situation of PWDs.

Community based rehabilitation (CBR) is one of the programmes developed for helping PWDs (Vanneste, 1997). CBR was considered as the appropriate concept to provide services to PWDs in developing countries (WHO, 2002). WHO researchers suggested that in order to make CBR more effective, designers of CBR programmes should also look at the human rights perspective as the programme is generally delivered using the medical model. CBR promotes collaboration among community leaders, PWDs, their families, and other concerned citizens to provide equal opportunities for all PWDs in the community (WHO, 2004). It should therefore be a tool to implement existing international agreements such as the World Programme of Action, Standard Rules, the Salamanca Agreement and the UN Convention on the Rights of the Child. CBR was developed to empower PWDs and their communities (UN, 2002).

Where CBR is operational in different parts of the world, PWDs have started to benefit from the services provided through the programme. In the opinion of the authors of a report by WHO (2004), the experience of CBR has changed not only the lifestyle of

PWDs and integrated them into their communities, but it has also facilitated service providers to offer more accessible services to PWDs. CBR in Vietnam helped a number of children with disabilities to obtain rehabilitation and orthotic devices. Sometimes whatever materials were available were used to make these devices as they were needed long before the appropriate materials were available (Hai & Chuong, 1999). The same authors added that CBR in Vietnam has also increased awareness of disability among teachers and the community in general by removing barriers that could stop the children from going to school.

In Rwanda, CBR programmes were initiated in two areas and are run by international NGOs. These programmes are Inkurunziza in Kigali, the capital city, and Gahini in the southern part of Rwanda. They were implemented in 1997, with an overall objective of facilitating accessibility to services and full participation of PWDs in the community (Thomas, 2005). Up to the time of the present study, CBR programmes have been operating at the district level. The results of a study done in Rwanda by Muremyangango (2005), on clients' satisfaction with activities and services provided by the Inkurunziza CBR programme, indicated that clients were satisfied with all services delivered to them. The same author recommended that an evaluation of the impact of this programme on PWDs be conducted. This is in line with an observation reported by the WHO (2002[add a or b]), which stated that there is little documentation about experiences of PWDs and service providers with CBR programmes, especially in developing countries. Miles (2003, p. 3) stated that it is difficult to know exactly the effectiveness of programmes rendered to PWDs as "there is a lack of description of activities and services provided to

PWDs as well as experiences from the perspective of PWDs, their families, CBR personnel, and health care professionals regarding CBR programmes".

1.2 Statement of the problem

The Inkurunziza and Gahini CBR programmes started in the capital city and southern parts of Rwanda in the years 1997 and 1999 respectively. Their overall objective was to identify PWDs and make rehabilitation services more accessible. From the available documentation in the Ministry of Health of Rwanda (Minis ante) on existing CBR programmes, information relating to the experiences of PWDs and service providers regarding CBR programmes is lacking. Since the two CBR programmes were started in Rwanda, there has been no research done to establish whether the two CBR programmes are meeting the objectives set at the beginning. In most parts of the world, the CBR programmes are mixed with out-reach activities, resulting in failure to achieve the objectives fixed at the beginning of these programmes. Very few studies have been done in Africa to show how CBR programmes are operating and how CBR has benefited PWDs who are involved in this programme as the number of PWDs is escalating in these areas. For the programme to be successful, it is important for the programme to meet the needs of its clients. Nobody knows whether the programme is addressing the needs of PWDs in Rwanda. Since the programme started more than 10 years ago, only information regarding the satisfaction of clients is available.

1.3 Research questions

-- What are the positive and negative experiences of PWDs with Inkurunziza and Gahini **CBR** programmes in Rwanda?

-- What are the service providers' positive and negative experiences regarding the provision of the CBR programmes in Rwanda?

1.4 Aim of the study

To determine the experiences of PWDs and service providers of CBR programmes in Rwanda.

1.5 Specific objectives

1. To determine the positive experiences of PWDs regarding the services received from the Inkurunziza and Gahini CBR programmes.
2. To determine the negative experiences of the PWDs regarding the service received from Inkurunziza and Gahini CBR programmes.
3. To determine the positive experiences of service providers regarding services provided in Inkurunziza and Gahini CBR programmes.
4. To determine the negative experiences of service providers regarding services provided in Inkurunziza and Gahini CBR programmes.

1.6 Significance of the study

This study will assist in identifying weaknesses and strengths of the CBR programme in Rwanda. It is envisaged that the results of this study could assist in improving the activities and delivery of quality CBR services to PWDs in Rwanda. It will help the researcher to strengthen the CBR programme initiated at his work place. The study could provide recommendations to CBR workers and managers on how to implement CBR programmes.

1.7 Definition of Terms

1. **Disability:** Any restriction or lack of ability to perform an activity in the manner that is within the range considered normal for human beings (WHO, 2001).

2. **Impairment:** Loss or abnormality of psychological, physiological or anatomical structure (WHO, 2001).

3. **Assistive devices:** Aids and appliances used by people with disabilities to improve function (WHO, 2002[add a or b]).

4. **Caregiver:** The person who has the main responsibility of looking after the person with a disability (Schofield et al, 1999).

5. **CBR:** Provision of affordable and accessible rehabilitation services within the community, utilizing available community resources, focusing on empowering PWDs and their families with active participation of families and communities (WHO, 2002[add a or b]).

6. **People with Disability (PWD):** A person who has a moving, hearing, seeing, learning, feeling and mental disorder, which restricts function (WHO, 2002[add a or b]).

7. **CBR manager:** The therapist in CBR programme coordinating the CBR programme (WHO, 1994).

1.8 Summary of chapters

Chapter One describes the background of the study. The number of PWDs is escalating while services rendered to them are still limited. This chapter demonstrates that there has been an attempt to use CBR approaches to help PWDs, but when it comes to developing countries, findings have shown that rehabilitation services, especially in rural areas, are limited. The CBR programme has been recommended by WHO as the best strategy to increase the rights of PWDs and facilitate more community ownership. This programme started in Rwanda 10 years ago, but no research was done to find out whether this programme met the expectations or needs of the users and facilitated service providers. The chapter also includes the problem statement, specific objectives and significance of the study.

Chapter Two presents the literature review relevant to the study. It includes the definition of disability and presents disability in Rwanda in particular, models of disabilities, needs of PWDs and models of rehabilitation. CBR is described in terms of its operation worldwide and how it has been implemented in Rwanda. Then, finally, the experience of CBR in relation to its benefits, advantages and challenges are also presented.

Chapter Three describes the methodology used in this study. The research settings, study design, study population and sampling method are also given. The chapter also gives information about the procedure used during data collection. Finally, analysis and ethical considerations are described.

Chapter Four presents the results of the study. The results are presented in themes drawn from PWDs' focus-group discussions and service providers' interviews.

Chapter Five discusses the findings in relation to the literature available, to interpret the findings.

Chapter Six includes the summary of the study and the conclusion. The recommendations related to the findings of this study are presented. The limitations of the study are also mentioned.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter presents the literature review regarding the concepts applied by the disability movement and includes models of disability. It also highlights the history of community-based rehabilitation programmes and experiences in different countries where these programmes have been operational. The concepts of rehabilitation and CBR, and the experiences of CBR from different countries, including Rwanda, are discussed. Finally, various perspectives of CBR, as provided by service providers and PWDs, are explored.

2.2 Definition of disability

According to the Standards Rules of Equalisation of Opportunities for People With Disabilities, the term *disability* includes a great number of different functional limitations occurring in any population in any country of the world. People may have a disability by presenting with physical impairment, sensory impairment, intellectual impairment, medical conditions or mental illness (UN, 1994).

In 2001, the WHO created the International Classification of Functioning Disability and Health (ICF), a new global standard of disability concepts that look at a multidimensional concept of disability. ICF defines disability as functioning in multiple life areas. Disability is seen as a result of an interaction between a person with a diagnosis and that person’s contextual factors (environmental and personal factors). Within the same context of the ICF, disability covers a spectrum of various levels of functioning at body level, person level and societal level. Disability denotes all the following: a) impairments in body functions and structures, b) limitations in activities, and c) a restriction in participation. Traditionally, disability was considered under the medical model and welfare framework, identifying PWDs as ill, different from their non-disabled peers, and in need of care. Since the emphasis was on medical model needs, there has been a corresponding neglect of their wider social needs.

2.3 People with disability in Rwanda

According to a UN report (2002), between 300 and 500 million people around the world live with a significant disabling condition. Of these, between 120 to 150 million are children, adolescents and youth. A number of causes lead to disability. Disability has always been part of the human condition. Many individuals are born with a disability, while others acquire a disability later in life due to a variety of factors, including infectious disease, inherited conditions or accidents, as a consequence of malnutrition, lack of adequate preventative health care, exposure to environment pollutants or as a result of warfare or landmines (Helander, 1999).

According to Thomas (2005), in Rwanda, as is the case in most developing countries, there are a number of causes of disability. War is the most common cause of disabilities, followed by poverty, malnutrition, lack of adequate and appropriate medical care (such as limited access to health care and poor maternity care), ignorance (use of traditional healers), disease, accidents and congenital conditions. Other causes include poor hygiene, bad sanitation, lack of adequate information about the causes of impairments, conflicts, and dangerous working and living conditions.

However, according to the Ministry of Health of Rwanda (Minisante), the government of Rwanda is committed to tackling illnesses related to poverty and ignorance and improving the health status of the population through the sector strategy process (Minisante, 2005). The purpose of this strategy is to achieve the millennium development goals by 2015. As stated in the strategic plan 2005-2009, the overall objective is to expand geographical access of the population to a functioning health system for all the Rwandan population, including PWDs (Minisante, 2005). When it comes to the PWDs, the strategic plan stipulates that health-care services for the physically handicapped and the blind should be integrated into the primary and secondary health-care packages in order to improve access to the services. Rwanda is a signatory member of the UN and the country has also ratified the Lusaka agreements concerning the decentralisation and health district system (WHO, 1997). However, despite the country having introduced a national policy regarding the rights of PWDs and a national policy on inclusive education, and also possessing documents related to the needs and rights of PWDs, there is persistent lack of well-coordinated activities related to PWDs and a failure to implement those existing policies at national level (Minisante, 2002; Mineduc, 2003).

2.4 Models of disability

A model of disability provides a framework for understanding the way in which people with impairment experience disability. It can provide a reference for society as laws, regulations and structures are developed that impact on the lives of PWDs. Three models of disability exist: the medical model, the social model and the bio-psychosocial model (WHO, 2002[add a or b]).

2.4.1 The medical model

Disability, in the context of the medical model, is seen primarily as a disease and purely in medical terms. It is essentially a problem within the individual and is perceived as a deviation from the norm. Therefore, the role of the medical and paramedical profession is to cure, to correct or to ameliorate this problem (Lang, 1998).

This model is the most commonly used in Rwanda. , (Thomas, 2005). The medical model is based on traditions of objective professional assessment and a prescription for rehabilitation and support services (Barnett & Penny, 2004). This model relies on standardisation of measurement and the ability to assign levels of severity of disability and is characterised by the old WHO classification of Disability, Impairments and Handicap (WHO, 1980).

2.4.2 The social model

The social perspective postulates that it is society's response to the individual's impairments that actually creates disability and limits participation in society, and that changes in social and institutional environments are required (Bricher, 2000). Currently, in the early 21st century, despite the "weighty presence" of the medical perspective, the social model has become increasingly important. The concept of the social model has been widely and internationally acknowledged among both academics and activists, and given appropriate local orientation. Although this is the case, the social model has been the subject of many criticisms. Crow (1996), asserted that the social model has failed some individuals by making it hard to talk about the difficulty and discomfort arising from the impairment itself. He further argued that the reluctance to incorporate impairment into the social model leaves certain conditions and their consequences misunderstood by both lay people and health professionals.

2.4.3 The bio-psychosocial model

This model is the integration of the medical and social models. According to the WHO (2002[add a or b]), disability is a complex phenomenon that is both a problem at the level of the person and in features of the overall context in which the person lives, but some aspects of disability are, however, almost entirely internal to the person, while other aspects are almost entirely external. In other words, both medical and social responses are appropriate to the problems associated with disability and neither kind of intervention can be wholly rejected.

2.5 Rehabilitation

2.5.1 Introduction

Over the years, the concept of rehabilitation of PWDs has undergone several changes, especially in developed countries. There has been an expansion of the definition of rehabilitation, ranging from helping PWDs to survive to ensuring equal human rights for PWDs. Today, rehabilitation services for PWDs aim to reach the largest proportion of this population, utilising available resources within the community in a cost-effective way, through community-based rehabilitation (Kay, Kilonzo & Harris, 1994).

The term *rehabilitation* refers to a process that aims to assist PWDs reach and maintain their optimal sensory, physical, intellectual, psychiatric and social functional levels, thus providing them with the tools to live more independently (WHO, 1994). Davis (2006) mentioned that rehabilitation is a complex process that involves a number of health-care professionals, the individuals and their families. In order to achieve this kind of rehabilitation, a number of models and theories that could assist rehabilitation professionals are available.

2.5.2 Models of rehabilitation

The models of rehabilitation that are most frequently used by health-care professionals are institution-based and outreach services (Stubbs, 2002). With an increase in the availability of health services to the population, health-care reforms are seeing an increasing emphasis on service users' involvement in shaping future models of health service delivery (Bury, 2003). Therefore, with more focus on community settings rather than institution-based centres, CBR is one model developed for providing rehabilitation. There is another model, which is referred to as "outreach". It shares common goals with the other models developed to help the local community but has fundamental differences (Kay, Kilonzo, & Harris, 1994).

2.5.2.1 Institution-based rehabilitation (IBR)

Under this model of rehabilitation, the locus of control is based in the institution. O'Toole (1995) suggested that IBR may be provided in a residential setting or in a hospital where

PWDs receive special treatment or short-term intensive therapy. These services meet just a few of the PWDs' needs (Stubbs, 2002). Currently, there is an increased shift from delivering health service managed in institutional care facilities to primary health services centered on the needs of the local community and delivering services in the community (WCPT, 2003).

2.5.2.2 Outreach programme

Like institution-based rehabilitation, the locus of control is still within an institution. Typically, health-care personnel, for instance, physiotherapists who operate from institutions, provide outreach rehabilitation services. Visits to PWDs are organised by rehabilitation personnel. With this model, more people can be reached, but there are limits depending on the distance from the institution and on whether the needs of the disabled people are similar to what the institution offers (Stubbs, 2002).

These types of services have limited effect, in that they lack community involvement, education and vocational training, which results in little social change (WHO, 1994). Stubbs (2002) indicated that these types of services are controlled from an institution and there may be a mismatch between what the people need and what the institution can provide. Because of the inherent weaknesses of these approaches the WHO (1976) developed the community-based rehabilitation approach (ILO, WHO & UNICEF, 2002).

2.5.2.3 CBR versus IBR

CBR is both a philosophy and a strategy of providing more equitable and sustainable quality rehabilitation services to the majority in the community. In CBR, the disabled person, the family, the community and health professionals collaborate to provide the needed services in non-institutional settings, and in an environment or community where services for disabled persons are seriously needed or totally absent (Rodgers, 2003). In contrast to CBR, IBR services are provided in a health or educational institution, for example, a hospital or rehabilitation centre for in-patients. Such services are usually inadequate and they only reach a limited number of PWDs. IBR is therefore a limited approach and could deny PWDs their rights to access rehabilitation services. In many instances, where IBR services are available, they may be cost prohibitive as the majority of disabled persons live in rural areas far away from the urban areas where most of these institutions are located. However, institutional models of rehabilitation are essential for CBR to work effectively. Mpofu (1995) argued that the two models of rehabilitation are not separate but are independent of each other. She argued that CBR requires IBR services for referral and assistance in problems that cannot be resolved at the community level, while IBR requires CBR because of its roots in primary health care (PHC) and because CBR services are provided at the community level.

In an effort to clarify what CBR is and to draw a comparison with other types of care that take place in the community, there are a few key points to note. CBR involves partnerships with disabled people, adults and children, their families and caregivers. It also involves capacity building of disabled people and their families, in the context of their community and culture, a holistic approach, encompassing physical, social, employment, educational, economic and other needs, promoting the social inclusion of disabled people in existing mainstreaming services, and a system based in the community, using district- and national-level services for referral (Vanneste, 2001).

2. 6 Community-based rehabilitation

2.6.1 Introduction

The World Health Organisation defined CBR is as “a strategy within community development for rehabilitation, equalisation of opportunities and social integration of all people with disabilities. CBR is implemented through the combined effort of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services” (WHO, 2001, p. #). According to the WHO (1994), CBR started as strategy to be used to reach the goal of ‘health for all’ because of its success in working in the community. CBR is actually part of primary health care and uses the settings of primary health care.

2.6.2 CBR background

CBR has been developed in different contexts since the 1970s (Thomas & Thomas, 1998). According to Miles (2003), CBR in Africa started in the 1970s because in developing countries, the governments have limited resources and establishing a wider coverage of intervention is a problem. There are an estimated 300 CBR programmes in sub-Saharan Africa, which average between five and six programmes per country. In the early 1990s, it was estimated that as many as 80 countries worldwide had established

CBR programmes (Miles, 2003). Despite the large number of CBR programmes, services for PWDs in most regions of Africa are still limited to what people can achieve themselves (Boyce & Lysack, 2001). In its early days, CBR was often associated with the health sector because many programmes started within that sector and used primary health-care workers as the liaison persons with PWDs and their families (ILO, UNESCO & WHO, 2002).

Some CBR programmes are funded by government and others by NGOs. In national CBR programmes, government takes the leading managerial role (WHO, 2004). One ministry usually takes the lead and then provides the organisational framework. The ministry responsible for health, social affairs, or other ministries such as education (Mineduc) or labour often do this (WHO, 1994). CBR programmes are mostly financed and often named by international NGOs and emphasis is direct service delivery for the disabled, through the NGOs' own salaried employees, who are trained and monitored by the programme. Most of the CBR programmes work only part-time in the communities, while operating out of the centre, a hospital, or other social services, and they encompass only some CBR components, such as outreach work, clinics, parental guidance, referrals and so on. Nevertheless, all these programmes must firstly adhere to the agenda of the donors (Thomas & Thomas, 2002).

CBR involves the community in planning, decision making and evaluation of the programme. Utilisation and strengthening of referral services at district, provincial and national levels is another principle. Finally, CBR utilises a coordinated and multisectorial approach. At the time of writing, CBR comprises a variety of programmes, applying different strategies, having different ambitions and operating at different levels in society. According to Thomas and Thomas (1998), CBR is a concept which, in practice, varies from place to place, depending on the setting. Unlike institution-based approaches, there is no universal model of CBR which is applicable everywhere and each CBR programme has to evolve its own strategies and methods as appropriate to its context. It is unlikely that rigid standardisation of CBR can ever become possible, as long as there are different cultures. Any attempt at standardisation is as good as trying to standardise different cultures and races.

The principle of CBR is to provide primary health care and rehabilitative assistance to PWDs by using human and other resources already available in their communities (Sharma & Deepak, 2001). According to Bagheri, Benwell and Holt (2005), primary health care (PHC) is an essential strategy for providing "health for all" and is widely acknowledged as a universal solution for improving people's well-being in the world. CBR is part of the PHC strategy to deliver services to PWDs. The PHC strategy was identified by the Alma Ata declaration in 1978 as the key to attaining the target of "health for all" by the year 2000 (WHO, 1978). Although the declaration does not mention PWDs, it does mention that health is "a state of complete physical, mental and social well being as a fundamental right" (WHO, 1978, p. #).

As one aspect of its broad approach, CBR is a means of delivering health services in the primary health-care setting and therefore the two are intricately linked. CBR is not an approach that only focuses on the physical or mental needs of a person and, as such, extends beyond the health-care domain. It is also viewed in some countries as encompassing all care that takes place in the community, more analogous to the wider concept of PHC. CBR is not the only means by which rehabilitation can be delivered in PHC settings. Both CBR and PHC focus on the needs of individuals and the wider population. It is important, though, to understand that rehabilitation in the context of CBR extends beyond a purely medical interpretation.

2.6.3 Objectives of CBR

To be effective, CBR has established objectives that can facilitate the programme to achieve its vision. According to ILO, UNESCO and WHO (2004), the main objectives of CBR are to ensure that PWDs are able to maximize their physical and mental abilities. This also includes enabling them to gain access to regular services and opportunities. One of the important issues behind the CBR approach is "coverage", the attempt to shift from "everything for a few" to "something for everyone". This issue was perceived as important from the very beginning because it was estimated that in most developed countries, hardly 2-3 % of those in need of rehabilitation services received them (WHO, 1981). Accessibility for PWDs can mean many things, ranging from physical access to services and the built environment, to access to appropriate services such as an adapted curriculum and rehabilitation services, to access to civil and political participation, including voting and the justice system.

Another objective of CBR is to enable PWDs to become active contributors in their community and the society at large.

2.6.4 Community participation

Community participation implies the active involvement of PWDs, their families and communities in planning, implementation and governance, as well as sharing the risks of the programme. This is expected to make the programme more sustainable. According to Lysack and Kaufert (1995), primary health care and its commitment to community participation have been part of the development of health-care systems internationally. CBR and its grassroots approach to disability are closely allied with PHC and have adopted many of its principles, including that of participation. Although community participation is most often considered in the development and implementation of programmes, more recently, participation is seen as an essential component of programme evaluation.

According to Boyce and Lysack (2001, p. #), community participation in CBR is the "organisation of activities by groups of persons with disability (or their family members or friends), in conjunction with other relevant sectors to increase their ability to influence social conditions, and in so doing improve their disability situations". However, the concept of the community participation in CBR has generated much debate. It involves the readiness of the community to take up the ownership and the risks of the programme. It is however not as easy as it sounds because the disabled people are neither a majority group in the community, nor are their needs seen as a priority by the community. In most communities, the more vocal members control the provision of services, and most PWDs are excluded from this group because of their disability. It is not yet clear that community ownership of rehabilitation programmes will sustain PWDs better or marginalise them more and be detrimental to them.

With this trend of community participation, some of the CBR programmes are at advanced stages. They have started to shift from a top-down approach to community involvement. Taking the example of Uganda, participation of PWDs has become a key ingredient. The Ugandan CBR programme managers realised early on that using volunteers as service deliverers was not a feasible solution. The programme trained community development assistants who are officially paid cadres who operate at the community level. Their role was to identify and rehabilitate PWDs, counsel families, mobilize and sensitise the community, and form groups, including cultural groups and socio-economic activities. It has been realised that their involvement and high level of community participation has become a key ingredient in the success of the programme (Rifkin & Pridmore, 2001). These same authors have mentioned that sharing information and facilitating consultation fortify collaboration, hence bringing empowerment.

2.6.5 CBR and human rights

A number of universal human rights are, by definition, intended to be applied to all people (ILO, UNESCO & WHO, 2002). Most of the contributing organisations and states recognise the importance of the human rights framework in improving the opportunities and inclusion of PWDs. PWDs were excluded from mainstream society and provided with special schools, sheltered workshops, and separate housing and transportation. This was based on the assumption that they were incapable of coping within either society at large or in all or most life activities (WHO, 1994). Poverty and lack of access to basic services is one of the major phenomenon interfering with human rights of PWDs. The Convention of the UN (2006) on the Rights of Persons with Disabilities marked a paradigm shift in attitudes and approaches to PWDs. It takes a new turn from viewing a person with disability as the “object” of charity, medical treatment and social protection. The Convention moves towards viewing people with disabilities as “subjects” with rights, who are capable of claiming those rights and making decision concerning their lives, based on their free and informed consent as well as being active members of the society. As a member of the United Nations, Rwanda is a signatory to the United Nations Standards Rules on the Equalisation of Opportunities for PWDs (Republic of Rwanda, 2003). Up until the time of the current study, there was no national policy on disability that could drive activities to promote the rights of PWDs. However, there is a political will as the government recognises the need for this policy to facilitate PWDs’ access to facilities in the society.

One of the key principles of CBR is the understanding that disability is essentially a human rights issue. CBR has been criticised for many years for focusing much of its activities on the medical model (Lang, 1998). Now, there has been positive response from different organisations that CBR has shifted from this model to the social model and it is playing a big role in advocating for the rights of PWDs. This trend has been realised more in developing countries. However, only a few organisations manage to connect the objectives of CBR io the context of millennium development goals and the mainstream development policies (ILO, UNESCO & WHO, 2002). CBR is committed to activate the community to promote and protect the rights of PWD through social and structural change within the community by removing barriers to participation. According to Stubbs (2002), placing CBR in a human rights framework can be powerful in giving it a solid foundation and a clear set of goals. For example, CBR without a clear human rights framework could concentrate on delivering therapies and equipment to disabled people. This could have temporary benefits, but will not necessarily result in empowering PWDs. Those applying this approach do not try to remove the barriers to participation in society because a disabled person may have calipers but still be denied access to a school or a job. Therefore, in accordance with the UN Convention on the Rights of Disabled Persons (UN, 1994), CBR with a clear human rights framework would create a strategy to address the comprehensive rights of disabled people, working alongside other useful strategies. The provision of therapy, aids and equipment could be part of this, but with the aim of promoting full human rights. Within the context of human rights, some countries do their best to allow PWDs to be more involved in the society like their peers, but others are still struggling in the process (Lisbert, Hjort & Arne, 2004).

2.6.6 Components of CBR

Components of CBR are elements that demonstrate the orientation of CBR activities indicating the way forward to achieve its objectives. According to Mannan and Turnbull (2007), the primary component of CBR as a concept and ideology is that community members are willing and able to mobilise local resources and provide appropriate services to PWDs. The UN (1998) has mentioned other components of multidisciplinary CBR programmes, including creating positive attitudes towards PWDs to ensure equalisation of opportunities for PWDs within their own community. Positive attitudes among members can be created by involving them in the process of programme design and implementation, and by transferring knowledge about disability issues to community members.

Another component is that CBR provides functional rehabilitation services where PWDs require assistance to overcome or minimise the effects of their functional limitations. In communities where professional services are not accessible or available, CBR workers should be trained to provide primary rehabilitation services in the following areas of rehabilitation: medical, eye-care services, hearing services, physiotherapy, occupational therapy, orientation and mobility training, speech therapy, psychological counseling,and help with orthotic and prosthetic or other devices. According to the WHO (2001), an analysis of the status of PWDs in developing countries indicated that the following are obvious, immediate needs: basic awareness and understanding of the current concepts of disability and relevant human resources and specific skills in such areas as special diagnostics, including the prevention and detection of disabilities in children. Physiotherapy and psychosocial rehabilitation, availability of and access to a reliable supply of basic assistive devices, such as orthopaedic devices, eyeglasses, hearing and mobility aids, and devices for gastro-urinary tract disabilities are also important needs to be catered for in the environment. Providing education and training opportunities where PWDs must have equal access to educational opportunities, creating micro- and macroincome generation opportunities and providing care facilities are other components that can meet the needs of PWDs.

In a study to determine the impact of CBR in Ghana, Guyana and Nepal, the WHO and SHIA (2002) found that there were a number of initiatives that were perceived to be most useful for a CBR programme. These included social counseling, training in mobility and daily living skills, providing or facilitating access to loans, community awareness raising, providing or facilitating vocational training apprenticeship, facilitating formation of local self-help groups, parents' groups and disabled people organizations and facilitating contracts with different authorities.

In South Africa, different authors have reported about the needs of PWDs. A study done in South Africa by McLaren, Philpott and Mdunyelwa (2000), in Kwazulu Natal, showed that PWDs experience emotional, spiritual, financial and physical barriers, as they are not generally accepted in the community as persons who have their own rights. Hess (2003), in her study in Mitchell's Plain and Nyanga, South Africa, found PWDs needs were emotional support, acceptance and understanding, social support, income generating activities, integration into the community and acquisition of skills to be more independent. The sustainable solution to addressing these obvious needs requires careful consideration because these problems are systemic and have long historical roots in the country.

2.6.7 Community-based rehabilitation programmes in Rwanda

The idea of launching the CBR in Rwanda came after the war and genocide that occurred in this country and left many people disabled. Both CBR programmes operate as centres of rehabilitation where different departments deliver only medical-related services. When these two programmes were introduced to the community, the next step was to identify social workers, who were then trained to identify different types of disabilities. After this, a house-to-house survey in the two respective areas was conducted wherein children with different types of disabilities were identified and sent to the rehabilitation or medical team to be screened. However, when this programme was implemented for the first time in Rwanda at Inkurunziza, only children under the age of 12 years were cared for. With time, the programme became inclusive of people of all ages with physical and mental disabilities. Up to the time of the present research, there is no national CBR programme and none of the services available in the ministry of health concentrates on activities of CBR.

As confirmed by the CBR manager, the original objectives of the CBR programme were to identify PWDs and their needs, facilitate accessibility to health services and follow up PWDs in their respective communities through day-center programmes. In addition to advocating for PWDs and increasing awareness among the community, these programmes also disseminate information and education about disability and facilitate micro-economic groups for PWDs to generate some income (Seka, personal communication, July 05, 2007).

The Gahini CBR in the eastern province of Rwanda is located completely in a rural area. The Gahini CBR programme delivers almost the same services as the Inkurunziza CBR programme and is supported by CBM. The latter does not have mobility and training programmes. Instead, it has a small orthopaedic workshop that can assist children and adults with physical disabilities with minor problems. The 10-day centres of the Gahini programmes are located in different locations of the province, where professionals organise visits to meet clients either at the day centre or during outreach for screening for different types of disabilities. The centre operates within the district hospital but it has autonomy in management of everyday activities, human resources and finance. However, the CBR approach in Rwanda is limited and is typically characterised by out-reach activities and covers only 23 % of the Rwandan population (Minisante, 2002).

2.6.8 Expectations of PWD with regard to rehabilitation

When PWDs decide to attend a rehabilitation programme, they have their own expectations of the programme, but the programme also has the package of activities it delivers to meet these expectations. In a study done in Rwanda by Muremyangango (2005), clients attending CBR activities reported that their highest expectation of the programme was to obtain information relating to the family involvement. The clients least expected activities related to hearing training. Helander (2000, p. #) noted that the expectations of people with disabilities with regard to rehabilitation include the following:

-- Like any other individual or citizen of a country, PWDs expect and hope to get a good education, suitable vocational training leading to eventual socio- economic rehabilitation so that they can lead independent lives.

-- To be provided with regular medical care to improve their functioning as far as possible as well as to prevent disability from deteriorating any further.

-- To be helped and guided in their orientation and readjustment in the family, community and society with full participation.

-- To actively participate in their own rehabilitation, deciding for themselves the goal that they wish to achieve. It is essential that they are trained in accordance with their potential and inclination.

-- To be provided with suitable aids and appliances that can help to bring their mental and physical potential to the maximum.

-- To be provided easy access to physical environment including rehabilitation services through the removal of structural barriers and communication problems.

-- To be placed in a suitable job after training where facilities and safeguards are provided for the basic adjustment of their disability in order to enable them to function to their maximum capacity.

-- To receive evaluation and follow-up exercises until such time that they are fully settled with success in their jobs. This evaluation and follow-up is a combination and co-operative process between PWDs, the placement offices and employers.

2.6.9 Experiences of CBR

A number of studies evaluating CBR programmes have been conducted in Africa and in Asia. Most of them have used quantitative research approaches and very few of them have included PWDs and service providers (WHO & SHIA, 2002). A research study was done in Ghana, Guyana and Nepal by WHO and SHIA (2002) to find out how PWDs have experienced CBR. As mentioned before, no similar studies have been done in Rwanda. Also no studies have been done on evaluation of CBR programmes in Rwanda. The study carried out in the three countries was to determine the impact of CBR programme initiatives with regard to the involvement of PWDs and their families in the programmes and how programmes have changed their life conditions. During that study, a participatory research method was used to collect information and local CBR staff helped to identify the individuals concerned. The research findings show evidence that CBR has changed processes in the communities targeted and improved quality of life of PWDs in areas such as self-esteem, empowerment and influences, social inclusion and self-reliance. However, they demonstrated limitations in areas such physical well-being and confidence and trust in society in its human rights obligations.

2.6.9.1 Contribution and advantages of CBR

Many different agencies are now reviewing their experience of many years of support for CBR. These evaluations are in line with the global review of CBR by the World Health Organisation's disability and rehabilitation guidelines to meet the needs of PWDs (WHO, 2002[add a or b]). A wide range of opinion prevails about what the CBR actually is. In addition, projects and programmes that are called "CBR" can cover just about anything that is disability-related. According to ILO, UNESCO, UNICEF (2002), CBR benefits all people in the community because an accessible and human rights-sensitive environment makes life easier for everyone. The participation and influence of PWDs on the individual level as well as on the organisational level are emphasised and are seen as a precondition for the successful planning, implementation and monitoring of the CBR programme.

Researchers who conducted studies carried out in India and Thailand have reported positive aspects of the CBR programmes in these countries. They have recorded contributions of CBR as a strategy for promoting positive attitudes of society towards PWDs and improving coverage of services for PWDs, who otherwise could not gain access to the institution-based services for a number of reasons. These include the cost constraints, transportation problems, and limited availability of professionals or services. Furthermore, in these studies, CBR has been identified as a valid and crucial strategy for enhancing the quality of life of all PWDs in the community (Sangsorn, 1998).

The WHO (2004) claimed that much of the advantage of CBR relies on the fact that all the disabled people in a community can be reached and their basic needs met. Rehabilitation programmes can be established, based on the individual’s capacity and needs, and focused directly on his/her integration into the family/community. CBR can evolve and adapt to such fluid situations, while the rehabilitation centre will often only be able to “take a photo”, that is, deal with one set of problems at one point in the life of the disabled person. Through CBR, family members can witness and participate in the progress of a disabled relative, thus enhancing faith in that person’s abilities and potential, and challenging their own prejudices. CBR services, apart from carrying out their core work in rehabilitation, can also contribute towards the prevention of impairments and disabilities through activities such as primary health care, vaccinations, nutrition and hygiene. CBR again can trace many disabled people who could never be found by institutions, and through referral can make the work of the existing specialised services more effective. It allows early detection and also early intervention, which is very important given the increase in childhood disability in Africa (Thomas & Thomas, 1998).

Apart from these advantages, CBR can go beyond what is being done in institution-based rehabilitation. According to Kangere (2003), Uganda adopted CBR as a service strategy for reaching many PWDs in 1990. In the 2000s, the country runs a CBR model district in the eastern part of the country. Activities include identification of PWDs, assessment, referral, rehabilitation and home programmes. Families of persons with disabilities are also encouraged to participate in income-generating activities. The uniqueness of this project is that it involves multisectoral committees at national, district and sub-country levels. All these committees are geared to mainstreaming disability in general community development. As a result of such increased efforts, PWDs are beginning to benefit from other programmes, such as agriculture, which was not possible a few years ago. Different civil servants have learnt about the needs of PWDs. Persons representing disabled people are able to demand their rights and there is more representation of PWDs in a number of district committees that are looking at general developmental issues.

The evaluation of a CBR programme in Moshupa village in Botswana found that PWDs experienced an improvement of their quality of life in various aspects, like self-care, school, work and leisure activities (Nordholm & Lundgren-Lindquist, 1999). In addition, PWDs reported that they were integrated into the community as a result of the programme and there was increased participation of the community in the activities of PWDs by attempting to obtain employment for disabled adults, such as working in small shops and in petrol stations. The same study also reported that CBR programmes for children had promoted integration into normal schools for physically disabled children and referral to some special schools for those with hearing and seeing difficulties. The community has also been informed about the rights of the PWDs.

Since its inception in the late 70s, CBR has evolved, using a social model approach for enhancing quality of life for PWDs, particularly those living in developing countries (WHO, 2004). Based on a social model, the tenets of CBR have been defined by various authors as follows: CBR focuses on empowerment, rights, equal opportunities and social inclusion of all PWDs, CBR is about collectivism and inclusive communities where PWDs, their families and community participate fully for resource mobilisation and development of intervention plans and services, and CBR needs to be initiated and managed by insiders in the community, rather than by outsiders for its sustainability (Thomas & Thomas, 2003).

As mentioned above, various CBR programmes are initiated and led by NGO’s and supported by international partners. CBR programmes are often separate operations supported by donors rather than being standard policies included in the national and local government plans and budgets. Therefore, the sustainability and growth of CBR requires the programme to be soundly rooted in its social, cultural, administrative and financial environment.

2.6.9.2 Barriers and constraints of CBR

Some studies have identified negative and paradoxical aspects of CBR programmes (Kendall, Buys & Larner, 2000; Rehman, 1999). For instance, financial support for CBR projects have been inadequate as such support is from external donors, particularly international non-governmental organisations (NGOs) and other charity-based organisations (Cheausuwantavee, 2005). Thus, CBR project supporters have found it difficult to sustain their activities upon withdrawal of external donors and funding. In addition, due to poverty and the influence of capitalism, CBR workers have become stakeholders who need salaries and benefits (Brinkman, 2005) rather than volunteers and collectivists who could devote themselves to their work without wages or any benefits.

While promoting positive attitudes toward PWDs has been one of the contributions of CBR, much of the community has continued to hold negative attitudes towards PWDs. These include seeing the PWDs as incapable and/or sinful or as people paying for the sins of previous births (Bury, 2005). As a result, PWDs tend to be discriminated against, stigmatised and labeled, without empowerment, equal opportunities or social inclusion. Some communities believe that it is difficult and even impossible to provide rehabilitation services to PWDs, while others believe that families or professionals must manage rehabilitation services (Coleridge, 2005). Many CBR projects have adopted a top-down approach and are run by outsiders without adequate attention to community concerns and participation. These problems and their complexities are a major challenge for the further development and progression of CBR. According to Cheausuwantavee (2007), analysis of the results obtained in these studies and examination of the relevant literature has identified three discrepancies or paradoxes between CBR as an ideal and CBR in usual practice. First, although CBR supports or focuses on empowerment, rights, equal opportunities and social inclusion of all PWDs, in practice most of the community members have negative attitudes towards PWD. Second, CBR is about collectivism and inclusive communities, but in practice, CBR workers are stakeholders and individualists who need wages and benefits. Third, CBR is supposed to be managed by the community, while in practice, CBR projects often are top-down in approach and run by outsiders without consideration of community concerns and participation (Cheausuwantavee, 2007). The WHO and SHIA (2002) reported some barriers on rehabilitation and support services mainly due to limited skills of the CBR community workers. Additionally, they reported that few PWDs received appropriate assistive devices from the CBR programmes, and accessibility to medical care was limited.

To understand more about barriers to access to primary health-care services, of which CBR is a part, Penchansky and Thomas (1981) categorised barriers into five types: 1) availability, 2) accessibility, 3) affordability, 4) acceptability and 5) accommodation. However, Vanneste (1997) argued that together with these barriers, the following problems may interfere with CBR programmes:

1. Poor family priorities may be at the level of survival needs rather than solving problems of a disabled member. Poor living conditions of most of PWDs also

increase the need for rehabilitation. The objectives of individual CBR programmes, therefore, have to be realistic, focusing on essential needs.

2. The organisation and management of good CBR programmes are complex and difficult in a country where people often have no tradition of formal management and handling of funds.

3. Highly educated workers do not like to go into the rural areas, and many find it difficult to communicate well with disabled people, who are often uneducated or under-educated. Front-line CBR is a low profile job, which gives no social status to people who already have higher education. These factors influence the type, level and quality of the services that can be provided by CBR programmes.

4. For several reasons, CBR programmes might often be over-taxing to the community. It is precisely the ‘lack of the community’, that is, the breakdown of traditional social structure that contributes to many problems facing developing countries. Thus, it is unlikely that these same weakly constructed communities could organise appropriate services for PWDs.

According to the UN (1998), the complexity of the CBR is the result of the current concept that CBR programmes should be multisectoral (or multidisciplinary) so that they can provide assistance in all areas which are central to the improvement of the quality of life of PWDs. This complexity demands the need for close coordination, collaboration and cooperation between governmental and non-governmental organisations of all types and at all levels. The basic concept inherent in the multisectoral approach to the CBR is the decentralisation of responsibility and resources, both human and financial, to the community organisations. In this approach, government and non-government institutions and outreach rehabilitation services must support community initiatives and organisations (WHO, 1994).

2.6.10 Sustainability of the CBR programmes

Many programmes recognise the importance of community-based organisations in respect to ownership and sustainability of CBR programmes. Capacity building of orgaisations of PWDs and parents means working with them to enhance their resource mobilisation and management capacities to prioritise, plan, implement and finance their activities (Asindua, 1995). In a joint position paper, ILO, UNESCO and WHO (2002) have identified six prerequisites for sustainability of CBR programmes. Countries' approaches for implementing CBR have varied a great deal, but their experiences have identified some common factors that affect the sustainability of CBR programmes. These include the recognition of the need for CBR programmes based on a human rights approach; the willingness of the community to respond to the needs of PWDs; the availability of resources and support from outside the community; multisectoral collaboration, including collaboration with the disabled peoples' organisation (DPO) and NGOs; the presence of community workers; and the integration of CBR within government, with the allocation of adequate resources.

2.7 Summary of Chapter Two

This chapter covered different models of disability and of rehabilitation. In this chapter, CBR programmes' objectives and principles and how they work in general have been described and mention made of experiences of CBR in different countries. Different authors have demonstrated that there **is** inconsistency between CBR in practice and the ideal of CBR. Studies have shown that most CBR programmes in operation tend to focus on the medical model, yet many of the needs of PWDs can be overcome under the social model. The context in which the CBR programmes should operate in order to deliver the services as intended to PWDs was described and their advantages to services providers also mentioned. Findings have shown that where these programmes are operational, they have helped to promote positive attitudes by society towards PWDs and have helped in improving coverage of services for PWDs who otherwise would not have had access to institution-based services. This chapter ended by demonstrating the contributions and limitations of this programme, which can assist in the construction of a sustainable programme for the future.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter outlines the methods that were used in the study and provides the description of the research settings, the study design, instrumentation, study sample, pilot study, data analysis and ethical considerations.

3.2 Research settings

The current study was conducted in the Republic of Rwanda and involved the Inkurunziza and Gahini CBR programmes.

3.2.1 The Inkurunziza CBR programme

The Inkurunziza CBR programme is located in Kigali, capital city of Rwanda, 10km away from the city centre. The Association des Eglises Inkurunziza au Rwanda runs the Inkurunziza CBR programme. This programme has different activities that are dominated by rehabilitation services, delivering assistive devices to PWDs at the institution. Services are mainly delivered by qualified physiotherapists and trained orthopaedic technologists. In order to access a larger number of PWDs, the area in which the programme operates has been divided into 12 zones. In each zone, the programme has established a one-day centre so that the PWDs may go to the day centre closest to their home. At these day centres, a team composed of a physiotherapist, a person trained in detecting eye problems and sometimes an orthopaedic technologist meet on a regular basis and PWDs can be screened. Furthermore, social workers trained in basic skills in techniques of rehabilitation physiotherapy are employed at the day centres. Sometimes, social workers visit PWDs in their respective communities. Each social worker is assigned a specific area, where he/she plans to meet PWDs either at the day centre or in their respective homes. To reach the day centre, each social worker is given transport money per month, and these social workers are paid regularly per month. At the day centre, a social worker provides rehabilitation service to PWDs, who are mainly children with mental disabilities, but people with physical disabilities also visit the centre. People in need of assistive devices either can receive them at the day centre or are referred to the institution, depending on the assessment of the social worker or the field physiotherapist. A field physiotherapist normally supervises the work done by social workers and decides on the way forward. Apart from the above-mentioned activities, there is an outreach clinic programme and an Inkurunziza mobility and training centre.

Outreach: This is an extensive outreach project in which doctors and nurses consult and help clients all over the country suffering from epilepsy or eye and hearing problems, as well as clients with different types of disabilities.

Inkurunziza mobility and training centre: The main objective of the mobility workshop is to produce mobility aids to assist children with physical disabilities. The centre consists of different departments: a physiotherapy-training unit, where patients come for treatment, the teaching unit, the carpentry department, the metal department, the toy unit and the thermoplastic unit.

3.2.2 Gahini CBR programme

The Gahini CBR programme operates mainly in the rural areas of the eastern province, which is 150 km from the capital city. It was started in 1999 and is also run by CBM. The Gahini programme has a centre for rehabilitation services, where people with physical and mental disabilities are accommodated at the institution for a specific period for treatment. The same centre has an orthopaedic workshop that makes assistive devices. Qualified physiotherapists and assistant physiotherapists provide these services. To facilitate those who cannot come to the Gahini centre, the area in which the programme operates has also been divided into 10 zones, and in each zone, a one-day centre has been established. The 10 day centres are Nyamugali, Cyamburana, Munini, Nyakayaga, Nyarurema, Rukomo, Musha, Bicumbi, Rushashi and Matimba. The CBR manager, in collaboration with physiotherapists, organises visits to these day centres, using the only car available. Some day centres are visited once a month, others once in two months because of financial problems, poor infrastructure and the geographical features in that area. Gahini CBR programme managers inform PWDs on when they will visit with the help of the volunteers from churches or local community leaders. These volunteers collaborate with the programme organisers but are not paid. During the visit, a screening of PWDs is done and PWDs or caregivers are trained to carry out different exercises and basic physiotherapy techniques by either the assistant physiotherapist or a qualified physiotherapist so that they can assist themselves. Those in need of assistive devices can be given them at the day centre or at the institutions. For some PWDs to reach their respective day centres, it takes from one to two hours walking. Others live in inaccessible areas where a bus passes once a week and it would take days to walk to the day centre. Some day centres are visited by many PWDs due to the impact of the war in that area or the large number of children with disabilities in that area.

3. 3 Study design

The present study is a descriptive study using qualitative methods. Secker, Winbush, Waston and Millburn (1995) stated that the role of the researcher using a qualitative design is to explore, with the aim of discovering new issues, rather than verifying what is already known by participants. In qualitative research, the researcher relies on his/her ability to describe and write how events occurred in a manner that brings to mind the events as they happened in the research situation, and in a manner that conveys the environmental context and the process involved in arriving at the conclusions (Dickie, 2001). This design was deemed appropriate for the study as the aim was to explore the experiences of PWDs and service providers in relation to CBR.

3.4 Study population and sampling

3.4.1 Study population

The study population comprised all service providers (CBR managers, social workers, physiotherapists and therapist assistants) and PWDs with all types of disabilities, as well as caregivers accessing CBR day centres of both programmes. According to the annual report of 2006, the Inkurunziza CBR programme has 12 social workers, 1 field supervisor (physiotherapist), 2 physiotherapists working at the centre, 3 orthopaedic technologists and, finally, the head of the programme, who is a physiotherapist. Additionally, the programme has contracted 30 volunteers who assist the programme to find new cases in the operating area of the country.

The Gahini CBR programme has the manager of the programme who is a physiotherapist, four other physiotherapists, an orthopaedic technologist, and three assistant physiotherapists. There are also some volunteers who assist in the programme. Their number is not specified.

3.4.2 Study sample

3.4.2.1 Selection of day centres

As stated above, the Inkurunziza CBR programme has 12 day centres where people receive rehabilitation services. A convenient sampling method was used to select one day centre from Inkurunziza, named Nyamirambo day centre, for the focus group with PWDs and caregivers. At Gahini CBR programme, which has 10 day centres, a convenient sampling method was used to select one centre, named Nyarurema day centre, for the focus-group discussion with PWDs. In total, two focus groups were then used to collect information from PWDs. The selection of the two day centres was based on their easy accessibility to the area and the number of PWDs attending the day centre, which offered a greater chance of representation from people with different types of disabilities.

3.4.2.2 Selection of PWDs/caregivers for the focus group

This study involved PWDs, caregivers of children with disabilities in the focus group discussion and service providers for the interview.

A convenient sampling technique was used to select participants for the focus groups. In total, 11 participants (PWDs/caregivers) who fulfilled inclusive criteria were recruited. Using this technique, only six participants at Inkurunziza fulfilled the criteria, whereas five at Gahini met the criteria. Of the six participants at Inkurunziza, two were PWDs and four were caregivers to speak on behalf of PWDs who could not explain themselves, whereas at Gahini, among five participants, two were PWDs and three were caregivers to speak on behalf of PWDs. The selection of PWDs took into consideration age, gender and the types of disabilities. Creswell (1998), Flick (1998) and Krueger (2000) further recommended that a focus-group discussion should comprise of 6 to 10 participants during sampling. However, according to Morse (1991), theoretical richness has nothing to do with how much or how many; rather, the researcher seeks to describe experiences as richly as possible.

3.4.2.3 Selection of service providers

The selection of service providers was conducted at Inkurunziza and Gahini centres. In total, six service providers participated in the study from the two centres. A purposive sampling technique was used to select three service providers, including the CBR manager (physiotherapist) and two social workers at Inkurunziza. The selection of the two social workers was based on the fact that they participate in daily activities at the day centre. They were believed to possess sufficient knowledge of activities at the day centre. The physiotherapist plays a role in supervision and intervenes when consulted by the social workers. The same technique was applied to select three service providers at

Gahini, where the CBR manager, one physiotherapist and one assistant physiotherapist participated in this study. According to Armitage and Berry (1996) and Bless and Higgson-Smith (2000), purposive sampling is used in special situations in which a researcher selects unique cases that are especially informative for in-depth investigations.

3.4.2.4 Inclusion criteria

Only PWDs who had been involved in the CBR programmes for at least one year and were able to communicate participated in the study. For children with disabilities, their parents or caregivers participated in the study, provided they also attended the programmme for at least one year. The in-depth interview for the service providers included those who had been employed for the past two years and had enough knowledge of how the programme works but were also involved directly in CBR activities rather than the programme in general.

3.5 Data collection methods

Patton (2002) identified three kinds of qualitative data collection methods: (1) in-depth interviews, open-ended questions, conversions and stories; (2) direct observations of such things as behaviours, actions, organisational or community processes, and any other aspect of observable human behavior, and (3) written documents such as clinical records, letters, official publications and reports, and correspondence.

During this study, two focus-group sessions were conducted to collect data from the PWDs (see Appendix A) whereas individual in-depth interviews (see Appendix B) were used to collect information from the service providers. Both the focus groups and individual interviews were held in Kinyarwanda (the local language). According to Mouton (2001), in-depth interviews have the following advantages: they permit the collection of extensive data; they allow the interviewee to answer the questions as they choose, and motivate their responses when required; and they allow both parties to explore the meaning of the central themes. In this study, the researcher used an interview guide used in the study done by WHO and SHIA (2002) looking at experiences of PWDs of CBR in Ghana, Guyana, Nepal and the interview guide used to evaluate CBR in Botswana in1999 and in Zimbabwe in 1998 to collect data from PWDs and from service providers. The structure of the adapted interview guide for focus groups consisted of a variety of constructs covering demographic data, accessibility, benefits and barriers experienced by PWDs and expectations on the future of the CBR programmes in Rwanda. An interview guide for the in-depth interview for service providers consisted of the position they occupy in the programme, contribution of CBR to the service, and challenges experienced. The wording and the order of the questions to the interviewee were kept as basic as possible (Simmons, 2001). The researcher and the research assistant each used notebooks, and notes were compared and discussed after each interview to ensure trustworthiness of the responses. A tape recorder was used to record the interview after seeking written consent from the respondents. One respondent refused to be recorded.

3.6 Trustworthiness

According to Skosana (2006), qualitative research is trustworthy when it accurately represents the experiences of the participants. This has been supported by Patton (2002), who stipulated that validity and reliability are two factors that any qualitative research should be concerned about while designing a study, analysing results, and judging the quality of the study.

Trustworthiness is based on systematic collection of data and allowing the procedures and findings to be open to critical analysis from others. To establish trustworthiness, Babbie and Mouton, (2001) and Denzin and Lincoln (1998) suggested the concepts of credibility, transferability, dependability, and confirmability as essential decisive factors for quality in qualitative research. To ensure trustworthiness in the present research, the participants' words were interpreted and quoted verbatim. Triangulation, brought about by the different research strategies used by the researcher demonstrates credibility. Auditors, who in this case are the researcher's supervisors, have examined the researcher'' notes and documentation of critical incidents, such as interview notes and an account of the process of the inquiry to attest to their dependability and conformability. "Purposive sampling, which is also one of the methods used, demonstrates transferability. Since there is no credibility without dependability, a demonstration of the former is sufficient to establish the existence of the latter" (Babbie & Mouton, 2001, p. #). The research process and analysis will be described in detail.

Credibility: To ensure this, the chosen method and procedure for identifying participants were discussed with the supervisors. After interviewing the group, the data were transcribed and analysis memos were prepared.

Transferability: PWDs and service providers who participated were representative and met the desired goal of this study.

Confirmability: The data collection process and analysis were described to make it clear for the reader to follow the trail.

3.7 Translation

As most of the people in the Rwandese community speak their mother tongue, two professional translators helped to translate the interview guide. One assisted in translating from English to Kinyarwanda (see Appendix C and Appendix D), then another one from Kinyarwanda to English to avoid any loss of information.

3.8 Pilot study

A pilot study of the interview guide was conducted at Humura CBR centre, located in Kigali’s rural area. Individual interviews were held with two PWDs and two service providers that are involved in and exposed to the CBR programme at this centre. For the PWDs interviews, one was conducted with a caregiver who had a child with cerebral palsy and the other with a hemiplegic patient.

The identification of the PWDs was done by rehabilitation workers and was done according to their knowledge and having been exposed to the programme for at least one year, and thereafter an appointment was made. Service providers involved in the pilot study were the ones working closely with CBR but not at the institution. The results of the pilot study demonstrated that there were some questions that were not relevant to the topic. The pilot study also helped the researcher to gain more confidence by trying to keep the participants more focused. The focus-group discussion took between 40 and 45 minutes and the individual interviews took between 35 and 40 minutes.

3.9 Procedure

This research was conducted after first obtaining permission and ethical clearance from the UWC Senate Research Grant and Study Leave Committee and the Higher Degrees Committee, (Appendix E) and permission from the Ministry of Health in Rwanda (Appendix F). Thereafter, permission was requested from both the managers of the Inkurunziza (Appendix G) and the Gahini CBR programmes (Appendix H). After obtaining permission from these authorities, the next step was to recruit and train a research assistant; then the data collection proceeded. Two focus-group discussions were conducted, one at Inkurunziza and another at Gahini. In-depth interviews were conducted among service providers.

3.9.1 Data collection at Inkurunziza

Before starting data collection at Inkurunziza, a meeting was held between the researcher and the CBR manager to introduce the researcher and the research assistant and explain the overall purpose of the study. The interview was arranged for the following day. The interview was conducted in one of the rooms of Inkurunziza centre, which is used for conducting meetings. The interviews started with introduction and explanation of the overall purpose of the study (Appendix I). Privacy was observed in the room where the in-depth interview took place. In-depth interviews were conducted after gaining consent from the participants (Appendix J). The interviews with the social workers and the CBR manager were done on consecutive days. Permission was obtained to tape-record the interview with service providers (Appendix K). On the last day of the interviews with the service providers, the social worker working with PWDs at the selected day centre and the field physiotherapist arranged appointments with PWDs. When the social worker went for the usual sessions, normally occurring three times a week, she requested PWDs/caregivers to be ready for the interview during the next session of treatment.

Although 23 PWDs regularly attend Nyamirambo day centre, only 10 responded to the invitation to participate in the interviews. Only 6 of these 10 fulfilled the inclusion criteria. Prior to the focus-group discussion that was held at a convenient time at Nyamirambo day centre, PWDs/caregivers were informed about the research (Appendix L) and requested to participate in it. The researcher, together with his assistant, explained the purpose of the focus-group discussion to the participants in the study and requested them to sign a consent form (Appendix M) before commencing. The focus-group discussion was tape-recorded after getting consent. **(**Appendix N**)**. The research assistant took notes to avoid any loss of information. He also noted the reactions of participants during the discussion. The focus-group discussions lasted for about 43 minutes and were conducted in a quiet room, and each participant was given 1000 Rwandan francs.

3.9.2 Data collection at Gahini

Prior to the visit to the Gahini CBR programme, the researcher arranged a meeting with service providers in order to explain the research and to ascertain if the service providers would be available. On the day of data collection at Gahini, a meeting was held in the presence of the CBR manager in which the study was explained to the service providers and the CBR manager. Thereafter, consent forms were signed by all participants (Appendix K). Service providers were interviewed in the morning, and the manager was interviewed in the afternoon. The interviews with service providers took approximately 46 minutes and were done in an isolated room for privacy. Each interview was tape-recorded and consent was obtained for this, and the assistant took notes. A method of identifying PWDs for the focus group at their location was discussed with the service providers because day centres are situated in inaccessible areas, where it is difficult to find the participants. It was agreed that PWDs would be informed about the study and encouraged to participate. During the visit to the day centre, PWDs/caregivers meeting the selection criteria were gathered in a room, where they were briefed about the study and asked to sign consent forms (Appendix L). Using the available list of the PWDs coming to the selected day centre, 46 PWDs were expected to be present. However, at the time of data collection, 15 managed to come. Of the 15, five met the inclusion criteria. The focus-group discussion took 40 minutes and ended when no new ideas were forthcoming from the respondents. Each participant was also given 1000 Rwandan francs.

3.10 Data analysis

The analysis of the data was done in three phases, as is suggested by Creswell (1998). First, after collecting data, the researcher, listened to all audio-taped information and did the transcription verbatim. According to Brokopp and Hastrings (cited in De Vos, 2002), in qualitative research, data analysis begins with verbatim transcription of data, followed by a description of the account that was as close to the data originally recorded as possible. This provides a basis for data indexing, storage and retrieval. At this point, the researcher transcribed the audiotape recording personally. The transcriptions were supplemented with additional data obtained from observations and notes made by the research assistant. The transcriptions were compared to the audiotape recorded data to verify accuracy by the researcher. To check that English translations of the recordings were an accurate reflection of the responses in Kinyarwanda, an independent translator listened to each recording. Next, an independent person translated the transcripts from Kinyarwanda to English. Second, the researcher read the transcripts twice, and the sections that were relevant to the research questions and objectives were highlighted in margins. The data were classified systematically by means of coding, to identify key factors such as concepts. Specific units were identified and then assigned categories using different colors of ink, as Strauss and Corbin (1999) suggested. The successive data were then compared with the previously identified units. After all data had been assigned into categories, these categories were refined into themes, which constituted the third stage of analysis. The outcome of the analysis of the research findings will be presented in Chapter Four.

3.11 Ethical consideration

The researcher first obtained permission and ethical clearance from the Senate Research Grant and Study Leave Committee at the University of the Western Cape before commencing with the research. Permission was then requested from the Ministry of Health in Rwanda and, finally, authorization from managers of the two CBR programmes to access service providers and PWDs was obtained. The aim and objectives of the study were explained to all participants and their written consent was obtained. The researcher assured the participants of their anonymity, and the confidentiality of the interviews, and their right to withdraw at any time without any consequences. None of the respondents' rights were infringed upon while carrying out the research.

3.12 Summary of Chapter Three

This chapter dealt with the methodology used in this study. A qualitative approach was used to achieve the aim and objectives of the study. The sampling techniques used to select the two settings and participants in this study were also mentioned. The procedure followed during analysis and the ethical considerations involved were described in this chapter.

CHAPTER FOUR

RESULTS

4.1 Introduction

The results obtained through the focus groups with people with disabilities (PWDs) and in-depth interviews with service providers are presented in this chapter. The thematic analysis of the transcripts of the focus groups and in-depth interviews yielded different themes. Therefore, the themes will be presented separately for PWDs/caregivers and service providers. Verbatim quotes will be used to further illustrate the themes.

4.2. Demographic status of the persons with disabilities and caregivers of children with disabilities

Two focus groups were held. At Inkurunziza the focus group comprised of 5 respondents while at Gahini it comprised of 6 respondents. The demographic data of the respondents are presented in Table.1

Table 1. Distribution of participants in the focus group discussion

Pseudonym	Diagnosis	Age	Gender	Participant	Location of programme
P. 1	Sequelle of polio	22 years	Female	Himself	Gahini
P. 2	Hemiplegia	45 years	Female	Himself	Gahini
P. 3	Cerebral palsy	8 years	Male	Caregiver	Gahini
P. 4	Cerebral palsy	1.4 years	Female	Caregiver	Gahini
P. 5	Cerebral palsy	5 years	Female	Mother	Gahini
P. 6	Cerebral palsy	3 years	Female	Caregiver	Gahini
P. 7	Club foot	5 months	Male	Grandmother	Inkurunziza
P. 8	Stroke	12 years	Female	Herself	Inkurunziza
P. 9	Cerebral palsy	2.5 years	female	Caregiver	Inkurunziza
P. 10	Cerebral palsy	3 years	Male	Caregiver	Inkurunziza
P. 11	Paralysis of left arm	15 years	Female	Herself	Inkurunziza

Two focus groups at Inkurunziza and Gahini respectively were conducted. The majority of the participants (72 %) were females. The participants of the focus groups included PWDs and caregivers of PWDs who were minors. The majority of the PWDs (54.5%) had a diagnosis of cerebral palsy, and the majority (63.6%) was under the age of 12 years. The mean age of PWDs at Gahini and Inkurunziza were 14.06 and 6.5 years respectively. Thus, the majority of the participants of the focus group at Inkurunziza were the caregivers of the PWDs (60%).

Table 2. Distribution of participants in the individual interview

Pseudonym	**Occupation**	**Gender**	**Experience in CBR**	**Location of CBR**
P. 12	Physiotherapist	Male	3 years	Gahini
P. 13	Assistant physiotherapist	Female	10 years	Gahini
P. 14	Head of CBR	Male	5 years	Gahini
P. 15	Social worker	Female	10 years	Inkurunziza
P. 16	Social worker	Female	5 years	Inkurunziza
P. 17	Head of CBR	Male	10 years	Inkurunziza

Three service providers were interviewed from both Inkurunziza and Gahini community based rehabilitation centres respectively. These service providers included physiotherapists, social workers, an assistant physiotherapist and the heads of the CBR programmes. Half of the services providers were females and another half were males the mean years of experience of all was 7.197 years.

4.3 Emerging themes for PWDs

The themes that emerged from the focus group were accessibility, awareness, support, and income generation. Within these themes, the respondents highlighted positive as well as negative experiences regarding Inkurunziza and Gahini CBR programmes.

4.3.1 Accessibility

The focus group discussions highlighted accessibility to the day centre and accessibility to rehabilitation service providers. The majority of the PWDs and their caregivers commented that the CBR programme made rehabilitation services more accessible to them. The close proximity of the programme were experienced in a positive light as illustrated by the following quotations:

… for me, I used to take my child to CHUK (Central University teaching Hospital in Kigali) for physiotherapy and I had to take 3 hours walking…… Now to reach here at the day centre it takes me 30 minutes walking…

Mother, 3-year-old PWD

…I am feeling impressed as the programme is now close to my house where I can plan my daily duties without so many inconveniences…

Mother, 5 year old PWD

….I appreciated the fact that the day centre is close to my home. Before, when it was the day of taking my child to the institution, my whole day was taken so that I could not do my business in order to feed my children…

Grandmother, 5 months

…. I thank the CBR programme for having organised home visits because in our area we face a big problem of transport where we can spend a whole week waiting for a taxi to drop us to the centre…

Mother, 5 years old PWD

Some participants from rural areas however felt that the distance to the programme was still experienced as a problem by them. The following quotations illustrate this.

…I was expecting that I will no longer do long distance.. … (Pause)….. you can see the problem persist…

PWD, 22 years

…I would suggest the programme being expanded so that it can become closer in our community…

Caregiver, 8 year old PWD

Easier accessibility to the day centre facilitated attendance **at** treatment sessions and improvement of rehabilitation, as outlined in the examples below.

… I used to go to collect orthopedic devices at the institution and now they can bring them here at the day centre…

PWD, 22 years

…we live in an area where we only get a taxi twice a week, and sometimes the arrival do not match with the date of day centre, this may lead to missing the treatment sessions due in inaccessibility…

Caregiver, 3-year-old PWD

*"….There is a social worker who came to see me at home and contributed to adapt **the** home environment*

which has facilitated the improvement of the condition of the child…

Caregiver, 3-year-old PWD

4.3.2 Awareness

Participants of the focus group expressed mixed feelings about their awareness of the CBR programme and the role of the community based rehabilitation worker. Some of the PWDs and/or caregivers were aware of CBR programme and their service offered as expressed below.

…by the help of one volunteer working for CBR, I came to know where to get rehabilitation services because I believed that my child would get treatment at the hospital only….

Grand mother, 5 months old PWD

Another respondent had to say this regarding the programme:

… Social workers visit our area only twice in two months and also when they come it is too late such that they seem to have less enough time to be with us because there is a long distance between the institution and the day center….”

Mother, 5 year old PWD

… to know where the day centre of the programme operates… I have been informed by some mothers who used to bring their children to the day centre…

Caregiver, 3 year old PWD

It was however highlighted that the CBR workers were often only seen at the day centre and seldom in the community. The following quotations illustrates this.

…for us we don’t have any social worker who visits us in the community. We only rely on the day centre, and for that reason we don’t expect too much on the improvement of the situation of our children...

Grandmother, 5 months old PWD

….nobody came to look for me at home and we only meet health professionals at the day center…

Caregiver, 8 year old PWD

…well… (Pause)…..I don’t have any idea of what you are talking about when asking me about social workers…

Caregiver,1.4 year old PWD

Although some participants were not clear on the role of the CBR workers, most caregivers perceived treatment provided by qualified professionals as a better option for their children. These sentiments are illustrated by the following quotes:

…. I don’t know what am I supposed to be doing as this is not my field?…. We should leave the work to those who are qualified to treat our children...

Caregiver, 3 year old PWD

… we have to work on our own to feed and take care of our children as the family ignore this child….. they give them bad names …

PWD, 15 year old.

… To me there is no difference between the service rendered by the CBR and the centre. I believe that the day centre which is part of CBR was organised so that we can exercise our children at the area close to our home…

Caregiver, 2.5 year old PWD

4.3.3 Support

Support or lack there of was expressed and highlighted from different sources. These included families, the community and the CBR programme itself. Participants expressed that they received support from their immediate family members as illustrated in the following quotations:

…. This is my child's daughter…. I decided to leave my home and live with them here in Kigali in order to allow them to find money to take care of their children including this one who is disabled…

Caregiver, 3 year old PWD

... I got support from my sister-in-law who paid all the bills during 3 months of my stay at the centre……. Without her help my child wouldn't have reached this stage…

Grandmother, 5 months old PWD

Contrary to the sentiments above, other participants felt that no help or support were forthcoming from their family members. Furthermore, alienation from family members were highlighted as illustrated by the following statements.

… I was abandoned by my husband saying that our family believed in witchcraft…... This the reason why I have this stupid child…

Caregiver, 1.4 year old PWD

... I lost hope from my immediate family… They think that this disability comes from my family… This pains me…

Caregiver, 8 year old PWD

Moreover, participants also expressed lack of support from the local community. The role of community was also questioned. The excerpts below elucidate this.

… Local people don't like to assist us and our children….. they say that they are not paid for that…

Caregiver, 2.5 year PWD

Some participants did not think that the community had any obligation to support PWD.

... I don't know exactly what they are supposed to do….. This is my child…. How can someone else take care of my child who is like this…

Caregiver, 1.4 year old PWD

… only few people can understand the situation of our disabled… (pause)…. something must be done…….may be they need to be informed……

PWD, 45 year old

There seem to be a general acceptance among the focus group participants that the CBR programme should provide support other than only rehabilitation.

… I am very poor…. I can not even feed my own children……….what would be the future of the rest who are normal…………..the programme should think what I can do…(reported angrily).

Caregiver, 2.5 year old PWD

… the best thing I'm waiting from the programme to do is to be connected to the community based health assurance scheme …otherwise we wont be able to pay the money required to get assistive devices…..”

Caregiver, 3 year old PWD

… when the "mutuelle de santé" (community health assurance scheme) started, I hoped that they were going to overcome charges relating to rehabilitation…..they never did it….

Mother, 5 year old

The majority of the respondents reported that the programme is not doing enough to meet their needs. PWDs/caregivers reported that CBR services are limited to rehabilitation only. This was expressed as follows:

…I am very poor….my need is not only treatment…. The programme should find some thing for me to do so that I can feed my child…

Caregiver, 3 year old

…. To me the programme is still inaccessible and limited to giving me assistive devices yet is not the only thing that I need…"

PWD, 22 year old

Many expressed a further concern regarding the lack of support in assistance to further education.

...I am not happy at all…. When I started coming here at the day centre, I had a hope that soon after recovering I will soon go back to school…..l but now it is 4 years already that I am still waiting for them to do something for me…

PWD, 12 year old

…. I am disappointed that the programme is doing nothing to assist our disabled children to go to school… (Anxious)…….. what will be their future if they don't study?…

Caregiver, 1.4 year old PWD

… The programme should think about vocational training for those who are late to catch up……… it is been a long time without going to school…

PWD, 45 year old

4.3.4 Income generation

A few of the participants indicated to have learned some activities to assist with income generation. This was illustrated by the following quotation:

... there is someone who came to teach us about how to make baskets and cards, but it takes time to reap benefits out of them yet we have to eat and feed our children ……(pause)….. I' d rather prefer not to attend any more to that session…

Caregiver, 2.5 year old

Most the participants however were ignorant about this. Some participants questioned whether this is part of the programme, as illustrated below.

… I have never heard about that…

Caregiver, 8 year old

… does the programme also include that?....I mean giving loans...

Mother, 5 year old PWD

... Nobody told us about that…….. I think it is a new information to me…

Caregiver, 3 year old PWD

4.3.5 Suggestions for improvement

Majority of respondents suggested that the programme should accept the "mutuelle de sante" for them to facilitate treatment, including services that can allow them to overcome their financial problems. They also suggested that the programme to be more close to their home. This was expressed as follow:

...it would be greatfull if the programme would assist us in the future to participate in the activities that can generate interest as most of us are very poor…

Caregiver, 3 year old

…when we joined this programme we thought that it receives people who uses mutuelle de sante….i would suggest that if the programme could talk the relevant administrationto include this insurance in order to facilitate us…

4.4 Emerging themes for Service Providers

The main themes that arose from the thematic analysis were accessibility of CBR to PWDs, empowerment of community, CBR approach/philosophy, CBR in practice and its implementation, lack of resources, and suggestions for improvement.

4.4.1 Accessibility to PWDs

Participants agreed that an increased number of PWDs have access to CBR programmes. The quotation below illustrate these sentiments.

... PWD accessing to CBR services have increased every year so that we could see the positive effort we have made…

Head of CBR, Inkurunziza

It was reported that PWDs accessing CBR services included individuals with different types of disabilities coming from all age categories.

…Currently, the programme includes all types of disabilities classified in different category of age. At the beginning, the programme was dedicated for disabled children only…

Head of Gahini CBR

…the programme helped to reach PWD where they live in the area and far from the institution because this was a very new system of working that was introduced ……..we are happy now that some members of the local community understand what we are to achieve.. .

Social worker, Inkurunziza

As far as accessibility is concerned again, service providers working at Inkurunziza are given monthly transport allowance to reach the day centre in the areas each one is assigned to take care of PWDs. Those working at Gahini organise visit to different day centres using the one available car, which is also used for other activities of the CBR. This was expressed as follow:

…for us to reach the people we are supposed to do visit in community or our respective day centre, each one of us is given transport money that has to cover the whole month irrespective the change of exchange rate …

Social worker at Inkururunziza.

… we have one landcruser (vehicle) which assist us to reach the day centres however the distance between the institution and where we find people is too long due to the area of coverage mainly geographical features…

Expressed the head of Gahini.

As expressed by service providers from both Inkurunziza and Gahini though PWDs appreciate service received from the programmes, there is disappointment regarding services offered by the CBR programmes and what PWDs expect from the programmes.

…some of the caregivers or parents expect the CBR to keep children for them and be treated at the institution so that they can cultivate freely… others need to be given wheel chairs or assistive devices for free yet the CBR programme is not in position of assuming these responsibilities…
Head of Gahini.

…. Majority of PWDs we meet are in rural area, inaccessible and are very poor. A part from being treated, they prefer being assisted financially as to facilitate in their daily life…
Social worker at Inkurunziza

Sometimes PWDs who come to these programmes seek for intervention that the two programmes do not offer.

…during my visit at the day centre as an assistant physiotherapist when a person comes to me and I realise that I do not qualify to assist him/her, I refer the case to the qualified physiotherapist when this one also can not assist he/she refers the person to specialised centre situated in Kigali/the capital city for further treatment…
Assistant physiotherapist at Gahini

….when we receive a case on the field that we are not in position of treating, we refer the case to the field physiotherapist and then this one refer it to the orthopaedic surgeon who works with the programme. I would remind you that we have a theater in our centre where we can carry out some operations. For the cases that are severe, the surgeon refers the patient to CHUK. (Nearest University hospital of Kigalil).
Head of Inkurunziza

The service providers also highlighted accessibility of services to PWDs as improved to people who normally would not have been able to access these services.

…Using the available resources, we are using the only car we have to identify and access to PWD living in areas where they can not get easily to the day centre or at the institution…

Head of Gahini CBR

…yes, I believe that it (CBR) has helped those who could not reach our services as we operate in areas where accessibility to service is a big problem since the transport issue is a problem…

Physiotherapist at Gahini

… the programme has also facilitated meeting the disabled people in areas close to their home commonly called day centres who otherwise could not come to the centre…

Assistant-physiotherapist at Gahini

Other factors that could possibly render the CBR services inaccessible were highlighted.

…it was very challenging to convince the community that they have to take part in the programmes in which they don't benefit out of it…..thank God that their level of understanding has improved…

Social worker, inkurunziza CBR

… Gahini CBR programme covers a large area where people are poor, lack of volunteers who are willing to work in the community. All these factors render our services inaccessible…

Assistant-physiotherapist at Gahini CBR

4.4.2 CBR approach/philosophy

Several participants were positive about the CBR approach and regarded this as a way to reach more PWDs in the community. These sentiments are expressed as follows.

…we have learned about a new approach on how to assist people who are suffering especially in their communities …

Social worker, Inkurunziza CBR

…Using the CBR philosophy, we are able to reach a good number of PWD and also discover more about the needs of these people which would not be possible to determine at the centre…

Assistant-physiotherapist, Gahini CBR

… I would say that CBR has increased awareness and cultural beliefs about disability where we are operating….…it has given us also the opportunity to use biopsychosocial model which is difficult to use in traditional treatment…

Head of Gahini CBR

The approach/philosophy of CBR was further viewed as a means to empower the community regarding issues of disability. The following excerpts elicited this.

…Through volunteers and social workers, the community has realised that they can play a role in helping PWD a part from health professionals…

Physiotherapist at Gahini

…there is this mother who after several visit in the community I managed to convince her to bring her daughter for consultation.…..now she is among the team of the mothers who are helping CBR to identify children with disabilities in their homes…

Social worker at Inkurunziza CBR

...CBR has helped to transfer the knowledge and skills to the community…….They (caregivers/parents) can handle themselves some minor cases…

Head of Gahini CBR

Another physiotherapist expressed that CBR can assist them also reduce the percentages of recurrence of the condition but also the CBR has given them an opportunity to remove the misconceptions about physiotherapy role.

…The community came to know that we can assist people with disability and the population in general that under social model, a physiotherapist can assist people to go to school, obtain health insurance scheme and loan...

Head of Inkurunziza

4.4.3 CBR in practice and its implementation

In addition to the positive experiences highlighted by participants, the head of the programmes questioned the authenticity of the CBR programmes in Rwanda. The lack of participation of the community was especially highlighted.

... recently we did an assessment of our activities to set up the future with our sponsors, we realised that this is not a CBR as intended to be………the community is not playing a role……"

Head of Inkurunziza CBR

One assistant physiotherapist revealed that the community was not consulted in any case. PWDs or their caregivers do not know their role apart from observing the date of appointment for treatment as the case is in traditional treatment.

.. according to the little knowledge I have basing on the training we had a few years ago……..this is not CBR…… may be part of it because the community is not immediately involved…

Assistant- physiotherapist at Gahini CBR

" ……I had different opportunities to learn better how other CBR programme which are operating in Africa, and I can say that we are more likely to do institution based….."

Head of Inkurunziza CBR

Different health professionals working with both CBR programmes indicated that there were discrepancies between the services provided by CBR programme in Rwanda and a authentic CBR programme. This was expressed as follows:

… I can say that what we are doing is not the real CBR as it is supposed to be done…

Head of Gahini

Despite the concerns raised above, some participants were of the opinion that certain expectations of the CBR approach was met as illustrated in the following excerpt.

…we assist PWD in changing home environment so that it can be adapted to their disabled situation but also we help them to come out of the situation brought by the disability…..

Social worker, Inkurunziza

4.4.4 Empowerment of community

Participants agreed that their roles were beyond that of addressing the needs of PWDs. Furthermore, they were of opinion that they empower the community in various ways. These sentiments are illustrated the following quotes.

…During our visit to the day centre, we normally train the available volunteers on how to identify PWD in their community. We also transfer skills to the immediate family by showing them some exercises to do for their children at home rather than coming to the centre…

Social worker, Inkurunziza CBR

Still at this stage, an assistant physiotherapist reported this:

… Through the CBR programme at Gahini we assisted a paraplegic patient who after being rehabilitated, the programme assisted to buy a sewing machine. Now as a tailor, he can help his family and the level of independence has increased…

Assistant physiotherapist, Gahini CBR

…During my visit in the community, I came to discover a blind person who has been abandoned by his family. I trained him to use the walking stick for the bind and by the help of CBR managers the programme managed supported him to grow his small project of keeping goat. Now as a 'goat herder', the family realised that he can do something they now give him some respect. This has shown that PWD can do something when given attention...

Social worker, Inkurunziza CBR

4.4.5 Lack of the resources

In both CBR locations, participants reported having large numbers in need of their services though they had limited personnel in the programme to assist in the community. These problems and other challenges have been illustrated in the statement below:

… we don't have enough personnel to assist our programme but also those who are working with us are not training to reach our objectives…

Head of Inkurunziza CBR

..every time we go in the community and at the day centre they always bring the issue of poverty……..how our programme is going to assist my child to get something to eat?(said one caregiver)…
Assistant-physiotherapist at Gahini CBR

… we are facing a big challenge of community ownership of the programme as the community does not yet understand that they are the ones to be involved first…
Head of Gahini CBR

The failure to deliver the needed service relates also to the complexity of CBR that requires a multidisciplinary approach.

…. Our clients need services that fall under social model that requires different resources and a multidisciplinary approach which is yet difficulty to put in place because it is not the priority of the donors…
Social worker at Inkurunziza CBR

Another problem noted by participants is failure of the health system in Rwanda to include CBR programme in its activities hence leading to malfunctioning and implementation of the programme.

…. if Minisante (the Ministry of Health) could have included CBR programmes in its activities and programme we would not have met such problems….
Physiotherapist at Gahini CBR

…..in our visit, we discovered many people who have been left home, when asked why they told us that disability is treated by witches……..there is no sense of taking somebody who can not take care of you when you are old..

Social worker at Inkurunziza CBR

4.4.6 Suggestions for improvement

Most of the respondents suggested that PWDs and the community in general should be involved in the CBR activities thereby assisting its the sustainability.

…There is no hope for the future of this programme if at all the role of the community and PWD themselves is not emphasised on…

Physiotherapist at Gahini CBR

The CBR managers emphasised that for the programme to reach its intended objectives, a national policy should be in place, guiding all CBR programmes.

…we need to see the CBR programme is planned at national level to facilitate our activities………you know that most problems faced by PWD are socially based therefore there should be a well coordinated governmental basis…

Head of Inkurunziza CBR

In addition to the above, participants suggested that the national law relating to disabled people and the national plan for rehabilitation should be reconsidered.

…. most of the times, the social model is ignored because it requires a national framework and multisectoral collaboration among different institution. This can be reached in case where there is a national plan for rehabilitation facilitated by the national law relating to PWD…

Head of Gahini CBR

Furthermore, the majority of CBR workers were concerned about CBR itself as a programme. Participants suggested that the CBR programme be revised so that it can be conducted in the way an ideal CBR programme is supposed to.

….what we are doing currently is not a real CBR…(pause)…….may be outreach…..This is why I would suggest the programme to be revisited in order to deliver the service in the community…

Head of Inkurunziza CBR.

4.5 Summary of chapter four

The results have highlighted negative and positive experiences encountered by PWDs and during service delivery in two CBR programmes in Rwanda. Service providers acknowledged that the programme has increased the number of PWDs accessing CBR services and have been able to address some of their needs. PWDs attending CBR day centres of both CBR programmes appreciated that they could access rehabilitation services at the day centre. Most of the concerns highlighted by both groups were related to the lack of community participation and poverty. The next chapter will present a discussion of these findings.

CHAPTER FIVE

DISCUSSION

5.1 Introduction

In this chapter, the results in relation to the research questions as well as the aim and objectives of the study will be discussed. The findings will be compared with the findings of other studies. The aim of the study was to describe the experiences of PWDs and service providers with regard to community-based rehabilitation programmes in Rwanda. This chapter follows a thematic approach rather than presenting a discussion of the individual study objectives.

The present study involved service providers and PWDs as participants in both CBR programmes in order to obtain a clear picture of the programme. People with physical disabilities, and who were able to speak, were recruited, whereas caregivers spoke on behalf of children with severe disabilities. Physiotherapists, social workers and assistant physiotherapists were the health therapists who also participated in the current study. In other similar studies done in Guyana and Nepal on experiences about CBR programmers, both PWDs and service providers were involved (WHO & SHIA, 2004). Miles (2003) has observed that most of the studies that have been conducted to try to understand the effectiveness of the programmes rendered to PWDs do not describe the activities and services provided to PWDs nor the experiences from the perspective of PWDs, their families, CBR personnel and health-care professionals regarding CBR. The researcher intended to include physiotherapists, occupational therapists, volunteers, managers of the programme and CBR workers, but unfortunately, this was not possible as the CBR programmes in Rwanda only employ social workers and assistant physiotherapists to provide services. People with disabilities that are representative of all types of disability were also not included in the present study because of the structure of the programme and the way it is implemented. This is contrary to the view of WHO (2000) and to reports from other similar studies done in Thailand and Vietnam, where people with different disabilities were included, namely, people with moving difficulties, hearing difficulties, seeing difficulties, and learning difficulties, when evaluating CBR programmes. However, when it comes to CBR in Rwanda, it is not clear how this programme is designed and implemented. Cheausuwantavee (2007) maintained that there is no universal CBR programme because of socio-economic and cultural differences that exist.

5.2 Experiences of PWDs

Themes that emerged concerned accessibility to the day centre and to the rehabilitation service providers. There were positive and negative reports from PWDs regarding this theme.

5.2.1 Accessibility

Accessibility to rehabilitation services is a challenge in developing countries, including Rwanda. The WHO (1981) highlighted that one of the issues behind the CBR approach is the attempt to shift from “everything for a few” to “something for everyone”. This would facilitate accessibility of CBR services. Participants in the present study viewed accessibility of the two CBR programme in Rwanda both positively and negatively. They indicated that the day centers have increased access to rehabilitation services since their introduction in the communities. A further benefit of these day centres was that they minimised the long distances that participants had to travel to the hospitals and rehabilitation centers to receive rehabilitation and assistive devices. These findings are similar to those reported by Hai and Chuong (1999) in a study to investigate a CBR programme in Vietnam. According to Hai and Chuong (1999), the programme assisted children in Vietnam to access rehabilitation and orthotic devices.

However, some of the participants reported that the number of day centres is still limited, which contributes to some of them not accessing the services easily. Furthermore, participants reported that even though day centres are closer to their respective communities, some of the day centres are still difficult to reach. People often have to walk for more than three hours to reach the day centre. Currently, there are only 12 day centres at Inkurunziza and 10 at Gahini available to assist more than two million of the Rwandan population, 10 % of whom present with different types of disabilities. These day centres are also scattered in areas difficult to reach with regular transport. The accessibility of health facilities is still a problem in Rwanda even if the government of the country is putting effort into making them more accessible. All of these aspects highlight the limited resources available in Rwanda. Youzafzi and Edouards (2004) indicated that developing countries cannot make services available due to limited resources. Several other factors are responsible for the inability of PWDs to access rehabilitation services. According to the United Nations (2002), these factors are geographical features or physical and social barriers that make it impossible for many people to take advantage of the rehabilitation services available. Currently, Rwanda does not have a clear set of activities and policies to provide services to all PWDs. The initiative of providing services to PWDs is mainly run by international NGOs, organisations run by PWDs and Rotary Club International.

The United Nations Development Programme in Rwanda reported that disabled persons are classified among the poorest. This hinders them in gaining access to rehabilitation services (Thomas, 2005). Participants in the present study cited geographical features, lack of transport and generalised poverty as barriers to accessing rehabilitation services. This corresponds with the findings of a study done by Kent, Chandler and Barnes (2000), where participants consistently cited a lack of transport as a barrier to accessing services and to participation in community life.

WHO (2001) reported that the basic or immediate needs of PWDs can be addressed if health professionals are available for primary intervention. Mannan and Turnbull (2007) emphasised that in a community where professional services are not accessible, CBR workers should be trained to provide primary rehabilitation services. The CBR approach thus facilitates the accessibility of rehabilitation professionals to PWDs in their respective communities. This was highlighted by the findings of the present study, in which participants reported that the availability of social workers has helped them to adapt their home environment. However, many of the participants had never had contact with social workers. In Rwanda, a generalised lack of personnel such as social workers may lead to the lack of the services available to PWDs. On the other hand, ignorance on the part of the community regarding availability of services could also play a role. Most of the

Rwandan people are of the opinion that medical personnel should be seen at the hospitals and not in the community. There is thus a real need to increase the number of health professionals to assist PWDs with a variety of activities and services, thereby sustaining the various CBR programmes

5.2.2 Awareness of CBR programmes

One principle of CBR programmes centres around community participation that involves the readiness of the community to take up ownership of and recognise the risks of the programme (ILO, UNESCO & WHO 2004). According to Boyce and Lysack (2001), community participation in CBR (or of their family members or friends), in conjunction with other relevant sectors, helps to increase their ability to influence social conditions. Generally, the lack of awareness regarding the role of health professionals and their involvement in the activities of CBR was a concern raised by the PWDs in the present study.

The PWDs in the present study did not have information on what exactly the role of social workers was. These results differed from the findings of Chidyasiku et al. (1998), in which PWDs/caregivers indicated clearly that the role of the social workers was to identify and refer PWDs, to organise home visits and follow up, to give treatment and advice, and to provide education and raise awareness. It is well known that CBR is a community-oriented strategy to care for PWDs. To accomplish this objective involves an awareness of the community regarding disability, value of disability prevention, and rehabilitation methods. In order to base the rehabilitation in the community, it is important to inspire the community and recruit volunteers for this task, even though it is not an easy process.

The members of the community should be aware that they have to facilitate programmes whereby PWDs will be able to enjoy their rights in society as their peers do. CBR should be committed to activating the community to promote and protect the rights of PWDs through social and structural change within the community by removing barriers to participation. According to Stubbs (2002), placing CBR in the human rights framework can be powerful in giving it a solid foundation and a clear set of goals. In accordance with the UN Convention (1994) on the Rights of Disabled Persons, of which Rwanda is a signatory member, CBR, with its clear human rights framework, would create a strategy to address the comprehensive rights of disabled people, working alongside other useful strategies. The provision of therapy, aids and equipment could be part of this but with the aim of promoting full human rights. These results would thus suggest that there is a need to increase awareness among the community in general as to what the CBR programme/approach involves. This would further facilitate sustainability of programmes, with communities possibly taking ownership of programmes.

The implication of the current research results demonstrate that there is a need to explain what CBR is to the community and the PWDs. According to Asindua (1995), some people in Africa still think that CBR is an out-reach or extension service, with the objective of bringing professional rehabilitation service to a large number of PWDs, particularly in rural areas, and to refer those people in need of more sophisticated services to institutions outside the community. Asindua went on to say that in this model, regular and programmed visits are made to the community by a multisectoral team, but the involvement of the community is often restricted to their participation in the out-reach activities (clinics).

5.2.3 Support for PWDs

The WHO (2004) suggested that for CBR to be effective, it should promote collaboration between PWDs and their families. The WHO further stipulated that the community should be a ready source of support in CBR (WHO, 2002). In the present study, however, PWDs/caregivers reported minimal support from their immediate families. Only one participant reported giving support to her daughter by taking care of her grandchild while the mother works. These findings differ from those of Taanila, Jarvelin & Kokkonen (1999), who found 75 % of their participants valued social support from friends and family. Connor and Adams (2003) also stated that, despite the burden in terms of physical, financial and emotional demands of PWDs, many members of family are willing to offer support. Problems stemming from stress and a perception of being a burden have been quoted as being the major reasons for the lack of support to PWDs (Kalana & Young, 1990).

One of the principles of CBR is the support of community for PWDs. In the study done in Botswana by Kilonzo (2004), results have shown that compliance of the caregivers has been facilitated by constant support received from immediate family and the local communities in that area. This is in contrast to the responses given in the present study, where participants reported a lack of support received from their families, the community and the CBR programme. Participants emphasized that they were not sure of the role of the community. However, this concurs with the study done in Zimbabwe by Chiadyasiku et al, (1998), where the majority of PWDs/caregivers reported that they had no role to play or did not contribute to the CBR programmes. Some of them perceived their role as that of recipients. This is of real concern as Tunga (1999) stressed and Sangsorn (1998) reported, in studies in India and Thailand respectively, that community involvement has increased the quality of life of all PWDs.

The UN (1998) claimed that the complexity of the CBR approach is the result of the current concept that it should be multisectoral and should provide assistance in all areas that are central to the quality of life of PWDs. Furthermore, for a CBR programme to succeed as a strategy to improve the life condition of PWDs, it has to go beyond the medical model to meet the needs of PWDs. The participants of the present study, however, indicated that they received support from the programme related to rehabilitation but not to their social needs. They further reported that much of the support expected from the programme was related to the health insurance scheme, returning to school and advocacy. Another major area of support needed was related to poverty as most of them are classified amongst the poorest, as confirmed by Thomas (2005). However, relief of poverty requires more resources and a multidisciplinary approach.

The support provided to PWDs should facilitate access to basic human rights. According to a UN (1994) report, the rights-based approach to disability is aimed at empowering

PWDs, to ensure their active participation in political, economic, social and cultural life situations.

Therefore, the managers and all people involved in the CBR management should seek to promote awareness amongst the community about disability. There is also a need to advocate for a multisectoral approach in CBR programmes. These programmes should go beyond the traditional treatment, which focuses on the medical model only.

5.2.4 Income generation

CBR is aimed at making PWDs economically self-sufficient. A limited number of participants spoke about how the programme trained them to generate some income. Rwanda shares this problem with other countries. In a study conducted in a CBR project in Nyanga and Mitchell's Plain, Cape Town, South Africa, only one participant reported having been involved in income-generating activities (Hess, 2003). This is contrary to studies done in Uganda, where findings have shown that different initiatives in agriculture have allowed PWDs to generate income (Kangere, 2003). Such initiatives would assist PWDs to alleviate poverty as most of them live in critical conditions. Other studies (Hutcherson, 1991; Thomas, 2005) have shown a correlation between poverty, education level, poor nutrition, gender and the prevalence of disability. Poverty and lack of access to basic services due to lack of income is one of the major phenomena interfering with the human rights of PWDs. Therefore, implementation of income-generating activities can assist in improving the quality of life of PWDs.

5.3 Experiences of service providers

This study included both PWDs and service providers. During this section, experience of service providers was expressed in terms of accessibility to PWDs, empowerment of community, CBR approach and its implementation and Lack of resources.

5.3.1 Accessibility to PWDs

The service providers participating in the present study perceived that the CBR programmes increased accessibility of rehabilitation services as a result of CBR programmes. The provision of services has, however, changed to detection of cataracts, providing epileptic medication, and repairing orthotic devices. This finding is similar to that of studies done in India and Thailand that pointed out the positive aspects of CBR (Sasad, 1998). Sased stated that CBR promotes and improves provision of services for PWDs who would not have had access to institutions because of cost constraints, transportation problems and limited availability of professionals and services for PWDs. Penchansky and Thomas (1981) stated that affordability of a service can constitute a barrier to accessing the CBR services.

5.3.2 Empowerment of community

One of the principles of the CBR approach is the transfer of knowledge and skills regarding disability and rehabilitation (WHO, 1994). According to Finkenfuel et al (1996), transferring skills is one of the major strategies CBR uses to empower PWDs to become more active in the programme. One of the advantages highlighted in the present study was that through CBR, service providers managed to transfer skills to parents and caregivers to enable PWDs to continue with rehabilitation at home. This also concurs with results of the study done in Botswana, in which the CBR programme has been reported to empower PWDs to play a role in the improvement of the children's lives (Kilonzo, 2004). Some of the service providers in the present study, however, felt that they were not providing appropriate support as the services that they were providing were medically based.

CBR workers and health-care professionals should become enablers and facilitators facilitating effective community participation by PWDs and the community, to establish what their needs and aspirations are and to support PWDs to achieve their aims. In terms of CBR, PWDs, the local community and CBR professionals would interact with each other. Through this interaction, the potential of PWDs becomes more fully recoginised by themselves and their community. Thereby, PWDs are enabled to empower themselves, secure human rights and make the decisions that affect their lives directly. In a project conducted in Southern Africa, the researchers found that when disabled adults and parents have been centrally involved in design and development of CBR, the programme priorities have shifted from medical rehabilitation to education, employment and poverty reduction (Miles, 1996). Thereby, CBR programmes have become more consumer-focused and disability has become recognised as a development issue, not a medical or technical individual problem.

5.3.3 CBR approach and its implementation

A CBR programme, as suggested by WHO (2002), should operate in the community to reach its objectives of equalising opportunities and social integration. It has been remarked, however, that CBR varies from country to country due to the socio-economic and cultural context of those countries. With an outreach approach, more people can be reached, but there will be limits according to distance from institution, and according to whether the needs of the disabled people are similar to what the institution offers (Stubbs, 2002). These types of services are usually limited, in that they lack community involvement, education, and vocational training, which results in limited social change (WHO, 1994). The clients and the community are only the beneficiaries.

From the findings of the present study, it became clear that most of the service providers had little knowledge about what the CBR approach entails. Others were of opinion that what is being done in Rwanda is not CBR. The majority of the activities and services provided through both CBR programmes are through outreach by health professionals from either Gahini or Inkurunziza. PWDs and caregivers that were of opinion that the services they received at the day centre are a continuation of the service received from the institution confirmed this.

In a study done by Meyer and Moagi (2000) in the North West Province, South Africa, findings have shown that most of the needs of PWDs were education and skills training to assist in handling and training their children. Support groups to share problems, income-generating activities, and resources for the day centre, such as transport, were also needed. Many of the service providers in the present study reported that the CBR services do not match the expectations of their clients. PWDs/caregivers have highlighted their needs for income-generating activities, keeping their children in the centres, facilitating their children’s return to school or accessing vocational training.

Participants were of the opinion that the “failure” of the CBR implementation is due to the lack of knowledge amongst service providers about CBR and also due to the fact that donors impose restrictions that require them to focus mainly on the medical model. Warner (1998) has also stated that a weakness of CBR is that it is focused on impairments, therefore leading to less attention being paid to aspects of equalisation and opportunities for social integration. According to Hartley (2001), it is not generally recognised that CBR activities are holistic in nature and should include all or some activities such as awareness raising, parents’ and carers’ income generation, rehabilitation referral, and networking for education, employment and health services. Lorenzo (2001) suggested that the identification and removal of barriers to the social integration and economic independence of PWDs have a positive influence on their families, as well as on the community in which they live.

When looking at responses given by both service providers and PWDs, one problem is a lack of information on the role of CBR. One would expect CBR programmes to be focusing on human rights and empowering PWDs so that they can actively participate in the activities of daily living. The current CBR programmes operating in Rwanda do not offer these services, which may be a limitation to provision of services. In most of the CBR programmes operating in Africa, there is a tendency to deliver services only to PWDs. In contrast, PWDs and their family members and the community should be working together so that they can find solutions themselves rather than expecting people from outside to decide on their behalf. In CBR programmes, the disabled person, the family, the community and the health professionals collaborate to provide services in non-institutionalised settings, where services for PWDs are limited or totally absent. In the case of both CBR programmes in Rwanda, some elements of this partnership can be found, but in general, such a partnership has to be established because when looking at the way services are being offered, researchers find that service providers mainly come from institutions to meet PWDs in their day centres close to their community. As stated by Vanneste (2001), the failure of the implementation of CBR programmes in Africa is due to the fact that governments have other priorities, related to poverty, rather than focusing on PWDs. Furthermore, the complexity of the programme itself makes implementation difficult as it requires many more resources. It is in this regard that CBR should be done in a socio-cultural context so that each country, and its people, may feel that it is the owner of the programme, hence facilitating its implementation. In Rwanda, government do have socio-political-economical values that facilitate this through the decentralisation programme and community-based workers that normally serve to increase awareness of the community about fighting malaria.

From responses given by PWDs and service providers, it is clear that the two CBR programmes are still using the top-down approach. If the two programmes in Rwanda continue in the present way, they will continually deliver services that are not meeting the needs of the recipients. There is thus a need to think about how to design a CBR programme which meets the socio-economic and cultural context of the Rwandan society.

5.3.4 Lack of resources

The WHO and SHIA (2002) reported that barriers to rehabilitation and support services are mainly due to the limited skills of the CBR community workers. According to Asindua (1995), inadequate training of personnel in CBR provides the biggest challenge in providing family/community-oriented services. The service providers in the present study reported that a lack of volunteers working closely with the community is a challenge. Furthermore, even those who are working as part of the CBR programme have limited knowledge about the programme. This was one of the reasons why the programmes recruited social workers and assistant physiotherapists to assist PWDs at the day centres. Concerns have also been voiced about transport to access the community and lack of personnel working in the CBR programme, such as occupational therapists and speech therapists. There is a need, therefore, to recruit and educate personnel to provide CBR services at community level.

5.4 Summary of chapter

The discussion dealt with the major findings of the present study. The findings have shown that some areas of CBR are useful. These include accessibility to rehabilitation and services that are more affordable to people with disabilities. The conclusion and summary, the limitations, and the recommendations of the study are presented in the next chapter.

CHAPTER SIX

SUMMARY, CONCLUSION, LIMITATIONS OF THE STUDY, AND RECOMMENDATIONS

6.1 Introduction

In this chapter, a concise summary of the study is provided. Details of the major issues in the study are given in the conclusion, and thereafter, some recommendations are proposed based on the results.

6.2 Summary

This study was aimed at describing the experience of PWDs and service providers of the CBR programmes in Rwanda. Data from this study were collected by means of focus-group discussions with PWDs and in-depth interviews with service providers. The thematic analysis of the transcripts of the focus groups and in-depth interviews yielded different themes for PWDs and the service providers. The themes that emerged from the focus-group discussions with PWDs included accessibility, awareness of CBR programmes, support and income generation and suggestions for improvement. Those that arose from the service providers were the accessibility of CBRs to PWDs, training, CBR approach/philosophy, CBR in practice and its implementation, empowerment of community, lack of resources, and suggestions for improvement. Within these themes, the respondents described positive as well as negative experiences regarding the Inkurunziza and Gahini CBR programmes. PWDs were positive about availability of rehabilitation services. Mixed feelings regarding PWDs' awareness of the CBR programme were raised. The roles played by the families of the PWDs were also highlighted. CBR programmes operating in Rwanda have facilitated service delivery to PWDs, reaching an increased number of PWDs in need of their services. However, findings from the present study indicated that community participation was not emphasised enough in the CBR programmes. Furthermore, challenges such as the continued difficulty in reaching distant rural areas were highlighted. Sustainability of these CBR programmes is thus questioned.

This study has also revealed that these programmes are delivering services that do not necessarily match the needs of the consumers. The needs were identified as more income generation, access to vocational training, and education. Service providers cite a lack of enough personnel and a lack of involvement of community in owning the programme.

6.3 Conclusions

The results of the present study indicate that the CBR programme addresses some of the needs of PWDs, which includes provision of assistive devices. The programme is, however, failing to help the PWDs with activities for income generation or with facilitating accessibility of schools and vocational training facilities.

6.4 Limitations of the study

This study was a qualitative study, with a sample of PWDs and service providers, from two CBR programmes, who took part in the focus-group discussions and in-depth interviews. Therefore, the findings of this study cannot be generalised to all PWDs or service providers in CBR programmes in developing countries or even in Rwanda, where this study was done.

6.5 Recommendations

Based on the findings of this study, the researcher recommends the following:

1. That the Ministry of Health in Rwanda accelerates the development of policies relating to PWDs. Furthermore, that the development of a national CBR programme to expand CBR activities in the country is encouraged.
2. That the CBM and CBR managers revise the objectives of the programmes. This will enable programmes to meet the needs of PWDs, facilitate community participation, promote multisectoral collaboration and increase awareness regarding disability.
3. That service providers acquire more skills and information regarding the CBR approach.
4. That the communities and PWDs be made aware of community ownership of these programmes.

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APPENDICES