CONSUMERS' NEEDS AND PERCEPTIONS OF A COMMUNITY-BASED REHABILITATION PROJECT

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ABSTRACT

This minithesis is a qualitative research study of the needs and perceptions of some consumers of the University of the Western Cape (UWC) Community-based Rehabilitation (CBR) Project, which serves two low socio-economic areas of the Western Cape, South Africa. The aim of the study was to gain an understanding of the needs of people with disabilities and to explore their perceptions of services provided by the Project. Qualitative data collection methods was used and included document reviews, participant observation, semi- structured interviews with eight consumers of the Project services, and focus group discussions with the same sample of participants.

While it was found that the Project has been successful in addressing some of the needs of its consumers, the need for the Project to give wider recognition to the social model of disability in service provision was highlighted. Key findings of the study revealed the deprivation that people with disabilities experience due to physical, social and economic barriers to equal participation in society. The most marked concerns of participants were related to attitudinal barriers caused by a lack of understanding of disability in the broader community.

One of the limitations of the study is the lack of investigation of staff perceptions on the service and issues of disability. This would have contributed to understanding the relationship between consumer needs and their perceptions on the strengths and weaknesses of the programme. It is recommended that a process of increasing consumer participation, and capacity building of staff and consumers be embarked upon to strengthen the programme in the future.

ABBREVIATIONS

ADL	Activities of Daily Living
CASE	Community Agency for Social Enquiry
CAHD	Community Approaches to Handicap in Development
CBO	Community-based Organization
CBR	Community-based Rehabilitation
CDCF	Crossroads Disabled Consumer Forum
CRW	Community-based Rehabilitation Worker
DPO	Disabled Peoples' Organization
ILO	International Labour Organization
INDS	Integrated National Disability Strategy
MP	Mitchell's Plain
MPAM	Mitchell's Plain Ability Movement
NGO	Non-governmental Organization
NY	Nyanga
OT	Occupational Therapy
PAWC	Provincial Administration of the Western Cape
PHC	Primary Health Care
UNESCO	United Nations Educational, Scientific and Cultural Organization
UWC	University of the Western Cape
WHO	World Health Organization

CONTENTS

CHAPTER 1

INTRODUCTION

It is estimated that at least 7% of the world's population suffer from various types of disabilities. Of this population, two thirds are residing in developing countries (WHO, 1995). According to the 1996 Census, the prevalence rate for disability in South Africa is 6.6% (Statistics South Africa, 1998). Despite a high prevalence of disability, most people with disabilities in developing countries, if they received any services at all, have experienced only a medical model of rehabilitation which treat them as passive recipients of rehabilitation services.

The World Health Organization (WHO) promoted Community-based Rehabilitation (CBR) in an attempt to de-institutionalise rehabilitation and as an approach for providing services to people with disabilities, particularly in developing countries (WHO, 1994). CBR promotes awareness and responsibility for rehabilitation in the community. There is an expectation that the community and people with disabilities themselves should be actively involved in the planning and evaluation of CBR programmes. In outlining guidelines for the monitoring of CBR programmes WHO (1996) stresses that it is important to explore if people with disabilities feel that their needs are met when rehabilitation programmes are evaluated.

Rehabilitation services in South Africa are in a process of transformation (Office of the Deputy President, 1997, Department of Health, 2000). This involves an increasing willingness on the part of service providers to engage in partnerships with people with disabilities in the planning and delivery of services.

The need for increased consumer involvement in rehabilitation services is emphasized in the literature. Social change, legislative initiatives, growing empowerment among consumer groups and changes in service intervention strategies have increased awareness and demands of persons who utilize rehabilitation services. With regards to obtaining consumer opinion, researchers such as Hawkins (1991) have stressed that the needs of persons seeking services are individualized. Consequently, their expectations and perceptions of services will likely influence their opinions regarding the success or failure of services that they receive.

The University of the Western Cape (UWC) CBR Project was initiated by the Occupational Therapy (OT) Department in 1986. It offers rehabilitation services to the communities of Mitchell's Plain and Nyanga. The Provincial Administration of the Western Cape (PAWC) is currently the only funder, as funding from the Christoffel Blindenmission (CBM) ceased at the end of 2002. The implications of the budget – cut for the Project included the termination of some services for example, the activity groups. The staff includes two occupational therapists and eight Community-based Rehabilitation Workers (CRWs). An advisory board, which meets on an ad hoc basis, comprises of a representative from PAWC, the dean of UWC's Faculty of Community and Health Sciences and the chairperson of the UWC OT Department. A co-ordinating committee comprising the two occupational therapists and two CRWs, is responsible for the efficient operation and administration of the Project.

The aims and objectives of the Project ***(appendix 1)*** include among others, the following:

- Providing home-based rehabilitation services to promote an improved quality of life.
- Providing cost effective assistive devices to improve independence in activities of daily living.
- Facilitating Day Care Centres to develop a resource that is appropriate and accessible to the community.
- Facilitating social and support groups to promote community involvement and encourage support amongst members.
- Facilitating employment to provide opportunities for income generation and skills acquisition.
- Providing community courses, workshops and health promotion groups to facilitate the healthy development of communities.
- Encouragement of social integration and the equalization of opportunities of people with disabilities.
- Ensuring appropriate training and practice for students within community work.

Through the years, the Project has evolved from providing and training students in individualized OT services in clients' homes, into an inter-disciplinary CBR service. It caters for people of all ages who present with various impairments. Services provided include home visits and social, health promotion, and income generation groups. The Project regularly undertakes a number of community projects that include disability awareness workshops for community members. Networking is done with a number of health services, government departments, non- governmental organizations

(NGOs) and community-based organizations (CBOs) for the purpose of strengthening partnerships in addressing disability issues in Mitchell's Plain and Nyanga.

In the past two years, the Project has taken a more holistic view of people with disabilities. This was in response to the White Paper on an Integrated National Disability Strategy (INDS) of South Africa that acknowledges the social model as an approach to disability (Office of the Deputy President, 1997). The Project is currently assisting with the formation of Disabled People's Organizations (DPOs), namely the Crossroads Disabled Consumer Forum (CDCF) and the Mitchell's Plain Ability Movement (MPAM).

Evaluation, as in the case with the Project, has not been given much emphasis in CBR and people with disabilities have often been ignored in issues that affect their lives. There was a need to determine how effective the Project was in meeting consumers' needs. It was envisaged that the identification of its strengths and weaknesses would inform the facilitation of improvements of the programme. As no evaluation of the Project has been conducted before, the need arose to gain an indication of the effectiveness of the programme in addressing consumers' needs. The Project had a need to gain a better understanding of matters that are important to their consumers and to involve them in the monitoring of a service that is designed to serve them.

The purpose of the study was to document the needs of some people with disabilities and to gain an understanding of their perceptions of services provided by the UWC CBR Project. By aligning consumers' needs and perceptions with the Project's objectives and literature regarding CBR programmes, it was envisaged that the study could be used to inform the development of the Project in the future. Results and recommendations from the study will be utilized by the Project to assist in the planning of services and as a motivator for funding. As the study is intended as a partial evaluation of the CBR programme, it could be regarded as a pilot study for a more formal evaluation of the Project in the future. The results will also contribute to the development of CBR within a district health system in South Africa.

CHAPTER 2

LITERATURE REVIEW

This review provides an overview of the models of disability, the current prevalence of disability in the Western Cape, and approaches to CBR. Studies that investigated the needs and perceptions of people with disabilities are highlighted. The review further explores the concept of CBR and investigates the evaluation of CBR programmes. Finally, approaches to programme evaluation, including qualitative research, will be highlighted.

2.1 Models of disability

There are two distinct models of understanding disability namely the social and medical models. The social model of disability has its origins in the 1970's when people with disabilities started to use their experiences to show that disability was rooted in society's failure to make allowances for their bio-medical differences. This indicates a move towards an understanding of disability that is situated in a wider social context. Disability is understood as a social and developmental issue rather than a medical one. The social model makes the important distinction between impairment and disability. Impairment refers to an individual's biological condition, while disability denotes the collective economic, political, cultural and social disadvantages encountered by people with impairments (Coleridge, 1993). The social model moves beyond the personal limitations that impaired individuals may face, to social restrictions imposed by an unthinking society (Oliver, 1998).

The medical model of disability defines disability in terms of bio – medical characteristics. According to Oliver (1998), this model views people with disabilities as helpless individuals in need of care and welfare. The problem with rehabilitation based on the medical model is that it focuses on the individual's impairment, without relating to the overall social and environmental context.

Hartley (2001) argues that the solution to the tension between the medical and social model is in the form of a universal or comprehensive model of rehabilitation. She asserts that this tension is necessary for the development of rehabilitation and that it needs to be harnessed constructively. The literature proposes a need for health professionals to give wider recognition to the social model in service provision and research. Bricher (2000) states that health professionals have played a significant role in the marginalization of people with disabilities while Kitchin (2000) argues that research that uses the medical model as an approach, presents the researcher as the expert on disability issues. He reasons that this implies that the knowledge and experience of people with disabilities do not count. Coleridge (1993) suggests that what people with disabilities want is to join with professionals in formulating policy on rehabilitation, and then to work with them to implement it. In agreement with Coleridge (1993), Kendall et al. (2000) suggest that professionals should change their attitudes. They argue that there is a need for them to develop a new professionalism which involves a change in their reductionist, imposed approaches to rehabilitation.

2.2 Disability prevalence in the Western Cape

Historically, there has been a lack of reliable information on the nature and prevalence of disability in South Africa. Available statistics need to be treated with caution, as differences in definitions of disability used in surveys mean that results cannot be compared. The 1996 Census reported a disability prevalence rate of 3.7% for the Western Cape (Statistics South Africa, 1998), while the Community Agency for Social Enquiry (CASE) reported a prevalence rate of 3.8% (CASE, 1999). The Census further indicates that the Cape Town Magisterial district that includes the Nyanga area, had a disability prevalence rate of 3.9 %, while that of the Mitchell's Plain magisterial district was 5.7%. For both districts disability prevalence was higher than the average rate (3.7%) of the Western Cape Province.

The disability prevalence data for the Western Cape may be an indication that the prevalence of disability in low socio-economic areas, such as Mitchell's Plain and Nyanga, is higher than in other areas and thus highlights the need for rehabilitation services in these communities.

2.3 Understanding the needs of people with disabilities

Over the past decade there has been an emphasis on viewing persons seeking rehabilitation services as involved consumers who have a say in the rehabilitation process. Danek et al. (1991) report that studies, which involve consumers in research, are important for forging an improved provider-consumer alliance in all areas of rehabilitation service delivery. They found that when rehabilitation consumers' and their counsellors' opinions were compared regarding what were important counsellor characteristics, perceptual differences emerged. For instance, counsellors reported valuing behaviours that were more task-oriented while consumers believed it more important that counsellors be understanding of their individual needs.

The results of a survey conducted by Marshall et al. (1992) to determine the needs of urban American Indians with disabilities, revealed the need for service providers to be more responsive to the advocacy needs of people with disabilities. Only a third of the population surveyed reported being satisfied with advocacy efforts in the community. The population was relatively unsatisfied with the amount of knowledge they had regarding their legal rights as citizens with disabilities. While the advocacy needs of people with disabilities were important concerns in the Marshall et al. (1992) survey, Kent et al. (2000) found that factors such as the presence of informal family networks, access to services, access to employment and access to transport, were regarded as important in reducing the disadvantage and isolation suffered by people with disabilities in the United Kingdom.

To add to the understanding of quantitative data about health outcomes, Hildebrandt (1999) gathered and analyzed qualitative data concerning the perceptions of vulnerable people regarding their health needs and barriers to health care. The term "vulnerable people" was used to refer to persons in the United States that were disadvantaged because of poverty, living in high-risk environments, social bias and having a disability. Central problems identified in the study included access, self-care, consumer/provider attitudes and networking. In another qualitative study by Turmusani (1999), to investigate the economic situation of people with disabilities in Jordan, focus groups were used to gain insight into the perceived economic needs of people with disabilities and to highlight their perceptions of services designed to address their needs. The research concluded that awareness of economic need such as a need for employment, is a key element in changing attitudes towards people with disabilities.

In South Africa, the needs of people with disabilities have been investigated and described by several authors. The aim of a study done by Meyer & Moagi (2000) in the North West Province, was to determine what the needs of mothers who had children with disabilities were. The needs identified by the mothers included a day centre for their children, education and skills training in handling and training children, a support group to share problems, income generation activities, and resources for the day center, including transport.

Another South African study done by McLaren et al. (2000) in Kwazulu Natal, showed that people with disabilities experience emotional, spiritual, attitudinal, financial and physical barriers as they are not generally accepted in the community as persons who have their own rights and feelings. This leads to poor self-esteem and disempowerment on the part of the person with a disability as they lack the resources that will enable them to take control of their lives. Lorenzo (2001) reported similar findings in a participatory action research study in Khayelitsha, South Africa. The study focussed on the needs of women with disabilities. Analysis of the women's stories revealed their need for identity, emotional support and protection. The study further revealed that if disabled women can be assisted to become active, competent participants in their own development, they will be able to overcome feelings of isolation and dependency. Lorenzo also asserts that the identification and removal of barriers to the social integration and economic independence of women with disabilities will have a positive influence on their families, as well as the communities in which they live.

2.4 Community- based rehabilitation (CBR)

The WHO promotes CBR in an attempt to de-institutionalise rehabilitation and as a realistic and appropriate way of meeting the service provision needs of people with disabilities, particularly in the developing world. CBR is defined as "a strategy within community development for the rehabilitation, equalization of opportunities and social integration of people with disabilities. It is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services" (ILO/UNESCO/WHO, 1994).

The WHO – model (WHO, 1994) lists the five basic principles of CBR-strategy as follows:

1. Utilization of available resources in the community.
2. Transfer of knowledge about disabilities and skills in rehabilitation to people with disabilities, families and communities.
3. Community involvement in planning, decision making and evaluation
4. Utilization and strengthening of referral services at district, provincial and national levels.
5. Utilization of a co-ordinated, multi-sectoral approach.

Since CBR was promoted by WHO, many authors have described views of what it could mean. According to Helander (1992), the aim of CBR is to enhance the quality of life of disabled people by improving service delivery, by providing opportunity that is more equitable and by providing and protecting human rights. O'Toole (1987) elaborates on this by stating that the goal of CBR is to give responsibility back to the individual, family and community, with the primary objective being the integration of people with disabilities into society. This is mainly achieved by mobilizing local resources, where people with disabilities and their families are the most important resource of all.

According to Hartley (2001), it is now generally recognized that CBR activities are holistic in nature and usually include all or some of the following activities: awareness raising, parents' and carers' groups, income generation, rehabilitation, referral, and networking for education, employment and health services. The concept of CBR has thus evolved as a process of social change as it is based on the belief that rehabilitation of people with disabilities should be part of the overall development of a community and should not be seen as a separate process (Coleridge, 1993).

Historically, the implementation of CBR has taken several forms of implementation, apparent by the variety of CBR programmes that exist in the world. The programmes range from being consumer driven, to professional outreach, and home-based therapy oriented. The first type is developed through the efforts of people with disabilities themselves as described by Werner (1998) in Mexico, combined with a focus on disabled rights as described by Cornielje (1993) & Miles (1996) in Southern Africa. The second type is based on the outreach of professional rehabilitation services as described by Lagerkvist (1992) in the Philippines and Zimbabwe. The third type focuses on rehabilitation strategies and mini-therapy programmes such as described by Loveday (1990) in South Africa and O'Toole (1988) in Guyana. According to Helander (1992) the needs of people with disabilities should inform the way in which a CBR – programme develops. Chrisna (1999) asserts that interventions should be responsive to the change in needs that takes place as a service progresses in time and that this will only happen when service providers are sensitive to the messages being given by the consumers of the service.

CBR has been criticized for being medically based and focused on the impairment (Werner, 1998), therefore distracting attention from aspects of equalisation of opportunities and social integration. Werner (1998) argues that a major weakness of CBR is the way in which services are delivered, as it tends to follow pre-determined recipes rather than finding liberating solutions. One of the dangers of this approach is that it can easily become focused, for example, only on physical rehabilitation of clients at home, and nothing else happens. Coleridge (1993) claims that this is because activities are designed as service delivery systems rather than development processes. Werner (1998) argues that the challenge is to guard against CBR becoming a form of institutionalisation in the community, with people with disabilities and their families being passive recipients. He suggests that a departure point in addressing this weakness could be to encourage people with disabilities to take on more organisational and service providing roles in CBR. Miles (1996) argues that it is important that programmes strive to develop services that have appropriately high standards, while at the same time ensuring equal partnerships between consumers and service providers. While not wishing to devalue the efforts of CRW's to provide therapy and support to individuals, Miles (1996, p.509) states that "home visiting is in danger of becoming an institutionalised activity which has lost its original purpose". She argues that home visiting should therefore be a strategy that is adopted by the community rather than one performed and monitored by outsiders.

In view of the above criticisms on CBR, a new approach named Community Approaches to Handicap in Development (CAHD) was developed in Bangladesh to deliver CBR through mainstream community development (Krefting, 1998). CAHD is aimed at mobilizing and co-ordinating existing resources, and at capacity building at primary, secondary and tertiary levels of service provision. This includes activities that combat ignorance in society, ensure inclusion of people with disabilities in all community activities, and provide rehabilitation services that enable people with disabilities to participate. Training for members of community organizations is provided throughout Bangladesh. Following their training, participants return to their organizations to implement new ideas for social inclusion and their newly acquired advocacy skills.

In South Africa, health and rehabilitation services were historically structured according to the ideology of the apartheid government, resulting in the lack of the Primary Health Care (PHC) approach. During the 1980's, Non-governmental Organizations (NGOs) predominantly took the initiative for CBR as an alternative to the inadequate institution-based services provided by the South African Government. After 1994, based on the policies of the new democratic government, changes were made to health policies and specific legislation relating to people with disabilities was introduced. This resulted in rehabilitation being seen as an integral part of the Primary Health Care (PHC) service in South Africa (Department of Health, 2001).

The White Paper on an Integrated National Disability Strategy (INDS) of South Africa identifies the need for the development of policy and guidelines for the implementation of CBR (Office of the Deputy President, 1997). It recognizes that establishing partnerships between consumers and service providers is an important principle for the provision of rehabilitation services in South Africa. The National Rehabilitation Policy (Department of Health, 2000) emphasizes that CBR, as an integral part of PHC, should ensure accessibility and affordability of appropriate and acceptable services to target communities. Strategies proposed to do this include the strengthening of community rehabilitation services through the reorientation of service providers to the principles of CBR, intersectoral collaboration and establishing partnerships with NGOs in the planning, implementation and monitoring of CBR programmes.

2.5 Evaluation of CBR – programmes

In general, there is a lack of information on which to base planning, monitoring and evaluation of rehabilitation services in South Africa. In the light of the historical inequitable provision of rehabilitation services in South Africa, Bhangwanjee & Stewart (1999), propose that there is a need for evaluation of services. They argue that the efficacy of rehabilitation programmes needs to be validated through research that demonstrate that such services are necessary, appropriate and accessible within specified contexts. Most CBR research in South Africa explores the need for, and describes the development of CBR projects (Lorenzo, 1991; Philpott, 1992, McLaren

& Philpott, 1998). In a study done by McLaren et al. (2000), the researchers addressed the issue of insufficient information on disability in South Africa in their attempt to establish a disability information system in KwaZulu Natal. They stressed that key issues like discrimination of people with disabilities, required more analysis of where the root problem originated and needed to be located in a specific reality in the lives of people with disabilities. This type of information is required for planning of services as well as for monitoring and evaluation of service provision.

Evaluation of CBR projects is often coupled with monitoring as an ongoing process rather than a study of the outcomes of a programme. Krefting (1998) states that the reasons for evaluating CBR programmes are to assess worth, to show accountability to funders, to add to the knowledge base of CBR and to identify innovative approaches and methods for future direction and development of the programme. According to Mitchell (1999), the features of CBR on which evaluation should focus include service delivery systems, technology transfer and community involvement. He suggests that the relationship between service providers and consumers, change in community attitude towards people with disabilities and their role in the management of the programme are specific issues that should be examined.

Although evaluation has not been given much emphasis in CBR, there is evidence that it has been successful in improving the lives of people with disabilities through community participation, transferring skills, creating leadership opportunities and lessening discrimination (Finkenflugel et al, 1996). O'Toole (1988) reported on the results of an evaluation of a CBR programme initiated for 53 pre-school children with disabilities in rural areas of Guyana. A pre-test-post-test study showed significant improvement in the children's functioning because of the CBR programme. It is also reported that there were positive changes in the attitudes of the parents, the community and people with disabilities themselves, towards disability. These latter findings are generally regarded as essential outcomes for a CBR programme and are echoed by Myezwa (1995) who investigated the impact of CBR services in Zimbabwe. The results revealed that CBR has a positive impact on people with disabilities and communities in terms of development of skills and more positive community attitudes.

Sharma & Deepak (2001) conducted a participatory evaluation of the CBR programme in North Central Vietnam to ascertain the extent of success with the programme. A framework of strengths, weaknesses, opportunities and threats was used. Data was collected using semi-structured interviews and focus group discussions. Specific strengths were found in the areas of resource utilization, community participation and knowledge transfer. The CBR programme assisted people with disabilities in making progress towards achieving their rehabilitation goals. This included independence in Activities of Daily Living (ADL), achieving social integration and emotional support received from rehabilitation workers. Insufficient co-operation with other programmes and sectors, inadequate opportunities for income generation and little change in community attitudes towards people with disabilities were indicated as weaknesses of the programme.

Two South African studies were particularly useful in providing comparative data on perceived benefits of CBR and its effect on clients' functioning. In an evaluation of the WitsTintswalo CBR training programme, Dolan et al. (1995) interviewed clients of community rehabilitation workers (CRWs) to assess whether they were satisfied with the service offered and whether or not the CRWs were fulfilling the rehabilitation and development functions envisaged by them. The results revealed that clients' self-esteem had been raised and that their independence in ADL had improved. Shipham & Meyer (2002) conducted a similar study in the North West Province to evaluate the effectiveness of the CBR service. Mothers of children with disabilities were interviewed about their perceptions regarding changes that were brought about by the service. The results showed that the mothers perceived that their lives had changed through their acquisition of skills in managing their children. Other changes related to functional activities that the children could perform more independently with the use of assistive devices.

2.6 Approaches to programme evaluation

A traditional approach to programme evaluation has been to define program evaluation as determining the extent to which a program attains its goals (Fink, 1993). Patton (1997, p.113) puts more emphasis on the utilization of evaluation results. He defines program evaluation as "the systematic collection of information about the activities, characteristics and outcomes of programs to make judgements about the programme, improve programme effectiveness, and/or inform decisions about future programming".

Patton (1997) further states that using evaluation results to improve a programme is fundamentally different from rendering judgement about overall effectiveness. He suggests that improvement-oriented approaches tend to be more open-ended. The researcher attempts to gather a variety of data about a programme's strengths and weaknesses with the expectation that both will be found and that each can be used to inform an ongoing cycle of reflection and innovation.

Programmes can be evaluated on two levels namely summative and formative (Potter, 1999). Each level addresses different aspects of the programme and has different purposes. Summative evaluation focuses on program results. Data from summative evaluation which is often obtained through the use of surveys, is used to support a judgement about a programme's worth (Feuerstein, 1992). Concrete evaluative criteria for judging program success are therefore established. Stubbins (1984) however, argues that professional providers usually develop surveys of services with little or no input from consumers. Consequently, many surveys may not have adequately addressed consumer concerns about the services provided. On the other hand, formative evaluation focuses on programme development. The aim of evaluation is to gain an understanding of how the programme can be improved.

Potter (1999) suggests that a goal-free approach to formative evaluation in which programmes are judged on the evidence of what they actually do, combined with consumer interpretations of their value, is an appropriate approach to lay the basis for the summative evaluation of programmes. He argues that quantitative methods do not necessarily provide information on how a programme affects its users. To get to that level of understanding, in-depth information from the clients' perspective is required.

This argument is complemented by the results of a literature review on rehabilitation research in Southern Africa by Finkelflugel (1998). The review revealed that self-defined needs and satisfaction of people with disabilities with the CBR methodology are under researched. He asserts that a more qualitative research approach is needed to gain information on how people with disabilities live their lives and to what extend rehabilitation services meet, or are expected to meet their needs. Green & Britten (1998) also argue that the value of qualitative methods lies in their ability to pursue the kind of research questions that are not easily answerable in experimental methods. They suggest that qualitative methodology is well – suited to investigate consumers' perceptions of a service as it allows for in-depth, descriptive information that could assist one to better understand a programme.

The role of the evaluator in programme evaluation is influenced by the location of the evaluator inside or outside the programme. Patton (1997) asserts that internal evaluators are active participants in developing and implementing organisational improvements. He states that the defining characteristic of external evaluators is that they do not have an ongoing relationship with the programme being evaluated. They are therefore less able to facilitate the implementation of recommendations derived from the evaluation.

This review highlighted the difference between the two models of disability. Definitions of disability grounded in the medical approach do not consider wider aspects of disability, while the social model's definition refers to socially – imposed restrictions that prevent people with disabilities from fully participating in mainstream society. Research findings on the needs of people with disabilities revealed the barriers to equal participation on society that are experienced by people with disabilities. The literature further revealed the importance of capacity building for people with disabilities in overcoming these barriers. The examination of some of the main features of CBR showed how CBR has evolved as a process of social change. Although it is practised in various forms, the main objective of CBR is to ensure that people with disabilities achieve full integration within their communities. This main aspect of CBR is based on the belief that rehabilitation should take place as part of the overall development of a community. The reorientation of service providers to the principles of CBR, empowerment of people with disabilities and intersectoral collaboration were highlighted as important strategies in achieving the goals of CBR. The literature also provided insight into clients' experiences with CBR programmes. Some evaluation studies demonstrated a positive influence of CBR on the lives of people with disabilities in terms of social and functional benefits. These include non-tangible qualitative benefits such as a change in self-esteem and community attitudes towards people with disabilities. Tangible benefits have also been found such as improvements in ADL and the acquisition of knowledge and skills for independent living. Formative evaluation, using qualitative methodology, is proposed as an appropriate approach to utilization-focused programme evaluation.

CHAPTER 3

METHODOLOGY

3.1 Aim and objectives

The aim of the study was to gain an understanding of the needs of people with disabilities and their perceptions of services provided by the UWC CBR - Project.

The objectives were:

1. To describe the services offered by the Project to people with disabilities.
2. To describe the needs of people with disabilities.
3. To describe the ways in which people with disabilities make use of Project services.
4. To determine how people with disabilities perceive the strengths and weaknesses of services provided by the Project.
5. To solicit suggestions from people with disabilities on how the Project can improve services to meet their needs.
6. To evaluate how the five principles of a CBR-strategy are implemented by the Project to meet consumers' needs.

3.2 Study design

This is a descriptive study using qualitative methods to describe the services provided by the Project, and consumers' needs and perceptions regarding the service.

3.3 Definition of terms

Disability - denotes the collective economic, political, cultural and social disadvantage encountered by people who have a physical, sensory, intellectual or psychological deviation or loss, and which result in restricted participation in life-situations (Coleridge, 1993).

Occupation – denotes the performance of functional roles, tasks and activities by an individual in a specific context (Neistadt & Crepeau, 1998).

Occupational performance – refers to performance of occupations within the areas of self-care, work and productive activities, and play or leisure activities (Neistadt & Crepeau, 1998).

Rehabilitation outcome – relates to an individual's ability to perform occupations with or without assistance (Neistadt & Crepeau, 1998).

3.4 Setting of the study

The setting of the study was the UWC CBR Project. It offers a comprehensive rehabilitation service to the communities of Mitchell's Plain and Nyanga (see map ***appendix 2***). The Project is housed independently from community health services in two separate buildings: one in each area. The majority of people in these communities face conditions of poor living standards, poverty, unemployment and crime. The Nyanga office is housed within the Zolani Community Centre. This centre is situated closely to the Nyanga bus- terminus and taxi rank. Unlike the Nyanga office, which is situated in the centre of the community, the Mitchell's Plain office is situated in an industrial area of Mitchell's Plain that is a little separated from the main housing and everyday community life.

3.5 Approach

Before commencement of the study, a meeting was held with the staff of the Project to inform them of the study and to gain their permission and cooperation. This study used the social model as an approach to disability (Oliver, 1998) as it focused on the needs of people with disabilities as reported by them, combined with their interpretation of the value of the services that they received. The five principles of the WHO – model (WHO, 1994) of CBR was used to evaluate how effective the Project was in meeting consumers' needs. As a staff member of the UWC – OT Department, I have been closely associated with the Project through student training and staff development. The approach used was therefore that of an internal evaluator, as my ongoing involvement with the Project is that of an active participant in the development of the programme (Patton, 1997).

3.6 Ethics

Participants in the study were requested to provide informed and written consent ***(appendix 3)*** before participation. They were informed of their right to withdraw participation at any time, should they wish to do so. Before interviews, the researcher had a meeting with individual participants to establish rapport and to explain the nature of the study, methods and dissemination of results. This was done to inform participants what their participation in the study would entail. Participants were ensured of confidentiality and anonymity in presenting interview extracts from the findings in the written report and possible publications that may result from the study. Ethical approval was furthermore obtained from the UWC Higher Degrees Committee in order to conduct the research.

3.7 Data collection methods and sampling

Data was collected using document reviews, participant observation, semi – structured interviews, and focus group discussions with the same sample of participants. The sampling procedure for each method will be discussed following a description of the method used.

3.7.1 Document reviews

Document review is a method used to supplement data obtained through other sources. Atkinson & Coffey (1997) describe documents as “social facts” as they are produced and used in socially organised ways. They warn that documents are not necessarily transparent of organizational routines or decision-making processes and should not be used as substitutes for other kinds of data. Researchers should therefore be clear on what they will be used for.

A variety of documents were selected for review to ensure a comprehensive understanding of the past and current operations of the Project. The documents that were reviewed include participant records, annual reports (1997, 1998, 1999, 2000, 2001, and 2002), media releases (2002), minutes of rehabilitation planning meetings (2002) and summary of activities (2001/2002). Additional documents reviewed were examples of student projects and funding proposals for the Project, the Crossroads Disabled Consumer Forum and the Masibonisane work group. Informal discussions were held with the Project’s staff to clarify my understanding of documented information.

3.7.2 Participant observation

Participant observation is one of the oldest methods of qualitative data collection. An advantage of participant observation is that it offers a wide range of first-hand information, while one of its limitations is the fact that the presence of the observer may influence the situation being observed (Sarantakos, 1998). The purpose of observations was to supplement data from the interviews and document review. At times, observations were validated through questions and informal discussions with the staff. Regarding reflexivity, Rice & Essy (1999) assert that researchers should constantly reflect on their role in the research process and subject this to the same scrutiny as the rest of the data, therefore detailed field notes were kept.

Participant observation was conducted at the Project office and on community visits. Observation was done by spending one morning a week over a period of four weeks at each of the Mitchell's Plain and Nyanga sites. This included the observation of staff networking with other community organizations and providing consultation to consumers, as well as performing administrative tasks. Other observations included four home visits, three groups (two support groups and one work group) and two meetings of the disabled people's organizations (DPOs).

3.7.3 Semi-structured interviews

Face-to-face interviews allow for the clarification of questions and the in-depth exploration of complex issues. One of its drawbacks is that it can be intimidating for the interviewee (Patton, 1990). It is therefore important that the researcher establishes trust at the beginning of the research process. Owing to the nature of the study, which was to encourage an open sharing of opinions, questions were based on a broad guideline ***(appendix 4)*** that was developed in accordance with the study objectives. This allowed me to vary the wording and sequence of the questions, give explanations and leave out or include additional ones as suggested by Rice & Essy (1999). The focus of interviews with people with disabilities was on their needs and perceptions of the services that they received from the Project. This was followed by the solicitation of suggestions for the improvement of services. The interviews were conducted within participants' home settings, with the exception of two that were conducted at the Project offices in Nyanga. Participants were allowed to use their preferred language during interviews. Most of the interviews were conducted in English while one was conducted with the assistance of a Xhosa interpreter who was a consumer of the Project and known to the community. Interviews were tape-recorded and transcribed verbatim after every interview.

Purposeful sampling, designed to provide information-rich cases that will provide an in-depth understanding about particular processes or contexts (Gifford, 1996), was used. A small sample size of eight consumers of the Project services was selected. A technique of purposeful sampling namely maximum variation sampling, allowed for the selection of cases that provided for variations in the sample (Patton, 1990). Criteria considered for the inclusion of participants were age, gender, socio-cultural background, services involved in and rehabilitation outcome. Staff of the Project assisted with the identification of participants. Caregivers were invited to participate where it was indicated by the circumstances of the participant.

3.7.4 Focus groups

According to Kitzenger (1995) focus group methods are popular with researchers who are concerned with the empowerment of research participants because it allows participants to become an active part of the analysis process. In discussing sensitive topics, he suggests that the group may provide mutual support in expressing feelings that are common to all participants. This is particularly important when researching stigmatised experiences, such as disability.

Two focus group discussions, one in each geographical area, were held with the same sample of participants interviewed to assist in verification of the findings. This method of ensuring validity of findings called member checking (Mays & Pope, 2000), is a technique by which the researcher's findings are compared with those of the participants to establish the level of correspondence between the two sets. Participants were presented with a poster that described the issues that emerged from the study. The groups were then asked to comment on the findings, and the main points of the discussion were noted on newsprint. Most of the discussion in the focus groups was conducted in English. Where participants' preferred language was Xhosa, an interpreter was used.

3.8 Data analysis

Data from the interviews was analysed through the process of thematic analysis. Gifford (1996) describes thematic analysis as a process of uncovering the common patterns that are woven throughout an entire data set. As the study is a formative evaluation with specific objectives, a more deductive or structured approach (Gifford, 1996) was used. First, a description of each interview in the form of a case-summary was produced. This included a description of the central topics mentioned by the participant concerning the research issues. Open coding was done to generate units of meaning that was categorized. A thematic structure was modified as new aspects emerged. Within these themes, coding was done to isolate emergent categories and trends from the interviews. The focus group discussions, documents and field notes from participant observations were analysed using thematic content analysis. This consisted of frequency counts of participants' responses, documented information and observations in relation to the themes that were identified.

3.9 Trustworthiness

The methods utilised to guard against researcher bias and to ensure trustworthiness in the analysis process were triangulation, reflexivity, peer debriefing and member checking. Mays & Pope (2000) explain that triangulation is established by using multiple data collection sources and cross-checking information with each data source in order to ensure its validity. Reflexivity (Mays & Pope, 2000) means sensitivity to the ways in which the researcher and the research process have shaped the collected data. Writing field notes allowed me to be explicit about reflections that occurred concerning the data. Also, owing to the qualitative nature of the research, it was important to counteract any personal bias in data collection and analysis. Lincoln & Guba (1985) describe peer debriefing as a process whereby the researcher's biases are probed, meanings explored and the basis for interpretations clarified. This was achieved by having discussions on the research process and findings with two of my colleagues of whom one is a person with a disability. Member checking (Mays & Pope, 2000) was done by giving participants an opportunity to verify the findings of the interviews in the focus groups.

CHAPTER 4

RESULTS

In this section, a description of the sample of participants interviewed is given followed by the findings of the study. The results identified from the coding process across all data sources were categorised in relation to the three main themes that evolved, namely the needs of people with disabilities, strengths of the Project and weaknesses of the Project.

4.1 Description of sample of participants interviewed

The sample consisted of eight participants. In all but one case, the person interviewed was also the person with a disability. The exception was the mother of a child with a disability. Table 1 indicates the demographic characteristics of the sample of participants interviewed. The age range of participants was between 21 and 60 years. Males and females were equal in number. Most of the participants were single with three married and one divorced. Of those participants who were single, one lived alone while the rest all lived with their families. Most participants have a history of unemployment while one was dismissed from work after the onset of the disability. Most participants had completed active rehabilitation and were involved in activity groups and services provided by the CRWs during home visits.

Table 1: Description of sample of participants interviewed

Age	Gender	Marital Status	Area	Socio – cultural Background/ Impairment	Services received	Rehabilitation Outcome
60	M	MR	NY	Early retirement after back injury & TB, 8 children	work group	Indep. in occupational performance
26	F	S	M/P	Spinal muscular atrophy, confined to wheelchair Institutionalised since birth until completed grade 8 never employed	Support groups Home visits	Requires assistance with occupational performance
21	M	S	NY	Developed polio as a child, dependent on crutches. Completed matric, Never employed	sports group	Requires assistance with occupational performance
46	F	MR	NY	Caregiver of 11yr old son with cerebral palsy	Home visits	Son dependent. Mother requires assistance to care for son
30	F	S	NY	TB, paraplegic, unemployed	Home visits	Requires assistance with occupational performance
30	M	S	NY	Gunshot, paraplegic, unemployed	Support Groups	Requires assistance with occupational performance
31	F	D	M/P	Hemiplegic , Employment terminated after disability	Home visits	Requires assistance with occupational performance
40	M	MR	M/P	Rheumatoid arthritis, hearing impaired, self-employed	Home visits	Requires assistance with occupational performance

KEY TO TABLE:

S- single

F – female

M-male

MR- married

D- divorced

M/P- Mitchell's Plain

N/Y – Nyanga

4.2 The needs of people with disabilities

The needs of people with disabilities include the need for emotional support, acceptance and understanding, social integration and income generation.

4.2.1 The need for emotional support

For most participants having an impairment resulted in initial feelings of shock and disbelief followed by a sense of despair and hopelessness.

"...To a certain extent it causes you to become disillusioned... everybody else gives up and you're on your own..."

Participants highlighted the feelings of dependence they experience as the loss of their independence led to feelings of helplessness and of being a burden on their families. This is more intense when assistance is needed with mobility and performing self-care activities, especially when they lack their families' support.

"So it is always a problem that you must plead with people or you must wait for them to give you your bath water, you must wait if you want to go to the toilet and so on."

Facing the reality of having an impairment was traumatic for participants as it implied major changes for their lives in terms of living as people with disabilities. Most participants' dreams and future plans were shattered. The perceived implication of this loss is expressed in the following response:

"...It changed my life...I was telling myself...I am too young to be in a wheelchair because there's a lot of things I want to achieve in life, whether it means to go to school or to have some children, to get married and look after my parents."

It was evident from observation that women with disabilities do not have much support from their families. They were willing to participate in activities, but due to circumstances at home, were not always able to do so. However, the women interviewed did not articulate this as a problem, and were observed to be generally reserved about issues directly affecting them as women. A male participant, in relation to women's absenteeism from the work group, acknowledged the lack of support that women with disabilities experience.

" *Sometimes these four women are not very happy...sometimes they don't want to come work for two or three days because of something that they must do at...at home... they don't like to be not here but they can not do otherwise...* "

4.2.2 The need for acceptance and understanding

Participants expressed dissatisfaction with having to struggle with gaining access to participation in community life due to the community's lack of understanding of people with disabilities. This results in negative attitudes displayed towards them by community members. Negative attitudes were related to a general lack of awareness of disability-issues in the broader community. The community views people with disabilities as different and in need of assistance, which they are not always happy to provide.

"*...the community...they don't take disabled people as, as...they're like them, I mean... let's say if one is walking with a chair... you don't take them as the same as you.*"

"*... sometimes when I go to other family members then people look at you strangely and so on and sometimes it looks like the family is ashamed of you when you want to go to another place...*"

For one participant her own acceptance of her disability was a question of "*getting used*" to her loss. It appeared to be a kind of resignation in the face of unalterable circumstances. This seemed to imply that the feelings she had were insignificant, as she needed to accept the way things were, as evident in the following quote:

"*People in the community do not always accept you as a person and that is something that you need to accept, but it is difficult.*"

It was evident from participation observation that there was a general lack of disability awareness in the broader community. Some community members appeared uncomfortable around people with disabilities evident in their avoidance of the person. A lack of understanding of people with disabilities also results in discrimination in the workplace, as evident in one participant's experience with an employer:

"*…he said to me that I can come back …that is what kept me going…I phoned and then he said to me that my job has been terminated.*"

Some participants, however, were particularly passionate about the right of people with disabilities to be treated with dignity and respect.

"*… people with disability need to be treated as everybody else…take this person with respect…don't think that you should say something over the person, or in the presence, disregarding the person just because he or she is disabled.*"

4.2.3 The need for social integration

Besides their dependence on others, feeling isolated and not being able to get out into the community resulted in feelings of loneliness for participants.

"*…people long to get out of their homes, but. ehm, that's actually where it ends*"

A lack of resources such as transport were physical barriers to social integration that were most cited by participants. The problem of lack of integration is related to the general lack of accessibility that people with disabilities experience in the community.

"*…they need to make shopping centres more accessible for people with disabilities so that one can also feel that we are part of society*"

"*…even the roads are not good for people who are in a wheelchair.*"

" *They* (Zolani Center Management) *brought offices here but you can't go up there, they have open offices but people who are using wheelchairs can't go…*"

Not having access to available, affordable and reliable transport enhances feelings of dependence and helplessness that already exist. Although subsidised transport for people with disabilities, like dial-a- ride do exist, there is concern that this service is not always available or reliable.

" *I was enrolled with dial-a-ride but they…always when I needed to go to the hospital they had excuses like the van broke and so on.*"

4.2.4 The need for income generation

Most participants reported a lack of income and the insufficient amount of the disability grant as problems that cause major financial difficulties.

"...one have two children that must go to school...and they didn't have enough money...because, even though they are getting a grant...that is sometimes not enough."

Hospital appointments, which are important, cannot always be kept due to lack of finances.

" Even if you must go to hospital and people want money, because of circumstances you don't always have money"

Having no or too little money also links with other problems such as unemployment and decreased opportunities for education. This also relates to an inability to pursue goals like starting a small business for income generation.

"...I am the breadwinner and I have to share my money and so on...and I need to go further in education, which is impossible when it comes to it..."

"I would like to start my own business. I have a computer, but need a mouse and printer, then I want to type people's CV's and so on. The computer was donated to me but I am struggling to get hold of the other things."

4.3. Strengths of the Project

The strengths of the Project include the provision of emotional support, transference of knowledge and skills and the facilitation of social integration.

4.3.1 Provision of emotional support

Most participants indicated that the Project was a source of emotional support for them.

"... you had that feeling of solace, the relieve, the comfort of there is someone other than your family that is out there, that cares and are prepared to do whatever they can."

It was evident from observation that family – members of people with disabilities are also in need of emotional support as they often discussed difficulties experienced with the CRWs, as evident in the following extracts from my observations:

"Reading through all of the field notes made me realize that the things that bother family members are not always related to the person with a disability but rather concern their day to day struggles with unemployment and a lack of income."

" I observed a number of community members approaching the CRWs for assistance with health, domestic and even financial issues"

It was evident from observation that the CRWs are overburdened with a huge caseload. Discussions with the CRWs also revealed that consumers who are not in need of active rehabilitation are retained as consultation clients and are encouraged to approach the Project office should they require any assistance.

4.3.2 Transfer of knowledge & skills

The convergence of findings from observations, interviews and focus group discussions showed that participants thought that the Project had improved their knowledge. Knowledge refers to input and skills training in the areas of ADL, use of assistive devices and counselling regarding disability issues.

Participants received a combination of services during home visits including family education, physical exercise, independence training & assistive devices.

"she became part of the concerns of the family...she got my wife involved whereby she showed my wife what to do..."

"...and then they gave me a walking stick and then I felt I don't really have to be confined to the wheelchair all the time I can move."

One participant regarded the income generation groups as one of the major successes of the Project, as he learned new skills, including marketing skills.

"...I think they have done a very good job for us...because we didn't even know how you can do something like weaving...we are taking our weaving to the college here at Nyanga where they...they market it! and they encourage us not to give up hope..."

4.3.3 Facilitating Social Integration

Whereas there is no mention of the social model in reports before 2000, its approach is gradually infused in the Project's work as indicated in later reports[1]. There was also a recognition of the health-promoting role of health workers[2]. The main evidence of a shift towards the social model of disability was found in the Project's move away from predominantly performing home visits to integrating clients into mainstream groups in the community. Although not observed, documents reported on community

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[1] Annual Reports 1997, 1998, 2000, 2001, 2001.

[2] Media Release : Vukani, June 27, 2002

awareness activities, the facilitation of workshops on disability issues and the development of task teams responsible for advocating for the rights of the disabled[3]. Most participants were involved in support and activity groups offered by the Project. The groups offered a variety of activities to participants as illustrated by the following quote:

"...every week there were different things, for example we did paper mache, or we worked with clay, or we made doilies and other things. Sometimes we played games, it was so that we could get out every week."

For some participants their involvement in the groups benefited them personally in terms of increasing their confidence and assisting with community integration.

"I was a very shy and introverted person as I was always at home and did not communicate with other people with disabilities...the groups helped me a lot and it gave me more confidence..."

"they have been trying hard for me to get out of the house during the week... like now I'm on the marketing thing for the fun run."

It was evident from observation that the groups mainly served as a means of peer support and socialisation for its members. Members seemed pleased to be together and shared information about their day to day experiences for example hospital visits, with each other.

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[3] Annual Report 2002, Summary of Project Activities July 2001-June 2002.

4.4 Weaknesses of the Project

The weaknesses in service provision revolved around a lack of participation in Project governance, empowerment of people with disabilities, community awareness, networking and sustainability of services.

4.4.1 Insufficient participation in Project- management

Some participants were of the opinion that they did not participate enough in a service in which they should be more actively involved. They felt that they should be more involved in the "*affairs*" of the Project and demanded greater participation in the organisation and running of the service.

"Sometimes there are things happening at the Project…then one hear that this or that happened afterwards…but they…it's seldom that one is involved with the activities that they have."

"*…that we get together and they inform us…ok, these are the affairs of the Project…where we, the disabled clients can also voice our opinions as to what we can do to make a success of the Project.*

Discussions with staff confirmed that there was no representation of people with disabilities on the organizational structures of the Project. It appeared as if the Project's focus is mainly on the development of the DPOs and its managerial structures. This weakness links with the lack of community participation in the Project that was observed. It appeared as if the community was only involved if they were on the receiving of end of things for example, being assisted with social issues. There are also no volunteers involved with the Project, other than citing this as a challenge, documentation did not provide reasons for this.

4.4.2 Lack of empowerment of people with disabilities

Although the principles underlying the rehabilitation process include capacity building, and partnerships between people with disabilities and service providers[4], a lack of capacity building of people with disabilities were evident in observations and the requests for skills training made by some of the participants.

"...I think maybe with management and so on they can help us with because we also still have to learn how to go about things and so on.

"...people with disabilities...They must make things happen for themselves, you see... by themselves...she knows that some of us, I haven't been in school...that's why she's supposed to assist us."

In one group it was observed that despite encouragement from the occupational therapist for the members to take a more active role in the planning of an outing, they seemed complacent. The result was that she undertook to perform most of the arrangements herself.

A lack of organizational skills of DPO members was also evident. In the meetings observed, members appeared reluctant to take on roles of chairperson and minute recorder. The focus group discussions confirmed the need for capacity building of participants, as evident in the following extracts from my observations:

"*The group was quite articulate in terms of their own lack of skills. They requested more skills training, and opportunities for them to perform administrative tasks themselves. Other issues that emerged were their lack of communication skills and the need for a changed attitude within the DPOs itself."*

It was also noted that some participants, particularly the males, spoke with ease and tended to dominate discussions, while the women needed extensive prompting from

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[4] M/P & NY Rehab Planning meetings, 25/01/02 & 31/01/02.

the facilitator. A lack of empowerment of some participants who were unable to articulate what seemed obvious needs was also evident during the interviews.

4.4.3 Inadequate community awareness

Most participants felt that the Project is not doing enough in terms of raising community awareness and advocacy for people with disabilities. There was an expectation that it was the staff's responsibility to increase community awareness.

"...they're supposed to do more then they are doing now...they are supposed to approach those members of this ward to take those offices down...even the games, the games they are playing are upstairs..."

" *They* (the community) *should try to spend one day with us, to take part in an activity together so that they can see what type of persons we are, that we are equal to them' that we are also eager to do things."*

Although the high level of involvement of some family members in the sessions observed were remarkable, what seemed apparent were the high and sometimes unrealistic expectations for "*recovery*" that family members had for the person with a disability. It appeared as if the families' lack of disability awareness resulted in them having difficulty accepting their family member's impairment. This was evident in the lack of support from her family that was experienced by one participant, as the following quote illustrates:

"*It's not always easy, I have my down moments and I have my up moments, especially with my family...they haven't come to terms with it...why must they be so upset because of me?"*

4.4.4 Inadequate networking & collaboration

Some participants felt that there should be more networking between the Project and other organisations to improve access to resources for people with disabilities.

"...there is still a missing link between many people that are disabled... yes...there is a very big gap between those organisations and all institutions and the community. 'It will be much important to us to network...to add actually to the networks that we have because we have Association for the Physically Disabled... so you can assist very much to network ourselves with all things actually...we should get more things..."

Documentation revealed that much of the staff's time and energy is invested in maintaining the involvement of government departments[5], the project has been unable to obtain the full interest of the Departments of Social Services and Labour.

4.4.5 Lack of sustainability of services

In the light of budget cuts and financial difficulties, services were decreased. This caused feelings of disappointment for participants.

"It was disappointing when we heard that we couldn't get together every week anymore. A person feels it, because you looked forward to going to the group...because you know at least you can get out a little..."

Some participants addressed the lack of resources for activities for people with disabilities.

"...there's not enough sponsors or donors to provide these facilities and one can understand there's no money around for everybody that everybody that cannot walk that they can acquire a wheelchair through whichever institution."

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[5] Discussion with Project OT.

No longer being able to attend the groups, one participant began to rely more on the home visits but expressed dissatisfaction around issues of availability of this service. "*...the rehab workers that visit so now and then... It's just sometimes that one struggles to get in contact with them and sometimes they take long to come to you...*" The present situation regarding service provision by the Project seems to be one of many small projects, with no direction towards large scale service delivery, and a collapse of the project when external resources are withdrawn. It was evident from observation that the sustainability of the service was a main concern for the staff as well as consumers. The staff was constantly involved with discussions around funding and writing funding proposals. However, a lack of community and consumer involvement in addressing the issue of sustainability was again evident from observations, interviews and focus group discussions.

CHAPTER 5

DISCUSSION

CBR is a strategy within community development to enable equal opportunities for people with disabilities in society. The evaluation of a CBR programme is geared towards improving programme effectiveness and thus it is important to explore if people with disabilities feel that their needs are met when a programme is evaluated. This study was therefore aimed at understanding consumers' needs and perceptions of services provided by the UWC CBR programme. The primary objectives of this study were to give participants an opportunity to share their experiences and perceptions of the Project's strengths and weaknesses and in so doing, provide new insights for the formulation of appropriate recommendations for the improvement of the service. As the following discussion will show, I feel that the study's aim and objectives were achieved.

The findings are examined against the five components of the WHO – model of CBR namely available resource utilization, transfer of knowledge and skills, community participation, strengthening referral services and intersectoral collaboration (WHO, 1994). Also, the Project's objectives and other literature on disability and CBR are reflected on in relation to the findings.

5.1 The needs of people with disabilities

The degree of deprivation that the participants experience due to barriers to equal opportunities for people with disabilities is evident in the findings. These barriers are related to community attitude (seeing them as objects of pity), economic barriers (poverty and discrimination in the labour market) and physical barriers (lack of accessible transport systems). The most marked inequalities appeared to be related to attitudinal barriers like ignorance and a lack of disability awareness in the broader community. This was an expected finding as it was a common result in other South African studies (Meyer & Moagi, 2001, McLaren et al., 2001 & Lorenzo, 2001). This also concurs with findings of the study by Marshall et al. (1992) which revealed that there was a need for service – providers to be more sensitive to the advocacy needs of people with disabilities.

One of the key issues for participants was the economic barrier to equal participation in society that they experienced. This relates to a lack of access to employment and discrimination towards people with disabilities in the workplace. The majority of participants live on a disability grant which, in most cases, substantially contributes to the overall family and household income. This impoverishes the individual who already lives in communities where for many, life is a daily struggle for survival.

As in the study done by Kent, Chandler & Barnes (2000), participants consistently cited a lack of transport as a barrier to accessing services and participation in community life. It is therefore not surprising that the majority of participants reported a lack of accessibility as a problem in general. Research has indicated that barriers to participation in society lead to a decreased self – esteem and lack of empowerment (O'Toole, 1988, McLaren et al., 2000) and that their removal is essential in assisting people with disabilities, particularly women, to overcome feelings of isolation and dependency (Lorenzo, 2001). The findings therefore highlight the necessity for the

Project to work within the full range of problems faced by its consumers and emphasize the need for this programme to become an agent of social change and development (Coleridge, 1993). The inclusion of more specific objectives related to the removal of the identified barriers will reflect a human rights and development perspective on disability by the Project.

5.2 Programme's strengths and weaknesses

It is clear that most participants particularly value the emotional support and encouragement that they received from the Project. The fact that there were people who could assist them and with whom they could share their concerns brought feelings of *"relief"* and *"comfort"* and the knowledge that they are not alone in their struggle to cope with their disability. This helped some participants to make a positive adjustment as persons living with a disability. This could be as a result of the rehab workers' affirmation of participants as people first. The family and caregivers' positive responses to the CRWs when performing home visits, is also indicative of the supportive role they play.

The first component of CBR is the utilization of available resources, where people with disabilities and their families are the most important resource of all (O'Toole, 1987). Other than the training and counselling provided during home visits, people with disabilities and their families rarely have access to any other form of support system. The majority of participants looked to their immediate family to solve day-to-day problems. Assisting a disabled person is demanding and many families may not be able to deal with some of the difficulties they experience. The result is that not only people with disabilities but also their families are disempowered by society's failure to ensure adequate provision of support systems.

The Project has been successful in addressing some needs of people with disabilities through the involvement of family members in the rehabilitation process. Although documentation indicates a gradual realization that people with disabilities should play a greater role in service-delivery, meaningful progress regarding this has been relatively slow. People with disabilities themselves for example consultation clients, could be utilized as resources. Successful attempts have also been made to integrate consumers into mainstream community groups at central venues. This was perceived favourably by participants. Further utilization of community resources and ensuring accessibility to these, need to be explored.

The second component of CBR is transfer of knowledge and skills. The role of the Project in home visits and the facilitation of groups were regarded as pivotal to the quality of life of all the participants. This related to an increased self-esteem and functional activities that participants were now able to perform more independently through the use of assistive devices and the techniques of assistance taught to family members. Despite participants' concerns, the home visits assisted several participants in making progress towards achieving their rehabilitation goals. These findings confirm the need for community-based rehabilitation services and validate the importance of CBR. This concurs with findings of evaluations on CBR done by Dolan et al. (1995), Finkenflugel et al. (1996), Sharma & Deepak (2001) and Shipham & Meyer (2002). It was however evident through observation that the CRW's are overburdened with a huge caseload. This could be indicative of the Project's approach to service delivery as there is a strong focus on impairments and the physical rehabilitation of clients. This is also evident in the Project's objectives. The Project has to guard against home visiting becoming an "institutionalized activity" with people with disabilities being passive recipients (Miles, 1996). As Werner (1998) and Coleridge (1993) suggested, this weakness could be addressed by encouraging people with disabilities to take on service provider roles.

The fact that only one participant was involved in an income generation project, while another who made an attempt at self-employment, did not have the necessary resources to follow through, is a concern. There is clearly a need for more income generation activities as well as the development of small business skills. Factors such as a lack of funding have influenced the Project's ability to fully achieve its objective of facilitating employment. To relieve this burden, Sharma & Deepak (2001), recommend linking skills-development programmes to outside organizations. Research has established that community support of skills-development and intersectoral collaboration are vital to successful integration (O'Toole, 1987, Turmusani, 1999). Collaboration with vocational training programmes and advocacy for employment services should be strengthened (Kent et al., 2000, Meyer & Moagi, 2000). Establishing firmer links with Disabled People South Africa (DPSA), NGOs, and the Departments of Labour, Transport and Social Services would be beneficial for the facilitation of employment.

One of the most crucial suggestions made by some participants was that of increased participation in the management of the service. As Werner (1998) suggested, being full partners in a service means that people with disabilities should take on more organizational and service providing roles. Currently people with disabilities are not represented on the management structures of the Project. This implies that they are recipients rather than decision makers. As suggested in the literature (Coleridge, 1993; Oliver, 1998; Bricher, 2000), this issue could be addressed if the Project gives wider recognition to the social model in service provision.

Participants also expressed a desire to take more ownership of the DPOs by suggesting that they should *"make things happen"* for themselves and in the process learn further life-skills such as managing organizations. The suggestions for increased participation and skills-development from participants confirm insufficient evidence of capacity building of people with disabilities. This suggests that the staff should be re-oriented towards the principles of CBR and the social model of disability (Dept of Health, 2000). This will assist the staff to make a shift from being service providers and working for people with disabilities, to being partners in service provision and working with people with disabilities.

The DPOs are in an initial phase and are still relatively weak. They therefore have great difficulty advocating for more resources. In discussing service delivery versus development programmes, Coleridge (1993) asserts that development is about people understanding the causes of their under – development and with that understanding, work towards changing their situation. It became clear through this study that people with disabilities need to be enabled to take ownership of their own problems so that they can advocate for the resources necessary to solve them. The DPOs should therefore be enabled to assert themselves as individuals and as a group. Capacity building of people with disabilities is needed so that they can develop positive self-identities and a shared consciousness. It needs to be part of an empowering and enabling process whereby people with disabilities are provided with the tools that they need to change their lives. The needs of disabled women, especially, need attention. A refresher course for CRWs in skills- development methodology would possibly be useful. Such training may include aspects of adult learning principles, and advocacy organizational management and self-efficacy building techniques (Sharma & Deepak, 2001).

The third component of CBR namely community participation appears to be a major challenge for the Project. Most participants identified a lack of community awareness and integration as programme weaknesses. One could therefore assume that awareness-raising campaigns have been relatively ineffective in the broader community. This could be because the Project's focus has been more on the individual and less on environmental and social barriers. The lack of disability awareness and acceptance of people with disabilities affect their empowerment and integration (O'Toole, 1988). Direct involvement of the community is essential for the sustainability of a CBR programme (Office of the Deputy President, 1997). Although there was evidence of community awareness activities in documentation, none of the Project's objectives address community participation and disability awareness. The form of CBR namely CAHD used in Bangladesh, provides some guidelines for how this weakness could be addressed. The training provided to community organizations offer participants a chance to develop new attitudes, beliefs, values and skills to assist people with disabilities to be included in every sphere of community living (Krefting, 1998). In addition to inclusion of people with disabilities and community organizations in awareness-raising activities, their inclusion in the management, monitoring and evaluation of development activities is also suggested.

This brings us to the fourth and fifth components of CBR namely strengthening of referral services and intersectoral collaboration. As was noted throughout this discussion, networking and intersectoral collaboration are vital to ensure successful disability awareness campaigns and for referral systems to be strengthened. It should involve all sectors of the community including CBOs. NGOs, health, social, transport and employment services, community leaders, schools and people with disabilities and their families. Successful intersectoral collaboration is dependent on collaborative goal setting, sharing of resources and sectors' acknowledgement of their interdependency in addressing disability issues. The Project should continue discussions with government departments, NGOs and CBOs to promote the concept of disability as a human rights and development issue. In Guyana (O'Toole, 1988) and Bangladesh (Krefting, 1998) such discussions helped to strengthen partnerships and to facilitate efforts that ensured that appropriate attention was given to disability issues in related areas of programme planning and development.

This discussion would not be complete without addressing the inadequate financial sustainability experienced by the Project. This relates to the requests for more activities and resources for people with disabilities made by participants while the Project has to cut back some programme components. The WHO (2001) calls for increased investments for fully accessible community-based services and facilities. While the Project has made efforts to mobilize some funding, it could be beneficial if more long-term funding can be harnessed. In addition to its own fundraising efforts, from NGOs and the private sector, the Project should pressurise government to provide a bigger proportion of the funding to ensure the sustainability and improvement of the programme.

5.3 Limitations of the study

This study focused on the needs of consumers' with disabilities of the UWC CBR Project. While findings on the experience of people with disabilities concur with other research findings, the conclusions that emerged from the study are towards improving services provided by the Project and cannot be generalized to all CBR projects in South Africa.

Methodologically, the study was limited by the choice of data collection methods for example in-depth interviews and focus group discussions. An emancipatory research approach (Oliver, 1998, Bricher, 2000 & Kitchin, 2000), whereby people with disabilities are directly involved in, and empowered through the research process, could have been more beneficial in addressing this issue. Also, methods like drawing, mapping and role- plays followed by group discussions, might have been more useful in assisting participants to articulate their feelings.

Language was a constraint that was addressed partially by using an interpreter and applying a translation-retranslation method. However, this method posed inherent weaknesses such as the quality of translation, loss of accurate meaning and misinterpretation. On the other hand, it offered advantages in terms of using a person that participants already knew and felt more comfortable with. This could have encouraged the free and honest expression of thoughts.

Finally, the identification of staff perceptions on the service, issues of disability and CBR would have contributed substantially to understanding the relationship between consumer needs and their perceptions on the strengths and weaknesses of the service. The short time- period in which the study was conducted only allowed for a partial evaluation of the Project and limited observations and interviews. However, the convergence of data gathered through the different methods is indicative of the validity of the findings.

CHAPTER 6

CONCLUSION

The major participants in this study were the sample of consumers of the UWC CBR Project. The study ensured that they were involved in expressing their needs as well as their perceptions of the services provided by the Project. This allowed them to identify aspects of the service that need more development. This information is valuable because firstly, it gives a voice to people with disabilities who so often have been silenced in the rehabilitation process, and secondly, it gives direction to the process of planning and implementing more effective community-based rehabilitation services in Nyanga and Mitchell's Plain.

The study revealed the degree of emotional trauma and deprivation that people with disabilities experience due to physical, social and economic barriers to equal participation in community-life. The most marked concerns of participants are related to attitudinal barriers caused by a lack of understanding of disability in the broader community. The findings highlight the need for Project- services to be more sensitive to the advocacy needs of its consumers and to give wider recognition to the social model in service provision.

The results of the study showed that the Project has been successful in addressing some of the needs of its consumers by providing emotional support, opportunities for integration and transference of skills for independence. However, objectives such as facilitating employment and promoting community involvement are not being met.

Formulating more specific objectives in the future such as improving disability awareness, developing life-skills of people with disabilities and promoting consumer involvement in management and service provision would address some of the weaknesses identified. Other difficulties identified include limited resources and staff capacity, which resulted in poor sustainability and management of the programme.

Many more issues related to the needs of people with disabilities in these communities should be researched. For example, what potentially beneficial resources and or services are available for people with disabilities? What referral systems are used and how effective they? What factors would enhance training as a means of reducing the vulnerability of people with disabilities? The involvement of people with disabilities in the research process should be ensured in accomplishing this.

CHAPTER 7

RECOMMENDATIONS

Of importance in this study is how its findings can be used practically by the Project to improve services in order for it to be more effective in meeting the needs of its consumers. It is therefore recommended that the Project undertakes a process of increasing consumer participation and control of the project, and then embarks on staff and consumer capacity building in order to strengthen the Project management and resetting of objectives:

1. Include people with disabilities in service provision and management by:

a) Ensuring the representation of people with disabilities on the advisory board and coordinating committee, and plan the recruitment of people with disabilities as staff in the future.

b) Training consultation clients as peer counsellors and to assist with raising community awareness, and monitoring and evaluation of services.

2. Revise the mission statement, aims and objectives by:

a) Revising the mission statement so that it reflects a vision in which people with disabilities are respected as valuable citizens who are integrated into community-life and have equal access to social and economic benefits.

b) Including objectives related to advocacy needs and removal of barriers to participation in society.

c) Including objectives related to improving disability awareness and developing life-skills of people with disabilities.

3. Provide staff and consumer capacity building by:

a) Providing training that focus on: the history of the disability movement in South Africa, the social model of disability and its implications for practice, the principles of CBR, advocacy strategies and self-efficacy building techniques.

b) Educating people with disabilities on their rights and disability related policies for example employment rights, the INDS and the National Rehabilitation Policy.

c) Providing training for DPOs in leadership, organizational management, fundraising, and advocacy and self-efficacy skills.

d) Facilitating the formation of a women's group to address the capacity building of women for example self-esteem building and assertiveness training.

4. Improve networking and intersectoral collaboration by:

a) Establishing firmer links with Disabled People South Africa (DPSA), NGOs, CBOs and the Departments of Labour, Transport & Social Services.

b) Fostering a working relationship with all Government Departments in developing partnerships with the Project and DPOs in addressing issues of disability awareness, employment opportunities for people with disabilities and accessibility of transport and public buildings.

c) Encouraging NGO's to work in co-operation with DPOs to develop skills and to obtain funding.

5. Organise regular and effective disability awareness programmes by:

a) Presenting programmes that focus on the community's understanding of the needs and problems experienced by people with disabilities.

b) Involving all sectors of the community in awareness programmes including CBOs. NGOs, health, social, transport and employment services, community leaders, schools and people with disabilities and their families.

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APPENDIX 1

MISSION STATEMENT

The Project aims to provide a multi-faceted rehabilitative service to people with disabilities, in Mitchells Plain, Gugulethu, Nyanga and Crossroads. We strive to unlock and develop their full potential so as to enhance their Physical, Mental, Spiritual, Social and Occupational well being.

AIMS AND OBJECTIVES

- ***By offering home-based rehabilitation services we aim to:***
  Promote an improved quality of life.
  Educate and practically involve family members within intervention Programmes.

- ***By providing cost effective assistive and mobility devices we aim to:***
  Encourage independent mobility skills.
  Improve independence in activities of daily living, which include personal management, work and school, leisure and play activities.
  Create equalization of opportunities for the disabled.

- ***Through the facilitation of Day Care Centres we aim to:***
  Develop a resource that is appropriate and accessible to the community.
  Increase the facility for Day Care Centres, thereby simultaneously expanding the availability of resources in the community.
  Encourage the full involvement of parents in the management of the centres.
  Be available to offer a consultative service.

- ***By facilitating the initiation of social, support and sport groups we aim to:***
  Promote enthusiastic community involvement on all levels
  Encourage a sprit of co-existence and peer support amongst community members, which are vital for self-perpetuation and sustainability of services.

- ***By facilitating employment through work groups and home industries we aim to:***
  To provide an opportunity for income generation.
  Equip people with specific work and business management skills, thereby fostering independence and fulfillment.

- ***By offering community courses and workshops we aim to:***
  Expose and train community members in creative activity as a medium to facilitate healthy Development.

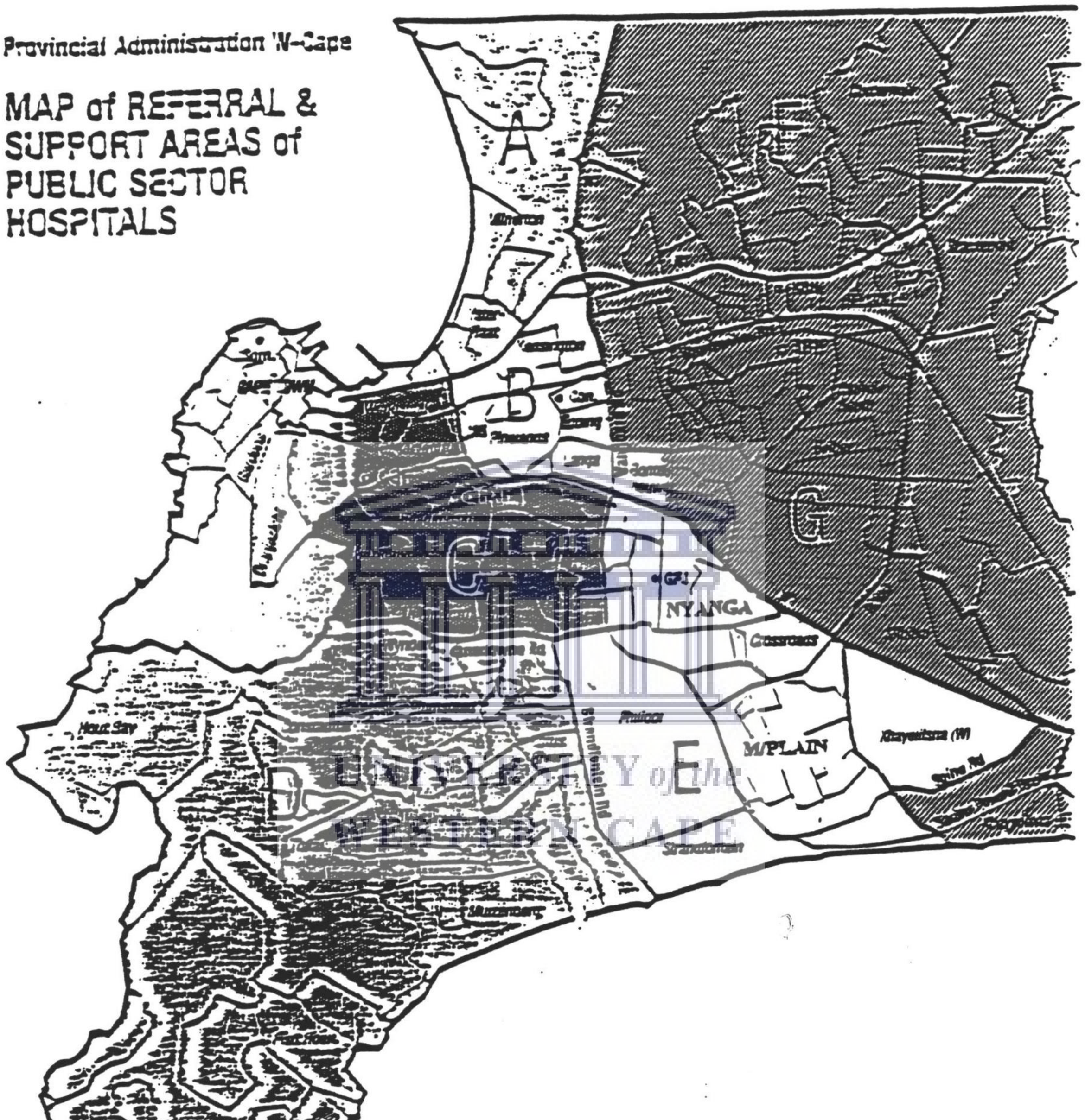
- ***By facilitating health promotion groups we aim to:***
  Create supportive environments.
  Develop personal skills.
  Strengthen community action.
  Lobby and advocate for healthy public policies.
  Assist within Re-orientation of healthy services.

- ***By encouraging clients social integration we aim to:***
  Improve independent community living skills.
  Encourage the equalization of opportunities for the disabled.
  Promote fun and therapeutic outings.

- ***By providing annual food parcels we aim to:***
  Offer relief to needy clients thereby uplifting community spirit.
  Eradicate mal-nutrition.

- ***By ensuring the appropriate and practical training of students within community work we aim to:***
  Provide the opportunity for university students to equip themselves with the necessary skills needed to fulfill their professional duties.

APPENDIX 2



Mitchell's Plain and Nyanga forms part of the Cape Town Metropole.

APPENDIX 3

TO WHOM IT MAY CONCERN

CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

TO BE COMPLETED BY THE PARTICIPANT OR CAREGIVER WHERE APPLICABLE.

I, -- hereby agree to participate in a research study on the UWC Community –based Rehabilitation Project.

I have been informed about the study and what is expected of me. I will be interviewed on my experience as a person with a disability. I will also answer questions on the services that I receive from the Project. Information from my records at the Project will be used to supplement information given in the interviews. The interview will be tape-recorded. The audio – tapes will be heard by the researcher and a transcriber. Participation in the study is voluntary and I have the right to withdraw my participation at any time. Confidentiality and my anonymity are ensured should extracts from the interview be used in the research thesis or any publications that may result from the study.

Should I have any questions about my participation, **Ms Lucia Hess** can be contacted at **the Project office tel .** 376 – 7846.

I have been given a copy of this form.

SIGNED : -- DATE :--------------------
(participant)

-- DATE : --------------------
(researcher)

-- DATE : --------------------
(witness)

APPENDIX 4

INTERVIEW GUIDE

1. Please tell me about your experience of living as a person with a disability.
2. Do you have any specific needs as a person with a disability? What are they?
3. What type of services should be provided to meet your needs?
4. Please describe how you make use of services provided by the UWC CBR Project.
5. What are your opinions about the services that you receive?
6. Do you have any concerns about the services that you receive from the Project?
7. Are there any problems you wish to discuss?
8. According to your needs, how can services be provided to meet your needs more effectively?