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Reviewing Evaluation Reports of
Community-Based Rehabilitation
Programmes in South Africa

by

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Declaration

I, Francia Morris, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work, nor any part thereof has been, or is to be submitted for another degree in this or in any other university.

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Abstract

CBR (community-based rehabilitation), a relatively new discipline, was initiated in South Africa in the 1980's. The methodology used in this study is that of a qualitative document analysis in order to gain a deeper understanding of CBR practice in South Africa. Two evaluation documents and one annual report, from three CBR organisations operating in South Africa, were analysed. The findings of these analysis show that the CBR programmes have made an impact on the lives of disabled people. It is clear that CBR still faces many challenges in the South African context. Recommendations were made on how these challenges could be addressed.

The first chapter gives the reader some background to CBR developments in international, African and South African contexts. The need for a study of this kind was identified at a workshop on South African CBR in June 2004. There is very little documentation on South African CBR, which limits the sharing of best practice and understanding of the current status of CBR in South Africa. A literature review was done on CBR and is presented in chapter two. The issues concerning CBR that this chapter focuses on are the definition of CBR, concepts of CBR derived from the definition, and sustainability of CBR.

The methodology used in this study is explained in chapter three. Qualitative analysis was used to identify themes in an inductive manner in documents, consisting of evaluation and annual reports. The sample consisted of three CBR programmes operating in South Africa. The findings are presented and discussed in chapter four. The three key themes that were identified are: collaboration of stakeholders, CRWs and the sustainability of CBR. Chapter five contains the recommendations in which the need for an umbrella structure for CBR in South Africa, government support, accreditation of CRWs and more participation from the community and disabled people in CBR, are highlighted.

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The researcher's position

I was exposed to CBR in 2001 when I started my career as an Occupational Therapist in a rural area in the province of KwaZulu-Natal, South Africa. I soon realised my skills and capacity were inadequate to meet the needs of the disabled people in the vast underdeveloped area of the Msinga sub-district. Fortunately, a community rehabilitation facilitator was allocated to work with me, and together with a physiotherapist, we explored strategies, of which many can be defined under CBR, for addressing disabled people's needs. I developed a strong personal interest in CBR through this experience.

Glossary

| | |
|----------|---|
| AIDS: | Acquired Immune Deficiency Syndrome |
| ANC: | African National Congress |
| APDRH: | Asian Pacific Disability and Rehabilitation Journal |
| APT: | Appropriate Paper Technology |
| CBO: | Community-Based Organisation |
| CBR: | Community-Based Rehabilitation |
| CBR-DSP: | Community-Based Rehabilitation Disability Support Project |
| CHW: | Community Health Worker |
| CORRE: | Community Rehabilitation and Research Education Project |
| CREATE: | Community-Based Rehabilitation Education and Training for Empowerment |
| CRF: | Community Rehabilitation Facilitator |
| CRW: | Community Rehabilitation Worker |
| DART: | Disability Action Research Team |
| DOH: | Department of Health |
| DPI: | Disabled People International |
| DPO: | Disabled People Organisation |
| DPSA: | Disabled People South Africa |
| GCIS: | Government Communication and Information System |
| HIV: | Human Immuno-deficiency Virus |
| HSRC: | Human Science Research Council |
| IDC: | International Disability Consortium |
| ILO: | International Labour Organisation |
| IMCSA: | International Marketing Council for South Africa |
| INDS: | Integrated National Disability Strategy |
| IUPHC: | Institute of Urban Primary Health Care |
| MRC: | Medical Research Council |
| NGO: | Non-Government Organisation |

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|---------|--|
| ODP: | Office of the Deputy President |
| OSDP: | Office on the Status of Disabled People |
| PHC: | Primary Health Care |
| RURACT: | Rural Disability Action Team |
| SACLA: | South African Christian Leadership Association |
| SAFCD: | South African Federal Council on Disability |
| SWOT: | Strengths, Weaknesses, Opportunities, and Threats |
| VT: | Valley Trust |
| UCL: | University College London |
| UCT: | University of Cape Town |
| UDW: | University of Durban Westville |
| UN: | United Nations |
| UNDP: | United Nations Development Programme |
| UNESCO: | United Nations Educational, Scientific and Cultural Organisation |
| UNICEF: | United Nations International Children's Emergency Fund |
| WHO: | World Health Organisation |
| WITS: | University of Witwatersrand |
| WPA: | World Programme of Action Concerning Disabled Persons |

Definitions and explanation of terms

Community-Based Rehabilitation (CBR)

CBR is a strategy within general community development for the rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of all disabled people. CBR is implemented through the combined efforts of disabled people themselves, their families, organisations and communities and the relevant governmental and non-governmental health, education, vocational, social and other services (ILO, UNESCO and WHO, 2004: 2).

Community Outreach Programmes

These are part time service deliveries to disabled people in the community from a central institution, for instance, a clinic or a hospital.

Community

Geographically, a community includes those living in the same area or district (Philpott, Pillay & Voce, 1995). Community also includes “people who are considered as a unit because of their common interest, background or nationality”¹.

Development

Development means only good change that is all-encompassing (Chambers, 1997 in Thomas, 2000b: 23). It implies improvement of living standards, of health and well being for all and the achievement of whatever is good for society at large. **Community development** “seeks to promote human development and is aimed at empowering

¹ Cambridge International Dictionary of English, 1995

communities and strengthening their capacities for self-sustaining development” (Monaheng, 2000: 125).

Disability

Disability is "the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community or on equal level with others due to physical and social barriers" (Barnes in Marks, 1999: 79).

Impairment is “the limitation in a person’s physical, mental or sensory functioning. Impairments only become salient and disabling in specific settings.” (Marks, 1999: 80).

Community Rehabilitation Workers (CRWs)

This term is used for frontline workers trained in aspects of community development, physiotherapy, occupational therapy, speech language and hearing therapy and social work to offer an integrated service to disabled people and their communities.

Rehabilitation

In this study, ‘rehabilitation’ first entails medical rehabilitation. This includes all type of interventions aimed at improving the functioning and participation of a disabled person (Finkenflügel, 2004). Secondly, it entails a broader concept of rehabilitation, which aims at removing barriers to participation of disabled people, to ensure their social integration. This includes the promotion of disabled people’s rights by providing relevant information to facilitate their decision-making regarding services needed and for enhanced participation. (ILO, UNESCO & WHO, 2004)

Social model of disability

The social model “sees disability as resulting from society’s failure to adapt to the needs of impaired people” (Abberley, 1996: 61). It implies that “the way to reduce disability is to adjust the social and physical environment to ensure that the needs and the rights of

people with impairments are met, rather than attempting to change disabled people to fit the existing environment” (Stone, 1999: 2). The **medical model of disability** on the other hand, locates the cause for the marginal positions of disabled people in their bodily impairments. The medical model forms the framework of the predominant traditional approach to disability as a health and welfare issue (ODP, 1997).

Chapter 1

Introduction

Community-based rehabilitation (CBR) is about more than merely developing rehabilitation services in the community, it also entails the equalisation of opportunities and social inclusion of disabled people. It “represents a serious attempt to address the inadequacies of past approaches to disability and rehabilitation” (Philpott, Pillay & Voce, 1995: 1). In South Africa this is especially important in underdeveloped areas. It is a response to the inappropriate approach of the institution-based medical model to disability where professionals, who manage disability matters from the viewpoint that disability is a medical problem that must ‘get better’.

Since 1976 CBR has been the preferred approach of the World Health Organisation (WHO), United Nations Educational, Scientific and Cultural Organisation (UNESCO) and the International Labour Organisation (ILO) for delivering services to meet the needs of disabled people (Sharma, 2004). CBR experienced a growth spurt in the 1980s and early 1990s (Philpott, *et al.*, 1995), and as a strategy has subsequently expanded all over the world (Zhao & Kwok, 1999).

This introductory chapter covers the history of CBR development on the international, African and South African fronts. Furthermore, it states the rationale, aim and objectives of this study.

History of CBR development

International developments of CBR

Finkenflügel (2004: 26) divided the development of CBR into five periods. The international developments of CBR will be discussed here according to these periods. The time periods before and after Finkenflügel’s periods have also been incorporated.

Before 1978

The starting point of CBR may be marked in 1976 by an unpublished WHO report called “Disability prevention and rehabilitation” (WHO, 1976 in Finkenflügel, 2004). Finkenflügel (2004: 3) states “CBR was presented as a new and promising approach to provide rehabilitation services to people with disabilities in developing countries”. Industrialisation played a significant role in the development of disability issues in developed countries. Before industrialisation, disabled people contributed to social life, but rapid industrialisation (between 1750s and 1830s) soon excluded disabled people from productive labour, which resulted in their placement into institutions (Marks, 1999). The context of disabled people in developing countries is more relevant to the pre-industrial context, as many of these countries’ populations are subsistence farmers living in rural areas where little industrialisation has taken place.

1978-1982: Early Beginnings of CBR

Finkenflügel sees this first period as the early beginning of the CBR strategy (Finkenflügel, 2004). The WHO coined the primary health care (PHC) approach at Alma Ata in Russia in 1978 (Parker & Wilson, 2000). The PHC approach aimed to make essential health care accessible to everybody, and was developed and promoted as the most appropriate way of improving health in developing countries (Walt & Vaughan, 1981 in Finkenflügel, 2004). CBR is in line with the PHC approach.

In 1981 the WHO Expert Committee on Disability Prevention and Rehabilitation published a document on CBR, called “Disability, Prevention and Rehabilitation” (WHO, 1981 in Finkenflügel, 2004). CBR was defined as follows:

Community-based rehabilitation involves measures taken at the community level to use and build on the resources of the community, including the impaired, disabled, and handicapped persons themselves, their families, and their community as a whole (WHO, 1981 in Finkenflügel, 2004: 3).

The WHO recommended the provision of essential services and training for disabled people through CBR (Finkenflügel, 2004). The bio-medical model still dominated the

approach to CBR, as impairment and disability were still associated with sickness, passivity and dependency.

1983-1987: A Rapid Expansion of CBR

CBR expanded rapidly after the publication of the manual, “Training Disabled People in the Community”, published by the WHO in 1983 (Helander, Mendis, & Nelson, 1983 in Finkenflügel, 2004). This sparked extensive discussion about CBR related issues, and heralded the implementation of many CBR programmes in developing countries. Despite the approach being adopted by seven United Nations (UN) organisations in recognition of the ‘Decade of Disabled Persons’ (1982 to 1992), CBR remained very much a concept bred and fed by the WHO, the main focus being medical rehabilitation (Finkenflügel, 2004). The ILO launched their Convention on International Standards to ensure equality of opportunity and treatment for disabled persons, in relation to employment and social integration, in 1983, which was more compatible with the social model of disability (Priestley, 2001).

1988-1992: Spirited Critiques on CBR

The discourse on CBR continued. Rehabilitation workers and social scientists extensively debated the basic assumptions of the WHO CBR strategy and the findings of the evaluations. The perceived benefit and potential, the model of CBR as ‘service delivery’ against the model of CBR as ‘more than rehabilitation’, and the definition of CBR, were all topics under debate. The most influential critics were people deeply involved in CBR or CBR-like programmes and not rehabilitation workers from the institutions who could have defended their concept of rehabilitation and their positions (Finkenflügel, 2004).

1993-1997: Seeking Consensus

In 1994 the ILO, UNESCO and the WHO came together and drew up a Joint Position Paper on CBR (ILO, UNESCO & WHO, 1994). This Paper marked the 1990’s as a period of consensus. The developments around CBR reflected the international developments regarding the general status and position of disabled people. A human

rights agenda for disabled people was established in 1993 when the UN Standard Rules on the Equalisation of Disabled Persons (UN, 1994) was adopted. Finkenflügel (2004) discussed the four emerging trends in rehabilitation at the time, namely human rights, expansion of CBR, standard terminology and the demand for information. Disabled people were no longer happy to be passive receivers of rehabilitation. Disabled people organisations (DPOs) began liaising with some CBR programmes and advocating the inclusion of disabled people in programme management, programme evaluation, and research.

1998-2002: The Scientific Basis of CBR

The need arose for an opportunity for those who worked in CBR to meet on an international level. In May 2003, the International Consultation to Review CBR was held in Helsinki, Finland, where the WHO, other UN organisations, international organisations of disabled people, representatives of governments and other stakeholders met. They discussed what they were doing in CBR and how they could continue to use CBR to promote the rights of all disabled people (WHO, 2003). Various topics were discussed and recommendations were made. (These recommendations are expanded on and compared with the findings of this study in Chapter 4.) Poverty, as a topic of discussion, grew in prominence and became a key issue for disabled people during this period. The eradication of poverty and the improvement of quality of life was the first priority of Disabled People International's (DPI) action plans of 1999-2002 (Priestley, 2001).

2003-current (2005)

WHO published a second Position Paper on CBR in 2004 after the Helsinki Conference. It reflects the changing emphasis of CBR in the 21st century towards a human rights approach with resultant action targeted against poverty (ILO *et al.*, 2004).

Continental: The African context of CBR.

The CBR approach has, to a certain degree, always existed in the African context, especially where the facilitation of families and communities of caring for disabled people is concerned. Official services and training for disabled people are, however,

fairly new and very rare in Africa. In the absence of any other services, families and communities have always been the source of care and training for disabled people (Asindua, 2002). A traditional system underlying care in Africa that is still very relevant today, can be described by the term 'Ubuntu':

The isiZulu / isiXhosa word "ubuntu" translates roughly as "humanity towards others". But it means much more than this. The spiritual foundation of African societies involves a belief in a universal bond of sharing that connects all of humanity, a unifying worldview, best captured by the Zulu maxim *umuntu ngumuntu ngabantu* - "a person is a person through other persons" (IMCSA, 2005).

The responsibility to care for one's neighbour, including the disabled person, is ingrained in the indigenous African culture.

The voice of the disabled people of Africa was strengthened when in 1992, in Nairobi, Kenya, the World Congress of Rehabilitation International took place for the first time on African soil. In September 2001, a similar conference was held in Uganda. Hartley (2002) published the ideas shared at this conference in a book called "CBR: A participatory strategy in Africa". The purpose of the conference was to bring key stakeholders together in order to provide the opportunity for them to share their experiences of CBR as a participatory strategy. It also aimed at laying the foundation for future co-operation and networking between groups and individuals. The publication (Hartley, 2002) provides evidence of a great deal of effort and good practice developing in CBR in Africa. It was mentioned that non-governmental organisations (NGOs) have fostered the development of CBR in Africa by bridging the gap between the grassroots and international organisations. Families, charities, NGOs, community-based organisations (CBOs) and the government, have made significant contributions to the rehabilitation of disabled people in the community.

Four key challenges for CBR in the African context were identified at the CBR Conference in Uganda (Mirembe & Hartley, 2002: 198):

- The need for a working definition of CBR.

- The need to raise awareness of the role of participation in effective CBR programmes.
- The need for CBR training and practice to be documented and synchronised nationally and inter-continentially.
- The need for all the stakeholder groups to have a clear understanding of their role in the CBR process and to know how this relates to the roles of others.

Following the resolution of the conference, the CBR Africa Network (CAN) was established in 2001. CAN is a NGO based at the Ugandan National Institute of Special Education, and aims to share information and promote best practices of CBR in Africa (Disability World, 2003). An international conference on behalf of CAN on CBR as part of community development was held in September 2004 in Malawi. The conference concluded that essential aspects important for the development of CBR were that the CBR programmes should address poverty in developing countries, share information and take a more pro-active stance at all levels (UCL News, 2005).

The South African context of CBR

The history of apartheid is very relevant to disability developments in South Africa. The 1970's played a significant role in the politicising of oppressed disabled South Africans, despite there being no disability rights movement in South Africa at that time (Nkeli, 1998). Many activists of the struggle against apartheid became impaired as result of violence in the struggle. The activist spirit did not become impaired in these disabled people, and they took the fight for liberation to a new level to reduce the oppression of disabled people. Today, South Africa has some of the best disability legislation in the world as result (Priestley, 2001).

South Africa became a democratic country in 1994. The first ten years of democracy in South Africa is marked by a phase of transition. The focus was on eradicating the inadequacies of the past to ensure equality for all people. Human rights became a prominent theme, as reflected in new legislations. Government took the responsibility for transformation, using strategies to fight poverty and underdevelopment, improved the

economy to reduce unemployment and allocated resources to ensure infrastructure for all (GCIS, 2005).

An example of such a strategy was the transformation of health services into a district health system to make it more accessible. Also, compulsory community service was implemented for newly graduated health professionals. This resulted in a wider distribution of health services in South Africa. Thus, South Africa differs from other African countries and countries who implement the WHO model of CBR. Although there is still a need under disabled people, it does have structures in place to bring services to most people in the community. CBR, had however, been implemented in South Africa even before these transformations.

Disabled People South Africa (DPSA) was formed in 1984 as a national cross-disability organisation to represent disabled people. DPSA shaped an organisation called the Rural Disability Action Group (RURACT) to spearhead the debate on rural development and CBR. This organisation was formed in 1986 by therapists all over South Africa who were working with disabled people in remote rural areas, especially in the province of KwaZulu Natal. At this time, DPSA and RURACT worked together to draw attention to the fact that disabled people were a neglected group (Cornielje, Ferrinho & Fernandes, 1994). They identified that institution-based rehabilitation services were often inaccessible and inappropriate and that the number of therapists trained in South Africa was insufficient to meet the need, particularly in rural areas where disabled people are geographically and socially excluded (Philpott *et al.*, 1995). They advocated that disabled people needed rehabilitation to be available in their own homes and communities and that a new cadre of workers, namely community rehabilitation workers (CRWs) fulfil this role (Ibid.). RURACT began mobilising and organising disabled people in rural areas.

As a result, CBR was first piloted in different parts of rural and urban South Africa during the 1980s (Rule, Lorenzo & Wolmarans, in press). RURACT also played the leading role in bringing stakeholders together – two meetings were held each year in different parts of the country. These interactions influenced the training of rehabilitation

mid-level workers through three pilot projects. The three CBR pilot training programmes were:

- 1987: The South African Christian Leadership Association (SACLA) Health Project in Khayelitsha, Cape Town.
- 1991: The Institute of Urban Primary Health Care (IUPHC) at the Alexandra Health Centre in Alexandra Township, Johannesburg.
- 1991: The Wits/Tintswalo CRW Project, later renamed Community Rehabilitation and Research Education Project (CORRE) in Bushbuckridge, under the auspices of the University of Witwatersrand, Johannesburg and Tintswalo Hospital, Acornhoek in Mpumalanga Province (Rule *et al.*, in press).

CREATE, which was a satellite of IUPHC in KwaZulu-Natal, and Mpumalanga Province's peer counselling initiative with DPSA, called the CBR-Disability Support Project (CBR-DSP), were more recent initiatives.

These programmes continued to operate after democracy, but there were numerous challenges, especially those of financial sustainability. CBR programmes in South Africa are mainly managed and funded by NGOs and little government involvement is in place. Despite the district health service system, policy support by the National Department of Health and strong commitment by rehabilitation professionals to meet the needs of all disabled people in South Africa, all disabled people are still not reached (Solarsh, in press). The CBR model for rehabilitation has not been adopted as a national strategy by government and other critical stakeholders (Ibid.).

Currently, the training of CRWs is a controversial issue in South Africa (Rule *et al.*, in press). Accreditation of CRW training has been under the auspices of the Professional Board for Occupational Therapy and Medical Orthotics/Prosthetics of the Health Professions Council of South Africa (HPCSA). From 2006, however, the Occupational Therapy Board would like to promote the training of Occupational Therapy Technicians for community work. They are likely to focus on medical rehabilitation with less consideration for equal opportunities and social inclusion of disabled people, as the

training will not have an in-depth input on, and understanding of, community development and skills (Ibid.).

In summary, CBR has expanded internationally and had been implemented in South Africa before it became a democratic society. The sustainability of CBR in South Africa seems fragile and the status of CBR after democracy is uncertain.

Statement of the problem

The statement, “the sustainability of CBR in South Africa seems fragile”, needs more exploration. Documented findings from evaluations of CBR programmes in South Africa have been poorly disseminated. The information gained from these evaluations has not been shared outside those involved in specific projects, nor has cross-referencing of findings between projects taken place. Few documented findings from these evaluations have been published, while those published usually only focussed on single aspects of these programmes. Two such published evaluations focussed only on management (M’Kumbuzi, 2003) and the value of CBR to parents (Shipham & Meyer, 2002). The opportunity to identify common trends and share lessons learnt in order to contribute to the sustainability of CBR programmes has not been seized. This has resulted in a lack of shared experience, duplication of mistakes, and the potential waste of resources. At present it is also difficult to gauge the specific or general status of development efforts and CBR programmes.

Rationale

The need for a study of this kind was expressed at a workshop held on 28 June 2004 at the Valley Trust in Botha’s Hill, South Africa (Philpott, 2004). CBR stakeholders identified the main challenges of the CBR strategy in South Africa at the workshop. The first challenge identified, is the lack of understanding of CBR in South Africa, especially in terms of the aim of CBR, lessons learned and the outcome of the impact of CRWs on communities. This study will provide an understanding of the successes, strengths, weaknesses, challenges and opportunities of approaches and methods used by CBR

programmes operating in the South African context. Secondly, it was realised that CBR as a strategy is not linked to the context in which it should operate, namely community development: there is a lack of common strategies for community development. The findings of this study could potentially contribute to future strategic planning concerning service delivery and community development by CBR workers. This will result in more successful planning and implementation of these programmes in the future, both in and outside the borders of South Africa, which would, hopefully, contribute to the sustainability of CBR in these regions. The need for inter-sectoral collaboration (NGOs, government, the private sector and training centres) and partnerships (e.g. with DPOs) was identified at the workshop as a third challenge. Findings from this study will be useful in identifying areas for collaboration between NGOs, the private sector and government; furthermore these findings could facilitate the formation of partnerships with regards to policy formation and implementation of CBR. The fourth challenge is the need for evidence-based motivation for CBR implementation in South Africa. Research and evaluation of CBR in South Africa is therefore crucial. This study will thus contribute to the evidence base by documenting existing evaluation reports on CBR. The training in CBR was identified as the fifth challenge. This includes the actual training of CRWs, the registration of CRWs and the training of therapists to work alongside CRWs. The findings of this study will potentially contribute towards future planning and motivation for such training. In summary, the results of this study could contribute towards the much needed development of CBR in South Africa.

Aim

The aim of the study was to analyse evaluation and annual report documents of CBR programmes to develop a deeper understanding of the current status of CBR practice in South Africa.

Objectives

The objectives of this study were:

1. To identify contextual issues of the CBR programmes, for example location and background.
2. To identify activities and projects put in place through the CBR programmes.
3. To identify the common trends, successes, strengths, weaknesses, challenges and opportunities of the CBR programmes in South Africa.
4. To identify innovative approaches and methods for future direction and development of CBR.

Delimitations

All CBR programmes operating in South Africa were not covered in this study. As the scale requirement of a mini dissertation had to be met, inclusion was limited to programmes actually in operation in CBR philosophy. This meant the exclusion of community outreach programmes that merely deliver medical rehabilitation (part-time service delivery to disabled people in the community from a central institution, i.e. a clinic or hospital). The availability of evaluation reports also limited inclusion.

Programmes focussing on the training of CRW's were also excluded. Training is an immense and controversial topic, especially in the South African context, and a proper appraisal is a subject for a separate study.

Chapter 2

Literature review

A literature review was done to develop a better understanding of the definition and philosophy of CBR. Key issues identified were: community development and poverty alleviation, inter-sectoral collaboration in and with stakeholders of CBR, and sustainability.

Defining CBR

CBR has been implemented in many different ways throughout the world. Different programmes have had different emphases (Rule *et al.*, in press). The WHO and other UN organisations played a major role in promoting CBR over the last two decades, which has resulted in the development of CBR programmes in many countries. The most used and accepted definition of CBR is stated in the Joint Position Paper on CBR (ILO *et al.*, 1994). It defines CBR as:

A strategy within community development for the rehabilitation, equalisation of opportunities and social integration of people with disabilities. It is achieved through the combined efforts of people with disabilities, their families, and communities and the appropriate health, education, vocational and social services (Ibid.: 1994: 3).

This Joint Position Paper was reviewed in 2003 at the International Consultation to Review CBR, in Helsinki, Finland. A second Joint Position Paper on CBR (ILO *et al.*, 2004) described and supported the evolution of the CBR concept. A few changes were made in the definition to include the broader aspects of CBR (changes underlined):

CBR is a strategy within a general community development for the rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organisations and communities and the

relevant governmental and non-governmental health, education, vocational, social and other services (ILO *et al.*, 2004: 2)².

The objectives stated in the Joint Position Paper (ILO *et al.*, 2004) are idealistic in the sense that implementation thereof is difficult in rural, poverty stricken areas, so predominant in the South African context. Where there is a need for basic nutrition, resources to ensure access to services and opportunities are usually low in priority. Social inclusion is only possible if cultural, communication and access barriers are removed, which in turn may only be accomplished over time and with perseverance. This study will shed some light on the situation of CBR in South Africa.

The value of the two ILO, UNESCO and WHO (1994, 2004) documents on CBR is that they outline a vision for policy makers and practitioners. Finkenflügel (2004) identified the need for discussion and research that extends beyond particular projects and provides a broader perspective on CBR to build the theoretical framework thereof. He said that theory building for CBR has been weak. He suggested that the WHO model of CBR could be used as a framework to develop a programme theory on CBR. He also stated that issues raised by critics of CBR appear to be of direct importance in constructing a programme theory, which pertains mainly to the relevance and the cost-effectiveness thereof. The benefit of the WHO model is that it could aid in clear goal formation for a programme theory that could in turn be used as an indicator for evaluating relevance and effectiveness. The limitation of the WHO model is that its principles are not always culturally relevant in terms of a community's understanding of, and interest in, the problem. The WHO model could more effectively be used, together with the UN Standard Rules (UN, 1997), as a framework for theory building to ensure that programme theory will lead to the equalisation of opportunities for disabled people.

The WHO model (ILO *et al.*, 1994, 2004) and the UN Standard Rules (UN, 1994) were used as conceptual frameworks for this study. A more comprehensive description of the concepts surrounding the definition of CBR, as presented below, was gleaned from literature reviewed for this study.

² Reference to the definition of CBR in this study will henceforce refer to this specific one.

Concepts on CBR

The concepts mentioned in this section are the “ingredients” of the CBR strategy, and therefore, should be understood and considered when reviewing CBR in South Africa. It is presented according to aspects of the definition of CBR (ILO, *et al.*, 2004).

“CBR is a strategy within general community development for ... poverty reduction...”

Poverty alleviation is one of the main focuses in CBR and the disability sector (Hartley, 2002). The first priority of DPI is to eradicate poverty of disabled people (Priestly, 2001). Poverty alleviation within community development is the newest addition to the definition of CBR for the reason that there “is a strong correlation between disability and poverty” (ILO *et al.*, 2004: 4). Poverty may cause impairment, for example lack of adequate nutrition, and it may cause disability, for instance denial of education (Stone, 2001). On the other side of the cycle, impairment and disabling societies causes poverty. The deprivation trap (Chambers, 1989 in Stone, 2001) is a framework that reflects the complicated nature of poverty and disability: Poverty is explained in terms of the complex nature between powerlessness, impairment, vulnerability, poverty, isolation and disability (Stone, 2001).

Poverty alleviation and sustainable development are first on the agenda of social development discourse in the world today. They are also a central theme of the ruling political party in South Africa, the African National Congress (ANC), as stated by Thabo Mbeki, President of South Africa: “We should do by consolidating the people's contract, ensuring that we work with local, provincial and national government to fight poverty and underdevelopment” (GCIS, 2005: 1). The implication of CBR, being a strategy within general community development, is that it does not take place in institutions but within the community itself. The definition of CBR highlights that CBR is not a separate initiative, but that developmental strategies aimed at disabled people should be included in general development agendas.

“...for the rehabilitation...”

The concept of rehabilitation in CBR includes the social model approach, as it aims to remove physical, social and physiological barriers for disabled people. It further focuses on human rights and participation of disabled people (ILO *et al.*, 2004). It encourages disabled people to reach their potential and enables them to develop their abilities. The question that arises is whether rehabilitation in South African CBR currently reflects this broader concept of rehabilitation, or whether it only includes medical rehabilitation.

“...equalisation of opportunities...” and “...social inclusion...”

The equity concept of CBR was included in the CBR definition after the UN declared 1982-1992 as the decade dedicated to disabled people and disability issues, and is in line with the UN Standard Rules (UN, 1994). The Joint Position Paper on CBR (ILO *et al.*, 2004) stated that the UN Standard Rules (UN, 1994) should serve as a guide to all CBR programmes, as it addresses the steps to ensuring disabled people’s rights.

Social inclusion implies the adaptation of structures and procedures to facilitate the inclusion of disabled people, rather than expecting disabled people to change to fit into existing arrangements of society (ILO *et al.*, 2004). In CBR, the community takes responsibility for the removal of barriers for disabled people (Ibid.).

“...of all people with disabilities...”

The word “all” implies that CBR is not just for certain categories of impairment but is a strategy for any kind of impairment. Further, CBR deals with impairment and disability, for example, CRWs trained in South Africa by IUPHC, CREATE, CORRE and SACLA represent a model of CBR that uses mid-level CBR workers who are employed to provide services, which include physical and psychosocial rehabilitation. They are thus trained to deal with impairment, but are also trained to facilitate community development, social integration and the equalisation of opportunities, thus all aspects of disability.

“CBR is implemented through the combined efforts of people with disabilities themselves, their families, organisations, communities and the relevant

governmental and non-governmental health, education, vocational, social and other services.”

With the development of CBR, programmes have moved from working in isolation from each other, to more sectorial collaboration in recent years (Rifkin & Kangere, 2002). They “have formed CBR committees, from the national to the grass root level, with members from all stakeholder groups” (Ibid.: 47). Government, NGOs, and training institutions have combined efforts for joint planning and training concerning CBR. This is also more and more the case in South Africa, as Rule *et al.* (in press) mentioned: “The concept of interdependence of the different stakeholders and DPOs to achieve the goals of CBR programmes is gaining more recognition, as it is culturally inherent in African beliefs, customs and values”.

Combined efforts imply “collaboration” of stakeholders, but although the word implies “working together”, it is the source of many challenges in CBR. Different stakeholders have different interests and objectives in mind for CBR programmes. Mirembe and Hartley (2002) identified the need for all the stakeholder groups to have a clear understanding of their role in the CBR process and to know how this relates to the role of others. Firstly, the role of disabled people was investigated.

Disability is currently seen as a human rights issue and CBR today has a human rights perspective (ILO *et al.*, 2004; Finkenflügel, 2004). CBR emphasises the participation of disabled people and ownership are expressed as underlying principles in the UN Standard Rules (UN, 1994). Almost all the rules state that disabled people need to be involved in the aspects of the programmes that concern themselves. The most important underlying principles in the implementation of CBR are that the programme belongs to the community and disabled people. Involvement leads to a sense of ownership of the programme. Rights are always interconnected with responsibility, and Thomas and Thomas (2002) has correctly stated that the promotion of the rights of disabled people is seen together with the promotion of their responsibilities to contribute maximally. It is therefore not strange that, with the emphasis on human rights in the current discourse around CBR, it is most appropriate that the central agenda is the ownership of CBR

programmes by the DPOs. Ndaziboneye (2002) suggested that DPOs should have a stake in the development, implementation, monitoring and evaluation of all CBR programmes at all levels.

NGOs have played a very significant role in pioneering CBR programmes. Their ability to be accountable to donors for the delivery of services at community level through consulting with the beneficiaries and their flexibility, are largely responsible for the metamorphosis of CBR and arguably, its survival as a viable strategy. But government involvement in CBR remains crucial.

The Helsinki Report (WHO, 2003) stressed that government support in terms of funding, policies, and the mobilisation of community resources, is needed for CBR development. Moreover, specialised services should be mainstreamed to include disability related issues. Strengthening of referral services is also essential. Government poverty alleviation strategies should incorporate disability dimensions, but the cost effectiveness of CBR will have to be demonstrated to ensure funding from government and donors. Rule *et al.* (in press) further stressed this for CBR in South Africa: “The challenge facing people involved in CBR is to bring the issue of CBR to the provincial and local levels of government and to encourage support and resources from the various government departments that could be involved”.

In summary, all partners, UN agencies, international and local NGOs, in collaboration with governments, should promote CBR in programmes for development and poverty alleviation as a strategy for the social inclusion of disabled people.

Sustainability

Asindua (2002) has correctly said that sustainability remains a challenge for CBR. There are many suggestions in the literature to ensure sustainability. The Joint Position Paper (ILO *et al.*, 2004) elaborates on the need to encourage existing CBR programmes to expand their activities to other communities, to pay attention to gender equality, and to include disabled people from all age groups. But the document (Ibid.) mainly addresses sustainability by mentioning three interlinked factors, namely, the articulation of a need,

the response from within the community indicating their readiness to meet the need, and the availability of support from outside the community. These factors are interlinked by the role of legislation, inter-sectoral collaboration, evaluation and sharing, and documentation of information, for contributing to the sustainability of CBR.

Effective legislation is needed to protect and facilitate CBR programmes, as this may facilitate the smooth organisation and delivery of CBR programmes. However, Hartley (2002) has noted that it has also been shown that legislation alone may not suffice, especially where the co-operation of other institutions is required. In South Africa for example, despite existing policies such as the INDS (ODP, 1997) and National Rehabilitation Policies (DOH, 2000a), there remains a need to develop implementation mechanisms that would contribute to the growth of a common understanding of CBR as a strategy within community development, for the alleviation of poverty (Rule *et al.*, in press). For the implementation of the policy, the co-operation of government institutions, community institutions, DPOs, and others, is needed.

Collaboration was discussed in the previous section, but it is important to realise that effective collaboration is vital for the sustainability of CBR. One reason, stated in the Helsinki report (WHO, 2003), is that collaboration among CBR programmes in different countries is important, as one programme may benefit from the experiences of others.

CBR is very diverse and although diversity is appreciated, it means that knowledge and experience gained in one project is not easily generalised with others, and thus comparing projects becomes difficult (Finkenflügel, 2004). It is here, however, that studies and evaluations that reveal knowledge and evidence for CBR become important. Zhao and Kwok (1999) recognised that the initial evaluation of a particular CBR project should focus on the core factors of effectiveness, efficiency, relevance, sustainability and impact. Evaluation and monitoring may reveal the challenges to making projects sustainable.

The benefits of evaluation are that it determines whether a programme is effective, it helps in directing improvements, as weaknesses are identified, it plays an essential role in securing programme funding and it increases knowledge of CBR (CBR News, 1998). Without evaluation the impact of CBR is not confirmed, which can, in turn, affect the

credibility of CBR programmes and lead to confusion for both the service providers and users (Hartley, 2002). A shortcoming of the literature on evaluation is that it does not recommend who the evaluators should be. This is, however, a very important aspect to identify, as evaluation requires highly developed skills.

The evaluation of programmes is common, but despite “the fact that self evaluation or regular external evaluation is recognised good practice, there is little collaborative sharing of such evaluations between programmes” (Wirz, 1996: 4). Hartley (2002) also stressed that there is a need for more effective sharing of information both within the African continent and internationally. She identified that information sharing is equated with professionals conveying information to lay people. Although this might be true in a formal sense, Hartley has neglected the fact that information sharing is usually reciprocal, which highlights the need to acknowledge the information gained from lay people’s experience. Moreover, Rule *et al.* (in press) identified that delegates involved in international consultations on CBR need to give feedback to the grassroots structures such as DPOs, community development, as well as to higher education institutions and centres.

Documentation used for networking is valuable as it helps to limit duplication of efforts, and assists in the sharing of experiences, techniques, created materials and lessons learned (Brar, 1992). Further, documentation serves various purposes, such as routine monitoring, the evaluation for accountability, policymaking and planning, training and motivation and public education. South Africa is plagued by resistance to CBR from some sectors. Documentation is thus a crucial need in South Africa.

Finkenflügel (2004) did a literature search on CBR in Southern Africa (South Africa and neighbouring countries, including Malawi and Angola) and found twenty-nine articles as well as much grey literature (progress and evaluation reports, brochures, electronic resources, annual reports, newsletters, theses, chapters in books). All in all he searched ninety-seven documents, covering approximately thirty-five projects. He then excluded South Africa from his study, although a number of projects on CBR in South Africa were found. His experience was that the available documentation described CBR projects only

marginally as it was fragmented and focused mainly on the training of CRWs. He commented:

It is therefore very hard for people interested in CBR to assess and become familiar with their projects unless they are directly involved in that specific project. This not only hampers sharing information and learning from each other, it also neglects the question of whether or not the chosen approach met the expectations of the disabled people as well as other stakeholders in the project. (Finkenflügel, 2004: 107)

It may thus be concluded that there is a need for critical documentation regarding CBR developments in South Africa.

Chapter 3

Methodology

The aim of this study was to develop a deeper understanding of the practice of CBR in South Africa. It was thus necessary to find a method of identifying common trends and of documenting lessons learned in the development and implementation of CBR programmes in South Africa. The research design and process are explained here, ethical considerations are mentioned, data analysis is described and the details of the scientific rigor of this study are given. The limitations of the methodology used, are also considered.

Qualitative research design

The study took the form of a qualitative research design. Instead of trying to explain the reality of CBR in South Africa by means of objective “facts” and statistical analysis, a more personalised interpretative process was used to understand “reality” (Vera, 1983 in Cornielje *et al.*, 1994). This study was, therefore, exploratory research. It took the form of document analysis of evaluation and of annual reports of CBR programmes in South Africa.

Research process

Population

The study *population* included all the programmes in South Africa that are implementing CBR.

Sample

The *type of sampling* was purposive because the selection of CBR programmes was deliberate. The type of purposive sample was a convenience sample that "... entails use of conveniently available [programmes] as study participants" (Sharma, 2004: 331).

The CBR programmes included in this study, met the following *criteria*:

- Operating within the borders of South Africa.
- Operating after South Africa became democratic in 1994.
- See CBR as a strategy for community development.
- Operating full time in the community, not community outreach.
- At least one year in operation.

The documents used for the study, met the following *criteria*:

- Any evaluation report done in the time frame of 1994 to 2004.
- Any evaluation report done on the activities, planning and implementation of the CBR programme.
- Any annual report where no evaluation reports were available for a programme.

Access to the programmes and choice of documents

Three programmes were identified for this study, namely the Valley Trust (VT) operating in the Valley of a Thousand Hills in KwaZulu Natal province, Mpumalanga CBR Disability Support Project (CBR-DSP) operating in the Mpumalanga province and the South African Christian Leadership Association (SACLA) Rehabilitation Project that operated in informal settlements surrounding Cape Town. The documents used were as follows:

- Dube, A. K. (2003). *Final evaluation report on the impact of the Mpumalanga Community-based Rehabilitation (CBR) Disability Support Project*. Unpublished document. Nelspruit: DPSA

- Lorenzo, T. & Saunders, L. C. (1999). *A general evaluation of the SACLA Rehabilitation Project*. Unpublished document. Cape Town: SACLA Rehabilitation Project.
- Valley Trust. (2004). *The VT 2003/2004 Rehabilitation Annual Report*. Unpublished document. Botha's Hill: VT.

SACLA merged with two other PHC NGOs to form Zanempilo Joint Primary Health Care Programme in March 2002. The researcher also had access to Zanempilo's final evaluation report (Haricharan & Rendall-Mkosi, 2002), but the focus of the report was on PHC and the organisational processes. It revealed very little information on the CBR project, and was, therefore, not used to derive findings from, but only as a reference.

Also, an evaluation study was done of the VT CBR project (Solarsh, in press). Data was collected from January 2001 to June 2002, but unfortunately, results were not yet available at the time of this study. The researcher did have access to an unfinished report of this study, and it was used to compare findings with where possible.

Data generation

Programmes were not visited at the time of the study due to time and distance constraints. Contact was made and kept via telephone and e-mail. The contact persons were mainly programme managers, rehabilitation managers in projects and administrative staff.

Documents were used as the source of information in this study. May (1993: 133) states that documents can “tell us a great deal about the way in which events were constructed at the time, the reasons employed, as well as providing materials upon which to base further research investigations”. The relevance of using documents was in the approach of secondary analysis used to generate new knowledge, but also to support existing phenomena of CBR in South Africa (Heaton, 2004). A benefit of document analysis was that “it reduces the burden placed on respondents by negating the need to recruit further subjects” (Ibid.: 3). Further, the use of documents allowed the researcher “a wider use of data from rare or inaccessible respondents” (Ibid.: 3), for illustration, the CBR

programmes under review were widely spread in the country and beneficiaries were from different language groups, thus creating distance and language barriers to the researcher.

Scott (1990 in May, 1993: 135) has defined documents as “a written text ... documents may be regarded as physically embodied texts, where the containment of the text is the primary purpose of the physical medium”. Documents can be classified into three categories. The first category consists of primary, secondary and tertiary sources (May, 1993). Primary source materials are documents written by those who witnessed the events described. In this study, evaluation reports done by members operating and benefiting in the particular CBR programme (for example CRWs and disabled people who were served through the programme) and annual reports were included. To see these sources in a social context, the researcher may employ secondary sources, written after an event, and which the author had not personally witnessed (Ibid.). In this study, documents in this group included the VT website (www.thevalleytrust.org.za). Texts that enabled the researcher to locate other references are grouped under tertiary sources and were used in the discussion section of this study to compare findings with existing literature (see Chapter 4).

In the second category, documents are grouped as private or public documents (May, 1993). The CBR reports used in this study were all classified as public, as access was not restricted. The third category consists of solicited and unsolicited documents: some documents might have been produced with the aim of research and others might have been for personal use (Ibid.). The evaluation reports of the CBR programmes had research approaches, but the main aim was of personal use to the programme and to report to funders. The annual report used in this study falls under the category of unsolicited documents.

Approaching a document

Two criteria, identified by Scott (1990 in May, 1993), for assessing the quality of the evidence available from the documentary sources were used. Firstly, documents *authenticity* may be assessed for obvious errors or inconsistencies in its representation,

internal inconsistencies in terms of style and content or inconsistent in relation to other similar documents. Documents used did not reveal such inconsistencies.

Secondly, the *credibility* of the document refers to “the extent to which the evidence is undistorted and sincere, free from error and evasion” (Scott, 1990 in May, 1993: 144). To assess this, it is important to look at the social and political context, and the author’s stand in this area, in which the document was produced. Unfortunately, it was not possible to comply fully with this requirement in this study, as the researcher was detached from the context in which documents were created.

Finally, the questions “what is it?” and “what does it tell us?” were asked to assess the documents *meaning*: “the clarity and comprehensibility of a document to the analyst” (May, 1993: 144). An idea of the background and social context of the organisations in which the document was produced, enabled understanding of meaning.

Procedure for data collection

The researcher asked for access to evaluation documents, preferably in electronic format. Mpumalanga CBR-DSP e-mailed their evaluation report from the DPSA office in Mpumalanga and the Valley Trust e-mailed an annual report from their centre in Botha’s Hill, KwaZulu Natal. A copy of the SACLA evaluation report was obtained from the compilers in person.

Ethical considerations

Informed Consent

Programmes were contacted telephonically and the research explained. A letter (Appendix 1) that explained the research with an informed consent form (Appendix 2) was then e-mailed to the programme.

Confidentiality

Information and documents were treated with confidentiality, especially in terms of access to privileged information. Only the researcher, auditor, supervisor and the persons of the participant organisations conducting member checks had access to the information at time of the study. Anonymity was respected if informants preferred this, or where otherwise applicable. The right to privacy was respected. This was stipulated in the consent form.

Possible risk and benefit from the research

The risk of participating in this study was related to the weaknesses of the CBR programmes possibly being exposed. On the other hand the benefit was that the findings on weaknesses would reveal lessons to be learnt by one another. Benefits were also described under the rationale for this study in Chapter 1.

Data analysis

The data analysis process is described in this section. Duffy (1985 in Krefting, 1991: 216) has correctly described strategies of qualitative research as “unstructured and often spontaneous”, as different analysis approaches was used.

Transcription of data and preparation for data analysis.

This section describes the transcription of data and preparation for data analysis. The data used were received in electronic format. Graphics and special characters were removed from the documents and the remaining text was then saved in rich text format and finally imported into the Nudist Nvivo® software tool. Graphics and special characters are not accessible to Nudist Nvivo®, but links to external documents were formed to increase access while analysing. Printed copies of the original documents were accessed during analysis to ensure that the relevant removed parts of documents were taken into consideration (for example, graphs and tables).

Methods and stages of analysis

Thematic analysis was used to create categories and to detect themes (a phenomenon), with the use of the computer assisted qualitative data-analysis software package, called Nudist Nvivo®. The process led to identifying the who, what, why and how.

The unit of analysis was the CBR programme documents. Coding involved the logic of conceptualisation, namely the problem of lack of understanding of CBR in South Africa due to limited dissemination of information, and operationalisation, namely the categories derived in analysis that were collapsed into themes (Babbie & Mouton, 2001).

Ryan and Bernard (2003: 2) defined themes as “abstract, often fuzzy, constructs, which investigators identify before, during and after data collection”. The method used for identifying themes in this study was a combination of techniques described by Ryan and Bernard (2003). Sharma (2004) described the steps of data analysis, and are also included.

The researcher read through the documents before starting the analysis to enable her to get a general idea of the content. The text used was not already associated with themes. Thus on first reading, prominent units of meaning were clearly noticeable and were therefore highlighted. This is described as the first stage of the “unmarked texts” (Ryan & Bernard, 2003). Documents were read for a second time and text were coloured to highlight very broad units of meaning. For example, the context in which the programmes were practicing was one colour and programme design another. One colour was used to eliminate text that was not relevant for this study. This technique is similar to the technique described as “pawing” (Sandelowski, 1995 in Ryan & Bernard, 2003). Pawing is the reading of text and marking it with different colours. Text is handled several times, and pawing starts with proofreading text and simply underlining key phrases. Pawing was thus done every time the text was handled, and in the later stages, instead of marking text with colours, codes were created within Nudist Nvivo® and stored in free or tree nodes.

From the above description of the early stages of analysis, it is clear that theme identification started as key concepts were identified. New concepts emerged as the text was searched, and were added in the process. Sharma (2003) described this as the first step of data analysis, called open coding.

In the next stage, namely axial coding, the concepts were sorted into categories of similar meaning, and then stored in tree or free nodes (Sharma, 2003). The categorising process repeated itself several times. Ryan and Bernard (2003) called this technique “Keywords-in-context”. Next, the technique of “cutting and sorting” was used. The categories were organised together in sub-themes of similar meaning. With cutting and sorting in the manual way, quotes are cut and pasted on cards with its references on the back (Ryan & Bernard, 2003). In Nudist Nvivo®, text were coded and stored in nodes as categories, and then sorted into sets (sub-themes). A node report was created on a specific sub-theme, and revealed where and in what document it appeared. Table 3.1 is a diagrammatic description of how nodes and sets of Nudist Nvivo® were used in this study.

Table 3.1: Stages of analysis

| Steps of analysis | Nudist Nvivo® | Units of meaning | Examples in this study |
|-------------------|--|------------------------------------|---|
| Open coding | Codes ↓ | Concepts | Occupational therapists, social worker |
| Axial coding | Nodes: Free or Tree ³ ↓ | Categories (and sub-categories) | Professionals (types of professionals, their role in CBR) |
| | Sets ↓ | Sub-theme | Stakeholders, Collaboration |
| | Set reports were sorted | Theme | Participation is key to progress |

³ Free nodes entail codes without organising and tree nodes are codes with hierarchical organising, thus categories with sub-categories.

It was a major challenge to present these findings in its current format, as categories in the sub-themes were overlapping and repetitive. The researcher then reviewed the findings on sub-themes. The cutting and sorting process was repeated. Data was re-organised and the sub-themes were collapsed into main themes. The point at which no new themes were identified is called theoretical saturation (Strauss & Corbin, 1990 in Ryan & Bernard, 2003). To ensure this was achieved, the researcher compared the categories with literature and dialogued with an auditor.

It is in this final stage of data analysis where text is refined, that Sharma (2003) suggested that concerns of data interpretation must be addressed, namely trustworthiness.

Scientific rigor of the study

The criteria applied for trustworthiness as described by Krefling (1991) were used. Four aspects of trustworthiness were relevant. Firstly, *credibility* was a reflection of the richness of “multiple realities that are multiply interpreted” (Sharma, 2004: 332). Strategies to ensure credibility included member checking, peer review and reflexivity. Member checking was done by disseminating findings to the participant organisations. Management delegates of the organisations confirmed the truth of findings on their programmes and irregularities were cleared. For peer review, the research process, results, problems and insights were discussed with the supervisor on a regular basis to stay impartial.

The strategy of reflexivity was used to ensure that the researcher was aware of influences on the data (Krefling, 1991). This entailed the assessment of the influence of the researcher’s personal history (Ruby, 1980 in Krefling, 1991). The researcher’s reflexive journal revealed perceptions of disability from both a medical model and social model perspective.

Reflexivity was also an important strategy for *confirmability*, the second criteria used. Confirmability is “the degree to which findings are a function solely of the informants and conditions of the research and not of other biases, motivations and perspectives” (Guba, 1981 in Krefling, 1991: 216). Further, the strategy of an audit was used to ensure

confirmability. Audibility “suggests that another researcher could arrive at comparable conclusions given the same data and research context” (Krefting, 1991: 221). An external auditor was asked to read through the research data (the three documents) after the researcher had already analysed some data. The researcher explained the methods of analysis and interpretation to the auditor to ensure a similar approach to the data. The researcher then dialogued with the auditor and compared results in terms of 'rich' descriptive themes and categories. This increased credibility, as it confirmed the categories developed by the researcher.

Thirdly, *dependability*, asks if the findings would be consistent if the inquiry was replicated in the same context (Krefting, 1991). A comprehensive description of research methods was given which would allow other researchers to repeat the study, in other words, make it auditable. The audit strategy contributed to the dependability of this study.

Fourthly, *transferability* (Ibid.) was determined through rich descriptions that were given to explain phenomena in this study. In this study, the reader is provided with descriptions of the context of the CBR programmes. This ensures understanding of the framework in which the programmes operated to allow for comparison with findings, therefore, allowing the reader to assess the transferability of findings.

Limitations of the methodology

The type of methodology used, as well as the way in which the researcher conducted it, did reveal some weaknesses. Limitations are presented in terms of the limitations of using documents, the sample, qualitative analysis, research design and criteria applied for trustworthiness.

The researcher was limited to the content of the documents, and, therefore, experienced that some information of the CBR programmes did not appear in the text. Lorenzo and Saunders (1999: 27) said that experience “shows that vital information may be missing from records. Data from records usually requires more preparation, care and effort in analysis”. Further, the quality of data from the various documents varied. Member

checking was done, but it is recommended that researchers doing a document search similar to this study should do in-depth interviews with relevant stakeholders to ensure all the required information is gathered.

The sample used was not a large representation of CBR intervention in South Africa. The findings did lead to a better understanding of CBR in South Africa, but may not be necessarily generalised. This is a characteristic of the qualitative research approach. It is thus recommended that the study be expanded to include all other CBR programmes that meet the sample criteria (see Chapter 3) in South Africa.

In terms of the design, the limitation of inductive analysis was that theme identification was influenced by concepts in literature accessed by the researcher. Qualitative analysis was “based on subjective interpretations, and therefore often have the potential to be biased” (Sharma, 2004: 334). Criteria applied for trustworthiness, were applicable to minimise bias, but the researcher was still limited by the restricted amount of her own knowledge and experiences in the topic of CBR.

Lincoln and Guba (1985, in Krefting, 1991) suggested that an auditor should be included at the beginning of the research and then be used in an ongoing manner throughout the research process, to determine the nature of the audit trail. The second step of data analysis is called audit trail and Sharma (2003: 332) described it as “means of linking the data identified in open coding with the source and context”. This was internal to the functions of the Nudist Nvivo® software programme. The auditor did not follow the audit trail. The auditor only became involved in the final stages of the research. Although this is not suggested in literature, it did prevent the auditor of becoming co-opted into the study and thus losing objectivity (Krefting, 1991).

Chapter 4

Findings and discussion

Introduction

This chapter presents the findings and discussions of three CBR programmes. It starts with the backgrounds of the programmes. Thereafter, the findings are firstly presented under the theme of stakeholders in CBR, followed by an elaboration on CRWs⁴ as a second theme. The final theme discusses the influences of the CBR programmes on sustainability. Discussions on each theme are included with comparisons to literature.

Background of the programmes

Descriptions of the backgrounds, location and staff establishments of the programmes were determined from the documents. The reader is also introduced to the evaluation methodology of the documents used. This section thus reveals contextual issues of the programmes.

CBR Disability Support Project (CBR-DSP), Mpumalanga

The CBR-DSP was the result of Mpumalanga Department of Health contracting DPSA in 1998 to implement a CBR programme in the Lowveld region of the province. The type of areas in which the programme operated, were described as rural, semi-urban and

⁴ It is important to note that the CRWs differed for the three programmes based on their training. SACLA used CRWs and the VT used CRFs that represent a cadre of mid-level workers doing medical rehabilitation and facilitate the social inclusion and equal opportunities of disabled people, as well as community development. CBR-DSP used disability consultants that represent grass root level workers focussing on the inclusion, equity and community development aspects. The term 'CRWs' will be used to refer to all three cadres of workers in Chapters 4 and 5 for the purpose of clarity.

urban, including farm and mine areas. The programme was formally implemented in October 2002 and extended throughout the province.

Twenty-nine disability consultants, mostly disabled people, were recruited and trained to implement the CBR service. Their training was not intense in terms of length of time (minimum 50 hours) in comparison to training of CRWs and CRFs. They worked province-wide in Mpumalanga with between one and three consultants per municipality (there are seventeen). They worked alongside professionals from the Mpumalanga Health Department and social workers from Health or other departments or organisations.

The document used for CBR-DSP was a final evaluation report for the year ending 31 October 2003 (Dube, 2003). The programme had been in existence for five years at the time of the evaluation. The aims were to assess the impact of the project and to identify approaches and methods to improve and expand the service. A participatory research approach was used and a Project Assessment Tool was designed to obtain input from professional rehabilitation staff of the Department of Health (DOH). The CBR-DSP consultants also completed and submitted statistical data forms.

The Valley Trust (VT), KwaZulu Natal

The Valley Trust is a PHC organisation in the Valley of a Thousand Hills just outside KwaZulu Natal Province's major metropolis, Durban. The rehabilitation programme was the result of the success experienced with a support group for parents with disabled children that was formed by the VT, in collaboration with the Department of Health Sciences of the University of Durban Westville and the community, in the early 1990's. Its start was marked by the launch of a Rehabilitation Centre in May 2001, at the Halley Stott Health Centre, based at the Valley Trust. In the year before the launch of the centre, six young people from the areas were selected and trained as CRFs for two years at the UIPHC, later CREATE. The programme was expanded in January 2003 by including another six CRFs. The programme was offered in nine rural areas, four of which fall outside the Valley of a Thousand Hills.

The programme also employed full time professionals. These included a rehabilitation co-ordinator, an occupational therapist, a rehabilitation assistant and a speech language and hearing therapist. A volunteer, a behavioural therapist, was also involved in the rehabilitation programme for a while. The staff of the CBR programme worked hand in hand with other staff employed by the organisation, especially with CHWs and the welfare assistant. Other professionals involved in the programme, but not employed by the programme, were usually health professionals from nearby institutions, for example, physiotherapists and community service therapists.

The VT CBR Rehabilitation Annual Report of April 2003 to March 2004 (VT, 2004) was used. The CBR programme had existed for 3 years at the time.

South African Christian Leadership Association (SACLA) Rehabilitation Programme

SACLA Rehabilitation Project came into operation in 1987. SACLA's area of practice was in informal settlements around the Cape metropolis. SACLA also operated in settlements around semi-urban and rural farm areas in the Boland region of the Western Cape Province. From 1998, the Project was in a merger process and Zanempilo was formed in March 2002. SACLA was then in a partnership with Health Care Trust (HCT) and Zibonele and the National Progressive Primary Health Care Network (NPPHCN) Centre for Learning (CFL).

A physiotherapist started the rehabilitation programme. The Project trained twenty-five mothers of disabled children as CRWs between 1987 and 2000. CRWs received three to six months training, as well as regular in-service training at SACLA. Volunteers working in day care centres, as carers, were part of the team. Professionals, for instance occupational therapists, physiotherapists and social workers, were also involved.

The General Evaluation Report of the SALCA Rehabilitation Project of 1999 was used (Lorenzo & Saunders, 1999). The programme had existed for eleven years at the time of the evaluation. It focused on the organisational effectiveness of the programme and the rehabilitation skills of the Community Rehabilitation Workers. Information was gathered

from staff and clients at workshops using story-telling, small group discussion, peer interviews and other participatory methods.

Discussion

Finkenflügel, (2004: 10) mentioned that formerly, “the community had been perceived as a relatively well-confined (geographical) entity. CBR was very much a model for rehabilitation of people with disabilities living in rural areas”. The CBR programmes under review operated in rural areas, as well as urban and semi-urban areas characterised by poverty. This is in line with the development of CBR, as the WHO approach to CBR was developed for the rural and urban poor of developing countries (WHO, 1982 in Finkenflügel, 2004). As CBR developed through the years, it was understood to be appropriate for all industrialised and developing countries (ILO *et al.*, 1994, 2004).

The approach to CBR differed to some extent in the three programmes. The ILO distinguished between two different approaches to CBR (Momm & König, 1989 in Philpott *et al.*, 1995). According to the ILO description, the CBR-DSP’s approach to CBR “conceives CBR as being the effort to entrust members of the family and community with the task to perform rehabilitation functions. This approach is entirely non-institutional” (Ibid.: 62). All the CBR-DSP CRWs were disabled people from the community. Also, SACLA’s CRWs were mothers of disabled children and the VT’s CRWs were either disabled people or community members and their approaches are thus similar. The ILO described the other approach as an outreach or extension service (Momm & König, 1989 in Philpott *et al.*, 1995). It is “based on the objective of bringing professional rehabilitation services to a larger number of disabled people” (Ibid.: 62). The approach makes use of referral to a rehabilitation unit for people in need of more sophisticated services. The VT did use a referral station, but also delivered service in partnership with the community through support groups and home visits and was thus not completely institution based. All three programmes were community-based and had some professional involvement through referral services. It can thus be concluded that the three programmes under review mainly adopted elements of the non-institutional approaches.

In the next section of this chapter, each theme is explored in depth.

Theme 1: Partnership is key to progress.

Collaboration between the CBR programmes and stakeholders was a general topic, revealing strengths and opportunities, but also weaknesses and threats, in all the reports. Stakeholders in CBR included disabled people and their families, the community, CRWs, rehabilitation professionals, CHWs, government, NGOs, DPOs, CBOs and universities. CRWs are presented as a separate theme (Theme 2). The community is presented under the theme of sustainability (Theme 3).

Two of the programmes were the result of partnerships and had some health organisation involvement: DPSA was in partnership with Mpumalanga Department of Health and the VT rehabilitation programme was established in collaboration with the Department of Health Sciences of the University of Durban Westville and the community. Although SACLA merged with three other NGOs, the merger was not successful.

A strength identified was partnerships with NGOs and their staff. Two of the CBR programmes under review (VT and SACLA) formed part of NGOs offer of primary health care through CHWs for addressing the main health problems of the communities. CHWs worked hand in hand with the CRWs. CHWs referred clients to CRWs, and CRWs gave them information on disability related aspects and they shared facilities. This resulted in CHWs learning new skills, including for instance how to assess people for hearing loss. Unfortunately, service provision by NGOs was affected by competition for funding.

The third programme (CBR-DSP) was a partnership between DPSA and the government of Mpumalanga Province, which proved to be an innovative approach for CBR. DPSA represented two stakeholders in CBR, namely disabled people and DPOs. The main aim of CBR was to improve the lives of disabled people, their caregivers and families. They were all seen as active participators of CBR. Empowerment and the promotion of rights of disabled people was an important aspect in the documents, particularly in the CBR-DSP report. DPSA believed that if disabled people's rights are acknowledged, this would

lead to their having equal opportunities and social inclusion, which would have a positive effect on the community as a whole. They further believed that equity could only materialise if disabled people are involved in decision-making and management in programmes related to them. Thus, CBR-DSP's strength was that disabled people themselves shared responsibility for CBR. The Mpumalangan government supported this, as an integral part of the provincial rehabilitation policy was that disabled people should be at the forefront of service delivery.

More government involvement was needed in the other programmes, especially in SACLA. Further, SACLA and the VT revealed little on the nature and extent of participation and involvement of disabled people in management. Very few professionals were employed in the programmes to assist with the CBR service and a high turnover of employed professionals was experienced at the VT and SACLA. But, fortunately all three programmes had strong links with professionals in the health sector. Many professionals, mainly occupational therapists, speech language and hearing therapist and physiotherapists, from the Department of Health were involved in the VT and CBR-DSP and this benefited the communities. Their role was to help with the implementation of the CBR programme, receive referrals from the CRWs, do home visits, mainly with the CRWs, evaluate and monitor CRWs' intervention and support CRWs in assessment and intervention planning.

Universities were other prominent stakeholders in SACLA and the VT. Their main involvement was through the development of the service and in student training. Students benefited in that they experienced development, attained experience in CBR, received preparation for real work situations, increased their knowledge and insight, learned new skills and had a shift in perspectives of roles and intervention in the community. The CBR programmes benefited in return through input from expertise and CBR was promoted in the professional and academic spheres.

A weakness identified was the continuing need for gaining increasing participation of non-health related departments to ensure resource support, collaboration with disability movements, and community structures. SACLA expressed the need for a stronger

alliance with the disability sector. Minimal reference was made to the collaboration with community-based organisations.

A concern about education for disabled children also continued to exist, for example, the need for training in sign language for deaf children and their parents, skills training for blind children, as well the need for community-based structures for intellectually disabled children. An aim of the CBR programmes was to increase access for disabled children to inclusive education, but little mention was made on how and if this was achieved. Further, more capacity building and participation of caregivers were necessary. The CBR programmes had a cross disability approach, but very little or no mention was made of community-based intervention for people with mental disabilities, specifically those with psychiatric conditions.

In conclusion, results of effective collaboration were improved service delivery at community level, recognition of the role of the programme in its area of operation and enhancement in its reputation.

Discussion

Strong partnerships result in effective community-based intervention. Inter-sectoral collaboration is a topic frequently discussed in CBR discussions and was identified as a priority for the way forward for CBR in South Africa (Philpott, 2004). Strong collaboration creates the opportunity to clarify the roles of stakeholders and prevent the geographic overlapping of similar functions. The findings of the theme revealed some weaknesses and needs concerning collaboration in the CBR programmes and are discussed here.

More networking with non-health related structures was needed to ensure progress of disabled people in all spheres of life. Health related NGOs made a significant contribution to CBR in South Africa and the progress made through the VT and SACLA, and the IUPHC should also be mentioned. But CBR is more than just about health, or rehabilitation for that matter, and support is needed from government departments and

NGOs involved in development as well as support from the social, education, employment and labour sector (ILO *et al.*, 2004).

Collaboration with the Department of Education specifically, is important concerning intervention for disabled children. The disabled children's needs were related to aspects of education, which area major problem for the disabled children in South Africa:

The limited capacity of special schools, particularly in rural areas, has resulted in the majority of learners from these areas being excluded from education opportunities, as the environment in regular schools does not facilitate integration (ODP, 1997: 37).

Little involvement in psychiatry mental health was identified as another weakness. The PHC package of South Africa (DOH, 2000b) sees services to mental illness concerns as an integrated part of PHC. The Mental Health Care Act (DOH, 2002) promotes services through a primary health care approach and community-based care of mentally and intellectually disabled people.

SACLA expressed the need for more collaboration with the disability sector. Rule 18 of the UN Standard Rules (UN, 1994) highlights that disabled people should be encouraged to participate in every initiative concerning them, by any service provider, the State or NGO. The important aspect behind the participation of disabled people and their families is that it leads to the empowering of disabled people and the community. In the context of South Africa's political history of oppression, empowerment of disabled people is very important and one means is to promote disabled people's rights. Finkenflügel (2004) could not find a programme in South Africa that was built mainly on the participation of disabled people, but his study was done before CBR-DSP was fully operational.

CBR-DSP is an example of a CBR approach where a DPO had clear roles in CBR. DPSA were involved in initiating, implementing, managing and evaluating the CBR programme. Rule *et al.* (in press) mentioned that if CBR projects become accountable to disability organisations and not only to the employer, as in the case of the CBR-DSP programme, it would enable CBR to be implemented with and not for disabled people. DPSA in CBR-DSP also fulfilled the role of DPOs in CBR as described in the Joint

Position Paper on CBR (ILO *et al.*, 2004: 7), namely, “educating people with disabilities about their rights, advocating for action to ensure these rights, and collaborating with partners to exercise rights to access services and opportunities”.

It can thus be concluded that the collaboration between DPSA and the Mpumalanga DOH resulted in an effective CBR programme. But, collaboration is usually unsuccessful because of the inability of stakeholders to synchronise their diaries, as they are just too busy or senior management does not open the path. Different stakeholders have different interests, methods and means; for example, professionals and disabled people may have different opinions about the aims and methods of the rehabilitation process. There is also a risk of using collaboration to shift responsibility for CBR onto the disability sector, which leads to a form of social exclusion. Further, inter-sectoral collaboration needs constant evaluation to see if it works, but the question is by whom? A co-ordinating body for CBR could fulfil this role, but the question that comes to mind is who should mainly be responsible for CBR on the whole in South Africa?

The National Rehabilitation Policy (DOH, 2000a) presupposes that the Office on the Status of Disabled People (OSDP) will play the co-ordinating and monitoring role. OSDP was established in the Office of the Deputy President to commit to the upliftment and improvement of the conditions of disabled people (ODP, 1997). The INDS (Ibid.) mention other structures for disabled people in place in South Africa, namely DPOs and the South African Federal Council on Disability (SAFCD) (an umbrella body for all national disability NGOs, in affiliation with some DPOs and represented by the disability desks of the premiers in the different provinces). The responsibility of CBR could also be that of the Department of Health or the Department of Social Services and Poverty Alleviation.

An umbrella structure to advocate and lobby for CBR in South Africa was recommended at the CBR workshop at the VT (Philpott, 2004). Such a structure could include all above mentioned possible structures and bodies, and thus provide an answer for fulfilling the co-ordinating and monitoring roles. It could also ensure the committed involvement and shared responsibility of all stakeholders in CBR (Ibid.). In summary, inter-sectoral

collaboration can work if stakeholders are committed and prepared to develop relationships based on trust and co-operation with each other, priorities of all involved are on the same level, all accept a network philosophy and successful projects are implemented.

Theme 2: Community rehabilitation workers as tools to progress.

The documents revealed extensive information on CRWs, as they were mainly responsible for carrying out the CBR service. Their activities reflected the activities and projects that were put into place through CBR. Descriptions of the disabled people's situation before CBR intervention are included. Also, strengths and weaknesses of the CRWs are included.

- **First, CRWs were the tools to change negative attitudes towards disabled people through awareness raising and advocacy**

... they had always said it wasn't their problem, but hers. One mother left her child alone in the house if she had to go out because of neighbours' unwillingness to look after her. It was the same with families, where often the disabled child seems to be seen as the mother's problem. One woman broke down as she spoke about her husband not only doing nothing to help, but also shouting at the children (Lorenzo & Saunders, 1999: 14).

These were just some examples of discriminatory attitudes towards disabled people in society. A great need exists to change attitudes towards disability. Further, there was little or no participation by disabled people in community activities. Disabled people were disempowered and disadvantaged. They were un-informed about human rights, social services and other opportunities. An important activity of the programmes was thus to improve the awareness on disability related issues. CBR-DSP especially focused on these aspects.

Awareness on disability was done through various means. CRWs held workshops and campaigns in the community, and general community meetings were used. Media, for instance, radio broadcasting or flyers, were used in SACLA and CBR-DSP.

Unfortunately, as result of poor planning, the SACLA's awareness raising talks on radio were terminated. A drama group, where disabled people participated as actors, was used by SACLA to perform at schools and other venues. This activity was very successful.

Service providers of disabled people worked alongside the programmes and were exposed to disability issues advocated by the CRWs. Service providers were challenged to rethink service delivery within the social model of disability: *"These stories show that there has been a shift from the individual, medical approach to disability where the person is seen in a sick role, to the social model of disability"* (Lorenzo & Saunders, 1999: 35).

The documents revealed some weaknesses of CRWs related to above activities. Uncertainty about effectiveness of the workshops was expressed by SACLA, who identified the need for more awareness raising to be done. To bring about attitude change was not an easy task and CRWs needed more training on how to achieve this. Further, planning was an overall problem. Clients at SACLA expressed their dissatisfaction with CRWs not keeping appointments and not giving details of workshops or changes in arrangements in advance and CRWs should be more organised.

But, despite these weaknesses, attitudes towards disabled people did change for the better. It was stated that disabled people became more visible and started contributing in family and community life after CBR intervention. With their contribution to social life, community members became more aware of aspects of disability, and disabled people became more accepted and valued, resulting in their social inclusion.

CRWs themselves also underwent a change in their feelings and position towards disabled people. Where this happened, clients expressed appreciation towards the positive attitude of CRWs working with disabled people. The documents revealed that change was also needed in the attitudes of disabled people themselves as their own fears were still a barrier to them for full participation in society.

- **Second, CRWs were tools to accessibility.**

“Very significant progress was made ensuring that persons with disabilities who participated in the programme had access to services and support” (Dube, 2003: 9).

Unavailability, poor quality and limited access of services for disabled people were a reality before CBR intervention. A very strong matter in all the documents was the role that the CRWs played in assisting disabled people to access social security grants. CRWs helped people obtain identity documents and furthermore, gave information about welfare services and negotiated for poverty relief for disabled people. CRWs also successfully facilitated access to assistive devices through referral. They were appreciated for their help in providing these needs for disabled people.

Another aspect of access where the programmes were involved in was the aim to improve the access of physical environments, but it was reported that housing specifically was still inaccessible. A daunting reality was the lack of adequate public transport for disabled people in rural, and even urban areas, resulting in their social isolation. However CRWs did deliver the service at community level through home visits. CRWs thus addressed the barriers to access in terms of time and distance constraints that disabled people experienced. They were especially appreciated for their availability.

- **Third, CRWs were keys in the strategy of poverty alleviation.**

People with disabilities need access to micro and macro income-generation activities, including obtaining financial credit through existing systems, wherever possible. In informal settlements and rural areas, income-generation activities should focus on locally appropriate vocational skills and reality of rural markets. Community members who, with minimal assistance, can easily transfer their skills and knowledge to people with disabilities could best conduct training in these skills (Dube, 2003: 26).

This quote motivates why CBR was effective regarding income-generation and financial needs of disabled people. The CBR programmes’ main position in poverty alleviation was through facilitating access to social grants. But, CRWs were also involved in various

other ways to improve disabled people's economic independence, such as workshops on community development, facilitating income generation projects, advice for business development, and facilitating employment or finances for projects. These made a significant impact on the lives of disabled people. They expressed gratitude for CRWs bringing about positive change and improvement in their lives in terms of development and capacity building. However it was not without challenges, for instance, client's poor understanding of business, their poor business potential and in volunteers in income-generation projects not committing themselves due to lack of compensation for their efforts.

- **Fourth, CRWs improved the self-reliance of disabled people**

Rehabilitation activities improved disabled people's independence and self-acceptance. The three programmes described the concept of rehabilitation differently. The VT and SACLA's CRWs did do some medical rehabilitation to improve disabled peoples level of independence, but included a broader concept of rehabilitation to remove barriers to participation for disabled people and to ensure their social inclusion. CBR-DSP's CRWs focused more on this broader concept of rehabilitation and promoted disabled people's rights by providing relevant information and counselling.

CRWs⁵ were involved in medical rehabilitation activities.

"My CRF has shown me exercises to do with my child, taught me how to do toilet training and feeding techniques with her" (VT, 2004: 2).

Medical rehabilitation took the form of physical therapy, for instance, exercises, mobility and hand function training, independence training and some speech therapy. CRWs also made assistive devices through appropriate paper technology (APT) techniques, e.g. standing frames. They further trained clients how to use assistive devices. Caregivers were also trained in skills on how to help a disabled person, but the SACLA document revealed that transfer of skills to caregivers should happen more to ensure self-reliance.

⁵ CRWs from SACLA and the VT did medical rehabilitation.

It was also said that future planning of client interventions was weak. CRWs needed to plan intervention with an end-result of client independence in mind, and towards a more holistic approach.

It was reported that CRWs had good observational and reasoning skills. They had the knowledge and understanding to deal with a wide range of problems and they could improvise. They showed insight into the impact of impairment on individuals and their families and acknowledged disabled people's context. They knew their limitations by referring to professionals when they did not know what to do. The referral system was seen as effective as clients were satisfied with the rehabilitation they received. They expressed improvements in emotional and physical well being as result of the intervention.

CRWs gave peer support and counselling.

The most appreciated aspect of the CRWs work is the general support and encouragement given: "She visits", "She cares", "I can talk to her" ... "She encourages me to feel like a human being, even if I am disabled" (Lorenzo & Saunders, 1999: 13).

Disabled people experienced poor support from family and the community. They had personal and relationship problems after the onset of impairment, for example relationship breakdowns, rejection, substance abuse and suicide. One identified reason was the lack of counselling of disabled people and their families. CBR-DSP especially focused on this aspect (56% of services provided were counselling services).

Peer support and counselling took on different forms and was done individually, to families and caregivers of disabled people, or to groups in all the programmes. Counselling took place through disability consultants in hospitals to newly impaired people and on community level. Advice was given on available services; understanding impairment; and what intervention should be done for a client. Disabled people expressed personal growth, hope, self-acceptance and contentment as result of counselling interventions. CRWs were appreciated for their support, patience, respect,

trustworthiness, care and encouragement, as well as their positive attitude towards disabled people and willingness to work with them.

Support groups, or self-help groups, complimented the encouragement which disabled people received through counselling. CRWs were significant in facilitating support groups. Support groups gave disabled people and care givers the opportunity to air their problems and share ideas, and as result, the pressure on CRWs to support their clients was reduced. Support groups in the community were sometimes the only resource for disabled people. The programmes built and strengthened existing groups and CRWs also played an active role in the development of DPOs in Mpumalanga. There was, however, still a need for more support groups and those especially involving males.

Another serious concern was the condition of the parents of disabled children because of the strains they experienced. Most parents of disabled children were single mothers and thus carried the sole burden of care. Childcare and single responsibility led to economic constraints. This had a negative effect on the children, as less time was spent with the child and this inhibited children's development. Day care centres were one way of giving support to disabled children. CRWs played a role in starting and assisting day-care centres, which was reported to function well. Families started taking responsibility for their disabled people and parents expressed the ability to handle disabled children better as result of the CBR intervention in their lives. CRW's regular contact with disabled people provided positive role models for disabled people and children.

Not only did disabled people experience positive change, but it was noted that the CRWs also had positive experiences in their work and enjoyed it in general, and especially esteemed their personal growth, being of value and making a contribution to society.

- **Fifth, CRWs made a contribution to student training.**

"Dear CRWs, it was really a very valuable experience for us and has helped us better understand the PHC challenges facing our country. Your work is truly inspirational. Enkosi" - UCT OT Student (2002) (Haricharan & Rendall-Mkosi, 2002: 62). CRWs assisted in student training at SACLA and the VT and had a positive impact on students.

Unfortunately, CRWs felt unsure of themselves when they worked together with students. They felt inferior to students as they thought clients would value the student's opinion more than their own.

An issue related to training, was a strong sense of insecurity in SACLA's CRWs regarding their status as CRW and of their training course. CRWs were not accepted as part of the government health system, but were recognised for the contribution they made. There was thus a need for programmes to advocate to government the role of CRWs and there was a need for accreditation of the CRW training course.

Discussion

The first aspect of progress through CRWs mentioned in this theme is related to awareness raising. Awareness raising is the first precondition for equal participation of disabled people in the UN Standard Rules (UN, 1994). The findings revealed that awareness raising amongst disabled people and the community was successful in most areas of operation. This, however, needs to be taken a step further to ensure that CBR enhances the self-advocacy of disabled persons (Miremebe & Hartley, 2002). Further, there is a need in South Africa to raise awareness on CBR amongst rehabilitation professionals.

The second aspect of progress was improved accessibility for disabled people. Accessibility is one of the target areas of the UN Standard Rules (UN, 1994) that is important to the process of equal opportunities. The CBR programmes were successful in improving access to services, but there was still a need to remove structural barriers. In the underdeveloped areas of South Africa, equal opportunities cannot be addressed if physical barriers to participation are not removed. CBR thus has a role to play in advocating barrier free access to relevant departments, e.g. the Department of Transport, Education, development agencies and others.

Third, CRWs were tools to the economic empowerment of disabled people through poverty alleviation strategies. Poverty is relative and manifests differently in different historical situations and has diverse causes (Wilson & Ramphele, 1989). Poverty may to

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be defined in terms of monetary measures (The World Bank uses the poverty line of US\$1 per day or Gross National Product and Gross Domestic Product) or alternative measures (UNDP uses the Human Development Index). In terms of monetary measures, disabled people experience poverty alleviation mainly through access to social grants. The CBR strategy, however, also addressed the fundamental human needs described by Max Neef (1991).

Max Neef's Human Scale Development Model entails nine fundamental needs⁶ that should be satisfied to ensure sustainable people-centred development. They are the need for subsistence, affection, protection, understanding, creation, participation, idleness, identity and freedom (Max Neef, 1991). Some examples of how CBR addressed these needs are: economic empowerment helps disabled people to access basic subsistence needs, peer support and support groups addresses the need for affection and understanding, and involvement of disabled people in the CBR-DSP programme addresses the need for participation, identity and freedom.

Poverty can also be defined in terms of social exclusion or the level of disadvantage experienced and the removal of barriers leading to social inclusion (Thomas, 2000a). Inclusion "implies a change from an 'individual change model' to a 'system change model' that emphasises that society has to change to accommodate diversity, i.e. to accommodate all people" (ODP, 1997: 79). CRWs proved to play a vital role in removing barriers for disabled people, and it can thus be concluded that CBR has contributed to the eradication of South African disabled people's history of social exclusion.

The fourth aspect in findings concerning CRWs was increased self-reliance of disabled people. Medical rehabilitation lead to increased independence of disabled people. Rule four of the UN Standard Rules (UN, 1994) focuses on support services, especially in terms of assistive devices. The CRWs were successful in ensuring access for disabled people to support services. The second and third precondition of the Standard Rules (UN, 1994) focuses on medical care and rehabilitation. But the aspect of peer support

⁶ See definitions of the nine fundamental needs in Appendix 3.

and counselling, seemed to be one of the most valuable aspects of CBR to the beneficiaries. Impairment may lead to many psychological problems, such as the trauma with the onset of impairment, coping with rejection, relationship problems, depression and isolation. In South Africa, accessible rehabilitation services are rarely available, but accessible psychological services are almost non-existing. CBR thus addressed a major need of disabled people through counselling.

The fifth aspect highlighted the threat that in South Africa, no consensus on the training, registration and post structures of CRWs have been reached. For example, the PHC package (DOH, 2000b) does not recognise any of the cadres of workers used in the three programmes under review, and only refers to the Therapy Assistant. Cornieljeet *al.* (1994: 37) argued that the acceptance of CBR development would lead to the recognition of CRWs, which will manifest itself in the development of fitting post structures. Ten years later, the problem still exists: “The need to develop an accredited training for CRWs in order that they can be registered and employed in South Africa remains a contentious issue” (Rule *et al.*, in press).

One reason for the lack of recognition of CRWs discussed in CBR discussion is the professional protectionism experienced on professional boards. Philpott *et al.* (1995) explained that the training of rehabilitation professionals at universities has been limited to an elite group who had the financial support and educational requirements. This led to the professionalisation of disability and the inaccessibility and scarcity of rehabilitation services. Cornielje *et al.* (1994) recommended that the role of CRWs is to be complementary to therapists, who are more medically orientated, as they work in a more socially orientated paradigm. Findings revealed that CRWs did not overtake the work of therapists, but they worked together with therapists to address the needs of disabled people.

In summary, it was clear from the findings that disabled people were reached through the CRWs. The activities done by CRWs reflected a holistic approach to disabled people. Not only did therapy intervention cover psychological, occupational, speech language and hearing and physiotherapy aspects, but also developmental, equity and human rights

issues were addressed to improve the lives of disabled people. An innovative approach in CBR was thus using CRWs as change agents to improve the lives of disabled people, as Lorenzo and Saunders (1999: 35) stated:

We should not underestimate the important role CRWs fulfil as change agents by enabling the disabled person and their families to stand up for their rights and by facilitating their participation and integration into the community activities.

Theme 3: Influences on sustainability

Sustainability is an immense challenge to CBR. The findings on different types of sustainability are described here. These findings revealed the strengths, weaknesses, opportunities and threats of the programmes.

Organisational sustainability

Organisational (or institutional sustainability) “places importance on ‘building sustainable organisations to achieve sustainable development benefits’” (Jordan 1996, citing Kean in Dube, 2003: 54). Findings are presented here according to the essential factors for organisational sustainability.

Democratic management skills are the first essential factor for organisational sustainability. CBR-DSP was managed by the existing DPSA provincial management team and was reported to be effective, although lack of inter-departmental co-operation in CBR-DSP was reported. A vision for high-quality management, regular meetings and feedback, adaptability and capacity building and training of the leadership, contributed to the effective management of the CBR-DSP programme by DPSA. It may be concluded that CBR-DSP applied management skills that were democratic and empowered participants, thus contributing to the programme’s sustainability, as disabled people were involved in all the stages of management.

The fact that the one part of the SACLA programme was run by the head office in a different area created managerial challenges. The rural area had different situations from the townships in the city, which necessitated different approaches. The situation was

used to excuse all problems, resulting in local problems not being solved: *“The problems with head office have led to the situation where problems, which could be solved locally, are being seen as part of the ‘head office problem’”* (Lorenzo & Saunders, 1999: 23).

The VT reports did not reveal the management structure or performance.

Flexibility in planning and a clear communication strategy are the second factors needed for organisational sustainability. The need for good planning was reiterated several times in the documents. At SACLA, heavy workloads and too many meetings lead to inadequate planning. Planning needs to be flexible in order to meet constantly changing needs. The documents also suggested that all stakeholders should be involved in planning. All three programmes had clear objectives, which is an essential factor for sustainability. However structures with allocated monthly, quarterly and annual times were still needed to ensure a communication strategy for adequate planning.

Poor communication resulted in a variety of problems. Examples from SACLA were: inconsistency in coordination of tasks; decisions not being made in the team; weak relationships between team members; and relationship problems with new staff and therapy students from universities. Thus, there was a need for better communication in the form of discussions, sharing of information and openness. Related to communication, was the need for a feedback system to be in place between people on the ground and management.

Meetings were one tool to communication that was prominent in the documents. They were used to plan, support, share information and even to clarify CBR and the role of CRWs. Meetings were held at different levels, between different people and for different reasons, namely on district/provincial level between stakeholders, between team members to share information and for support, and between management to discuss management issues. A complaint of the use of meetings was they took up too much time, which resulted in less time for doing the actual work.

Monitoring and evaluation is the third essential factor. Very little was revealed in the documents on monitoring and evaluation procedures. CBR-DSP had meetings to monitor

the implementation of the programme and performance. What was clear from the SACLA document was that there was a need for regular evaluation, monitoring, supervision and impact studies of the CBR work.

Record keeping was important to determine impact, to provide information to stakeholders and for future planning. Reports on the activities of the CRWs were kept in records, such as time sheets that clients completed, and monthly reports. CBR-DSP used the report method successfully but in SACLA, reporting presented challenges in terms of the complexity of the reporting system in place. At the VT, staffs were encouraged to document and present papers on the work done at national and international conferences.

The fourth essential factors for organisational sustainability, are **training, capacity building and support**. Team members of CBR-DSP and the VT participated in continuous training to develop their capacity and to improve their CBR intervention. Specific topics were addressed in training to ensure that the issues were handled effectively in the programme, especially training in management, administration and financial skills. Not only did the team receive training, but also they presented training to build the capacity of stakeholders. SACLA articulated the need for training in management and time management; report writing, business and financial skills, planning and life-skills.

Shared support was given in terms of expert input in service delivery and in general for the work done by the programmes. CRWs appreciated the support of professionals, but felt that there was still a need for more professional support in client intervention. Most important was government support in terms of policy and funding. This study revealed that only CBR-DSP had adequate support in this area.

Sound financial framework and resource management are needed as the fifth essential factors for organisational sustainability.

Financial sustainability is a component of organisational sustainability, [although] the two are often confused' (Jordan 1996: D2-D6). Most definitions of financial sustainability have to do with an organisation's ability to raise resources from a variety of sources (local, national and international, private and

public) and say that this mix of resources should include increasing amounts of local funding and earned income, to move the organisation away from dependency on foreign donors (Dube, 2003: 54).

Funding support for the programmes came from various sources: government financed CBR-DSP and funders funded the VT. SACLA received financial support from various funders, of which the Kaiser Family Trust was the main funder.

CBR-DSP was financially sustainable at the time of the evaluation, as the CBR programme was cost-effective and financially beneficial for government. This was mainly because fewer infrastructures were needed to implement the community-based service. Challenges experienced concerned resources, for example, poor commitment to supply resources, unequal division of resources, and expectations for resource provision were not met. These resources were, for instance, premises for projects. A further challenge for CBR-DSP was to establish linkages with businesses for the benefit of disabled people, as an identified opportunity for poverty alleviation was the existence of some wealthy areas in the fields of operation. An example of this is the areas where mining operations took place in Mpumalanga.

Finance-related needs expressed in SACLA had to do with the need for fundraising, funding, salary adjustments and restructuring of budgets. SACLA's challenges concerning resources were poor sharing of resources, inadequate transport and poor provision of assistive devices when funds were lacking.

The VT had a good infrastructure and people resources, but high staff turnover had a negative impact on the continuity of services. Community resources were used at the VT and the community was encouraged to do the same. The VT's documents did not indicate the status of the organisations financial sustainability.

In conclusion, organisational aspects showed that CBR-DSP was successful in most of the factors required for organisational sustainability. SACLA experienced various organisational problems and it was feared that the project would discontinue if the organisational problems were not addressed. Uncertainty of SACLA's funding and

merging with other health NGOs had a negative impact on the programme's organisational sustainability at the time of the evaluation. The VT documents revealed very little on the organisational aspects, and a conclusion can, therefore, not be made.

Benefit sustainability

Benefit sustainability refers to

... ongoing continuation of the benefits that result from an activity, 'with or without the programmes or organisations that stimulated that benefit in the first place'. The source of those benefits may change, but the benefit is still available because the community's demand for it is so strong (Jordan 1996, citing Van Sant, in Dube, 2003: 54).

Before the CBR intervention, formal rehabilitation services were scarce in the various areas and few community structures were available, for example DPOs, had poor capacity to deliver the required services. The CBR intervention had an impact on other stakeholders who provided services to disabled people, with the effect of improving the quality of formal rehabilitation. For illustration, government health services became more effective when working with the CBR programme because of the referral system put into place. Rehabilitation teams reported that the CBR intervention helped them to reach disabled people who would not have been reached otherwise. New DPSA groups were formed in Mpumalanga, thus more disabled people benefited from peer support and had access to interventions provided by DPSA.

All documents reflected that the CBR approach has the ability to accommodate more people than does an institution. Many disabled people were reached (for example, more than 6000 disabled people were reached in Mpumalanga Province) as result of CBR delivered in remote areas. An outcome of intervention was the improved self-reliance of disabled people. As result, disabled people reached a new level of empowerment as they also started to participate in aspects concerning themselves. An opportunity for CBR to benefit sustainability, was that disabled people and their caregivers learned skills through the CBR intervention in their lives, and now had the potential to carry these over to others:

Parents become proud when their children accessed childcare or disability grants, improved their social behaviour, developed new skills, and communicated better. In addition, they become proud when they are able to use their experience to help other parents (Dube, 2003: 32).

A threat for disabled people, which may also have an effect on CBR programmes, was the HIV/AIDS epidemic. HIV/AIDS is a very distressing reality in South Africa. SACLA and the VT, as organisations have projects in place to address this issue. CRWs supported these projects or participated in the general fight against HIV/AIDS through facilitating strategies against it and through basic counselling to affected clients.

Community sustainability

Sustainable communities will not become dependant on an organisation in the long term for the provision of services, but will be empowered to create their own community-based organisations to provide service, effectively lobby government to provide services, create services in collaboration with the public/private sectors (Dube, 2003: 54).

CBR was beneficial to all people in the community because CBR promoted human rights, but documents indicated that there was still a need for more community involvement and ownership. None of the three CBR programmes revealed substantial participation of the community. The impression in terms of ownership was that DPSA and then government owned CBR-DSP, and SACLA and the VT was owned by the NGO's. Factors that hindered community involvement were, for example, high levels of ignorance and stereotyping of disability in rural areas and the lack of community and family support for disabled people, especially the perceived lack of male interest.

The community support received for SACLA was an opportunity to become truly community-based and thus ensure community sustainability. The nature of the support included the local community supporting the projects put into place by CRWs. Documents reported that community support resulted in CRWs being more motivated and that CBR activities improved.

Socio-cultural sustainability

Socio-cultural sustainability includes strong relationships and networks with the community and an understanding and incorporation of cultural aspects. The result is a valuable contribution to social capital (Haricharan & Rendall-Mkosi, 2002).

The main service provider for disabled people in South Africa, mainly the Department of Health, experienced challenges to deliver services to disabled people. This was mainly due to the lack of professionals to deliver required services or high staff turnover, emotional burn out of staff and language and cultural barriers between professionals and disabled people. Most of the CRWs worked in the communities from where they originally came. They, therefore, had insight into the client's situation in the community. They also did not have the language and cultural barriers that hindered effective intervention between service providers and disabled people.

In CBR-DSP CRWs were disabled people themselves, SACLA's CRWs were all mothers of disabled children and some CRWs at the VT were disabled people themselves. The benefit was that the clients found it easier to relate to other disabled people. Thus, strong relationships and networks with CRWs in the community added to social-cultural sustainability of all three programmes. Also, the VT and CBR-DSP had effectively collaborated with rehabilitation and other service providers to ensure effective services. SACLA still needed to build on this opportunity.

Political sustainability

Political sustainability has to do with the policy environment that a programme operates in, and the programme should support the current policy. The policy environment created by government had an effect on the political sustainability of the CBR programmes. CBR was seen as a comprehensive approach based in the community and regarded as part of Primary Health Care (PHC) in all three programmes. These programmes operated in a context of provincial policy that promoted community-based service delivery and the decentralisation of health care services. But, some challenges with government support were experienced. For example, SACLA operated in the

environment where health care services were to be more community-based according to the province's Health Plan 2010, but support from government was not adequate and the organisation was only accountable to their foreign donor. It was further threatened by structural changes demanded from its donor. But district health management systems were strengthening and public health services had increased their commitment and capacity to align their plans with municipalities in the Cape metropolis, thus creating an opportunity for CBR to form an integral part of PHC.

The VT had support from individual organisations and institutions, but they had no formal responsibility to the VT and the CRWs were not recognised in the province's policy. CBR-DSP was an outflow of the implementation of Mpumalanga's provincial rehabilitation policy. The result was that government and DPSA shared accountability for the programme, securing its political sustainability.

Discussion

Various factors contributed or threatened the **organisational sustainability** of the programmes. CBR-DSP was an example of a democratic management structure as result of DPSA's co-responsibility for the programme. The programme was still very young at the time of evaluation and Asindua (2002: 33) mentioned that

...many of us see the responsibility for sustainability of CBR, as lying with the institutions of disabled people's organisations (DPOs). However, these organisations are fragile with low self-esteem and lack the wider community support.

DPOs need capacity building through leadership training, small enterprise development, organisation and management, communication and advocacy skills and linkage with other established organisations (Ibid.). These aspects should be considered to ensure the sustainability of the effective management of all three programmes.

First, findings revealed poor communication and planning. M'kumbuzi (2003) also found communication to be poor after she compiled a capacity audit of seven generic CBR programmes in South Africa .

Second, there was still a need for more monitoring and evaluation. A priority for CBR in South Africa is to “establish a system which continually monitors and evaluates CBR and CRFs” (Philpott, 2004: 3). Boyce and Ballantyne (2000: 69) identified the importance of evaluation in CBR:

... CBR cannot survive without appropriate evaluation mechanisms to explore and understand the information base upon which CBR lies. Furthermore, evaluation, if appropriately conducted, can actually help the development of community programmes.

Aspects that needed more evaluation are the extent of community and disabled people participation and the cost-effectiveness of the programmes. Linked to evaluation, is documentation. Participants at the CBR workshop at the VT identified that “lack of published documentation and research in SA, which could prove the value and impact of CBR in particular communities” challenges the sustainability of CBR in South Africa (Philpott, 2004: 3). The programmes had well enough established models, and adequate documentation could lead to policy that could benefit CBR’s sustainability.

Training and support needs were mentioned, and is the third challenge. M’kumbuzi (2003) was of the opinion that weakness in management and administrative capacity reveals a lack of efficient CBR training. A necessity to sustainability according to the first Position Paper on CBR (ILO *et al.*, 2004) is the availability of support outside the community. The lack of support in the accreditation of mid-level worker training, and the lack of post structures that goes in hand with it, is a threat to the survival of CBR in South Africa.

Fourth was the challenge to financial sustainability. This challenge to CBR in South Africa was expressed as “the lack of formal inter-sectoral collaboration between government, NGOs and training centres, and the associated lack of integrated budgeting” and it was recommended to “establish funding channels for CBR programmes” (Philpott, 2004: 3). Inadequate resources were another challenge, but CBR could make a significant difference, for instance, in public transport in their areas of operation if they advocated the transport needs of disabled people.

CBR was found to be complementary to formal rehabilitation services, contributing to the **benefit sustainability** of the programmes. In the social model of disability, “the term and concept of 'rehabilitation' is not positively applied; instead the key terms used in the debate are 'mainstreaming', 'de-institutionalisation', or 'equalisation of opportunity', since disability is viewed as social constraint” (ILO, 1989 in Dube, 2003: 49). DPI (1985 in Dube, 2003: 49) described equalisation of opportunities as follows:

Equalisation of opportunities means the process through which the general systems of society, such as the physical environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all. This involves the removal of barriers to full participation of disabled persons in all these areas, thus enabling us to reach a quality of life equal to that of others.

Further, a CBR strategy could set up an ideal framework for implementing the provisions of the Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, an initiative developed by the UN General Assembly to strengthen the UN Standard Rules (Priestley, 2001). The Disability Rights Charter of South Africa (Lawyers for Human Rights, 1992) and the INDS (ODP, 1997) are other useful documents to be used as frameworks to ensure disabled people's rights. Disabled people should not only be made aware of their rights, but strategies should be put into place to ensure that they take responsibility in aspects concerning their rights.

The problem of HIV/AIDS in South Africa was mentioned. The AIDS epidemic across sub-Saharan Africa is very real and cannot be ignored, as it affects all strata of society, including disabled people. This concern was discussed at the CBR conference in Uganda in 2001 (Nganwa, Batesaki, Balaba, Serunkuma & Yousafza, 2002). It was concluded that the role of CBR in fighting against HIV/AIDS, is to ensure that disabled people have access to intervention and that it is in an acceptable form.

Community sustainability goes hand in hand with aspects of community development. A priority identified for African CBR, is that CBR must collaborate with all sectors to ensure the inclusion of disability issues in all developmental programmes (Thomas &

Thomas, 2002). It would appear from the documents that CBR is mainly a separate development initiative, rather than being integrated with other community development strategies. Monaheng (2000) argues that community development seeks to address the needs of the people, that the people themselves must identify their felt needs and that people's participation forms the basis of community development. Community development needs to be an educative process, and people need to learn new technical, administrative and problem solving skills (Monaheng, 2000).

Monaheng (2000) also identified the major role players in community development:

1. local people are the main actors;
2. government in terms of financial, advisory and training support;
3. NGOs; and
4. the community development worker.

CRWs in CBR have in many ways fulfilled the role of the community development worker as described by Monaheng (2002), for instance, they facilitated group formation and access to resources and acted as sources of information.

The need for more community involvement was revealed in the findings. In development discourse, community participation has been promoted as a key to development (Rifkin & Kangere, 2002) and is seen by many governments, the United Nations agencies and NGOs as critical to programme planning and poverty alleviation (World Bank, 1996 in, Rifkin & Kangere, 2002). In the CBR concept, rehabilitation of disabled people relies explicitly on the involvement of lay people, i.e. family members, volunteers, schoolteachers and village community workers (Finkenflügel, 2004). The National Rehabilitation Policy (DOH, 2000a: 67) supports community involvement in rehabilitation: "Communities and particularly people with disabilities should be involved in designing, implementing and monitoring services for people with disabilities". The Joint Position Paper (ILO *et al.*, 2004) mentioned that the articulation of a need and

response from within the community indicating readiness to meet the need are factors necessary for sustainability of CBR programmes.

The Joint Position Paper on CBR (ILO *et al.*, 2004) suggests the use of leadership of existing community development structures, or other structures where a leader of the community is in charge, to implement CBR. Another option suggested is that these structures have a separate CBR committee with representatives from the community included. Rakolojane (2000) recommends that CBOs should be used as a tool to promote community involvement. The nature of the culture of the Nguni (black) people in South Africa is an opportunity for community involvement in CBR. The principles of Ubuntu are building networks amongst each other, care for one another and sharing compassion and care.

Socio-cultural sustainability is about appropriate networking. One of the recommendations at the Ugandan CBR conference was that “CBR must take into consideration local cultures, resources and practices” (Mirembe & Hartley, 2002: 199). Professionals working in underdeveloped areas faced many cultural barriers, which in many cases resulted in ineffective service delivery. The CBR approach of using local people to deliver the basic aspects of professional services, helped to overcome cultural and language barriers.

Most of the CRWs were disabled people themselves or mothers of disabled children. Werner (1994, in Dube, 2003) discussed the benefit of disabled people as CRWs. He mentioned that they are more committed as they are more sensitive to needs and feelings of other disabled people, they allow disabled people to evaluate their own needs and therefore meet the real needs of disabled people. The most important aspect for him was that they become a role model for society, thus adding to the empowerment process by liberating disabled people and changing attitudes.

In South African CBR, there is still a “need for strong formal partnerships (an underlying principle of CBR) between Disabled People’s Organisations (DPOs) and professionals employed by government or Non Governmental Organisations (NGOs)” to ensure socio-cultural sustainability (Philpott, 2004: 3).

Policy-making and legislation are important regarding **political sustainability**, and are seen as implementation strategies to ensure equal opportunities for disabled people according to the Standard Rules (UN, 1994). The Helsinki report (WHO, 2003) stated that government support and policy is essential to CBR development. Mpumalanga's Provincial Rehabilitation policy supported CBR as a service delivery with disabled people at the forefront, and the lesson learnt is that the responsibility of CBR should be stated in the policy to enable it to survive.

The National Rehabilitation Policy (DOH, 2002a) sees rehabilitation as an integral part of PHC. PHC aims at accessible health for all. It therefore promotes a decentralised community-based approach. It is "a strategy that aims to respond more equitably, appropriately, effectively to basic health care needs, whilst also undressing the underlying social, economic and political causes of health" (Saunders, 2004: 12). The key principles underlying PHC are similar to the key principles of CBR, namely accessibility, comprehensive care, community and individual involvement and self-reliance, inter-sectoral action for health and appropriate technology and cost-effectiveness in relation to available resources (Ibid.).

Rehabilitation is, however, still medical model orientated in the PHC package (DOH, 2000b) and the National Rehabilitation Policy (DOH, 2002a). References to CBR in these documents indicate a poor understanding of CBR. The only aspect resembling CBR as described in this study, is the focus on the participation of disabled people on all levels of society. This is repeated several times under the norms and standards of the CBR section in the document (Ibid.), leading to contradictive impressions that all responsibility for CBR is shifted onto disabled people, but at the same time that the participation of disabled people in CBR should remain under the influence of health personnel.

In summary, government policy in South Africa promotes the decentralisation of services, but this study revealed that policy reflected an inappropriate understanding of CBR. However, as Mirembe and Hartley (2002) stated, CBR programmes have the

responsibility to advocate for adequate policy to support CBR, and need to take up this role in South Africa.

Table 4.1 is a summary of how aspects covered in findings answered the objectives of this study.

Table 4.1. Summary of how aspects covered in findings answered the objectives of this study.

| <i>Objective</i> | <i>Aspects covered in the theme</i> |
|--|--|
| Background of the programme | |
| Contextual issues | <ul style="list-style-type: none"> • Description of the programmes' histories • Description of staff establishments • Description of location and type of areas |
| Theme 1: Partnership is key to progress | |
| SWOT Innovative approach | <ul style="list-style-type: none"> • Description of stakeholders and nature of partnership in CBR • Focus on DPSA and Mpumalanga Government partnership as innovative approach |
| Theme 2: CRWs as tools to progress | |
| Contextual issues Activities and projects of CBR SWOT Innovative approach | <ul style="list-style-type: none"> • Description of client: situation of disabled people • Description of intervention within family set up • Description of intervention within community • CRW training • Focus on CRWs as an innovative approach |
| Theme3: Influences on sustainability | |
| Contextual issues SWOT Innovative approaches | Organisational sustainability <ul style="list-style-type: none"> • Description of organisational aspects • Focus on DPO partnership as tool to democratic management |
| SWOT Innovative approach Context | Benefit sustainability <ul style="list-style-type: none"> • Focus on CBR approach as innovative approach to reach and empower disabled people |
| SWOT | Community Sustainability <ul style="list-style-type: none"> • Community involvement |
| SWOT Innovative approach | Socio-cultural sustainability <ul style="list-style-type: none"> • Focus on CRW as innovative approach |
| SWOT | Political sustainability <ul style="list-style-type: none"> • Policy support of CBR |

Limitations and weaknesses of the study

The findings of this study would be more relevant to explain the current situation of CBR in South Africa if all CBR programmes could be used. It is thus recommended that the study be expanded to include all other CBR programmes that meet the sample criteria (Chapter 3) in South Africa.

The documents used focused on different aspects in the three programmes, which made comparison of findings on specific topics, for illustration, 'management', difficult. The annual report of the VT used in this study, was not as comprehensive as the other two documents, resulting in fewer findings and conclusions with regards to the VT.

The researcher had a strong interest in CBR and belief that CBR is the way forward to address the needs of disabled people in underdeveloped areas. This might have influenced findings and discussions. A co-coder, who has obligations against CBR, could have been used to reveal biases, assumptions and comments through following the researcher's audit trail.

Chapter 5

Conclusion and recommendations

The impact of the three programmes under review made a positive difference in many disabled people's lives. Findings revealed activities, approaches and successes leading to this, but also revealed some challenges the programmes experienced contributing to a deeper understanding of CBR in South Africa. Recommendations are based on conclusions concerning the findings of the objectives of this study. Conclusions are included in each recommendation point.

Contextual issues of the CBR programmes

1. The CBR programmes operated in rural and urban areas where rehabilitation and support services for disabled people were scarce or inaccessible. The CBR programmes endeavoured to change this situation for the positive, as they contributed to the eradication of the disabled people's history of social exclusion in South Africa, especially in terms of disability, geographical distance, poverty, discrimination and access. The CBR programmes were an opportunity for service providers to improve the quality of their service. CBR as presented by the programmes, should, therefore, be recognised as an accessible model to rehabilitation and as an approach for South Africa to improve the lives of disabled people.

Strengths, successes and innovative approaches as examples for the way forward.

2. The CBR programmes were in various partnerships with health NGOs, government, and universities which led to shared expertise and service delivery. Partnerships for CBR should therefore be strengthened.
3. The DPSA and Mpumalanga government partnership of CBR-DSP proved to be an innovative approach for CBR. It was effective because:

- Disabled people were involved from the start of the programme, which led to their empowerment.
- The CBR-DSP's model of using a DPO's management system proved to be democratic, ensuring organisational sustainability.
- The Mpumalanga Rehabilitation policy supported CBR and the lesson learned is that policy support is essential for CBR's financial and political sustainability.
- The programme was financially beneficial for the Mpumalanga Department of Health.

It might, therefore, be viable to use CBR-DSP as an approach to CBR for the rest of CBR programmes in South Africa.

4. The use of CRWs was another innovative approach in CBR, as they were change agents in the lives of disabled people. They addressed cultural, language, distance and time barriers for disabled people and tackled rehabilitation from a broader perspective. They were successful in educating disabled people and the community, improved accessibility for disabled people, were the tool for disabled people's economic empowerment and independence and fulfilled the role as community development worker. CRWs still required support from professionals, and should thus be used complementary to rehabilitation services to reach disabled people in underdeveloped areas.

Recommendations concerning the weaknesses, challenges and threats identified

5. CBR are threatened by the lack of accreditation of CRWs' training, registration and post structures. This problem has affected the CRWs' sense of worth. Without CRWs, less disabled people would have been reached and disabled people would not have experienced the progress described (Chapter 4: Theme 2). CRWs should be recognised in South Africa as an all inclusive rehabilitation worker, community development worker and a tool to ensure the equalisation of opportunities for disabled people.

6. The participation of disabled people in all stages of CBR needed more promotion. DPOs could be used to ensure disabled peoples' involvement.
7. CBR programmes still need to take up the supportive role they are able to play in the decentralisation of mental health, specifically with psychiatric conditions, in South Africa. CBR programmes, therefore, need to link up with stakeholders delivering a service in the field of mental health.
8. There are still concerns about the education of disabled children. CBR can improve access to education for disabled children through advocating inclusive education, help in overcoming physical barriers at schools, and play an advisory role to educators on impairments of children. Collaboration with the Department of Education is crucial.
9. The poor capacity of caregivers was another mentioned concern in the CBR programmes and, therefore, parents of disabled children should be part of the inclusive education process to ensure that they take responsibility for their children's education. Further, CRWs should expand on facilitating support groups for parents of disabled children and teachers who educate disabled children to create an opportunity for sharing feelings, ideas and concerns to address their needs.
10. The majority of disabled people in South Africa still experience barriers in terms of physical structures, public transport and communication. CBR programmes should make it priority to address these and collaborate with appropriate experts and departments to ensure the removal of these barriers. CBR programmes should use the opportunity to collaborate with organisations such as the National Environmental Accessibility Programme (NEAP) to ensure physical access for disabled people.
11. HIV/AIDS is a daunting reality in South Africa. The role of CBR in the HIV/AIDS crisis is to ensure that disabled people have access to intervention and that it is in an acceptable form, but it should not become the focus of the programme and overpower its main objectives.

12. CBR has an important contribution to make to community development, and the CBR programmes should still make it a priority to ensure the inclusion of disabled people in existing or general community development.
13. The CBR programmes need more community involvement to ensure community ownership. CBOs, community leaders and building on the Ubuntu principles, should be used as tools to ensure community involvement
14. The challenge to the financial sustainability of CBR programmes could be addressed through formal inter-sectoral collaboration between government, NGOs and training centres, and integrated budgeting with funding channels for CBR programmes.
15. Evaluation and monitoring systems are needed to ensure the programmes' sustainability. Evaluation requires high skills and this raises the question of who should be responsible for evaluation? Options for evaluators could be the donors of an organisation, the HSRC, MRC or universities, OSDP or other departments of government, or DPOs. DPOs should be involved, but they usually have other agendas at stake, which makes their commitment unreliable. The benefit for universities and research councils to be involved is that this could develop into broader issues.
16. More published documentation of South African CBR is needed. CBR programmes have a responsibility to document CBR practice to ensure sharing of best practices. Information reflecting effective practices and the change in disabled people's well being as result of the CBR intervention should be used to motivate for aspects of CBR to be incorporated into policy and legislation.
17. An umbrella structure, representing all stakeholders in CBR, is needed in South Africa. There is also a need to identify whom the responsible department in government/s for CBR is/are. Responsibility needs to be stated in policy to ensure its survival. It is crucial that identified responsible government departments and other partners be represented on this structure to

ensure involvement of all stakeholders. This structure should become responsible for CBR in South Africa and could fulfil the following roles:

- Lobby and advocate for CBR.
- Ensure adequate policy support.
- Co-ordinate and evaluate the collaboration of CBR stakeholders.
- Ensure the involvement of non-health related departments.
- Monitor and evaluate CBR programmes and CRWs.
- Channel funding for CBR programmes.

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Appendixes

Appendix 1: Letter to participant projects

289 Driehoek Street

Meyerspark

0184

Date

To ...

CBR programme ...

Re: Request for your participation in a research study on Community-Based Rehabilitation in South Africa.

I am a second year part time student in the Masters in Philosophy programme in Disability Studies at the University of Cape Town. Part of our course requirements is to do a mini-dissertation. I was exposed to Community-Based Rehabilitation (CBR) when I worked as an Occupational Therapist in rural KwaZulu-Natal, and I developed a strong interest in the field. I have decided to use it as the topic of my mini-dissertation.

I have identified the following problem: Presently, CBR programmes have been evaluated, but the dissemination of findings has been poor – it has not been beyond the immediate stakeholders. There has been no cross-reference of findings to draw out common themes and lessons learnt to contribute to the sustainability of the programmes. The result is a lack of shared learning, duplication of mistakes and the potential waste of resources.

The aim of the study is to analyse evaluation documents of CBR programmes to identify common trends in the development and implementation of CBR programmes in South Africa. Further, it is to document lessons learned in order raise awareness and develop a

deeper understanding of the current status and key lessons of CBR programmes in South Africa.

The objectives are

- To identify contextual issues of the CBR programmes, for example location and background.
- To identify activities and projects put in place through the CBR programmes.
- To develop a deeper understanding of CBR practice in South Africa.
- To identify the successes, strengths, weaknesses, challenges and opportunities in the CBR programmes.
- To identify innovative approaches and methods for future direction and development of CBR.

The study takes the form of qualitative research as the study seeks to discover patterns and develop themes from evaluation documents of the phenomena of CBR in South Africa. Descriptive statistics will be used to analyse the demographic characteristics of the programmes if this information is available in the reports. Content analysis will be used to analyse evaluation reports of CBR Programmes. This qualitative thematic analysis will be used to detect common themes, create categories and to develop theories with the use of computer assisted software, called Nvivo®. In-depth interviews will be used after analysis when there is a need to consult the programme managers (assuming you are available) in order to clarify the original data used.

Findings will be disseminated to the following organisations with your approval:

- SACLA (South African Christian Leadership Association) SACLA Health Project operating in the informal settlement of Khayelitsha, Cape Town.
- Mpumalanga Province's peer counselling initiative with Disabled People South Africa (DPSA).
- The Valley Trust, operating in rural areas of KwaZulu Natal.

Findings will firstly be sent to the above participants for feedback. Your permission to disseminate the findings to a wider audience is asked. The final results will also be

published, with your approval, in relevant journals and made available on the Internet. This ensures wider dissemination of information.

The following aspects will be applied to the study:

Information and documents will be treated with confidentiality, especially in terms of access to privileged information. Only my supervisor and I will have access to the information at time of the study. Anonymity will be respected if you prefer it or where otherwise applicable. The right to privacy will be respected.

The risk of participating in this study is that weaknesses of your programme might be exposed. But the benefit is that the findings on weaknesses will reveal lessons to be learnt by each other. Another benefit is that findings can be used for programme planning. The study will hopefully contribute to a deeper understanding of CBR practice in South Africa and to the sustainability of CBR in our country.

Please find an included consent form to be completed, attached, and send to:

289 Driehoek Street

Meyerspark

Pretoria

0184

Email address: francia@absamail.co.za

CBR Programme evaluation reports can be emailed or posted to above address if an electronic copy is not available. Please indicate if any of these evaluations have been published. The researchers will cover costs involved and the amounts, proof of payment and banking details must be sent with above information.

Please feel free to contact me at:

Work: 012-318 6697

Cell: 082 940 9685

Home: 012-803 1785

Fax: 012-318 6699

Your participation will be highly appreciated.

Yours truly,

Francia Morris

M. Phil Disability Study Student

Appendix 2: Consent form

Research title:

Common trends of Community-Based Rehabilitation Programmes in South Africa

Researcher: Francia Morris

Address:

289 Driehoek Street

Meyerspark

Pretoria

0184

Contact Numbers:

Work: 012-318 6697

Cell: 082 940 9685

Home: 012-803 1785

Fax: 012-318 6699

Email address: francia@absamail.co.za

I appreciate your willingness to participate in this research project. The researcher will contact you to make arrangements for the accessing evaluation reports and to arrange a possible interview.

I have read the letter and understand the context of this document and the purpose of the research. I agree to participate in this research and make evaluation reports available to the researcher.

Signature:.....

Date:.....

Name:.....

Name of Project:.....

Appendix 3: Definitions of the nine fundamental human needs

These definitions are described by Max Neef (1991) and are the same in all cultures and historical periods.

| | |
|-----------------------|---|
| IDENTITY: | the need to feel that you yourself are important, that you are worth something, that you have something to offer |
| AFFECTION: | the sense that you are appreciated, accepted, loved; the need to have close friends or people that you love and who love you |
| PROTECTION: | the need to feel safe, secure; not scared that you are in danger |
| SUBSISTENCE: | the need for food, shelter, water – the things commonly referred to as “basic needs”, without which a person can die |
| UNDERSTANDING: | the need to understand what is going on around you as well as the need to be understood by others |
| CREATION: | the need to be creative, to make things, invent things, use your own ideas and imagination |
| FREEDOM: | the need to be free and not restricted; free to make your own choices and not to have everything said and decided for you |
| PARTICIPATION: | the need to be part of what is happening, to belong to something, to take part in decisions that affect you; the need to not be isolated or ignored |
| IDLENESS: | the needs to rest, reflect, relax, take time out, play, do nothing |

Report on corrections made to the dissertation:

Reviewing Evaluation Reports of Community-Based Rehabilitation

Programmes in South Africa

by

Francia Morris

KRGFRA009

SUBMITTED TO THE UNIVERSITY OF CAPE TOWN

In partial fulfillment of the requirements for the degree

M Phil in Disability Studies

Faculty of Health Sciences

UNIVERSITY OF CAPE TOWN

15 August 2005

Supervisor: Dr. Theresa Lorenzo, Faculty of Health Sciences,

University of Cape Town

- All recommended grammatical and typographical corrections were made.
- All recommended corrections and queries to references were corrected and addressed unless stated otherwise.
- All abbreviations used in the text were included in the list of abbreviations.
- The convention for referencing three or more authors involved recording all three names were recorded the first time and *et al* thereafter.
- The convention for direct quotes of three or less lines involved the use of inverted commas, and where the quote was more than four lines it was indented. This was done in a consistent manner.
- Consent for the use of evaluation documents of the three CBR projects was received verbally or in written format.
- p32: The three CBR projects did not raise objections to their names being used in the text..
- p38: The text only refers to weaknesses, as the heading is “limitation of methodology”. Mentioning the positive here will result in repetition.
- p59: The reference of Jordan was not listed in the particular evaluation document. The reference of Jordan is quoted as it were in the evaluation document.
- The term ”speech therapist” was changed to “speech language and hearing therapists”.
- The term “Occupational Therapy Board” was changed to “Professional Board for Occupational Therapy and Medical Orthotics/Prosthetics”.
- Text that needed references:
 - p10: CBR expanded rapidly after the publication of the manual, “Training Disabled People in the Community”, published by the WHO in 1983 (Helander, Mendis, & Nelson, 1983 in Finkenflügel, 2004).
 - p16: They are likely to focus on medical rehabilitation with less consideration for equal opportunities and social inclusion of disabled people, as the training will not have an in-depth input on, and understanding of, community development and skills (Rule *et al.*, in press). (Ibid. was used)
- Aspects that needed clarification:

p13: The last sentence on the page was not changed, as it is a direct quote from the reference (Mirembe & Hartley, 2002: 198).

p16: The sentence “The sustainability of CBR in South Africa seems fragile, but the status of CBR after democracy is uncertain.” was changed to “The sustainability of CBR in South Africa seems fragile and the status of CBR after democracy is uncertain.”

p17: The word “evidence based” was used at the workshop mentioned here and the word “knowledge based” would not be representative of what was discussed at the workshop.

p34: The sentence “Thus on first reading, prominent units of meaning were clearly visible and were therefore marked.” was changed to “Thus on first reading, prominent units of meaning were clearly noticeable and were therefore highlighted.”

p41: The text that was analysed used the term “behavioral therapist”, and was therefore not changed.

p48: The word “to” is used in the heading, and not “of”, as the theme is about disabled people experiencing progress through the CRWs, for example, “CRWs were tools to accessibility”.