Towards a Critical Curriculum for Mid-level Community Based Rehabilitation Training in South Africa

By

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SUPERVISOR'S DECLARATION

As the candidate's Supervisor I agree to the submission of this thesis.

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ACKNOWLEDGEMENTS

DECLARATION OF ORIGINALITY

I, Sarah Anne Rule, declare that

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ABSTRACT

This study, conducted in Pietermaritzburg and surrounding rural and township areas, is a critical exploration of the training of mid-level Community Based Rehabilitation workers with a specific focus on the ability of course participants to understand and address the oppression and empowerment of people with disabilities. The aim of the study was to develop a conceptual framework for curriculum construction of a mid-level Community Based Rehabilitation course, through examining a Community Based Rehabilitation course and the changes that were made to it.

The study was conducted within a critical theory paradigm. The social model of disability and an understanding of disability as a form of oppression were the key constructs that guided the research. Participatory action research was used in the initial phase of the research, followed by a second phase that adopted a life history approach. The initial phase of the study consisted of one cycle of action research, beginning with a reflection on the existing curriculum. The action research cycle then moved through stages of planning changes to the curriculum, implementing the changes, observing the effects of the changes and reflecting again. Data collection comprised interviews with staff members, students and community rehabilitation facilitators who had previously completed the Community Based Rehabilitation course, as well as focus groups with people with disabilities and parents of children with disabilities. Several participatory rural appraisal techniques were also used with the students. The action research cycle raised further questions about how the life experiences of the students influenced their responses to the changed curriculum. This stimulated the development of the second phase of the research which used life history methodology, comprising in-depth interviews with four students.

The study found that several changes occurred in the students' attitudes and understanding as well as in some of the activities they undertook. Some students worked with rather than for people with disabilities, indicating a change in the power relationship with their clients. The students were able to analyse their own oppression and that of people with disabilities, unlike previous students. The students also engaged in social action for the rights of people with disabilities. These findings cannot be solely attributed to the changes in curriculum. However, they raise the possibility that Community Based Rehabilitation personnel can work to address the oppression of people with disabilities rather than focusing entirely on technical rehabilitation, which is a common approach in the literature. An analysis of the life histories revealed that those students identified as 'activists', more willingly engaged in social action during the Community Based Rehabilitation course than other students. This challenges the dominant discourse in the literature of Community Based Rehabilitation personnel as rehabilitation workers rather than activists.

One key contribution of this thesis is to research methodology through its combination of life history methodology and action research in the study. A second is its proposed framework for curriculum construction that incorporates findings from the action research and the life histories. This framework, with its macro-environment, organisational and student influences on the curriculum, contributes to the under-theorised field of Community Based Rehabilitation training.

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LIST OF ABBREVIATIONS

ABET	Adult basic education and training
ANC	African National Congress
ATM	Automatic teller machine
CBR	Community based rehabilitation
COSAS	Congress of South African Students
CRF	Community rehabilitation facilitator
CRW	Community rehabilitation worker
CREATE	CBR Education and Training for Empowerment
DPO	Disabled people's organisation
DPSA	Disabled People South Africa
GDP	Gross domestic product
HPCSA	Health Professions Council of South Africa
IFP	Inkatha Freedom Party
ILO	International Labour Organisation
INDS	Integrated National Disability Strategy
IUPHC	Institute of Urban Primary Health Care
NECC	National Education Co-ordinating Committee
NGO	Non-government organisation
NQF	National Qualifications Framework
OBE	Outcomes based education
OSDP	Office on the Status of Disabled Persons
OTT	Occupational Therapy Technician
PAC	Pan African Congress
PRA	Participatory Rural Appraisal
PTSA	Parent-Teacher-Student Associations
PWD	People with disabilities
RDP	Reconstruction and Development Programme
RSA	Republic of South Africa
RURACT	Rural Disability Action Team
SACLA	South African Christian Leadership Assembly

SRC   Students' representative council

UDF   United Democratic Front

UNESCO   United Nations Education, Scientific and Cultural Organisation

UNISA   University of South Africa

WHO   World Health Organisation

Note: The term "people with disabilities" is used in this thesis rather than "disabled people" or "persons with disabilities" on advice from people who are involved in the disability sector in South Africa.

PROLOGUE

This research begins with my own story so that the reader may understand and identify the possible biases that I may have brought into the study, particularly being both researcher and participant in the action research. I do not claim to be a neutral observer or researcher and certainly my own orientation to social justice has both framed the study and guided my actions and my thinking about the findings and the model I have developed. The other participants in the study, community rehabilitation facilitators, students, staff and people with disabilities, may also have responded in particular ways in the research because of my presence as an able-bodied, white woman who is concerned with issues such as oppression, empowerment and social justice.

As a white South African in the 1960s and 1970s, I grew up as part of the privileged race and class, not being aware of the racial oppression that dominated the lives of so many of my compatriots. Early on, however, I did become aware of difference. My sister and I were the only Jewish children in the Catholic school we attended from Grade 1 to matric. When I tried to join the choir in my early years at school, I was asked to sing a Christmas carol which, of course, I did not know and therefore I was not accepted into the choir. This is my earliest memory of discrimination. As a young child I was not particularly aware of disability although my father was a stutterer.

In primary school, I began to become aware of poverty, marginalisation and race through the teaching of the nuns. Our school admitted a few black children prior to 1976 and when Soweto erupted in June 1976, although parents and teachers tried to protect the pupils from the knowledge of what was going on, we became aware that all was not well for our black friends at school.

My years at university in the early 1980s were especially formative regarding my concern with social justice. I had converted to Christianity after school and at university I became involved in two organisations that were particularly interested in liberation theology and the God of the oppressed. One of the organisations was a

member of the United Democratic Front and through this involvement I became more connected with township youth, other progressive student movements and the broader struggle in South Africa. I participated in a number of student protests and at the beginning of my final exams for my undergraduate degree I took part in a protest of women against troops in the townships in which we attempted to surround an army base with a peace ribbon. My awareness of the injustices of the Apartheid system as well as my interest in liberation theology stimulated my concern with oppression in all its forms.

I was a critical student, frequently questioning the dominant modes of speech therapy which I was being taught, which were based on a knowledge of English linguistics, literate clients and a strong sense of the professional as expert and the "patient" not having much control over the therapy. One course that I took during my speech therapy training was especially powerful in challenging students' ideas of disability and the oppression of people with disabilities. Cathy Jagoe, a quadriplegic, ran the course entitled "The Psychology of Disability" which exposed us to a large number of people with disabilities and their experiences. The course was an elective in our Psychology major and there were only two or three speech therapy students who attended the course. I also became more aware of disability issues through forming a friendship with a blind student who was involved in one of the student organisations I belonged to. This student has since become the Director in the Office on the Status of Disabled Persons in the President's Office.

Following my university education, I started working as a speech therapist at Baragwanath Hospital in Soweto. Here, I found a home with a number of like-minded, progressive speech therapists, several of whom were also involved in the anti-Apartheid struggle. At this time, in the mid- to late 1980s I got to know and work with several disability activists who were also active in the anti-Apartheid struggle. Friday Mavuso of the Soweto Self Help Association of Paraplegics (SHAP) was particularly powerful in shaping me to become a disability activist. I helped to start a self help organisation of people with strokes and head injuries who had communication problems and through this group I learnt about the oppression that people who have communication impairments experience, even within the disability movement.

In the early 1990s I moved from the field of speech therapy to community based rehabilitation. Part of the reason for the move, was because I saw CBR as a vehicle for getting rehabilitation to the most marginalised people with disabilities. I worked at the Institute of Urban Primary Health Care (IUPHC) based at Alexandra Health Centre, which in the pre-1994 days was a site of struggle and employed a number of radical health workers, including some who had returned from exile. Huib Cornielje at the IUPHC had a powerful influence on my conceptualisation of CBR and its links with disability activism and the work of Paulo Freire.

My journey of growing awareness of oppression in all its forms and the need for social justice has been a life project and informs how I interact with people and the activities I choose to get involved in. In this way, it has no doubt permeated my interactions with the students and other participants in this study, prior to, as well as during and after the research.

APPENDIX 1

INTERVIEW SCHEDULE FOR PAST STUDENTS ON THE CBR COURSE

1. What are the main activities that make up your work as a CRF?
2. Which of these activities do you feel comfortable doing? Why?
3. When you were a student you learnt about the social model of disability. Do you use this understanding of disability in your work? Please explain.
4. Do you think the training gave you an understanding of people with disabilities being oppressed? Please explain.
5. Based on your working experience, what tasks do you think make up community work / development for a CRF? Do you do any of these? Please explain.
6. How do you think the training did or did not prepare you for work as a CRF? Prompts:
    i. What activities can you do well now because of what you learnt on the course?
    ii. What was missing from the CBR course to prepare you for working?
7. Is there anything else you would like to tell me?

APPENDIX 2

INFORMATION ON LESSONS TAUGHT

MODULE: __PHC & CBR__

Topic of session: __Liberation__

Date of session: __4/4/05__

Facilitator / trainer: __Sarah__

Time spent on theory:

Time spent on practical work:

Outcomes of the session: __Think how to overcome oppression__

      __Reflect on what has worked in other struggles__

Methods used: __Small groups - discussion on human sculpture from previous week - how can liberate__

 __Memory game to liberate themselves in small groups, discussion - what worked__

 __As whole class, how does liberation happen__

Resources used:

Results:

INFORMATION ON LESSONS TAUGHT

MODULE: <u>PHC & CBR</u>

Topic of session: <u>Liberation & empowerment</u>

Date of session: <u>4/4/05</u>

Facilitator / trainer: <u>Sarah</u>

Time spent on theory:

Time spent on practical work:

Outcomes of the session: <u>Understand theories of liberation and empowerment</u>

   <u>Relate own thinking on oppression & liberation to Cycle of Liberation & empowerment triangles</u>

Methods used: <u>Go through Cycle of Liberation & empowerment triangles</u>

   <u>Link theory to own experiences and thoughts</u>

   <u>Small groups - work out what CRF=s role is related to disability</u>

Resources used: <u>Harro=s Cycle of Liberation</u>

   <u>Nchabeleng=s article on empowerment & changing leadership</u>

Results:

Recommendations:

INFORMATION ON LESSONS TAUGHT

MODULE: <u>PHC & CBR</u>

Topic of session: <u>Liberation & empowerment</u>

Date of session: <u>4/4/05</u>

Facilitator / trainer: <u>Sarah</u>

Time spent on theory:

Time spent on practical work:

Outcomes of the session: <u>Relate ideas on empowerment & liberation to</u>
<u>disability</u>

   <u>Start to think of their own role in empowerment of people with</u>
<u>disabilities</u>

Methods used: <u>Role plays on CRF=s role in Cycle of Liberation</u>

 <u>Power inventory activity from Training for Transformation</u>

   <u>Discussion</u>

Resources used: <u>Harro=s Cycle of Liberation</u>

   <u>Training for Transformation 4</u>

Results:

APPENDIX 3

CASE STUDY

One day when the CRF is meeting with a group of people with disabilities in his area, Thulile, a lady who uses a wheelchair, complains that she wanted to go to a particular shop in town but although she could get into the shop, she could not pay and get out because the space between the tills was too narrow. The people in the shop were rude to her and they did not help her. As she is talking, some other members of the group think of times when they have had problems in town. Andile tells the group of one experience he had in another shop. Because he is partially sighted, he has great difficulty in seeing the price on something he wants to buy. Once, the shop assistant in a shop in town asked him to leave before he had bought anything. The shop assistant thought Andile might try to steal something because he kept taking things off the shelf and peering at them. Another member of the disabled people=s group, Thandokuhle, complains that some shops in town are not accessible because they have many steps.

1.   What are the barriers that different group members experience when going shopping in town?
2.   Explain how this relates to the oppression of people with disabilities.
3.   What could the CRF and the group of people with disabilities do to change this situation?
4.   What would be the benefit of doing these things?
5.   If there was an organisation of shopkeepers or businesses in the town, what could they do?
6.   If this situation happened in your area, what skills do you feel you still need to be able to deal with such a situation?

APPENDIX 4

Example of a timeline created by a student

APPENDIX 5

FOCUS GROUP INTERVIEW SCHEDULE

1. What changes, if any, have there been in your life and in your community since the CRF has been working in CBR/disability?

2. What did you expect the CRF would do when he started working in CBR/disability?

3. In what ways are people with disabilities oppressed in your community?

4. What do you understand by the term 'empowerment'?

5. Do you think people with disabilities in your community are empowered? Why or why not?

6. Do you think the CRF could have / has had any role in empowering people with disabilities? Please explain.

7. a) From what you have seen in the CRF's work, what skills do you think he has to work with people with disabilities to help empower them?
   b) What skills do you think he still needs?

8. Has the CRF done anything to overcome the oppression of people with disabilities? Please explain.

9. Do you have anything else you would like to say?

APPENDIX 6

Memorandum presented to the eThekwini municipality after a march by people with disabilities and 'Wandile' in Impola

APPENDIX 7

Newspaper article written by a student during the advocacy module

APPENDIX 8

INTERVIEW SCHEDULE FOR SECOND LIFE HISTORY INTERVIEW

1. Please tell me about your early childhood and the family you grew up in.
2. Please describe your mother to me.
3. Please tell me about your father.
4. Please tell me about your brothers and sisters.
5. Please tell me about your experiences at school.
6. What was going on in your community as you were growing up?
7. What is the first time you can remember when you noticed that some people were different to other people?
8. Please can you describe a specific event that you can remember from childhood or teenage years that was particularly important with regard to oppression or social action.
   Probe: What impact has that event had on your life?
9. Please can you can you tell me a specific event from your adult years that is important to you concerning oppression or social action.
   Probe: What impact has that event had on your life?
10. Can you tell me about a low point in your life in relation to oppression or social action?
    Probe: What impact has that event had on your life?
11. Can you tell me about a high point in your life related to social action or oppression?
    Probe: What impact has that event had on your life?
12. Please tell me about a turning point in your life.
    Probe: What impact has that event had on your life?
13. What do you think has been the biggest challenge that you have had to deal with concerning oppression or social action?
14. Which person or organisation has had the biggest impact on your understanding of oppression and social action?

CHAPTER 1

THE SOCIAL AND HISTORICAL CONTEXT OF COMMUNITY BASED REHABILITATION TRAINING IN SOUTH AFRICA

1.1 Introduction

Community Based Rehabilitation (CBR) is a relatively new concept internationally that tries to address the lack of access that millions of people with disabilities have to rehabilitation services. CBR is an attempt to bring appropriate rehabilitation to people with disabilities at community level. Since the late 1970s, CBR programmes have been developed in many developing countries around the world, particularly where there are few rehabilitation professionals. The definition of CBR that is now commonly accepted and which was used in this study is that CBR is:

> "a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services" (International Labour Organisation, UNESCO and World Health Organisation, 2004, p.2).

This study is a critical exploration of the training of mid-level CBR workers with a specific focus on the ability of course participants to address the oppression and empowerment of people with disabilities in order to facilitate the equalization of opportunities and social inclusion of people with disabilities. Mid-level workers in the health sector are seen as those who fit into the service provision system between grassroots personnel such as home based

carers and those with professional qualifications, such as physiotherapists. This study used both action research methodology and life history methodology to investigate and make changes to the curriculum of a CBR course run in Pietermaritzburg at a local non-government organisation – CBR Education and Training for Empowerment (CREATE).

This chapter aims to give the reader an insight into the social and historical context in which the CBR training programme at CREATE is situated. This context has helped to shape the CBR training programme into its current form. In addition, through delving into the historical context of South Africa in the 1980s and 1990s I aim to deepen my understanding of possible historical influences on the CBR students who participated in this study which may have influenced their response to the challenge of social change with regard to disability. In this chapter I explain the rationale for the study and then go on to explore the contested aspects of community based rehabilitation in South Africa. The section that follows, gives a brief overview of some key moments in South African history that may have influenced the CBR course and the students. I then take a brief look at the historical context of education in South Africa at the time when the CBR course was being developed.

1.2 Rationale for the Study

Community based rehabilitation, as it is conceptualised by the three United Nations agencies, ILO, UNESCO and WHO (1994 and 2004), tacitly acknowledges that disability can result in oppression and that CBR should attempt to overcome this through equalisation of opportunities and social integration or inclusion. The recognition that people with disabilities may be oppressed by society through the existence of barriers such as negative attitudes means that at least some proponents of CBR are influenced by the social model of disability (Barton, 1994; Marks, 1997).

However, as Disabled People's International (2003) indicates, CBR is still medically oriented

in some areas and in some cases the ideas of people with disabilities and their concerns are not weighted equally to those of professionals. This medical orientation is seen to some extent in various CBR international training programmes mentioned in the literature (Helander, Mendis, Nelson & Goerdt, 1989; Thorburn, 1994b; Valdez & Mitchell, 1999). The curricula of these training courses tend to focus more on assessment and the physical rehabilitation of individual people with disabilities, with little or no emphasis on overcoming the social oppression of people with disabilities. Lorenzo (2003, p. 761) writes of a similar situation in South Africa:

> "many of the CBR programmes in South Africa have focused on the rehabilitation component, while doing little to address the equalisation of opportunities or social integration of disabled people and their family members."

Sharma and Deepak (2001) found in their evaluation of CBR in Vietnam that CBR supervisors and workers identified the lack of training as one reason for their difficulty in providing services beyond medical work. Kendall, Buys and Larner (2000) stress that CBR workers need skills in community development and advocacy as well as techniques to help empower people with disabilities.

There is a distinct gap in the literature on CBR training about how to teach skills to empower people with disabilities and to overcome their oppression. Only two studies (Cornielje & Ferrinho, 1995; Twible & Henley, 1993) were found that deal with community development and social rehabilitation in CBR training, rather than purely focusing on physical rehabilitation. Twible and Henley (1993) developed a curriculum model for CBR training in the form of workshops. This curriculum model is based on the participation of people with disabilities, community leaders, volunteers, health professionals and others who together "identify physical, psychological and socio-cultural barriers and explore(s) strategies to remove those barriers that can contribute to or cause problems for people with disabilities." (Twible & Henley, 1993, p.50). Cornielje and Ferrinho (1995) describe how the community development section of a CBR course in Alexandra Township, Johannesburg was

implemented and the resulting involvement of community rehabilitation facilitators (CRFs) in social action and community development activities. The aim of the current study was therefore to contribute to the field of CBR through developing a conceptual framework for curriculum construction for mid-level Community Based Rehabilitation training based on research and taking into account multiple intersecting influences such as political and personal issues.

With specific reference to CBR training in South Africa, Cornielje and Ferrinho (1995) describe the nature and importance of training in community development for mid-level CBR personnel. According to these authors, social rehabilitation (dealing with social integration) is part of community development and it is crucial in empowering people with disabilities. However, an evaluation of the training of mid-level CBR personnel found that a number of these CRFs were not doing social rehabilitation in their work although social rehabilitation was included in the training (Cornielje, Ferrinho & Fernandez,1994). One of the reasons for this appears to be that the management of the organisation some CRFs were working for expected the CRFs to play a clinical therapeutic role rather than being involved in community development.

1.3   The Context of Community Based Rehabilitation in South Africa

1.3.1   Introduction

As CBR is a relatively new field of study and practice in South Africa and it was initially implemented by a number of independent organisations, there has been no uniformity in either the training of CBR personnel or the practice of CBR throughout the country. CBR in South Africa comes from a contested background and there is still conflict as to the way forward for CBR in this country. It is therefore necessary to understand the current study within this context of multiple contested understandings of community based rehabilitation and the training of personnel to work in this field. This section of the chapter attempts to

situate this study within the various sites of contestation that have impinged on the training of community rehabilitation facilitators at CREATE, both historically and currently.

1.3.2   Different models of CBR training and service provision in South Africa

According to Lorenzo (1996) the roots of CBR in South Africa lie in the work of RURACT (Rural Disability Action Team), a grouping of people with disabilities together with rehabilitation professionals (mainly working in rural areas), beginning in 1986. RURACT challenged rehabilitation professionals to recognise and work with the disability rights movement while addressing the issues of accountability within CBR programmes and the role of people with disabilities and parents of children with disabilities in the management of CBR programmes. The 1992 RURACT conference also foregrounded the issue of the focus of the training of community rehabilitation workers or facilitators – development versus therapy skills.

At about the same time as RURACT was stimulating dialogue between people with disabilities and rehabilitation professionals concerning CBR in the late 1980s, the professional bodies of the three therapy professions (physiotherapy, occupational therapy and speech and hearing therapy) engaged in discussions about the development of rehabilitation worker training (Randall, 1998). Notably, no mention is made of people with disabilities participating in these discussions. Resulting from this meeting of the therapy professional bodies, the South African Medical and Dental Council authorised the setting up of three pilot CBR training programmes – in Khayelitsha, Cape Town, under the auspices of SACLA; in Alexandra township, Johannesburg run by the Institute of Urban Primary Health Care (IUPHC) and in Acornhoek, Limpopo Province, under the joint auspices of Tintswalo Hospital and the University of the Witwatersrand. The three pilot training programmes were developed independently and differed to some degree in length of training, trainees, orientation of content and structure of the course.

The SACLA training in Cape Town recruited and trained mothers of children with

disabilities as grassroots community rehabilitation workers. These women, who were functionally literate, underwent an initial training of 6 weeks followed by ongoing in-service training. Later SACLA changed the length of training to three months of full-time training. The SACLA community rehabilitation workers were employed to visit the homes of other mothers who had children with disabilities to engage in individual problem-solving, which included practical skills in handling children with disabilities, setting up parent support groups and assisting people to obtain disability grants or referring them to hospitals (IUPHC, 1993).

The Wits/Tintswalo CRW (Community Rehabilitation Worker) Training Programme in Acornhoek had its first intake of students in 1991. According to Dolan, Concha and Nyathi (1993) the curriculum for the CBR course was developed by a team of occupational therapists, physiotherapists, and speech and hearing therapists. No mention is made of any input into the curriculum by people with disabilities. The Wits/Tintswalo CBR training was 2 years in duration and students were recruited from villages following a disability awareness campaign in the village and the involvement of community leaders. Approximately 50% of the students who had trained at the Wits/Tintswalo CRW training programme by 1997 had relatives who were disabled. In addition about 10% of the trainees were disabled themselves (Randall, 1998). Recruits to the CBR course were required to have completed matric. Training in community development was integrated into the rest of the content of the course which focused on topics such as different disabilities, health education, working with groups and economic independence for people with disabilities. According to the Wits/Tintswalo CBR course co-ordinator in 1997, the most important topics in the curriculum at the time were screening, working with groups and health education (Randall, 1998).

The IUPHC Community Based Rehabilitation training programme started in 1990 and similarly to the Wits/Tintswalo CBR course, the course was 2 years in duration. The course content was similar to that of the Wits/Tintswalo course, although community development and social rehabilitation (rather than physical rehabilitation) enjoyed relatively more

prominence in the Alexandra township course. As the CBR course co-ordinator at the IUPHC in 1993 said "the main thrust of the CBR course is the socio-political and economic aspects of disability." (IUPHC, 1993). In 1997, the view of the most senior CBR trainer at the IUPHC was that the most important topics covered in the CBR course were community development, integration of people with disabilities into their communities and disability rights (Randall, 1998). Students who had ten years of formal schooling (Std 8) were accepted onto the course and as at 1997, 16% of the IUPHC students were disabled, while about 65% had a relative who was disabled, according to Randall (1998). A unique feature of the early IUPHC CBR training programme was its relationship with the local disability movement. As Cornielje (1993, p.18) writes:

> "The most essential, but also most difficult aspect of the Alexandra CBR
> programme was the facilitation and development of a local disability movement
> in an extremely politically divided society."

The Alexandra Disability Movement which developed from the CBR programme, aimed to have people with disabilities participating in developing and running rehabilitation services in the township (Cornielje, 1993). (See Table 1.1 for a comparison of the three pilot CBR training programmes).

In 1998, I moved from being a CBR trainer at IUPHC in Alexandra township to the province of KwaZulu Natal. The two-year CBR training course was then started in Pietermaritzburg in 1999, based on the same principles and curriculum as the IUPHC CBR course run in Alexandra. In 2001, the organisation running the CBR course in Pietermaritzburg became independent of the IUPHC and became known as CBR Education and Training for Empowerment or CREATE. It is this CBR course that is the subject of the current study.

	SACLA CBR training	Wits/Tintswalo CBR training	IUPHC and CREATE CBR training
Duration of training	6 weeks, later extended to 3 months	2 years	2 years
Level and title of person trained	Grassroots community rehabilitation worker	Mid-level community rehabilitation worker	Mid-level community rehabilitation facilitator
Students	All mothers of children with disabilities	Few people with disabilities, mostly able-bodied. Some had relatives with disabilities	Few people with disabilities, mostly able-bodied. Some had relatives with disabilities
Entry requirements	Functional literacy	Matric	Std 8
Trainers	Therapists, people with disabilities, mothers of children with disabilities	Therapists, social workers, people with disabilities	Therapists, social workers, people with disabilities
Emphasis in content	Practical problem-solving, support groups, handling children with disabilities, obtaining resources e.g. social grants	Health education, screening for disabilities, therapy skills, group work	Disability rights, community development, intersectoral work, different disabilities
Accreditation	None	With Health Professions Council of South Africa (HPCSA)	With Health Professions Council of South Africa
Final qualification		Diploma	Certificate
Registration of course graduates	None	Worked to achieve registration with HPCSA	Initially not supportive, later course graduates registered with HPCSA

Table 1.1: Comparison of formalised CBR training courses in South Africa

In spite of support for CBR training at the highest level in South Africa in the White Paper on disability, the Integrated National Disability Strategy (RSA Government, 1997), due to a lack of funding CBR training was discontinued at the IUPHC in Alexandra at the end of 1999. For a similar reason and due to lack of support from the Limpopo Department of Health, the Wits/Tintswalo CBR training was forced to close at the end of 2003. Thus, by 2004 CREATE was the only remaining organisation that provided CBR mid-level worker training. The training of grassroots community rehabilitation workers at SACLA in the Western Cape continued until 2002 (Lorenzo, personal communication, September 2005)

A workshop hosted in 1993 by the Alexandra (IUPHC) CBR training programme sought to create dialogue and understanding between different providers of CBR training (IUPHC, 1993). At this workshop, in addition to the three pilot CBR training programmes, two other training programmes were presented – one specifically focused on physiotherapy and one on mental health. Already from 1993, one of the strands of contestation became apparent – whether there should be mid-level or grassroots workers with (therapy) profession-specific skills rather than the generalist or multi-skilled person who was being trained in the CBR pilot training projects. Although under the auspices of Health Professions Council of South Africa (HPCSA) discussions were held from 1997 with the Physiotherapy, Occupational Therapy and Speech Therapy Professional Boards regarding the multi-skilling of mid-level workers (HPCSA, 2004), the Physiotherapy Board in particular, pushed to have only profession-specific mid-level workers. From 2007 this became reality (see Section 1.3.4 of this chapter).

Although there have been attempts over the years to standardise the length of training and level of CBR workers (Report on CBR workshop, 1996), until the demise of the three CBR pilot training projects for financial reasons, CBR workers in the Western Cape remained as grassroots workers, while in the other provinces there are mid-level workers. All of these CBR workers are multi-skilled rather than profession-specific, with proponents of CBR asserting that true CBR cannot be provided by mid-level workers trained in just one of the

therapy professions. Linked to this debate was the issue of whether CBR workers needed to be registered with the HPCSA and also the issue of the level at which there should be posts for CBR workers in government departments.

In spite of conflicts around registration, from the mid to late 1990s mid-level community rehabilitation workers and facilitators were able to register with the Occupational Therapy Board of the Health Professions Council of South Africa. Although this has enabled community rehabilitation facilitators to be employed on posts for therapy assistants within the Department of Health (thus getting the government to take responsibility for CBR service provision), the disadvantage is that the Occupational Therapy Board of HPCSA has had to accredit the CBR training. Thus, when the policies of the Occupational Therapy Board changed, this affected the CBR training (see Section 1.3.4).

Recently, there has been a new model of CBR provision operating in Mpumalanga province, which has again fuelled intense discussion around who should provide CBR services (Rule, Lorenzo & Wolmarans, 2006). In the Mpumalanga CBR model, Disabled People South Africa (DPSA) is funded by the Department of Health to provide a service. CBR consultants, who are all people with disabilities, provide peer counselling and access to government-provided services through information-sharing and referral to these services, such as rehabilitation and assistive devices (Rule et al, 2006). These CBR consultants have minimal training and can be seen to operate at a grassroots level. They co-ordinate their work with therapists who provide outreach services at clinics in the province. The Mpumalanga provincial rehabilitation co-ordinator tried to ensure that there were no mid-level CBR workers in her province. Those who were working in the province prior to the new CBR programme, now have to be employed as profession-specific mid-level workers in institutions (Zitha, personal communication, July 2007). Although it is beneficial that all the CBR consultants are people with disabilities who provide a positive role model to others, they do not have training in community development and there is no other person employed in government services who takes the role of ensuring that disability issues are included in

general community development initiatives. Another drawback of the Mpumalanga CBR model is that only peer counselling and referral are provided at home of the person with a disability. For any services beyond this, the person with a disability has to travel to the nearest point at which the government department provides a service.

1.3.3   CBR – A contested terrain

A critique of CBR programmes internationally (and in South Africa) has been that people with disabilities and local communities have frequently been inadequately involved in the management and running of such programmes (Lang, 1999). Power has often resided with the professionals who manage these programmes, with the role of people with disabilities being reduced to compliance with what others have decided (Lang, 2000b). In South Africa the issue of the relative power of people with disabilities and service providers within CBR programmes and training has been a contentious issue with different programmes addressing it in different ways. In addition, in relation to CBR training programmes, the power of bureaucratic structures that look after the interests of therapy professionals also needs to be taken into consideration.

As highlighted in the previous section of this chapter, the three pilot CBR training programmes addressed the need to include people with disabilities (as a way of dealing with the power differential) in different ways. In all three programmes, people with disabilities were involved as trainers although the co-ordinators of the programmes were all able-bodied, and in most cases, through the years they were therapy professionals. In the early years of the IUPHC training programme, there was a specific attempt to give power to people with disabilities concerning the development of CBR in Alexandra township (Cornielje, 1993). Through the initiation of a local Disabled People's Organisation (DPO) and community rehabilitation facilitators reporting regularly to this DPO, it was intended that people with disabilities would control CBR in their own community.

In a similar bid to encourage ownership and control of the CBR programme by people with

disabilities and parents of children with disabilities, SACLA trained mothers of children with disabilities as community rehabilitation workers. In contrast, Wits/Tintswalo, IUPHC and CREATE were not so successful in handing power to people with disabilities through the selection of students to train. Most of their students were able-bodied and it is this fact that has caused some polarisation between the disability movement and the mid-level CBR worker training programmes. Recently some members of the disability movement have opposed CREATE because there have been insufficient numbers of students with disabilities trained in CBR. This is in contrast with the Mpumalanga CBR programme where all CBR consultants are disabled.

In an international review of CBR it was recommended that disabled people's organisations should become part of CBR programmes at all levels, including management and as CBR workers (World Health Organization, 2003). This should be extended to CBR training programmes which have in general been initiated and run by professionals, most of whom are able-bodied. As Kronenberg (2003) indicated in an international position paper, occupational therapists (who are often the therapists involved in CBR) are poor at analysing imbalances in power, and without the active involvement of people with disabilities in CBR, it is likely that existing power imbalances between professionals and people with disabilities will continue. In order to address equity and the issue of power, CREATE has a board of directors of whom half are people with disabilities. In addition, currently, three of CREATE's four staff members are people with disabilities.

Another facet of the issue of power and control in CBR training in South Africa has been the control that therapy professional bodies have wielded over training institutions and the form which the training has taken. Due to the concern with obtaining government posts for community rehabilitation workers, the Wits/Tintswalo CBR Training Programme in particular, pushed for official (HPCSA) recognition for mid-level community rehabilitation workers. Although the purpose of obtaining recognition was laudable, it unfortunately led to the Therapy Professional Boards of the HPCSA having a large degree of control over the

length, content and outcomes of CBR training. These bodies specifically look after the interests of the therapy professions and have little or no representation from people with disabilities. The CREATE CBR training course was accredited by the Occupational Therapy Board of the HPCSA which ensured that there was an occupational therapist responsible for the CBR course. Although CREATE experienced a relative amount of freedom to add topics to the course e.g. empowerment of parents of children with disabilities, changes in policy at the Board (which are guided by professional self-interest) have changed the nature of CBR training (and thus service provision) in South Africa during the period in which this research was conducted.

1.3.4   Current status of community rehabilitation facilitators

Community rehabilitation facilitators (CRFs) who have been trained by the IUPHC or CREATE have been eligible to register with the Occupational Therapy Board of the HPCSA since the mid 1990s. In addition the CBR course run by CREATE was accredited by the Occupational Therapy Board. The curriculum which was accredited until December 2006 is very similar to the original CBR course curriculum at IUPHC and includes a large section on community development, general issues such as disability rights and the social model of disability, skills from speech therapy, physiotherapy, occupational therapy and social work and long periods of practical work in the community.

In 1997 the three therapy boards of the HPCSA embarked on a process of determining the content of a new course that would have similar outcomes to the CBR course (HPCSA, 2004). The plan was that students would be able to study for one year as a profession-specific therapy assistant and then the second year would include community work and skills from the other therapy professions (multi-skilling). Although representatives from Wits/Tintswalo and IUPHC were requested to join members of the three therapy boards in these discussions, no people with disabilities were invited. The envisaged course was never finalised and eventually representatives from the Physiotherapy Board indicated that they would not support any form of multi-skilling of mid-level rehabilitation workers.

This has led to the current situation in which the Occupational Therapy Board has also indicated that it can no longer accredit the CBR course with its multi-skilling component and that for reasons of professional and practical expediency, only profession-specific mid-level worker training will be accredited and supported (HPCSA, 2004). The policy guidelines indicate that the mid-level Occupational Therapy Technician (OTT) training content will have to consist of 70% focusing on occupational therapy, 20% on community work and 10% on 'generic' skills (which will help the Occupational Therapy Technician to know when to refer to other professions). The aim is that OTTs will be trained to work both in the community and in (mostly health-related) institutions. The introduction of profession-specific mid-level workers will not be cost-effective in terms of meeting the needs of people with disabilities. With the reduction in time in the curriculum to cover community work issues, it is unlikely that these new mid-level workers will be able to achieve as much in terms of community development. The organised disability sector was not consulted concerning their point of view on CBR and who provides a service. Another difficulty with this new move of the Occupational Therapy Board is that OTTs will only be allowed to be supervised by an occupational therapist, thus limiting services in the community to areas where there is already an occupational therapy service. It is likely that many people with disabilities will in the future be unable to benefit from the type of services that CRFs have been providing up until the present. Lorenzo (personal communication, August 2003) also points out that by simply giving the OTT course a module in community work, it does not account for the fact that in the CBR courses students have been selected from the community they are to serve and they are therefore accountable to this community.

The decision-making around the discontinuation of CBR training and the structure of the proposed new mid-level worker training illustrates that power has been vested in therapy professionals and specifically those who have been elected to Therapy Professional Boards of the HPCSA. It is notable that people with disabilities were excluded from any decision-making about the training of mid-level workers, even though the services the mid-level workers will provide will directly affect people with disabilities. Similarly, CBR personnel

were not included in any discussions of the future of rehabilitation mid-level workers. The systematic silencing and thereby disempowerment of people with disabilities and CBR personnel with regard to decision-making about the future of rehabilitation mid-level workers demonstrates the tensions and relative power of professionals to determine the future of CBR in South Africa.

The present study was conducted with the second to last group of students studying CBR at CREATE as the courses have existed since 1990. Since December 2006, because of the move to OT technician training, there has been no further training of CRFs to serve people with disabilities in disadvantaged areas of South Africa.

The CBR students who participated in this action research were all sent for training by organisations which expressed the need for community rehabilitation facilitators rather than occupational therapy technicians as members of their workforce. Five of the students themselves came from rural areas in the midlands of KwaZulu Natal and two were from townships in the eThekwini (greater Durban) municipality. The students who varied in age from 21 to 40 years all grew up in KwaZulu Natal. The following section of this chapter details some of the events that occurred during the childhoods of the CBR students who participated in this study.

1.4 Situating CBR Training in the South African Socio-political Context

1.4.1 Introduction

This section of the thesis will specifically look at two periods in the history of South Africa, the 1970s to1994, when CBR students in this study were growing up, and the post-apartheid era, the current socio-political context of the CBR course. I have focused selectively on particular aspects of the history of South Africa during these periods that may have had an impact on the CBR students and/or the CBR course. Specifically there is a focus on

KwaZulu Natal in the section on the history of South Africa from 1970 to 1994 because all seven students who participated in this study were growing up in this province during this time period. It is possible that their experiences of events during this period may have affected their perceptions of social justice and oppression.

1.4.2   Events in South African history from the 1970s to 1994 and the childhoods of the CBR students

Readers Digest' s Illustrated History of South Africa (1994) characterises the period from 1976 to 1994 in South African history as one of resistance and negotiations. During the 1970s, the South African government's policy of 'Bantu Education' was in force, condemning African children to an inferior education system that lacked resources. According to Clark and Worger (2004), although the enrolment of African children in schools increased rapidly between 1955 and 1975, the actual amount of GDP spent on the education of Africans declined. Hyslop (1999) describes the increased political awareness of youth in the 1970s as being due to strikes that their parents were involved in and Mozambique and Angola attaining independence from Portuguese colonial rule. Steve Biko's ideas of Black Consciousness were also taking hold amongst the youth and at universities with black students, the South African Students' Organisation was formed as a breakaway from the multiracial National Union of South African Students. From 1974, the Nationalist government in South Africa was becoming more hard-line in enforcing their fifty-fifty rule concerning the education of Africans. According to this rule 50% of secondary school subjects had to be taught using the medium of Afrikaans in African schools (Hyslop, 1999). African students were extremely unhappy about this because most of their teachers were not fluent in Afrikaans and most students did not understand nor see the relevance of the language. In June 1976 the Soweto Students Representative Council (SSRC) organised a mass protest against the use of Afrikaans. Police responded with gunfire, thus beginning days of violence in which hundreds of people were killed and many buildings and vehicles were damaged (Clark & Worger, 2004). In the following days and months, the unrest spread

to other parts of the country, including to Durban and surrounding areas and other parts of KwaZulu and Natal. Several of the CBR students who participated in this study were young children growing up in KwaZulu or Natal, some attending primary school, at this time of disruption and resistance.

At the time that this turmoil was occurring African people in South Africa were seen by the government of the day as citizens of homelands which were ethnically divided areas of land mostly in unproductive rural areas of South Africa (Maylam, 1986). As opportunities for local employment in the homelands were minimal and poverty great due also to the unproductive land, many families were forced to survive with a member (often the father) providing migrant labour in one of the large South African cities or on the mines. This situation is evident in the life histories of Life and Zanele told later in this thesis. In what is the present day province of KwaZulu Natal, the homeland areas were called KwaZulu while the province governed by the White government of the 1950s to 1994 was called Natal.

During the 1970s Chief Buthelezi revived the Inkatha Movement which had been founded in 1928. Although Inkatha had started out as a mainly cultural movement of Zulus, in the 1970s it became an increasingly political movement that won control of the KwaZulu homeland. During this time the tribal authorities, particularly chiefs and indunas, in KwaZulu were civil servants paid by the KwaZulu homeland government and as such were members of Inkatha (Kentridge, 1990). According to Kentridge, Inkatha leaders espoused politically conservative ideas and a number of them became vigilantes, commanding obedience and allegiance from groups of armed men sometimes in exchange for food, money and favourable pieces of land. After 1977, the Inkatha movement's ideology also penetrated into school curricula in the homeland (Davenport, 1989). A number of the CBR students who participated in this study, grew up in rural areas which were part of the KwaZulu homeland. Thus, at least some of their schooling would have been influenced by Inkatha's ideology. Davenport (1989) also writes of Inkatha vigilantes who undertook acts of violence against 'radical' students in schools in 1980 and again in 1983. One of the CBR students spoke of her experiences as a

school child of being sucked into violence related to Inkatha.

Davenport (1989) records that 1980 was another year of massive unrest in education in South Africa, with a boycott of schools lasting until September of that year. Pupils and students had a wide range of grievances, including the use of white national servicemen as teachers in black schools; unqualified or poorly paid teachers in African schools and that few textbooks were supplied to schools. These boycotts extended to areas such as Pietermaritzburg and Durban in Natal, where at least one of the CBR students was attending school at this time.

In 1983, the White parliament of South Africa passed an Act with a new constitution for South Africa (Clark & Worger, 2004). The new constitution brought into being a tricameral parliament, with separate Houses for Indians and Coloureds. African people remained excluded from government and a large number of Indian and Coloured people rejected the tricameral parliament. Extra-parliamentary opposition to the new constitution and tricameral parliament was boosted with the formation in August 1983, of the non-racial United Democratic Front or UDF. According to Seekings (2000), the UDF brought together over 600 organisations around the country with approximately 3 million members. Such united opposition to the government had not been experienced in South Africa since the days of the Congress Alliance and the Freedom Charter in 1955. The Congress of South African Students (COSAS) became the school wing of the UDF (Hyslop, 1999). In the context of this study, it is necessary to look at the relationship between the UDF and Inkatha, particularly in KwaZulu and Natal, as this may have affected the CBR students growing up in townships and rural areas during the mid-1980s.

Although there was communication between Chief Buthelezi of Inkatha and Archie Gumede of the UDF, starting early in 1983, the relationship between the two organisations became progressively polarised following the South African government's move to incorporate some Durban townships into the KwaZulu homeland (Seekings, 2000). In October 1983, supporters of Inkatha killed a number of students and others aligned to the UDF who were

opposed to the incorporation. UDF-affiliated organisations were excluded from KwaZulu schools and colleges. The UDF refused to meet with Buthelezi or address the KwaZulu Legislative Assembly and the relationship deteriorated further (Seekings, 2000). During 1984 and 1985, protests and conflict increased in KwaZulu and Natal with education being the focus of protest, particularly by the youth. According to Motala and Vally (2002), over 650 000 students nationally supported the COSAS call for a boycott of schooling in 1984, which included schools in Natal. The State's response was to ban COSAS and impose a partial state of emergency. Hyslop (1999, p.172) points out that "During 1985 it became clear students' demands had shifted from specific educational demands to broad political ones." Students were demanding political change in the country.

At about this time, Inkatha leaders led vigilante groups that brutally repressed the youth and UDF activists in Umlazi and KwaMashu (townships outside Durban) and later in Imbali (Pietermaritzburg). According to Seekings (2000), the violence also produced large numbers of refugees within the province. Later, in 1987, there was again violence between Inkatha and UDF supporters in the Natal Midlands with police detaining almost all the UDF leaders from African areas. Although a peace initiative was brokered by the Pietermaritzburg Chamber of Commerce, this too broke down. Four of the CBR students grew up in the Midlands area where Pietermaritzburg is situated. However, they were living in rural areas rather than the urban areas where much of the above-mentioned UDF – Inkatha struggles took place. Some of the CBR students had teachers at their schools who had come from the urban areas and brought their knowledge and experience of struggle with them.

From late 1987, violence escalated through KwaZulu and Natal, with almost a thousand people being killed in 1988 and 1300 in 1989 (Seekings, 2000). People were killed for wearing a UDF T-shirt or even just for living in a 'UDF area'. State repression and Inkatha violence were connected, with very few, if any, Inkatha leaders being detained although most of the UDF leadership was detained in the Natal Midlands. KwaZulu and Natal were extremely dangerous places for youth to be growing up and developing an awareness of

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society and community. Several of the CBR students reported their experiences of conflict and real danger when growing up in the mid to late 1980s and early 1990s in this province. It is likely that these experiences of the CBR students will have, in some way, affected their understandings of struggle, injustice and social action.

1.4.3   *Situating disability, CBR and CBR training in post-apartheid South Africa*

With the release of Nelson Mandela in 1990 and the unbanning of the African National Congress (ANC) and a number of other organisations, the ANC began talks about negotiations for a future South Africa with the Nationalist government (Clark & Worger, 2004). Negotiations began and by July 1993 a date had been set for elections for a new democratic South Africa. As a new democratic government was elected in April 1994, many education non-government organisations (NGOs) which had developed in strong opposition to the apartheid government from the 1970s, now struggled to move from an era of opposition to one of co-operation with the government (Morrow, 2004). Increasing the difficulties for NGOs was the fact that the post-apartheid state tried to integrate and centralise the types of activities often done by NGOs, in the Reconstruction and Development Programme (RDP). International donors then tended to put resources into the State's RDP projects rather than directly into NGOs. As Morrow (2004, p.323) describes it, "government, from being the enemy by definition, became both a rival for funding, and the major and often demanding customer for the products and services ….. of education NGOs." Morrow goes on to describe the mass extinction of NGOs because of the decline in funding and the normalisation of South African society. It should be noted that it was during this period that both the SACLA and IUPHC CBR training programmes had to close because of lack of funding.

The post-apartheid era heralded not only liberation for those oppressed because of their race, with the change of government in 1994, a new dispensation for people with disabilities also dawned. According to Philpott (2004), prior to 1994 most children with disabilities in South Africa were severely disadvantaged with little access to basic services. Provision of services

was biased towards White and urban children with disabilities and most facilities for people with disabilities were separated off from the mainstream.

 The passing of the Act to bring about a new Constitution in South Africa in 1996 meant that people with disabilities had their equality with all other citizens of South Africa entrenched in the highest law of the land. The Bill of Rights (Chapter 2 of the Constitution of the Republic of South Africa) enshrines the right to equality and prevention of unfair discrimination against people with disabilities (Constitution of the Republic of South Africa of 1996). Due to the changes brought about by the new Constitution, a number of new policies and guidelines were developed in different sectors of government. The White Paper on the Integrated National Disability Strategy (INDS) was adopted by the South African government in 1997 and this too, heralded a break with the past as regards people with disabilities. The INDS is based on the social model of disability and it promotes the integration of disability issues into all government programmes, planning and strategies (Philpott, 2004). According to the INDS, people with disabilities are central to the transformation process and thus the Office on the Status of Disabled Persons (OSDP) has been established in the Office of the President and the Office of the Premier of each province.

In addition to the wide-ranging INDS, a number of other sectoral White Papers and policies have been developed that are key to the situation of people with disabilities in post-apartheid South Africa. The Health Department drew up a National Rehabilitation Policy in 2000 in which they adopted CBR as an important approach to ensure that appropriate and affordable rehabilitation services are brought to all communities. The "Comprehensive PHC package for South Africa" adopted by the Department of Health in 2001 describes CBR as part of the Primary Health Care package, and specifies the types of rehabilitation services and personnel who should function at different facilities and in the community (Philpott, 2004). This document mentions the use of community rehabilitation facilitators. In spite of these progressive national policies, the implementation of these policies is not uniform throughout

the country and in the Northern Cape province, there was no CBR service at all.

The National Education Policy Act (1996) upholds the protection of the rights mentioned in the Constitution with specific reference to its implications for education. In particular this Act supports the right of

> "(1) every person to be protected against unfair discrimination within or by an education department or education institution on any ground whatsoever; (2) of every person to basic education and equal access to education institutions"

This statement in the National Education Policy Act together with the White Paper on Education and Training (1995) and the South African Schools Act (1996), with its focus on quality education for <u>all</u> learners, sets the underlying principles for the Department of Education's policy on meeting the educational needs of learners with disabilities. The Department of Education published its White Paper 6: Building an Inclusive Education and Training System in July 2001. This white paper proposes the development of inclusive education as the way to overcome the barriers facing children with disabilities as well as other learners in the education system.

The various pieces of legislation and policies mentioned above have made a qualitative difference to the environment in which service delivery to people with disabilities can occur. As Philpott (2004) mentions, there have been a number of difficulties in implementing these policies, such as lack of capacity in government departments and lack of co-ordination. However, the situation in which CREATE was training people to deliver CBR to people with disabilities in 2006, is markedly different to the times in which CBR in South Africa was first conceptualised.

1.4.4 *The educational context of CBR training*

As mentioned in the previous section, the roots of the CBR training at the IUPHC were in the historical period between the end of the States of Emergency and the first democratic elections in South Africa. Not only was this a time of significant political change, the

educational context was also changing and some of these changes impacted on the development of the CBR training course at the IUPHC.

In the mid 1980s, the People's Education movement developed in response to the school boycotts by students who were protesting against mass detentions and the banning of COSAS (Congress of South African Students) (Rule, 2002). People's Education promoted the idea of the classroom as a site of struggle (against apartheid) and developed a radical pedagogical alternative to the education taking place under apartheid. According to Hoadley and Jansen (2002), People's Education aimed to develop critical consciousness and democratic participation in the classroom. It rejected the idea that education could be neutral and its intention was to work towards emancipation. Much of People's Education was rooted in the work of Paulo Freire. The National Education Co-ordinating Committee (NECC) was formed in December 1985 to take forward the concept of People's Education and they set up commissions to develop the ideas of People's Education and to develop new materials for use in schools (Motala & Vally, 2002). In addition, the NECC stimulated the development of students' representative councils (SRCs) and Parent-Teacher-Student Associations (PTSAs) as alternative governance structures in education.

The initial curriculum of the CBR course run by the IUPHC was developed in 1989 and 1990, when People's Education still had currency in townships around the Witwatersrand. The first co-ordinator of the CBR training at the IUPHC explicitly used Freire's idea of conscientisation in developing the CBR course and there was a strong thrust towards both the emancipation of people with disabilities as well as that of the students on the course. The CBR course at IUPHC also used participatory teaching methods and there was community involvement in developing the curriculum and in management of the course, which Kraak (1999) records as being associated with People's Education.

The more recent systemic discourse in education together with Outcomes Based Education (OBE) has also impacted on the CBR course run by the IUPHC and then CREATE.

According to Kraak (1999) the systemic discourse in South African education led to the creation of a unified education and training system in which the National Qualifications Framework (NQF) plays a key role. The HPCSA which has accredited CREATE, has ensured that the CBR course is aligned with the requirements of the NQF. In addition, CREATE has now framed the CBR course in terms of outcomes, as required in OBE. For an analysis of the curriculum and the effects of stating the course in terms of outcomes, see Chapter 4 of this thesis.

1.5   Conclusion

The CBR course that was investigated in this study has been shaped by a number of socio-political and historical forces as well as by developments within the fields of rehabilitation and CBR in South Africa. The transition to democracy in South Africa provides a particular context for this study's concern with the oppression and empowerment of people with disabilities. It is therefore important to acknowledge the influence of a variety of contextual factors on the CBR curriculum being studied in this research, as well as on the students and on myself as researcher. A CBR course will be affected by specific national, regional and local social, political and historical factors as well as being shaped by the national and international theoretical context of rehabilitation and disability studies.

CHAPTER 2

THE THEORETICAL CONTEXT OF COMMUNITY BASED REHABILITATION TRAINING

2.1   Introduction

Although Community Based Rehabilitation is a relatively new field of study and practice with a small but growing body of literature, it can be linked to the larger body of work on disability issues. As mentioned in Chapter 1, CBR in South Africa developed in relation to challenges from people with disabilities concerning rehabilitation and accountability. This chapter aims to situate the CBR training programme in this study within international, as well as local debates on the conceptualisation of disability and appropriate models of rehabilitation and CBR. In addition, I aim to examine theoretical construction of oppression as it relates to disability and CBR. I also explore the literature on curriculum in relation to the CBR course being studied in this research.

2.2   Discourses of Disability

In the following section of this thesis, I examine three dominant discourses on disability: the social model of disability, the rights discourse of disability and the medical perspective of disability. In addition, I explore disability as a form of social oppression which is linked both to the social model of disability as well as the rights discourse of disability. In doing this, I aim to contextualise the understanding and discourse of disability that is dominant in CREATE and that underpinned this research.

2.2.1   The social model of disability

One of the theoretical constructs underpinning this research is the social model of disability. In this model disability is understood as a form of oppression in which the social environment excludes and oppresses people with disabilities through failing to adapt to their needs and aspirations (Barton, 1994; Marks, 1997; Walmsley, 2001). Michael Oliver has been a strident voice in proposing and supporting the social model of disability, as indicated by his view of disability being a social creation, created by societal institutions and processes (Oliver, 1993). Oliver (2004) writes about some of the defining aspects of the social model of disability. Firstly, as mentioned previously, there is a focus on barriers and disabling environments and cultures. Secondly, within the social model, problems experienced by individuals are seen within the totality of disabling environments. However, Oliver (2004) is careful to state that proponents of the social model of disability do not necessarily claim that interventions with individuals with disabilities are always counter-productive. Lang (2000b, p.3) states that the social model of disability Agives central importance to politics, empowerment, citizenship and choice.@

The Union of the Physically Impaired Against Segregation (UPIAS) is credited with first conceptualising and publishing the ideas behind the social model of disability, in 1976 (Barnes and Mercer, 2003; Matshedisho, 2005; Oliver, 2004). UPIAS was expressing their conceptualisation of disability based on their own experiences of disability, which was radically different to the way in which able-bodied people, and particularly professionals, had defined and conceptualised disability up until that point. Proponents of the social model of disability have argued that the restrictions people with disabilities experience in their daily life are not intrinsic to their impairments but are rather a result of the social environment not taking into consideration their differences.

In his critique of the social model of disability and some of the literature dealing with this model, Matshedisho (2005) criticizes the social model for having a basis that is essentially negative and adversarial (towards the medical model of disability). He claims that the primary aim of the social model of disability is the liberation of people with disabilities from the medical model of disability, with the disability rights

movement referring blanketly to everything it does not like as the medical model of disability. What Matshedisho does not appear to take cognisance of is the tremendous <u>positive</u> power of people with disabilities speaking for themselves and assertively unmasking their own oppression through naming societal barriers as the cause of their negative experiences of disability.

Lang (2000a) also critiques those who take a radical position concerning the social model of disability in which they do not allow any space for able-bodied people in their struggle. However, according to Lang (2000a), there is a more conciliatory position as regards able-bodied people which may not lead to their alienation. According to Watson (2004), the social model of disability has been a particularly useful tool for the mobilisation of disability movements. Certainly, in South Africa members of Disabled People South Africa (DPSA) subscribe to the social model of disability and the White Paper, the Integrated National Disability Strategy (RSA government, 1997) is based on the social model approach to disability which they also link to the issue of social rights. From personal discussions with people with disabilities in South Africa (P. Chappell, personal communication, September, 2004; B. Zuma, personal communication, April, 2004), it is clear that for at least those people with disabilities who have been exposed to the thinking behind the social model, this model enables them to externalise the causes of their negative experiences and it gives them the legitimacy to address the environmental and attitudinal barriers that they perceive as oppressing them.

Rather than seeing opposition to the medical model of disability as a weakness of the social model, the social model of disability can be seen as taking a stand for justice and "the good society". In this conceptualisation of "the good society" equalisation of opportunities and social rights are paramount. The social model of disability can be aligned with critical theory in its grounding in the concept of a "good" society – a just and democratic world, and in its concern to give people an understanding that will free them from oppression. Other aspects of the social model of disability that authors such as Oliver (1992; 1993) and Barnes and Mercer (2003) have written about also place the social model of disability within a critical theory framework. For example, Oliver (1992) emphasizes the need for disability research to fit into an emancipatory paradigm that addresses the oppression of people with disabilities, in part through the

participation of people with disabilities in the research process. This is similar to what Brookfield (2005) describes as one of the five distinctive characteristics of critical theory – that it breaks down the separation of the subject and object of research.

Unlike critical theory, the social model of disability should not be seen as an all encompassing or explanatory theory. Rather, as Oliver (1996) points out, the social model should be used to aid one's understanding of the experiences of people with disabilities. Matshedisho (2005, p.86) criticizes various authors and members of the disability movement for their conceptual misconstruction in equating the social model with a social theory of disability, pointing out that:

> "a theory is a proposition. It offers a systematic explanation of a body of empirical data. In contrast, a model is merely an explanatory device; it is more like a hypothesis that is yet to be tested."

Oliver (1996, p.41) agrees with this distinction between a model and a theory, and claims that "It [the social model] is not a social theory of disability and it cannot do the work of social theory".

One criticism of the social model of disability and some of its proponents is that it does not account for the complexities of the experiences of people with disabilities (Marks, 1997; Matshedisho, 2005; Watson, 2004). Certainly people with disabilities experience 'disability' and oppression because of social structures and disabling environments. However, there is also the reality of the person's own experience of her/his impairment which may include experiences such as pain and weakness which are not necessarily socially reproduced. It seems to be reductionist to claim that one can only understand impairment in terms of socially constructed disability. Imrie (1997, p.268) also points out that "by objectifying bodily experiences in a social model, the subjective, real experiences of, for example, physical incapacity and pain, will be ignored or just dismissed." Morris (1993), a key disability activist in Britain, stresses the necessity to 'bring the body back in' to the conceptualisation of disability within a social model framework. In the United States a "crip-politics" has developed which asserts the need for the recognition and acceptance of impairment as difference, which nevertheless should be accommodated in social environments and institutions. This acknowledgement of impairment as difference makes it clear that even if the

social and physical barriers that people with disabilities experience were overcome, and disability as defined in the social model was transformed, still the reality of the body would be recognised. In discussing the ideas of Pinder (1996) and Bury (1996), Watson (2004, p.103) writes that: "What is required, they suggest, is a working definition of disability linked to impairment." Such a definition would give credence to the social construction of disability at the same time as acknowledging the body of the person with a disability. This would avoid the dualism created by the social model of disability in which the body is seen only as biomedical while disability is purely a social construction (Lang, 2000a).

2.2.2 *The rights discourse of disability*

The social model of disability can be linked to the Arights discourse@ of disability (Fulcher, 1989) which emphasizes the rights of people with disabilities to independence, equality and self-reliance. In order to respect the rights of people with disabilities, various societal barriers must be overcome. As the Office of the High Commissioner for Human Rights (no date, p.1) writes:

> "The human rights approach focuses on the human being, and locates the "problem" of persons with disabilities to fully participate, benefit and contribute to social life outside the person and in the society."

It is then the responsibility of the State in particular, and civil society, to address socially created barriers so that the dignity and human rights of all people are respected. This human rights discourse of disability has, with its close links to the social model of disability, gained currency internationally. The recent revision of the Joint Position Paper on CBR (ILO, UNESCO & WHO, 2004) has added the issue of respect for the human rights for people with disabilities to the list of major objectives for community based rehabilitation. Recently, a number of country governments, international disabled people's organisations and non-government organisations under the auspices of the United Nations engaged in a process known as the Convention on the Rights of Persons with Disabilities (UN Enable, 2006). The United Nations Convention on the Rights of Persons with Disabilities consists of a list of articles concerning the rights of people with disabilities to which it hopes member States of the United Nations will sign up. This enables a mechanism of monitoring the status of people with disabilities in different countries, while recognising that it is the State

that has primary responsibility for ensuring respect for the rights of people with disabilities.

The rights discourse of disability is important because it situates disability in the context of all forms of oppression, including racism and sexism. The International Convention on the Elimination of All Forms of Racial Discrimination (1969) and the International Convention on the Elimination of All Forms of Discrimination against Women (1981) are two of the international conventions dealing with the rights of other oppressed groups. At last the United Nations has recognized that the situation of people with disabilities is similar to that of other groups of oppressed people and that it requires similar measures to protect the rights and freedoms of people with disabilities. The rights discourse of disability is not exclusive of the medical or social models of disability, and in the language of the Convention on the Rights of Persons with Disabilities (UN Enable, 2006) it is possible to see the influence of the social model of disability. For example, in the preamble it states:

> "*Concerned* that, despite these various instruments and undertakings, persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world," (UN Enable, 2006, p.2).

Although the rights discourse of disability provides a framework for the empowerment of people with disabilities, people with disabilities at a grassroots level may find it difficult to access these rights. If a particular sector or tier of government is not respecting the rights of people with disabilities it may require legal remedy which presupposes the person with a disability has access to information and possibly financial backing to challenge the situation in court as well as social power.

2.2.3 *Disability as a form of social oppression*

One of the first groups of people to claim that disability (in particular, they mention physical disability) is a form of social oppression, was the Union of the Physically Impaired Against Segregation in 1976 (UPIAS, 1976). To those who are proponents of the social model of disability such as UPIAS, the links between disability and oppression are clear. The attitudinal and physical barriers that people with disabilities experience are manifestations of their oppression by able-bodied people. As Barnes

and Mercer (2003, p.10) put it, "Common experiences of exclusion led to disabled people's growing sense of themselves as an oppressed minority." A number of other authors (Northway, 1997; Oliver, 2004; Werner, 1993) also liken the experiences of people with disabilities to that of oppression. Watson (2004) goes so far as to claim that the social model of disability defines the term 'disability' as social oppression, rather than as the form of impairment that a person has.

However, the conceptual linking of disability and oppression is not only a focus of the social model of disability. The rights discourse of disability can also be connected to an understanding of disability and social oppression. When a person with a disability experiences oppression in the form of discrimination, exploitation or marginalisation, it may frequently be because his/her rights to dignity, freedom of choice and expression and equity are not being respected. Oppression of people with disabilities can also result in their social rights being ignored. For example, a child with a disability who is hidden by his family (marginalised) is also being denied his right to education. In this study I use the term 'oppression' to refer to the concept as it is explained by social model theorists – exclusion, marginalisation and exploitation due to externally imposed barriers. I also incorporate the rights discourse of disability into this conceptualisation of oppression by including ideas of the denial of human rights and equity as components of the oppression of people with disabilities.

In order to understand disability as a form of social oppression, it is necessary to examine the perspectives of different authors on oppression and then to relate these perspectives to the situations people with disabilities find themselves in. Hardiman and Jackson (1994) allude to the difficulty in coming up with one single definition of oppression that will satisfy all aspects of this complex phenomenon. Different authors have defined and described oppression in a variety of ways. Freire (1972) describes oppression as the dehumanization of oppressor and oppressed involving exploitation, violence and lack of recognition of the oppressed as human beings. Barnes and Mercer (2003, p.19) define oppression as "a structural concept, and that it is evidenced by a highly unequal distribution of material resources and uneven power relations and opportunities to participate in everyday life." Hardiman and Jackson (1994) add to this definition that oppression is not only a situation but also a process whereby one group attains privileges and power through controlling and exploiting

others. Oppressed people thus experience disadvantage and injustice (Northway, 1997). Oppression does not just consist of a set of beliefs or individual discriminatory actions, according to Hardiman and Jackson (1994, p.2)

> "It is first and foremost a systematic phenomenon that involves ideological domination, institutional control and the promulgation of the dominant group's ideology of domination and culture on the oppressed. Oppression is not simply an ideology or set of beliefs that asserts one group's superiority over another. Nor is it random acts of discrimination or harassment toward members of the subordinate group. It is a *system* of domination with many interlocking parts."

Thompson (1998) proposes a model for understanding oppression that looks at the different levels at which discrimination and the oppression arising from it, occur. The personal, cultural and structural levels at which discrimination takes place are seen as interrelated and the system of domination usually occurs at all three levels. At the personal level, the thoughts, feelings and actions of an individual e.g. a person in a position of power, can cause inequality and oppression. However individual behaviour needs to be considered in the broader context of cultural patterns of beliefs and behaviours and in the structural aspects of society. Culture can create boundaries which consequently marginalise particular groups. According to Thompson (1998) at the cultural level, discrimination and the resulting oppression such as racism can occur. However cultural acts occur within the social, economic and political aspects of the social order (which is seen as the structural level). The issue of power is key to understanding the structural level of oppression and as Thompson (1998, p.18) writes, "Structured inequalities are part and parcel of the social order and play a part in maintaining that order."

Another model to understand oppression has been developed by Hardiman and Jackson (1994). These authors suggest that in order to eliminate oppression it is important to be aware of the forces that keep oppression functioning. The framework that Hardiman and Jackson propose to understand the forces at play in oppression is known as a dynamic model of oppression. This model considers oppression to function at the levels of the individual, institution and society / culture through conscious or unconsciously held oppressive beliefs that are enacted through

oppressive attitudes and behaviours. The three levels of social context at which Hardiman and Jackson propose oppression operates can be roughly equated with the levels of oppression proposed by Thompson (1998). Hardiman and Jackson (1994) in addition mention the psychosocial processes which keep oppression in place which may be conscious, when oppression is knowingly advocated for or supported through individuals, institutions or society. Psychosocial processes maintaining oppression may also be unconscious, when the oppressor or oppressed person accepts the dominant oppressive ideology as normal and right. The third dimension of Hardiman and Jackson's model of oppression concerns how oppression is applied or manifested – through behaviour and attitudes of systems and individuals.

Young (1994) has a slightly different view of oppression based on her interaction with and study of different groups of oppressed people. She therefore writes that "Because different factors, or combinations of factors, constitute the oppression of different groups, making their oppression irreducible, I believe it is not possible to give one essential definition of oppression." (Young, 1994, p.37). Instead Young writes about five Afaces@ of or forms that oppression takes, which are exploitation, marginalisation, powerlessness, cultural imperialism and violence. A group of people can be considered to be oppressed if they are subject to one or more of these conditions or faces of oppression. Young's explanation of oppression deals with the manner in which people are oppressed rather than the levels at which this happens or the processes that maintain oppression. Although Young (1990) has developed her conceptualisation of the five faces of oppression based on the experiences of different social groups, her conceptualisation of exploitation in particular, is based first and foremost on class oppression and an analysis of the labour of different groups and the benefits accruing to them. This appears to be a narrow view of exploitation as people may be exploited for their status (as in an affirmative action appointment for employment equity purposes) or for the benefits that may accrue to the family (such as a person with a disability being exploited for her social welfare grant), without any labour being involved.

In an early article on disability and oppression, Abberley (1987) asserts that a theory of disability as oppression needs to recognise the social origins of impairment and it should oppose the social, environmental, financial and psychological discrimination

experienced by people who have impairments. He goes on to develop his ideas which are very similar to the social model of disability although it is not termed as such.

In subsequent literature on disability and oppression, the social model of disability is more apparent and authors go into more depth on the nature of the links between disability and oppression. Some authors, (Barnes and Mercer, 2003; Northway, 1997) use Young's (1994) 'five faces of oppression' to describe the situation of people with disabilities. A number of these faces of oppression can easily be related to the experiences that many people with disabilities have. For example, a number of CBR students have experienced that some people with disabilities are washed and dressed well by their family to go and collect the disability grant, which the family member then does not spend on the person with a disability. At other times, the person with a disability is not cared for by the family. Judging from verbal reports of CRFs around the country, this form of exploitation appears to be quite common in South Africa. Many people with disabilities are also marginalised, particularly with regards to formal employment and the lack of Aordinary@ people with disabilities in the media, including advertising, shows the cultural imperialism of able-bodied people. Northway (1997) adds a sixth face of oppression, which she feels is particularly relevant to people with disabilities, discrimination. Many people with disabilities can relate stories of discrimination that occur from the family or personal level up to the societal and sometimes legislative level.

The different levels at which oppression operates according to the models of Thompson (1998) and Hardiman and Jackson (1994) can also be easily applied to the experiences of people with disabilities. As Reeve (2004, p.83) writes, Adisability is seen as a form of social oppression that operates at both the public and personal levels, affecting what people can *do* as well as who they can *be*.@   An example of the oppression of people with disabilities at a public and cultural level is the lack of sign language interpretation or sub-titles on most South African television programmes, affecting the ability of deaf people to keep in touch with current affairs and entertainment. At a structural or institutional level, Coleridge (1993) gives the example of people with disabilities being oppressed by government departments that

claim that it is too expensive to cater for the transport or housing needs of people with disabilities.

In a study comparing disability with other categories according to which people are oppressed (e.g. race and sexual orientation), Gordon and Rosenblum (2001) detail the process through which people become identified as a group and subsequently experience oppression. According to these authors, first different categories of people are named (as disabled, Black etc.) by society. These named groups of people may then disaggregate into smaller subgroups such as the Deaf, visually impaired people etc. or they may maintain the larger group identification. In the process of discrimination and oppression a dichotomy is identified such as able-bodied versus disabled, with one of the groups then being stigmatised. The stigmatised group is then denied certain attributes that are valued in that culture. For example, people with disabilities may be denied the value of independence. These psychosocial processes seem to lay the foundation for further experiences of oppression which could then be explained in terms of Young's 'five faces of oppression'.

Through developing an understanding of disability as a form of oppression, it is possible to posit what a more just world that accepts difference would be like. This vision of a world where the discrimination and oppression of people with disabilities does not exist, guided this study and it was through uncovering the nature of oppression that strategies were designed for teaching CBR students to overcome the oppression of people with disabilities. As previously indicated, this study can be located within a critical paradigm and Brookfield (2005) indicates that one of the distinguishing characteristics of critical theory (and in this case, research) is that it is normatively grounded in the notion of a fairer and more democratic world.

2.2.4   *The medical perspective of disability*
As mentioned above, the social model of disability is frequently contrasted with the medical perspective of disability in which the individual with an impairment or disability is seen as having a deficit. The medical model of disability focuses on the 'pathology' or loss of physical, sensory, behavioural, cognitive or psychological capabilities of the individual, as compared to 'normal'. According to Marks (1997), a central concern of the medical perspective is to diagnose the 'condition' of the

individual in order to provide curative interventions, or if this is not possible, to care for the person. Gilson and DePoy (2002) go so far as to name this model the 'diagnostic approach to disability'.

According to Matshedisho (2005), the origins of the medical model of disability can be traced to the Age of Enlightenment, during which time scholars began to describe what would previously have been termed aberrancy or deformity, as impairments that could be classified according to their biological cause, diagnosis, care and cure. In the 19th century scholars in Europe and America became more concerned with deviation from the 'normal' human being as the use of the statistically based "normal curve" gained currency. Matshedisho (2005) describes how scholars used the normal curve to separate the 'abnormal' (particularly as regards intelligence) from the 'normal' and that institutionalisation of people with disabilities was a common way of separating them from 'normal' people.

Barnes and Mercer (2004) and Oliver (2004) remind us that in the 20th century, the medical perspective of disability has been the dominant view of disability that was accepted by policy makers and service providers as well as the general public. This concept of disability being biological inferiority also led to the view of disability being a personal tragedy. Thus service providers who are concerned with the adjustment of people with impairments usually use psychological 'loss' or bereavement models to guide their intervention with these people (Barnes and Mercer, 2003).

Imrie (1997) highlights a number of difficulties with the medical perspective of disability. The medical model creates a duality between able-bodied and disabled or normal and abnormal, as if these categories are completely discrete from each other. They do not allow for fluidity in time or space in which a person may move in and out of a categorisation of 'disabled' or 'normal'. This dualism not only proposes two distinct states of being, it also categorises being able-bodied as being better and superior, while the emphasis of the medical model on physical impairment perpetuates the idea of people with disabilities being weak and dependent. In terms of theories of oppression, this construes able-bodied people as being dominant while people with disabilities are subordinate (Lang, 2000a). This conceptualisation of

disability and the way it socialises people with disabilities into an inferior role is incompatible with the fairer and more democratic world envisaged in critical theory. According to the Frankfurt School's view of critical theory, one of the central tasks of adulthood is ideology critique (Brookfield, 2005). When one considers the medical perspective of disability as the dominant ideology guiding service provision to people with disabilities, then, through engaging in ideology-critique, it is possible to identify that this unjust culture is dominant and uncritically accepted in many services provided to people with disabilities. Another critique of the medical model as the ideology guiding services for people with disabilities is that professionals (the service providers) are assigned the power to determine the needs, type of assistance required and diagnosis of people with disabilities without any consultation with the people with disabilities concerned. Thus people with disabilities are disempowered and become objects of scrutiny and interventions rather than active subjects in the process of service delivery. Burbules (1995, p.59) refers to this form of ideology-critique which judges the ideology according to the effects it has in supporting particular social and political systems, as "an *argument from effects"*.

The medical model of disability and the view of a person with a disability as being 'less than whole', has also led to people with disabilities being seen as objects of charity (Coleridge 1993). In this view the person with a disability is also seen as inferior to 'normal' people and s/he is expected to be a passive recipient of the beneficence of well-meaning people.

In this study I have used the social model of disability with its links to social rights and oppression as the discourse that guides the research as this is the discourse of disability that dominates the thinking and practice of CREATE staff members. However, I do agree with the critique of the social model that it does not take into account the personal experiences of impairment that people have and that it creates a dualism. Through the action research cycle in this study I tried to examine how the CBR students made sense of disability and what discourse was dominant in their understanding of disability.

2.3   Understanding Disability and Rehabilitation in Developing Contexts

Although it is important to situate this study within the theoretical discourses that guide thinking on disability, it is also necessary to examine the contexts in which people with disabilities find themselves, particularly in developing countries. CBR is more frequently implemented in developing countries and poorer contexts within countries (such as South Africa) than in developed nations. This section of the chapter explores the situation of people with disabilities in developing countries and then moves on to a discussion of rehabilitation and a specific response to some of the inadequacies of rehabilitation in developing contexts, the development of community based rehabilitation.

2.3.1   Disability, poverty and developing contexts

Several authors describe the situation of people with disabilities in developing countries in terms similar to those used in the description of oppression – powerlessness, discrimination, marginalisation and social exclusion (DFID, 2000; Lorenzo, 2005; Thejane, 1999; Yeo, 2001).

Both Yeo (2001) and the report by DFID (2000) write of the massive scale of poverty amongst the millions of people with disabilities in developing countries, which is in part caused by the exclusion and marginalisation of people with disabilities from the social, political and economic life in their communities and countries. Although there is no reliable empirical data on the poverty of people with disabilities globally because they are so excluded, there is evidence that people with disabilities make up a greater proportion of people living in chronic poverty than the global prevalence of disability would indicate. Quoting the World Bank, Yeo (2001) indicates that there are approximately half a billion people with disabilities amongst the poorest of the poor. In a study of the living conditions of people with disabilities in Malawi, Loeb and Eide (2004) found that more households with a person with a disability had no-one employed when compared to families without a member with a disability. In addition, households with a person with a disability were found to have a significantly lower standard of living with regard to fuel for cooking and lighting, access to water and sanitation and refuse removal. Literacy rates amongst people with disabilities are

much lower than that of the general population according to DFID (2000) and the IDDC quoted in Yeo (2001) claims that up to 98% of children with disabilities in developing countries do not receive formal education.

Disability and the resulting marginalisation, discrimination and exclusion are not only causes of poverty, poverty itself also causes disability. Common causes of disability include malnutrition, poor hygiene and sanitation, difficult access to immunisation against diseases such as polio and measles, lack of access to health care and maternal care, dangerous working and living conditions and situations of conflict e.g. with the planting of landmines. It is estimated that 100 million people globally have impairments due to malnutrition and poor sanitation (Yeo, 2001). Thus it is possible to see poverty and disability as elements of a vicious cycle which affect each other. Disability may cause poverty because low literacy rates and discrimination in the workplace mean that people with disabilities are less likely to be employed. At the same time, living in poverty increases the chance of a person becoming disabled. For example, being exposed to unhealthy living conditions increases the possibility of contracting TB, which can cause paralysis if it affects the spine.

Recognising the devastating effects of international poverty in general, similar to those mentioned above, the United Nations and 189 member states developed the Millennium Development Goals in 2000 (UNDP, no date) which drew on the recommendations of a number of international conferences held in the 1990s. The Millennium Development Goals include amongst others, achievement of universal primary education, reduction of child mortality and developing global partnerships for development. However, the eight millennium development goals and their targets and indicators do not mention disability at all. A number of international disability organisations (IDDC, 2008; Inclusion International, 2006; Millennium Development Goals and Disability Regional Workshop, 2008) have recently responded to this major omission by calling on governments to hear the voices of people with disabilities and their advocates, to include people with disabilities in their poverty reduction programmes and to ratify and implement the UN Convention on the Rights of Persons with Disabilities. Both the IDDC (2008) and Inclusion International (2006) restate the Millennium Development Goals in terms that demonstrate the exclusion of people

with disabilities but also that show the possibilities of including people with disabilities in development.

As well as understanding the international context of poverty and disability, it is also important to examine more local experiences of disability and poverty. Within the South African context, Lorenzo (2005) has captured the subjective experiences of people with disabilities in her work with women with disabilities living in poor communities on the outskirts of Cape Town. The women described the result of acquiring an impairment and the associated disabled status as an experience of powerlessness and losing dreams and hope. At the same time however, they wanted to work and act to overcome the barriers they experienced in their situation. The women with disabilities who participated in Lorenzo's (2005) study also experienced financial and emotional exploitation as well as being marginalised by different sectors of society. For example, many of the women complained of a lack of awareness of disability issues amongst health and social service staff which led to the women being marginalised in the provision of these services. Millward, Ojwang, Carter and Hartley (2005) made similar findings in their study of services for people with disabilities in Uganda. They found that negative attitudes, lack of training of staff, lack of disability awareness and a lack of resources were the main barriers affecting the provision of services to people with disabilities in Uganda. Similarly, the caregivers of children with disabilities in the rural area of Qwaqwa in South Africa reported having received little support from professionals in the health and social services, with many of the professionals being unable or unwilling to give appropriate advice to the caregivers (Thejane, 1999).

Both Thejane (1999) and Lorenzo (2005) report the disabling effect of cultural myths about disability on women and children with disabilities in impoverished rural and urban contexts in South Africa. Such myths are the source of further stigmatisation and discrimination against people with disabilities. However, the women with disabilities from Khayelitsha, a township near Cape Town, found that by having to play the role of provider for the family, they were able to dispel at least one of the myths, that of women with disabilities being lazy (Lorenzo, 2005).

In Thejane's (1999) exploration of the lives of children with disabilities from rural Qwaqwa in the Free State province of South Africa, he found that most of the children had difficult or no access to rehabilitation services. One parent was recommended to take her child hundreds of kilometres away to receive speech therapy. In the case of the women with disabilities in Khayelitsha, Lorenzo (2005) records that the presence of community rehabilitation workers in the community made a substantial difference to the women's ability to access services.

Although there are many negative aspects of being disabled in a developing country, according to Millward et al (2005), in some developing countries, such as Uganda, there is increased representation of people with disabilities in decision-making and legislative bodies. Millward et al (2005) also report that in Uganda, services for people with disabilities are beginning to be conceptualised and planned from a social model approach to disability. It is not clear whether this includes rehabilitation services, but as discussed below, rehabilitation services are usually implemented form a medical model perspective.

2.3.2   The notion of rehabilitation and its complexities
According to the Encyclopedia of Disability, "Rehabilitation is used as a term for different medical, psychological, social and vocational measures that aim to support a person with a disability to regain as normal a life as possible." (Ward & Grimby, 2006, p.1367). In South Africa, the Integrated National Disability Strategy (INDS) extends this definition by asserting that the purpose of rehabilitation is to enable people with disabilities to become fully participating members of society who can make use of all the opportunities that that society has on offer. In this country, the term rehabilitation is usually closely linked to the term "therapy", a service which may be provided by professionals such as physiotherapists and speech and language therapists.

Traditionally rehabilitation, in the form of therapy, has been based in the medical model of disability which focuses on the deficits of the individual (Barton, 1994). This can be seen in the definition of rehabilitation by Ward and Grimby (2006) quoted above, which implies that people with disabilities are not 'normal' or have a deficit. Rehabilitation professionals such as therapists, are frequently trained to assess and

diagnose the problem or Adeficit@ of the individual and then to remediate the problem. As Werner (1993, p viii) writes:

> AConventional rehabilitation tries to change or *normalize* disabled persons to fit into society as it exists, rather than trying to change society so that it accepts and accommodates to a wider range of human differences.@

Barnes and Mercer (2003) concur with this view and they describe the discourse of professionals who provide rehabilitation as one that concentrates on the merits of regaining "normal" functions. According to Barnes and Mercer, this discourse also encompasses a sense of what bodies should be like (the "normal" body), against which the disabled body is compared and found wanting. One of the problems with this normalization approach to rehabilitation is that it assumes that being as close to "normal" as possible is not only good, but also that it is what people with disabilities want for themselves. Such assumptions are refuted by disability activists such as Oliver (1996) and Barnes and Mercer (2003). Another difficulty with traditional rehabilitation is that by focusing on the individual 'with the deficit', realities that the person with a disability experiences in her everyday world as barriers, such as buttons in lifts without Braille, are ignored. This leaves the person with a disability still unable to fit adequately in to society, although the therapy has helped him/her to become 'more normal'.

Another difficulty with this traditional approach to rehabilitation is the inequality in power between the professional service provider and the client of the service (the person with a disability and/or her family members). The rehabilitation professional will have power because his/her knowledge and skills gives him/her the legitimacy to name the client's 'problem' and determine what intervention needs to be made (without necessarily consulting the person with a disability). The rehabilitation service provider may also have power because s/he is able to use the professional discourse and s/he has control over the allocation of resources to which the person with a disability requires access (Thompson, 1998). In contrast, the person with a disability is usually in a relatively powerless position within the context of traditional rehabilitation or therapy, in part because the professional relationship is usually hierarchical and encourages dependence and helplessness (Barnes and Mercer, 2003).

The power differential between service provider and client may be exacerbated because in most circumstances the rehabilitation professional will be an able-bodied person while the client is disabled.

In spite of these difficulties with rehabilitation, the INDS recognises that access to appropriate rehabilitation services can make the difference between a person with a disability leading an isolated life and being dependent on others, instead of leading an economically independent life and participating in society (RSA Government, 1997). However, the INDS does caution that rehabilitation services should be provided within a social model framework, where power will shift from professionals towards people with disabilities and their families. In this light, it is important for rehabilitation professionals to be sensitive to the extent to which a person with a disability is able to control or overcome the structural or social barriers s/he encounters (Crisp, 2000). In addition, Burton and Kagan (1996) recommend that service providers should analyse the power relations in their work with people with disabilities and others in order to decide how to intervene to transform such relationships.

Imrie (1997) writes of an empowerment model of rehabilitation which emphasizes the idea that a person with a disability should have equal opportunities to maximise his or her potential. However he cautions that it is important not only to focus on the individual with a disability but also to address institutional discrimination. This type of empowerment model of service delivery does not seem to be practised much in traditional rehabilitation in South Africa, although according to Burton and Kagan (1996), it has gained currency in social welfare in the United Kingdom. However, community based rehabilitation as it has been conceptualised internationally and in South Africa specifically tries to address the issue of power in the provision of rehabilitation services. The following section of this chapter will explore the conceptualisation and practice of CBR in more depth.

2.3.3   Contested aspects of community based rehabilitation in theory and in practice
Although conventional rehabilitation often falls squarely into the medical model approach to disability, community based rehabilitation does, at least in theory, have a different approach to disability. Community based rehabilitation, as defined by the

ILO, UNESCO and WHO (2004), places at least equal importance on social inclusion and creating equal opportunities for people with disabilities as it does on rehabilitation. This definition also indicates that people with disabilities are partners in the process of CBR. Thus this orientation to disability issues and the role of people with disabilities can be more closely allied to the social model of disability as well as the social rights discourse of disability than the medical model.

Historically, CBR was formalised by the World Health Organisation (WHO) as a form of service delivery to people with disabilities in the late 1970s and the early 1980s. According to Miles (1994), at this time the WHO conceptualised the community base of CBR as being a key issue, in stark contrast to rehabilitation based at institutions such as hospitals, which was seen as catering to an urban elite and as providing inappropriate residential care. During this period there was also an emphasis on rehabilitation as being the service required at community level. This is illustrated in the CBR training manuals developed for the WHO by Helander et al (1989), which focus largely on the physical rehabilitation of people with disabilities. By the end of the 1980s and in the early 1990s, the official view of CBR from the three United Nations bodies, ILO, UNESCO and WHO, had begun to include the concepts of community development, social integration and the equalisation of opportunities for people with disabilities. This is reflected in the 1994 definition of CBR as: "a strategy within community development for the rehabilitation, equalization of opportunities and social integration of people with disabilities." (ILO, UNESCO & WHO, 1994, p.4). Further developments in the conceptualisation of CBR have led to the issues of human rights, poverty alleviation, inclusive communities and the role of disabled people's organisations being included in the latest Joint Position Paper on CBR (ILO, UNESCO & WHO, 2004). This has led to the situation in which some authors claim that the term "community based *rehabilitation*" no longer reflects the practice in communities. As WHO and SHIA (2002, p.10) put it, "The word "rehabilitation" is seen as too medical and narrow and no longer reflects the CBR concept."

Within the literature on CBR various authors debate and explore the meaning of a number of concepts and issues which are thought to be fundamental to understanding community based rehabilitation. Kendall et al (2000) highlight the issues of

empowerment and community inclusion, which they claim are key forces behind CBR. These authors suggest that, rather than understanding empowerment as a process of shifting power from one person (CBR worker or family) to another (the person with a disability), empowerment should be seen as expanding power to all. This can be achieved through rehabilitation workers mentoring people with disabilities with training, skills and information, and changing their own self-concept away from being the 'expert' (Kendall et al, 2000). This notion of empowerment happening through expanding power to all, does not seem to take into account the asymmetrical nature of many relationships and the fact that it is unlikely that people with disabilities will exercise power in relationships with service providers unless they have a strong sense of self-worth.

Werner (1993) explains that the process of empowering people with disabilities can be initiated in CBR through having people with disabilities themselves providing services. These people with disabilities are then role models for those seeking their services, who are enabled to see what is possible in their lives. Lang (1999, p.137) stresses the important role of true community participation in empowering people with disabilities:

> Aeffective community participation (and thereby the empowerment of disabled people) will only be realised when disabled people become aware of their abilities to achieve within the social contexts of their local communities.@

Kendall et al (2000) point out that in some CBR projects the focus on inclusion of people with disabilities into the community has diverted attention away from other necessary tasks, such as the provision of appropriate assistive devices, which in fact could facilitate social inclusion. No specific examples of such a situation are cited in the article, but it is possible that the authors may have encountered CBR programmes with this problem in their native Australia. Certainly literature on CBR programmes in other parts of the world do not raise the issue of CBR programmes focusing on community or social inclusion to the detriment of other facets of CBR. That Kendall et al (2000) make such a remark however, points to the need for balance in CBR

programmes between a focus on social and community level issues and the interventions at an individual or personal level that can facilitate social inclusion.

Another concept which is considered to be central to an understanding of CBR is that of community participation. The meaning of community participation is contested and is not always made clear in documents dealing with CBR and participation (of people with disabilities, their families and/or their communities). According to Boyce and Lysack (2000), a distinction can be made between three functions or purposes of community participation in CBR. The function of community participation may be for the community to contribute their resources towards achieving a particular goal or 'the common good'. In this situation, community participation is a means to an end and is often initiated in a top-down way by various authorities. Boyce and Lysack (2000) describe the second function of community participation as being to organise people in common activities. In this sense of participation, it is both a means and an end. The process of organisational development is valued as a means of achieving social integration of people with disabilities. The third purpose of community participation is that of 'empowerment' in which local people (and people with disabilities) are enabled to manage their projects and make decisions that affect their lives. Boyce and Lysack (2000, p. 44) warn that

> "Unfortunately, these different purposes of participation are often not clarified in project planning, thus creating the potential for the rhetoric of 'instrumental participation' to mask the maintenance of inequality in community activities."

The ILO, UNESCO and WHO (1994, p. 4) definition of CBR that was accepted internationally for a decade, incorporated the concept of community participation in the statement that "CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services." The 1994 Joint Position Paper of the ILO, UNESCO and WHO in theory tries to promote an understanding of community participation in CBR in which community leaders have decision-making power (community participation as empowerment). Other CBR literature also emphasises community participation and empowerment of people, particularly with disabilities, in CBR (Werner, 1993; Mohale & Miles, 1998). However, in practice, many CBR

programmes (particularly those implemented from a central government initiative), reduce community participation to the level of contribution or simply complying with what is requested by the service provider (a top-down approach), which in fact perpetuates powerlessness or disempowers people. The function of participation as contribution can be inferred from the WHO CBR manuals by Helander et al (1989), which recommend that communities contribute their resources through selecting a local person (community member) to oversee the way in which families train their family member with a disability. The language of participation that is used may in fact mask the fact that people with disabilities, and to a lesser extent their communities, have little say at all in a centrally imposed CBR programme. As Miles (1996) indicates, the voices of people with disabilities are rarely heard in CBR debates and this is at least in part due to CBR programmes not taking a Abottom-up@ approach in which people with disabilities could be in control of the programme.

As illustrated above, there are a number of pivotal issues in the literature on CBR, the meanings of which are contested or may be implemented in various ways in different CBR programmes. The theory and debates in CBR literature can, however, be distinguished from conventional or traditional rehabilitation through its engagement with the issues of empowerment, social inclusion and community participation. In spite of the move towards the inclusion of people with disabilities and respect of their rights in theoretical debates in CBR, the practice of CBR does not always mirror the emancipatory rhetoric.

A model of CBR that has dominated the implementation of CBR in many parts of the world is known as the World Health Organisation (WHO) model, based on a set of manuals by Helander et al (1989), in which local supervisors work with family members who train the person with a disability to overcome the difficulties s/he experiences. Although these training manuals do include some information on inclusion of people with disabilities into social situations, the focus of the WHO model is the individual with a disability and the methods of rehabilitation that will make him/her more independent (Helander et al 1989).

Jaffer and Jaffer (1994) report on the implementation of CBR according to the WHO model in the Punjab province of Pakistan in the early and mid 1980s. The medical

orientation of the WHO CBR model used in Pakistan can be seen in the reported impact of CBR on people with disabilities in selected urban slum and rural areas in Punjab. According to Jaffer and Jaffer (1994), an external evaluation of the CBR project identified that only 16% of the people with disabilities interviewed reported some progress due to the project. The areas of progress identified were mobility, speech, limb movement, control of fits and self-management. These areas of progress are typically those that could be addressed in conventional rehabilitation, while no mention is made of improved attitudes towards disability, social inclusion or opportunities to make decisions for oneself. Even more revealing of the medical orientation of this CBR programme is the type of help people with disabilities reported receiving: doing exercises, receiving medicines, training to do various tasks and receiving assistive devices. In their critique of the WHO CBR programme in Punjab, Jaffer and Jaffer (1994, p.333) describe the communities' perceptions of the CBR project thus:

> "In fact, there was a continuous tug of war between the project and the
> community, with the project trying to focus on CBR and the people trying
> to convert it into a medicine-distributing programme."

Jaffer and Jaffer critique the implementation of CBR according to the WHO model in Pakistan on the grounds of inadequate training, the use of volunteers, the feasibility of doing home visits and the use of foreign consultants. However they do not address the more fundamental issue of the conceptualisation of disability within the WHO model of CBR and the focus of CBR on the impairments of the individual person rather than the societal barriers that create disability. Perhaps because the social model of disability was conceived by disability activists from developed countries, this model may not have penetrated thinking on disability and CBR by the early 1980s in Pakistan.

Nordholm and Lundgren-Lindquist (1999) report on a CBR project that was initiated in a village in Botswana in 1990. Although the authors do not state that the CBR project in Botswana was based on the WHO model, it is clear in their article that the CBR manuals developed for the WHO by Helander et al (1989) were the basis of the project, at least in the initial phases. Following an initial survey of the village to locate and identify people with disabilities, various interventions were suggested for the people with disabilities who were part of the CBR project. Judging from the list

of interventions enumerated by Nordholm and Lundgren-Lindquist (surgery, medical treatment, blind/deaf school referrals, orthoses, prostheses and technical aids), this CBR programme appears to have had a very medical focus. Subsequent to the implementation of the CBR project in Moshupa village, two follow up studies were conducted. The first study examined the perceptions that people with disabilities had of the impact of the CBR project. Although this study is only reported on briefly by Nordholm and Lundgren-Lindquist in their 1999 article, the authors select the degree of independence achieved by people with disabilities as a key issue in the first follow up study. The reason for this selection is unclear as the data from their table shows no significant change in the degree of independence that people with disabilities had in various activities of daily living. In other words, in this chosen area of evaluation, the CBR project appears to have had no impact, although the authors claim (with no substantiation) that the project may have contributed to the maintenance of these competencies.

Although the CBR project in Moshupa village may have been based on the WHO model of CBR, there are differences to the CBR project in Punjab, Pakistan, which may be related in part to the historical development of the concept of CBR. Both CBR projects appear to have had a strong medical orientation, but the project in Botswana (which was initiated eight years after the Punjab project), seems to have started dealing with the issues of social inclusion (through the referral of children with physical disabilities to mainstream schools) and community participation (through the formation of a rehabilitation committee). In an evaluation of CBR based on the WHO model in Vietnam a number of years later, participants identified that difficulties in extending CBR beyond medical work were a threat to the CBR programme in North Central Vietnam (Sharma and Deepak, 1999). Although Sharma and Deepak do not explicitly state that the CBR programme in Vietnam aimed to address barriers experienced by people with disabilities, it is apparent that participants in the evaluation felt that the change in attitudes towards people with disabilities was a strength of the programme. Findings from the three studies of CBR programmes in Pakistan, Botswana and Vietnam illustrate the shift in implementation of the WHO CBR model over time, to include such issues as social inclusion, community participation and changing attitudes towards disability. However, the WHO CBR manuals have not been changed to incorporate a social model understanding of

disability nor an understanding of the rights of people with disabilities. Therefore the focus of CBR programmes based on the use of these manuals is still to improve the functioning of the individual with a disability rather than to overcome the barriers that people with disabilities experience in their communities or to work towards respecting their rights. In implementing the WHO model of CBR, there does not seem to be any recognition of barriers that people with disabilities may face in their communities and whose responsibility it is to address these barriers. There is no apparent recognition of a human rights perspective of disability in the WHO model of CBR either.

Although the WHO model of CBR is not as prominent as it was two decades ago, even in 2003, Disabled People=s International in its position paper on CBR, bemoaned the fact that a number of CBR programmes were still based on the medical aspects of disability rather than being grounded in the social model (Disabled People's International, 2003). In considering such CBR programmes, Stubbs (no date, p.1) warns that:

> ACBR without a clear human rights framework could concentrate on delivering therapies and equipment to disabled people. This could have temporary benefits, but will not necessarily result in disabled people being empowered. This approach does not try to remove the barriers to participation in society@

In spite of the dominance of the World Health Organisation model of community based rehabilitation in some parts of the world, there are many different approaches to the implementation of CBR, with different emphases. Neufeldt (1995) describes a programme in the Philippines which used a 'community based vocational rehabilitation' strategy. This project was in part sponsored and supported by the International Labour Organisation (ILO) in order to determine whether a community based approach could be used to enable the full participation of people with disabilities in employment and income-generating opportunities in their communities. Thus the focus of this CBR project was specifically vocational rehabilitation and employment of people with disabilities. Another CBR programme with a different emphasis is the national CBR programme in Guyana, which has focused on children with disabilities and their families (O'Toole, 1995). According to O'Toole, as from

1995 this CBR programme intended to expand its scope to include adults with disabilities. The CBR programmes in the Philippines and Guyana mentioned above, are but two of several mentioned in the literature which do not use the WHO model of CBR.

In 2002 the World Health Organisation and Swedish Organizations of Disabled Persons International Aid Association (SHIA) evaluated the impact of three CBR programmes on the quality of life of people with disabilities (WHO & SHIA, 2002). WHO and SHIA expressly selected the three programmes (in Ghana, Guyana and Nepal) to represent different approaches to CBR. However the criteria used for selection of the CBR programmes may also have biased the results of the study because many CBR programmes do not include the participation of disabled people's organisations (Miles, 1996) or have a gender perspective. The study demonstrates good use of participatory methodology, which, in line with more recent thinking in CBR, was used to give people with disabilities and parents of children with disabilities decision-making power. Through their qualitative study, WHO and SHIA (2002) found that all three CBR programmes have had a good impact on the self-esteem, self-reliance and social inclusion of people with disabilities while there was limited impact on the physical well-being of the participants. The positive effect on social inclusion of people with disabilities seems to illustrate that the impact the three CBR programmes have is different to what would be expected from conventional rehabilitation. In contrast to some South African CBR programmes (Dolan et al, 1995), the CBR programmes in Ghana and Guyana were perceived to have been unsuccessful with regard to physical rehabilitation and provision of assistive devices. This may be attributable to the relatively long training of community rehabilitation workers in South Africa in comparison with the training and skills of CBR workers in the countries studied.

The WHO and SHIA (2002) study also found that most of the CBR programmes studied were weak in their ability to empower people with disabilities and their organisations, in spite of the CBR policy documents stating the need for people with disabilities and DPOs to be involved and have influence. The study indicates that although the CBR programmes were able to encourage people with disabilities and parents to share experiences and to try to come to solutions for problems, on the

whole, people with disabilities were seen as passive beneficiaries. This finding illustrates the gap between the implementation of CBR and the theoretical debates in CBR literature. A fundamental concern which WHO and SHIA raise is the sustainability of CBR programmes, in particular because government authorities seldom allocated resources to the CBR programmes. The concern with sustainability is not limited to the three countries in the WHO and SHIA study. As mentioned in Chapter 1, the three pilot CBR training programmes in South Africa all had to close down because of lack of financial support, in spite of the one programme winning the World Health Organisation's Sasakawa prize for innovation in health related training programmes. This points to a particular dilemma in CBR – a top-down imposed CBR programme is more likely to get government resources to sustain it, but the participation of people with disabilities in such a CBR programme is likely to be for the purpose of contributing resources rather than aiming at the empowerment of people with disabilities (Boyce and Lysack, 2000).

Kuipers, Kuipers, Mongkdrisawat, Weawsorn and Marungsit (2003) provide a useful scheme to understand different models of CBR service delivery. The Roi-Et classification of Kuipers et al (2003) understands that CBR services may be delivered in different ways and at different levels. According to their classification system, services may be delivered by providing, assisting, participating or advocating, with the latter three methods of delivery involving the recipients of the service to a greater or lesser extent. CBR services may be seen to be delivered at the level of the individual with a disability or at the levels of his/her family or community or structures (such as the social welfare system) or even at the level of attitudes and beliefs (Kuipers et al, 2003). Those CBR programmes based on a medical model approach, are more likely to involve providing and assisting at an individual and family level, whereas one would hope that a CBR programme focused on the social model of disability might include more advocacy and participation at the level of community, structures and attitudes and beliefs. Kuipers et al (2003) also indicate that the particular context may determine which method(s) and level(s) of service delivery may predominate at a particular time.

The benefits of using Kuipers et al (2003) approach to understanding CBR is that it enables changes that occur in CBR projects over time to be monitored. Also, a wide

range of ways in which CBR may be implemented can be captured using the Roi-Et classification. Although the authors do not see it as the function of a classification system to put a value judgement on different types of service provision, in my research I have used this classification to chart what I would term as improvements in the implementation of CBR by the students involved in this study (see Chapter 5). The Roi-Et classification is also a useful tool to examine and perhaps plan the structure of a CBR curriculum (see Chapter 4 of this thesis).

2.3.4   Community based rehabilitation training: Examining international practices
One of the issues a CBR programme has to address is who will provide the service. Many CBR programmes use volunteers who may have other occupations such as teachers, community development workers, health workers or farmers, or the volunteers may be unemployed members of the community such as housewives (Lysack & Krefting, 1993; O'Toole, 1995; Thorburn, 1994a). These volunteers would be considered to be grassroots CBR workers. Within a WHO model of CBR, these grassroots workers would usually be designated the title of local supervisor and it would be their responsibility to work directly with the families of people with disabilities. Another level of personnel which is recognised as playing a role in some CBR programmes is the mid-level CBR or rehabilitation worker. Wirz (2000) notes that many CBR programmes internationally do not have a common idea about the role of the mid-level worker although the role of the mid-level worker could encompass supervising grassroots workers and monitoring the implementation of CBR. The World Health Organisation (1992) has developed a document regarding the training of mid-level rehabilitation workers. The third level of personnel involved in CBR is the planners and managers of CBR programmes. According to Wirz (2000) in many situations where the WHO model of CBR is being implemented, there is no recognition of the need to train at the levels of mid-level workers and professionals.

The literature on training these different levels of personnel for CBR is scant and much of what there is makes reference to the training of grassroots workers in CBR. Although my study deals with the education and training of mid-level CBR workers (known as community rehabilitation facilitators or CRFs) some useful insights can be gained from examining the literature about all levels of training in CBR. For example, Thorburn (1994b) writes about the training of community (grassroots)

workers for CBR in the Caribbean, but her list of issues to be addressed by training courses is also pertinent to the training of mid-level workers. According to Thorburn it is important to consider the philosophy of the training programme as well as the content, selection of students, length of training, hands-on or practical skills training and who will supervise the students.

The articles that make reference to CBR training do not necessarily deal with all the issues mentioned by Thorburn. However I have selected some of these issues for the purpose of comparing different CBR courses mentioned in the literature (see Table 2.1 below for a summary of various CBR courses).

When comparing the three levels of training mentioned in the literature, it is apparent that while community development may be covered in the training of CBR managers and mid-level workers, none of the programmes training grassroots workers have included community development or related topics, such as entering or mobilising the community. This, together with the focus on types of disability and specific rehabilitation interventions for these disabilities in grassroots CBR worker training, may be linked to the description of many CBR programmes as being medically oriented. If the frontline CBR workers are not made aware of the links between community development and CBR, CBR as a "strategy within community development" (ILO, UNESCO, WHO, 1994) is unlikely to be realised. That the CBR manager knows about community development is insufficient to ensure that rehabilitation and other interventions for people with disabilities are integrated into community development at a local level. Cornielje and Ferrinho (1995, p. 31) write that "Indicators of the involvement in community development initiatives [in CBR] include the adoption of a supporting role to disability movements, parents groups, day care centres and crèches, income generating projects and participation in committee meetings." In order to fulfil such roles in a CBR programme, it would be necessary that the CBR worker's training include community development as a topic.

Name and place of course	Level	Length of training	Content	Methods used	Who are the trainers?	Role of people with disabilities
International course for professionals and administrators in CBR in Sri Lanka (Mendis, 1995)	CBR managers and planners	6 weeks	Rehab programme development Disability concepts Community development Adult learning Appropriate technical aids	Learner-centred and participatory	International & Sri Lankan resource people	None stated
M.Sc and diploma in Community Disability Studies in England (AIFO, 2003; Wirz, 2000)	CBR managers, professionals	MSc 1 year	Includes community development Information & skills enabling policy makers, planners & people responsible for implementation to evaluate options e.g. info on different interpretations of CBR from technical rehab to human rights perspective	Student- led rather than curriculum-led	Not stated	None stated
International Management and Planning Course in CBR by AIFO in Italy (AIFO, 2003)	CBR managers and planners	3 weeks	Management & supervision Planning Human resource training Medical rehabilitation Inclusive education Occupational rehabilitation Disabled People's Organisations Monitoring & evaluation	Includes time for individual planning	International teachers	DPOs collaborate with participants
Training for local supervisors in Negros Occidental, the Philippines (Valdez & Mitchell, 1999)	Grassroots CBR workers (local supervisors)	3 day workshop then weekly for two months	Mobility Visual impairment Communication impairment Later included intellectual disability	Not stated	Not stated	Participated in some training sessions as clients, family observed
Training of community workers in Sri Lanka (Mendis, 1995)	Grassroots	Initially at least 14 days then continuous period of field	Introduction to rehabilitation Rehabilitation activities such as activities of daily living, schooling, social interaction Meeting the needs of people	Not stated	Divisional core team which includes a therapist, social service officer	As clients for students doing home visits

			teaching	with different disabilities e.g. simple aids, info on dealing with fits Starting a CBR programme Using the adapted WHO manual		& 1 other (possibly a community development officer)	
Community worker training in Jamaica and the Caribbean (Thorburn, 1994b)	Grassroots	Initially 6 weeks then observed on the job & further training	Physical disabilities & exercises Communication disability Sign language Behaviour management Screening for disability	Includes hands-on training with people with disabilities	Local professionals, sometimes from other developing countries	As clients for hands-on training
Community rehabilitation worker training in South Africa (Dolan et al, 1995)	Mid-level but community based	Two years	Orientation to CBR Specific disabilities incl. burns, amputations, hearing Conflict resolution Administration Health education Community development Work for people with disabilities Interpersonal relations Group work	Problem-oriented approach using adult education principles Theory followed by community blocks	Not stated	None stated
Community rehabilitation facilitator training in South Africa (Cornielje & Ferrinho, 1995)	Mid-level but community based	Two years	Community development Primary health care Clinical therapeutic intervention Impact of socio-economic env. on people with disabilities	Conscientisation Participatory methods Problem-solving Critical thinking	Not stated	Not stated

Table 2.1:   Summary of selected CBR training courses mentioned in the literature

Another gap identified in the comparison of CBR training programmes mentioned in the literature is the lack of information on the model of disability which informs the CBR training course. Given the nature of the content of the grassroots workers' training, with no stated focus on the barriers that people with disabilities face, it is possible that the medical model is the basis of this training. By using the medical perspective of disability in CBR the service providers (CBR workers), many of whom are able-bodied, may be cast in a more powerful position than the people with disabilities they serve. The CBR workers are likely to be seen as more knowledgeable than the person or family they serve, in terms of identifying the disability and determining appropriate rehabilitation, without consideration of the disabling environment.

The majority of the training courses listed in Table 2.1 do not clearly state what role, if any, people with disabilities play in the training of different levels of CBR personnel. This appears to be a gap in the literature on CBR training. It is encouraging to note however, that in AIFO's CBR management course, participants collaborate with disabled people's organisations (AIFO, 2003). This collaboration may help to engender an understanding of the importance of the participation of people with disabilities in the management and control of CBR programmes. It is quite likely though, that grassroots CBR workers do not gain the same understanding concerning the role of people with disabilities in CBR programmes. According to the three training courses for grassroots workers mentioned in Table 2.1, the experience that these trainees have is of people with disabilities being their clients. If grassroots CBR workers are not trained to collaborate with people with disabilities on a more equal footing than in a client-service provider relationship, it may be difficult for these same people with disabilities to participate in the monitoring and managing of a CBR programme.

One of the key themes dealt with in my research is how CBR personnel are trained to empower people with disabilities and deal with the social creation of disability. When exploring the literature on CBR training I was only able to find two articles on the issue. Twible and Henley (1993) write about a model of using workshops to train workers in CBR in the Solomon Islands and Fiji, based on a community development

approach. In outlining their perspective on CBR, Twible and Henley (1993, p. 47) quote Fried (1980):

> ΑIn today=s world it is not sufficient to provide only knowledge and skills related to rehabilitation; additionally one must address the issue of empowerment versus service delivery.@

Twible and Henley explicitly define their understanding of empowerment and identify it as one of the three foundational issues on which their model of CBR training is based. Their model of CBR training also emphasizes the demystification of disability and gets participants to view disability from the perspective of the person with a disability. Twible and Henley's model of CBR training is clearly based on the social model of disability as they describe participants in the workshop being encouraged to identify the barriers people with disabilities experience and then exploring strategies to remove the barriers (rather than spending much of the time learning about rehabilitation techniques). This model of CBR training appears to differ quite markedly in its orientation from other short training courses in CBR mentioned in the literature. Although Twible and Henley (1993) describe a model of CBR training that is very similar in its concerns to my own in this research, the length of their workshop (5 days) must mean that the content e.g. strategies for community development, cannot be covered in much detail. Thus the participants may have some skills in problem-solving concerning the situation of people with disabilities, but they would probably require substantial assistance with specific situations. Local constraints in Fiji and the Solomon Islands determined the length of the training. The challenge to my research is to evaluate and determine which aspects of Twible and Henley's CBR training model may be adapted or extended and used in the development of an appropriate course for mid-level CBR workers.

Cornielje and Ferrinho (1995) write about the training of mid-level CBR workers in the context of the socio-political situation in South Africa in the early 1990s. In response to what the authors describe as a failure of bio-medically trained rehabilitation professionals to respond to the changing reality of people with disabilities in South Africa, a CBR course was developed which was based on social action. The aim was to train CBR personnel for rehabilitation programmes that "lead towards emancipation and integration of the disabled in society." (Cornielje &

Ferrinho, 1995, p.29). The CBR training course described by these authors demonstrates coherence between its emancipatory objective and the content covered and training methods used. Teaching community development skills such as mobilising community members was paired with emancipatory teaching methods, such as using the conscientization process described by Freire (1972). The orientation, content and methods used in this CBR training course may be seen as having arisen in response to the particular context of South Africa at the end of the apartheid era. Nevertheless, most of this course is appropriate for training CBR personnel within a human rights and social model perspective of disability in the current era of democracy in South Africa.

In contrast with the emancipatory orientation of the mid-level CBR training described by Cornielje and Ferrinho (1995), the World Health Organization (1992) suggests that 3% of the training time for mid-level rehabilitation workers be spent on issues such as social mobilization and community participation. At the same time WHO recommends that 32% of the training time should be spent on applied rehabilitation such as managing specific disabilities. This allocation of time is in spite of the WHO (1992, p. 7) stating that

> "The management tasks of the MLRW [mid-level rehabilitation worker]
> are what distinguish this worker from the rehabilitation specialists, who
> are not skilled in community work. …… a great deal of the MLRW's
> management responsibility relates to community work."

Clearly with the time allocation recommended by the WHO (1992), the mid-level rehabilitation workers they envisage must either have skills in community work prior to the CBR training or they will be relatively unskilled in getting communities to participate in CBR. The suggested content of the training also seems to illustrate inconsistencies in the philosophy behind the training of mid-level rehabilitation workers – the (medically-defined) disability process and medical sciences are covered in a fair amount of detail alongside human rights and advocacy for these rights.

In the literature on CBR training some articles make reference to the content of the training, while very few articles deal with other aspects of the curriculum such as teaching methods and teaching and learning materials (Cornielje & Ferrinho, 1995; Twible and Henley, 1993; Wirz, 2000). The only article which mentions the

curriculum development process for a CBR course is that by Twible and Henley (1993), which also outlines their understanding of curriculum. My research aims to contribute to an understanding of the process of curriculum development in CBR training to the field of community based rehabilitation, particularly with reference to mid-level CBR personnel

2.4   Theorising the CBR Curriculum

2.4.1   Introduction

In order to develop an understanding of CBR training and how to change and improve a CBR course, it is necessary to situate CBR training within broader debates and models of curriculum development. According to Kelly (1989, p.1), Αthe curriculum is the very foundation of any education system@. The concept of curriculum is defined or used in different ways by different theorists and authors. For some, curriculum refers only to content or syllabus, whereas other authors use much broader concepts of curriculum, where the term can even refer to the whole of the learning situation (Fotheringham, 1998). In the precursor to the development of inclusive education in South Africa, the Department of Education (1997, p.vi) in the report of NCSNET and NCESS stated that

> "According to the framework of Curriculum 2005, the curriculum can be defined as everything that influences the learner, from the educators and the work programmes, right down to the environment in which teaching and learning takes place."

The Department of Education (1997) goes on to specify that the built environment, the culture of learning and teaching, the content of learning programmes, the language of teaching and learning, teaching practices including timetabling, the materials and equipment available and assessment practices all need to be considered as influencing learning.

Onore and Lubetsky (1992, p. 255) have a less specific but more problematized conceptualisation of curriculum when they state that

"Curriculum can represent a coming together of understandings of the social and cultural relationships in the larger world, the reformulation of relationships within the classroom, and organized bodies of knowledge called subject matter."

These authors also refer to their concept of curriculum as a space that unites the students and the world outside of school with ways of knowing and organised subject matter from within the school system. Although Onore and Lubetsky (1992) specifically refer to school curriculum, the concept of a space to unite the world outside the training institution with the subject matter (of disability) and ways of knowing is useful when considering curriculum in the context of CREATE. Specifically, this conceptualisation of curriculum makes it possible to examine and challenge curriculum from a critical perspective. Although this conceptualisation of curriculum is useful, on the whole, in this research I use the term curriculum in its more traditional form to refer to the intended objectives, content, methods, organisation and evaluation of the learning programme as well as what actually transpires in the course (Fotheringham, 1998; Kelly, 1989).

Lovat and Smith (1995) and Bertram, Fotheringham and Harley (2000) suggest that it is important to study the intended and the actual curriculum as well as the gap between the two. This gap could be seen as the hidden curriculum, which, in the school context may refer to what is learnt implicitly through the school experience, such as learning to accept unequal power in the classroom (Graham-Jolly, 2002). Marsh (1992) explores a number of aspects of the hidden curriculum through reference to the writings of Apple, Willis and Seddon. The hidden curriculum may include the norms, beliefs, attitudes and values learnt from the rules, regulations and rituals of the learning environment. Another aspect of the hidden curriculum relates to which curriculum knowledge is given high status and who is excluded from this high status knowledge.

2.4.2   *Situating CBR training within curriculum theory debates*

In studying curriculum it is vital to be aware of the influence of ideology on curriculum (Kelly, 1989; Lovat & Smith, 1995). Curricula are developed by people within a society who hold a particular ideology and this influences the choice of content, teaching methods, objectives etc. that are drawn up. According to Lovat and

Smith (1995, p.33) ⒶGenerally, it is the knowledge and messages associated with the views of the dominant group(s) in any society that form the basis of the curriculum.Ⓐ Carr (2003) characterises decision-making for a curriculum as being an expression of political questions about whether to transform or reproduce existing patterns of economic, cultural and political life. During the 1970s, curriculum scholars such as Bowles and Gintis, Apple and Giroux argued that the school system functioned to reproduce the class structure (and the dominant ideology) of society and the workplace (Pinar, Reynolds, Slattery & Taubman, 1995). By the early 1980s, political curriculum theorists turned to theories of resistance (from learners and also from teachers). According to Pinar et al (1995), Giroux and others then focused on pedagogy and the possibility of transformation through the education system and the curriculum. Within this discourse, Giroux and McLaren (1996, p.303) refer to teachers who are "transformative intellectuals" as those who "treat students as critical agents, question how knowledge is produced and distributed, utilize dialogue, and make knowledge meaningful, critical and ultimately emancipatory." These ideas of Giroux and McLaren are components of a critical pedagogy which challenged the dominance of the educational reform discourse in the United States in the 1980s and early 1990s. Both Greene (1988) and Giroux and McLaren (1996) characterise the educational reform discourse as one dominated by a technicist approach (or ideology) in which teachers are seen as functionaries to turn out 'products'.

Hoadley and Jansen (2002) discuss four discourses of curriculum in the South African context which can be related to various ideologies. The authors name the discourses as the utilitarian discourse (education for the workplace), the progressivist discourse (focusing on broad personal development), the nation building discourse (focusing on social justice and citizenship) and the systematic development discourse, which focuses on assisting learners to progress within the education system. In the context of my study it appears that the HPCSA and the therapy professions seem to be engaging in the utilitarian discourse of curriculum while CREATE subscribes more to the nation building discourse of curriculum and its attendant ideology.

The impact of dominant ideologies on education in different periods in South African history is an important part of the context of this study. Some of the students who

participated in this study have gone through Bantu Education (with the curriculum shaped by apartheid ideology) while the CBR course curriculum in this research was influenced by and initially developed at the time of People=s Education (shaped by a liberation ideology). There is no explicit mention in any CBR literature of the ideology that has shaped the curriculum of various CBR training courses. It seems to be that those involved in CBR training have not (in published form) engaged with debates that come from the mainstream of education theorising.

Another aspect of curriculum that CBR curriculum developers need to engage with is the model of curriculum which may shape all aspects of the course. According to Grundy (1987), curriculum is a social construction that can be linked to the technical, practical or emancipatory cognitive interests of humans (as elucidated by Habermas). Grundy (1987) describes how different models of curriculum arise from the different knowledge-constitutive interests - curriculum as product comes from the technical cognitive interest. Curriculum as practice (also known as curriculum as process) arises from the practical cognitive interest and the emancipatory knowledge-constitutive interest spawns curriculum as praxis (Grundy 1987).

Curriculum as product is informed by the technical cognitive interest which is concerned with managing and controlling the environment and finding Alaws@ that govern behaviour and the world (Grundy 1987). Positivism, which is structured by predictive hypotheses and empirical observations, is the form of knowledge associated with the technical interest. According to Cornbleth (1990) in this model of curriculum (also referred to as a technocratic curriculum), knowledge is seen as a commodity. Posner (2002) describes the school being conceived of as a production system in a technocratic curriculum, with the product being the individual learning outcomes. One of the first considerations in a product model of curriculum is the specification of learning objectives. Once the objectives have been stated, content, activities and means of assessing whether objectives have been attained are set. Grundy (1987) explains that teaching in this approach to curriculum involves reproducing in students the guiding patterns and ideas that will lead to a particular product (the set objectives).   The article on curriculum development in CBR by Twible & Henley (1993) uses the ideas of Taba to plan and design the CBR course.

According to Posner (2002), Taba's model of curriculum planning falls within the technocratic perspective, eschewing any notion of curriculum development as being a political activity. Curriculum theorists and developers who use the product model of curriculum claim to be ideologically neutral, and recommend that all ideological positions should be avoided.

In contrast, curriculum as practice, otherwise known as the process model of curriculum (Stenhouse 2002), is based on the practical cognitive interest which is fundamentally concerned with understanding situations and the environment and making meaning through interaction. The process involved in education is fundamental in this model of curriculum and Stenhouse (2002) elucidates how a curriculum can be drawn up based on Aprinciples of procedure@ (guidelines of how the teacher can interact with the learners to develop understanding). In the curriculum as process model evaluation is part of the whole educational process, rather than being a separate entity at the end of the process as it is in curriculum as product. The teacher's judgement of the process of learning is crucial in the process model of curriculum, which contrasts with the supposedly more objective evaluation used in the curriculum as product approach.

The model of curriculum which is perhaps most crucial for this study is Grundy's (1987) conception of curriculum as praxis, which is informed by an emancipatory interest. Grundy describes the emancipatory cognitive interest of Habermas as having a basic orientation of people moving towards freedom and as being concerned with empowerment. This emancipatory cognitive interest informs curriculum as praxis in which participants come to recognise distorted views of the world (that are based on the domination of some people over others). An emancipatory curriculum is one that builds critical consciousness in participants and it involves educator and learner in changing the structures in which learning occurs (Grundy 1987). Grundy describes the curriculum being constructed through a process of teacher and students making meaning together using reflection and action in this model of curriculum. In the curriculum as praxis approach the curriculum is not a pre-determined plan specifying the outcomes, content and/or process. Rather, the curriculum as praxis approach promotes a collaborative process with the sharing of power. The critical emancipatory approach to curriculum does not claim or intend to be value-free (as in curriculum as

product). Rather, within curriculum as praxis, curriculum planning is seen as an ideological and political issue (Posner, 2002).

Through the process of this research and reviewing the existing curriculum of CREATE's CBR course, I situate the course within these models of curriculum (see Chapter 4).

2.4.3   Community based rehabilitation, Freire and critical pedagogy

As mentioned previously in this chapter, a number of authors link CBR with concerns for the empowerment and emancipation of people with disabilities (Cornielje & Ferrinho, 1995; Kendall et al, 2000; Lang, 1999; Lang, 2000a; Lang, 2000b; Werner, 1993). Cornielje and Ferrinho (1995) and Lang (2000b) specifically explore the usefulness of the work of Paulo Freire in orientating CBR programmes towards the empowerment and liberation of people with disabilities. This section of the chapter examines the work of Freire and other authors who have conceptualised the links between education and the move towards emancipation from oppression. Many of the issues highlighted within this field of critical pedagogy concerning transformation and education may inform aspects of CBR education and training.

The concept of liberating or empowering education (Freire, 1972; Shor, 1992) underpins the nature of this study. Shor (1992) defines empowering education as being a pedagogy which enables critical thinking in order to bring about change in the self and in society. According to this pedagogy, education cannot be neutral. Either education maintains the unjust status quo or it can lead to transformation and greater social justice. The liberating or empowering pedagogy of Freire (1972) and Shor (1992) is one involving reflection and action (praxis) which leads to changing the status quo. Mayo (1999, p.63) describes Freire's pedagogy thus:

> "Through a 'pedagogy of the question' rather than a prescriptive pedagogy, the educator enables the learners to reflect on the codified versions of their 'reality' (their own world of action) in a process of praxis."

Freire (1985) explains how praxis and dialogue can lead to the conscientisation of people in which they attain a critical consciousness. This critical consciousness together with action, are key elements of revolution or a change in the status quo.

Gay and Hanley (1999) give an example of this through their experiences of critical multicultural education in which students critically reflect on their own and others= experiences of oppression and then learn skills (particularly through drama) to work collectively towards a vision of a socially just society.

Freire (1972) contrasts his liberating pedagogy with Abanking education@ that is used in traditional forms of education. While Abanking education@ involves the teacher giving knowledge to the learners who are seen as empty vessels, Freire=s pedagogy of liberation involves teachers and students learning from each other. According to Freire, although the teacher must be open to the students and learn from them, it is not possible for the teacher and students to be equal. Rather, the teacher continues to be different from the students but the democratic teacher does not allow the difference to become antagonistic (Freire & Shor, 1987). Shor (1992) claims that participation of learners in the classroom is an important aspect of liberating or empowering education. Through participation, the unequal power relations in the traditional classroom can be addressed, and changed.

Another important aspect of Freire=s pedagogy of liberation is the use of dialogue around certain Agenerative themes@ - issues or themes which are of concern to the learners. According to Freire and Shor (1987, p. 98),

> "Dialogue is a moment where humans meet to reflect on their reality as they make and remake it….Through dialogue, reflecting together on what we know and don't know, we can then act critically to transform reality."

Shor (1992) explores this use of dialogue around generative themes which happens through posing problems (based on the generative theme) to learners. Problem-posing education recognises that learners have experiences and can contribute to the creation of knowledge which is an unfinished product, rather than the preserve of the teacher as in banking education. Hughes (1998) describes her experience of using a problem-posing pedagogy with students in a Women=s Studies course at an Australian university. She concluded that it was possible to help university Women=s Studies students to engage with themselves and their communities for social change through using dialogue around a generative theme.

Foley (2000) argues that a dialogic mode of teaching is one of the main theoretical tenets of critical pedagogy. Other aspects of critical pedagogy that link to the work of Freire are the situating of teaching and learning in its social context and the focus on relations of domination, both within the classroom and education system and within society. In making a distinction between critical thinking and critical pedagogy, Burbules and Berk (1999, p. 47) claim that critical pedagogy is mainly concerned with social injustice and "how to transform inequitable, undemocratic, or oppressive institutions and social relations." In the light of this, a critical person is seen as one who can recognise injustice and who is sufficiently empowered to seek justice and emancipation. It is this type of person that I have tried to create through this action research on the CBR course at CREATE. According to Giroux (1988), schools need to be seen as sites where there is the possibility of students learning the discourse of social responsibility and where they can learn self and social empowerment through dialogue and critical inquiry. So too with training institutions that run CBR courses – they should be democratic sites of learning, which promote learning through critical inquiry. It is not apparent in the literature whether there are any CBR training institutions or organisations that run CBR courses which situate themselves within a critical approach to education.

Freire (1972) explains that a result of a liberating pedagogy can be that oppressors take a radical stand of solidarity with the oppressed. As with Freire's liberating pedagogy, McLaren and Giarelli (1995) suggest that critical pedagogy can result in expressions of solidarity with the other. However they warn that the student should speak in solidarity *with* the other rather than *as* the other. One of the purposes of this research is to see how community based rehabilitation *training* can build solidarity between students on the course and oppressed people with disabilities. Expressed differently, the aim of this research is to identify ways in which the pedagogy and curriculum of the community based rehabilitation course can enable students to change the status quo with regards to the situation of people with disabilities.

2.4.4   Some reflections

Curriculum theorising with regard to CBR seems to be a rare activity. As mentioned above, the article by Twible and Henley (1993) is the only one I could find that expressly examines curriculum as it relates to CBR training. In this light, I have

explored a few curriculum issues which I have deemed topical and connected to the purposes of this study. I have focused specifically on critical pedagogy, ideology and curriculum and models of curriculum as a way of narrowing the vast field of curriculum studies and relating it to the construction of a critical curriculum for mid-level CBR workers. Although much of the literature refers to critical pedagogy and curriculum at the school level, the work of Freire has specifically been related to the education of adults. Much of the other work examined also has a broader applicability to adult education.

2.5 Summary

In this chapter I have explored the theoretical context of this study. This study is situated within competing discourses of disability, the complexities of rehabilitation, and specifically community based rehabilitation, and within educational debates on curriculum and different pedagogies. Throughout this chapter I have tried to elucidate a critical theory perspective of the context of this study, particularly with respect to the discourses of disability and curriculum debates. In this light, I have situated this study within the social model of disability with its links to the rights discourse of disability and an understanding of people with disabilities as being oppressed. Similarly, bearing in mind a critical perspective, I highlighted issues of empowerment, community participation and barriers that people with disabilities experience, in the discussion of community based rehabilitation. There are few analytical articles concerning CBR training in the literature and therefore I conducted my own analysis of the information that exists concerning CBR training of grassroots workers, mid-level workers and CBR management. Finally I contextualised the CBR curriculum in this study within broader debates about curriculum and critical pedagogy. Having placed this study within its historical, socio-political and theoretical context in Chapters 1 and 2, I go on to explore methodological considerations of the action research in this study in the following chapter.

CHAPTER 3

ACTION RESEARCH WITHIN A CRITICAL PARADIGM: METHODOLOGICAL CONSIDERATIONS

3.1 Introduction

The purpose of this chapter is to locate this study within a particular approach to social and educational research which then has implications for the research design and methodology of the study. Having motivated the selection of action research as an appropriate design for the first phase of the study, I will describe the various research techniques used in the different phases of the action research cycle, as well as the data analysis methods used. I will also critically examine the use of participatory action research in a study for degree purposes before motivating the use of life history methodology for the second phase of the study.

3.1.1 Background to the study

This study took place within the organisation CBR Education and Training for Empowerment, known as CREATE. CREATE is based in Pietermaritzburg and ran a two-year course in Community Based Rehabilitation (CBR) between 1999 and 2006 in KwaZulu Natal. CREATE is a small organisation with four staff members who all took part in the research in various ways – myself as researcher and the other three who participated in the action research through teaching students. They were also interviewed towards the end of the action research cycle. The aim of the study was to investigate the extent to which the curriculum of a CBR course can enable or hinder community rehabilitation facilitators to address the issues of the oppression, social inclusion and rights of people with disabilities. The action research part of the study was undertaken with a class of 7 students who started the CBR course in October 2003, although the research only began in December of that year. The action research data collection was completed at the end of July 2005 when four of the

students completed the course. Unfortunately, due to failures by the other 3 class members to meet all the course requirements in time to write exams in July 2005, two of the three remaining students completed the course in March 2006 and the other student dropped out of the course. However, all 7 students were involved in generating data for the study and in making suggestions for changes. Four of these students then participated in life history interviews in 2007. Much of the research took place in Pietermaritzburg in the classroom and offices of CREATE. However data was also collected in the communities of Impola (near Marianhill), Ntunjambili and Centocow, where the students were based while doing their practical work.

3.1.2   Orientation of this research

As indicated in Chapter 2 of this thesis, I have situated this research within a critical theory framework. The subject matter of this study, the ability of a course in Community Based Rehabilitation to enable students to participate in the empowerment of people with disabilities through social inclusion and confronting the oppression of these people, can be construed to fit into the emancipatory knowledge-constitutive interest of Habermas as elucidated in Grundy (1987), which guides critical theory. The emancipatory cognitive interest of Habermas deals with the human concern with autonomy, freedom and empowerment (Carr and Kemmis 1986; Grundy 1987). Emancipation is linked to justice and equality which constitute the conditions in which Anon-alienated@ communication and interaction can take place. Not only is my study concerned with empowerment and justice in terms of its content, it has also attempted to embody these concepts and critical theory in the methodology and design of the study.

3.2   Situating This Study Within Critical Social Science

Critical social science can be seen to arise from the application of critical theory (particularly from the Frankfurt School tradition) to the study of the social sciences. Brookfield (2005)

describes one of the distinctive characteristics of critical theory as being a concern with giving people understanding to free them from their oppression. Linked to this, critical social science is described as involving self-reflection and working to understand restrictive situations and how to overcome them. Both critical theory and critical social science envisage a fairer and more democratic world, an ideal that should be pursued, according to critical theorists. In relating critical theory to educational research, McLaren and Giarelli (1995, p.9) go so far as to warn that

> "Unless we have some provisional narrative of liberation, we can easily and unknowingly establish pedagogies and research practices that fall prey to the very error that critical educators seek to correct, that duplicate the original silencing of the Other, that replicate the concepts and systems of power they seek to revoke, that relegitimate the very terms they seek to reject."

Neuman (2000) describes the purpose of critical social science research as transforming social relations and the world. The aim of this study was to change the curriculum of the CBR course with the purpose of changing the relationship between community rehabilitation facilitators (CRFs) and people with disabilities, and with the ultimate aim of changing the relationship between people with disabilities and society. By conceptualizing the research questions in terms of the oppression and empowerment of people with disabilities it is necessary to understand the context in which people with disabilities experience oppression and the power structures that exist in these situations. Neuman (2000) classifies this concern with examining social reality in terms of its socio-political and historical context as critical social science. According to Giroux (1988) in the tradition of radical (critical) scholarship, power and politics should be central to educational research.

Unlike the positivist approach to science and social science, critical social science does not claim to be value-free or neutral. Rather, proponents of critical social science would see a positivist approach as supporting the status-quo. Additionally, critical social science does not treat all points of view as equal, as in an interpretivist approach to social science (Neuman

2000). My study openly takes a standpoint of the value of justice for and empowerment of oppressed people with disabilities. Although taking a particular standpoint could be seen as a weakness of this study in terms of positivism or interpretivism, I feel it is important to articulate such a viewpoint because the purpose of this research was to change the status quo with regard to CBR and people with disabilities.   Changing situations necessarily involves power. In positivist research the power of the researcher and the way science is regarded is not acknowledged.   In this study my intention has been to de-mystify the role and values of the researcher and to place the study in a particular socio-political and historical context. According to Carr and Kemmis (1986, p.152) in critical social science

> Aa new role for the researcher is discovered whereby his or her participation in the development of knowledge is comprehended as social and political action which must be understood and justified as such.@

A critique of critical theory and critical research arises from postmodernism. Clarence-Fincham (1998) highlights some concerns that several postmodernist feminists have with the application of critical theory to education (critical pedagogy). These concerns can also be related more broadly to critical theory and critical social science. The first critique is that in spite of its concern with open-endedness and dialogue, critical research and critical pedagogy has a tendency to impose its own set of social assumptions. With regard to my research, I acknowledge that I have framed the study with the values of the empowerment of and social justice for people with disabilities. I have used semi-structured interviews and focus groups with open-ended questions and participatory rural appraisal in an attempt to avoid imposing my own assumptions on the outcomes of the research, although clearly this is not entirely possible. The second critique of critical research by postmodernist feminists is that such research does not adequately account for difference and diversity. Clarence-Fincham (1998) cites Ellsworth (1989) who claims that post-structuralism, which is based on multiplicity and epistemological diversity, has greater potential to include historically marginalised groups than critical theory. However, as Kemmis (2003, p.321) points out in his article exploring emancipatory education in a postmodern era, post-structuralists generally try to distance

themselves from human and social affairs,

> "they seem to want to deny a sense of responsibility for taking a role in the reconstruction of society that has become burdensome because – as they see it – emancipatory perspectives no longer seem justifiable."

In spite of the above-mentioned critiques, this research is grounded in critical theory, because my understanding is that postmodernist theory is on the whole unable or unwilling to accommodate concerns with social transformation, which is the central theme of this research.

Having chosen to situate my research within a critical social science paradigm, it is necessary to explore the implications of this choice for the methodology used in this study. Neuman (2000) states that within a critical approach to research any technique or research method can be used. However, it is important that the research should exemplify emancipation and justice in its methodology as well as in the topic being researched. According to Brookfield (2005), one of the distinctive characteristics of critical theory is that it breaks down the separation between researcher and the focus of research. A participatory research design can therefore be appropriate for studies undertaken within a critical paradigm. Kemmis and McTaggart (2003) list three of the distinguishing attributes of participatory research as shared ownership of the research project, analysis of social problems that is based in the community and having an orientation towards community action. Emancipatory disability research shares these characteristics and in addition has a particular interest in the contribution of the research outcomes towards the emancipation of people with disabilities (Lorenzo, 2005). Critical collaborative research is another form of research which addresses the asymmetry in the relationship between researcher and the researched. Power and the lack of it, is a central concern in critical collaborative research. LeCompte (1995, p.99) describes critical collaborative researchers as being concerned "to give voices to their subjects, and to bring together scholarship and advocacy in ways that generate new ways of knowing, capable of interrupting (existing) power imbalances." From the description of critical social science as Aa process of reflection which requires the participation of the researcher in the social action

being studied.@ (Carr & Kemmis 1986, p.149), it is clear that another of the appropriate methodologies for critical research is action research. The various forms of action research that have been used by researchers are described in the section below.

3.3   Action Research

As Kemmis (1993) mentions, the notion of what action research is has been debated for at least the last 50 years. Hart and Bond (1995) refer to action research as critically reflexive practice that gives the participants power for change, while in a more detailed definition Carr and Kemmis (1986, p.162) describe action research as a process of Aself-reflective enquiry@ that enables more rational and just practice and better understanding of the practice and the situation in which the practice takes place. Many authors describe action research as consisting of a number of cycles or a spiral of identifying the problem, planning action, taking action, observing and reflecting (Hart & Bond, 1995; Kemmis & Wilkinson, 1998; Nunes & McPherson, no date). For the purpose of this study, I have followed the action research cycle or spiral as described by Altrichter, Posch and Somekh (1993) and Kemmis and Wilkinson (1998) - finding a starting point for the study; clarifying the situation; planning action strategies; putting the action into practice; observing the effects of the action and reflecting on the action taken and the changes that have occurred.

3.3.1   Characteristics of action research

The distinguishing characteristic of action research is that it systematically integrates research with practice. Unlike other methods of research, in action research the practitioner can study his/her own actions and the impact of them within the context in which the action occurs. As Carr and Kemmis (1986) point out, a key aim of much action research is to involve role players (for instance, the learners, teacher and other school staff members in the case of classroom research) in the research. The attempt to work jointly to take into account the diverse views of those involved in participatory (action) research extends to the level of

writing the research findings in a way that is accessible to all research participants (Fals Borda, 2001).

Another key characteristic of most action research is the aim to improve practice and /or to improve the situation in which the particular practice takes place and to improve understanding of the practice. Improvement of practice happens in action research through the interplay of critical reflection and action, in other words, praxis. According to Carr and Kemmis (1986) and Fals Borda (2001), in action research and participatory research this improvement in practice should take a particular direction - towards social justice and democratic practices.

An additional characteristic of action research mentioned by several authors (Carr & Kemmis, 1986; Hart & Bond, 1995; Reason, 2001) is the development of theory. In action research, practitioners and those engaging in the research are involved in theorising their own practice and through the cycles of action and reflection, "revising their theories self-critically in the light of their practical consequences." (Carr & Kemmis, 1986, p.198). According to Reason (2001), not only does the theory arise out of practical experience, it also captures the qualities of the action and practice which the research participants aspire to achieving. Theory that is developed in action research takes into account the context in which the practice occurs and may lead to challenging that context.

Phase 1 of this study can be said to be characteristic of action research with its concern with improving or reconstructing a CBR curriculum that will focus on equity, social justice and the empowerment of people with disabilities. Through adopting the use of an action research cycle it is possible to integrate critical reflection with action in this study. AInvolvement@ in this study was enacted through the researcher being one of the trainers in the CBR course. In addition, the development of a research team that was made up of myself (as researcher and trainer), a colleague who is disabled and who has previously been a student on the course, a past student and a member of CREATE=s board who is disabled, was an attempt to make

this study participatory. See Chapter 4 for further discussion on the research team and whether this study in fact could be considered to be participatory action research.

3.3.2   Types of action research

In an attempt to locate this study within the context of international perspectives on action research, it is necessary to look at different types of action research. Carr and Kemmis (1986) describe Atechnical@, Apractical@ and Aemancipatory@ action research. One of the distinguishing factors between the different types of action research is who initiates and stimulates the research.   In technical action research an external facilitator co-opts practitioners to work on a problem or question generated externally to the practitioners, the findings of which then feed into external research literature. An outside facilitator is also present in practical action research although s/he will work co-operatively with practitioners who may raise their own concerns and problems to work on. Emancipatory action research would be conducted by a practitioner group who work collaboratively and develop their own understandings of situations as socially constructed. Practitioners engaged in emancipatory action research take responsibility for their own emancipation from patterns of thought, habits etc. that may be unjust or anti-democratic. Carr and Kemmis describe the practitioner who engages in emancipatory action research as an activist, one who takes action on the basis of critical reflection. Through her experience of action research, Walker (1993) reflects that the action research process, even an attempt at emancipatory action research, does not of itself shift practitioners= ability to engage in critical reflection and emancipatory action. In fact Walker (1993, p.112) suggests that:

> Acritical or emancipatory action research is inherently political and **arises** [own
>
> emphasis] from the practitioner=s commitment to emancipatory politics.@

The activist nature of the researcher- practitioner in emancipatory action research appears in practice to precede the onset of the research.

In contrast to the three types of action research outlined by Carr and Kemmis (1986), Hart and Bond (1995) detail in their typology, four types of action research, ranging from

experimental action research through organizational and professionalizing action research to empowering action research. Each type of action research is distinguished by its handling of various criteria that include where the problem to be studied emerges from, what degree of collaboration there is between researcher and participants and who leads the process of change. Professionalizing action research may be grounded in such professions as nursing, teaching and social work where the interests of research may dominate over practice. Hart and Bond describe empowering action research as being most closely linked to community development. Empowering action research may challenge existing power relationships by allowing less powerful groups / individuals to negotiate the definition of the problem to be studied and the change intervention is decided from the bottom up. According to Hart and Bond, within the life span of one action research project, the research may shift from one type of action research to another.

Kemmis and Wilkinson (1998) refer to participatory action research. The description that these authors give of participatory action research seems to be similar to the earlier description that Carr and Kemmis (1986) give to emancipatory action research. Participatory action research is described as a practical and collaborative social process that helps to liberate people from unjust or unproductive social structures. According to Kemmis and McTaggart (2003, p.381) "participatory action research is directed toward studying, reframing, and reconstructing practices that are, by their very nature, social." These authors discuss the development of participatory action research and how, by 2003, it had become a contested concept which has been applied to a number of approaches to research such as action learning, critical action research and action science. Hagey (1997) in fact warns of a number of abuses of participatory action research, including one which according to her, occurs quite commonly. That is, research may be conducted in the name of participatory action research while the researcher actually maintains control and is accountable to his/her bureaucracy, rather than control residing in the community, which may not respect institutional deadlines.

Zeichner (2001) does not classify different types of action research but rather mentions and gives examples of different dimensions along which educational action research may vary. The dimensions that Zeichner deals with are the purpose and motivation of those who undertake the action research; the conception of the action research process; the form and content of the action research; the sponsorship of the research; the assumptions about knowledge and the ways in which the findings of the research are represented to others. The description of the possibilities along each of these dimensions is open-ended and therefore it seems to be necessary to be aware of these dimensions in the current study and how this understanding of action research may interact with the classifications mentioned previously.

This study can clearly be located within Carr and Kemmis' (1986) understanding of emancipatory action research. The researcher is also a practitioner - I have studied my own practice, with the intention of liberating myself and my organisation from patterns of teaching and practice that are not socially just. Hence the question, "How does the current curriculum function to make students aware of the oppression and need for empowerment of people with disabilities?" guides this research. Bearing out Walker's (1993) perceptions of the researcher-practitioner in emancipatory action research, I have been an activist for CBR and more broadly for social justice for many years before undertaking this study, as mentioned in the prologue. The one area in which this study deviates from the description of emancipatory action research is that there has not been a collaborative group of practitioner-researchers in this study. The research was initiated and conducted mainly by myself, with the research team playing a guiding role in some phases of the project. It can be seen as a limitation of this study that the research team did not consist of all the staff (practitioners) in CREATE who teach on the CBR course. Thus there was not a collaborative group of practitioner-researchers and staff did not feel such ownership of the problem and solutions as I did. Part of this problem stems from my understanding of the purpose of this research being to obtain a postgraduate qualification and thus being uncertain how much to involve other staff.

Hart and Bond (1995) mention that in practice the four types of action research they outline in their typology overlap. This study seems to incorporate elements of the professionalizing and empowering types of action research. That there is a practitioner researcher and a vision of structural change and empowering oppressed groups seems to place this study within the empowering type of action research. However, the problem has been defined by the professional (myself), rather than in negotiation with the user group (students and people with disabilities), which is a feature of professionalising action research.

3.3.3   Action research and CBR

Barton (1998) articulates the characteristics of good disability research as neither trying to be neutral (as in positivist research) nor being embedded in the medical model. Barton also stresses the importance of debate and dialogue with people with disabilities within the research and that control of the research should not be entirely by non-disabled people. Participatory action research allows for the collaboration of people with disabilities with non-disabled people in research and through this collaboration, people with disabilities enjoy power to define the issues and the potential improvements in the research. In this study, the participation of two people with disabilities in the research team enabled some concerns of people with disabilities to be heard within the research. Specifically, the use of an action research design with its cycles of reflection and action allowed for the debate and dialogue with people with disabilities to permeate the study.

CBR is fundamentally concerned with social justice, as the definition indicates its central concern with equalisation of opportunities for people with disabilities. It therefore is appropriate to select a research design that can accommodate and reflect social justice in its process and content. Action research appears to fit this need. Price and Kuipers (2000) also suggest that action research is appropriate for studies in CBR because action research accommodates an empowerment framework in CBR. Traditional rehabilitation research methods (including experimental studies) have given very little control to participants and often do not take into consideration some important social factors. Price and Kuipers point

out that action research is consistent with the commitment of CBR to demystification. Rose and Grosvenor (2001) describe the use of action research in special education and how through the process of action research practitioners are able to question their own practices and take ownership of the approach to find solutions. Price and Kuipers assert that it is time within the relatively new field of CBR that practitioners question their own practices.

3.4   Locating This Action Research in CREATE

3.4.1   *CREATE and the CBR course in this study*

The action research cycle in this study was located within the two-year CBR course run by CREATE. CREATE is a small non-government organisation based in Pietermaritzburg which expressly focuses on disability and rehabilitation training. It ran the CBR course from 1999 which was developed from the CBR course that was started by the IUPHC in 1990. The students trained by CREATE on the two-year CBR course have come from the provinces of KwaZulu Natal, Gauteng and North West in South Africa as well as a neighbouring country, Namibia.

The CBR course entailed blocks of theory interspersed with blocks of practical work and short periods in which students were introduced to topics through distance learning materials and assignments. The theory blocks took place at CREATE's offices in Pietermaritzburg and included some guided visits to people with disabilities in nearby townships and peri-urban areas. All the CREATE staff were involved in teaching sections of the CBR course. In addition, a number of consultant trainers ran particular sessions in which they have expertise and experience. During the practical blocks, the students worked in the communities they came from, doing tasks that were set by CREATE and that relate to what they learnt in the theory block. CREATE staff members visited each student during each practical block to monitor their work and also to assist the student with problem-solving. Each student also had a supervisor (usually a therapist or a nurse) who came from the organisation or

Department of Health which sent the student for training. The student's supervisor provided guidance and also monitored the progress of the student.

3.4.2 Participants in the action research

In this study there were different participants in different phases of the research. I was the practitioner researcher throughout the cycle and there was a research team which helped to guide me in the initial reflection, planning and action and observation phases.

During the first step of the action research cycle (reflection), I gathered data from six CRFs who had completed the CBR course run by the IUPHC or CREATE between 1998 and 2002. This was done in order to assist me with reflecting on the course as it had been and to gain the perspective of participants in the training. These CRFs were all based in disadvantaged areas, either townships or rural areas, where poverty is rife and people with disabilities are amongst the most marginalised. These six CRFs who were interviewed during the initial reflection phase of the action research were selected to represent the two provinces of South Africa from which students came during the period 1998 to 2002 (KwaZulu Natal and Gauteng). Two of the CRFs were male and four female. Two of the CRFs worked in urban areas, one in a peri-urban area and three in rural areas. None of the CRFs interviewed in the first phase of the action research are disabled themselves.

The main part of the study was conducted with a class of 7 students who started the CBR course in October 2003 with some completing the course in July 2005. This group of students were all from KwaZulu Natal, two from township areas in the Ethekwini municipality while the others were from deep rural areas – Centocow and Ntunjambili. In these rural areas, homesteads are widely spread and therefore, it was at times difficult for the students to organise collective activities which would have required some people with disabilities to travel long distances to meet with others. Five of the students experienced great poverty themselves whilst in training and thus they could identify closely with their clients with disabilities. All students were between the ages of 21 and 40 and had grown up

receiving at least part of their education during the apartheid era. One of the youngest students experienced some difficulty in being accepted in his community as a community rehabilitation facilitator because his age gave him low status within the community. As one focus group participant explained about this student:

> "Initially we did not believe that he can help us because he is a young boy from this village. We thought we know better about our children. We are mothers, we have got children. He does not even have a child, but he proved us wrong."

In addition to the relatively low status of young people, in one of the rural areas there is also political rivalry between the younger and older generations, adding to the complexities in which the CBR students had to work. Two of the seven students who started the CBR course are themselves disabled but unfortunately one of the students with a disability dropped out of the course in April 2005 because he was not coping with the academic requirements of the course. Of the six students who participated in the action, observation and reflection phases of the action research cycle through completing the CBR course, four were male and two female. Four of these students (two male and two female) were interviewed for their life stories approximately two years after completing the course. This constitutes the second phase of the study which is discussed in chapters 6, 7 and 8 of this thesis.

The three staff members of CREATE (apart from myself) participated in different aspects of the research. One staff member participated in the research team, thus giving her more insight into the research than the other staff members. All staff, including myself, took part in implementing changes to the course and we had a number of discussions about the action research. In addition the three staff members were interviewed in the phase of observing action during the action research cycle. Two of the staff members are disabled and one is male.

During the action and observation phase of the action research I also ran two focus group discussions with clients of the students in order to gather information and understand the perspective of people who had worked with the students. One focus group was held in

Impola (an urban area) with six participants, all of whom were disabled. One participant was deaf and required a sign language interpreter and another participant had a mental illness. The other participants had physical and communication disabilities. The second focus group discussion was held near Centocow (a rural area) with six participants. Four of the participants in the Centocow focus group discussion were parents of children with disabilities and the other two participants had disabilities themselves. All the participants selected for the focus group discussions had worked directly with the students from their area (Impola and Centocow) during 2004 and 2005.

My own role as participant researcher is not uncomplicated in this action research. Although as mentioned earlier in this chapter, there are benefits to researching one's own work using action research, there is also a power dynamic involved in my participation in this research. I initially worked in the CBR training programme at the IUPHC and then started CREATE in KwaZulu Natal and continued with the CBR training from IUPHC. Being both the founder of CREATE and now its managing director, has given me power to initiate changes in the CBR course. The situation would no doubt be different if I had a different position in the organisation. In addition it is likely that the staff, students and CRFs whom I interviewed may have responded differently to a researcher who did not have the same power because of her position. This is one of the difficulties of being a participant researcher in action research and will be explored further in section 3.7.

3.5   The Action Research Cycle in this Study

The action research part of this study was conceptualized as consisting of one cycle within an action research spiral. The phases of the research entailed identifying the problem and reflecting on the current curriculum, planning changes to the curriculum, acting (implementing changes), observing the process and consequences of the changes and reflecting on these observations. Such a cycle follows the recommendations of many authors

concerning action research (Altrichter et al, 1993; Hart & Bond, 1995; Kemmis & Wilkinson, 1998; Nunes & McPherson, no date; Rose & Grosvenor, 2001). In the following sections of this chapter I will discuss the data collection methods as well as the process involved in each phase of the main action research cycle.

3.5.1   Reflection phase - Identifying the problem

Although Kemmis and Wilkinson (1998) describe the cycle of participatory action research as beginning with a phase of planning, in this study I chose to begin with a reflection phase in order to focus on the problem. This follows the recommendation of McKernan (1991) in his explanation of critical-emancipatory action research, where he suggests focusing on the problem through posing the questions: 'What is happening now?' and 'In what sense is it problematic?' These questions then lead on to the final question: 'What can I do about it?' which, in this study is dealt with in the planning phase.

Prior to the formal beginning of this study, I engaged in my own reflections concerning the direction the CBR course had taken since its inception using the readings I had done and my own experiences over the years of being involved in CBR training. Although these reflections were not formally part of the current study, they shaped this study and guided me to look at specific aspects of the CBR curriculum, namely empowerment, oppression, the social model of disability and social inclusion.

Within the formal study, in the initial reflection phase of the action research cycle I undertook document analysis, which included analysing documents such as course timetables, statements of outcomes, assessments of students and a detailed syllabus. As McKernan (1991) indicates, document analysis can be useful in discovering the goals and rationale of a curriculum, as well as the background history of the topic being investigated.

In addition to the document analysis, the first reflection phase of the research cycle involved in-depth interviews with Community Rehabilitation Facilitators (CRFs) who have been

through the CBR course previously, in order to obtain another perspective of the CBR course prior to any changes in the action research. Six CRFs were selected to be interviewed using semi-structured interviews representing different places of training (IUPHC in Johannesburg and CREATE in Pietermaritzburg), different years of qualification (from 1998 to 2002), rural and urban places of work and representation of both genders. During this phase of the research, the objectives of the interviews were to describe the CRFs= interpretations of their work and to examine their understanding of the concepts of the social model of disability and the oppression of people with disabilities.

3.5.2   Planning phase

The following phase of the action research, planning changes to the curriculum, was done with the research team. Reference was made to the data collected in the first phase and also to literature on empowering education, curriculum planning and education for social justice.

3.5.3   Action and observation phase

During the action phase, from March 2004 to July 2005, the planned changes to the course were implemented and documented. Throughout this time I kept a research journal or diary in which I recorded my ideas and insights on the research process and my role as researcher. Altrichter et al (1993) point out that a research diary can contain in-depth reflections, a memo of particular events and interpretation.

Reflecting on the current problem
* ∗ Document analysis
* ∗ In-depth interviews with CRFs

Action planning
* ∗ With research team
* ∗ Use data from first phase
* ∗ Look at curriculum & philosophy

Reflecting on the changes
* ∗ Make recommendations for further action
* ∗ Initiate life history research

Taking action and observing
* ∗ Implement changes in curriculum
* ∗ In-depth interviews with students and staff
* ∗ Analyse documents
* ∗ Focus group discussions with people with disabilities
* ∗ PRA exercises with students

Figure 3.1: Action research cycle undertaken in this study
(Adapted from Kemmis & Wilkinson, 1998 and Nunes & McPherson, undated)

Observing the implementation of the changes to the curriculum entailed documenting aspects of the curriculum such as assessments of students and observations of their work in communities. These documents were then analysed. I also conducted in-depth interviews with the six students who completed the CBR course with the changed curriculum. CREATE's three staff members were interviewed about the changes in the curriculum using semi-structured interviews. Two focus group discussions with people with disabilities and parents of children with disabilities were held in order to gather information on their perspectives of the skills and training of the CBR students and the service provided by them. An isiZulu-speaking interpreter, who is familiar with correct terminology concerning disability, assisted me with the focus group discussions. In order to assess and observe the effect of the changed curriculum I also used participatory rural appraisal techniques (Chambers, 1997) with students.

3.5.4   *Final reflection phase*

During the final reflection phase I analysed the findings from the observation phase. Using these observations and analysis, I developed some ideas for a CBR curriculum that is geared towards the empowerment of people with disabilities. However during this phase of the action research, I also came to the realisation that the issue of students' participation in social action needed to be explored further. This issue raised new research questions for me which then prompted me to design the second phase of this study, using life history methodology.

3.6   Research Techniques Used in the Action Research

3.6.1   *Document analysis*

Mc Kernan (1991) describes documents as a rich source of evidence which can be used in action research that explores a curriculum. Often, as in this study, document analysis may be done prior to other forms of data collection, thus guiding and informing the rest of the research process. Using existing written documents for analysis also increases the credibility

of the data, as they existed prior to any intervention or interest in the research, according to Altrichter et al (1993). The CBR course is well documented, with documents including a detailed description of the course for accreditation purposes, a statement of outcomes for the course, module timetables, various assessment documents, evaluations by students, mark schedules, students' reports on their practical work etc.

The above-mentioned documents were analysed using content analysis, as described by Marshall and Rossman (1989) and Bauer (2000). The procedure involved selecting data relevant to the objectives of the analysis, devising a classification system, coding the data and analysing the coded data (Bauer, 2000; Marshall & Rossman, 1989). In addition, I used the time allocation analysis described by Neuman (2000) to analyse the module timetables of the CBR course. This procedure involved using the CBR classification system of Kuipers et al (2003) to code the topics taught in the different modules of the CBR course. The course was then analysed according to the time allocated to each category within the classification system.

3.6.2 *Semi-structured interviews*
In this study, I conducted interviews with CRFs who completed the course prior to 2003, with CREATE staff members and with the students who completed the CBR course during the study. I used semi-structured interviews because Bell (1993) indicates that having a loose structure for the interview ensures that crucial topics are covered, while at the same time such loose structure enables the interviewer to probe responses for further depth. A semi-structured interview also allows a certain amount of freedom to the respondent to talk about what is of central importance to him or her. One of the difficulties with being a researcher as well as being a participant in this action research was the problem of bias in the interviews. I conducted all the interviews myself and all the various respondents had either been taught by me or are working with me. I chose to conduct the interviews myself because I felt that my knowledge of the CBR course and my involvement in the training would enable me to probe the responses of the interviewees in a way that an outside interviewer would not have been

able to do. This enabled me to have control over the data which would not otherwise have been possible. Because of my involvement in the interviews it was impossible to avoid the possibility that some respondents may have responded in particular ways to please me. However, I was aware of this possibility and tried to use each interview guide in a similar way for the different respondents. Judging by some of the critical comments given to me, it appears that the bias that may have crept in is not so severe as to nullify the usefulness of the data collected.

All the interviews were conducted in English although not all the interviewees were home language English speakers. I had chosen to use English as English was the medium of instruction in the CBR course and I thus assumed that all the interviewees had a certain proficiency in the language. Every interview was audio-recorded and transcribed in full before being analysed. In addition, I took notes during every interview which assisted the transcription process in cases where the audio recording was poor. In analysing the data from the interviews, I followed the process described by Neuman (2000). After transcribing the data I engaged in open coding, which Neuman describes as assigning initial codes to the data that start to bring out themes from the data. These initial codes came in part from the research questions, but also from new insights raised by respondents. This process of open coding can be equated with McMillan and Schumacher's (2001) description of the process of developing an organising system from the data, the first phase in analysing data qualitatively. Following the open coding, I examined the codes that I had used in order to identify commonalities or clusters of codes and other links between the codes. This second process of coding (in which categories or themes are identified) is known as axial coding (Neuman, 2000). This ties in with McMillan and Schumacher's suggested phases of developing topics as categories and searching for patterns. Finally I returned to the data to look for material that illustrated the themes I had developed and which might shed more light on the themes. Neuman refers to this as selective coding.

3.6.3   Focus group discussions

During the action and observation phase of the action research I ran two focus group discussions with people with disabilities and parents of children with disabilities. According to Gibbs (1997) focus group discussions are particularly useful for obtaining a number of perspectives of the same topic. It was important in this research to gain insight into the perceptions of a number of people with disabilities and parents of children with disabilities regarding the oppression they had experienced as well as their work with the CBR students. The benefit of using focus group discussions was also that there was some interaction between participants during the focus group discussion, which may have stimulated more ideas coming from participants than if they had been interviewed individually.

The focus group discussions were audio-taped, transcribed in isiZulu and then translated into English. I followed the same process for analysing the data from the focus group discussions as mentioned above for the analysis of the interviews.

3.6.4   Participatory rural appraisal

Participatory rural appraisal is an approach to research which includes a number of techniques that rely on the community or group being researched to generate and analyse their own information. According to Pretty, Gujit, Scoones and Thompson (1995), the key principles that guide participatory rural appraisal (PRA) include obtaining multiple perspectives on an issue; using group analysis and interaction; being sufficiently flexible to adapt the approaches to the specific context and using the methodology to stimulate changes and bring about improvement. Chambers (1997) writes that PRA is fundamentally about challenging the dominance of professionals and PRA techniques are designed in a way to allow the participation of all, especially the marginalised such as the poor and the illiterate. However Crawley (1998) warns that in spite of the language of empowerment used in PRA, in practice PRA does not always address gendered power relations. If PRA is truly to empower those who are disempowered, it needs not only to change people's consciousness but also to address and change the relations that the marginalised group has with structures

and others external to the group (Crawley, 1998). In this study I chose to use PRA because of its power to enable participants to generate and own their own information. I used three PRA techniques with the CBR students because the use of visual methods (particularly in the Venn diagramn and the matrix) enabled those students, who are not so good at writing English, to participate fully.

The three PRA techniques that were used in this study were the timeline, the Venn diagramn and the matrix. I used the timeline technique in order to assist the CBR students to chart the changes in their attitudes towards people with disabilities over time and particularly noting any changes during the CBR course. Although PRA is usually done in a group, I asked the students to complete the time lines individually to represent their personal changes in attitude. I followed the procedure outlined in Pretty et al (1995) to facilitate the students to develop a Venn diagramn of their difficulties in working within a social model approach to disability. This involved brainstorming the difficulties they experienced, then prioritising the difficulties and arranging them into a Venn diagramn. During the process the students analysed their responses and the diagramn they developed, although I also analysed the Venn diagramn further on my own. Pretty et al (1995) describe matrix scoring as a process in which participants are interviewed to identify the categories and criteria for ranking particular issues. The process continues with the development of a matrix in which items are compared and contrasted. In this study I facilitated the students developing a matrix of the topics and methods of teaching and learning used in the CBR course. The topics which the students identified as being important formed the X axis of the matrix while the methods of learning and teaching formed the Y axis. Each intersecting block (of a particular topic and method of teaching) was then ranked with the method of teaching being given a score of 1 to 5 for a particular topic.

3.6.5   Triangulation

The use of different research techniques and different sources of data enabled me to triangulate the data. The data obtained from the Participatory Rural Appraisal (PRA) with

the students was triangulated with data obtained from their interviews as well as a document analysis of their reports, exams and community work presentations. The data obtained in the focus group discussions from people with disabilities was triangulated with data obtained from the students. As Krefting (1991) indicates, triangulation is a powerful strategy to enhance the credibility and quality of qualitative research.

3.7 The Theory and the Practice of Action Research: Some Reflections on the Use of Participatory Action Research as a Methodology for this Study

Much of what I have written earlier in this chapter speaks to the ideal, the theory of action research. My experience of implementing and being involved in participatory action research in this study is that it is a lot messier, less democratic and more open to abuse than is initially suggested in much of the literature. In my reflections below, I raise a number of questions which do not necessarily have neat and contained answers that fit in with any theory of action research. However, as suggested by a number of authors (Heikkinen, Huttunen & Syrjälä, 2007; Herr & Anderson, 2005; Robertson, 2000), I am being a reflexive researcher which should, or perhaps could, contribute to the validity of this research.

3.7.1 *This study as participatory action research?*
In this study I tried to enact the participatory nature of the action research by constituting a research team made up of the categories of people whom I decided were key stakeholders in the research – people with disabilities, CRFs (past students) and staff. My intention was to give a 'voice' to those people participating in the research. And so the first question arises, "Who decides who constitutes the participants anyway?" (David, 2002 p.13). As the researcher who initiated the study I selected the participants for the research team. Immediately this may have brought a bias into the research because although the decision was a pragmatic one in terms of who was available, I also considered who I could work with. Perhaps, unconsciously at the time, I selected participants who had a similar viewpoint to my

own. David (2002) questions what happens in participatory action research when the interests of the researcher and those of the participants do not coincide and he suggests that research should not be limited to situations where the interests of all parties in the research are the same.

Another question related to the participatory nature of the action research in my study is linked to the use of a research team. What happens when the research team collapses during the lifespan of the research? In my study, the research team disintegrated due to my colleague going on maternity leave and other team members having great time pressures at work (see Chapter 4 for further discussion). These are the realities of participatory action research in context, not the theory as in the literature. The collapse of the research team was due in part to my own ambivalence about pressurising people to participate when the research was for my own benefit (for furthering my education). But in the end I cannot claim that my study really was participatory – people with disabilities, CRFs and staff were not involved in much of the data analysis nor were they involved in the decision-making of what to write up subsequently. What constitutes participatory action research in reality? Is it sufficient to claim an attempt or an intention to be participatory? Hagey (1997) would possibly classify this as an abuse of the name of participatory action research.

3.7.2   Who has had the power and control over this action research?
Although I would like to think of myself as democratic, when I reflect on this research, I have to admit that I have claimed most of the power and control of this study. According to Kincheloe (1995), *democratic* action research is an essential component of developing critical, reflective practitioners. I believe that through my experiences in this action research I have become a more critical and reflective practitioner, but I am not certain that the same can be said about the other participants in the research team. I initiated the research and developed the research questions for the action research before the research team was constituted. This gave me a degree of control and power over the research process which the other team members did not have. Gaventa and Cornwall (2001) write about participatory

action research democratizing the power of the experts, but in this study I, as the expert (the one who had done more reading on the subject), do not feel that I achieved this maximally. It is a difficult task to democratize control and power when one member of the team seems to have more at stake because she is doing the research for the purpose of obtaining a degree. As Herr and Andersen (2005, p.4) write, "the culture of dissertations discourages collaborative work." Not only does the culture of a dissertation inhibit power-sharing, as Hagey (1997) points out, the timeline for the research can also be an area in which the researcher controls the study. This is certainly an area of difficulty in research for degree purposes and has to some extent been an issue in this study. Another aspect of the action research in which I did not give up control was the consideration of whose agenda the research followed. I had determined the perspective of the research as well as the research questions and methodology before the research team existed and it was into this existing situation that the team members were initiated.

3.7.3   *My own position in the research*

When reflecting on the complexities of the action research in my study, I realised that my positionality in the research may well have influenced the outcomes of this study. Herr and Andersen (2005) discuss a continuum of positionality in action research which ranges from insider research (the researcher studies herself) to research where an outsider studies an insider. Along this continuum, my research could probably be categorised as "insider in collaboration with other insiders" or perhaps "insider in collaboration with outsiders" (Herr & Andersen, 2005, p.31). Ladkin (2004) classifies participatory action research as third-person research. She goes on to suggest that all third-person research should be grounded in first-person research in which the researcher attempts to identify her own biases and constructions of experience that may influence the research.

These conceptualisations of positionality in action research seem uncomplicated, but again, not necessarily in line with my experience of the realities of implementing action research. In this study I am not only the researcher and a course facilitator for the community based

rehabilitation course, but I am also the managing director of the non-government organisation running the CBR training. All these identities may be seen as insider identities, but each of these aspects of my position in the research can easily have had a variety of effects on the participants. In their interviews, did the staff respond to me as the manager who employs them, telling me what they thought I wanted to hear? Or did they respond to me as a fellow course facilitator who shares their experiences of developing and facilitating the CBR course? What effect did it have on the students that I interviewed them before all their marks for the course were finalised and I was responsible for some of their marks? Simply being classified as insider researching with other insiders (the research team) does not take account of the complexities within the insider (or outsider) designation. Herr and Andersen (2005) discuss the possibility of researchers occupying multiple positions which can even bring them into conflicting alliances within the research. These authors suggest that it is necessary for researchers to interrogate these multiple positions in relation to the research question, which can then enrich the research through multiple perspectives on the research question.

Another perspective on positionality is David's (2002) characterisation of participatory action research as requiring commitment from the researcher to including the people to be researched and to some extent using the research to further their goals. This then can be seen as a form of advocacy which leads to the question 'Whose side is the researcher on? What is her position in the research?' I find the first question a difficult one to answer. As a critical researcher, I would like to think I am on the side of oppressed people with disabilities, but how do I know that to be the case? What also, is the effect of acknowledging and recognising whose side I am on?

3.7.4   The question of validity of action research

Perhaps the point of my reflections on the realities of implementing action research has something to do with being transparent about situating myself within the research, rather than being the so-called "neutral observer" of positivist research. This notion of situating myself

and my potential biases within the research, foregrounds the question of validity of action research. Ladkin (2004) and Heikkinen et al (2007) suggest several criteria that may be used to assess the validity of action research. These criteria include usefulness of the research, reflexivity in the research, the extent to which relational aspects are demonstrated, such as collaboration and whether the research shows how the action has evolved historically. I hope that by reflecting on my position, the power that I have held and the nature of participation in this study I am fulfilling one criterion of valid action research – that of reflexivity.

3.8   The Politics of Researching Disability

Researching disability, particularly as a non-disabled researcher, needs careful consideration of methodological and accountability issues, as well as considering the paradigm in which one will conduct the research. As Stone and Priestley (1996, p.700) point out, "the inherent power relationship between researcher and researched is accentuated by the unequal power relationship which exists between disabled people and non-disabled people in the wider world." Historically much disability research has been seen by people with disabilities as part of their oppression, rather than improving their quality of life and material circumstances (Oliver, 1992). Much research conducted by rehabilitation professionals has been conducted within a positivist paradigm which casts the researcher as the expert and the knowledge and experience of people with disabilities counts for little.

As disability research contributes to the construction of disability in society, it is important for disability researchers to understand that the research cannot be apolitical or disinterested (Swain & French, 1998). The researcher may be an unwitting oppressor of the people with disabilities in the research, especially if the medical model of disability guides the research. Dyson (1998) goes so far as to caution prospective disability researchers that if they cannot get rid of their oppressive consciousness, there may be no place for these people in the research process.

A number of authors propose participatory and emancipatory disability research as viable alternatives to the oppressive nature of positivist disability research (Dyson, 1998; French, Reynolds & Swain, 2001; Stone & Priestley, 1996; Swain & French, 1998). According to French et al (2001, p.235) in participatory disability research

> "The research process is viewed as a potential source of change and empowerment for the research participants as well as a process for influencing professional policy and practice by reflecting the views and opinions of service users."

Participatory disability research is concerned with equality in the relationship between researchers and researched, thus attempting to break down the oppressive nature of relationships in much disability research. Through people with disabilities participating actively in the research, participatory research aims to build the skills and self-confidence of participants so that they are able to get involved in social action (French et al, 2001). The product of participatory research about disability issues should reflect the views, concerns, feelings and experiences of the research participants (Swain & French, 1998).

Emancipatory disability research is research that is controlled by people with disabilities throughout the process of the research. The social model of disability guides emancipatory disability research. In this approach research is seen as a political action with the research process and product being tools for people with disabilities to achieve their liberation (French et al, 2001). Emancipatory disability research also enables the voices of the 'subjects' of the research to be heard. A fundamental concern of emancipatory disability research is the oppression of people with disabilities and the transformation of oppressive relationships. Although emancipatory disability research is often associated with the use of qualitative data, Stone and Priestley (1996) caution that simply using qualitative data is not sufficient to qualify research as emancipatory. It is the theoretical paradigm that guides the data collection and analysis that is important.

In this study I have attempted to take cognisance of the criticisms of disability research which is seen as oppressive. Therefore I have chosen a participatory methodology for this research and I have situated the study within the social model of disability. In this study I have tried to hear the perspectives of at least some people with disabilities and other participants through the use of a representative research team and through choosing participatory rural appraisal and focus group discussions as two of the methods for data collection.

CHAPTER 4

REFLECTING ON THE PAST TO GUIDE CHANGES IN THE CBR CURRICULUM

4.1   Introduction

This chapter deals with the first two phases of the action research cycle conducted in this study. The purpose of the initial reflection phase of the action research was to clarify the situation and identify the problem which was to be acted upon within the study (Altrichter et al, 1993; Kemmis & Wilkinson, 1998). In order to understand the situation of CREATE's CBR training and the skills, knowledge and attitudes of the community rehabilitation facilitators (CRFs), I first reflected on my own understanding of the CBR course since I had been involved in it. I then conducted in-depth interviews with 6 CRFs who had previously completed the CBR course at CREATE or the Institute of Urban Primary Health Care (IUPHC). An analysis of the findings of the interviews is presented in this chapter together with the results of document analysis of the CBR course, in order to come to a more comprehensive understanding of the curriculum for mid-level CBR worker training that has been used in South Africa. This chapter goes on to discuss the planning phase of the action research cycle and it details the changes that were implemented in the CBR curriculum as a result of the initial reflections.

4.2   Reflecting on Current Practice in the CBR Curriculum

Although the action research in this study officially began at the end of 2003 with the acceptance of my research proposal by the University of Natal, in fact I had started to reflect on my own experiences of teaching and co-ordinating the CBR course some time before that. In this section of the chapter I briefly share some of these reflections which guided the conceptualisation of the research and the initial research questions

before detailing my findings from the document analysis and interviews with the CRFs.

4.2.1   Researcher's reflections

From 1993 I was employed at the IUPHC and I worked together with the team that was responsible for developing and teaching the CBR course for mid-level workers known as community rehabilitation facilitators or CRFs. During the time I spent at the IUPHC in Alexandra township in Johannesburg, the organisation was known to be guided by progressive thinking with regards to health training and advocacy as well as being politically progressive. This progressive thinking permeated the CBR course with regards to its design and content and my early experiences of CBR training included encouraging the students to adapt a slogan of the times, "Mobilise and organise" to their work in the community and visiting the Alexandra Disability Movement to assess how accountable the CRFs were to this organisation in their work.

With these roots as my background, I then engaged in reflection on the CBR course and the CRFs we had trained in CREATE from 1999 onwards. I was aware that the political situation in the country had changed dramatically and that this had influenced the students and staff in many ways. In the early years of the CBR course many of the students had experienced and participated in the activism to overthrow Apartheid as teenagers and young adults. This was different to some of the students who attended the CBR course after 2000. This may well have affected students' receptivity to the progressive aspects of the course although I also reflected that we had become less critical and progressive in the content of the CBR course. I felt that over the years, CBR students were less critically aware and concerned with social justice than previous cohorts had been. I was particularly concerned with the oppression, rights and empowerment of people with disabilities because it seemed as though the racial oppression and denial of rights under Apartheid was being addressed in our country, while the rights and oppression of people with disabilities were not being addressed adequately. These informal reflections then stimulated me to formulate a study which would help me to investigate this situation further.

Hence, the research questions that guided the action research phase of this study as outlined below, have a particular orientation to social justice. The initial phase of the research was guided by the following questions which can be seen to originate in my early reflections on the CBR course.

- What links, if any, do students studying Community Based Rehabilitation understand between community development, the social model of disability and overcoming the oppression of people with disabilities?

- How does the current curriculum function to make students aware of the oppression and need for empowerment of people with disabilities?

- What factors in the historical and socio-political context may have influenced the nature of the existing Community Based Rehabilitation curriculum?

- What changes need to be made to the existing Community Based Rehabilitation (CBR) curriculum to assist students to understand and address the oppression of people with disabilities?

4.2.2   *Revelations from the document analysis*

Once the research formally began, in the initial reflection phase of the action research I analysed documents relating to the CBR course curriculum to assess which model of curriculum most closely fits the CBR course. In addition, the CBR curriculum was analysed to determine the coherence and consistency with its stated purpose. Using these analyses, I also examined the 'curriculum conscience' – the assumptions underlying the curriculum and what is taken for granted (Posner, 2002). The reason for examining the 'curriculum conscience' was to attempt to expose the hidden curriculum, that some critical theorists feel is at least as important as the official curriculum in terms of the implicit messages it gives to students (Posner, 2002). The documents analysed included the description of the curriculum and statement of course and module outcomes used for accreditation, CREATE's mission statement, timetables for each module of the course, assessments of students, distance learning notes for the course and examples of students' practical workbooks.

Grundy's (1987) three approaches to curriculum – curriculum as product, practice or praxis, were used to guide the analysis of the CBR curriculum. In the *curriculum as product* approach the specification of objectives and the related content and activities

is important. The *process approach* to curriculum does not focus on the acquisition of specified content. Rather, curriculum as process or practice may be based on principles that guide interaction between teacher and learner and as such is more learner-centred than the curriculum as product model, according to Kelly (1989). *Curriculum as praxis* involves a focus on critical consciousness so that students come to recognise distorted views of the world that are based on the domination of some people over others.

4.2.2.1 Purpose and outcomes of the CBR course. The stated purpose of the CBR course, "to empower people with disabilities and communities through providing well-trained CBR personnel", illustrates the values behind the CBR course which are consistent with the curriculum as praxis model. Cornielje and Ferrinho (1995, p. 29) also situate the IUPHC CBR training programme (which CREATE has continued to run) firmly within the emancipatory ideals of a praxis approach to curriculum:

> "Given that rehabilitation is an approach aimed at contributing to the struggle for human rights of disabled people, the ideology of training people whose tasks it would be to facilitate change in society and conscientize a marginalised group of disabled people, undoubtedly prescribes a radical approach to a large extent but not unconditionally based on the consciousness raising philosophy as formulated by the Brazilian educationalist Paulo Freire in his 'Pedagogy of the Oppressed'."

The CBR course also appears congruent with curriculum as praxis in its concern with enabling students to understand and critically engage with disability within the South African socio-economic and political context (Cornielje & Ferrinho, 1995). According to Grundy (1987), curriculum as praxis involves developing critical consciousness in which issues and topics are examined critically with reference to their context. An example of this in the CBR course is that in some worksheets in the distance learning materials there is a section entitled "Thinking critically about the article". This section of the worksheet encourages students to evaluate whether what they have read is applicable to their own context and why and/or to think about the reasons for the author's stance on a topic.

As illustrated by Cornielje and Ferrinho (1995), the CBR course was initially developed within a strong emancipatory framework. With the advent of outcomes based education and the National Qualifications Framework in the late 1990s, outcomes were then superimposed on the CBR course in an attempt to meet the requirements for accreditation. Although the use of behavioural objectives or outcomes can be linked to the curriculum as product approach, according to P. Rule (personal communication, November 2003) the shift in the CBR course from implicit to explicit outcomes does not in itself necessarily mean that the course is 'product-centred'.

When examining the outcomes of the modules of the CBR course, most of them can be seen as instructional or behavioural objectives e.g. "At the end of the module the student will be able to teach a client (person with a disability) to maintain a wheelchair and do basic repairs". The outcomes are not narrowly defined with specified levels of performance, but there is an assumption of means-end rationality in the way they are stated and Cornbleth (1990) links this to curriculum as product.

In contrast, however, there are a number of desired outcomes that are perhaps more related to process, which are not written down but which are an important part of the ethos of the CBR course. For example, critical thinking, problem-solving and respect for human rights are key issues that run through the entire course, but they are not written as outcomes. All the staff members of CREATE encourage students to critically engage with the topics they are teaching, valuing questions from the students. Tests and exams questions are set as problems to solve, requiring students to relate their knowledge to case studies, rather than requiring rote recall of information. Some of these unwritten values and desired outcomes of the CBR course, such as problem-solving and working in a team, fit in with Stenhouse's (2002) idea of 'principles' within a process model of curriculum. A difficulty is that because these principles or values remain unwritten, visiting course facilitators do not necessarily incorporate them into their teaching.

The stated outcomes of the CBR course modules include knowledge and skills, but little on attitudes or values. Although the stated purpose of the CBR course is "to empower people with disabilities and communities", there is no specific mention of

the term 'empowerment' in any of the outcomes for the modules or the course as a whole. Some of the outcomes for particular modules e.g. "At the end of the module the student will be able to involve people with disabilities in developing services for themselves" indicate skills leading to the ability to empower other people. However there is a shortcoming in the course documentation that no mention is made of empowerment. This is a problem with using outcomes as behavioural objectives because it is difficult to make empowering people into an objective, observable behaviour, as a large part of the empowering process involves attitudes and values such as trust, self-confidence and personal responsibility (Nchabeleng, 2000).

Another aspect of the lack of coherence in CREATE's approach to the CBR curriculum is that with the pre-determined plan and specified outcomes (typical of curriculum as product) there are not many opportunities for the teacher and students to negotiate the curriculum, although this, together with a concern for empowerment and emancipation are part of curriculum as praxis (Grundy, 1987). The power relationship between the teacher and students in the CBR course does not reflect that suggested by the curriculum as praxis approach. The power, particularly in curriculum construction in the CBR course, resides strongly in the teacher, while the curriculum as praxis approach promotes a collaborative process with the sharing of power (Grundy, 1987).

4.2.2.2 The teaching and learning process in the CBR course. The learning process in the CBR course is varied and tries to avoid "banking education" which Freire (1972) indicates is common in more traditional approaches to education (where curriculum as product would be located). Different methods of teaching and learning are used during the course, including short periods of reading and completing worksheets and assignments; group discussion, role plays and problem-solving during 'theory' blocks and 'practical' blocks during which students put their newly learned skills into practice. The purpose of using these different methods is to enable students to actively participate in the learning process, rather than being passive recipients of knowledge transmitted by the teacher (as in "banking education" or curriculum as product). In fact, one of the guidelines given to those facilitating sessions in the CBR course is to use methods that involve participation of students and build on their

existing knowledge and experience (based on Knowles' premises of andragogy, or adult learning, as cited in Jarvis, 1995).

Although this distinguishes the CBR course from the curriculum as product approach, the CBR course does not use the idea of a negotiated curriculum (between students and teacher) that can be found in the curriculum as praxis approach (Grundy, 1987). However, there are some elements of praxis in the practical blocks of training, when students are taught to reflect on their actions with clients with disabilities and then to develop new plans for action with their clients, based on these reflections. In spite of this, the technical knowledge interest which informs curriculum as product and sees action as the implementation of knowledge which is applied to the realm of practice (Grundy, 1987), does seem to be the approach to practical work (action) used within the CBR course.

There are however, aspects of the learning process which are more closely aligned to curriculum as praxis. As Grundy (1987) indicates, the process of conscientization is closely linked to the emancipatory interest and thus also to empowerment. A number of people with disabilities are involved in teaching on the CBR course. This not only gives the students role models of empowered people with disabilities, it also creates a space for dialogue with oppressed people (people with disabilities) which Freire (1972) claims is a necessity to rehumanise (and conscientise) the oppressed and oppressor (able-bodied students). Although there are elements of curriculum as praxis in the learning process of the CBR course, it seems that the learning process cannot be neatly placed into one approach to curriculum.

It appears that, based on the documents analysed concerning the purpose, outcomes and learning process, it is difficult to place the CBR course entirely in one approach to curriculum. It is possible that in the original curriculum planning and in subsequent modifications, those involved in the curriculum construction and reconstruction have not had a clear theoretical framework for this work.

4.2.2.3 The hidden curriculum or curriculum conscience. Through examining different components of the CBR course in relation to the different approaches to curriculum, part of the 'curriculum conscience' of the course has been exposed.

There appear to be some conflicting assumptions in the curriculum of the CBR course which can be confusing particularly to students but also to course facilitators.

As indicated previously, the outcomes do not specifically state that empowering people with disabilities is a crucial aspect of the CBR course. To some extent the value of empowering people with disabilities is taken for granted by course facilitators and is demonstrated in the attitudes that the course facilitators have when interacting with people with disabilities during the course. However the fact that this value is assumed rather than openly stated could send a different message to students – that empowering people with disabilities is not as important as some other aspects of the course. Another aspect of the curriculum that may cause confusion is that the written outcomes of the CBR course mainly concern knowledge and skills. The effect of this (or the curriculum conscience) is that students may have placed much emphasis on skills in their learning, without paying adequate attention to the values that lie behind the skills.

Another aspect of the CBR curriculum which may have given conflicting implicit messages to the students is the relative emphasis in terms of time allocated on aspects of the content of the course in comparison to the overall stated purpose of the course. Using the timetables for each module of the CBR course and the classification of CBR activities of Kuipers et al (2003), I analysed the time spent on different types of content of the CBR course. In terms of time spent on teaching, the relative emphasis in the course (44% of the course duration), was on issues related to individual people with disabilities and their families e.g. dealing with specific disabilities such as arthritis and cerebral palsy. Teaching on community development and issues related to communities such as the interrelationship between poverty, health and disability took 19% of teaching time. In spite of the stated purpose of the CBR course, very little time was spent on attitudes and beliefs (3%) or on the structural level (institutions, the social model of disability and overcoming barriers experienced by people with disabilities), where much of the oppression of people with disabilities occurs. (See Figure 4.1). Oppression of people with disabilities was not a topic that was included in the content of the CBR course at all.

Total Hours Spent on Content of CBR Course

- No. of hours teaching individual disability issues & family
- No. of hours about community
- No. of hours about structures
- No. of hours about roles, attitudes & beliefs
- Other e.g. first aid, visit to facilities,

44%
28%
3%
6%
19%
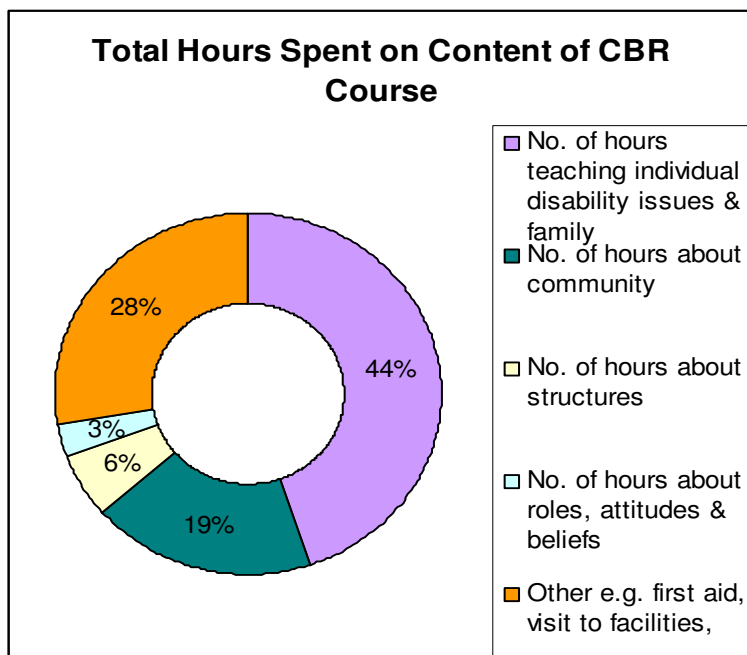
Figure 4.1: Time analysis of content of CBR course

In summary, the CBR course curriculum, as analysed at the end of 2003, did not neatly fit into any one approach to curriculum. Although the ethos of the course appeared to coincide with the values in curriculum as praxis (Grundy, 1987), other aspects such as the outcomes of the course were more aligned to different approaches to curriculum. Together, this lack of consistency in theoretical approach and orientation to curriculum may have caused some confusion in students and thus may have had some effect on the practice of the CBR students.

4.2.3   Reflections of community rehabilitation facilitators trained between 1997 and 2002

Using the interviews conducted with six CRFs who had completed the CBR course at the IUPHC in 1997 or at CREATE between 1999 and 2002, I have been able to construct a picture of the knowledge and practice of these CRFs, with particular reference to community development, the social model of disability and the oppression of people with disabilities (see Appendix 1 for interview schedule). This reflects both on the curriculum of the CBR course (which stayed essentially the same during the period in which these CRFs studied CBR) and on the changes that the CRFs have made to their practice of CBR based on their own experiences.

4.2.3.1 Different types and levels of intervention.   From the limited number of interviews I conducted for this first phase of the action research cycle, the CRFs have indicated that their work entails quite a wide variety of activities: introducing CBR into the community; working with stakeholders from different sectors (such as Health, Education, Home Affairs and Social Welfare); prevention of disability; providing assistive devices; raising awareness about disability in the community; working with groups, including helping them with income-generating activities; home visits to people with disabilities and running workshops. The activities that the CRFs engage in, illustrate that they understand CBR to consist of action at all the different levels Kuipers et al (2003) mention in their classification of CBR projects – individual, family, community, structural and attitudes and beliefs.

Using the Kuipers et al (2003) classification, it seems that there are number of ways in which the CRFs interviewed are providing services - providing, assisting, participating and to some extent advocating. One CRF told a story of how she was involved in advocacy for the dignity of a woman with a disability. The sons of the woman with a disability were not caring for her and were using her disability grant money for alcohol for themselves. The CRF was an advocate for the woman's needs and she managed to encourage the family to use the disability grant money to pay for someone to clean and cook for the woman three times a week, rather than using the money to satisfy their need for alcohol.

The CRFs were specifically questioned about their interventions at a community level and their understanding of community development. The CRFs were able to identify a number of key issues that lead to the success of a CRF being involved in community development.   Firstly a CRF has to ensure that s/he enters the community appropriately:

> "And you find that at some stage you beg with the stakeholders to meet
> them because you can't go out to the community without meeting the
> stakeholders because you need to sit down with the stakeholders, explain
> to them what is it that you've got, what you're here to do, how are you
> going to do that. It's not that they are going to say 'no, you can't do that'.
> But you can't go to the community without them. You definitely need

them. You first need to explain everything to them. Then you can go out." CRF F

Another aspect of working successfully in community development is the need to be known in a variety of community structures so that CBR is prominent in the various aspects of community development. As one CRF put it:

"I think if you are a CRF you have to make sure that you liaise with people like councillors, like *inkosi* (chief), people like *induna* (headman). Any structures which are around in our community like community development, health committees. All the structures that we have. You have to put yourself in, not exactly looking to be a member there but make them aware that there are persons like you in the community. Just because it's easy for them to contact you, if there are some things that they want to do, just because they know you. But if you are not well-known in the community, it's a problem. You need to sell yourself in these structures." CRF A

This is not something that was taught on the CBR course. Rather the CRF, through his involvement in community development initiatives in his area, was able to reflect that his own success in inserting CBR into community development in his area is because he is known in a number of community structures. This CRF has demonstrated this in practice - because the chief knew him to be involved in disability issues, he was invited to become involved in a water and sanitation project in his community with the aim of making the new facilities accessible to people with disabilities. According to the classification by Kuipers et al (2003), this work could be classified as participating at a structural level. In order to be classified as advocating at a structural level, the CRF would have to be involved with people with disabilities in the advocacy for structural change, not only doing it himself. As Cornielje and Ferrinho (1995, p.31) point out:

"Indicators of the involvement in community development initiatives include the adoption of a **supporting role** [own highlight] to disability movements, parents groups, day care centres and creches, income generating projects and participation in committee meetings."

4.2.3.2 The social model of disability: impact on the CRFs' practice. As Oliver (2004, p.19) states, "the idea behind the social model was that of externally imposed restriction." Although three of the CRFs who were interviewed needed to be reminded of what the social model of disability is, most of them were able to report on activities that they have been involved in to address environmental and/ or attitudinal barriers or restrictions experienced by people with disabilities. One CRF illustrated how she is attempting to break down attitudinal barriers:

> "We used to call workshops and do the disability awareness in churches, communities and even in schools. So that is where we are trying to fight that negative attitude about people with disabilities. We want people of the community to recognise them as human beings."   CRF C

There were a number of exciting stories from the CRFs about removing physical barriers and respecting the right of people with disabilities to environmental accessibility. One CRF told of motivating a bank to place an automatic teller machine (ATM) at a level that a wheelchair user could reach the ATM, while another told of encouraging the municipality to build toilets with ramps. The CRFs are also involved in advocacy concerning the social model of disability and barriers that people with disabilities experience:

> "Even though you keep stepping on other people's toes, but you don't have a choice if you see that person needs to be corrected. You can't just keep quiet. You just talk to the manager friendly and tell him, 'But have you ever thought of people with this disability in this situation. Do you think they can cope?' And then try to explain. Then they end up seeing your point. They said 'No we've never thought about that, but now that you're saying it, we'll try and do something about it.'"   CRF E

My concern however, is that the CRFs are often operating within an understanding of disability as externally imposed due to barriers of various types, but they are not involving people with disabilities in their lobbying, advocacy and removal of barriers.

An important issue raised by the majority of CRFs interviewed was that of social integration. This is part of the ILO, UNESCO and WHO (1994) definition of community based rehabilitation, so it is gratifying to see that the CRFs are taking it

seriously in their work. One CRF has taken the responsibility of social integration right to the level of community leaders:

"Like in my community, I talked to the councillor, the community leader, about integrating people with disabilities when electing committees in the community, like the development committee, policing forum, all those sub-committees. And he didn't think about that before, but right now when he is calling a community meeting, he also calls the people with disabilities."   CRF C

Another CRF shows that a social model approach to disability services, removing barriers, is an enabling factor for social integration:

"now in the community you find out that maybe the house is not accessible. So he's always in the house. So I'll make sure I do home visit and do follow ups that 'Please, the ramp must be there. And then I'll come next week to see.' When I went there I don't find the client. He's visiting the friend because of the ramp. You know, those things, ja. Because most of the time you go there in the house, he can't get himself out. But now because they've got a ramp even in the gate, you know, he can push himself now to the community. So that's social integration, not to isolate himself."   CRF B

Although some of the CRFs were not at first able to explain the theoretical construct of the social model of disability, it is clear from their practice that some of them have been able to begin implementing the social model principle of removing barriers in a way that leads to the social integration of people with disabilities.

4.2.3.3 Disability and oppression. There is however, a difficulty in that most CRFs did not have a clear understanding of disability being linked to oppression. Barton (1994) equates the social model of disability with disability as a form of oppression. Some CRFs were able to identify oppression on an individual or personal level, but they were unable to talk about the oppression at a cultural and structural level. The CRFs had some ideas about the rights of people with disabilities, but again they could not relate this knowledge to oppression. Because the concept of oppression had not been taught in the CBR course up to 2003, it is not surprising that the CRFs did not

have the tools to analyse what is happening to people with disabilities in terms of oppression. Barton (1994) states that unless one speaks out against oppressive images and conditions, one consents to the discrimination of people with disabilities. Some CRFs have been able to speak out about discriminatory conditions and this could be an opening for further training on oppression and empowerment. Again it was concerning that CRFs often seem to act on behalf of, rather than with, people with disabilities. As Barton (1994) indicates, part of the disability struggle is the struggle against asymmetrical power relations. At present most, if not all, of the CRFs interviewed take on a position of dominance rather than having equal power to the people with disabilities they are working with.

4.2.4   Summary of the reflections on the initial phase of the action research

Although the analysis of the content of the CBR course showed that the largest allocation of teaching time was spent on individual disability issues and causes of disability, those CRFs who were interviewed indicated that they do many activities during their work, with home visits to individuals with disabilities not occupying all their time. From the CRFs' reports of their work in community development and overcoming barriers that face people with disabilities, it appears that the CRFs were able to assimilate something of the ethos and values of the course when they were studying, rather than simply basing their work on the content of course. Relatively, it appears that the implicit values in the CBR course and the attitudes and actions of the course facilitators have had as much of an effect on the practice of the CRFs as the content.

Many of the CRFs were unable to describe the social model of disability, although their work on overcoming barriers shows a social model orientation to their practice of CBR. Perhaps this fact points to the lack of time spent on 'structural' issues (including the social model) in the theory part of the content of the course, although the workbooks used for practical blocks in the CBR course framed the tasks set within the social model. The lack of understanding of oppression of people with disabilities that the CRFs displayed may also be a direct consequence of the fact that students were not taught about oppression in the CBR course and thus did not have analytical tools to deal with this concept.

4.3   Planning Changes and Action with a Research Team: Participatory Action Research?

In trying to frame this study as participatory action research, I chose to form a research team comprising representatives of the key groups affected by or involved in the research.   Kemmis and Wilkinson (1998) and Fals Borda (2001) describe participatory action research as a collaborative process which involves those acting as well as those affected by the action. The purpose of forming the research team was to facilitate collaboration from the planning stage of the research cycle.

4.3.1   Members of the research team

The initial members of the research team were myself, a colleague at CREATE who is both disabled and a community rehabilitation facilitator (CRF), another CRF who had completed the CBR course at CREATE previously, and a member of CREATE's board who is disabled and who has research experience. Each of these research team members was identified and invited by myself to participate in the research.   In selecting the members of the research team, I considered the need for people with disabilities as well as CRFs to have a 'voice' in the research. Barton (1998, p. 30) explains that giving people with disabilities a voice "implies participating in decision-making that will have a real impact on their lives." Barton continues, indicating that good disability research does not exclude people with disabilities from the process and production of the research. Through involving people with disabilities and CRFs in the research team, my intention was to have these people guiding the research process and helping to make key decisions concerning the CBR course and analysis of the research data.

During the first two years in which the action research was conducted, the research team changed in composition before finally collapsing altogether. Due to work and personal pressures, the CRF pulled out of the research team fairly early on in the study. Towards the end of the first year, my colleague with a disability also pulled out as she went on maternity leave. This colleague was replaced by another colleague who is neither disabled nor a CRF. Thus towards the end of the life of the research

team, there was no CRF involved although there was still a person with a disability in the research team.

4.3.2   Role and functioning of the research team

Barton (1998) describes being a researcher as a learning experience. I certainly found this to be true of my experience of working with a research team.   Initially, I requested the research team members to reflect with me on the data gathered from interviews with CRFs, and to then make decisions concerning the nature of the changes to the CBR course. The research team played a role in planning the broad outline of the changes to be made but I planned the details of each session to be taught. Later in the year, the research team, without CRF representation, helped to plan in more detail the module on advocacy which was to be added to the course. By the time data was being gathered towards the end of the action research, the research team had disbanded, and therefore, they were not involved in the analysis of data coming from the changed CBR course. I found it difficult to maintain a research team whose members were not all working with me at CREATE. It is not easy for people to find time in their schedules for a research project in which they do not personally stand to gain anything.

My own role in the team always seemed to be that of initiator, and I was unsuccessful in getting the research team to feel ownership of the study. They were participants in my study, rather than co-owners of the research. This is probably an unavoidable situation in a study where one person is to obtain a higher degree from the research. In addition, I was the person who initiated the research and defined the problem, which is characteristic of the "professionalising" type of action research rather than "empowering" action research (Hart & Bond, 1995) which can be more closely aligned to participatory action research.

That the research team did not function throughout the study is certainly a limitation of this research, as I cannot claim that the voice of people with disabilities or CRFs is heard throughout this study. I cannot claim that "The people in the community or workplace are involved in controlling the entire research process." which Hagey (1997, p. 1) claims is a characteristic of participatory research. However a number of authors who write about participatory action research (Hagey, 1997; Kemmis &

Wilkinson, 1998; Fals Borda, 2001) deal with the ideal of participation throughout the life of the research, but not with the realities of maternity leave, busy diaries, and the nature of research for the purpose of gaining a degree. Can this study really be construed of as <u>participatory</u> action research? Perhaps the various participants and stakeholders should decide.

4.4 Taking Action: Implementing Changes in the CBR Course

As part of the action phase of the action research cycle, a number of changes to the CBR course were implemented. The research team suggested changes and additions to the content of the course and the outcomes (particularly for the practical work) which would be made by the staff of CREATE. In addition the research team decided that CREATE should enhance and emphasise particular methods of teaching and learning. Due to the time taken to conduct the initial reflection phase of the action research, changes were implemented to the CBR course from February 2004 onwards. This means that changes were implemented to all modules of the CBR course except the module on sensory impairment, which the students completed in January 2004.

4.4.1 *Focus on social model of disability and oppression*
In order to try to remedy the situation of CRFs struggling to explain the social model of disability, the initial teaching about the social model was changed during this action research from being largely theoretical to include experiential learning. Students were involved in simulations of disability where external barriers, such as a mop and water lying on the floor, were barriers for people with disabilities (in this case, blindness) who were otherwise able to move around and conduct their affairs independently. In addition, to assist the students to relate the social model to their practice of CBR, the staff of CREATE introduced the social model of disability as a framework for the students to use to help review their practical work throughout the course. At the end of each block of practical work that the students had done in their communities, the students spent a day reflecting on their work as a class. Students were required to critically think about the barriers that face the people with disabilities they had worked with and what they had done to overcome these barriers. This critical reflection on reality and the students' experiences, with the aim of improving the

students' practice can be seen as similar to the process of conscientisation using action and reflection or praxis that Freire (1985) refers to. This process of developing critical awareness in the students concerning their understanding of disability and how it relates to practice was not linked to just one module, as was the case previously in the CBR course. It was integrated into the entire course.

The research team decided on an additional way in which to expand the students' understanding of disability - a number of lessons on oppression and liberation were added to the CBR course (See Appendix 2 for examples of these lesson plans). The lessons on oppression started with the students' own identities as oppressor and oppressed, and their experiences of oppression such as sexism and racism. By starting with dialogue about the students' own experiences and only afterwards giving input on oppression, I was following one of Shor's (1992) guidelines for creating empowering education. In the lessons on oppression I used Harro's (1994) cycle of socialisation as the framework for understanding how the oppression of people with disabilities happens. The students worked through the cycle looking at specific examples of the experiences of people with disabilities and also how these people experienced oppression at individual, institutional and societal levels, following the model of oppression espoused by Hardiman and Jackson (1994).

The sessions on liberation and empowerment used codes, such a game and human sculptures to begin discussion within the class on how liberation can happen. Hope and Timmel's (2003) suggestions for the use of codes in teaching about various forms of oppression and liberation which were used in the CBR course, are based on Paulo Freire's pedagogy for liberation. Through the use of this methodology, the students first analysed what they had seen in the codes before relating critically to their own experiences of liberation or empowerment. This then enabled them to engage with the theories of liberation and empowerment that were presented to them – Harro's (2000) cycle of liberation and Nchabeleng's (2000) triangles of empowerment.

4.4.2 Social action, advocacy and lobbying
Linked to the additional teaching on the social model of disability and the oppression of people with disabilities, one of the students together with people with disabilities in his area, organised a march to protest against the various barriers experienced by these

people in the community. The march was held (see following chapter) and a memorandum was presented to the local municipality. As none of the other class members had engaged in such social action (for the liberation of people with disabilities) at this point in time, I added a session to the CBR course so that the class could learn from this experience. Again I incorporated Freire's concept of praxis into the session in order to help conscientise the class. Initially a video of the march (the action) was shown to the class as the basis for reflection. The students and I engaged in dialogue about the social action and its meaning and the response of the supervisor of the student who had organised the march (she refused the student permission to participate in the march during work time because it was "too political"). According to Freire and Shor (1987), dialogue is a key element of education for liberation and all students should be encouraged to express themselves. Resulting from this dialogue was a request from the students to learn how to deal with people in positions of power. One session on dealing with people in positions of power was added to the new module on advocacy and lobbying. Although this was insufficient to do justice to a complex topic, it raised the issue amongst the students and gave them an opportunity to share their own successes and failures in dealing with people in positions of power.

Another addition to the CBR course to assist the students in developing skills to undertake action to overcome the oppression of people with disabilities was the development of a week of teaching on advocacy and lobbying. Although I had a basic outline for the week, the students and I negotiated the curriculum for this week. My intention in negotiating the curriculum was to bring some coherence into the curriculum, based on the findings in the first reflection phase of the action research cycle in this study. Grundy (1987) writes that curriculum as praxis involves negotiation of the curriculum between students and teacher as well as the concern with issues of emancipation. Negotiation about the curriculum had certainly not been the experience of the students up until this point in the CBR course. In order to assist the students in their negotiation of the curriculum, I first presented them with a case study which would enable them to form ideas on what they wanted to know about advocacy and lobbying (see Appendix 3). Based on the dialogue following the case study, the curriculum content and outcomes were decided upon. The week included practical sessions such as how to make a banner and write a letter to the press,

learning from people with disabilities about mobilising people with disabilities and confrontational, peaceful action and more theoretical sessions on the advocacy cycle and dealing with people in positions of power. One of the difficulties that arose out of this week for some of the students from rural areas was a feeling of being overwhelmed by the difficulty of working and living in an area where there is tight control by traditional authorities (*amakhosi* and *izinduna*). These students felt that they might be victimised if they undertook advocacy and action for transformation, even to the extent of being asked to move out of the area. In such rural areas the power vested in the traditional leaders makes it difficult for the CBR students who are relatively low in status to challenge the status quo. The course facilitators were all from urban areas and were unable to give the rural students much assurance or advice. This issue certainly needs to be dealt with in future CBR courses.

4.4.3   Changing outcomes of the CBR course
As was highlighted in the reflection on the CBR course curriculum, the outcomes of the course did not mention empowerment or much on the values leading to empowerment. Although the overall outcome of the CBR course and the outcomes of the modules were not revised during this study, CREATE staff did modify the outcomes of each block of practical work that the students did, based on the findings of the first phase of the action research. The outcomes still refer mainly to skills but there was an attempt to include outcomes that might be considered as the building blocks to empowerment. For example, some of the reworked outcomes are: "Educate people about and promote the rights of older people" and, "Assist visually impaired clients to become more independent".

Insufficient work was done on restating the outcomes of the CBR course during this research due to time constraints and this is another limitation of the study. In continuing action research cycles, it would be useful for CREATE to perhaps draw up a statement of principles which could include the values behind the course and an explanation of how CREATE understands empowerment.

For a summary of all the changes made to CREATE's CBR course during this action research study please see Table 4.1 below.

	Changes made to the CBR course
Content	- Social model of disability brought into every module, particularly relating it to the students' experiences in their practical work - Sessions on oppression and liberation added - Session added to reflect on social action undertaken by a student - Week-long module on advocacy and lobbying added
Teaching methods	- Social model taught using experiential learning - Curriculum for advocacy and lobbying module negotiated with students - Increased number of sessions using dialogue, codes and praxis (from Freirean pedagogy) - More people with disabilities used as facilitators
Outcomes	- Outcomes of practical blocks changed to include empowerment more explicitly

Table 4.1: **Summary of the changes made to the CBR course during the action research**

4.5   Conclusion

The initial reflection phase of the action research in this study revealed some inconsistencies and lack of coherence in the CBR curriculum as it existed in 2003 and in the documentation of the curriculum. The CRFs who had been trained prior to 2003 described their practice of CBR as consisting of a number of activities at the levels of the individual, family, community and attitudes and beliefs. They did not have the tools to describe or analyse the oppression of people with disabilities. A number of the CRFs were unable to explain the social model of disability although they engaged in activities to overcome the barriers experienced by people with disabilities.

Although participation in this research was fraught with difficulties, there was some influence of both people with disabilities and CRFs in the planning of changes to the CBR course. The changes and additions mainly concerned the content of the course with effort also being put into the use of Freire's (1972) ideas of praxis and conscientisation. For one additional module the curriculum was negotiated between

students and teacher, which is in line with Grundy's (1987) concept of curriculum as praxis. Not enough effort was put into changing the outcomes of the CBR course, and thus although there was a move towards greater coherence between the ethos and values of the course and curriculum practice, there are still a number of changes that could be made in future action research cycles.

CHAPTER 5

OBSERVING THE EFFECTS OF CHANGES IN THE COMMUNITY BASED REHABILITATION COURSE CURRICULUM

5.1   Introduction

This chapter investigates the effects of the changes that were introduced into the CBR course curriculum during the action research phase of this study. In other words, this chapter represents the observation phase of the action research cycle. In order to observe the effects of curriculum change, I gathered data from using several participatory rural appraisal (PRA) techniques with the students as well as using interviews with students and staff members, observation of students' work, focus groups with people with disabilities and parents of children with disabilities and document analysis. Through combining and comparing the data from the different sources, I will explore a number of themes related to the changes in the curriculum as well as analysing two key issues arising from the students' responses to the changes to the CBR course, namely oppression and social action.

5.2   Working With, Rather Than For, People with Disabilities

One of the key changes that staff members identified in the students who participated in this study, as compared with students who went through the CBR course prior to this action research was their attitude towards people with disabilities in their work. As one staff member put it:

> "I think this again relates to like previous groups where they would do things <u>for</u> people with disabilities, whereas, for example working with people like Student F, when I went to see him on marking day. He's very

much geared to working <u>with</u> people with disabilities and making it clear that you know, he did things with them instead of doing things for them."

<div align="right">(Staff member 3)</div>

Kuipers et al (2003) in their classification of CBR service models, distinguish between different ways in which CBR services are made available to people. One way of making CBR services available to people is to provide a particular service, therapy or assistive devices <u>for</u> people with disabilities. Kuipers et al distinguish 'providing' services from 'participating' in which the CBR worker works in a participatory way <u>with</u> the recipients of the service. It seems from the perceptions of the staff that the students in this study have been able to make the change from only 'providing' services to 'participating' in CBR with their clients and communities.

Staff member 1 describes both the actions and the personality traits of students that have enabled them to take on board this participatory way of engaging in CBR.

"You know he (Student E) is, in Zulu "*nobuntu*". He's got this thing of working together with people you know. He's not like he want to tell them, but he's willing to start something together with them and he's kind of a person who really want the people to own whatever that has been started."

Similarly, she describes the actions of Student F, as delivering CBR in a participatory way.

"But he met with people with disabilities, find out from them *ukuthi* how they could solve the problem. They came with different options. Then at the end they decided to do the march. That means he just didn't go to the community and feed them but instead he worked together with them."

Thompson (1998) characterises 'human service work' (which would include rehabilitation, social work and CBR) as having an intrinsic difficulty in terms of promoting equality – people in relative positions of power try to help or serve people in relatively powerless positions. The practice of CBR or rehabilitation in which service providers (including CRFs) do something <u>for</u> people with disabilities ties in with the service provider having power over the people they serve, through their ability to control resources and through their knowledge and skills. Townsend,

Zapata, Rowlands, Alberti & Mercado (1999, p. 31) mention a contrasting form of power, "power with" which they define as "the capacity to achieve with others what one could not achieve alone". According to the staff of CREATE, it appears that the students who participated in this action research were beginning to shift in their practice from having power over the people with disabilities they were working with, to rather having power with people with disabilities.

In order to try and understand this shift in the way students on the CBR course related to and worked with people with disabilities, I engaged with the students in a PRA task to chart their own change in attitude towards people with disabilities. The students used timelines to record the attitudes they had towards people with disabilities at different phases of their lives (see Appendix 4 for example of a timeline). Several students recorded their fear and negative attitudes towards people with disabilities when they were children and teenagers. Some were exposed to various myths about people with disabilities. For example:

> "When I first saw an albino child. We were in the same class. No one wanted to sit near her. There was that thing we were told that albinos are not real people. Even if they die, they don't go to heaven. They have their own land. Are not buried." Student D

All the students recorded in their timelines that their attitudes about disability changed and improved once they came to study CBR at CREATE.

> "Since from 2004 all people that came to teach me about people with disabilities and all what I learnt from CREATE has changed my attitude and now I have positive attitude about people with disabilities"
> Student A

> "I met Musa Zulu, Sipho Mdletshe (disability activists) and many others then I started to see that people with disabilities are also playing a role within the S.A. (South African) community." Student E

> "(Staff member 1) likes to make jokes about people with disabilities or about herself as a disabled person and that has changed the way I used to feel about people with disabilities. That makes me realised that people

with disabilities do not feel ashamed of themselves, therefore I do not need to…… Meeting people with disabilities as clients /colleagues / trainers helped to relate to them without thinking that there is difference between us."   Student C

Although the student with a disability in the class, Student B, did not start off with the same negative attitudes towards disability, her early experiences were ones of discrimination and disempowerment. In her timeline, she records how it helped her to see that people at CREATE treated people with disabilities the same as everyone else. In addition, Student B wrote about the impact that one invited trainer who is a disability activist, had on her: "Mr (Musa) Zulu make me proud of myself and give me more (desire) to work with people with disability and change the bad attitude to (in) my community."

As seen through the data from the students' timelines, it seems that meeting people with disabilities during the CBR course and learning from them was an important factor in enabling the students to work with, rather than for, people with disabilities. Perhaps meeting and developing a relationship with people with disabilities on a more even footing than simply meeting people with disabilities as clients has helped CBR students to begin relating equally and not in a dominant-subordinate way with people with disabilities. This coincides with the perspective of one of the members of staff who indicated that the key change that was implemented in the CBR course was the involvement of people with disabilities teaching on the course. Although CREATE previously did ask people with disabilities to facilitate sessions in the CBR course, during the period of this study more people with disabilities than previously were involved in the course. As staff member 1 indicates:

"To see a person with disability teaching. That alone, it change your attitude……. It's kind of we are practising what we are preaching, you know. Once they (the students) go out to the community they actually implement what they actually see in the class and what was actually happening. ..…..like if you are doing social model, social model has been done (taught) by disabled people themselves. So that alone, it really helped the students and also changed their attitude."

By having people with disabilities as facilitators on the course, the power differential between those who are learning to be service providers and people with disabilities shifts. In this context the people with disabilities whom the students meet are no longer 'relatively powerless' consumers of a service. The facilitators with disabilities who taught the students are empowered people who, according to the description of Townsend et al (1999), have 'power from within'. According to Townsend et al (1999, p. 30):

> " 'Power from within' arises from a recognition that one is not helpless, nor the source of all one's own problems, that one is restricted in part by structures outside oneself."

Although descriptions of curriculum do not usually include who does the teaching as a category of analysis, in this study it has emerged that the particular facilitators or teachers have had an important impact on the learning of the students. It is unlikely that by having only able-bodied teachers or facilitators we would have been able to achieve the same changes in attitude and practice of CRFs that we have observed in this study.

Through analysing documents relating to the CBR course, such as module timetables and the database of course facilitators, I was able to determine the relative amount of time that able-bodied facilitators and those with disabilities spent teaching on the CBR course (see Figure 5.1). Of the total time spent teaching (as opposed to supervising students' practical work), 20% of the time students were taught by facilitators with disabilities, while 79% of the time able-bodied facilitators were used. Parents of children with disabilities only taught for 1% of the CBR course duration. Although the students were taught by people with disabilities for a relatively small percentage of the course, as shown above, their exposure to these facilitators seems to have been beneficial, both in terms of the content they were taught and that they met empowered people with disabilities.
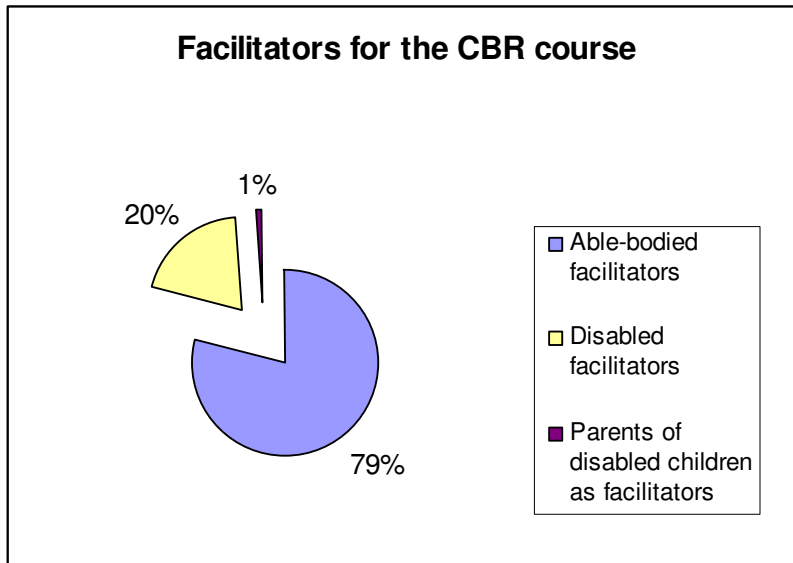
Figure 5.1: Amount of time different facilitators spent teaching on the CBR course

There are however, some difficulties in extending the use of facilitators with disabilities in the CBR course. CREATE has not been able to find people with disabilities with the requisite knowledge and skills and at a suitable cost, to teach in different modules of the CBR course. Ideally CREATE would benefit from employing another person with a disability who can teach in the CBR course. Towards the beginning of this action research cycle CREATE did employ a second person with a disability and this contributed to the increased amount of time that students were taught by a person with a disability. The issue is not only the amount of time that people with disabilities teach, the quality of teaching and interaction with students is also crucial. Perhaps this points to an activity for a future cycle of action research - developing the skills of people with disabilities to facilitate participatory adult education sessions.

5.3   Beginning to Understand the Complexities of Empowerment

According to Chambers (1997), empowerment is a complex process that is interactive and involves changes in power relations and behaviour. With the changes that were implemented in the CBR course the students in this study were made more consciously aware of the need for the empowerment of people with disabilities than

were other groups of students who have been through the course. From the interviews with staff, the timelines drawn up by the students and the observation of their practical work, it is apparent that for at least four of the students, the change in power relations between able-bodied students and people with disabilities has begun. That people with disabilities are working together with students (in other words, participating in decision-making and other processes) in CBR, illustrates what Pettersen and Solbakken (1998) refer to as one of the three aspects of empowerment, namely participation, with the other two aspects of empowerment being conscientisation and solidarity.

I engaged with the students in another PRA exercise, matrix ranking, to understand their perspectives on the empowerment of people with disabilities. Pretty et al (1995) describe a matrix ranking or scoring exercise as being a particularly useful method of exploring participants' perspectives and understanding their criteria and choices in judging the chosen topic. During this exercise, the students drew up a list of topics which they had learnt about in the CBR course and which they felt were most helpful in enabling them to facilitate the empowerment of people with disabilities. Out of all the topics covered in the entire CBR course, the students selected the following topics that they felt were most important in the empowerment of people with disabilities:

* disability awareness
* counselling
* removal of barriers in the community
* individual assessment of the needs of people with disabilities
* finding an appropriate job for a person with a disability
* rehabilitation for independence
* awareness of rights
* access to inclusive education
* advocacy
* conflict resolution
* business management
* integrating people with disabilities into the community and
* leadership skills for people with disabilities.

This list of topics was placed along the X-axis of the matrix.

The Y-axis of the matrix listed different methods of teaching and learning that were used to present these topics during the CBR course. Through a process of consensus, the students then ranked the different methods of teaching according to their usefulness in learning about the topics related to empowerment. (See Figure 5.2 for the completed matrix). Each topic mentioned in the above list was ranked separately per teaching method. The scale used for ranking ranged from 1 as least useful method of learning to 5 as most useful method of learning. According to Pretty et al (1995), the final scores in the matrix ranking or scoring exercise are not more important than the process of discussion and the debate that occurs when creating the matrix.

MATRIX DONE BY SECOND YEAR CBR STUDENTS - MAY 2005

	Disability Awareness	Counselling	Removal of barriers	Individual assessment of needs	Find appropriate job for PWD	Rehabilitation for independence	Awareness of rights
Practicals	3	1	2	5	1	5	3
Role plays	2	5	4	1	3	5	1
Discussion	3	1	2	2	4	2	3
Self study	1	1	1	1	1	1	1
Assign-ments	3	3	3	3	3	3	3
Brain-storm	2	2	3	2	3	2	
Presenta-tion	3	2	2	2	3	3	4

	Access to inclusive education	Advocacy	Conflict resolution	Business management	Integrating PWD into the community	Leadership skills for PWD	
Practicals	3	4	3	2	2	1	
Role plays	2	1	5	1	2	1	
Discussion	3	2	4	2	4	4	
Self study	1	1	1	1	1	1	
Assign-ments	3	3	3	3	3	3	
Brain-storm	2	2	3	2	2	2	
Presenta-tion	2	3	2	4	2	2	

1 = least useful method of learning   5 = most useful method of learning

Figure 5.2:   PRA Matrix concerning learning to facilitate the empowerment of people with disabilities

In his book 'Disability, Liberation and Development' which was based on hundreds of interviews with people with disabilities, Coleridge (1993, p. 51) takes the view that the empowerment of people with disabilities to take action for themselves is a necessity because:

> "No matter how much power they have, the professionals will never be able to see to the individual needs of all disabled people, at least not in developing countries."

A number of the topics selected by the students as contributing to the empowerment of people with disabilities (the X axis of the matrix) reflect the ideas of Coleridge. For example, the students identified the awareness of rights and disability awareness as two important topics related to the empowerment of people with disabilities. Coleridge mentions that through the raising of awareness in society, people with disabilities begin to feel a sense of empowerment and at least in part awareness can be raised through advocacy, which was also listed by the students. The raising of awareness, particularly amongst people with disabilities of their own rights, could be seen to constitute part of conscientisation which is an important aspect of empowerment according to Pettersen and Solbakken (1998). Coleridge also writes about the need for a spread of leadership skills amongst members of disability movements and the fact that there may be conflicts (and hence the need for conflict resolution) within disability movements. Two other factors contributing to the empowerment of people with disabilities, according to both Coleridge and the CBR students, are the removal of barriers in society and the integration of people with disabilities into their communities.

However, Coleridge (1993) raises one key issue that the CBR students have omitted that of the formation of a disability movement or grouping. The formation of a disability movement can be a result of the conscientisation of people with disabilities. In her cycle of liberation, Harro (2000) also mentions that people coming together and working together is an essential step towards attaining liberation. Crawley (1998, p. 29) states more emphatically the necessity for people to work together as a precondition of empowerment, when she writes:

"Empowerment only occurs when the disempowered become able to take *collective* [own emphasis] social action to alleviate particular socio-economic and political conditions, and claim power."

That the students on the CBR course do not see group formation and collective conscientisation as a key part of the empowerment of people with disabilities shows a real gap in their understanding and it points to an area for further change and development in the CBR course.

The students' mention of topics such as counselling, rehabilitation for independence and assessment of individual needs fall into the traditional scope of rehabilitation professionals whose practice has often not been empowering of people with disabilities. A shortcoming of this research is that I did not probe the students for their reasons for selecting these particular topics for their PRA matrix. The students' experiences during their practical blocks with people with disabilities in their disadvantaged communities helped them to decide on the importance of including topics related to economic empowerment and access to appropriate education in the matrix.

The second part of the matrix exercise was to rank the teaching methodologies used during the CBR course in relation to the content linked to the empowerment of people with disabilities. The students considered that presentations or lectures given by course facilitators were the most useful method of teaching for only two of the thirteen topics, awareness of rights and business management. For all the rest of the topics, the students preferred more participatory and/or experiential learning activities. The use of role plays was seen as being most helpful when they learnt about counselling, removal of barriers, rehabilitation for independence and conflict resolution. The students appreciated discussions when learning about finding jobs for people with disabilities, conflict resolution, leadership skills and integrating people with disabilities into the community. Practicals were considered particularly valuable in learning about assessment of needs, rehabilitation for independence and advocacy.

In order to get the personal change that is required in the attitude and mindset of professionals so that poor and marginalised people (such as people with disabilities)

can be empowered, Chambers (1997) advocates for the use of experiential and participatory methods in the training of professionals. CREATE is also concerned with changing CBR personnel and has certainly tried to incorporate various participatory and experiential teaching methodologies into the CBR course. As the students indicated in their matrix, these methods are appreciated and may have contributed to the change in attitude towards people with disabilities that was discussed in the previous section of this chapter.

According to Chambers (1997) another aspect of changing professionals and enabling them to empower the weak is that in their training they need to reflect on the realities of others and go into the field with people (with disabilities). The CBR course achieved this through including practical work that students did in their home communities as part of the course. During these practical blocks, students came into contact with a number of people with disabilities and they reflected on their realities. One staff member indicated that the workbooks we provided to guide the students doing their practical work changed and improved during this study, particularly in relation to the empowerment of people with disabilities.

> "And I would also say you know, even the way we designed the timetable
> and the workbook, it's not therapy any more. It's really community……
> it is also stressing that you know once they have started something, the
> community members or the people with disabilities themselves, they must
> own and run that project."   Staff member 1

Similarly, staff member 2 commented on the community work aspects of the tasks explained to students in their workbooks.

> "I know what's really helpful is looking at not just individual client work
> but also focusing on the other types of tasks that they need to do within
> their community…… I think just having that component of group work
> and community tasks, like the networking meetings or the support groups
> or we've had tasks where they've had to try and address barriers in their
> community. Ja, I think it's good to balance those two components."

From the different sources of data, both from students and staff, it appears that the students have obtained the basis of an understanding of empowerment through the CBR course curriculum. Participatory and experiential teaching methodologies as

well as course requirements stipulated in the practical workbooks and having people with disabilities as course facilitators seem to be the enabling factors in the curriculum in terms of learning about empowerment.

5.4 Implementing CBR Through the Lens of the Social Model of Disability

According to one of the staff members of CREATE, the CBR course gives the students the skills to implement CBR from a social model perspective, including addressing barriers that affect people with disabilities. In interviews with the students participating in this research, they demonstrated a greater orientation towards the social model of disability and working for change at the structural level that was different to the CRFs who were interviewed in the first phase of this action research. As staff member 3 put it:

> "you can see the previous people are more focused on trying to meet basic needs and assistive devices etc., whereas the groups (of students) now tend to be focused more on removing attitude and physical barriers in communities."

5.4.1 Students' perceptions of using the social model as a framework for CBR practice

Towards the end of the CBR course in this action research cycle, I discussed with the students how they had managed to do their practical work within a social model framework, particularly using the concept of barriers in society. In order for me to understand their perceptions and to encourage ownership of the information generated, I used a PRA technique called a Venn diagram together with the students to chart the difficulties that they experienced with implementing CBR within a social model framework. Pretty et al (1995) recommend visualisations and diagramming in PRA (such as a Venn diagram exercise) as a method of generating local (in this case, students') analysis and ownership of information, rather than using verbal methods, such as interviews, which extract information. The process of creating a Venn diagram involved brainstorming the key factors affecting the students'

implementation of CBR within the social model and then prioritising these factors and assessing the relationships between the different issues. (See Figure 5.3).
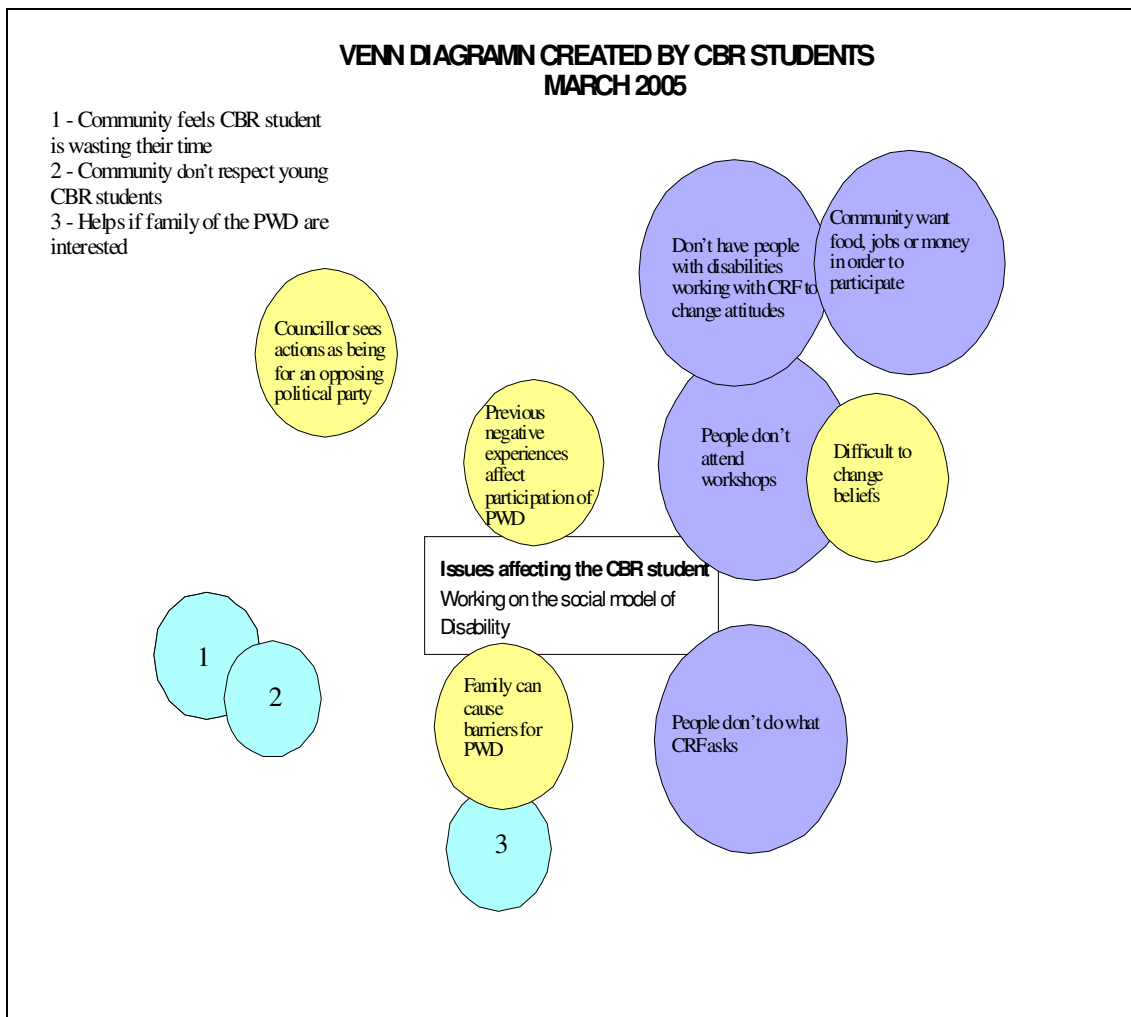
Figure 5.3: Venn diagramn done by CBR students

The four issues that the students identified as having the biggest impact on their work were that many people from the community do not attend the workshops that the students run; community members want food, jobs or money in order to participate in CBR; people do not do what the CBR student requests and the students do not always have people with disabilities working with them to help change people's attitudes. The issue of community members wanting tangible benefits such as food, money and jobs in order to participate in CBR is an illustration of the dire poverty that exists in some of the communities that students work in. As the ILO, UNESCO and WHO (1994) define CBR, community based rehabilitation should be a strategy that is part of

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community development that targets poverty and under-development in the broader community (not only people with disabilities). The 2004 Joint Position Paper on CBR (ILO, UNESCO and WHO, 2004) goes further to state that, with its emphasis on equal opportunities in education and work for people with disabilities, CBR should be considered as a poverty reduction strategy within community development. Perhaps if the students situated their efforts in CBR within community development initiatives that were happening in their areas, community members would understand how CBR along with other development initiatives would attempt to address their needs. It is also possible that little development is happening in these areas and that the CBR projects may be the first sign of development, particularly that includes people with disabilities. This latter interpretation appears to tie in with another issue identified by students as affecting the implementation of CBR projects – that the political councillor of the area sees the actions of the students as being linked to an opposing political party. Several of the students experienced the suspicion of councillors who felt that the students were involved in development-related tasks in their communities in order to show up the lack of service delivery by the councillor and his party. Student F had a particularly antagonistic relationship with the councillor in his area, which highlighted issues of how students deal with people in formal positions of power.

The issue identified in the Venn diagram, of students not working with people with disabilities to change the attitudes of others could be indicative of some students still working for rather than with people with disabilities. It may also indicate that students have a narrow and linear view on how attitudes change and that they feel they can do it themselves, while in fact attitude change is a complex issue. That students prioritised the issue of people not doing what the student requests, may also indicate that there is some degree of misunderstanding by the students about the way they should be working with community members. As Chambers (1997) suggests, people working in development should learn to listen to community members and other marginalised people, and maintain only the minimum of control, in order to empower the people with whom they are working. The fact that students perceived people not doing what they request as a large problem also seems to contradict the perception of the staff that the students are working with people with disabilities rather than for them. In future research this would be an area to explore further,

particularly to examine whether people with disabilities feel the CRFs are working with or for them.

The students identified some other issues that hindered their ability to work within a social model framework - the difficulty in changing beliefs and the influence that previous negative experiences have had on the participation of people with disabilities in current projects. For example, in one community there was previously a project for people with disabilities where money was misspent and this created a sense of unwillingness to participate in the current project. This highlights the importance of people with disabilities being able to trust the CRF and vice versa. Other issues that hampered students were: families creating barriers for people with disabilities and in one situation, the community did not respect a CBR student because of his age. These issues illustrate the very real difficulties experienced in community work. It would be difficult to design a CBR curriculum that would address all these issues as some are specific to particular communities and students. However, the selection of these issues by the students shows that more emphasis could be placed on teaching students problem-solving skills. The data from the Venn diagram can also contribute to the design of an improved CBR curriculum (in a future action research cycle) through pointing towards the need for sessions on dealing with people in positions of power, a greater emphasis on the links between CBR and development and paying more attention to discussing how to change people's beliefs. Another way in which the course could be improved would be to provide the students with skills to examine their political, social and cultural context and how it impacts on their work.

In addition to the issues that were prioritised by the students in the Venn diagram exercise, one of my colleagues, staff member 3, identified a further hindrance to the students' practice of CBR in a way that takes into account the social model of disability:

> "we really give the students the skills, you know, what they need to face these issues and look at barriers in their own community but I think the issue that stands out to me the most is the issue that what support do they get in their own communities to be able to do this. Because often students go out on their practical block with good intentions of going to look at barriers and then they take it maybe to their supervisor who then

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turns round and says, 'well, what's that got to do with me?' And then basically their enthusiasm is curbed and ja they don't do anything about it, which then makes them question why do we need to change barriers if they've got no support systems to help them do this."

This same staff member then went on to suggest that the CBR course could address this difficulty through CREATE staff spending time individually with each student's supervisor to orientate her / him better towards the social model of disability.

The factors that were identified as hindering the implementation of CBR within a social model framework by both students and staff illustrate that it would be simplistic simply to judge this research and particularly the changes implemented in the curriculum by just observing the output of the students. Whether change is produced in the practice of the students is dependent on far more than just changes that are made to the content, teaching methodology or even who teaches. Students need guidance and encouragement from their community and/or supervisor, as well as problem-solving skills, the capacity to interrogate their context and possibly some practical support in difficult situations, such as working with people in positions of power. The students' positive or negative experiences in doing practical work as students may well affect their willingness to work within a framework that challenges the traditional medical model approach to rehabilitation.

5.4.2 Understanding the links between the social model and the oppression of people with disabilities

During the interviews, the CBR students were not asked specifically to elucidate their understanding of disability or of the social model of disability. However through their explanations of the oppression of people with disabilities it became clear that most of the students made a direct link between understanding disability as a process of social exclusion through the presence of barriers to participation [the social model (Barton, 1994)] and oppression.

Student C saw a causal relationship between attitudinal barriers created by able-bodied people and the oppression of people with disabilities:

"I think most of the time the problems [oppression] that people with disabilities face are problems that are caused by the attitude of the able-

bodied people….. What I'm trying to say is that their problems are something that we [able-bodied people] cause. We are the cause of the problems."

Student B had a similar point of view in her response to a question on the links between the social model of disability and oppression. She described a situation in which the negative attitudes of an adult education facilitator were the cause of the marginalisation of a deaf woman.

Student F used the social model concept of barriers to participation to explain the oppression (specifically marginalisation) of people with disabilities in his community. Physical barriers such as steps and communication barriers such as a lack of sign language interpreters at community meetings have reportedly worked to marginalise people with disabilities in his community. When asked to relate an incident illustrating the oppression of people with disabilities, Student A also recounted a number of situations in which physical and attitudinal barriers were responsible for the marginalisation and/or exploitation of people with disabilities:

"If we are talking about oppression of disabled people it is … like the taxi drivers who used to charge them double when they are using the wheelchairs. Ja, and it is also when it comes to those places that are not accessible to them [without] the ramps."

This student went on to describe a situation of cultural imperialism linked to communication barriers around HIV/AIDS education for people with sensory disabilities.

"when it comes to HIV education, it is like awareness campaigns. They do not reach the disabled because, I think it is because …. I have never seen even one poster that is used that is written in Braille for people who are unable to see. About HIV and AIDS, I have never seen one. Also if you are talking about awareness campaigns, I have never even seen one for people who are using sign language. So I think there is more oppression."

The CBR students in this study who participated in the action research and experienced the changes in the CBR course curriculum were clearly more aware of the implications of the social model of disability and its links with oppression than

CRFs who completed the CBR course prior to the changes. In the interviews conducted with the CRFs at the beginning of the study, only two of the six were able to discuss briefly the nature of oppression experienced by people with disabilities. Neither of them related their insights to the social model of disability and they were only able to give examples of the marginalisation of people with disabilities.

5.5 Students' Growing Awareness of the Oppression of People with Disabilities

The data on CBR students' understanding of the oppression of people with disabilities was gathered through interviews with the students towards the end of the CBR course. This data has been triangulated with data gathered from two focus group discussions that were held with people with disabilities who live in areas where two of the CBR students had been working (see Appendix 5 for the focus group schedule). Although the people with disabilities and parents of children with disabilities involved in the two focus groups were not formally trained regarding oppression, I was interested in triangulating their reports of their own experiences of oppression with the perceptions of the students. I have applied Young's (1990) "five faces of oppression" and Thompson's (1998) description of oppression occurring at the personal, cultural and structural levels to the data in order to situate the students' understanding within a theoretical framework.

5.5.1 Using the "Five Faces of Oppression" to describe the situation of people with disabilities

Young (1990) proposes that oppression refers to a group of related conditions and concepts which she terms the "five faces of oppression" – exploitation, marginalisation, powerlessness, cultural imperialism and violence. In their explanations of oppression, the students identified all five faces of oppression through practical examples from experiences in their own lives and in the lives of people with disabilities with whom they have worked in their communities. The most commonly mentioned faces of oppression in relation to people with disabilities were exploitation and marginalisation. Although the teaching on oppression that was included in the CBR course only involved the students, parents of children with disabilities and

people with disabilities were asked about their own understandings and experiences of oppression in the focus group discussions. In the focus group discussions, the parents and people with disabilities most frequently mentioned marginalisation as the way in which they experience oppression.

5.5.1.1 Exploitation. When asked about the meaning of oppression, Student A immediately related a personal experience of oppression as a black and working class person which illustrated exploitation.

> "The term oppression. Let me put it [this way]. Let me make the example about when I was working with my uncle for the white man. So I can say that there was part of oppression there because the job that we were doing there, it was a very tough job. But when he was coming to pay, he was paying very, very small money. He was paying peanuts."

Student F also reported experiencing exploitation in the workplace.

Students A, C and E all related situations in which people with disabilities were exploited for their disability grants. As Student C explained:

> "But what really hurts me is that when the families of people with disabilities, they use these people as a source of income, because they bring the grant in the family. So for them, that's like a blessing in disguise for them because they've got this person to bring in the money…..Because these people, the families, only take care of these people on the pension day. From then they forget about them until another pension day. And they don't like use this money to help these people [with disabilities]. It's just their money."

Student E spoke of an equally serious situation in which family members of a woman with a disability worked together to steal her first social welfare grant payment of about R9 000. These examples of exploitation illustrate the complex nature of the oppression of people with disabilities and thus the difficulties that the CBR students face in trying to address the oppression of the people with disabilities they work with.

Young (1990, p. 49) writes of exploitation that "this oppression occurs through a steady process of the transfer of the results of the labor of one social group to benefit another." Although Young (1990) refers to exploitation occurring in relation to both

paid work and unpaid work e.g. domestic labour, her explanation does not take account of a situation such as that described by the CBR students, in which labour is not involved. In spite of this, I feel that the situation described by Student C can be classified as exploitation because benefits accruing to a member of the oppressed group (person with a disability) are being used and transferred to the oppressor group (able-bodied people) for the benefit of the oppressors. The mechanism of oppression is the same although in the case of a disability grant, no labour is involved. For this reason, I feel that Young's explanation of exploitation would benefit from broadening out to incorporate the use that the privileged group make of the benefits that accrue to members of the oppressed group, whether through social welfare provision, paid or unpaid labour or even simply associating with the oppressed group because of potential benefits.

5.5.1.2 Marginalisation. Thompson (1998) refers to marginalisation as the situation wherein oppressed people may be excluded from decision-making processes and the workings of power. Young (1990, p. 53) extends this definition to a situation where, "A whole category of people is expelled from useful participation in social life and thus potentially subjected to severe material deprivation and even extermination." Both Young and Thompson specifically mention people with disabilities as a group who experience marginalisation and findings from the CBR students' certainly bear this out. Student A reported an extreme version of marginalisation which, unfortunately, is not that uncommon in the areas where CRFs work. "If we are talking about oppression it is something that is when like normal people, like the families of those disabled people used to lock them in the houses".

Student B, who is disabled, found that the source of her marginalisation was not her family, but other able-bodied people in her environment – a nurse at the hospital and visitors to her home. As Student B recounts:

> "Sometimes my mother asked me to make tea for the visitors. The visitor, she said 'No, why are you asking this child because she is not able to do all things?' and she said it's not right."

The stereotype this visitor had of people with disabilities as not able to do anything useful, contributed to her attempting to marginalise Student B. According to Bishop

(2002) stereotypes are most often used in a damaging way against marginalised people.

A number of the participants in the focus group discussions, both people with disabilities and parents of children with disabilities, spoke of similar damaging stereotypes that community members have in relation to people with disabilities in their areas. One mother (S3, Focus group 2) lamented the views of people from her area concerning people with disabilities, including her child:

> "Our community is not educated. People with disabilities are not accepted at all, and that hurts us as parents because we love our children. But the way they are being treated, it is like they don't belong in this society, they belong to the zoo or a cage."

One person with a disability has had painful reminders of her own oppression resulting from negative attitudes that have marginalised her.

> "Like myself when I visit other people in their houses, I could see that I am not accepted. They even ask you "Can we help you?" as if you are lost or you are not the kind of person to visit them. And I realise I made a mistake by coming there, then I leave immediately."
>
> (S4, Focus group 2)

In the experience of the CBR students, marginalisation of disability did not only happen through community members who may have been relatively uninformed about the rights and potential of people with disabilities. Student D reported that in a forum where participants should have known better – a meeting on inclusive education with the Department of Education – disability issues were still marginalised.

> "At the [inclusive education] meeting that I went to, they have high things that they want to do for the school. Childline [call centre for victims of child abuse] is there, whatever is there, social workers and everything is there but if you come to disability, they don't talk about disability in schools….. They put it as a last resort, you know, they knew the disability team was the last resort."

Thompson (1998) makes special mention of speakers of minority languages experiencing marginalisation. This can be extended to those who use sign language

and in the field of disability, those who may not be able to speak any language very well. A number of the CBR students gave examples of people with communication disabilities being marginalised because of their difficulty in using the standard forms of language used in those communities. Student F spoke of his own brother being marginalised and refused an education because he was hearing impaired and could not speak clearly. Similarly Student B was aware of a deaf woman in her community who felt marginalised in her experience of adult education. Student E told the story of the oppression of one woman with a communication impairment in his community.

> "There's an old lady who's maybe forty to fifty, plus or minus fifty yes, who's suffering from a stroke. She can't talk. Ja, she's always kept inside the room. And the family is looking after her but the problem is that she can't tell everybody what she likes because she hasn't got speech …… So that lady, I saw her like a person who's still oppressed because she hasn't got the freedom of property, to own her money. There's someone to look after her. She's like no-one…… So as a person who is disabled, she can't say anything. She's always inside the room, sitting and sleeping."

In response to a question to identify the oppression of people with disabilities, one of the participants in the focus group discussions who is deaf, recounted her own marginalisation.

> "Before I know [the CBR student] it was quiet. People did not know me. Others did not want to communicate with me. They were not prepared to learn how to communicate with me. I was isolated, let alone getting a job."   (S5, Focus group 1)

The marginalisation of people who do not use the majority language happens not only at an individual or personal level but also at a structural level as Student F illustrates when talking about the participation of sign language users in community meetings.

> "If you take a loudspeaker and shout, they [deaf people] cannot hear that you have a meeting, you see. Which means they do not have rights to attend those meetings. Even in a meeting, they can go to a meeting but no interpreter there to accommodate them"

Society also marginalises people with disabilities through physical barriers that prevent people with disabilities from participating in the life of the community. Barnes and Mercer (2003, p. 64) mention a number of these exclusionary barriers which they claim are "deeply embedded in the structures and processes of contemporary societies." Student A gave a number of examples of such barriers and how they marginalise people with disabilities.

> "Also when it comes to the shops, like if you and me when we are shopping we are able to pay for what we are shopping there, but those guys in the wheelchairs, they are unable to go to the tills, the space is not enough."

One of the participants in the focus group discussions who has a disability concurred with this view of Student A, indicating that difficulties with access to public transport as a person with a mobility problem effectively marginalised her from participating in a useful social life.

5.5.1.3 Powerlessness. Power is the ability to control or influence people, events, processes and/or resources (Thompson, 1998). Barnes and Mercer (2003) describe powerlessness as a situation in which the oppressed person has little control over his or her life and s/he also has minimal choice concerning what to do with his/her life. In this study, the most strident voice on the powerlessness of people with disabilities was the student with a disability, Student B, who reported a number of her own experiences at the hands of able-bodied people. When Student B had applied to study nursing, she was interviewed along with other applicants. On seeing that Student B was disabled, the head of the nursing school summarily dismissed Student B without completing the interview. Student B was powerless to change the situation.

Similarly, one of the participants in the focus group discussions described his powerlessness to contribute to decision-making within a close personal relationship.

> "And the other thing, my girlfriend is not treating me like a normal person. She is taking decisions for me as if she is the only person with rights. We cannot share ideas. She is Miss Know-all."
>
> <div align="center">(S4, Focus group 1)</div>

This experience of disempowerment at the hands of someone close was particularly hurtful and troubling to this person with a disability.

Powerlessness is not only created by the intentional and negative use of power over someone or some group. As student B discovered, in some of her earliest recollections of being oppressed, powerlessness can also be the result of a person's well meant actions which are nevertheless very hurtful and disempowering.

Within human service-related fields of work (such as social work, nursing and CBR) there may be well-intentioned professionals providing a service who are nevertheless in positions of power relative to the clients or users of the service. This power stems from the service provider's knowledge and skills, his/her ability to control the allocation of resources and the professional discourse of which s/he is part (Thompson 1998). The professional may reinforce the powerlessness of the client without necessarily being aware of the effects of his/her well-intentioned actions. It may be precisely for this reason, that only one of the able-bodied students in the CBR class was able to relate powerlessness as a form of oppression experienced by people with disabilities.

The CBR students seem to be largely unaware of the effect of their power relative to the people with disabilities with whom they work. Clearly this is a crucial issue which needs to be addressed with the CBR students if the service they provide is supposed to empower people with disabilities. The issue of power, particularly in relation to the position of CRFs in their work, was not sufficiently dealt with during the implementation phase of this study and it is possible that this has contributed to the lack of ability of the CBR students to identify powerlessness as a form of oppression experienced by people with disabilities.

Student E, who did identify his client as experiencing powerlessness, explained this in relation to the client's difficulty with using language. As mentioned previously, Thompson (1998) indicates a number of ways in which language is linked to power, including the ability of powerful people (in this case, able-bodied family members) to use language to put forward their construction of the world in a way that protects their own power. In the case of Student E's client, the family portrayed themselves as her carers, while at the same time planning to defraud her of her disability grant. Because of the client's language problem, she was powerless to challenge her family members.

This example of powerlessness cannot be linked to a class analysis, which Young (1990) uses to describe this face of oppression. Similarly the powerlessness of a child in the face of oppressive behaviour from adults (as Student B described her own experiences) also cannot purely be explained using a class analysis. The concept of powerlessness may have applicability to any situation where there is a hierarchy of power, whether it concerns gender, language, class, race etc.

5.5.1.4 Cultural imperialism and violence – the remaining faces of oppression. Cultural imperialism refers to the form of oppression in which the experiences and understandings of the dominant group become the norm against which members of subordinate groups are judged. This process is similar to that termed by Thompson (1998) as invisibilization – where the dominant group is represented in the media and in language and imagery, but the oppressed group is rarely seen or becomes 'invisible'.

A number of the CBR students referred to experiences that people with disabilities have of oppression which may be classified as cultural imperialism. Student D related the experiences of a deaf woman who received the wrong medication at the hospital because the doctor was not able to use sign language nor did he find and use a sign language interpreter. Spoken language is the norm and the hospital was unable to adapt to the needs of a person who does not fit this norm. In Student B's community, another deaf woman similarly experienced the cultural imperialism of hearing people when she was attempting to go to adult literacy classes. The literacy facilitator taught in a way that suited the hearing norm, but was unable or unwilling to adapt to the deaf person by facing the learners and speaking slowly and loudly.

Violence is the last of the five faces of oppression mentioned by Young (1990). None of the students mentioned violence with regard to the oppression of people with disabilities although one student had had personal experience of the violence of oppression while working on a farm. According to Barnes and Mercer (2003) violence against people with disabilities is, in fact, widespread and may take the form of physical or sexual attacks, verbal abuse or eugenic policies (abortion of foetuses that have disabilities). It is therefore important in future research to investigate the

understanding that CRFs have of violence against people with disabilities. It would also be beneficial to understand this "silence" amongst the CRFs on violence as a form of oppression of people with disabilities, particularly because the sexual abuse of people with disabilities in South Africa is documented in newspapers and other accessible forms of media.

5.5.2 Oppression at the personal, cultural and structural levels

As mentioned previously, Thompson (1998) describes oppression as operating at three distinct but interrelated levels – personal, cultural and structural levels. The personal level of discrimination and oppression is when the thoughts, feelings and actions of an individual, including his/her prejudices, work to oppress other people. Discrimination at this level is unable to explain all instances of oppression and the individual has to be considered in the context of her/his culture and the structure of society. As Thompson (1998) explains, a culture often creates boundaries around the group, leading to an 'us and them' situation in which the marginalisation of others occurs. The cultural level operates within the social, economic and political aspects of the social order – the structural level.

The group of students involved in this study were able to identify oppression operating at all three levels mentioned by Thompson (1998). Student B experienced oppression at a personal level when, as a child in Standard 1 at primary school, she was told to leave the local mainstream school by her teacher because she was disabled. Student C's account of the exploitation of a woman with a disability for her grant could also be considered as oppression at the personal level. It occurs due to the exploitative actions of her family members, rather than at a broader level. S4 from Focus group 1 also experienced oppression and powerlessness at the personal level, when his girlfriend made decisions for him.

Student E is clear that there is oppression of people with disabilities at a cultural level in his community:

> "People they believe that people become disabled because of certain things, like they are being witched and they are maybe, it's a gift from God. I think those are two that people believe. So like to oppress people with disabilities, they just think they are useless. So they [people

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with disabilities] are people who were to be left behind. I don't know what is happening in terms of churches and schools but within their families, I've seen that the parents are become shy to take them out and seen by other people, like people will laugh at us if we have got such children."

Through this quotation it is clear that Student E sees the oppressive actions of family members as occurring within the broader context of cultural beliefs and practices. Student A was concerned with the inappropriate and hurtful names that people in his culture use to refer to people with disabilities as well as being concerned about various myths around HIV/AIDS and people with disabilities. This awareness of the oppression of people with disabilities happening at a cultural level is borne out by participants in focus group 2, most of whom described people from their community seeing children with disabilities as 'monsters' or similar to animals.

"The other thing is, when you go to the doctor they want you to stand in the queue, whereas our kids are scared of many people and people are looking at you as if they are seeing animals from the zoo. They can even say 'Shame'." (S1, Focus group 2)

These cultural manifestations of discrimination and oppression operate within the societal or structural level in which there are systemic inequalities. Both Student F and Student D mention systematic and structural level oppression as occurring within the education system. "I can say the thing that worries me a bit is the school and disabled people. I do not know why these schools do not want to take disabled people" (Student F). Only one of the participants in one of the focus groups identified with being oppressed at a structural level – the lack of access to schooling for people with disabilities. It is possible that because of the medical model of disability which prevails in the communities where the CBR students work, disability is seen as an individualised, personal tragedy, which deflects attention from the way in which the social, political and economic order conspires against people with disabilities. Thus local people with disabilities have not had the tools to analyse their own oppression as occurring within the 'structural' level.

5.6 Community Based Rehabilitation Students and Social Action

In this study, during the action and observation phases of the action research cycle, I found that most of the CBR students in this study engaged in some forms of social action in response to their understanding of the oppression of people with disabilities at a structural level. The following description and analysis is based on data that was gathered through observation, analysis of written documents and interviews.

I have used the definition of social action that it is "action directed toward social change" (Wade, 2001, p. 25). Frequently, although not always, this is collective action and it could involve a range of types of action, including activities such as participating in a rally or march, campaigning for a change in policies or laws, boycotting goods or services or writing a letter to a local councillor (Roker, Player & Coleman, 1999).

In order to understand the place of social action within the totality of the students' experiences and activities during the CBR course, it is necessary to understand the course structure. The CBR course is structured with alternating blocks of learning theory in Pietermaritzburg and practical work that the students complete in their home communities. Not only do the students implement skills that they have learnt during practical blocks, but at the beginning of the following theory block the students are assisted to reflect on their practical work. This creates cycles of praxis, which Freire (1972) claims are a vital part of educating people for liberation.

Students are set particular tasks that need to be completed during each practical block. Although a workbook sets out guidelines for the tasks, the specifics are up to each student. For example the workbook may set a task such as, "*Together with people with disabilities in your area look at the barriers that people with disabilities face concerning access to public buildings, transport and other facilities. Then plan a strategy to make community leaders and/or other key people (e.g. shopkeepers, priests or taxi drivers) aware of the need to make places, transport and meetings accessible to disabled people.*" and it is then up to each student to determine in his/ her own community which barriers to work on. In addition, students are encouraged to undertake any other activities relating to

disability and CBR that they can fit in within the practical period. The activities described and analysed below are the students' responses to some of the tasks set for them to do during the practical blocks of the course in 2004 and 2005.

5.6.1   Working with community members – Forming a CBR committee
One of the tasks set for each CBR student was to try to set up a CBR committee in his/her community to whom the student would be accountable for his/her work. Although CREATE did not stipulate who the members of the CBR committee should be, it was expected that people with disabilities as well as people with some interest in disability issues and/or community leaders should be involved. The roles of the CBR committee were also not entirely laid down by CREATE. Students were expected to negotiate the role of the committee with its members. However, it was envisaged that the committee would play a role in monitoring the CBR activities in their community, as well as guiding the student in his/her CBR work. The CBR Joint Position Paper of the ILO, UNESCO and WHO (2004) describes the role of a CBR committee as raising awareness of the needs of people with disabilities, working with different sectors to co-ordinate the services they provide and working in the community to promote inclusion. Due to difficulties such as lack of support from community leaders, not all students were able to get a CBR committee off the ground by the end of their studies. One of the youngest students found it difficult to gain credibility and support from older community members, such as *izinduna* (traditional leaders below the level of chief), because of his age. From analysis of students' written reports about their practical blocks, it also appears that some students put more effort into activities with more tangible results, such as teaching a blind person to recognise money.

However, one student from a rural area was able to stimulate the formation of a CBR committee which includes the chief, *induna* and local councillor as key participants, through his advocacy on behalf of people with disabilities. Given that such community leaders are usually busy with a multitude of tasks and that people with disabilities are a marginalised grouping, it is impressive that the student managed to get all 3 leaders to participate in the committee. This CBR committee has undertaken some of its own CBR activities, such as raising awareness of disability rights, as well as monitoring the student's work through requiring regular reports from the student.

Another student initiated the formation of a CBR committee that is chaired and run by people with disabilities in his area. This committee requested the CBR student to participate with them in several advocacy events for disability. According to the classification of Kuipers et al (2003), forming and working with a CBR committee could be seen as participating at a community level. They describe this as working alongside the community and being involved in community decision-making and problem-solving around disability issues. As Kuipers et al (2003, p. 139) explain, "A goal of this approach might be to build greater community solidarity on disability issues." Although the formation of a CBR committee may not be seen as social action in itself, these committees are often used as vehicles for social action.

In one urban community, the CBR student together with the CBR committee organised a march of people with disabilities to demand that the city council address the barriers to inclusion faced by these people in their community. The demands included the need for sign language interpreters at community services such as the police station and the need for street lighting to prevent further disabilities from occurring through accidents on the steep paths and roads at night. (See Appendix 6 for memorandum). Although the city councillor did not come to receive the memorandum, the march was successful in making community members aware of the ways in which people with disabilities are excluded or marginalised. The memorandum was later delivered to the municipality. Clearly, this is an example of action aimed at social change, or as Kuipers et al (2003) describe this kind of activity, advocating at a structural level:

> "Advocacy can be defined as arguing in favour of, or working for a cause, idea or policy, such as to improve the rights and role of people with disabilities or engaging in activities such as lobbying for access or services." (Kuipers et al 2003, p. 134).

One of the tensions that the student mentioned above, experienced, was how to deal with people in positions of power. This student (Student F) is quite assertive and in his early dealings with the city councillor, it appears that the student alienated the councillor and caused him to respond antagonistically to both the student and later the CBR committee. According to the reports and documents reviewed during the research, it seems that the city councillor felt threatened by the student. The student's

perception was that the councillor felt his own lack of action on behalf of people with disabilities in his community would be shown up by the student and CBR committee and that he might lose support within his community. Although I responded to the student's difficulties in dealing with the councillor by adding one session to the course on dealing with people in positions of power, a shortcoming of the CBR course is that students were not given sufficient skills to work with people in formal positions of power. This shortcoming affected Student F in an ongoing manner in that throughout his time as a CBR student he was refused permission by the councillor to use the community hall as a venue for workshops and other meetings about disability issues. Foley (1999, p. 21) however points out that through involvement in action one can learn, "how people who hold power think, behave and can be influenced." Therefore it could have been particularly useful to the students if I had reviewed with them Student F's experiences of working with the councillor and then we could have planned remedial action (bringing praxis into the classroom).

5.6.2   *Overcoming barriers through social action*

Another example of the CBR students advocating at the structural level was when two of them addressed the issue of physical accessibility at the hospital that employs them. The students spoke to senior management about accessibility of the personnel and administration departments (up stairs with no lift) of the hospital for people using wheelchairs and who have other mobility impairments. The students were then asked to draft a disability policy for the hospital which was distributed for comments and tabled at a management meeting. Subsequent to the students' advocacy for physical accessibility, the human resources department of the hospital has moved to a downstairs office so that it is accessible to all people. With a similar aim in mind to the above action, one student approached the management of an old age home in her community to make the corridors between buildings accessible for people in wheelchairs and later she also approached the local taxi association to request them to stop the practice of charging double for wheelchair users. In these examples of social action it is possible to see the influence of the social model of disability on the actions the students undertook. The students' choice of action was guided by the identification of and need to overcome barriers that people with disabilities experience in those areas.

In the above-mentioned examples, the students managed to work successfully with people in positions of power – the management of the hospital and old age home and the taxi owners. Perhaps the situation of elected councillors is different because they are only assured of a position of power for a 5 year period and to extend this, they have to be re-elected based on the will of people in their community. Because of the relative insecurity of their position, this may make councillors more sensitive to people taking initiative in developments in their community, which the councillor perceives as his/her own prerogative. Based on the experiences of Student F it will be particularly important to gear future mid-level rehabilitation students to work with elected officials.

5.6.3   Advocating for the rights of people with disabilities

During the CBR course students also engaged in other forms of social action. A couple of students had letters and articles concerning the oppression and rights of people with disabilities published in newspapers (see Appendix 7). The students painted a banner which they displayed at a celebration of International Day of Disabled People to make the community aware of the rights and abilities of people with disabilities. According to the categorisation of CBR services by Kuipers et al (2003), these activities could be seen as advocating at the level of attitudes and beliefs - advocating through the media and social leadership for changes in attitudes, roles and social beliefs concerning disability.

Kuipers et al (2003) describe CBR service delivery that is classified as participating at a structural level as service in which, "The CBR worker works with the community to influence the formal structures that impact on people with disabilities." (p. 140). This description is apt for the work that one student has done regarding inclusive education. This student initiated the formation of an inclusive education committee that includes a staff representative of each of the local primary schools, school health nurses, community health workers and parents of children with disabilities. The aim of the committee is to assist with the implementation of the government's Education White Paper 6 in the area and to advocate for the right of children with disabilities to receive an education. This committee has pre-empted the efforts of the Department of Education but through the CBR student, they have built links with the local district office of the Department of Education.

5.6.4   Students' achievements and challenges in undertaking social action

Kuipers et al (2003) in their description and categorisation of CBR service delivery describe a number of different levels and ways of providing services. Although the above description of the social action that the students have undertaken only covers some of the work that the students did in their practical blocks in the 2 years, all of the above-mentioned activities fit into the community, structural and attitudes and beliefs levels of intervention.

There is little in the literature on CBR programmes which illustrates or describes CBR workers addressing in particular, the structural level of service delivery. The CBR training programme outlined by Thorburn (1994b) deals briefly with attitudes related to disability but it does not include any training on working at the structural level and little, if anything, on the community level. The CBR programme described by Jaffer and Jaffer (1994) in Pakistan does not seem to have done any work at the structural level, with little if anything being done at the level of attitudes and beliefs or community level. Other articles in the literature indicate a similar situation (Disabled People's International, 2003; Sharma & Deepak, 2001; Valdez & Mitchell, 1999). Even an evaluation of a CBR programme in which the CBR facilitators had been taught social rehabilitation (including acting at the community and structural levels) found that the CBR facilitators were not implementing social rehabilitation (Cornielje, Ferrinho & Fernandez, 1994).

Thus it appears that the kind of social action that the CBR students in this study have undertaken may be groundbreaking in CBR. From the examples of students' actions given above, it can be seen that CBR students are able to address systemic inequalities as well as the empowerment of individuals with disabilities, which Kendall et al (2000) recommend is necessary for the development of CBR.

In spite of the students' achievements in addressing the situation of people with disabilities through social action, the CBR students also experienced a number of tensions and challenges in trying to do this work. Although I have described a number of activities undertaken by students which may be described as social action, within the confines of CREATE's CBR course, the students spend far more time on

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activities that would be classified as providing, assisting or participating at an individual or family level by Kuipers et al (2003). Such activities include visiting people with disabilities to do rehabilitation exercises and activities such as practicing walking in parallel bars (which have been made by the student), counselling family members to help them accept the family member with a disability and educating families about the dangers of drug abuse. Although the reasons for the students' allocation of time to different activities were not explored in this research, there seem to be at least two possible explanations for the relatively small amount of time spent on social action. Firstly the tasks laid down for the students' practical blocks included a significant number of activities related to families and individuals with disabilities. Secondly, as indicated by one of the CRFs interviewed during the first phase of the action research cycle, the rewards and progress seen may be more immediate when working with an individual (e.g. helping her to wash herself) than the progress and rewards related to social action (e.g. few or slow rewards for writing a letter to the press).

Another challenge the staff of CREATE experienced while encouraging the students to initiate and participate in social action were the fears and difficulties faced by some of the students from rural areas. It is notable that the two students from urban areas undertook more activities that could be seen as social action than their rural counterparts. For collective social action to take place, it is necessary for those taking part to be able to communicate and share ideas with each other. This is difficult in rural areas where distances between homesteads are far (especially for people with mobility impairments) and people with disabilities do not necessarily live close together. Another difficulty of embarking on social action in rural areas (perhaps particularly in KwaZulu Natal with its political history) is the fear that students have of being seen as politically active by the traditional leaders of the area. On a number of occasions in class discussions, students spoke about traditional leaders seeing young, socially active community members as being members of an opposing political party in an area where there is little tolerance for anyone who does not express allegiance to the party that the traditional leaders belong to. Both Student C and Student E have been able to rise above the fear of being penalised for their social activism, but Students A and B seem to have taken the approach of working within the boundaries that the traditional leaders have set. This latter approach does not

preclude social action, but may make the type of actions they can undertake, more circumscribed.

One particular challenge to the students' involvement in social action was the issue of how much power students had or how much power they perceived they had, to change things. The students' different identities, as students, able-bodied people (mostly) and in some cases as employees, meant that they experienced "power over" (Townsend et al, 1999; Bishop, 2002) or the lack of it in different ways. As students, they had little power over decision-making with regards to activities for the CBR course. Therefore it would have been difficult for a student to decide to leave out some of the tasks set for the practical block in order to spend more time on social action. Student F also experienced his lack of power as both a student and an employee who was relatively low in the organisational hierarchy, when his supervisor forbade him to take part in the march of people with disabilities in his area. However, he was able to use his power within the CBR committee and amongst people with disabilities in his area to get them to change the day of the march to a Saturday when he could participate outside of work hours. Student F seems to have had "power from within" which according to Townsend et al (1999) enables him to develop self-reliance and internal strength whilst recognising that one can be restricted by structures external to oneself. It is possible that one of the reasons Student B did not engage in much social action during the CBR course was that as a black woman student with a disability she did not experience any "power over" and her experience of "power from within" was limited.

5.7 Conclusion

During the observation phase of the action research, I found that there have been changes in the attitude and practice of both CBR students and staff. Although it is not possible to ascribe all the changes to the action research, it seems that the changes made to the curriculum did influence the CBR students to work in a way that reflects CREATE's concern with social justice for people with disabilities.

One of the marked changes that was observable was that the CBR students in this study have a greater understanding of the complexities of oppression than did their predecessors who studied CBR. The students were aware of the exploitation, marginalisation and powerlessness that people with disabilities face in their communities. This mirrored reports by people with disabilities themselves and their family members.

During the observation phase of this action research, the CBR students also undertook a number of activities that could be construed of as social action, either together with or on behalf of people with disabilities. There were differences amongst the students with regards to the type of social action they undertook as well as how comfortable each of them felt in being an activist for change in the lives of people with disabilities. Thus the action research raised new questions for the construction of the CBR curriculum that related directly to the students' lives.

The following part of this thesis explores the CBR students' previous experiences of social action and their life histories with regard to social activism to help determine the reasons for the differences between the students in their involvement in social action. The findings of the action research cycle as reported on in this chapter, together with the analysis of the life histories contributes to the development of a framework for construction of a CBR curriculum for mid-level workers at the end of this thesis.

CHAPTER 6

LIFE HISTORY METHODOLOGY AND SOME OF ITS COMPLEXITIES

6.1   Introduction

The second phase of this study is a response to questions that arose in the observation phase of the action research cycle. I was specifically interested to discover why students had differing responses to the CBR curriculum and how this could impact on a framework for CBR curriculum development. These new questions necessitated adding an extra component to the research design and it is this that is discussed in this chapter. Firstly I will list the new research questions that arose during the action research. I will then go on to discuss life history methodology, which I have chosen to use in order to answer the research questions.

The action research cycle in this study, as is most likely with most action research, has generated more questions, some of which I chose to follow up in the second phase of this study. I felt that my knowledge of what makes a CBR curriculum that focuses on the empowerment of people with disabilities work was incomplete without examining the possible reasons for the differing responses of students who participated in the action research. Thus I embarked on the second part of this research project which was guided by the following questions:

- What life experiences do CBR students of the 2003/2005 class have that may relate to issues of social action and oppression?
- In what way do the life experiences of a CBR student impact on his/her willingness to undertake social action following the CBR training?
- How can the life experiences of CBR students impact on the development of a framework for a CBR curriculum?

- What are the key components of a curriculum framework for mid-level CBR training?

6.2   Life History Methodology

In order to answer the first two research questions mentioned above, I have chosen to use life history methodology. As Plummer (2001, p.130) writes, "(life stories) will be at their most helpful when what you want to understand are people's direct understandings of the social worlds in which they live". Plummer goes on to suggest that life history methodology is useful to generate new ideas, to complement other research methods and as a way of ending a project, all of which apply to my study.

6.2.1   Approach to life history methodology

A number of authors (Chase, 2005; Grbich, 2007; Plummer, 2001) indicate that different approaches to life history methodology can be determined, with distinguishing factors being the length and comprehensiveness of the life history, the disciplinary background and interests of the researcher and whether the life stories are researched and solicited, naturalistic or reflexive.

With regard to the length of the life stories I have used in this research, they would certainly fall into Plummer's (2001) categorisation of the short life history, which does not in any way attempt to capture the complete life experiences, emotions and thoughts of the participants. The short life history tends to be more focused, and studies using short life histories may piece together a wider account of a phenomenon, time or particular type of life experiences based on a number of short life histories. Plummer (2001) links to this the question of whether the life history will be comprehensive, topical and/or edited. I have chosen to collect topical life histories in this research because my aim was to throw light on a particular issue: CBR students' life experiences of oppression and social action. In the following chapter I have included four life histories of CBR students which are mainly written in the 'voice' of each student and therefore these documents would probably not be considered *edited* life documents by Plummer (2001) who

describes an edited life document as one in which the subjects' stories may be used to illustrate the author's (or researcher's) account, often through the use of extracts of life histories.

Chase (2005) describes five approaches to narrative inquiry that are in the main linked to different academic disciplines. Although it is difficult to characterise the approach that I have used as fitting neatly into one of Chase's descriptions, the life history aspect of this study probably most closely links to the sociological approach to narrative inquiry. This approach is concerned with the 'identity work' the storytellers or participants engage in while relating their experiences in different organisational and other contexts. A similar conceptualisation of one approach to narrative inquiry and analysis is Grbich's (2007, p.130) description of the 'socio-cultural approach' which encompasses "the broader interpretive frameworks that people use to make sense of everyday happenings/episodes, usually involving past-present-future linking."

6.2.2 Data collection

The data that was gathered to construct the life histories of the CBR students in this study was collected through the use of two interviews with each participant. Although Plummer (2001) mentions a number of data collection methods, including autobiographical writing, observation and collection of archival material including diaries, I chose to use interviews because the participants are more skilled at telling their stories orally than in writing, particularly as I used the medium of English. Although all the students were isiZulu-speaking, English was used as the medium of instruction for the CBR training. Van der Riet, Hough and Killian (2005) discuss some of the tensions and difficulties that transpired in using research assistants who were master's degree level students to conduct and translate focus group discussions from isiZulu into English. I did not have access to a research assistant with a similar level of education and I hoped to avoid some of the tensions related to dealing with emotional and sensitive issues that van der Riet et al (2005) experienced. Also, the particular aspect of the participants' life experiences that I was interested in did not easily lend itself to observation at pre-arranged times. I did however observe the student who called himself 'Wandile'

participate in and help to organise a march of people with disabilities before I conducted the life history interviews.

McCray, Sindelar, Kilgore and Neal (2002, p. 272) recommend the use of multiple interviews at different points in time because they "provided the participants with multiple opportunities to remember, reconstruct and refine events and to increase the credibility and trustworthiness of the data." In this study, I conducted two interviews of just over one hour each about two years apart. Due to a number of unavoidable constraints related to the upgrading of the study from a master's degree to a PhD, the interviews were conducted with a greater gap between them than I would have liked. The initial interviews were conducted while the CBR students were still studying at CREATE and although they were not initially intended as full life history interviews I did gather information about their family backgrounds and the beginnings of life history data. It was interesting to note that, in line with the comment of McCray et al (2002), without exception, all the narrators revisited some of their experiences and refined accounts of events in the second interview. Although the interviews were short in comparison with many life history interviews (Plummer, 2001; Reddy, 2000; Smith & Sparkes, 2004), the topical nature of the life histories meant that less time was required for the interviews than if I was trying to construct a more comprehensive life history of each participant. In fact, Drake (2006) conducted interviews lasting up to 90 minutes using an interview schedule which I adapted for the second of the life history interviews.

Once the life storytellers had told their stories of family and educational background, the interview schedule for the second interview focused more specifically on their experiences of oppression and social action. As with Drake's (2006) interview protocol, I asked participants to tell their stories through looking at significant events in childhood, adolescence and adulthood, as well as high points, low points and turning points in their lives related to oppression and social action (see Appendix 8). Plummer (2001) suggests that questions about pivotal events in a person's life, such as crises, turning points and epiphanies, may add a useful dimension to a life story interview. Throughout the

interviews I used open-ended questions and I explored the narrators' responses with further probes, allowing the storytellers to direct the flow of the interview to some extent.

All the interviews were tape recorded and I took notes during the interviews as well, to complement and assist the transcription process. Once I had transcribed the interviews, I constructed each participant's life history using information from both interviews and created a chronological order for the life histories. The life histories were constructed using some direct quotes from the life storytellers. Goodson and Sikes (2001) make a distinction between a life story and a life history, in which the life story is the first layer of the research – a person relates his or her life story. The second layer, the life history, is constructed using the transcribed interviews and documentary data and may provide an historical context for the life story. In this study I have adhered to the different concepts of life story and life history as used by Goodson and Sikes (2001)

Each life storyteller was shown his/her completed life history and asked to comment on the veracity and style of the life history. According to Goodson and Sikes (2001) this is known as respondent validation. A few minor errors were subsequently corrected. One life storyteller's response to seeing his life history in writing was to suggest that he would like to publish his story in book form.

6.2.3 Data analysis

Following the transcription of both interviews for each of the four CBR students, I constructed a life history of each participant. Each life history combines data from both interviews and follows a chronological order of the life, rather than necessarily keeping to the order of the information as it was told to me. Thus an elementary analysis of the data was conducted in order to construct the life histories.

Having constructed the life histories, I then used multiple tools to help me analyse the data. For the first analysis of the four life stories, I chose to use the holistic-content method of analysis of Lieblich, Tuval-Mashiach and Zilber (1998). Using this method of analysis, I focused on the content of each life story and analysed sections of each story

within the context of the whole story. This form of analysis yielded themes which I then tracked throughout that particular story. In this holistic-content method of analysis, I did not impose any categories or themes from the literature. Rather, I tried to find patterns or foci that emerged from multiple readings of each life story. A similar theme emerged from three of the students' life stories and this theme was then related to the literature.

Another method that I used to analyse the life stories was to search for redemption and contamination sequences (McAdams & Bowman, 2001) in each of the life stories. McAdams and Bowman (2001) describe a redemption sequence in a narrative, as ending a story which begins with negative affect and events, with positive outcomes. In contrast, a contamination sequence is one in which a sequence starts with a positive event and affect and is then presented to have a negative ending. I counted both the number of contamination and redemption sequences as well as noting the specific content of these sequences. This analysis of each life story was then linked to the literature on life satisfaction, generativity and social activism.

Finally, I applied Giddings' (2005) model of social consciousness to the life stories to analyse each CBR student's level of social consciousness and thus his/her availability for social action. The combination of methods of analysis that I used, have contributed to gaining a composite picture of CBR students as social activists.

6.3   Key Methodological Issues in Life History Research

Life history research, as with any other methodology, raises particular concerns with aspects of the methodology that are specific to that methodology. In this section I will discuss four issues as they apply to this study: the representativeness of the lives I have chosen to write about, the relationship between the researcher and life storytellers or narrators, the issue of whose voice is represented and the question of validity in life history research.

6.3.1   Whose life stories to include?

Issues of sampling and sample size are usually a concern of quantitative research which works with large numbers of subjects and hopes to draw generalizable conclusions from research on a large representative sample. In life history research large numbers of participants are usually not possible and the purpose of the research is often not to produce generalizable findings. Rather, the issue in life history research may be the degree of uniqueness or typicalness of the life histories to be included (Reddy, 2000). Although the life stories are individual stories, they do relate to the broader patterns of culture and the history of the time, and Reddy feels that it is the researcher's responsibility to draw out elements of the life stories that are unique and those that are representative of the place and time. Plummer (2001) discusses a continuum of representativeness with reference to the particular people whose life histories are told in a piece of research. The one end of the continuum is where the researcher tries to ensure and explain how typical the participants are of a particular group while at the other end of the continuum the researcher feels that generalization and representativeness do not matter. According to Plummer (2001) a useful midway point is to search for key informants who have a deep understanding of their cultural world.

This relates to Plummer's (2001) mention of 'intensity sampling' and 'critical case sampling' in relation to life history research, where intensity sampling refers to selecting a key informant who can give good insight into a particular area of interest. Critical case sampling involves selecting life stories that give detailed information about key, critical experiences. In this study I could be considered as having used intensity sampling in my choice of CBR students to interview for their life stories. The total number of CBR students in the class that participated in the action research was only seven, so in order to deepen my understanding of what happened during the action research, I only had a very small number of potential participants for the life history research. From this group of CBR students, I selected the two students who most readily engaged in social action during the CBR course. In addition, I interviewed the only student with a disability to complete the course, as I was interested in understanding her perspective of oppression and disability and whether that had any links to her willingness to engage in social action.

Finally, I selected a fourth student who was the most reticent in the class to undertake any form of social action. I chose to interview this last student because I felt that in order to understand more fully students' willingness to undertake social action, I needed to explore the perspectives and experiences of those who readily engaged in social action, as well as those who did not. Although I did not set out to ensure representativeness in the group of students I selected to interview for their life histories, the sample does represent the type of students in CREATE's CBR courses along certain dimensions. Two of the life history research participants were from urban areas and two were from rural areas. Two of the participants were male and two were female.

Reddy (2000) suggests that good participants for life history research should be articulate, be able to tell a story and have a grasp of their cultural world. The CBR student with a disability who participated in the life story interviews in my research was not very articulate, particularly in English. Unfortunately at the time she was available for the first interview I did not have access to an isiZulu interpreter. However, it was important to include her in the research because, as Reddy warns, life history research can be in danger of not telling the stories of the most disempowered, if it excludes people who are not confident to articulate their experiences.

6.3.2   The relationship between the researcher and the participants / narrators

Life history research by its very nature, is dependent on a relationship between the researcher and the participant(s) in the study. As Du Plessis, Higgins and Mortlock (2000, p. 285) explain, "Life stories are relational: they are the product of interpersonal interactions in which stories about biographical 'episodes' are used to construct selves".

Several authors (Chase, 2005; Kazmierska, 2000; Plummer, 2001) describe the relationship between researcher and participant in life history research as going beyond the more classical relationship between interviewer and interviewee in other forms of research. The interviewee or participant in life history research is not seen as a passive vessel holding the answers to the researcher's questions, but rather as a person who actively constructs a narrative or life story and has a voice of his/her own. This change in

the conceptualisation of the participant or narrator's role consequently requires a shift in the role of the researcher. The researcher needs to become a good listener, inviting stories to be told as well as trying to understand the narrator's frame of reference and voice (Chase, 2005; Kazmierska, 2000). In order to invite stories to be told, the researcher needs to know what is "storyworthy" in the narrator's social and cultural setting (Chase, 2005).

Kazmierska (2000) points out that it can be especially difficult both to tell and to listen to traumatic life experiences. One approach to life history research is the psychological approach and within this framework the telling of a life story may at least in part be therapeutic for the narrator (Chase, 2005). Kazmierska discusses how, within life history research, the telling of traumatic experiences to a good listener (the researcher) can be cathartic for the narrator. In my research two of the participants had particularly traumatic experiences in their childhood which they narrated in the life story interviews. Although I am not a trained counsellor, the student who called herself "Nomusa" in her life story, clearly found some catharsis in telling her story to someone who was listening closely to her. She poured out her early history and relationship with her mother, with barely a probe or question from me and her body language indicated relief when she came to the end of the interview. For "Wandile" catharsis was a less obvious outcome of the life story interviews and his stories of severe child abuse, although his response when I showed him the written up life history, was that he should publish his story in book form. I found it difficult to listen to the terrible stories of abuse that Wandile experienced at the hands of his stepfather, without becoming judgemental and affecting the stories that Wandile was telling me. One cannot predict that such stories will emerge from life story interviews and yet it is important for the interviewer to be prepared in advance to deal with stories of trauma and suffering. Du Plessis et al (2000) mention that a researcher constructs a self to gain and maintain rapport with the narrator. In order to maintain rapport with the narrator through stories of trauma and suffering the researcher is challenged to be aware of her own experiences of and reactions to suffering, so that they enable an empathetic response to the narrator.

In the telling of a life story, the narrator creates a self for the particular audience listening to (or reading) the life story. Du Plessis et al (2000) point out the importance for some narrators of becoming a certain person through the telling of particular chosen stories. It seems that during this research, "Life" chose to tell stories of his growing political awareness as a way of representing himself as a politically aware, social activist. He may have chosen to portray this aspect of his identity knowing both the purpose of the research and my own interest in social justice. As Chase (2005, p.657) reminds the reader, narratives are "socially situated interactive performances" and the story told will depend not only on who the audience is, but also on the social setting in which the story is told. The storyline in a person's life story may also be closely linked to particular cultural storylines which are related to the social and political circumstances of that group / culture (Goodson & Sikes, 2001). The life story may also vary if told at different times or for different purposes. For example, in this study, at the time of her second interview, "Nomusa" related the story of neglect and abandonment by her mother with great emotion and anger. She may have given this aspect of her story particular prominence at the time she was interviewed because it was at this time that Nomusa's husband was undergoing crucial medical treatment about which her mother did not show any concern.

A post-modernist view of the narrative identities that people create are that they are dynamic, partial and context-dependent. According to Goodson and Sikes (2001, p.87) within a post-modernist framework, "The life history should focus on emergent categories, on process, on movement, as well as on stability and static notion of context." This approach links to the above-mentioned ideas that the narrators in this research may have constructed particular selves related to the particular audience, time and social context in which the stories were told.

6.3.3   Whose 'voice' is represented in the life histories?
In life history research, often the intention is to 'give voice' to the people whose stories are told, perhaps because they represent a marginalised group or because their stories are not otherwise visible to the intended readership. However, the notion of 'giving voice' is

not straightforward and a number of issues arise when considering this aspect of life history research.

One key question in the presentation of life history research is, 'whose voice is heard through the life history?' The actual story told may to some extent be framed by the questions asked by the researcher as well as by the nature of the relationship between the interviewer and the narrator. Thus although the narrator tells his or her own story, certain aspects of the story may have particular emphasis because of the research interests of the interviewer. The question of whose voice is apparent in the life history becomes more of an issue in the process of editing and interpretation of the life stories. Plummer (2001, p. 177) describes a very common strategy for writing up life histories thus:

> "get your subject's own words, really come to grasp them from the
> inside, and then yourself turn it into a structured and coherent statement
> that uses the subject's words in places and the social scientist's in others
> but does not lose their authentic meaning."

This is what I have done in this study to create the life histories in Chapter 7. Thus I cannot claim that the life histories are purely the voices of the narrators. I have intruded into the stories in the process of editing the data and constructing the life histories. As I did not intend presenting an exact transcription of each of the interviews, which would have been messy with hesitations, repetitions of information and no particular chronological order to the stories as they were told, it was necessary to intrude into the stories through editing them to make them more readable. As I was aware of this intrusion and wished to make the reader aware of my own influence on the life histories, I have chosen to write up the life histories in the third person. As Pillay (2003) indicates in her exploration of teachers' narratives from different perspectives, reporting the voice of the narrator in the third person makes the presence of the researcher overt. Had I chosen to write the life histories in the first person, my own presence in the life history would still have been there (through the construction and editing) but would be less transparent for the reader. Pillay (2003) acknowledges that even in acting as vehicle for the transmission of the narratives she writes in the first person, she had power and influence in the relationships with the narrators and the construction of the narratives.

Interpretation of the life histories also represents an intrusion of the researcher into the voice of the narrator. Plummer (2001) describes a continuum along which the degree of the researcher's intrusion into a sociological life story can be described. Both the narrator and the researcher are seen as involved in interpretation of the life story, from the subject's own world view to the sociologist's scientific theories. In this study, I could probably be described as approximating the mid-point on the continuum – where subjects speak for themselves but their stories get organised around themes, often linked to theory.

Chase (2005) has developed a typology to classify the strategies that researchers use in asserting their own voices, particularly in the interpretation and representation of the narrator's voice. Chase characterises the three voices of the researcher as the authoritative voice, the supportive voice and the interactive voice. In writing up the life history aspect of this study, my voice as the researcher, could be classified as the authoritative voice. I do not engage in much of an examination of myself and my own voice through using the narrators' voices (Chase's "interactive" voice). Rather, in the interpretation of the life histories I have maintained a separate voice from the narrator, bringing my own interests and conceptualisations to bear on the narrated stories. In order not to privilege the researcher's voice over the narrator's voice, it is helpful to demonstrate that the researcher's voice is different to, but not disrespectful of the narrator's voice (Chase, 2005). The way the narrator's story is written up (particularly with quotations) should also allow the reader to make alternative interpretations to those of the researcher.

It is important to acknowledge the voice of the researcher as a presence in the research and as influencing the interpretation and presentation of the life histories in the study. As indicated in the previous section of this chapter, life history research is moulded by the relationship between researcher and narrator. Although positivist research views the researcher as an outsider and neutral observer whose voice is not acknowledged, in both interpretivist and critical research (which include life history research), the researcher's voice can be an integral part of the study. Plummer (2001) indicates that much academic

writing is characterised by distance, objectivity and neutrality in which the author is seen as the expert who frames the voices of others. However, he indicates that it is possible to create democratic texts which are "polyvocal" and may even read like a dialogue between author and reader (Plummer, 2001, p.183).

6.3.4   Validity and reliability in life history research?

Although the questions of reliability and validity are very important in quantitative research, in qualitative research, these concepts are more problematic. As Plummer (2001) indicates, reliability, or the assurance of obtaining the same results when the research is conducted by another person, is of questionable usefulness in life history research, especially if the validity of the data is uncertain. As mentioned above, the relationship between narrator and researcher is crucial in life history research and the story told may be adapted to the particular audience (researcher) listening to it. Therefore, it is not an expectation, or even desirable, that a life story will be 'reliable' in the sense that the word is used in quantitative research. In a postmodern orientation to life history research, it is expected that the context of the telling of the life story will affect which of the multiple selves is represented and in which way. Rather, it is more valuable to explore the concepts of trustworthiness, authenticity and truth value in qualitative research (Geelan, 2003; Reddy, 2000).

Geelan (2003) explores the work of Guba and Lincoln in relation to the trustworthiness and authenticity of qualitative research. These authors align the concept of credibility with that of internal validity in positivist research. According to Lincoln and Guba (1985) cited in Geelan (2003), the five techniques for improving the credibility of qualitative research are peer debriefing, negative case analysis, referential adequacy, using triangulation or prolonged engagement and member checking. Of these five techniques, the one that I have found easiest to employ to try and ensure the credibility of the life histories I have written is member checking. The participants in the life history aspects of the research have checked the way that I have represented and interpreted their lives through reading and commenting on their life histories as I have written them up.

According to Geelan (2003), member checking is the most important technique for establishing credibility.

Several authors (Goodson & Sikes, 2001; Reddy, 2000) refer to the term 'verisimilitude' in life history research in a similar way to Lincoln and Guba's concept of credibility with regard to qualitative research. Goodson and Sikes (2001, p.50) describe verisimilitude thus:

> "a key 'test' for assessing whether or not qualitative research writing is representational of 'real' life has been the extent to which it achieves what has been called verisimilitude (Bruner 1986): that is, how far it seems to be true, how far people who have personal experience of the focus of the research regard it to be likely, or the extent to which 'experts' in the field consider theories, conclusions etc. to be plausible."

Reddy (2000) mentions two aspects that she considered in establishing the 'verisimilitude' of her life histories – having a plausible plot and ensuring consistency in what is told. With reference to ensuring consistency in what is told, one can check for contradictions when the life story, or parts of it, are told on more than one occasion. In my study the narrators were interviewed on two occasions with the intervening period being close to two years. None of the narrators contradicted themselves in any way and although some new stories were elicited in the second interview, all the narrators retold some of their stories from the previous interview, albeit in a slightly different way. This, I hope, indicates a consistency in what was told. The narrators' stories can also be considered to be externally consistent when they are compared with events in the particular times and places in which the narrators lived. For example, "Life" tells of a teacher being dismissed from his school in the mid 1980s, probably because he educated the pupils about the political situation in the country and about the then banned African National Congress. Although I do not have specific validation of this event in the particular community Life lived in, the event is consistent with what the literature says about schooling in the Inkatha-controlled KwaZulu homeland where Life lived during the mid 1980s.

In relation to Reddy's (2000) second aspect of establishing credibility or verisimilitude, a plausible plot, the plot is imposed on the data from the life story interviews by the researcher. It is therefore for participants in the research and others to determine whether they find the plot used to organise the participant's life history, plausible. Clearly in this study the CBR student narrators have found their own life histories to have plausible plots as they have not complained or made recommendations to change the plot for their own stories when doing a member check. In addition, the life histories were shown to the staff members of CREATE who appear to have found the plots of the life histories plausible.

Plummer (2001) links the concern with validity of life history research with identifying, acknowledging and where possible getting rid of sources of bias within the research. He identifies three sources of bias in life history research, the informant, the researcher and the interaction between researcher and informant or narrator. A number of these sources of bias, such as the gender and race of the researcher cannot necessarily be eliminated but should be acknowledged and accounted for in the writing up of the research. Throughout this study I have tried to make explicit characteristics of myself, the narrators and our interactions which may potentially have biased the outcomes of the life history research. I cannot claim to have eliminated biases such as my own attitudes and political interests or the fact that the narrators may have been trying to please me. However, my intention is that by recording these aspects I have made it easier for the reader of this research to determine where elements of bias have crept into the research.

6.4   Ethics and Life History Research

In life history research certain ethical issues need particular scrutiny because of the nature of the research. The relationship between researcher and research participant may be deeper than in many other forms of research. In addition, the personal and intimate information that may be shared in life history research requires the researcher to pay

attention to issues of confidentiality and anonymity, which are not uncomplicated in this form of research.

As with other research methodologies, the life history part of this study began with obtaining informed consent from the four participants. The participants were told about the nature and aims of the research, that they could withdraw at any time and that they would be shown their life histories when written up. However, as Kazmierska (2000) reminds us, life story narrators are seldom told how their stories may be analysed. The researcher may be concerned with how the story is being told as well as what is being told and what is not being said. Muchmore (2002) raises other concerns with the process of getting informed consent from participants and ethical clearance from institutions or review boards. According to Muchmore, institutions granting ethical clearance are much more concerned with obtaining signed consent forms than finding out about issues such as how disputes will be resolved in the case of the participants not agreeing with the interpretation or findings of the researcher and whether such findings will still be disseminated.

One of the key ethical concerns in research is to do no harm to the participants. It is unlikely that any physical harm will befall a participant in life history research, but there is a question of emotional hurt, either through the process of telling the story and /or through how those who read the research may use and interpret the life history. Kazmierska (2000) reminds the researcher that telling a life story can require much psychological effort. This must have been especially so for the participants in my study whom I requested to recall instances of discrimination and oppression. In the case of Nomusa it appears that the process of telling the story, although difficult, was cathartic. However, in the case of Wandile, as I am not a trained counsellor, and although I was unaware of it, I risked creating emotional hurt by asking him to recall his childhood experiences and his relationship with his stepfather. I did not realise that he had stories of shocking abuse to tell. It is difficult, if not impossible, to predict such a situation but the researcher needs to be able to take steps to address the narrator's psychological and emotional hurt if necessary.

Plummer (2001) writes about the frequent situation in which the researcher gathers the information he or she needs and then leaves the situation, without regard for what happens next. When this happens, the researcher may be unaware of any harm that the research has caused. Not only may the narrator be traumatised or hurt through the telling of his or her story, there may also be difficulties when knowledgeable insiders can identify the person whose life history is told. Another potential source of harm to the narrator can arise when others interpret and use the research (including the life history) for purposes that may be against the wishes or interests of the narrator (Muchmore, 2002). Once the researcher has disseminated his or her research, there is little control anyone has over how it is used.

Maintaining confidentiality is a difficult ethical issue in life history research because through eliciting many personal details of the individuals who tell their life stories, it becomes more possible for others who have a link in some way to the narrator, to identify the person. Although in my study, as in much other life history research, the narrators chose pseudonyms to give them a degree of anonymity (Plummer, 2001), because there were only seven students in the class, it becomes easier for anyone associated with the CBR training at CREATE between 2003 and 2006 to identify which students' life histories are told in the research. All the participants in the life history research did agree that their life histories could be written up and included in my research. However, if I decide to publish aspects of the research, including the life histories, in spite of the pseudonyms, I feel that I would go back to the participants and request their permission to publish the life histories. This is in contrast to how Reddy (2000) dealt with the situation in her PhD study, where she asked the participants to give her copyright of their stories. For me, this raises the difficult question of ownership and intellectual property rights to the life histories. As with many other ethical concerns, there are no easy answers to this question. In my study, I do not feel that I could have sole ownership of the life histories and therefore if Wandile decides that he does want to publish his story in book form, I would help facilitate this. Muchmore (2002) points out that one problem

with giving the narrator anonymity is that it is more difficult to truly credit the participants for the contribution they have made to the research.

6.5   Life History Research in Disability Studies and Community Based Rehabilitation

Life history methodology appears to be gaining popularity in disability research. Goodley (1996) mentions a seminal study by Bogdan and Taylor in 1976 which recorded the life history of a person with intellectual disability. Since that time, and particularly in recent years, there have been a growing number of studies using life histories and narrative inquiry with regard to people with disabilities (Admi & Shaham, 2007; Atkinson, 2004; Fisher & Goodley, 2007; Madriaga, 2007; Smith & Sparkes, 2004; Traustadóttir, 2006). These studies represent research with people with a variety of disabilities (including spinal cord injury, dyslexia, intellectual disability and epilepsy), a range of ages (from adolescents through to young parents to older people) and with a variety of purposes.

Several authors have examined the narratives of their research participants for narrative forms that of themselves tell a story (Smith & Sparkes, 2004; Fisher & Goodley, 2007). In their examination of the narratives of men with spinal cord injuries, Smith and Sparkes identify three dominant forms of narrative amongst their participants – the restitution narrative, the chaos narrative and the quest narrative. The narrative form used by each participant characterises his perceptions of his life since the spinal cord injury. Fisher and Goodley (2007) identified that many mothers of babies and young children with disabilities in their study were resisting the traditional linear narrative of acquiring the disability, diagnosis, treatment and progress that is used by professionals dealing with children with disabilities and which the authors claim is typical of the medical model of disability. Rather, these mothers used a narrative of challenge and a narrative of "the present and becoming". This latter narrative form was typified by mothers expressing their living in the moment with the child and expressing hope for the future.

Some disability researchers who use life history methodology appear to be more concerned with the content of the narrative than its form. For example, Traustadóttir (2006) captures the life history of an older man with intellectual disability who spent most of his life in institutions but was nevertheless a self-advocate. From his article, it appears that Traustadóttir is concerned with the content of the life history and what he and the readers can learn about self-advocacy and the support that people with intellectual disabilities need to become self-advocates.

Life history methodology seems to be becoming more popular in the field of disability studies because of several benefits it offers to the field. People with disabilities are frequently marginalised in society and therefore their stories and experiences are often absent in dominant mainstream historical documentation. Research which includes life histories of people with disabilities therefore offers an opportunity for people with disabilities to reclaim their place in the making and experiencing of history. According to Goodley (1996, p.334) "life histories may be viewed as a resource for transforming historical understanding and analysis." Several authors (Atkinson, 2004; Traustadóttir, 2006) have used life history research to capture the perspectives and effects of an era of institutionalisation that people with intellectual disabilities were subjected to in the United States and Britain that was largely invisible to mainstream society. Not only can life history research with people with disabilities help to transform mainstream historical understanding, as Atkinson (2004) describes her "Past Times" project with people with learning difficulties (intellectual disability), the people with disabilities themselves may come to a greater understanding of their own past through the narrating of their life histories. According to Atkinson (2004, p.700) "Historical awareness – of one's own history and the history of others – is an important step towards empowerment and, therefore, towards inclusion."

Life history research with people with disabilities can be seen as 'giving voice' to people with disabilities. Within the dominant medical model approach to services for people with disabilities, people with disabilities are seen as passive recipients. Through life

history research, such as that by Madriaga (2007), the voices of people with disabilities can be more accessible to and influence service providers. Several authors (Atkinson, 2004; Goodley, 1996; Traustadóttir, 2006) specifically write about the value of life history research in 'giving voice' to people with intellectual disabilities who may not be very articulate and yet have some stories to tell. Goodley (1996) discusses the challenge of life history research with inarticulate people and the degree to which the researcher impacts on the life story. Life history research may be one of the few types of research in which people with intellectual disabilities who are fairly inarticulate are able to participate in the research process. Bornat and Walmsley (2004) warn that top-down research and biographical practice do not automatically 'give voice' and they may instead generate materials such as case notes and patient histories, in which the voice of the person with a disability may be absent.

One of the benefits of life history research in the field of disability studies is that it links the individual and his or her social world. Through the life history the narrator may highlight the social constraints on him or herself as well as making sociocultural understandings of disability apparent (Goodley, 1996). In my study, Zanele makes clear in her life history some of the prejudices, myths and misunderstandings that existed in her sociocultural environment. Thus we not only get an insight into her personal story but we also gain an understanding about how disability was perceived in her community and the various attitudinal barriers she experienced. According to Goodley (1998) life history research should be seen as a form of solidarity with the narrators of the stories in order to work towards both individual and societal change. In the writing of the life histories it is important to balance the individual experiences with the social context so that readers are not led to interpreting the life history as individual pathology rather than examining the disabling environment (Goodley,1996).

According to Smith and Sparkes (2004, p.624) the use of narratives can also assist people with disabilities to transform their lives:

      "self stories may be built by accessing counter-narratives about disability

      and impairment via, for example, the narratives of the disabled people's

movement, or listening to the individual and collective stories told by other disabled people that deviate from standard plots, provide new narratives, and legitimize the replotting of one's own life."

In my study, through coming into contact with role models who have disabilities such as Musa Zulu, Zanele acknowledged that she had seen another way of being disabled. This may to some extent have helped her to see another plot for her life, particularly as regards work.

Although there are a number of examples of life history research in disability studies and theorising around some of the issues, I have been unable to locate any studies in community based rehabilitation that have used a life history methodology. Thus this study appears to be breaking new ground in community based rehabilitation research.

6.6   Life History Research in a Critical Paradigm

Although life history research is usually conceived of as taking place within an interpretive framework, in this study I do not feel that I have departed from the critical paradigm (which has guided my action research) by using life history methodology. Various authors (Chase, 2005; Heilman, 2003; Rickard, 2004) allude to the potential of narrative research to contribute to a move towards social justice and the removal of oppression. These are central concerns of critical theory and thus guide work within a critical paradigm. In fact, Fisher and Goodley (2007) specifically use the terms 'critical' and 'postmodern narrative researchers' to refer to several researchers who have conducted 'bottom-up' narrative or life history research.

Critical theory is concerned with the workings of power at different levels, including the micro-level, which includes people's experiences of control, oppression and freedom. Life history methodology can be used to tap into these experiences, as illustrated in my own study. Many life history and narrative studies have recorded the histories of marginalised and otherwise hidden people, thus exploring the notions of oppression,

control and emancipation through the lived experiences of a range of people. Critical pedagogy is more particularly concerned with hearing the voices of students, who may represent the oppressed in the education system. Thus in my study, the life history aspect of the research can be seen to fit in with a critical paradigm because through the life histories I am 'giving voice' to students who have been oppressed in various ways due to race and disability and I have explored their understandings of oppression and empowerment. Through the stories of the CBR students and the ways in which I have used them to inform the framework for CBR curriculum development, I am also attempting to change the status quo of CBR mid-level worker training.

By enabling the students' voices to be heard, I hope that I have changed the power relations in the research and in curriculum development for CBR training to some extent. According to Chase (2005) narrative research can disrupt oppressive social processes and facilitate more democratic public life. Although these are grand claims by Chase, it is possible to see such effects in some cases. For example, following the publication of the life history of Guatemalan Indian and activist Rigoberta Menchu, she was awarded the Nobel Peace Prize (Plummer, 2001). On a smaller scale, the publication of the life histories of people with intellectual disabilities who were institutionalised for long periods of their lives may have contributed to public awareness of these practices and their effects, thereby decreasing the chances that institutionalisation will be as popular in the future.

According to Heilman (2003) a critique of critical theory is that it is sometimes used and understood in a decontextualised way. By using life history research within a critical paradigm, the context can be brought back into critical theory. Narrators will often share the constraining effects that culture, structures and institutions have had on their lives. In my research, I have used the life histories to explore the issues that constrain or promote the CBR students to become social activists for disability. Through their stories it is clear that a number of cultural and socio-political happenings have affected the CBR students and their willingness to work towards social justice for people with disabilities. Without

the information from the life histories, part of the context for developing the framework for the mid-level CBR worker curriculum would be missing.

6.7   Merging Methods: Action Research and Life History Research

In concluding this chapter on methodology, it is important to look at the confluence of the two research methodologies used in this study. It is an unusual combination of research methods, action research and life history research. I was only able to find one example of such a study in the literature, that by Ashburner, Meyer, Johnson and Smith (2004). As part of a three-year action research study, older people in a long-term care facility shared their life histories with staff and the researchers.

Although so-called mixed-methods or multi-method research appears to be coming into vogue (Bryman, 2006; Bryman, 2007; Collins, Onwuegbuzie & Sutton, 2006; Hoppe-Graff & Lamm-Hanel, 2006; Morocco et al, 2006), this tends to refer to a research design which incorporates qualitative and quantitative research methods into one study or series of studies. In developing a mixed-methods research design of this nature, there are questions which arise from combining elements of two different research paradigms, such as what constitutes validity or trustworthiness of data. In the case of my research, I have combined two methodologies or approaches to research which, as explained above, can both fit into a critical paradigm. I therefore do not have to struggle with integrating elements from different philosophical and paradigmatic backgrounds.

Action research is an approach or methodology in which a variety of data collection methods can be used. In action research as it was originally propagated by Kurt Lewin, it is quite feasible that quantitative data collection methods such as a survey or questionnaire could be used. Action research also often involves qualitative methods such as focus group discussions and semi-structured interviews.   Therefore it is conceivable that life history interviews can be integrated into an action research approach. In my study, the final reflection phase of the action research cycle stimulated

the development of further research questions, which it seemed most appropriate to answer through the use of life history methodology. Bryman (2007) refers to the choice of research methods based on the research question as a particularistic discourse, as opposed to the universalistic discourse in which the researcher uses the same (mixed-methods) approach in all studies.

The value of combining the two approaches that I have used is that action research provides a picture of the organisation and a particular process (CBR training) over a limited period of time, while the life history approach has provided in-depth information of a particular aspect of the study. Both approaches, particularly if a participatory action research approach is used, value an active role for the participants in the research and they encourage the participants' voices to be heard. In both approaches, the researcher is seen as actively involved in constructing meaning, rather than as the neutral observer in positivist research. While action research can contribute to developing theory through praxis, life history research can uncover information at a personal level which illustrates or challenges theory. By combining the use of action research and life history research in this study I have a richer bank of data to assist in formulating the framework for a mid-level CBR curriculum than if I had used either approach on its own.

CHAPTER 7

THE LIFE HISTORIES OF CBR STUDENTS AS EMERGING SOCIAL ACTIVISTS

7.1   Introduction

In this chapter I present the life histories of four people who were CBR students at CREATE during the period in which the action research took place. The life histories as recorded here have a specific focus on the students' understanding and experiences of injustice, oppression and social action. The life histories are presented as they were told to me and then subsequently collaboratively written up. In this chapter I try to let the narrators speak for themselves. Each of the students who were interviewed has chosen a pseudonym for him/herself which I use in this chapter. The theorising of the life histories through an analysis of the histories and their relation to the CBR curriculum is reported on in the following chapter.

7.2   Life History of "Life"

Life was born in the early 1970s and grew up in a family of six siblings in a rural area of KwaZulu Natal, not very far from Creighton. Life lived with his mother and siblings, as his father was a migrant worker with the Railways in Durban. Life saw his father once a month and for a longer period of one month when he took his annual leave. When he was a young child, Life's oldest sister got married and left home and later his two older brothers also left home to live with his grandmother so that they could attend high school. Although Life's father did not have a good job, he was able to provide the family with their basic requirements and he also paid for the education of all his children.

Life describes his mother as being a loving mother who always made sure that her children attended school, although she herself was uneducated. In the absence of her husband, Life's mother also ensured that the children assisted her in taking care of the family's livestock. According to Life, his father was a very strict person who shouted at the children a lot, although he never hit them. Life's father insisted that all his children should go to school and he even managed to pay for his oldest son to go to teacher's training college, from his meagre salary. Life's father was uneducated and his insistence on the children attending school was reportedly because he wanted his children to avoid the difficulties he had experienced in his own life. Life's father had struggled to get a job and once he was working in the Railways, he was never promoted although he was particularly knowledgeable about his job and was required to teach others about the job.

According to Life, his family was much the same as other families in the area, who also had migrant worker fathers who were based in Durban or Johannesburg. The children of the community all had to walk the same long distances to school. However, Life distinguishes his family from others in his community by indicating that his siblings and parents had better attitudes towards schooling than those prevailing in the community. This led to himself and three siblings completing matric, whereas many of his older siblings' peers only finished primary school. Life's oldest brother became a teacher, he himself has completed a certificate course in Community Based Rehabilitation and his younger sister is a qualified ABET educator, having completed a course through UNISA.

Life's earliest memory of people being different from each other was when he was about 9 years old. At this time in his community, people were talking about white people being better than the people of his community. As Life recalled:

> "people keep on talking that whites were better than us. So if you were doing something good they would say that you did it like a white man. So though I'd never seen a white before, but I already knew that they were better people."

Thus people or families who had sufficient food and possessions were referred to as White. At around about this period in Life's life, his older brothers were also telling him

that if they came from a rich family, Life would go far with his education. In discussion with his brothers, Life found out that the reason they were not rich was because their father was not educated. Thus, at a young age Life became aware of difference both in terms of race and socio-economic status.

Life enjoyed his years at the local primary school and during this period he did well at school. Life recalled learning about Zulu culture and the Zulu kings from books he was given to read while at primary school. According to Life, he had an enquiring mind even as a primary school pupil. When he read about Zulu history and the fact that previous kings had fought the Whites, he began to question why the current Zulu king was not also fighting the white people. Life also imagined what he might do if he were the king.

> "When I was at primary school there were books that we have to read about the Zulu culture and the Zulu history. So some of the things were not in books, the teacher would tell us that that's what happened during the time of those Zulu kings. So that's how I became aware. So from then I started to have questions …. [The questions came] From my own thinking because I know that we still had the King but all the kings that came before him were fighting the Whites. But I couldn't hear what he was doing, so I was thinking, what I would be doing if I was him."

Life passed all his classes at primary school and was promoted to high school. As there was no local high school, Life and other children from his area faced a 10km walk to and from school every day. During the first three years of secondary school, Life would wake at 4a.m. so that he could leave home at 5 a.m. to walk to school which started at 7.45 a.m. The journey to return home started at 3 p.m. after school and Life would arrive home at about 5.30 p.m., to check that all the family's livestock were at home. Fortunately he was given little homework, but he had difficulty studying at home as he was required to do. In later years, Life realised that the long distance to and from school and the lack of time to study was probably the cause of his marks dropping in high school. Life enjoyed high school although there were some subjects which he did not enjoy at all. Life had difficulty with maths. He also disliked Afrikaans.

> "I didn't like Afrikaans because of Apartheid. So I had that attitude and really struggling to learn it. And I remember that when I was going into Std 9 and 10 I didn't even do it. I just refused to do it. But now I can see those are the mistakes that I made because if I was patient enough to do Afrikaans I could have got maybe a better matric result. So that really was not a good idea."

Life was good at physical science but when he changed high schools at the end of Std 8, science was not offered as a subject.

The high school years were also a time of growing political awareness for Life. As Life lived in an area that was part of the KwaZulu homeland, education in the area was controlled by Inkatha. During Life's first year of high school, all pupils were taught about Inkatha. Life was happy to learn that there were people (Inkatha members) who were doing something about the situation of Blacks under Apartheid. However, he reports that even at that time, he had questions about the tactics Inkatha were using. Inkatha apparently insisted that Black people must talk to the Whites, however, Life did not hear of any meetings between Inkatha and Whites at that time. Life felt puzzled about why there were no meetings between Inkatha and the Whites they were supposed to be negotiating with.

In his second year at high school, another teacher was employed at Life's school who took the opportunity to tell the pupils about the political situation in the country. During 1985 and 1986 this teacher helped to politicise the students and taught them about the African National Congress (ANC). What Life heard about the ANC and its armed struggle, resonated with his thoughts that the *amakhosi* (chiefs) should be engaged in armed conflict with Whites. Thus, according to Life's way of thinking, the ANC was the organisation that he felt was likely to change the situation in South Africa. However, at the same time, in his community, people were listening to the Zulu radio station which had a different view of things.

> "I'd already heard from the radio that there were people called *amaphekulaskoni* (literally the people who burn up your firewood, but

used with a very negative connotation to refer to ANC members). So the radio will say that they were very dangerous in the society. So when I, I wasn't aware why they really are. Just like a story that does not reflect reality. So when I, the teachers started teaching us about the ANC, he taught us that the people that are called *amaphekulaskoni*…. they were not really *amaphekulaskoni*. But it was the word that was given to them so that we fear them."

According to Life, the word *amaphekulaskoni* was used to create a sense of fear in the communities where people listened to the Zulu radio station, but for at least some of the students at Life's high school, the teacher clarified for them what the ANC members were actually doing. Towards the end of 1986, this teacher was dismissed from the high school. At this point, all the students of the school came together and demanded that the teacher be reinstated. Violence ensued which resulted in the school being closed. Fortunately the school was closed very late in the academic year and the school principal managed to use the students' marks for academic work done during the year to fail or pass them. The violence and closure of the school resulted in Life being moved to a different high school to complete the rest of his schooling. Life passed his matric at the new school, but he did not study further immediately after school.

According to Life, his own and his brother's experiences in the workplace provided significant learning about oppression during his adult years. During this time the issue of class oppression became more apparent to Life, although it was intertwined with racism. Life and his two older brothers were very close to each other and they shared a dream that if one of them managed to improve his situation in life, particularly economically, he would help the other brothers. Life's one brother was employed by the Railways and in 1990 there was a massive strike in the organisation. Life's brother was a shop steward during this time and he kept his brothers informed of how he and others were treated by their White co-workers as well as letting them know what was happening in the strike. Life felt that part of the reason his brother told them about the strike, was so that Life and the oldest brother would not think he was letting them down in their dream of improving their lives. Life agreed with his brother's motivation to participate in the strike and from

his own knowledge of history he had seen that strikes can produce change. At around the same time as the strike, Life recalls:

> "So there were a lot of things that were influencing me. So like I was listening to the radio at home and I was able to listen and by then I remember that I knew that the South West Africa was already out of the, was already independent. So I knew that everybody must do just something, then things will change.

These two events confirmed for Life that if everybody does something, a situation of oppression can change.

Some time after completing school, Life managed to find work in Durban. However, he describes one job he had there as a real low point in his experiences of oppression. Life was employed by a White man who exploited his workers and according to Life, he did not respect any of the labour laws. The workers worked seven days a week and were not paid for their overtime work. Although Life hated what was happening at the workplace, he felt trapped because he needed the work. Life was sure that his anger was apparent to his employer. The employer also saw on occasion, that Life was reading a book about difficult social conditions, which made the employer realise that Life understood that what was happening in the workplace was exploitation. This together with an occasion when Life wrote a letter to the employer complaining about working conditions, fuelled the dissatisfaction of the employer.

> "But I was also happy because I could see that he (the employer) also was in a tough situation because from the start I was the one who was like understanding the job better and helping others. So he couldn't just chase me away there. And one day I wrote him a letter complaining about the situation. He started calling me Mr Shop Steward. But I could see that he was calling me that like as a way of insulting me."

Although this experience of oppression was of a White person exploiting a Black person, Life related it clearly to an example of classism, saying that similar situations occur often between rich and poor, regardless of race. Life feels that rich people often treat the people who work for them as part of the equipment they use to make money.

During this period when Life was working in Durban, he received a letter from friends in his home community warning him that those members of the community who were labelled as ANC sympathisers were being targeted by IFP members in the community. Although Life was very concerned about the situation, he could not return to his community at that stage because his friends indicated that he would endanger himself by doing so. Even with the change to a democratic South Africa in 1994, it was still dangerous to be seen to be part of the group aligned to the ANC in Life's community.

> "even after 1994 it was still dangerous and if you were in the group that was seen to be aligned with the ANC it was not, it was always being targeted. They always said that for instance if they have their meetings, they would make sure that they bring you to the meeting by force, probably to show those who might want to join ANC that is how we deal with such people…. I remember when we went to vote, I even thought that it would be helpful if I vote for the ANC nationally and vote for the IFP provincially so that at least they have some power."

In spite of these tensions in his community, Life identified that the transition to a democratic South Africa has been the highlight of his life with respect to learning about and overcoming oppression. In a similar vein, he feels that the liberation movements, specifically the ANC and the PAC (Pan African Congress) have been most influential in developing his understanding of oppression.

When Life's job in Durban came to an end, he bought himself a car with the idea of starting a business with his brothers in his community. However, disaster struck eight months later when he was involved in an accident and his car was written off. This was a major turning point in Life's life, as his dream of improving his economic situation and that of his brothers was shattered. Life felt that getting a job again would be impossible and he had lost what he invested his finances in. He realised that he would have to start all over again although he had no idea what he would do. Life did get involved in activities in his community, but his dream of improving himself and his brothers took

another blow when his brothers died some years later. From these experiences Life has learnt to be cautious and that plans and dreams can be destroyed very quickly.

After Life returned from Durban, in 2001, he initiated and became involved in social action in his community. Life noticed that there was a problem in the local primary school, with teachers not coming to work on Mondays and Fridays. Although Life was very upset about the situation, he realised that if he acted on his own, the situation could backfire. Thus he encouraged the youth in his community to form a committee. The youth committee decided on several actions they would take to develop their community, including addressing the situation at the primary school. Initially Life and the youth committee asked the school governing body (SGB) chairperson to convene a meeting. The chairperson did not convene the meeting, so Life went to the school and talked to the teachers who were part of the governing body. Life asked for the school's constitution, which the teachers could not give him, but instead they gave him a copy of the South African Schools Act. He familiarised himself thoroughly with the Schools Act and found some loopholes that would allow for the youth committee and community to intervene. Life and the youth committee returned to the school and requested the teachers to convince the SGB chairperson to hold the meeting. However, the teachers went to the school inspectors and reported they were afraid for their lives. The police were called to the school to sort out the situation with the youth committee. When the schools inspector spoke to the police, he realised that there were no safety issues and he came to meet with Life and the youth committee.

> "Luckily when we had the book, the Schools Act book, I read it well, so I used it to explain the duties of the governing body and the rights that as a community member, I have at school. So the inspector was impressed with my explanation and he asked me to set the agenda of the meeting that I wanted. So I told him what I wanted. So he said "Okay, let us go now and discuss all the points that this committee wanted to discuss with the governing body and see what was wrong." Luckily the, in the minutes of the governing body they had, they had the problem of teachers who are not coming at school on Monday and on Friday. So we proved that we were not lying about it and

the inspector asked the teachers if that was true. And there was no way that
they could deny it because it was in the minutes that were not even on it. So
they had to tell the truth. And that's how we won that one."

This very positive experience of social action and the changes it can bring led to Life
being seen in the community as one who is active and wants to participate in community
activities. This in turn opened a number of doors for Life, particularly regarding further
training. When there was an opportunity given to Life's community for someone to be
trained as an eco-tourism bird guide, it was Life who was selected for this training.
Again when the opportunity arose for a member of the community to be trained in
Community Based Rehabilitation, it was Life who was chosen to attend training in
Pietermaritzburg. Life feels that since his participation in the action to address the
problem of the teachers at the local primary school, people in the community started
having confidence in him and because of his participation in community activities, he
was able to improve his networks with people.

Through reflecting on his experiences, Life identifies the biggest challenge he has
experienced regarding oppression and social action as:

> "I think maybe the biggest challenge is that people don't want to do
> anything. So if there is a situation that needs to be changed, people don't
> want to take action and I know that you cannot change the situation alone.
> So getting people to move is a real challenge."

In order to address this challenge, particularly with regard to issues in his own
community, Life has tried to influence a close group of family and friends to think the
way he does and to act on situations within his community. This group of 6 or 7 people,
including Life's younger sister, have got involved in both the development committee
and the school governing body in their area. Life has also developed a very active
understanding of change, realising that if change is to occur it has to start with one person
(often himself) and then spread to other people who will help the transformation to occur.

These reflections on social change and oppression have also influenced Life's current work in CBR and disability. He is concerned about the local councillors' lack of delivery to improve the situation of people with disabilities in his community. This has led to Life educating people with disabilities in his area about their rights, so that together with Life they can fight for their rights and improve their situation.

7.3 Life History of "Zanele"

Zanele was born in 1970 and grew up in a community near Kranskop in rural KwaZulu Natal. During her early childhood Zanele lived with her mother, two older sisters and two younger brothers. Zanele's father was a migrant worker in Durban. At the age of 4 years she contracted polio, an event that has subsequently defined her life. At this tender age, Zanele was hospitalised away from her family in Durban for over a year. During this period she had two operations on her hips and ankles, after which she was taught a new way of walking - with callipers. Following the two operations, Zanele's disability has not changed significantly throughout the rest of her life.

As a young child returning home from hospital, Zanele recalls that at home her parents and siblings treated her in the same way as all the other children.

> "My family treat me as other children, especially my mother. My mother let me play with other child and let me to work at home, the housework. To do all work as other children. She not treat me like a person who is sick, she treat me as other children and she helped me when other child look at me in fun and laugh. She told me, "Don't worry, the other child not understand about disability.""

Zanele played with other children and she was punished in the same way as any other child would have been for her misdemeanours. Although Zanele was beginning to think she was different from other children because of the way they treated her, her family affirmed her through their even-handedness in dealing with Zanele and all her siblings.

In the mid and late 1970s in Zanele's community, there was a prevailing attitude that people with disabilities should stay at home and they should not be involved in activities that contributed to the running of the home or community life. Thus it was in strong contrast to this dominant preconception, that Zanele's mother taught her to do different aspects of the housework. Zanele recalled one incident when she was a young child, where the attitude of a community member clashed openly with her mother's progressive ideas of what her daughter could do. A woman from the community came to visit Zanele's mother. In showing hospitality to the guest, Zanele's mother offered the lady tea and asked Zanele to pour it.

"The visitor said "No, why do you ask this child because she is not able to do all
things?' And my mother told the visitor "No. It's no problem. My child is
not sick, she is only disabled. She is able to do all kinds of work.' My
mother taught me everything."

The visitor felt that Zanele's mother was abusing the child. Zanele's mother explained to the lady that it was important for her child with a disability to learn to run a household so that if she passed away, Zanele would be able to cope on her own.

The negative attitudes and misunderstanding of the community towards people with disabilities were also evident to Zanele when she went walking in the community as a child. People would tell her not to go to the tuckshop because it was too far for her to walk and she should be staying at home. Numerous times she was also told to use crutches or a walking stick, although she explained to the people that she could walk adequately just using callipers. It seemed that some community members thought Zanele experienced pain when she was walking and others thought that Zanele was being rude when she refused their offers of walking sticks etc. One incident was especially hurtful to Zanele when she was a child. She was waiting in a queue in the local hospital when a nurse asked her to take a note to another staff member in a different part of the hospital.

"I was in the hospital, sitting there on a bench and a nurse asked me to go
to another ward to ask for a nurse. She gave me the paper and when I
stood up and took the paper, the nurse said to me 'Sorry, I didn't see you
(as a person with a disability). You cannot walk' And I told her 'No, no

problem, I can go.' And she refused to let me go. She told me 'No, thanks. Sit down. I'll ask someone else.' But I knew the place. It's not good because when the nurse is doing that, the person is not feeling good."

Zanele felt embarrassed and angry at the discrimination she had been subjected to. These experiences in the community and in the hospital awakened in Zanele a desire to help people understand disability and people with disabilities.

At the age of eight, Zanele began attending the local primary school. She walked to school and sometimes one of her older sisters carried her bag for her. Zanele's sister also helped her to pass the donkeys, which Zanele was terrified of, on her way to school. At school, Zanele experienced discrimination and marginalisation by the teachers. At break time, Zanele was told to stay inside and not to go to the playground with the other children. Zanele obeyed this instruction for two days and then she decided to join the other children in the playground, where the children played with her. In these junior primary years at the local school, the teachers also discriminated against Zanele by treating her differently to the other pupils. When Zanele did not know the answer to the teacher's questions, she was not punished as the able-bodied children were. She was also never punished for getting to school late, although her able-bodied peers were always punished for lateness. Zanele felt this discrimination keenly and was very unhappy about the way the teachers' treatment of her, pointed out to her peers that she was different to them. When she was in Std 1, Zanele's teacher told her mother to take her out of the school and to find a special school for Zanele where she would be with other children with disabilities. Zanele was very upset about this because she was able to walk to school and she felt that she could do all the activities that the other children in her school were doing.

At about this time, Zanele felt that she was the only person with a disability in her community. She was unhappy about this but she tried not to show her feelings to her family who were always loving and supportive of her. She was therefore very pleased one day when her mother took her to King Edward Hospital in Durban to have her callipers changed and she met other children with disabilities there.

After speaking to social workers at King Edward Hospital, Zanele's mother managed to find a space for her daughter to continue with her education at Mason Lincoln School, a special school in Umlazi, Durban. Zanele was a boarder at the school from Std 2 to Std 8. She was happy at the school and she was glad to meet other children with disabilities. This helped her to be less afraid of talking to other people. Zanele particularly enjoyed her father's visits to her. As her father was a migrant worker in Durban, he was able to visit Zanele every Sunday. Zanele experienced her father's love for her in these visits and she appreciated being able to talk to him about what she was enjoying about school, her friends and also being able to ask him for items that she needed. As Mason Lincoln School only went up to Std 8, Zanele returned to the Kranskop area to complete her high school education.

At about this time, Zanele's father died. It was a very difficult time for the family because there were five children to support and her mother was not employed. Zanele's mother started making and selling traditional mats (*ucansi*), as well as raising and selling chickens in order to support the family and pay the school fees. Once Zanele's older sister finished school, she found a job at a high school and started contributing to the family. Zanele's oldest sister has since paid for the second sister to train as a nurse and the second sister has enabled the older of the two brothers to also train as a nurse. In future it will be Zanele's responsibility to assist her youngest brother to reach his dream of training to become a paramedic.

In 1992 Zanele made friends with 2 people with disabilities near Kranskop. One of them was particularly significant in helping to empower Zanele and in enabling her to see the possibilities for independence as a person with a disability. Zanele's friend was a woman with a disability who lived independently with her two children.

> "That lady, she told me she doing everything at home, and she had 2
> babies. Other people in her community, she not separate (from) them.
> She told me she doing everything. She come and bought the grocery.
> And I tell my mother and my mother was, she send me to bought some

groceries. But in the first time she sent me with my younger brother to help me. I go with my brother and buy some groceries. The second time I wanting to go alone. I start to change. I'm not too afraid to go alone. 'Til now in my home I do everything."

Zanele recounted that the high point in her life, especially in her battle against discrimination and marginalisation, was when she passed her matric and her mother and sisters had an expectation that she would train further in order to get a job. This confirmed for Zanele that her family truly treated her in the same way as her able-bodied siblings and that they did not harbour the low expectations of people with disabilities that were prevalent in her community. Again this confirmed for Zanele the importance of assisting as many people as possible to understand disability and to change their attitudes towards people with disabilities.

In 1999 Zanele found a temporary job assisting with the elections at a polling station in her community. During her work at the polling station, Zanele saw many people with disabilities coming to vote. Some of these people did not have assistive devices such as crutches or a wheelchair to help them move. Zanele was especially concerned about one lady who came crawling to the polling station. Zanele wanted to assist this woman to obtain callipers or a wheelchair so that she would not have to continue with the indignity of crawling. Some time after the elections, Zanele found out where the woman stayed and she planned to visit her. However she was told that the woman had recently died. At around the same time, Zanele also decided that she would like to follow up a situation that she had seen when she was a high school student. Zanele had noticed a child with a disability who was about 9 years old who had not been taught by his mother to indicate when he wanted to go to the toilet. He was still in nappies and his mother kept him in the house. Zanele was also concerned that the mother had not tried to teach her child to walk. Although at this stage Zanele had not received any training on disability, she tried to share information about disability based on her own experiences.

Zanele described a low point in her life and her experiences of being oppressed as a person with disability when a few years later she applied to a nursing college to train as a nurse. After filling in an application form, Zanele and a number of other people were called for interviews by the principal of the nursing college. When Zanele's turn came for the interview, she entered the room with the principal of the nursing school.

> "When she (*the principal of Mepho Nursing School*) interviewed me, she did not ask me many questions for the interview. She asked me whether I can walk properly. She didn't see me (*my disabled legs*) because I was wearing a long skirt. She asked me to get up and walk and I walked. She told me that she would not take me into nursing because I'm disabled. I'm not fit to work in nursing. She told me 'I'm not going to continue to interview you.' .... But I think I'm able to do things like other people and I told her that I'm able to do all work except with things that are very heavy. But she didn't hear me. She refused to let me explain to her. Because she told me, "I know you're not able to work.'"

Zanele felt extremely hurt by the response of the principal of the nursing college as it destroyed her ideas of training for a job after completing matric. Zanele felt that this woman had no understanding of disability issues and that it was clear that she disliked people with disabilities. Although this experience was disempowering for Zanele, she still felt strongly that she needed to help people in her community to change their attitudes and to increase their knowledge of disability.

Some years later, Zanele was selected from her community to come to CREATE to study Community Based Rehabilitation. She was happy to learn more about disability, and her experiences of meeting a variety of people with disabilities at CREATE encouraged her to think about a wide range of jobs that people with disabilities can do. Zanele is not currently employed as a CRF. She works in her local hospital as a financial officer in the Revenue section. However, her colleagues at the hospital recognise her knowledge and understanding of disability issues and they often bring children with disabilities to her so that she can explain to the caregiver and hospital staff.

7.4   Life History of "Wandile"

Wandile was born in 1966 and grew up in the township of KwaMashu, just outside Durban, where he lived with his mother, stepfather, two of his three sisters and his younger brother.   Wandile's older brother and sister, who had a different father to Wandile, spent most of the time living with their grandmother, following many fights with their stepfather. Wandile remembers playing happily with his two younger sisters when they lived in KwaMashu. He also went to school with the sister closest to him in age. Wandile's older brother had a hearing loss and did not speak clearly but his family were unaware of disability and when he was stopped from attending school in Std 3 they blamed it on *muthi* (traditional medicine sometimes linked to witchcraft).

Wandile described his stepfather as a crook and an extremely abusive man. Wandile's stepfather gambled, smoked dagga and engaged in criminal activities.   As Wandile explained:

> "He didn't care about us because if he said, 'I don't want you here in my house', he mean it. Because once he see you in the yard here, he will maybe take a axe, even an axe just to chop you, you see because he was chasing us. Even if we tried to go to the neighbours and ask for a place to sleep until tomorrow, once he heard that we are at the neighbour even the neighbour as well is in trouble"

During his years of primary school Wandile experienced merciless abuse by his stepfather. At about 10 or 12 years old, on one occasion his stepfather tied his hands and feet together with a rope and strung him up from the roof. Wandile's father lit a fire underneath him which burnt for an hour. Wandile tried to swing to move away from the heat of the fire, but his stepfather sjambokked him when he caught him swinging away from the heat. On another occasion when Wandile's stepfather abused him in this way,

he left Wandile strung up while he disappeared for the day. When he returned and found that someone had taken him down from the roof, everybody was in trouble.

Wandile recounted another example of his stepfather's abuse when he was in Std 5. Wandile's mother was a businesswoman who ran several butcheries. On one occasion she realised that some money she had brought home from the shops had gone missing. Wandile's stepfather blamed him for taking the cash although the stepfather was reportedly the one who stole the money. Wandile tells the story:

> "He (the stepfather) will hit me and put me to the prison for that because
> he had a cousin who was a detective. Then they put me in prison for like a
> whole week in prison. By that time I was doing Std 5. Put me in prison
> for a whole week. I even go to court for cuts you see. For a thing that I
> did not even do."

This was not the only time that Wandile was imprisoned as a child, with the help of his stepfather and his stepfather's cousin. On another occasion, after Wandile had been playing truant from school, Wandile's stepfather beat him in front of everyone. The stepfather's cousin then took him to a police station and had him locked up for another week – preventing him from going to school.

The vicious and frequent abuse from Wandile's stepfather took its toll on Wandile as well as on other members of his family. Wandile's stepfather seems to have been the direct cause of the older children leaving the household, with physical fights occurring between Wandile's stepfather and his older brother until the brother left the house to live with his grandmother. Wandile describes his schooling as being disrupted, in part because of his abusive father:

> "It was 1979. I was in primary. Ja and I went out of school. You see
> sometimes I go out from home. At home they knew that I am in school
> but I am not at school. I work to taxi rank, just to wash taxis and to be a
> conductor. You see just walking around doing funny things at the taxi
> ranks. I think it's this thing of being taken out from school as well as this
> abusive from my father, you see. My father was abusing me so much, I

was, I lost interest in everything, you see…. Because I wanted to lead my

life you see."

Wandile wanted to try living his own life without interference from his father and so towards the end of primary school Wandile would go for periods of a month or so to work at the taxi rank and then he would return to school. In spite of this disrupted education, Wandile never failed a year at school. He was bright enough to be able to catch up the work he missed. However the abuse from his father did not stop.

"my father (if) he heard that I'm not at school he will hunt me until he find

me, you see. And then he will do the very same thing, to hit me and do all

these things and again tomorrow I will run away and I won't go back to

school."

Wandile's stepfather also raped Wandile's younger sister and his cousin, who fell pregnant from the rape. It appears that these two incidents were what finally pushed Wandile's mother to try and leave her husband. Wandile's mother ran away with the young children to Ixopo. Wandile describes his pain at finding his mother had run away and yet at the same time he admires her strength for trying to carry on with life.

"When I came back, my mother was not at home, even my sister. The

young one was at farm with granny, you see. I was so hurt, thinking my

mother has run away. I looked for her at Umlazi to my granny's home,

then she told me that, 'Do not tell your father. Your mother is not here,

she is at Ixopo.' She is hiding there and there is where she was selling

clothes at all the schools around and trying to carry on the life."

However, Wandile's abusive stepfather discovered his mother in Ixopo. He destroyed her home, took the contents of the house and beat the chief for allowing his wife to stay there. Although Wandile does not mention any further examples of his father's abuse, it is clear that his father continued to be involved in criminal activities. Some time between 1986 and 1991 Wandile's father died while committing a bank robbery in the Transkei.

In contrast to his experiences of his stepfather, Wandile describes his mother as a responsible person who looked after all her 6 children but who didn't like her children to

steal or be delinquents. When Wandile did something wrong, she always wanted to hear the full story before she commented and she did not cover up his wrongdoings but wanted him to suffer the consequences of what he did wrong. Wandile's mother was generous and showed hospitality to community members.

> "Like at home we were having four people staying at home. They were not even my relatives, but they were staying at home, which means that my mother likes the community and they like her. Because we can sleep without food but if a visitor comes, my mother will go out and look for food."

Wandile's mother was an astute businesswoman who started selling fruit and vegetables on the street. From there she saved enough money to buy first one butchery and then a second one in different sections of KwaMashu. Wandile feels that his mother stayed with her abusive husband even though she did not want to because she wanted security and her own brothers and sisters did not support her leaving him (probably out of fear). When she did eventually run away and her husband found and abused her in Ixopo, she divorced her husband and moved to Pietermaritzburg. Wandile's mother had to start again in Pietermaritzburg where she decided to sell clothes at a school. According to Wandile, the period of living with his mother alone (and not his stepfather) in Pietermaritzburg, led to a revelation for him that people could be different.

> "on the time I was staying with my mother and my father together, I thought they are the same…. because my mother didn't cover me from my father. She was doing the very same thing that my father was doing but she wasn't abusing me. But she was hitting me when I have done something wrong….. But when I'm staying with her alone, I started to see the other way now. I said "Oh she is good". She was not aggressive. Maybe she was scared of my father by that time, you see and again she was, she had a relationship with another man and that guy was very nice you see. That's when I started to think I'm having a nice father now, taking out for dinner, you see, playing with me. I never feel that when I

was young. Now I started to see that oh, people are really different, you
see."

While living with his mother and brother and sisters in Pietermaritzburg, Wandile realised how much his mother was suffering, not having her businesses but having to support himself and his siblings. He wanted to help support her. He became involved in crime, stealing cars and committing a robbery in order to raise money to support his mother. Wandile was caught by police soon after he started his crime spree, during his matric year. He was sentenced to five and a half years imprisonment, beginning in 1986.

During Wandile's late childhood and early teenage years in KwaMashu, the community was abuzz with anti-Apartheid protest. Wandile describes himself as first becoming aware of oppression during this period. He became friendly with a United Democratic Front (UDF) activist who conscientised the school children of Kwa Mashu.

> "I thought about that (oppression) when I was doing Std 5 because of all
> these, you remember the strikes? What is this? This march for the
> children at school. You see, the time of the UDF, that is where I saw that
> we are oppressed here, because there were leaders who told us about our
> rights and all these things, you see. That is where I started to see that we
> are oppressed, really oppressed."

Through this activist, Wandile became aware of and participated in marches and other social action such as barricading of roads and attending rallies in Kwa Mashu. He was part of a drama group that informed people of their rights. Wandile felt that this UDF activist had empowered him to fight for his rights.

Wandile's prison experiences also brought home to him the meaning of oppression, particularly in the form of racism. Wandile was incarcerated at Waterval prison in the Utrecht area, where there were a number of White, Afrikaans warders. Wandile describes his first experience of the harsh treatment of Black prisoners thus:

> "You see if you are Black, once you come from like Durban, they will
> beat you from morning to the afternoon. They said they taking out the

Durban dust, you see. And especially if you are Black, in that prison you will suffer actually ….. I felt very bad. I wished I was at least a Coloured or an Indian, because I saw the way they were treated. Once a Coloured came to that prison, they become 'A' group. 'A' group has a very soft way in that prison."

One of the prison majors was particularly vindictive towards Black prisoners, punishing them severely for a minor 'offence' such as not having all the buttons of their prison uniform done up. Wandile was punished for such an offence and had three days without food. During this time he tried to sell dagga to get some money to buy food. He was caught and was punished with 21 days of solitary confinement, of which 15 days were without food and for 6 days he was on a half ration of food. Although Wandile did not expect an easy life in jail, he identified the treatment that he and other Black prisoners received as part of their oppression.

"That's when I saw that this is oppression. The oppression is a very bad thing….. It's a lot in South Africa, because I was in jail here in South Africa and I saw that oppression came from a White person to a Black person, you see. And I really started to hate White people. Because even the Black warder he saw the difference it's not good that's happening there. It's done by this White warder. Because if there was no White warder, we were treated like softly better than that White people was treating us, you see. That's when I saw that oh, okay, which means it's the White people oppressing us really."

In spite of, or perhaps because of the harsh treatment Wandile experienced in prison, he took a decision never to go back to prison. During his period in prison, Wandile spent time reflecting on his life and he became determined to come out of prison and show his mother how he had changed. Unfortunately Wandile's mother died three or four months before he was due to be released from prison. This experience was a key catalyst for change in his life:

> "So when I came out they were dead, even my father. Then I said I have
> to work to look after my brothers and sisters. Helping my brothers and
> sisters, helping them go to school because they were younger than me. To
> buy a house for them, I did all that."

On his release Wandile told all his family and close friends about life in prison and the importance of leading a life that would not end up with a prison sentence. Since his release in 1991, Wandile has not been back to prison.

Once out of prison, Wandile's first job was with a company where he experienced racism. Wandile stood up to this bitter personal experience and attempted to overcome his oppression by confronting his boss.

> "That is where I saw that these people are trying to violate our rights
> because when you are working you have to be the same, you see. But the
> Indians, they were like on top of us. All the time they want us to do the
> job but they will get paid more than us. That is where I saw I cannot work
> like this. I have to talk to my boss about this. I talked to my boss about
> this, then he fired me. So that there is no truth. You can see what is
> happening, but once you talk, he fires you. He does not want you to talk,
> to fight for your rights."

Wandile continued his involvement in social action and addressing oppression once he started working in the field of HIV/AIDS. With the support of the youth, he formed a drama group that did dramas on human rights and also on HIV/AIDS in his community. He continued his work as an HIV/AIDS trainer and home based care co-ordinator until October 2003 when he was selected to study Community Based Rehabilitation at CREATE. During his training and subsequently when he qualified, Wandile was employed by a state-aided hospital. Here too, Wandile felt he was exploited because of his race. He felt he was expected to work harder than people of other races while receiving a lower salary. In addition he felt he was not taken seriously:

> "You can't even say a word, just for like, you can't say your opinion. If
> you have an idea like you want to say something or to ask them if you can

change this, you can't say that. You can't tell them what to do to change uh the environment or to change … But you find out at the end of the day or some day they will do exactly as you said. They taking your idea. They use your idea as their idea but the time you're saying it, they just ignore you, you see ……"

In spite of these negative experiences at work, Wandile managed, while he was a CBR student, to help organise a march of people with disabilities in his community at which the people with disabilities were to present a memorandum to the Ethekwini municipality outlining the various barriers that they experience in the community. Wandile encouraged the people with disabilities to organise a march, based on his previous experiences of social action.

"I was thinking about the march we were doing before. This makes me see that if you march, things are happening, because that is how the people can see that these people are serious.... If you just talk by yourself, they do not even take notice of you. If you are a crowd, they take notice of you. Even the media can rush to that place."

In 2007 Wandile participated in the public servants' strike because he was feeling very angry with his employer. He joined the union to pay revenge on his employer who he felt was discriminating against him and exploiting him. The result was that he was dismissed from work, although government employees who participated in the strike in other institutions were only given final written warnings. Although he is really suffering financially since his dismissal, Wandile feels that it is positive that he is now trying to set up his own business and be independent, rather than depending financially on an employer who may be oppressive. His hearing impaired brother helped him to develop his ideas for Wandile's own business.

While Wandile was studying CBR, he discovered he was HIV positive. This he identified as a key turning point in his life. Wandile describes himself as a person who enjoyed drinking a lot and smoking and going out with girlfriends before he discovered

his HIV status. Since that time he has stopped drinking, smoking and going out and he has started taking care of his family.

Having learnt from the various experiences in his life, Wandile now has the attitude towards social action that :

> "tomorrow I will say the thing happened because I struggled for it. You cannot say you struggle for a thing and you are at home.... Linda (UDF activist) came to me and empowered me to fight for myself like I am doing now. I am empowering these disabled people to fight for themselves - to fight for their rights. It is the same like before."

7.5 Life History of "Nomusa"

Nomusa grew up in the rural area of Makholweni, Centocow in KwaZulu Natal in the late 1960s and '70s. She was the oldest of 8 children born of the same mother but different fathers. Nomusa lived with her grandmother and later with one of her aunts. The only times she saw her mother were when her mother brought another child for the grandmother to look after and on the odd occasion when Nomusa's mother brought a new boyfriend or fiancé to Centocow. There was some confusion about who Nomusa's father was with two men claiming to be her father, until in 2002, Nomusa met her real father.

Nomusa experienced a very difficult childhood. Her mother did not contribute in any way to her upbringing, and the lack of financial support for the children she brought to the grandmother to raise, meant that the family lived in poverty and Nomusa's grandmother had to get a job in Cato Ridge, more than 100km away. Nomusa and her siblings often experienced hunger and when food ran out in the middle of the month, they would have to ask neighbours for food. Nomusa had no shoes and only one dress. She remembers the relief and joy of her grandmother coming back to Centocow on leave:

> "my granny was so supportive because I remember that her leave was always in July. She would come with a pack of these second hand clothes.

There was bread. I think it was bread when they cut the crust. She will come with sacks of that, dried, and we were enjoying that food and there was much of it."

Nomusa's earliest memories of people being different to each other were related to her experiences of poverty. She recalled noticing the difference between herself and her family and their neighbours who were the richest and most well-educated people in the area. This family gave Nomusa and her family milk and vegetables. Nomusa blamed her mother and her aunt that she lived with in Centocow, for the situation of poverty they were in, especially because neither had gone far with their education, although their father (Nomusa's grandfather) had been a school principal.

On two occasions, Nomusa missed weeks or months of schooling because of the family's poverty. When Nomusa was in Standard 1 she stayed at home because there was no money for her school fees. When her mother returned home during this period, the teachers asked her mother for the school fees. Nomusa's mother denied that she was the mother of Nomusa, claiming instead to be her sister. From that time, Nomusa stayed at home for about 3 months before the principal called her back to school. As Nomusa relates, a similar situation happened when she was in Std 4:

> "When I was doing Std 4 I couldn't go to school again because the uniform was compulsory at school…. I couldn't go because I had no uniform, no stationery. I stayed (at home) until April, it was around Easter. The priest from the Catholic Church was passing by. He asked why I am not at school. I told him that I have no money for uniform and stationery. He went to talk to the principal at the school and came back and said 'Tomorrow you are going to school.' He took me to town and bought me stationery and uniform and then I started school."

The poverty that Nomusa's family experienced not only kept Nomusa out of school, it also affected her school day. Frequently she did not have school lunch and her friends would share food with her. At one stage, before school, Nomusa would have to change

the nappy of her younger brother and feed him. Coming home from school in the afternoon, her duty was to grind the grain so that the family could eat *phuthu* that night, and often there would be no fat or salt with the *phuthu* and vegetables. Nomusa had a special school friend who helped her when they both needed shoes and Nomusa did not have any. When the girls went to church, Nomusa's friend would hide her shoes in the forest so that both girls would not have shoes and the priest would not say anything.

During her years growing up in Centocow, Nomusa often experienced disappointment at the hands of her mother. When her mother did come to Centocow, she would be wearing expensive clothes and shoes but she would bring nothing for the children. One occasion was different:

> "She bought (for) me once. It was a skirt, a six-piece skirt. It was yellow and (there was) a green T-shirt. Oh! I was happy. Maybe she was coming to her senses. It was Christmas when I was coming back to town and she took it (the skirt) away with her."

This event made Nomusa doubt whether this woman was really her mother. Nomusa's granny replied that her daughter (Nomusa's mother) would never change. Nomusa's mother appears to have been irresponsible with all her children and Nomusa recalled how her mother tried to dump one daughter with a domestic worker in Cato Ridge. Nomusa's grandmother found out about the baby and brought her home to Centocow. About six months later Nomusa's mother fetched the baby from Centocow, saying that she was taking the baby to her boyfriend (the child's father). Later Nomusa's granny found that the baby had been dumped at an orphanage at Marianhill. Another younger brother was also dumped at the orphanage.

In spite of Nomusa's very difficult experiences with her mother, she describes her grandmother as a very supportive and kind person. Nomusa's grandmother had trained as a nurse and she wanted her granddaughter to become an educated person. Her grandmother belonged to the banned South African Communist Party and on one occasion this impacted on Nomusa's life. Some Communist Party members had come undercover to the community of Centocow to preach socialism to community members.

Someone called the police to arrest the Communist Party members, but Nomusa's grandmother chose to hide some of them when the police came. Nomusa and her siblings were warned not to tell anyone about the hidden visitors. Nomusa was curious about these people who seemed to choose not to use trains and cars. Although Nomusa's grandmother was a member of the South African Communist Party, she also carried an Inkatha Party membership card in order to avoid trouble in her community. Inkatha was in control of the KwaZulu homeland of which Centocow was a part. Community members who did not have an Inkatha membership card were victimised and Nomusa's grandmother would not have received her pension without the Inkatha card. However the Inkatha membership cards also caused problems for Nomusa's family as some of her brothers refused to hold Inkatha cards and they had to move away from the family to town which was part of South Africa and therefore not under Inkatha control. At about this time, Inkatha was active in Centocow with a group of Inkatha members coming from Ulundi (capital of the KwaZulu homeland) to hold meetings in the community. Nomusa was afraid and didn't like these politics because she felt they were separating people and families.

Nomusa started her high school years in Centocow, up to Std 8. In Std 8, she had a boyfriend who was at university and she fell pregnant with her first child. While Nomusa was pregnant, her mother met Nomusa's boyfriend in a tavern. Nomusa's mother and her boyfriend ended up sleeping together which Nomusa found out about. Nomusa immediately broke off her relationship with her boyfriend and her relationship with her mother worsened considerably. Various family members urged Nomusa to talk to her mother about the incident, but she refused, wondering what there was to say to her mother.

By the time Nomusa was to enter Std 9, her aunt had finished her studies to become a teacher and Nomusa moved to live with her aunt in Clermont, near Durban, and to complete her high school years there. Nomusa describes this aunt as a sweetheart who cared well for Nomusa, buying her dresses and everything she needed. Their relationship was like a mother and daughter relationship which extended into Nomusa's adulthood, to

the extent that when her aunt died, Nomusa discovered that her aunt had named her as the beneficiary of her policies.

The high school years in Clermont were also a very troubling time for Nomusa, with the political turmoil in the area. There was much fighting between supporters of the United Democratic Front (UDF) and Inkatha in the area and schoolchildren were forced to take part in the turmoil. Nomusa remembers the events and her great fear thus:

> "there were those riots in Clermont. There was this fight against UDF and Inkatha Freedom Party because what I can remember is that most people who were targets were the stakeholder or people who were on top in the UDF, which were killed, killed, killed. And we had to be taken out of school to go to the house of Mhlahlo Mlotshwa to throw stones. We couldn't even see the house there because it was like a dam…. But there were those who were leaders, we had to throw stones….. but it was bad because if you were caught you had to go to jail, but I couldn't even go to school. I had to hide because I was afraid, I was afraid of something like that."

Many people were killed in Clermont, including the wife of the now, Judge Shabalala, some of the family of Archie Gumede, a prominent UDF leader, and others. The KwaZulu police who did the work of Inkatha Freedom Party, were seen as very dangerous and they injured a number of school children. On one occasion, Nomusa's brother was taken by one of the councillors and injured. The councillor seemed to think he was dead and covered him with mud. Nomusa's brother survived and she had to clean out the mud from his ears and mouth. Nomusa found Clermont a very scary place to live in and she was fearful of being out in the community or near bus stops by six in the evening because of the fighting.

These experiences of being caught in the fights between UDF and Inkatha in the struggle for freedom in South Africa have had a lasting effect on Nomusa, as she relates:

> "I was afraid of all these things, riots and all these things. I don't want all those things. I had enough of it because we were forced to do those

things. It was not (whether) we like it or not, we had to go. If they say 'Out of school' we had to go…. It had a bad impact (on me) because I don't want something that will cause problems to me. I don't want to involve myself in anything or whatever. That's why I thank for that I didn't go to the factories to work to do all these toyi-toyi (protests). I don't want that."

This fear of conflict and protests has permeated into Nomusa's work in CBR, as she explained that she was scared to make contact with local councillors and to get involved in community development meetings because of her experiences of involvement in politics and because at the one meeting she went to, someone was shot and there was fighting.

After Nomusa finished her schooling, she wanted to enter tertiary education. However there was no money for her to receive any further education. She felt oppressed because of her social class and she realised that it was because she was poor and because she didn't know anyone who was highly educated and from a well-respected family that she could not go further with her education. At the time, Nomusa felt that if one is poor, one ends up being "nothing". She blamed her situation on her mother, who she felt could have done something for her children. Nomusa stayed at home and then worked for a year as a domestic worker in Marianhill, which she did not enjoy at all.

Nomusa decided to try and get a job at a hospital in Marianhill. She applied to a nursing trainer with her application letter and certificate but was told that there were no jobs. She was given forms to fill in and she returned the following day with the completed forms. Because of her persistence, she was accepted for training as an assistant nurse at the hospital. Some time after becoming a nursing assistant, Nomusa was stationed in the Physiotherapy department of the hospital. She was then selected to train as a physiotherapy assistant at the University of Durban-Westville. Since that time Nomusa has worked in the Physiotherapy department at St Mary's hospital and it was from there that she was chosen to attend the community based rehabilitation course at CREATE.

Nomusa has a dream to study psychology one day, but in the meantime she feels that she is a role model for poor people who have little support as she came from such a background and yet now she has completed three courses and sees herself as an educated person. However, she is aware that social class and poverty do disadvantage people, as it is the richer people who can afford to send their children to better schools.

According to Nomusa, the most positive aspect of her adult life, especially in comparison to her childhood, is that she got married and has a happy family. The family have their own house and her children want to be educated. This experience of a happy family, even with its problems, has changed her life. Recently however, her family has also been a cause for concern as her husband became ill and was being investigated for cancer and other diseases.

7.6   Conclusion

In this chapter I have collated the written life histories of four people who were CBR students during the period of the action research in this study. Although, in the writing of the life histories I have tried to stay as close to the interviewees' words as possible and the stories have been checked by the storytellers, the life histories necessarily represent a particular version of the self and reality which the storytellers wanted to tell and to be heard. As Chase (2005) indicates, a narrative is produced in a particular setting for a particular audience and purpose. The storytellers were aware of the purpose of the research and, to some extent, of my own history. Thus what is captured in this chapter represents the storytellers' constructions of themselves for a listener who they knew to be interested in oppression in all its forms and liberation from this oppression. Not only will the participants have constructed their stories for a particular audience, they have also constructed their stories of past events and experiences in the light of who they perceive themselves to be now. Thus Life's overtly political story of his youth and childhood may have been framed as such to explain who he sees himself as now.

Through listening to the life stories and co-constructing the life histories, I have discovered a richness and a depth which can give meaning to what usually happens in the classroom. In the following chapter I will explore what can be learnt from these life histories in order to develop a model of CBR curriculum.

CHAPTER 8

WHAT MAKES A SOCIAL ACTIVIST? LEARNING FROM THE LIFE HISTORIES OF CBR STUDENTS

8.1   Introduction

Although each life history recorded in the previous chapter tells a particular, individual story, there are many issues we can learn about by analysing the life histories and by making some comparisons across the different stories. In this chapter I explore issues related to narrative and identity, with a focus on identity and activism. I then go on to examine the life histories through different lenses in order to obtain a fuller understanding of what contributes to CBR students' involvement in social action (see Figure 8.1 below). These lenses are different forms of analysis that I use, firstly to examine what arises from each life story by using holistic-content analysis and then by examining the life histories using two different theoretical constructs, contamination and redemption sequences and Giddings' (2005) theoretical model of social consciousness.
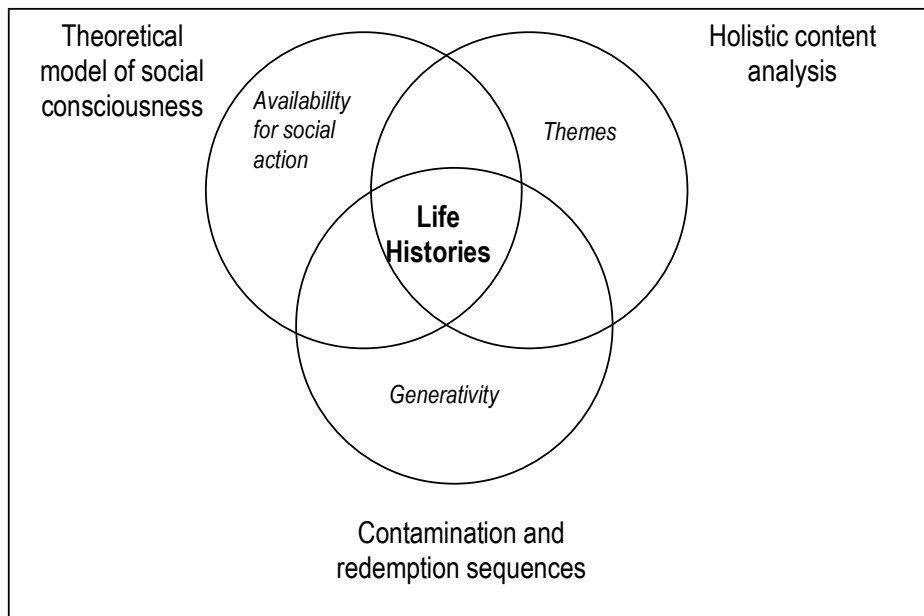

Figure 8.1: Different lenses for analysis of the life histories

The issues of agency, social action and resistance are found in the life histories through the different forms of analysis and I end the chapter with a discussion of what the CBR students' life histories can tell us about the different ways in which they responded to the CBR curriculum.

8.2 Narrative, Identity and Activism

In order to understand the relationship between the life histories of the CBR students and their identities as explored in this chapter, I will begin with a discussion of issues related to narrative and identity.

In the study of identity there appear to be two main approaches to or understandings of identity. One understanding of identity, which arises from Enlightenment and Romantic periods, views identity as essential, pre-discursive and stable, underneath whatever may be presented in different situations. An alternative view of identity, linked to postmodernism, is that identity is constructed or performed and thus interpreted by other people (Benwell & Stokoe, 2006). In this view, identity is linked to discourse and is seen as fluid, fragmented and dynamic. Thus identity is not an essence but rather a description which is a product of the dominant discourse and may be constrained by forces such as institutionalised power structures. According to Benwell and Stokoe (2006) discourse approaches to identity recognise that identity can either reproduce and/ or destabilise the discursive order. Thus an active speaker will contest and negotiate his/her identity through discourse.

In relating this view of identity to life narratives or life stories, Taylor (2006) explains that a life story can be seen as being a construction based on what has been said before, although it may be shaped to the particular situation in which it is told. Fischer and Goblirsch (2006) expand on this explanation of a life story, explaining that there are three key requirements for constituting one's identity through discourse and thus narrating a life story – interaction, memory (particularly autobiographical memory) and biographical experience. These authors appear to address a critique of the social constructionist and discursive approaches to identity that they underplay continuity and coherence in narratives of normal human experience. By positing the

importance of autobiographical memory, Fischer and Goblirsch (2006) claim that the self (selves) or identity does not only exist in the moment of talk. Rather, because of autobiographical memory, there are "consistent patterns residing in memory, constantly reconstructed and/or changed in actual discourse." (Fischer & Goblirsch, 2006, p.29). These authors make a distinction between 'performative narrations' in which a person positions her/himself favourably in the current time, and 'biographical narrations' in which a person gives an account of what s/he identifies as important in his/her development and self-understanding.

In this study I have taken what Lieblich et al (1998) refer to as the middle way in the debates around identity as essential and stable and a fragmented and fluid identity which is discursively produced. Lieblich et al (1998, p.7) refer to this middle course as one in which "narratives provide us with access to people's identity and personality". In constructing a life story narrative, the narrator uses freedom and creativity in selecting and interpreting a core of 'remembered facts'. Thus there are many possible constructions and presentations of one's selves and lives. The life story may also change and develop over time and it will differ in the different contexts in which it is told. This description of the relationships between narrative, life stories and identity resonates with that of Fischer and Goblirsch (2006). Tuval-Mashiach (2006, p.250) captures this relationship thus, "We know or discover ourselves, and reveal ourselves to others, through the stories that we tell." In fact, she explores a reciprocal relationship between narrative and identity, claiming that the narrative that a person creates, tells, revises and retells throughout his/her life is that person's identity although the identity is also shaped by the story.

The above conceptualisations of identity seem to indicate choice in the construction of identities through narrative, although at what level of consciousness, it is unclear. Particular memories are chosen and interpreted in particular ways. A particular identity may be negotiated, contested and chosen to be represented in a particular way. According to this understanding, the speaker or narrator does the selecting concerning his/her identities. However, Bobel (2007) raises an interesting issue regarding activists and identity. In her study, many of the activists she interviewed chose not to give themselves the identity of 'activist', although these people were actively engaged in social action in what Bobel terms 'Menstrual Activism', thus

'doing' activism. Bobel interprets the distinction that her participants made between doing activism and being an activist, as being the result of high value judgements being attached to the label 'activist', which many of her interviewees feel they did not attain. The question then is, who gives these participants the label of activist and of what value is it if the person does not self-identify as such? This relates to the negotiation of identity through discourse but it also raises the question as to whether identity is only something that is accepted and chosen by the person her/himself through language. To what extent do a person's actions confer an identity on her/him in a particular historical moment?

In my study, I have identified three of the CBR students who told their life stories, as activists. This identity was conferred by me on the students after the telling of their life stories, during the analysis of these life stories. Although my decision to call the three students activists was based on their life stories and the literature, there was no negotiation about this identity, and it is possible that the concerned students may not have accepted the label 'activist'. And so the question remains, can identity be purely a project of the self or is it possible for another person to confer an identity on someone else?

8.3   Holistic Content Analysis of the Life Histories

As Lieblich et al (1998) point out, narratives or life stories can be analysed along many dimensions, including content, structure, style of speech etc. I chose to use the holistic-content method of analysis of Lieblich et al (1998) as the first method to analyse the data. By focusing on the content of each life story in specific sections of each story as well as the whole story, I was able to identify themes through multiple readings of the life stories. What I describe below, therefore, is my reading of the themes of each student's life story. Clearly my lens is affected by my own personality, interests and life history. In addition, I had read literature about social activism and life histories before analysing the data and therefore, although I did not intend it, I may have been biased in what I looked for in the data. It is possible that another researcher could see these foci or themes somewhat differently. I have

however tried to justify my analysis through reference to specific events and situations in each life story.

8.3.1   *Lost opportunities yet acting for change*

A major theme running through Life's life story is that of *lost opportunities*. Life starts this theme early on in his narrative, when he talks about his experiences of high school. He feels that he lost the opportunity to obtain a good matric (end of high school exam) for a number of reasons, including that his teachers were poorly educated and that he was unwilling to learn Afrikaans because of its Apartheid connotations. The lost opportunity to do science for matric (which he was especially good at) when he had to change high schools was later a source of regret. In framing all these situations as lost opportunities, Life perhaps links them to one of his biggest "lost opportunities" – to study further after schooling and perhaps therefore to get a better job. When Life narrates his experience of the lack of opportunity to study further, he links it to his concern with financial insecurity. According to Life, his brothers indicated that had their father earned more money, Life would have gone far in his education.

The theme of lost opportunities is also apparent in Life's recounting of the car accident which wiped out his investment of the money he made in Durban to set up new work in the rural area. Not only was this a lost opportunity to make a living in his home area, he also lost the opportunity to contribute to the dream that he and his two brothers had to uplift themselves economically. This dream was dealt a final blow with the death of his brothers. Life's conclusion to this theme in his life story is to say that although things have improved for him, he feels cautious because he has experience of how quickly one can lose all one's dreams and possessions.

Another theme that permeates Life's life story is his *growing political awareness*. From his first memory of injustice through to key events in his childhood and teenage years, Life tells the story of becoming politically aware and he links this story to another theme in his life story, that of resistance and agency. According to Life his political awareness started in primary school with history of the Zulu kings and how they had fought the Whites. Life portrays himself as having a questioning mind at a young age and thus he questioned what the current king was doing during the 1970s

and 1980s. Life's high school experiences continued the growth in his political awareness, first with homeland government sanctioned lessons on Inkatha and then with lessons on the African National Congress (ANC) from a teacher who was later dismissed. At this time the intersection of the theme of growing political awareness with that of resistance and agency becomes noticeable – Life feels that the ANC is the organisation that he believes will bring about change in Apartheid South Africa because they are acting and engaging in armed struggle in comparison with Inkatha who talk about negotiations but there is no evidence that they were actually doing anything. The theme of Life's growing political awareness is also apparent in his telling stories of being labelled by the community as ANC and therefore being persecuted and ostracised. In Life's life story, the theme of growing political awareness seems to culminate in a demonstration of political maturity when Life discusses how he considered splitting his vote in the first democratic national and provincial elections in South Africa in 1994 (voting nationally for the ANC and provincially for Inkatha), so that he could support the ANC but give some power to Inkatha.

A strong theme in Life's life story, as he told it in this research, is the theme of *resistance and agency*, particularly into his adult years, although, as pointed out in the previous paragraph, his concern with taking action was clear in his story of learning about the Zulu kings during primary school. Life recalls that the teacher at his high school who taught the students about the ANC encouraged them to become agents for change in South Africa and Life and other students heeded this call when the teacher was dismissed. Later, Life recalls that Namibia's independence from South Africa was a motivating factor for him in his life because he realised that if many people in a country take action, situations can change. In Life's life there are a number of examples of him being an agent of change for unjust situations – writing a letter to the employer to change exploitative working conditions and acting with others to change the education situation in his community. The theme of resistance and agency is clear when Life reports that his biggest challenge is when people (from his community, his workplace etc.) are not willing to act to change a situation. To this end he has formed a group of six or seven people from his community with whom he can work to initiate action in his community. For Life the theme of being an agent for change is a positive one as he indicates that being a person who is involved and active has opened several

doors for him, including being selected to do an eco-tourism bird guiding course and being selected to do the Community Based Rehabilitation course at CREATE.

As mentioned previously in this thesis, the life histories in this research are topical life histories with a specific focus on the narrators' experiences of oppression and social action. Thus it is not surprising that Life develops the themes of his own political growth and of resistance and action for change through the telling of his life story. Perhaps with another set of questions, Life may have narrated his story with a slightly different emphasis. What is noticeable is that his feeling of having lost many opportunities to improve his life has not prevented him from being concerned with and actively initiating and participating in social action. Perhaps although one aspect of Life's self is disappointed with losing potential opportunities to improve his life, another aspect of his self celebrates the opportunities gained through his activism in his community.

8.3.2 *A public and a private discourse of disability*

It seems that in Zanele's life there has been a discourse of disability within her family which is at odds with the public discourse of disability that Zanele has experienced. The first theme, which begins from the first words of the second interview with Zanele, is of *equality with able-bodied people*. Zanele identifies equality as being treated the same as other children in spite of her disability. This theme is dominant as Zanele recounts stories of her life with her family. Zanele tells of her mother encouraging her to play with other children and to do the housework as her peers would. Although this theme is prominent in Zanele's stories relating to her relationship with her mother, she explains that her father and siblings also make no distinction between her and the other children in the family. She received no special treatment in her family because of her disability. In fact, Zanele recalls a highlight of her life was when she finished matric and her mother and sister had the same expectations of her as of her able-bodied siblings – to get further training in order to find employment. This was a triumph for Zanele as the public discourse around disability in the community was that people with disabilities should stay at home and collect their disability grants, as they would not be capable of doing any work apart from craft or handwork.

A tension that Zanele expresses with this theme is her knowledge that at the same time as she is striving for equality, she also knows that she is different, and this causes a sense of isolation and loneliness. As a child and teenager, she feared that she was the only person in her community with a disability. She was unable to talk to her family about these feelings because of the dominant family discourse of not distinguishing Zanele from other children. Zanele relates her meeting with a woman with a disability in her community who was independent and active, with a great sense of relief, that she could share her experiences and learn from this woman. Thus it seems that although Zanele values her family's discourse of disability, it did not give her the space to express all her fears and concerns.

This theme of equality with able-bodied people, forms part of the *family discourse of disability* in which disability is seen as clearly distinct from being sick. However, in contrast to this theme, Zanele recounts many stories of being treated differently to other people in the public realm. This starts with the teachers in her early primary school years, when she is told not to join her classmates in the playground for break. Other examples of being treated differently to her able-bodied peers include not being punished for arriving late at school or giving an incorrect answer and being refused entry into nursing college simply because she was disabled. Thus it is clear that Zanele was getting one message about her disability from home and another, antagonistic message from the community. Through the life story it is apparent that Zanele has a strong desire to be treated in the same way as everyone else and yet she also knows that she has a disability.

Zanele's life story is permeated with the theme of her mother's support for her. It is her mother who teaches her to do household tasks like her peers. Her mother expects her to complete matric and get further education to help her gain employment and it is Zanele's mother who goes against the cultural norms of letting a person with a disability sit at home doing nothing except collect a disability grant. In spite of Zanele's mother having no formal education, she has a more sophisticated understanding of disability than was prevalent in her community. Judging from Zanele's stories of her family life, it is her mother who is responsible for the difference between the prevailing discourse of disability in the community and the

family's discourse of disability. Zanele's mother has a powerful influence over the family and Zanele with regard to their perceptions of disability and equality.

It seems that it is because of the disjuncture between the family and public discourses of disability that the final theme in Zanele's life story arises. This theme is *speaking out about inequality*, which she particularly wants to do through changing people's perceptions of disability. This concern with speaking out for justice seems to be a bridge between the family and public discourses of disability. The theme is apparent from stories of Zanele's childhood through to her adult years. According to Zanele she was very shy in her childhood but she still had the desire to help people understand disability according to her family's perceptions of disability. During her voluntary work in South Africa's first democratic elections she met a number of people with disabilities. She had a strong desire to help these people understand their own disabilities and become more independent, even though she had received no formal education in disability issues. Before Zanele came to CREATE to study community based rehabilitation she felt strongly that she wanted to help her community change their attitudes towards disability. It was both the support from her mother and the negative reactions of community members to her that stimulated Zanele's desire to speak out about disability and inequality. According to Zanele, her experiences during training at CREATE helped to give her the courage to speak out in her community, to deal with what she sees as the biggest challenge in her life – helping people to understand disability from her perspective.

8.3.3 *Disillusionment in the face of great challenges*

Nomusa characterises her life as having multiple episodes of being "dragged down" by particular circumstances. Although in the life story she refers to being "dragged down" when she speaks about her adult life with her own children and the illness of her husband, this sense of not being able to achieve the expectations she has set herself is present from the stories of her childhood.

The first and most prominent aspect of her life story that Nomusa describes as preventing her from reaching her potential is her irresponsible mother. This concern is apparent right from the start of her narration when she tells of being one of eight children, each with a different father. In her own case, Nomusa reports that she didn't

know who her father was until she was an adult and she still does not know the exact date of her birth. Nomusa's childhood memories of her irresponsible mother include putting two of Nomusa's siblings into an orphanage, not supporting her children in any way and on one occasion when she did give Nomusa a new set of clothes for Christmas, she took them away again at the end of the holiday. Nomusa's disillusionment with her mother results in her asking her granny (who looked after her) whether this lady was really her mother. Nomusa recounts the height of her mother's irresponsibility when she found out that her mother had had a sexual relationship with Nomusa's boyfriend, by whom Nomusa was pregnant at the time. In spite of this disappointment with her mother, Nomusa continues, as an adult, to have a relationship with her, perhaps characterising herself as the responsible daughter in contrast with the irresponsible mother. However Nomusa's disillusionment with her mother extends into adulthood when, during the period of this study, Nomusa gave her mother a beautiful dress for Christmas. Her mother rejected the dress and asked for money instead. Nomusa recounts feeling extremely hurt by this turn of events and yet she continues to be in contact with and have some sort of relationship with her mother.

Another aspect of Nomusa's disillusionment or her sense of "being dragged down" by her circumstances is her experience of poverty. Nomusa experienced extreme poverty as a child, to the extent of having to drop out of school twice because she did not have money for school fees, uniform and stationery. Nomusa tells stories of having no shoes to go to church and having to beg for leftover food from neighbours. Later as an adult, Nomusa still experienced poverty and because of her lack of finances she was unable to obtain a tertiary education. Before she was accepted for training as a nurse, she worked as a domestic worker.

In spite of or perhaps because of the challenges of poor parenting and poverty, Nomusa recounts realising that education was the key to success. This theme appears early in her life story, when she speaks of her neighbours who were the wealthiest people in the area and also the most educated. In her life story Nomusa relates her ideas and stories of education or the lack of it with a sense of regret. She feels that education is linked to success and that she has been unable to attain this success to the extent she would like. Regarding her schooling, she complains that the quality of

education she received as a child was not as good as the education her children are receiving now. This theme is apparent in Nomusa's adult life where she has continually strived to improve her education through attending courses and obtaining certificates. Her dream was to do a degree and become a psychologist but she feels that she is too old and has few opportunities achieve that dream now. Thus although Nomusa frames her ideas of education in a positive light, the over-riding sense in her narration of this theme, is one of loss and unreached potential. In fact, Nomusa relates many of her ideas about education in response to the question, "What is the biggest challenge you have faced in your life, concerning oppression or social action?"

Nomusa's sense of being "dragged down" permeates her life story, which although told on two separate occasions over a year apart, may reflect her pre-occupation with difficult circumstances at the time of the interviews. She identifies oppression as being very personal and linked to her circumstances, rather than observing oppression at a cultural, societal or structural level.

8.3.4 *"The thing happened because I struggled for it" – Agency and self-determination*

In Wandile's narrative there appear to be three interconnected themes which permeate the life story. Some differences were noted between the two interviews with Wandile, with the themes generally confined to one interview or the other. This may have been because of the distinct difference in mood between the two interviews, seemingly due to events in Wandile's life that happened in the period intervening between the two interviews (the loss of his job).

The first theme, *being an example to others*, arises from Wandile's narration of a turning point in his life – his learning from experiences in prison and his mother's death during this time. Wandile tells of changing his ways after coming out of prison and wanting to act in a way that will ensure he does not return to prison. He claims that he has tried to be a role model of a criminal who has changed his ways, both for his children and the community he comes from. Wandile supports his claim with a story of a friend who writes to him from prison, indicating that he should have learnt from Wandile.

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As an adult, Wandile reflects on the life of his mother and claims that she has been a role model for both himself and his brother. Wandile describes his mother as being a responsible person who did everything she could to provide for her children and who tried to teach her children "good things". According to Wandile in the first interview, he is like his mother in the way that he treats his children – with his children preferring to go to him for help than their mother who shouts at them. He feels that he has followed his mother's example, except that he has no business of his own. Wandile contrasts this experience of his mother being his role model with his desire to be completely different to his stepfather. In spite of telling of this need to forget his stepfather and his abuse of children and his criminal ways, Wandile relates how, as a matric pupil, he was involved in stealing cars and robbery (similar to his stepfather's criminal ways). Also, although Wandile indicates in the first interview, that his mother has been a role model for him, his apparent emotions concerning his mother are less positive in the second interview. Although not directly spoken, Wandile indicates some disappointment at his mother's inability or perhaps unwillingness to protect him from his stepfather's abuse. He does indicate that his mother never abused him, but she also never covered up for him in the presence of his abusive stepfather. Reflecting on this, Wandile feels that his mother may have been afraid to disagree with his stepfather.

In the first interview, Wandile indicates that he is following his mother's footsteps, particularly in the way he looks after and treats his family. However, in the second interview, it becomes apparent that his behaviour has not been as exemplary as he has tried to portray himself. Wandile tells of another turning point in his life (probably just before the first interview) when he discovered he was HIV positive. He describes his behaviour before this point as involving drinking and smoking a lot and going out with girlfriends, even though he has a wife. It seems that Wandile has not always been able to live up to the image of his mother which he claims has guided him in his adult life.

A theme that is mainly apparent in the first interview with Wandile is that of *resistance and agency*. This theme first appears in a discussion of oppression and Wandile's work with people with disabilities. Although Wandile mentions fighting

for the rights of people with disabilities he also specifically mentions that he is standing up <u>for</u> them (rather than indicating that they are acting on their own behalf). However further on in his interview he talks about working with and standing beside people with disabilities. The theme of resistance and agency is apparent both in Wandile's childhood and also into his adult years. As a child / teenager, Wandile mentions fighting for people's rights by participating in rallies, a march and street barricades in KwaMashu as organised by the United Democratic Front. As an adult, in one of his first jobs Wandile spoke out for his rights as an exploited worker, and got fired for his efforts. Although he does not mention fighting for his rights specifically, in the second interview he reports about participating in a strike at the hospital where he was employed as a CRF and again he has been fired. In spite of these negative consequences of resistance, Wandile specifically explains the need to speak out for himself and to act for justice, when he says he must be able to know that "the thing happened because I struggled for it." In his mention of his participation in UDF activities and the story of his brother who has a disability fighting for his rights, Wandile explicitly links the concept of being empowered to agency and resistance.

The third theme of Wandile's life story is that of *self-determination*. Wandile views dependence as a negative characteristic and attributes some of his siblings' difficulties in their adult lives to earlier dependence on their mother. Wandile compares himself to his siblings, claiming that he has learnt independence and self-determination through his prison experiences and his mother's death. Wandile specifically links his attempts at independence to trying to escape from hardship. As a child, he describes his attempts at escaping from his stepfather's abuse by missing school and working at the taxi rank as trying to "live my life" (being independent of his family). In spite of the tremendous hardships in prison, Wandile explains that he worked towards independence from his family by choosing to go to a prison far from home where they would not be able to visit him. Similarly he frames the hardship of losing his job as a CRF as a move from dependence on an employer to working for himself which is a sign of independence and self-determination. In this sense Wandile uses the idea of independence synonymously with an aspect of the previous theme – standing up for oneself and one's rights. This becomes clear when he identifies the biggest challenge in his life as helping people to become independent in order that they can overcome their own oppression.

8.3.5 *What makes a social activist in the field of CBR?*

Qualitative research, and life history research in particular, does not lend itself to generalisation, but rather to an exploration of the meaning of particular phenomena. In this section, as I examine the intersection of themes and foci that I have identified in the four life histories, I hope to contribute to a deeper understanding of what makes an activist rather than providing generalisable results. Initially, in this section of the chapter I will relate the literature concerning the identity, "activist", to the CBR students. I then go on to explore the themes from their life histories drawing on the literature.

In the literature there are a number of conceptualisations of what an activist is. Several authors (Linden & Klandermans, 2007; McAdam & Paulsen, 1993; Wiltfang & McAdam, 1991) do not directly define activism or an activist, but they assume that social movement membership is equivalent to being an activist. Roker et al (1999) describe young people who have participated in voluntary and campaigning activities as activists. Similarly, Pancer, Pratt, Hunsberger and Alisat (2007) refer to adolescents who are active in community and political life, who help others and respond to requests for help and who have more developed social responsibility attitudes, as activists. Citing a number of sources, Bobel (2007) offers various definitions of an activist which are perhaps the most useful for this study. Citing Oliver and Marwell (1992), Bobel offers one definition of an activist as someone who is prepared to incur significant costs in their action to achieve a goal that they care about deeply. Another definition which Bobel refers to is that of Lee (1984) which explains that an activist is a person who uses 'direct action' to bring to the fore issues which have been neglected or trivialised. Perhaps the broadest definition of activism, but also a useful one, is "everyday acts of defiance" (Bobel, 2007, p.147).

Of the four students whose life histories are included in this study, I would consider Life and Wandile as social activists who have experience of acting for justice with others in their own communities and places of employment. Zanele appears to be less confident and more tentative, but is nevertheless committed to speaking out for justice for people with disabilities. She acts individually, mainly through raising awareness of disability and disability rights. Nomusa, however, describes herself as avoiding

community involvement and her concerns with oppression are very personal in nature. Using the descriptions or definitions of an activist from the literature mentioned above, only Life would be considered an activist if membership of a social (or in his case, political) movement was the defining characteristic. However, by using Pancer et al's (2007) description of an activist as a person involved in community and political life, Wandile may also be considered an activist. Although Zanele does not easily fit into these definitions of an activist, she may be considered as a person who engages in acts of defiance or resistance (regarding the community's perception of disability) and she uses direct action (speaking out) to bring the stigmatised and neglected issue of disability to the fore. Therefore in the rest of the analysis in this chapter, I will refer to Zanele, Life and Wandile as activists, while Nomusa cannot be characterised as such.

It is notable that all three activist students in this study have themes of action, agency or speaking out for justice running through their life stories. In their life stories, Life and Wandile portray themselves as agents for change. They have perceived various injustices and in several situations have acted to change these injustices. Although Zanele does not appear to think of herself as an activist or perhaps even as an agent of change, she too has concerns about the unjust treatment of people with disabilities in her community and she speaks out about this. Yarrow (2008) discusses the conjunction of beliefs or ideas and action in the life histories of Ghanaian activists in his study as well as referring to a similar finding in a study of British Marxists by Andrews (1991). In Yarrow's study, the activists portray their actions as being consistent with their beliefs and that their actions are also motivated by these ideas and beliefs. The three activist students in my study all narrate situations which lead them to think about injustice, inequality or oppression and although these situations may not have motivated immediate action, it seems that their experiences and ideas did indeed result in some action. These students' thoughts about oppression and injustice reflect an awareness of oppression not only at the personal level, but also the cultural and structural levels (Thompson, 1998). This is in stark contrast to Nomusa's fear of undertaking action against injustices or inequality. Nomusa's reaction to taking action resonates with the finding of Curry-Stevens, Lee, Datta, Hill & Edwards (2008) that fear of the risks and perceived dangers of activism as well as a sense of powerlessness were barriers for social work students in becoming activists.

In trying to understand the distinctions between those youth who engage actively with their community and those who do not, studies by both Pancer et al (2007) and Roker et al (1999) identified the importance of positive role models (particularly parents and peers) for young people engaged in action. In their life stories, both Wandile and Zanele, identify their mothers as being significant role models in the development of their understandings of the world and their ability to act. Although Life does not speak as clearly about his parents being role models for him with regards to his sense of injustice and the need to act, he does tell of a teacher and his brothers as playing important roles in his development as an activist. Certainly for Nomusa, her mother is anything but a role model, although it is because of her that Nomusa has a profound personal sense of loss and injustice. Through her narrative Nomusa does not clearly identify any other role model with regards to oppression, injustice and action. The studies by Pancer et al (2007) and Roker et al (1999) into young people's activism are conducted in Western societies where issues such as migrant labour, absent or unknown fathers and children being raised by grandmothers are not prominent as they were in the socio-historical setting of the students in my study. It is therefore interesting that in two of the activist students' life histories the issue of mothers as role models for their ideas and actions regarding oppression was prominent. Fathers are absent both physically and as role models in the stories of Life, Zanele and Nomusa while Wandile's stepfather has a particularly negative effect on him. However it is notable that there were other role models with regards to activism – the UDF leader in KwaMashu for Wandile, and an activist teacher for Life. This is particularly related to the historical times in which the students in this study grew up.

When analysing the life stories of Life and Wandile, particularly with regard to the themes of resistance and agency, it became clear that the experience of both of these students of participating in direct protest action such as marches and demonstrations during adolescence played a formative role in their lives. In his study of Chicana/o activists, Urrieta (2007) describes participating in such protests as a rite of passage for activists. Through examining the life histories of twenty four Chicana/o activists, Urrieta claims that it is in participating in marches and protests that the activists in his study came to see and understand their own ability to become agents of change. Certainly Wandile speaks about his experience of participating in marches as a youth,

informing his conviction that a march with people with disabilities in his community would bring visibility to the issues and possibly bring about change. Life's participation in the protests at his high school when the activist teacher was dismissed was his first personal experience of social action although he reports having thought about it before. Although these protests did not bring about the teacher's reinstatement, there were a number of occasions after this when Life participated in social action. Nomusa also participated in some social action as an adolescent. However, her report of such activities was permeated with a sense of fear and danger and being forced to participate. Perhaps a key difference between Wandile and Life on the one hand and Nomusa on the other, is the matter of choice to participate in the social action. Another explanation for the difference in these three students may possibly be the construct of personal political salience (Duncan & Stewart, 2007). According to Duncan and Stewart, personal political salience refers to an individual attaching personal meaning to social and political events. In their study of women activists and other women who had graduated from colleges in the United States in the 1960s, Duncan and Stewart found that personal political salience was positively linked to activism. They propose that this personality disposition helps to identify those who will become politicized and it may also provide the motivation for individuals to act on their beliefs. However, what Duncan and Stewart do not explore in their study, but suggest as an avenue for further research, is the extent to which personal political salience arises out of personal experiences. Thus it is difficult to attribute the difference between Nomusa and Life and Wandile solely to personal political salience, although this could be one factor of several that distinguishes Nomusa from the activist students.

An interesting distinction between Nomusa and the three activist students are their responses to the question about the major challenges in their lives concerning oppression and social action. Nomusa was inwardly focused, reporting that her own poor education was her major challenge. The other three students focused on assisting other people to overcome social injustice by: getting them to act (Life), helping them to stand up for themselves (Wandile) and helping them to understand disability from an equal opportunities perspective (Zanele). Again these responses of the three activist students reflect their concern with agency and social action.

Although no generalisations can be made from the life histories of such a small sample of students, it does appear from a holistic-content analysis of the life histories, that there is a distinction between Nomusa and the three activist students in this study. Whether the activist students' concern with agency and speaking out for justice is common in the life histories of other activists would have to be explored in other studies.

8.4.   Contamination and Redemption Sequences in the Students' Life Histories

In their study of the lives of midlife adults using life histories, McAdams and Bowman (2001) identified two types of narrative sequence that the participants commonly used in relating turning points and some other specific events in their lives. McAdams and Bowman have termed these redemption and contamination sequences. A contamination sequence narrates movement from a good experience to a bad ending. The good or emotionally positive experience is spoiled, or contaminated by an emotionally negative or bad outcome. On the other hand, a redemption sequence is one in which a bad or emotionally negative situation is redeemed by an emotionally positive or good outcome. Redemption or contamination sequences may be used by life story narrators to reconstruct events some time after they have occurred. Thus such sequences are seen as psychosocial or cognitive constructs which may also reflect in part, the life actually lived (Adler, Kissel & McAdams, 2006). Redemption sequences in particular, occur in the myths and stories of many cultures and religions from Ancient Greek times to the present (McAdams & Bowman, 2001).

As another analytic lens to try and understand the life histories of the CBR students in this study, I have examined the life stories with specific reference to redemption and contamination sequences. All the life histories contained both redemption and contamination sequences. For example, Zanele narrates the experience of being discriminated against at the mainstream high school (emotionally negative) as ending positively – it opened up the possibility for her to talk about disability to her classmates and teachers. Such redemption sequences also occur in the other students' narratives. Wandile frames his bad treatment in prison as a redemption sequence that culminates in his becoming a role model of a reformed criminal and educating others

to avoid crime. Life relates a rather poignant redemption sequence, starting with losing his life's savings when the car he had bought was written off in an accident, and ending with other opportunities being opened up for him, including being trained at CREATE. An example of a contamination sequence in Life's life story begins with him relating how he was good at science at school but this episode ended with him not being able to study science for matric as he had to change high schools and science was not taught at the new school. Life laments his inadequate matric. Nomusa's life story contains many contamination sequences. For example, she tells the story of falling pregnant with her first child with a positive emotional tone, which then turns bad as she relates finding out that her mother has had a sexual relationship with Nomusa's boyfriend.

In examining the four life histories it was interesting to note that Nomusa's story contained many contamination sequences with only one or two redemption sequences. In contrast, the life histories of Life, Zanele and Wandile contain many more redemption sequences than contamination sequences. In their study of midlife adults, Adler et al (2006) found that contamination sequences in a life story were negatively associated with life satisfaction and self esteem. Certainly in the life story that Nomusa told, which is dominated by contamination sequences, it is clear that she does indeed feel dissatisfied with her life, but no measures of self esteem were conducted. In contrast, finding a benefit after adversity (redemption sequence in a narrative) may help people to cope successfully and it can demonstrate positive adaptation which links to psychological well-being (McAdams & Bowman, 2001).

McAdams, Diamond, De St Aubin & Mansfield (1997) and McAdams and Bowman (2001) associate redemption sequences with generativity in adults. Generativity versus stagnation is the seventh of Erikson's eight psychosocial life stages, occurring in midlife adults (McAdams & Bowman, 2001). Generativity refers to a concern for and commitment to the well-being of future generations, which may be played out in actions such as parenting, teaching the next generation and engaging in activities to make the community a better place. According to McAdams et al (1997), generativity consists of seven psychosocial features which include concern for the next generation and generative action (acts that may create worthy outcomes which will benefit future generations). McAdams et al (1997) found that redemption sequences were

prominent, and often a distinguishing factor in the life story narratives of many of the adults they identified as being highly generative. These redemption sequences were often part of a pattern within the life story which McAdams et al (1997) term a commitment story.

It is possible that generativity and activism may be linked and this may be a reason for the prominence of redemption sequences in the life stories of the three activist students. Engaging in activities which aim to improve the community (as with Life's intervention in the local school) or the lives of specific people (Zanele's concern to assist children and adults with disabilities and Wandile's desire to dissuade potential criminals) may be considered illustrations of generative action and generative concern. Yet these actions and concerns are also symbolic of the students' activism. The narrative construction of positive endings to negative situations illustrates a world view in which it is possible to overcome suffering (or oppression) or to learn something positive from such a situation. Such a perceptual framework is consonant with one of Bobel's (2007) definitions of activism as incurring significant costs to achieve a goal that one feels deeply concerned with. It can also link with the belief that agency and resistance can produce change. In contrast, it is also possible to see that if one has a tendency to construct one's life as consisting of positive situations that turn bad, it will be difficult to believe that one can act for positive social change. This may help us to understand the differences between Nomusa and the other students.

Cole and Stewart (1996) discuss the construct of social responsibility which they describe as the desire to act for the benefit of a group and the belief in one's ability to do this effectively. These authors link this construct to generativity in adults and they posit that generativity in socially responsible midlife adults may play out as "a developmental press to act politically, particularly for those who had made political and ideological commitments in youth." (Cole & Stewart, 1996, p.133). Life seems to typify this description of Cole and Stewart, although the other two activist students, Zanele and Wandile, cannot easily be said to have made political or ideological commitments during youth. Cole & Stewart (1996) suggest, with regards to White and Black women in the United States, that participation in student activism may produce a sense of commitment and capacity to act which can stimulate political

activity later in life. This appears to be true of Wandile and Life. However, Nomusa also participated in student activism, albeit unwillingly, and she now seems to avoid all political participation. During the 1970s and 1980s in South Africa thousands of youth were involved in student activism, yet it is likely that not all these people are politically involved as adults. Therefore the suggestion that participation in student activism may lead to political participation in later life may only be part of the story.

In their study of generativity in adolescents, Lawford, Pratt, Hunsberger and Pancer (2005) found that community involvement in the late teenage years predicted generative concern in early adulthood in their sample of Canadian young people. They also suggest that community involvement during adolescence may contribute to the early development of generativity, which Erikson proposes as specifically being a concern in midlife adults. The student activism that Cole and Stewart (1996) mention may be seen as one form of community involvement in adolescence and early adulthood. From these two studies, it appears that community involvement, social responsibility and student activism are linked to generativity in adults, at least in the North American context.

From the life stories of Wandile and Life links can be drawn between community involvement as youth, student activism and having generative concern as adults. This is less obvious for Zanele, and does not seem at all apparent in the case of Nomusa. No specific measures of generativity were conducted with the students in this study and therefore it is not possible to conclusively state that the activist students can be seen as generative adults. However, in relating the life stories of all the students to the literature, and in particular through examination of the narrative strategies of redemption and contamination sequences, there do seem to be grounds on which to distinguish the life story of Nomusa from the life stories of the other students. Constructing life stories using contamination and redemption sequences does not seem to be a measure of how difficult a life is (both Wandile and Nomusa have had very difficult lives), but rather illustrates how the narrator perceives the world. These perceptions appear to be linked to generativity and the possibilities that the activist students see to change the world around them.

8.5   Applying Giddings' Model of Social Consciousness to CBR Students' Life Histories

In her study of the life histories of nurses in New Zealand and the United States, Giddings (2005) proposes a framework to understand social consciousness and "how people position themselves in relation to social injustice and social action." (p.233). In this framework, Giddings proposes three dialectical positions with reference to social consciousness – acquired social consciousness, awakened social consciousness and expanded social consciousness. These positions are not hierarchical and there can be a process of moving from one position to another, which may reflect shifts in personal, social, cultural and political contexts. According to Giddings (2005), the location of a person in the framework can influence the person's availability for social action.

When a person is located within the position of acquired social consciousness, s/he may refer predominately to the beliefs and values of the dominant cultural worldview and her/his place within this e.g. being privileged or oppressed by gender, class etc. (Giddings, 2005). In the acquired social consciousness position, inequalities in power and the resultant differences in the treatment of others are accepted as given. A person in this position will accept that there is a 'right' way to behave in different contexts and s/he may put much effort into fitting in. This is linked to an internalisation of the hierarchical systems of power in the dominant culture to the extent that the person does not see how s/he is oppressed or privileged. The final aspect of the acquired social consciousness position which Giddings proposes is that a person survives in this position by avoiding or withdrawing from open confrontation with the system.

The position of awakened social consciousness includes people who are aware of the processes of oppression and who are able to critique social structures or systems (Giddings, 2005). People in this position are active in their resistance to injustice and oppression and they may select actions to confront injustice from those already developed by a resistance / anti-oppressive group. A person with awakened social consciousness may see themselves as a victim of an unjust system or of an

individual's bad intentions. According to Giddings, in this position a person (who is oppressed) survives through continual active resistance.

The third position in Giddings' (2005) model is that of expanded social consciousness. In this position, a person may strongly identify with the marginalised culture or group they belong to, while becoming aware of how oppressive relationships are constructed. A person with expanded social consciousness will take action against social injustice by critically considering and selecting their option, rather than responding reactively. This position also assumes that a person will have an awareness of multiple social realities – including aspects of their identity that give them privilege, while also being aware of the processes of oppression on themselves and others. Giddings (2005) explains that a person with expanded social consciousness survives through acknowledging the contradictions in their relationship with mainstream culture and through developing ways to challenge dominance. In other words, "a person in this position knowingly stands on the margins" (Giddings, 2005, p.233).

When analysing the CBR students' life stories using the model of social consciousness by Giddings (2005), it became clear that the students may function predominantly in one or other of the dialectical positions, although their thinking and actions may also reflect aspects of other positions as illustrated below. Giddings acknowledges this in her study of the life histories of nurses but she also found that some nurses became fixed in a position on a particular social issue for a period of time.

Life's life story seems to typify that of a person in the expanded social consciousness position. In his example of social action at the primary school he demonstrates considered resistance and action against injustice that was critically chosen. Life is critical and reflective regarding oppression and he is able to identify his own multiple positions in terms of oppression – as an oppressed person because of his race, but as privileged and colluding in the oppression of others with regard to his able-bodied status. According to Life's worldview as reflected in his life story, he has depersonalised oppression and he seems to knowingly stand on the margins because of his class.

Aspects of Wandile's life story place him in the expanded social consciousness position, although he also appears to reflect some aspects of awakened social consciousness. At times Wandile engages in action against oppression which has been critically considered and chosen e.g. the march of people with disabilities in his community and presenting a memorandum to the municipality. However, at other times, Wandile responds to his oppression more reactively (participating in the strike which resulted in him being fired from his job as a CRF), which is more typical of awakened social consciousness. He is critical and reflective about his oppression (expanded social consciousness) and he is able to depersonalise oppression. His resistance to authority could be seen as reflective of an awakened social consciousness position.

Nomusa's life story seems to position her in both the awakened social consciousness and acquired social consciousness positions. She sees herself as a victim of class oppression (not enough money to be educated) and she blames others for her oppression, both aspects of awakened social consciousness (Giddings, 2005). However, she also has a strong tendency to survive by withdrawal from confronting what oppresses her and others, which is typical of the acquired social consciousness position. She also demonstrates the ascribed action of the acquired social consciousness position – fitting in, in her work situation, rather than challenging her ascribed class position or the oppression of her clients.

Zanele appears to be positioned in the awakened and expanded social consciousness positions. She is aware of the process of her own oppression and that of others, particularly with regard to disability (awakened social consciousness). Reflective of this position, she seems to survive through continual active resistance to her oppression as a person with a disability. However, she also depersonalises oppression, showing an awareness of the oppression of people with disabilities in general and she seems to knowingly stand on the margins. Both of these are aspects of expanded social consciousness (Giddings, 2005).

Using Giddings' (2005) model of social consciousness to analyse the life stories of the CBR students, has indeed seemed to accurately distinguish between those students

who are 'available' for social action and those who are not, perhaps also indicating who has the potential to be an activist for social change. In this study, those students who are located predominantly in the awakened and expanded social consciousness positions (Life, Wandile and Zanele) are those who have already chosen to engage in social action of some kind. Giddings' (2005) model of social consciousness seems to be based on an analysis of the life histories of nurses most of whom have experienced marginalisation in their profession due to colour, culture or sexual orientation. Although the fact that the model is based on the lives of marginalised people may be a limitation, it appears to be applicable in the case of the CBR students in my study, who have also experienced oppression due to race, gender and/or disability. Perhaps, therefore, rather than being called a model of social consciousness generally, Giddings' model should be one of the social consciousness of oppressed or marginalised people. She does make occasional reference to people in privileged positions, but this is not sufficiently explored.

8.6   Combining Multiple Lenses for Analysis of CBR Students' Life Histories

In this study, I have examined the life histories of four CBR students who all come from a particular generation and the same province of South Africa, with its specific historical and socio-political context. Yet in spite of the similarities in the context of the students, they responded differently to the changes in the CBR curriculum. Through analysing their life histories using different lenses I hoped to come to a clearer understanding of what may have led to these differing responses.

All three methods of analysis of the life stories seem to have made some distinction between Nomusa and the other three students whom I have termed activists. Without superimposing any analytical categories on the data, the holistic content method of analysis found that Wandile, Life and Zanele all incorporated themes of action, agency and/or resistance in their narratives. These three students also identified that making people aware of their own oppression and helping them to overcome injustice were the major challenges in their lives, while Nomusa was much more inwardly focused on her own problems.

Similarly, using the idea of redemption and contamination sequences from McAdams and Bowman (2001), there again appeared to be a distinction between the life story of Nomusa and those of the other students. Nomusa appeared to have many more contamination than redemption sequences in her narrative, while with the other students the situation was reversed. Through linking redemption sequences with generativity and the desire to make the world a better place for future generations, I showed how the students who displayed a worldview which encouraged narrating events in terms of redemption sequences (Zanele, Life and Wandile) were more likely to engage in social action.

Giddings (2005) uses her model of social consciousness to indicate that people located in the awakened and expanded social consciousness positions are more likely to be available for social action. Life, Zanele and Wandile were predominantly located in these positions while Nomusa appeared to be located in the acquired social consciousness position with some aspects of awakened social consciousness being applicable to her.

The question can then be asked as to whether the differences found in the life histories of the four students can explain the differences of the students' reactions to the CBR curriculum. I would like to think that the Giddings' model and the conceptualisation of redemption and contamination sequences (McAdams & Bowman, 2001) which I used as analytical categories for the life stories, can explain the *availability* of different students to engage in social action. Whether the students actually engage in social action concerning disability and CBR may be more closely related to the curriculum itself as well as to various other factors which will be explored in the final chapter of this thesis. It is not possible to generalise the findings of this study of only four life histories. However, it does seem that in the situation of this study, with students who have at least all experienced racial oppression and who were youths during the struggle in South Africa, the above-mentioned tools of analysis have been useful to understand the differences between students.

8.7   Conclusion

In this chapter I have analysed the life histories of four CBR students from different perspectives.   Each form of analysis has contributed to an overall picture of the students and their stories related to oppression and social action.   The analyses of the life histories have illustrated that the experiences and perceptions of the students seem to contribute to differences in their responses to oppression and their availability for social action.   Given that each student in a course has a particular life history, but also that it may be possible to identify and analyse the differences between the activist students and non-activists, I intend to explore in the following chapter whether there may be scope for a curriculum to influence students to engage in social action.

CHAPTER 9

A RESEARCH BASED FRAMEWORK FOR CONSTRUCTING A MID-LEVEL CBR CURRICULUM

9.1   Introduction

In this final chapter of my thesis, I will draw together the threads from the whole study – the investigation of the socio-political and historical context of the study, the literature review, the action research and the life histories of CBR students. I do this in order to try and address the questions that have guided the research and in particular, I will engage with the final question, what are the key components of a curriculum framework for mid-level CBR training? This study has been multi-faceted, especially in terms of the methodologies used. It has also raised my awareness of the various tensions in designing and implementing a CBR curriculum that deals with the oppression of people with disabilities. Through engaging with these tensions and aspects of the study, I suggest a conceptual framework that may be useful to guide curriculum construction with regard to the training of mid-level Community Based Rehabilitation personnel.

9.2   Methodological Considerations

This study was initially conceptualised as an action research cycle within a critical paradigm. As I believe happens with much action research, especially participatory action research, during the course of the research, it took a direction that was not pre-planned but arose out of observation and reflection during the action research cycle. This raised new questions for the research concerning the life experiences of the students with regard to oppression and social action, and how this may have impacted on their willingness to undertake social action following the CBR training. At this point in the research, I also questioned what the key components of a curriculum

framework for mid-level CBR training would be. It seemed most appropriate to use a life history methodology to answer the questions about the students' experiences of oppression and social action as this methodology can be used to explore experiences over the course of a life. Thus I gathered and analysed the life histories of four of the CBR students who had participated in the action research and so life history and action research were merged in this study.

During the course of the research, I became aware of a number of tensions regarding the methodologies I was using. In order to enact the participatory nature of the action research, I had constituted a research team which included a past CBR student, a CREATE staff member and a person with a disability who was also familiar with research. However due to some practical issues (such as one person taking maternity leave), the team fell apart during the action phase of the action research cycle. This raised the unresolved issue of whether I can indeed say that I used participatory action research because my intention was such, although it did not end in the way I had planned.

Linked to the question of the participatory nature of the action research was the issue of control and power in the study. Because I was conducting the study for the purpose of gaining a degree, I initiated the research and was responsible for developing the research questions. To some extent, I also controlled the timeline of the research. These issues gave me a degree of power and control over the research which was not available to other participants in the research team and thus the question of the democratic potential of action research arose. The issue of power and control in research for degree purposes is difficult, as by its nature, this research benefits one person in particular and discourages collaboration, particularly on key issues such as the research questions.

Another tension in the methodology of this study was my position in the research. I am the managing director at CREATE and I was a course facilitator for the CBR course. As I explored in Chapter 3 and again in Chapter 6, these positions as well as the students' awareness of my interest in social justice may have influenced the responses of students, staff and people with disabilities. I have tried to make my position clear as well as noting my own voice in the research. It is hoped that through

inserting myself and stating my potential biases in the writing of this thesis, the reader can make her/his own judgement about the validity of the study.

I hope that the merging of two research methodologies, action research and life history methodology which are not usually combined, has been a contribution of this study. I have challenged the conventional view that life history methodology essentially fits only into an interpretivist paradigm by discussing (in Chapter 6) the views of various authors that narrative research (including life histories) can contribute to social justice and the overcoming of oppression, which are key concerns of critical theory. Thus both the action research and the life history methodology in this study can be seen as fitting in to a critical paradigm. The action research in this study contributes to the field of CBR training through praxis, while the life histories illustrate, and to some extent challenge, this contribution.

9.3   CBR - Technical Rehabilitation or Addressing the Oppression of People with Disabilities?

From the outset of this study I have tried to open and explore a discursive space relating to the primary concerns and activities of CBR workers, particularly mid-level CBR personnel. Although the official discourse around CBR (as represented by the Joint Position Paper by the ILO, UNESCO and WHO, 2004) espouses equal opportunities and the social inclusion of people with disabilities, judging from the literature, the practice of CBR and CBR training around the world often focuses on the more technical and medical aspects of rehabilitation. Lorenzo (2003) locates this phenomenon in South Africa as much as it happens in other parts of the world. Thus there has been a gap between the official discourse and the discourse that dominates the practice of CBR.

The purpose of this study, to investigate a curriculum and develop a conceptual framework for a CBR curriculum that could assist mid-level CBR personnel to address the oppression of people with disabilities and their empowerment, has opened a discursive space within the context of CBR training internationally (at least as seen in the literature) as well as within the South African context. The World Health

Organisation's model of CBR as based on the manuals of Helander et al (1989) has historically been a powerful influence on the implementation of CBR in many parts of the world. It is the discourse of grassroots CBR workers (usually volunteers with little training except the skill to use the Helander et al manuals which involve technical rehabilitation skills) that has dominated what little literature there has been on the training of CBR personnel. Although the WHO's model of CBR and its training manuals were developed almost two decades ago, the World Health Organisation itself has not yet put forward a new model of CBR training which is more in line with the equalisation of opportunities and social inclusion that it now espouses as fundamental to CBR. Through this study and the exploration of training CBR personnel to address the oppression of people with disabilities I have tried to challenge the discourse of technical rehabilitation and CBR.

During the action research I have observed that the inclusion of specific content on oppression, liberation including disability rights and advocacy in CREATE's mid-level CBR training course appears to have helped the students to understand and be able to explain the oppression of people with disabilities as well as their own oppression. However, in line with current thinking on curriculum, I also explored other components of the mid-level CBR curriculum including teaching methodology, the stated outcomes of the training course and the hidden curriculum. Using the concepts of dialogue, generative themes, codes and problem-posing education from the work of Paulo Freire and Ira Shor, as well as Grundy's (1987) concept of curriculum as praxis, I made some changes to the teaching methods used in the CBR course. In a participatory rural appraisal exercise with the students, they identified experiential learning, in the form of practical work, as well as class discussions (dialogue) and role plays as often being the most useful teaching methods that were used by CREATE's facilitators, particularly when teaching about different aspects of the empowerment of people with disabilities. Although I did not consciously consider the profiles of the course facilitators to be of importance when I was making changes to the CBR course curriculum, we did use more people with disabilities as facilitators. From the perspective of staff members as well as the students, the increased number of lessons facilitated by people with disabilities made an impact on the students. The students had more exposure to positive role models of people with disabilities and a number of them indicated that this had helped to change their attitudes towards people

with disabilities. The issue of who does the teaching is seldom considered in discussions of curriculum and yet in this study I have found that the profile of course facilitators can be crucial to the outcome of CBR training.

I was less successful in changing the documentation relating to the outcomes of the CBR course. Although some changes were made to the stated outcomes in the students' practical workbooks to incorporate the ideas of empowerment and oppression, I did not address the course documentation as a whole. This is a shortcoming of this study but it seems that the moment has passed for such changes to be made, as the course is no longer running due to the machinations of the HPCSA.

The CREATE staff and I noticed a number of differences between the class of CBR students who participated in the action research in this study and previous students. The students certainly had more knowledge of oppression, social exclusion and advocacy related to disability than previous cohorts. Most of the students formed community CBR committees made up of a variety of stakeholders, including people with disabilities, traditional and political leaders and community nurses or health workers. A number of students engaged in social action concerning disability, including working with hospital administration to re-site their offices to an accessible venue and helping to organise and participate in a march of people with disabilities to present a memorandum of requests to the local municipality. However it became noticeable that there were differences in the responses of the different students to the new curriculum. These differences did not seem attributable only or mainly to such issues as urban or rural location of the students or gender. This then stimulated a further set of research questions and an exploration of the responses of the students to the curriculum through examining the life histories of selected students.

Not only have I tried to open a discursive space in relation to CBR training in the international arena, but also in relation to the local context in South Africa. The discourse around CBR and the training of mid-level rehabilitation personnel within the rehabilitation sector, and specifically the professional bodies and the HPCSA, has also been dominated by concerns with therapy and technical matters related to rehabilitation, with little or no concern for the oppression and empowerment of people with disabilities. Apparently a causative factor in the Occupational Therapy Board of

the HPCSA closing down the CBR training was a decision of the Physiotherapy Board not to support the multi-skilling of CRFs and CRWs because they felt these personnel did not have adequate physiotherapy skills (Concha, personal communication, 2006). This discourse has been more powerful than the emerging discourse of CBR in the disability sector (in particular, DPSA) which maintains that CBR should be implemented by people with disabilities, who usually have little formal training in CBR and who focus on peer counselling and referral to services. The institutional power of the HPCSA and its close links with the Department of Health, as well as the professional interests and power of therapy professionals have combined to enforce profession-specific mid-level rehabilitation workers who will be technically skilled in their therapy profession but who are unlikely to have an orientation towards equal opportunities, social inclusion, and the empowerment of people with disabilities. This is illustrated by the recently developed national examination for occupational therapy-specific mid-level workers (occupational therapy technicians) which contained only one question (worth 10% of the paper) on community work with the other 90% covering technical rehabilitation skills (van der Reyden, personal communication, October 2006).

Within this context, my study provides a challenge to the institutional and professional authorities in rehabilitation in South Africa. It highlights the possibility that mid-level CBR or rehabilitation personnel can be trained to recognise the oppression of people with disabilities and to try and address this situation through advocacy and working to overcome the barriers and exclusion experienced by people with disabilities. I join other authors such as Lorenzo (1996, 2003, 2005) and Cornielje (1993, 1995) who have written about CBR in the South African context, in their resistance of the dominant discourse surrounding CBR, CBR training and the provision of services to people with disabilities at community level. However the resistance to the discourse of the professional bodies concerning CBR remains fractured, with differing responses from DPSA and CREATE. Thus it can be seen that although it is possible to open a discursive space concerning CBR in the South African context, it is more complex to formulate joint action to resist the dominant discourse. The divisions between CREATE and DPSA's conceptualisations of CBR, who will implement it and how they will be trained then perhaps strengthens the hand of the institutional and professional authorities.

Another aspect of my study which has to be borne in mind is that the curriculum that I implemented and the changes I monitored have taken place in a very specific context. Apart from the context of professional interests mentioned above, there are a number of other issues in the context of this study that have impacted on the curriculum. The particular historical and socio-political context of South Africa during the time of the research as well as through the lives of the students and the development of the CBR course has influenced all the participants in the research. Concerns with oppression, liberation and empowerment are tenable in South Africa post-1994 because of our history. The new Constitution of South Africa and its Bill of Rights has created an environment in which people with disabilities can expect their rights to be respected and services (such as CBR) to involve them and to work towards justice.

There are also more local contextual factors which have made it possible for me to challenge the dominant discourse on CBR training in this study. CREATE has not had such a precarious funding situation as the other organisations offering CBR training in South Africa and the donors have been happy with the direction CREATE's CBR training has taken. Being a small non-government organisation has also helped CREATE to implement changes to the CBR curriculum easily, without going through many committees to approve the changes. These factors together with the macro issues at a country level have afforded me an opportunity to orientate CREATE's mid-level CBR training towards addressing the oppression of people with disabilities and to challenge the discourse of technical aspects of rehabilitation in CBR. Clearly the situation of other organisations offering mid-level CBR training internationally could be vastly different. For this reason, the conceptual framework for mid-level CBR personnel training that I propose at the end of this chapter does not contain specifics of content, teaching methodology etc. Rather, I suggest issues that need to be taken into consideration when developing a mid-level CBR curriculum.

9.4   Mid-level CBR Personnel – Activists or Rehabilitation Workers?

Although various authors (Disabled People's International, 2003; Kendall et al, 2000; Stubbs, no date; WHO & SHIA, 2002) write about the empowerment of people with

disabilities and CBR, there is no mention in the literature of CBR personnel being seen as activists. The dominant discourse around CBR personnel is of CBR workers who visit individual people with disabilities to help them with mobility, activities of daily living, exercises to improve function, adapting the home environment etc. Another level of CBR personnel mentioned in the literature is that of CBR managers, while there is little written on mid-level CBR personnel. In spite of the issues of empowerment, equalisation of opportunities and social inclusion being apparent in some CBR literature, there is little to indicate how CBR personnel should engage in action based on these concepts.

In my study, particularly following the changes in the CBR curriculum and the different responses of the students, I explored the students' engagement with social action and their own understandings and experiences of oppression. Through the study of the life histories of four of the CBR students I came to classify three of the students as activists on the basis of their acts of defiance or resistance and their involvement in community and political life. From analysis of the life histories of the four students I discovered that there seem to be several factors which predisposed these students to become activists in the context of learning about CBR. Previous experience of social action did not appear in itself to be a determinant of social action. In the case of Nomusa, her experiences of participating in social action during the anti-Apartheid struggle seemed to have put her off, rather than encouraged her to engage in social action. One of the factors that was linked to these specific activist students was their ability to see the world in terms of the possibility of bad situations or events ending well, a redemption sequence (McAdams & Bowman, 2001). This ability or willingness to see benefits arising from adversity seems to link both to generativity in adults and activism. Conceptually, concern with the well-being of future generations and engaging in social action towards this end make sense, and in the lives of Life, Wandile and Zanele it was clear that generative concern, generative action and social action were linked.

Using Giddings' (2005) model of social consciousness to analyse the CBR students' life histories, I was also able to see that the students' different positions in this dialectical model seemed to tally with their psychological availability to engage in social action. Those students who predominantly displayed expanded or awakened

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social consciousness were also those whom I classified as activists because of their involvement in social action of various types. On the other hand, Nomusa, who withdraws from confronting what oppresses her and who rather tries to fit in than challenge her situation (typical of acquired social consciousness), was less willing to engage in social action in CBR than other students in her class.

The findings from studying the life histories of a selected group of students in CREATE's CBR course illustrated that some of the students in the class could be considered activists, while others were not. It appears that students' responses to the CBR curriculum which incorporated issues of oppression and advocacy are in some ways linked to their status as activists in their home and community life. A challenge is to build on these experiences and perceptions of activism in CBR training to assist the students to become outgroup activists or allies (in the case of able-bodied CBR students) or to become disability activists if their social action has been in other fields.

However, it is not entirely possible or even desirable to pre-select for a CBR course only those students who have an activist background, who have an expanded social consciousness or who see the world in terms of redemption sequences. There are a number of examples in the literature of courses in various universities which aim to change the behaviour of students from different backgrounds, concerning social justice issues (Curry-Stevens et al, 2008; Laird, Engberg & Hurtado, 2005; Nagda, Kim & Truelove, 2004; van Soest, 1996). The field of CBR and CBR training can certainly learn from the experiences of others as described in the literature. However, a decision also needs to be made, perhaps at each training site or by the communities, organisations and government departments employing the services of particular CBR personnel, as to whether the CBR personnel are to be activists or more traditional rehabilitation workers. Is the focus of their work to be medical rehabilitation and therapy or social justice and overcoming oppression? Or is it possible in some way to combine the two, as we attempted at CREATE? I would like to suggest, based on the changes to the curriculum that I implemented at CREATE, that it is possible to train mid-level CBR personnel to engage in social action concerning disability issues, while they also learn about the more traditional tasks of a rehabilitation worker. The eventual role and activities of the CRF or CBR worker may differ according to her/his own history and preferences as well as the support that s/he receives from the

supervisor, community, people with disabilities and the employing body. Although I think it is possible in CBR training to assist students to become activists for CBR and disability, I concede that this study has not explored in sufficient detail, the nature of the activities and understanding of an ally or outgroup activist, which is what those CRFs who are able-bodied, would be. This indicates a direction for further research.

As with all action research, if one engages in reflection after a period or phase of action, new questions may arise which require a further cycle of research. Another aspect of the debate about whether mid-level CBR personnel should be activists or rehabilitation workers that needs to be researched is what these CRFs or CBR workers do once they are employed. To what extent can a CRF be an activist and challenge institutions and authorities while s/he is also employed by such a body? In situations where the CRF is accountable to and possibly employed by the community or community organisations it may be easier to engage in social action. As we see in the case of Wandile, engaging in social action such as a strike can result in losing one's job. Thus the question arises as to the dominant discourse of CBR in the employing body and the environment in which the CRF or CBR worker works. If the prevailing discourse is one of service delivery through provision of medical rehabilitation and individual intervention, CBR training with an orientation to empowerment and overcoming the oppression of people with disabilities will have to strengthen the students and give them support to challenge the dominant discourse.

9.5   One CBR Curriculum for All?

As discussed previously in this thesis, the World Health Organisation's model of CBR based on the use of local supervisors and grassroots CBR workers (often volunteers) was promoted as being viable for use all over the world. To support this model of CBR, a series of training manuals were developed by Helander et al (1989). These manuals may not be considered as a full curriculum because they only deal with content and not issues such as teaching methodology, assessment and outcomes. In fact, it is not entirely clear from the manuals to what degree the content should be taught and to what extent the manuals are simply resource documents for a CBR worker when visiting a person with a disability. Nevertheless the same manuals have

been used to develop CBR workers' skills in vastly different parts of the world including Vietnam, Botswana, the Phillipines and Pakistan. There is nothing inherently wrong with CBR workers around the world having similar skills. However, this study has shown me the importance of taking context into account when constructing a CBR curriculum.

There are various levels at which context impinges on a CBR curriculum. At the macro or national (and possibly international) level there are issues such as the prevailing conceptualisation of disability, the actual situation of people with disabilities and the socio-political environment. In my study, the issue of professional interests of therapy professionals has also been an important part of the macro context of the CBR curriculum, as has the history of the implementation of CBR in South Africa.

Another level of the context which can be an important influence in constructing a mid-level CBR curriculum is the level of the organisation or institution which provides the training. My own orientation (as a staff member and trainer) towards social justice has influenced the direction the curriculum has taken. With CREATE being a non-government organisation and being adequately supported by donors who have appreciated the direction the CBR course has taken, we have had the latitude to make innovations in the CBR course. However, a government institution which provides CBR training may have less freedom to challenge the status quo of CBR and the situation of people with disabilities. Another aspect of the context that influences a CBR curriculum which I have explored in detail is the students themselves. Issues such as whether the student has a disability, his/her life experiences (particularly of oppression and social action) and whether s/he is from a rural or urban area may impact on choices made about content, who will train and assessment. Each student's profile may also affect how s/he uses what is taught.

The above-mentioned contextual factors have had an impact on both the construction of CREATE's mid-level CBR curriculum as well as its uptake and implementation by the students. From analysing this experience as well as examining some of the difficulties with the World Health Organisation's model of CBR as expressed in the literature, I suggest that it is not desirable to have one CBR curriculum (particularly

for mid-level CBR personnel) which is implemented as is, in a variety of contexts. For the purposes of comparison and monitoring the implementation of CBR, it may be necessary to have some standardisation of aspects of the curriculum within a country or province. However, there also needs to be some latitude given to training providers to adapt the curriculum to the specific context in which the organisation finds itself. For this reason, the framework that I present in the next section of this chapter does not propose a fixed, inflexible curriculum. It does not propose a curriculum at all, but rather suggests factors that need to be considered when constructing a curriculum for training mid-level CBR personnel.

9.6 A Conceptual Framework for Curriculum Construction for Training Mid-level CBR Personnel

In this section I present a conceptual framework for curriculum construction for mid-level CBR personnel. The framework (Figure 9.1) which I propose for constructing a curriculum that can assist mid-level CBR personnel to address the oppression of people with disabilities is based on issues that have arisen in this study. I have tried to capture the dominant influences on the curriculum as I have come to understand and experience them, both in the action research and life history phases of the research. However, it has been difficult to capture diagrammatically the complexities of such a curriculum and issues affecting it. Therefore, I suggest that this framework is a work in progress and it is a basis from which to explore CBR curriculum construction and theory building further.

The CBR curriculum in this study, as with curricula of other courses, is situated within a context of multiple influences – the immediate context of the organisation, CREATE, in which it is situated and also within a context of broader external influences. The actual curriculum that emerges from considering these various influences will be specific to the context, but I suggest that the factors in the external environment and within the training organisation have wider applicability. Of course, the particular nature of each factor in its geographical and historical context may have a different impact on the CBR curriculum and the interplay of factors may be

completely different to the context of this study – post-Apartheid, 21st century South Africa.

In this framework, the curriculum is depicted as four interlinked circles at the centre of which is the student. The curriculum is placed within a hexagon (the organisation or training institution) with a dotted line, a permeable boundary, indicating that the organisation which offers the training is both subject to external influences as well as itself influencing the external environment.

The student and her/his identity are at the centre of this framework because s/he is influenced by the curriculum, organisation and external environment. However, the student is also at the centre because the student's own history, concerns and identity have an impact on the curriculum, training institution and possibly on aspects of the macro environment. For example, Wandile's concern with social justice and the march that he participated in influenced the curriculum (I added a session with a video of the march as a code on which to base dialogue, using Freirean methods) as well as intending to impact on the situation of people with disabilities in his community (the external or macro environment). Another illustration regarding the students' position and role in the framework comes from Chapter 8, the analysis of the life histories of a group of students. This analysis demonstrated that those students who perceived their lives in terms of agency and resistance were also more willing to engage with social action in the CBR course, given the constraints of their rural or urban locations.

As I have illustrated throughout this study, as a staff member my own interests and concern with social justice, oppression and empowerment, have influenced the CBR curriculum. I was also in a position of power to implement changes to the curriculum in accordance with these concerns. This may not be the situation in many CBR training institutions and in fact, based on research into the role of occupational therapists in CBR worldwide, Kronenberg (2003) indicates that although occupational therapists may be in positions of power in CBR (and presumably CBR training) many have not had community experience and concepts of CBR integrated into their training as occupational therapists. Thus an important factor in my framework at the level of the organisation or training institution is the knowledge and interests of staff members. Other issues that I have included at the organisational level are the funding

situation and donor requirements as well as the organisation's culture and any research that may have been undertaken in the training institution. As illustrated in Chapter 1, all other CBR training organisations in South Africa except CREATE were forced to close down because of the funding situation. Donors, too, can put pressure on CBR organisations to incorporate particular issues or themes into their work, as Lang (1999) demonstrates in his case study of Sourabha. The CBR training organisation's culture, which includes its values, ethos and stated mission, can also facilitate or hinder the implementation of a CBR curriculum geared towards addressing the oppression of people with disabilities. In Chapter 4 I discussed how the values and ethos of CREATE were consonant with a concern with empowerment of people with disabilities but that this was not reflected adequately in the outcomes of the CBR course. Another influence on the curriculum is research and evaluations that may have been done in the training institution. My own research had a direct impact on the curriculum in CREATE. Such research may also have an impact on the theoretical context in the macro environment.

Within the external environment I have chosen six issues which appear to have a major impact on the organisation and curriculum. In different geographical and historical contexts there may be different influences and consequently the CBR curriculum might in fact look fairly different or need to be changed to achieve similar effects. The six factors in the external environment may also vary in the degree of their impact in different contexts. For example, in a country such as Botswana, where there are few rehabilitation professionals, professional interests may have a weak influence on any CBR training that may be undertaken whereas in South Africa, the influence of the Health Professions Council of South Africa is of key importance. The context of a CBR course is dynamic and will change over time, thus impacting on the curriculum and requiring changes to be made if CBR personnel with similar skills are to be trained. For example, in South Africa, the socio-political context has changed from 1990, when the CBR course was first started in Alexandra, to 2005, when the action research was being conducted. This has had an impact on the students selected to attend the course, donors who support the course and the organisational culture of CREATE, which in turn has affected the curriculum. Although each of the external factors is indicated as a discrete entity in this

framework, there is indeed interaction between these different factors which may also affect the student and the training organisation and thus the curriculum.

In the framework, the educational context in the environment external to the training institution refers to the dominant concerns and policies regarding education in the province or country in which the CBR training institution is situated. In Chapter 1 I discussed the influences of People's Education and also outcomes based education on the CBR course and training institutions. Another influence on the CBR curriculum which I have represented in the external or macro environment is the theoretical context. This refers to issues such as the theoretical conceptualisation of disability which permeates policies and practice as well as theoretical understandings of oppression and curriculum. Discussion of these issues can be found in Chapter 2 of this thesis. The theoretical context is also linked to the socio-political and historical environment in which the CBR training takes place. Again in Chapter 1 I illustrated how current policies in South Africa concerning disability are guided by the social model of disability. The socio-political and historical context of this country has affected the students as well as the training organisation (see Chapters 1 and 7). Its impact on CBR curriculum construction may be very different in a more stable community or country although it is still likely to have some impact on a CBR curriculum. The lives of people with disabilities are affected by the socio-political climate within a country as well as by issues such as poverty. However, the situation in which people with disabilities find themselves also has an impact on a CBR curriculum because it is this very situation that CBR is trying to ameliorate. Therefore the CBR curriculum should speak into the lives of people with disabilities as well as itself being influenced by this situation. The history of CBR and the model on which it is based in a particular country or province may be linked to the situation of people with disabilities as well as rehabilitation professional interests. The chosen model of CBR in that environment will have a direct impact on the CBR curriculum.

Socio-political
context & history of
country

Educational
context of
country

Theoretical
context

Donor
requirements

Staff interests &
experience

Content

Pedagogy in
action: teaching
methods

**Students'
identities**

Course
facilitators

Pedagogy
in action:
outcomes

Research

Organisation's
mission, values
& ethos

Lives of people
with disabilities in
context

Rehabilitation
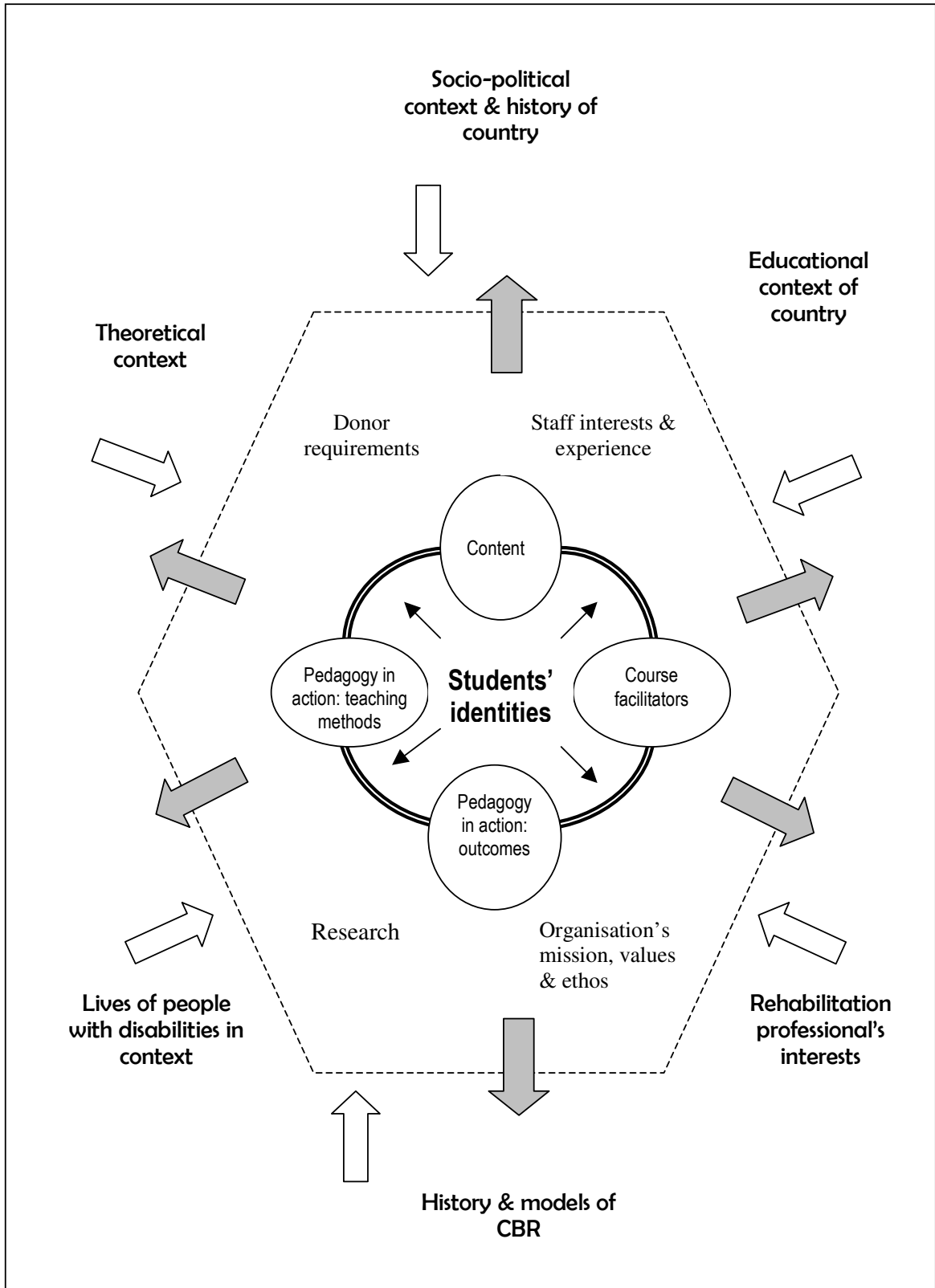professional's
interests

History & models of
CBR

Figure 9.1: Framework for constructing a mid-level CBR curriculum

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The framework of a CBR curriculum that I have proposed in this chapter demonstrates the different factors that need to be taken into consideration when developing the curriculum. This conceptual framework may be used specifically to orientate, or re-orientate a CBR curriculum towards the empowerment of people with disabilities. As illustrated, curriculum changes need to be considered within the organisational as well as the macro context. This process of understanding the context requires reflection and can be incorporated into an action research cycle or spiral of cycles, where the reflection leads further action to develop the curriculum.

This study, situated within a critical theory paradigm, has been concerned with justice and overcoming the oppression of people with disabilities, particularly at a structural level. The conceptual framework for mid-level CBR curriculum construction developed here addresses this concern with justice and emancipation at four levels. At the centre, I have considered the effect that the students' personal histories of oppression and social action may have on their learning about the oppression of people with disabilities. At the level of the curriculum, I have discussed the need to incorporate teaching on oppression in the content as well as demonstrating emancipation through the teaching process. At the level of the organisation, I have considered issues such as the interest and knowledge staff members have, concerning social justice. Finally, at the level of the external or macro environment, consideration of the situation of people with disabilities and the socio-political context will have an impact on how the oppression of people with disabilities is understood and what can be done about it.

Another important theme that has run through this study is the issue of power and empowerment. Differences in power between professionals and people with disabilities, between CREATE and the HPCSA, between students and clients with disabilities and between myself as researcher and the research participants have all been discussed. Through the changes to the curriculum, some of the students were able to change their attitudes and work with rather than for people with disabilities. The students then have an impact on the situation of people with disabilities. Hence there are arrows flowing from students, the curriculum and the organisational context outwards to the macro environment. At each level of the framework, the student, the

curriculum, the organisation and the macro environment, there is power vested in different groups which may cause conflict or enhance the opportunities to overcome the oppression of people with disabilities. In the macro context, professionals may have some power over the development of a course and over the situation of people with disabilities. Some people with disabilities may have power from within, thus affecting the conceptualisation of disability in society. The power of course facilitators to influence the students in the organisation can also have beneficial effects on the way the students interact with factors in the macro environment.

9.7 Final Reflections of the Researcher

When reflecting on the outcomes of this study, I feel pleased that I was able to observe the start of changes in the understandings and actions of CBR students as regards the oppression of people with disabilities and the social model of disability. Overcoming oppression and stimulating the empowerment of any people, particularly people with disabilities is a complex, multi-layered issue which needs to be addressed in a variety of ways. The CBR students in this study demonstrated their understanding of oppression and willingness to begin confronting the oppression of people with disabilities after participating in a CBR course that has a particular emphasis on the social model of disability and engaging with the oppression of people with disabilities in its content, teaching methodology, outcomes and facilitators. However, these actions of the students were observed while they still had much support and encouragement from CREATE. The challenge both to CREATE and the CBR students is to see whether the CBR students can maintain their willingness and ability to act against the oppression of people with disabilities once they are away from the supportive environment of the training institution. The experience that Wandile had with his supervisor refusing to allow him to participate in social action during work time because it was "too political", may well happen to other CRFs. Will such attitudes from work colleagues and supervisors deter the CRFs from engaging with the oppression of the people they are working with? This study took place in an environment which supported and encouraged the CBR students to undertake social action with and on behalf of people with disabilities. I did not explore all the facilitating factors that made it possible for the students to act in the

ways they did, but it is possible that the supportive environment may have played a role. Thus I am unable to claim that the training offered by CREATE during the period of this action research has necessarily had any impact on the CBR students' willingness to act against the oppression of people with disabilities in the long term and as they work as qualified CRFs. Certainly I hope that the understanding they have gained concerning the social model of disability and oppression will enable them to engage with the oppression of people with disabilities when other factors facilitate them taking action.

Perhaps a limitation of this study can be seen in that I did not examine the carry-over of the knowledge of the CBR students into their working life and whether indeed any more lasting change has occurred in CRFs' ability to engage with the oppression of people with disabilities. It was beyond the scope of the current study to investigate the knowledge and actions of the CBR students once they graduated and began working as CRFs. However, it would be beneficial for a future study to examine the practices in the work of the CRFs who have been through the changed course. Such a study could contribute further to understanding the various factors that facilitate or enable CRFs to engage actively with the oppression of people with disabilities.

On reflection, another limitation of this study has been the small size of the class that I worked with during the action research. The group of seven CBR students who participated in the research are not necessarily representative of the students that we have had in other classes at CREATE and therefore other CBR students might respond differently to the content, teaching methodology, facilitators and outcomes of the CBR course. In the group of students who were part of this study, there were more males than females, which is an unusual situation for a class of CBR students. Also, the majority of the students were sponsored and supervised by a non-government organisation, whereas in other classes we have usually had a majority of students sponsored and supervised by the Department of Health. This difference may be significant as non-government organisations tend to be more flexible with the activities that constitute the work of their employees (the CBR students or CRFs). However in the case of this study, it was the students from the Department of Health who engaged in the most visible activities that could be seen as social action e.g. the march of people with disabilities. The reason for this may be that the two students

who were from the Department of Health were also the two students from urban areas, where they felt less vulnerable in undertaking social action than those from rural areas. This demonstrates the complex interplay of factors which contribute to the CBR students being able to act on their new understanding of the oppression of people with disabilities and the social model of disability.

I feel privileged to have been able to share in the lives of four of the CBR students through the life history component of this research. All of these students have in different ways had difficult lives, not least of all experiencing racism and oppression due to their class or disability, from people similar to myself. Their willingness to share openly has enriched this study and I hope that the confidence and trust they put in me to tell their stories will have benefit for future cadres of people who will work with people with disabilities. Through the experience of listening to the students' life stories I have learnt of the importance of getting to know and understand each student and her/his background. I have the utmost respect for each of these students and I hope that they have gained as much from the process and their participation in this research as I have gained from them.

Through conducting and participating in this study I have become a more critically reflective practitioner, which I hope will benefit the development of CBR and CBR training in this country as well as in CREATE. Unfortunately due to the circumstances of the termination of mid-level CBR training in South Africa, the lessons learnt from this study may have to be implemented in other forms of mid-level worker and CBR training in this country.

Perhaps then, one of the most important learning points from this research is that changing the curriculum without also addressing the external or macro context of that curriculum, may have limited impact. CREATE's efforts at advocacy for CBR only reached a peak after the action research was completed, too late to save the CBR course. Had the study focused on multiple levels of change, the impact of developing a curriculum that facilitates the empowerment of people with disabilities could have been felt more broadly.

I feel inordinately sad at the prospect of having no further CRFs in this country. This study has shown me the tremendous potential that CRFs contribute to the overcoming of injustice and the oppression of people with disabilities, at least on a local level. The lessons learnt from this study need to be implemented in the training of other rehabilitation personnel and possibly community development workers, so that we can continue to work towards a just society for all South Africans. In addition, a future study should examine the long-term effect of the CBR curriculum as it was changed and developed in this study. This could then guide future curriculum developers.

9.8   Conclusion

Through conducting this study I hope to have made a number of contributions to the field of Community Based Rehabilitation and specifically CBR training as well as those interested more generally in research methodology. I think I have made a contribution to research methodology by merging action research and life history methodology and reflecting on this combination. With regards to CBR and CBR training, I have tried to capture my learning in the form of a conceptual framework for curriculum construction for training mid-level CBR personnel. My contribution to the field of CBR training is not only the framework itself, but the ideas and challenges captured within it: that it is difficult to implement one model of CBR and the associated training in many different locations, without considering the context of the curriculum at the level of the training institution as well as the macro environment. Another idea I hope to have contributed is the intersection of the lives and identities of the students with a CBR curriculum that has a focus on the oppression and empowerment of people with disabilities. I think that I have shown in this study that it is possible to guide mid-level CBR students to engage in action to address the oppression of people with disabilities and to implement CBR from a social model perspective. The challenge remains for decision-makers in CBR to determine whether CBR will live up to the ideals of equalisation of opportunities, social inclusion and rights for all people with disabilities or whether it will predominantly be a method of taking technical rehabilitation to disadvantaged people with disabilities.

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