

The impact of CBR as implemented by Community Rehabilitation Facilitators on people with disabilities, their families and communities within South Africa

EXECUTIVE SUMMARY

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INTRODUCTION

People with disabilities (PWD) and their families face physical and attitudinal barriers to participation in their communities. The Social model of disability views this exclusion as ‘disabling’ and as caused by the way in which society is organized, making PWD more vulnerable to poverty and exclusion. Current estimates for the proportion of the South African population with disabilities converge at five to six percent of the population, equating to around 2.5 million PWD in South Africa (CASE¹, 1999; StatsSA², 2001) There is thus a need for appropriate policies and services for this sector of the population.

In recognition of this, Community Based Rehabilitation (CBR) has emerged as an effective strategy to address community and rehabilitation services to people with disabilities and their families. Although its implementation differs from country to country, there is a general consensus around its definition. According to the ILO, UNESCO and WHO Joint Position Paper³ (2004, p2.), CBR is defined as ‘a strategy within a general community development for the rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of all people with disabilities’.

In South Africa the majority of CBR programmes use mid-level rehabilitation workers, otherwise known as Community Rehabilitation Facilitators (CRFs) or Community Rehabilitation Workers (CRWs). There are approximately just over 200 CRFs/CRWs (henceforth referred to only as CRFs), that work in over 100 urban and rural communities in six of the nine provinces in South Africa. This cadre of workers have received a minimum of two years training in CBR and are involved in physical and social rehabilitation of PWD as well as raising awareness of disability issues amongst families and community members

¹ Community Agency for Social Enquiry (CASE) (1999) We also count! The Extent of Moderate and Severe Reported Disability and the Nature of the Disability Experience in South Africa. For Department of Health, 1999. Accessed from <http://www.case.org.za/htm/wecount2.htm> .

² Statistics South Africa (StatsSA) (2001) Census in Brief. Accessed from <http://www.statssa.gov.za>

³ ILO, UNESCO, UNICEF, WHO (2004) Joint Position Paper on CBR with and for people with disabilities. Geneva

RESEARCH PROBLEM

While there have been a number of different evaluations of CBR programmes worldwide, this is less clear in South Africa, given the lack of evidence with regards to the impact of CBR programmes and the efficacy of CRFs. Furthermore, very few CBR evaluation studies have incorporated either a mixed methodology (quantitative and qualitative) or have used a participatory approach.

This study therefore aimed to evaluate the impact of CBR as implemented by CRFs, from the perspective of PWDs themselves. According to Peat⁴ (1997, p.91), evaluation is a 'systematic process of learning from experiences and using this information to improve activities and promote effective planning of future programmes'. In view of this, carrying out evaluations of CBR programmes is essential in order to monitor its effectiveness and relevance. Without evaluation the impact of CBR is not confirmed, which in turn could affect the integrity of a CBR programme.

METHODOLOGY

In order to gain the information required for this study, a mixed method, participatory research design was used. The following data collection methods were used in both urban and rural areas within 6 provinces of South Africa:

Individual interviews with time-line activity: were carried out with 18 PWD/parents. During the interview they drew a line depicting highs and lows in their lives. This showed the differences in their lives before and after they met CRFs.

Focus groups: were done in 9 areas. This involved discussion with 6-8 people with various disabilities, including mental/intellectual disability, as well as children with disabilities (CWD) and their parents.

Transect walks were carried out in 7 areas and involved walking through part of the community where PWD/CWD live. This enabled them to point out what it was like to live in that community and challenges they face.

Surveys of CRFs: 20 out of 40 questionnaires were received from the CRFs and outlined the demographic details regarding not only the clients they currently see, but also the reasons why previous clients left the CBR programme.

⁴ Peat, M. (1997) Community Based Rehabilitation W B Saunders Ontario

RESULTS

The quantitative findings include gender, age range, type of disability, years seen by CRF and reasons for leaving CBR programme. For example:

Type of Disability- The majority of CRFs current clients have a physical disability. Interestingly, there are less clients with a sensory impairment compared to those with a mental or multiple disability. Other disabilities included congenital conditions. For 1 client the type of disability was not recorded. See Figure 1.

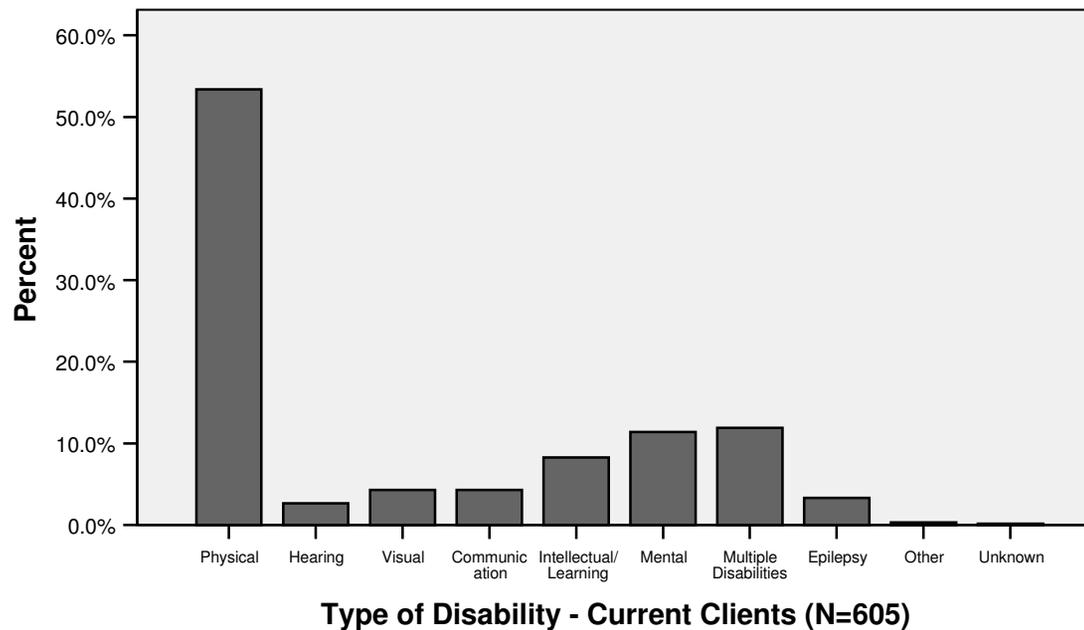


Figure 1.

In relation to reason for leaving and type of disability, a cross-tabulation reveals that a high number of clients with a physical disability had died. Furthermore, a large number of those with a physical and mental disability reported no longer needing intervention. See Table 1.

		Reason for Leaving					Other	Total
		No longer needs help	Client died	Client moved area	Client refused help	Referred to other services		
Type of Disability	Physical	92	125	75	11	7	10	320
	Hearing	9	3	4	2	4	1	23
	Visual	2	5	16	8	5	3	39
	Communication	7	3	7	1	1	0	19
	Intellectual/ Learning	14	4	11	1	2	3	35
	Mental	16	10	10	7	3	2	48
	Multiple disabilities	8	18	11	0	6	1	44
	Epilepsy	4	5	1	0	1	1	12
	Other	1	5	1	1	1	0	9
	Total	153	178	136	31	30	21	549

Table 1: Type of Disability and Reason for Leaving CBR Programme (N=549)

The qualitative results were analysed by identifying key themes that emerged from the interview transcripts and with reference to relevant disability theory and policies. The results highlighted that although CRFs work with individuals, groups, families and the community, they appear to have had a stronger impact on individuals rather than the community at large. Various gaps were also identified and were related to the poor recognition of the scope of practice of CRFs and also in relation to individual CRFs abilities to carry out certain tasks. These results are summarised and presented in Table 2 on the following page.

	INDIVIDUAL	GROUP	FAMILY	COMMUNITY
CRF INTERVENTION	<ul style="list-style-type: none"> <input type="checkbox"/> Exercises <input type="checkbox"/> Home visits <input type="checkbox"/> Advice and counselling <input type="checkbox"/> CRF Approach <input type="checkbox"/> DG application <input type="checkbox"/> Welfare assistance <input type="checkbox"/> Assistive devices <input type="checkbox"/> Training in ADL <input type="checkbox"/> Referral <input type="checkbox"/> Health Education <input type="checkbox"/> Help with employment <input type="checkbox"/> Other 	<ul style="list-style-type: none"> <input type="checkbox"/> Formation of groups <input type="checkbox"/> CRF approach Support groups <ul style="list-style-type: none"> <input type="checkbox"/> Peer support <input type="checkbox"/> Therapeutic activities <input type="checkbox"/> Group counselling <input type="checkbox"/> Social activities DPO/Business group <ul style="list-style-type: none"> <input type="checkbox"/> Skills training/ income generation <input type="checkbox"/> Business support <input type="checkbox"/> Training in disability rights <input type="checkbox"/> Group development Parent's group <ul style="list-style-type: none"> <input type="checkbox"/> Training parents <input type="checkbox"/> Advice <input type="checkbox"/> Children's activities 	<ul style="list-style-type: none"> <input type="checkbox"/> CRF approach Parents of CWD <ul style="list-style-type: none"> <input type="checkbox"/> Counselling and advice <input type="checkbox"/> Training <input type="checkbox"/> Welfare assistance Family of PWD <ul style="list-style-type: none"> <input type="checkbox"/> Counselling <input type="checkbox"/> Training <input type="checkbox"/> Welfare assistance 	<ul style="list-style-type: none"> <input type="checkbox"/> Disability awareness and education <input type="checkbox"/> Networking for inclusion <input type="checkbox"/> Helping in organizing IDDP <input type="checkbox"/> Increasing physical access
IMPACT	<ul style="list-style-type: none"> <input type="checkbox"/> Independence in ADL <input type="checkbox"/> Socialization and social integration <input type="checkbox"/> Self-awareness <input type="checkbox"/> Mobility <input type="checkbox"/> Sense of improvement <input type="checkbox"/> CRF relationship <input type="checkbox"/> Awareness of other's situation 	<ul style="list-style-type: none"> <input type="checkbox"/> Value peer support <input type="checkbox"/> Self-awareness <input type="checkbox"/> Increased social interaction <input type="checkbox"/> CRF relationship <input type="checkbox"/> Other 	<ul style="list-style-type: none"> Parents of CWD <ul style="list-style-type: none"> <input type="checkbox"/> Acceptance of child <input type="checkbox"/> Increased self-esteem <input type="checkbox"/> Improvement in child <input type="checkbox"/> Increased knowledge and skills <input type="checkbox"/> Awareness of other parents Family of PWD <ul style="list-style-type: none"> <input type="checkbox"/> Improved family relationships <input type="checkbox"/> Acceptance by the family <input type="checkbox"/> Increased social integration <input type="checkbox"/> Awareness of PWD's needs 	<ul style="list-style-type: none"> <input type="checkbox"/> Change in community attitudes <input type="checkbox"/> PWD aware of own rights <input type="checkbox"/> Enjoyment of school by CWD <input type="checkbox"/> Increased social integration
GAPS	<ul style="list-style-type: none"> <input type="checkbox"/> No home visits <input type="checkbox"/> Basic needs not met <input type="checkbox"/> No follow-up <input type="checkbox"/> Lack of employment <input type="checkbox"/> Poor awareness of clients' needs <input type="checkbox"/> lack of counselling/ advice <input type="checkbox"/> Limited Orientation & Mobility training <input type="checkbox"/> Dependence in ADL 	<ul style="list-style-type: none"> <input type="checkbox"/> Lack of transport to group <input type="checkbox"/> Poor business feasibility <input type="checkbox"/> No group in area 	<ul style="list-style-type: none"> <input type="checkbox"/> Family conflict not addressed <input type="checkbox"/> Abuse of DG by family <input type="checkbox"/> Caregiver not trained <input type="checkbox"/> Poor assessment of family needs 	<ul style="list-style-type: none"> <input type="checkbox"/> Physical access not addressed <input type="checkbox"/> Non-effective disability awareness <input type="checkbox"/> Transport <input type="checkbox"/> CRF role undefined <input type="checkbox"/> Lack of disability awareness at schools <input type="checkbox"/> Employment discrimination <input type="checkbox"/> Lack of FET/skills training <input type="checkbox"/> Lack of housing <input type="checkbox"/> Poor community advocacy and networking

This table indicates CRFs interventions for individual PWD, groups of PWD, family members and their communities. It also highlights the impact of these interventions and perceived gaps in service delivery. Examples of quotes from each of the categories the CRFs worked with are given below.

Individual

“[The CRF] came to visit me a lot, to check on me. It changed my life. I changed my style, I know I am disabled. Before I was crying, afterwards I wasn’t...[The CRF] advised me that it is not the end of the world, you need to admit your disability, you cannot just be sad...And I am still strong today...If the CRF hadn’t come I would have died of stress.” (Female, rheumatoid arthritis, North West)

“[The CRFs] moulded me to become this mama – who can work, stand and do things on her own. I must stop saying: ‘give me tea, give me water’- I don’t do that anymore. I stand on my own... They make you feel like you are a person too, that you are not neglected...If I say ‘I can’t do this’, they say ‘no you must do it gogo’, but they say it with a good spirit.” (Female, stroke, Gauteng)

Group:

“What I can say is that the DPO that the CRF started really helped me. It was very helpful, because this is where we meet as people with disabilities and discuss our problems and encourage and motivate each other.” (Male, paralysed arms, KZN)

“The group benefits us. We water the garden. We get vegetables. We eat bread together.” (Female, intellectual disability, KZN)

Family:

“She [the CRF] also showed me how to handle my child and showed me exercises I could do to help her. She showed me how to do many daily activities with my child, like washing and feeding.” (Mother of child with CP and intellectual disability, KZN)

“She [the CRF] changed my own mentality in how I perceived my child. She helped me to accept my child. She helped me to realise my child is not ‘sick’ but disabled.”
(Mother of child with CP, KZN)

Community:

“The disability awareness campaigns, workshops about disability rights and accessibility did help a lot. Most people have changed their negative attitudes towards us.” (Male, paralysed arm, KZN)

“The main problem is accessibility, even the government buildings are not accessible, like for example the police station. So my question is how can [the CRF] help us because these problems don’t fall under the health department, because its another department” (Mother of child with physical disability, FreeState).

DISCUSSION

The aim of this study was to evaluate the impact of CBR as implemented by CRFs on PWD, their families and communities. The findings and discussion have unpacked the interventions and impact that CRFs have had on PWD and CWD. This study highlighted the difference between interventions (actual tasks done by CRFs) and the impact that these have had (the aspect in life that has changed). There were many complex interrelationships between interventions that were aimed at individual PWD, groups of PWD, their family members and at the broad community, and the impact on PWD was therefore the result of such a multi-faceted approach. The study showed that the impact of CRFs was not just the result of individual medical rehabilitation, but included aspects of community development, poverty reduction, social inclusion and equalisation of opportunities, as set out in the joint position paper definition of CBR (ILO, UNESCO, WHO³, 2004). Furthermore, it also showed how CRFs addressed a number of the rights of PWD as set out by the UN Convention⁵ (2006).

The participatory research methods used not only helped identify the impact of CRFs but also provided the opportunity for PWD to become active participants in the research process. For example, using the time-line activity in the individual interviews highlighted the difference in people’s lives before and after they had met the CRF. Many PWD described their various needs and challenges before they met the CRF, including aspects of hopelessness and isolation, compared to improvements in physical capacity and ability to do ADL independently, restored hope, improved self-esteem, and even increased awareness of their rights and challenges still faced. The study therefore showed that psychosocial aspects of rehabilitation are just as important as its physical components.

By using the transect walk as part of the methodology, more insight was gained in terms of the impact CRFs have had on changing the communities in which PWD live. While the transect walk identified positive changes, such as accessibility of buildings or changed

⁵ UN (2006) Convention on the Rights of Persons with Disabilities www.un.org/esa/socdev/enable/rights/convtexte.htm

attitudes, it also served to highlight the many remaining barriers still faced by PWD, and the great need for any CBR service to work broadly, using the social model as its framework.

Furthermore, the impact of CRFs was also evident in that they did not only work with individual PWD in isolation, but involved parents of CWD or family members of PWD, either directly or indirectly, and that this influenced the PWD and their family environment. Where CRFs worked with groups, it showed the impact and value of using peer support to decrease isolation of PWD and improve their self-awareness and understanding their own disability. The impact was increased where group-work focused on rights of PWD, group development and aspects of income-generation.

However, the impact of CRFs was not only evident through the types of interventions done. It also became clear that the way in which they approach or interact with PWD is significant. Where CRFs worked with patience, encouragement and treated PWD or parents as equal human beings, this had a significant impact on their lives, but also served to strengthen the 'therapeutic' relationship between them. This also brings to the fore a unique aspect of CRFs, namely that they were often known members of their communities – a local person who was available and approachable, based in the community and able to visit PWD at home. This highlights that it is not just the "WHAT" of CBR that is important, but also the "HOW"

It can therefore be concluded that CRFs have had valuable impact on PWD, CWD, groups of PWD, families and communities. This study, however, went further in pointing out gaps in service-delivery perceived by PWD, as well as challenges pointed out by CRFs themselves. Gaps included poor identification of the needs of individual PWD, basic needs that were unmet, poor business feasibility, social situation in family not taken into account, and inadequate community interventions (regarding, for example, disability awareness, employment of PWD, schooling, housing, transport).

It became clear that gaps differed by area worked, which may show that individual CRFs differed in which aspect of CBR was a strength for them, their understanding of CBR and motivation. It however also showed that there may be factors external to the CRF that influenced the gaps in service delivery. Where the CRFs role was misunderstood, where transport was not available to go out into the community, or where there was inappropriate support or supervision – this affected the way in which PWD and other professionals related to them – and therefore would influence the potential impact of CRFs.

RECOMMENDATIONS FOR FUTURE PRACTICE AND RESEARCH

On reflection of the findings and discussion, the following recommendations are put forward:

- ❑ Although the definition of CBR is understandable and helps set out the framework for its implementation, there is however a lack of clarity in relation to the role and training of mid-level rehabilitation workers. Therefore, it is recommended that the WHO enter into further dialogue with relevant global CBR stakeholders to develop more comprehensive policies with regards the training and role of mid-level rehabilitation workers.
- ❑ In view of the lack of clarity with regards the role of CRFs, clearer guidelines need to be developed both by HPCSA and DoH. In doing so, they should also incorporate the main components of CBR (e.g. community development, poverty alleviation, equalization of opportunities and social inclusion).
- ❑ Given the lack of proper supervision and misunderstanding of the CRFs role by health practitioners, further continuing education should be arranged by the DoH surrounding the strategy of CBR and issues of supervision.
- ❑ In order for CRFs to have a greater impact in the communities where they work, there needs to be more intersectoral collaboration between DoH and other government departments surrounding issues of community development. In the meantime however, CRFs who are currently based in the health sector, should not be limited in their ability to work broadly in a community development framework.
- ❑ It became clear that in many areas CRFs work in a context of poverty. Where these are not met, PWD or family members described this as a gap. It shows clearly that poverty alleviation needs to form part of CBR, and that it is not just a narrow, individual health issue. Thus aspects of CRFs work that focus on income-generation need to be strengthened (including training, resources and funding to improve the feasibility of such projects).
- ❑ CRFs often work in vast areas, where public transport in general is patchy, and where it is also inaccessible to PWD. Where CRF transport was unavailable, this severely hampered the impact they could have in the community. The value of CRFs having transport to reach PWD at home, or to transport them to group activities was therefore noted.

- ❑ Given the fact that PWD point out that many government buildings and public shops, libraries, police stations etc. are not accessible, Government departments and the private sector need to take more responsibility for these issues, especially in light of the UN Convention on the Rights of Persons with Disabilities.
- ❑ Throughout the study it was observed that incorporating psychosocial issues (e.g. developing self-awareness, self-esteem, acceptance etc.) in rehabilitation, as well as the approach of the CRF played a key role in developing PWDs independence and overall well-being. Therefore, it is recommended that Universities and other training institutions responsible for training healthcare practitioners should give equal attention to both psychosocial and physical components of rehabilitation. Furthermore, health practitioners should receive ongoing training with regards their 'therapeutic relationship' with PWDs.
- ❑ The results of this study clearly demonstrate the positive impact and valued role CRFs have on PWD, groups, families and the community. Despite this there are gaps within CRF service delivery, particularly with regards to their ability to incorporate all four aspects as mentioned above. Rather CRFs need to be encouraged to build on their strengths and not see the gaps as a failure but as a challenge to take CBR forward.
- ❑ Given the lack of research surrounding the impact of mid-level rehabilitation workers within an African context, further research is required using participatory methods that see PWD and their families as equal partners in the research process