

CHAPTER 9

CBR Research as Part of Community Development

Harry Finkenflügel, Servious Dube, Alister Munthali, Mitchell Loeb

SUMMARY

Over the past 25 years, many developing countries have initiated CBR projects. Articles on CBR have been published in international journals indicating that CBR has become an accepted approach in supporting people with disabilities, in their own community. Exploration of these articles indicates that the research base for this assumption remains weak. In this chapter, studies on CBR published between 1978 and 2002, are reviewed to assess the evidence base for CBR. It is shown that although there are an increasing number of publications on CBR, the research they describe concentrates mainly on theory and less on the evaluation of interventions. Organisations involved in setting up CBR programmes are in a unique position to combine the implementation of projects with systematic documentation of efforts and outcomes. This is illustrated by the work of the Leonard Cheshire Foundation in Southern Africa, where they integrate community-intervention-based research within the projects. This approach is perceived to be promising and powerful. Other approaches based on utilising the theory of disablement also have potential for future research in CBR. An example given is related to utilising the ICF classifications

for structuring disability surveys. The chapter concludes by suggesting that CBR research is vital for the development and accountability, of "CBR as part of community development".

INTRODUCTION

In CBR, people work together in an inter-dependent way and rely on each other to achieve programme and individual objectives. Within this framework, they have distinct roles and so their individual objectives will differ. Objectives might be directly related to the needs of people with disabilities, to other stakeholders, or to more general community development issues. As such, "empowerment" does not only apply to people with disabilities but to all people involved. It is important to recognise people's own interest in CBR to avoid disappointments and to fully appreciate their input. Their particular interest can be used to build the competence of other stakeholders in the CBR process and to enhance the decision-making capacities of these stakeholders. Every stakeholder has a say, "a stake", in the process and should be allowed to exert influence and gain a feeling of ownership. CBR is about people, not just people with disabilities, but people living together in a community with a desire to develop their community. CBR is most of all, a learning experience. People learn by getting involved in a project and by taking note of other people's experiences through, for example, workshops, conferences, project documents or articles. Articles in national and international journals have a specific function for the development of CBR. Not only do these attract attention to the concept of CBR, they create a knowledge and evidence base for CBR and thus contribute to the efficacy, transparency and accountability of the concept.

The academic community, in direct cooperation with disabled people and service providers, have much to contribute to the CBR debate. Accurate descriptions of successful and unsuccessful CBR activities, critical analysis of the contributing factors, discussions about CBR in relation to Primary Health Care, community development, poverty and the millennium development goals can serve to influence policy makers, governments and NGOs. It provides information that helps to decide on

the most effective way of setting up a support system for people with disabilities, within community development.

STATE OF THE ART OF CBR

Following its debut in 1976 (WHO, 1976), the CBR concept gained momentum with many CBR programmes being implemented in developing countries after 1984. At the same time, an intense discourse developed on the underlying concept of CBR. In this discourse people agreed on the need to develop support services for people with disabilities, but held different views on the involvement of lay people and (semi) professionals, the roles of governments and (inter)national NGOs, the need for institutions and referral centres and the feasibility of an adequate support service at community level. In the 1990s a period of consensus emerged, marked by the production of the "joint position paper" of the UN organisations (ILO, UNESCO, and WHO, 1994). Surprisingly, this consensus did not lead immediately to improved information sharing. In 1991, Thorburn wrote, *"A major problem in the study and evaluation of CBR is that there is no forum for publication of information and experience, so it is very difficult to find relevant reports"*. Documentation on CBR (e.g. project proposals, evaluation reports, annual reports, brochures, books, articles) have gradually become available in the past ten to fifteen years. The database 'Source' - gives over 1000 references when searching for "community-based rehabilitation" (see Chapter 10 for more information). Nevertheless, at the turn of the century, researchers commented negatively on the number and quality of studies on CBR. Lagerkvist (1998) remarked, *"CBR is gaining increasing interest but very few studies have been published"*, and Mitchell (1999b) added, *"Little quality research on CBR has been placed in the mainstream of scientific literature"*. Wirz and Thomas (2002) concluded; *"CBR has not developed sufficient published literature about planning, implementation, and evaluation in the same way as other areas of service delivery such as primary health care, community development or income generation."*

¹ Healthlink: <http://www.asksource.info/>

In taking these comments seriously, questions arise regarding how many and what type of studies have been actually published, and what is the knowledge and evidence base for CBR after 25 years of experience with the concept?

WE DO NOT KNOW WHAT IS KNOWN

Scientific journals have published articles on CBR and at the same time multifarious "grey" literature such as programme reports, newsletters, conference proceedings etc. have become available. However, according to Miles (2003) *"no serious, critical appraisal had yet been made of even a quarter of this material"*. It would appear that we do not know what information is available, what the quality and usability of that information is and which aspects have been well covered or which should be a priority for further research.

As a first step in this process, a study looking at stakeholders' influences in CBR, examined articles in international scientific journals in order to assess the knowledge and evidence base for planning, implementation and evaluation of CBR, after 25 years of experience with the concept (Finkenflugel, Wolfers, and Huisman, 2005). For this literature review electronic databases (PubMed², PsycINFO³, Source⁴, CIRRIE⁵, Rehabdata⁶) and bibliographies⁷ were searched on (combinations of) the key words: "CBR", "disability", "rehabilitation", and "community". The search was limited to the time period 1978 - 2002 and only articles in English were included. Additionally, three more inclusion criteria were applied. First, only articles with "Community based rehabilitation" or "CBR" in the title, key words, abstract, introduction, or discussion were included. Secondly, CBR was described in the context of developing countries. Developing countries are defined here according to criteria

² PubMed: <http://www.ncbi.nlm.nih.gov/PubMed/>

³ PsychInfo: <http://www.apa.org/psycinfo/>

⁴ SOURCE: <http://www.asksource.info/databases.html>

⁵ CIRRIE: <http://cinie.buffalo.edu/>

⁶ REHABDATA: <http://www.naric.com/search/rhab/>

⁷ Miles: <http://cirrie.buffalo.edu/bibliography/SAfricatoc.html>

set by the World Bank (undated) and thus, only countries in the so-called lower and middle-income range were included in this review. Thirdly, to ensure a certain scientific standard and quality, only articles in journals that were either indexed by Index Medicus (IM)⁸ or the Social Sciences Citation Index (SCI)⁹, or listed in PubMed¹⁰ were included. Editorials, letters to the editors, and descriptions of more private experiences were excluded. This resulted in 128 articles that met all the inclusion criteria.

The number of articles published per year, is still increasing. The average over the last five years, is now eight articles per year. It was possible to specifically connect 100 articles to a little over 35 different developing countries". Sub-Saharan Africa, South Asia, and East Asia and Pacific are best presented in 34,27 and 22 articles, respectively. Figure 1 shows the distribution of articles on CBR in the different regions.

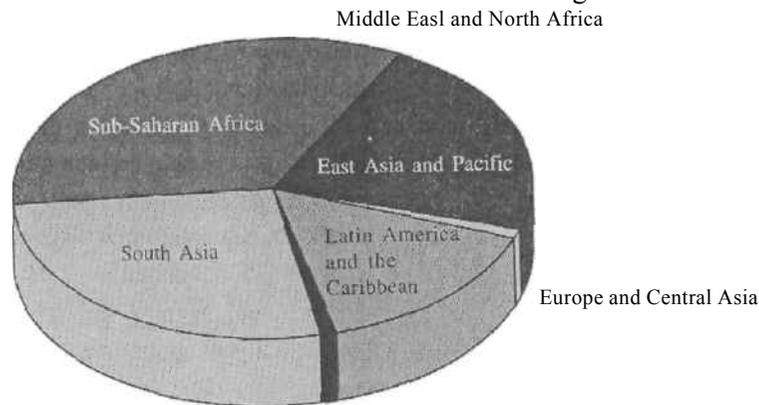


Figure 1. Distribution of articles per region N=102 (100 articles, two articles were counted in two regions)

Index Medicus: <ftp://nlmpubs.nlm.nih.gov/online/journals/ljiweb.pdf>
 Social Sciences Citation Index: <http://www.isinet.com/isi/products/citation/ssci/>
<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=PubMed>
 Palestine is not on the World Bank lists but for this thesis it has been made part of this review.

Looking more specifically at countries, it is noted that Jamaica (12) and India (10) are most frequently listed, followed by three countries in the Sub Saharan African region: South Africa, Botswana, and Zimbabwe (with 9, 9, and 8 articles).

Although 128 articles might seem an adequate number, it is hard to judge if the CBR concept is well covered or underexposed in scientific journals. More important than the actual number, is the extent to which these articles provide us with a consistent knowledge and evidence base for CBR. Therefore, the articles were analysed according to the methodology they used and the key aspects they covered.

TYPE OF ARTICLES

Scientific journals only publish a selection of the articles that are offered to them. The criteria for acceptance are different for every journal but in general, the work has to be original, of interest to the readers and based on a sound methodology. All articles are peer-reviewed to facilitate the highest possible quality. Generally, five types of articles can be distinguished (Helewa and Walker, 2000):

- **Intervention studies:** Reports on the effect of an intervention for a specific group (e.g. a training programme or therapeutic strategy)
- **Descriptive studies:** Articles describing outcomes of interest (e.g. income, ability to walk, educational needs, use of services) of a selected population at a defined moment (without an intervention being carried out)
- **Case reports:** Articles describing a particular CBR project, an approach to a specific problem, or other aspects of a CBR project
- **Review studies:** Articles based on earlier published work, which give an overview of knowledge in a specific area
- **Theory papers:** Articles that aim to provide a theoretical base for CBR. It includes ethnographic and phenomenological work as well as discussion papers and articles, presenting general information on CBR

The appreciation of evidence is directly related to the methodology used in the study. Studies using control groups or measuring at different points of time, provide the best evidence for the effectiveness of the intervention. Descriptive studies, theory papers (i.e. ethnographic studies) and case reports, also contribute to the evidence base of CBR, but their impact is rated lower.

Figure 2 presents the distribution of the type of the articles. It can be seen that the most common type of articles on CBR are "theory papers" (55 articles). This is followed by "descriptive studies" (40 articles), with only (10) "intervention studies." Over the years, "descriptive studies" increased considerably. However, no "intervention studies" have been published recently.

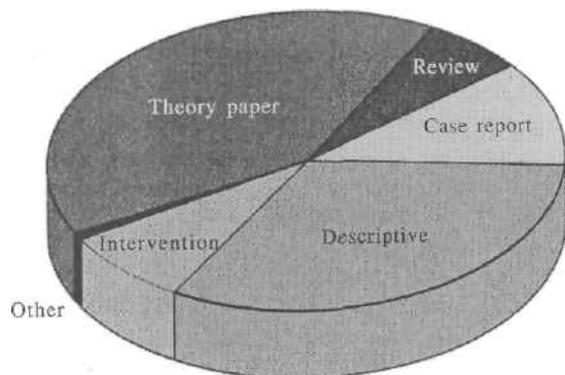


Figure 2. Types of articles published (n=128)

Intervention studies provide the best level of evidence but it is shown here, that this type of study is relatively rare within CBR. And even some of those that have been included here have problems applying rigorous scientific criteria when collecting data. For example, studies using a "before-after design" often define the "before" situation retrospectively and sometimes have serious problems reaching the original group of respondents. Another problem is that the instruments used, such as questionnaires and interviews, are seldom tested for reliability

and validity. An example of a solid intervention study is the one carried out by O'Toole (1988). He used N=1 designs for the 53 children included in the study. Also studies using control groups or alternative interventions (such as Finkenflugel et al., 1996; Mitchell, Zhou, Lu and Watts, 1993; Powell, Mercer and Harte, 2002) are considered to be of good quality.

Descriptive studies can be divided into prevalence studies and studies describing a situation, or change of a situation. A fifth of the descriptive studies under review were prevalence studies investigating the number of people with disabilities and their needs within the project area. Unfortunately, the instruments used and the classification of people identified differed widely, making comparisons problematic. Most studies used self-developed questionnaires and classification was done by medical condition as well as by types of impairment and disability according to the ICIDH (WHO, 1980). Only some sought to establish reliability and internal validity of the instruments used (Beach, Boyce, Peat and Malakar, 1995; Pal and Chaudhury, 1998; Thorburn, Desai and Davidson, 1992; Thorburn, Desai, Paul et al., 1992). A common way to test the external validity of a house-to-house survey, is a two-staged design where the outcomes of the initial survey are checked by professionals like medical doctors, psychologists, therapists (Finkenflugel, 1991; Mitchell, Zhuo and Watts, 1989; Rao, Venkatesan and Vepuri, 1993; Zaman et al., 1990). However, these studies are generally incomplete, as only people identified as "disabled" in the first stage are involved in the second stage, which denies the opportunity to check for "false negatives".

In descriptive studies researchers conscientiously describe characteristics of the research population, the programme and the context. Often, these observations are guided by hypotheses, in which one variable is assumed to correlate with another variable. In this way, they aim to get insight into, for example, different types of rehabilitation (Evans, Zinkin, Harpham and Chaudury, 2001), utilisation of services (Lopez, Lewis and Boldy, 1991), urban and rural populations (Hosain and Chatterjee, 1998; Khan, Ferdous, Munir, Huq and McConachie, 1998), the parents' view on CBR (Thorburn, 1992), the follow-up of clients in CBR (Rottier, Broer, Vermeer

and Finkenfliigel, 1993), neighbourhood support (Bischoff, Thorburn and Reitmaier, 1996), and the repayment of loans (Gershon and Srinivasan, 1992).

Case reports first give an overall picture of the country with a brief analysis of the perceived needs of people with disabilities and secondly, provide a description and discussion of the implementation process. Of the five articles describing the implementation of CBR projects, four relate to Asia and one to Jamaica. Another six articles focus on the role of different stakeholders in CBR. Case reports can be very helpful for learning about a project, but the information is very project-specific and cannot be generalised to other projects, or be used to establish the evidence base of CBR. More rigorous use of case reports can be made through the use of common indicators making comparisons possible between projects and contributing to establishing, "best practices" without making the mistake of presenting a blueprint and ignoring the specific situation in which the project developed.

In review papers, authors give an overview on a specific topic. The most generalised review available, only covers the first decade of CBR (Chermak, 1990). In this review, CBR is described as one of the initiatives to address social integration of people with disabilities in developing and developed countries. Other review papers dealt with more specific issues. Hartley (1998) and Wirz and Lichtig (1998) reviewed literature on services for people with "communication disorders", Mitchell (1999b) discussed the "research base" of CBR (see also next paragraph), Wirz and Thomas (2002) reviewed evaluation studies on CBR with the aim to determine indicators to measure the effectiveness of CBR, and Turmusani et al. (2002) looked for support of their argument, that disability should be included in the development discourse.

CBR has attracted a lot of discussion and this is reflected in the number of "theory papers" available. Most of these articles are related to specific aspects of a CBR project such as methods to set up screening programmes, the development of services, the implementation of projects and the stakeholders involved. Some articles discuss the fundamental

concept of CBR, including the implications of having a disability, the attitudes towards people with disabilities, and indigenous ways of handling and training people with disabilities. Unfortunately, only a few authors have combined ethnographic studies with a vision of how CBR can build on existing perceptions and knowledge. Studies on the implications of having a disability remain popular, although the attention has shifted from more ethnological studies, to consumer and human rights approaches.

KEY ISSUES COVERED

A further analysis of the articles relates to the key aspects covered. The 8 key aspects selected were based on the "research priorities" defined by the WHO (1988) and the review carried out by Mitchell (1999b). They were:

- **Screening:** Disability surveys, prevalence studies, screening instruments, assessments etc,
- **Knowledge:** Knowledge, awareness, attitudes, behaviour, traditional beliefs, traditional healers
- **Local resources:** Use of local resources (funding, technology), cost effectiveness
- **Participation:** Integration, inclusion, participation, mainstreaming, Accessibility
- **Implementation:** Development of services, implementation of projects, working with other organisations, ownership, disability rights
- **Stakeholders:** Stakeholders, community involvement, manpower planning, training, curriculum development
- **Evaluation:** Follow up studies, project evaluation, comparing different types of rehabilitation

This classification revealed (Figure 3) that most articles were about stakeholders (33) and implementation (32), knowledge (19), evaluation (17), and screening (16) are also fairly covered. However, the 'key

aspects' participation (5) and local resources (2) have hardly attracted the attention of researchers. This is remarkable as both issues are part of the definition of CBR.

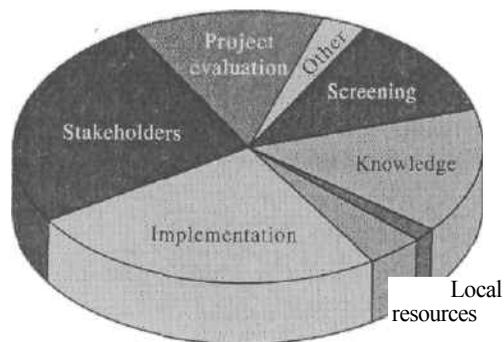


Figure 3. Key aspects of CBR covered in the articles (n=128)

Hereafter, the key issues will be discussed briefly. As project leaders and policy makers have a definite interest in establishing the need for support services, it is not surprising that we found ten prevalence studies in our data set. However, there were also six articles concerned with the methods like house-to-house screening versus Key Informants and instruments like Ten Questions Questionnaire (Thorburn, 1991, 1993; Thorburn, Desai and Davidson, 1992; Thorburn, Desai, Paul et al., 1992; Thorburn, Paul and Malcolm, 1993; Zaman et al, 1990).

Understanding existing knowledge and ideas about the disabling condition and possible functional improvements, should be seen a precondition for setting up appropriate and acceptable services. Local beliefs and customs regarding people with disabilities are studied in four articles (Ingstad, 1990, 1999; Kassah, 1998; Whyte and Ingstad, 1998) whereas Miles, with eight articles, focused on local knowledge of handling disability and disseminating appropriate information (1987, 1989, 1990b, 1990c, 1993; 1996, 1997, 1998). The five descriptive studies covered a wide variety of interests, ranging from parental adjustment (Pal and Chaudhury, 1998), attitudes of Community Rehabilitation Workers towards people with disabilities (Paterson, Boyce and Jamieson, 1999), traditional ways of

handling children (Werrij, Voeten, Adriaanse and Thorburn, 2000), the needs of families with children with mental retardation (Brodin and Molosiwa, 2000), and the training needs of relatives and Community Workers (McConkey and Mphole, 2000). Only one study actually reported on changes in the attitudes towards people with disabilities, after introducing a CBR project (Mitchell et al., 1993).

The use of "local resources" is generally seen as an important element for the sustainability of projects. To quote Pal et al. (1998) *"a successful control policy has to be affordable, sustainable, acceptable and effective"*. They compared the costs of identifying children with epilepsy using a house-to-house screening and using Key Informants and concluded that using Key Informants is, *"ultimately twice as cost effective"*. Jagannathan et al. (1993), assessed the costs of vocational training of leprosy patients by local craftsmen in the community. However, these are the only two articles explicitly dealing with the use of 'local resources'.

Only a few articles were available on 'participation'. This is indeed surprising since 'participation' is at the heart of the definition of CBR (ILO et al., 1994). In a descriptive study, Pal et al. (2002) reported on the social activities of children with epilepsy. The other four studies are 'theory papers' discussing issues such as educational services for children with disabilities (Cavanagh, 1994), a community development approach (Ferrinho, Robb, Cornielje and Rex, 1993), attitudinal obstacles in accessibility (Peat, 1997a), and constructing ideas of community (Lysack, 1997).

'Implementation' has been relatively well covered, but the studies and recommendations formulated for implementation of CBR projects were very diverse. More than half of the studies were theory papers discussing the supposed benefits and potential of CBR (Cardenal, 1981; Gregory, 1996; Hai, 1993; Johnston and Tjandrakusuma, 1982; Kibria, 1989; Marincek, 1988; Mitchell, 1999a; Peat, 1991; Thomas, 1992), different models that complemented and integrated the CBR approach (Serpell 1986; Miles 1990; Jelsma, Cortes- Meldrum et al. 1995; Miles 2002;

Miles 2002) or fundamental changes to the CBR concept, including changing the name CBR (S. Miles 1996; Momm and Konig, 1989). The five descriptive studies are more specific. Coetzee and Kemp (1982) studied the needs and rehabilitation potential of discharged schizophrenic patients. Utilisation of services was researched by Hosain and Chatterjee (1998) and McConachie et al. (2001) and they concluded that economic problems affected attendance. Boyce and Johnston (1998) discussed the collaboration between community-based rehabilitation agencies. Finally, on the basis of their study on the mortality of young children with cerebral palsy, Khan et al. (1998) suggested that PHC and feeding programmes be included in intervention programmes. "Case reports" appear to be a suitable method to describe the implementation processes of CBR. In general, the eight case reports included in this review, are positive about the implementation of CBR. However, Stuelz (1999) argued that it is easier to integrate people with disabilities through educational programmes than within a PHC system.

The discussion on key stakeholders in CBR focuses on: (1) people with disabilities, (2) families and family trainers, (3) the volunteers or Local Supervisors, (4) the Intermediate Local Supervisors or Rehabilitation Assistants, (5) the trainers, and (6) the specialists and project implementers (Finkenflugel, 1998, 2004; Peat, 1997b). To accommodate all of the studies, an extra category called "other stakeholders in the community" was added. This, for example, included the study about the neighbours of families with a child with a disability (Bischoff et al., 1996).

Although the people with disabilities are described as the primary beneficiaries of CBR, only three articles have been devoted to this stakeholder. Also, studies on the family and their perceived role in CBR were surprisingly limited. Different authors were shown to be concerned about the role of parents but only Thorburn (1992; 1999) discussed this topic explicitly. With ten and thirteen papers respectively, the main interest in discussing stakeholders was regarding the Local Supervisors and the Intermediate Local Supervisor.

Project evaluation was the main area of interest in seventeen articles. Five of these were intervention studies, describing the whole project

(Manga and McConkey, 1987; O'Toole, 1987), or specific issues within a project (Finkenflugel et al., 1996; Lagerkvist, 1992; Lundgren-Lindquist and Nordholm, 1996). Also some attention has been paid to the development of instruments to compare different types of services (Beach et al., 1995; Evans et al., 2001). Lopez et al. (1991) compared the actual services with the planned services and concluded that CBR, indeed represented a low cost intervention system. Similar conclusions were drawn by three other studies: Menon (1984) stated that CBR through PHC is feasible and acceptable, Sharma and Deepak (2001) concluded that the CBR project evaluated, had been successful on three of the five key components of CBR, and Gershon and Srinivasan (1992) illustrated that leprosy patients involved in CBR were better in repaying loans. A dissonant finding was presented by Rottier et al. (1993). In their study about client follow-up, they found that, after initial identification, rehabilitation workers did not see half of the clients again. Consequently, for these clients the training had not even begun. The only review paper on "project evaluation" was from Wirz and Thomas (2002). Their concern was that too few studies on the evaluation of CBR have been published and those that exist, describe practices rather than their effectiveness.

THE EVIDENCE-BASE FOR CBR

In conclusion, the concerns expressed by Lagerkvist (1998), Mitchell (1999), Wirz and Thomas (2002), and Miles (2003), and discussed in the introduction of this chapter, seem, at a general level, to be addressed by researchers and practitioners interested in CBR. A steady increase in articles about CBR has been seen and these articles cover a wide range of aspects in many developing countries. However, the quality and output from these articles often required attention and these showed little coherency: key aspects were insufficiently covered, for example participation and use of local resources. Theory papers and descriptive studies predominated and were not followed by intervention studies researching assumed relations and mechanisms. The evidence base for CBR, despite 25 years of experience with the concept, is still weak and fragmented. The nature and effectiveness of CBR cannot be sufficiently

established from examining this data set. There is a need for more high quality published research, before a meta-analysis can be conducted to draw together the evidence, into a coherent interpretation of the present situation concerning the development of CBR programmes.

The first challenge, is to continue to review already published articles and documents and make these available to researchers, project implementers, policy makers etc. Two types of reviews are potentially interesting. The first, is reviewing a specific aspect relevant to CBR. For example, in studying the involvement of volunteers, not only articles on CBR should be included but also articles on different development programmes (e.g. HIV/AIDS programmes, education for all). The second type of review includes chapters in books and 'grey literature' (newsletters, project reports, conference proceedings, annual reports, etc.). This "grey literature" has a limited circulation and is seldom critically assessed. When its merits are judged consciously, this type of literature can be used in creating a more comprehensive view on specific aspects of CBR, or in describing CBR in a specific country.

The second challenge, is to introduce research methodologies into CBR projects. Every CBR project collects data on the stakeholders involved, resources used, progress made etc. Many projects have developed a "Monitoring and Evaluation" system and collect information in a systematic way. However, up to now, very few projects have been able to make this information understandable and accessible to people outside the project. In the second part of this chapter, an example is given on how systematic data collection can be part of the project and can be used to judge the effectiveness of the interventions, and possibly make a contribution to the evidence base of CBR.

The third challenge, is to take the theoretical concepts reported in the CBR related literature and evaluate them in empirical research structures. An example of this is described later in this chapter, where the concepts in the ICF (WHO 2001), are utilised for the identification of disabled people. The ICF structures relate much more closely to the holistic nature of CBR, than to the impairment categories of the medical model which

have previously been the used as a basis for collecting and reporting survey data on disability.

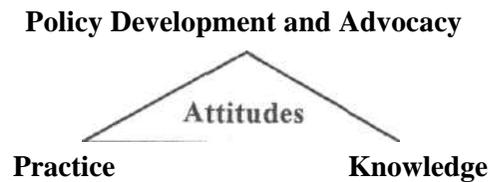
RESEARCH AS PART OF CBR PROJECTS

A digital search using Google and the search terms "community-based disability and rehabilitation research in Africa", revealed over 36,000 references. This illustrates that much more information is available, than the 34 peer reviewed articles on CBR reported in the first part of this chapter.. The scientific work on CBR is therefore, only the tip of the iceberg, the majority of information being generated by service providers. This information is rich, but often not systematically reported, so difficult to replicate and limited generalisation capacity. Of course, the information is vital for the development of individual projects but is too seldom used to develop and substantiate knowledge base of CBR itself. To establish what kind of interventions are effective in CBR, we need to collect systematically, the information used to set up, monitor and evaluate CBR projects.

CBR RESEARCH AS PART OF COMMUNITY DEVELOPMENT

To illustrate how research in CBR can enhance the capacity, build a knowledge base, inform practice and influence the development of policy and advocacy, an example from Leonard Cheshire International (LCI) in the Southern African region is explored. The first LCI services in the Southern Africa region were established in South Africa, in 1965. There are now 46 Leonard Cheshire (LC) services in the Southern African region. LCI have established a highly skilled and experienced regional support team. The team is there to support Leonard Cheshire services and other partners to develop strategies, build their capacity and influence national government to formulate policies directed to meet the needs of people with disabilities.

The LCI Training and Development Programme developed a conceptual framework, the "Three Pillars Approach" (figure 4), as a tool for programming.

Figure 4: The Three Pillars Approach (TPA)

The three distinguishable elements are:

Practice:

- Skills training programmes for disabled youths in the region
- Providing start-up kits for skills trained graduates and job placements
- Local communities sensitised on disability issues

Knowledge:

- A model for economic empowerment to be replicated
- Training materials developed and shared
- Interest and opportunities for further research

Policy and advocacy:

- Successful implementation turned into influence
- Linkages with Ministry of Education (Vocational Training Unit), community development, public and private financial institutions and money market
- Model guidelines for donors to use in funding similar projects

This concept integrates programme experience with the accumulated knowledge from reviews and community-based research, to enrich practice. This approach was conceived as a tool, which takes one through the process of designing and implementing programmes. The pillars are the building blocks of the programmes, that transform into research designs, implementation, dissemination and feedback (learning process). For example, action research uses programme activity interventions as opportunities and sources for collecting data, which is then analysed to produce evidence-based practice guidelines.

In LCI programmes, quality of care and rehabilitation interventions are usually implemented in residential or community settings. The service providers use a planning and assessment technique termed, "individual service planning" (ISP) approach, which involves parents or carers and multi-disciplinary service providers. The team includes social workers, physiotherapists, occupational therapists, doctors, nurses, carers, teachers, psychologists. They work together to draw short and long-term plans for disabled children and youths. The ISP assessment tool is incorporated into the design and provides the structure for the prospective data collection process, where a project information data bank is maintained. It keeps raw data that can be analysed retrospectively for various purposes such as, in developing guidelines of good practice, training materials, evaluation processes, theories and hypothesis, evidence for practice. In this manner, knowledge is used in informing and/or sharpening practice and for advocacy and policy development. The ultimate goal of this conceptual framework is to facilitate changes towards mainstreaming disability into all development work. The TPA is viewed and adopted as a guiding principle for planning, implementation, monitoring and evaluation processes of the programme activities. This framework is still into its infancy stage, the programme staff and stakeholders are keen to see this framework evaluated to determine its practical usage in the region.

SUGGESTED RESEARCH THEMES

Looking at the key elements of CBR and the work of LCI in the region the following research themes can be suggested:

Quality of care and rehabilitation:

Evidence and research is required to look into long-term benefits of the programmes that aim to improve the quality of care and life of disabled children.

Inclusive education:

A good intervention research project should be able to document the factors militating for inclusion and give easy and low cost solutions to make inclusion effective for all children.

Economic empowerment:

LCI Training and Development programme in the Southern Africa region has made economic empowerment a priority area for the current implementation period, but has no easy solution to implementing micro-financing models appropriate for disabled people.

Valid research into CBR is more likely to be achieved if the academic institutions and service providers work together during project design, implementation, monitoring and evaluation stages. Such an approach has the following strengths and benefits:

- a. Validity in terms of asking the relevant research questions
- b. Validity in terms of having the research skills and available time to carry out the research programme with rigour
- c. Long-term partnerships between independent partners through regional and national programmes
- d. Facilitation of access to resources for the target groups
- e. Supporting each other with technical assistance, training and specialised expertise
- f. Sharing of information and communications
- g. Global network of services and organisations (disability, development, mainstream)

Service provider organisations have an important role to play in the process of collecting evidence, to support the service strategies that they are promoting. Rigorous practices of monitoring and evaluation, together with documentation and dissemination of that information to interested parties, can go a long way towards closing the research gap in CBR. This process can also contribute towards clarification of the CBR concept and the nature of its various manifestations throughout Africa.

RESEARCH BASED ON THEORY GENERATED BY THE LITERATURE

The theoretical concepts which underpin The International Classification of Functioning, Disability and Health (ICF) (WHO 2001) have been well

reported in the literature. The ICF is a tool which conceptualises disability in a new way, one which encapsulates the dynamic nature of the phenomenon of disablement, but at the same time, identifies its different dimensions: physical impairments, activities limitations and participation restrictions, within a specific socio-environmental context. In this respect, the ICF has chosen to approach disability by focussing on how people live with their health condition, rather than merely classifying or grouping individuals according to their physical, mental or psychological impairment. Many of the articles mentioned in the review earlier in this chapter, have contributed to the formulation of these new classifications. As such, the classifications can be seen as a product of theorisation. These classifications have been used in the research process, to generate a new way of looking at disability, a new way of seeking information in a survey and a new way of introducing an intervention.

The ICF theory of what constitutes disablement, has been used in a project in Southern Africa to develop new ways of classifying the functional status of individuals and place disability as a part of a wider concept of health. The project has undertaken to examine Living Conditions among People with Disabilities in Namibia, Zimbabwe, Malawi and Zambia. It has used the ICF in national household surveys and focused on how people function and what they need, to live to their full potential. In this way the ICF has helped to change the way people think about "disability".

The project is in several phases:

- Phase 1 (1999-2000): design development and pilot studies in Namibia and Zimbabwe
- Phase 2 (2001-2003): national surveys conducted in Namibia and Zimbabwe and included capacity building activities of DPOs and relevant professionals and ministries
- Phase 3 (2003-2004): national living conditions survey conducted in Malawi, addressing how disabled people can improve their degree of activity and levels of participation and including capacity building activities (At this stage the survey intersects with the CBR approach)
- Phase 4 (2005-current) national living conditions survey in Zambia

Each national survey has been accompanied by a series of capacity building workshops targeting DPOs, relevant professionals and representatives from the ministries. The aim of these workshops has been to increase the participants' understanding of disability, how this affects living conditions and what can be done to maximise existing opportunities.

The approach used to screen for disability was agreed upon at a workshop in Kampala in 2001, organised by the UN Statistical Division which focussed on issues of measuring disability prevalence and relied on an understanding of disability, as encountering difficulties in doing day-to-day activities and/or restrictions in social participation. The screening questions used reflect an understanding of disability in accordance with the ICF.

Screening question 1: *Does anyone in this household ever have any difficulty in doing day to day activities because of a physical, mental or emotional (or other health) condition which has lasted, or is expected to last for six months or more?* (Response categories: yes, no).

Screening question 2: *Does anyone in this household need assistance in participating in any of the following activities? (walking, seeing, speaking, hearing, breathing, mental coping, learning/comprehending)* (Response categories: yes, no).

In order to operationalise the ICF in a large survey, we developed a matrix of 44 specific activities of daily living in 9 categories covering sensory experiences, basic learning and applying knowledge, communication, mobility, self care, domestic life, interpersonal behaviours, major life areas and community, and social and civic life. This matrix was intended to capture as many of the constructs as possible, in a simple and non-time consuming manner. The matrix attempts to capture activity limitations and participation restrictions through two questions:

1. How difficult is it for you to perform this activity without any kind of assistance at all? (That is, without the use of any assistive devices - either technical or personal).
2. Do you experience any problem(s) in performing this activity in your current environment? (*Current environment* refers to the surroundings in which one lives, works, plays etc. for the majority of their time).

For each of the 44 activities under these 9 domains, the degree to which an individual is capable of carrying out that activity without assistance (activity limitations) is recorded on a scale from (0) no difficulty, to (4) unable to carry out the activity. In the same manner the person's performance in their current environment (participation restrictions) is also recorded on a scale from (0) no problem, to (4) unable to perform the activity. By adding up an individual's responses to each of the 44 items, a single activity limitation score and a single participation restriction score is developed.

In addition to mapping an individual's degree of activity limitations and participation restrictions and determinants of a person's environment are sought through the categorising of facilitators and/or barriers that they may come up against, with respect to those activity limitations/participation restrictions they experience.

A few simple examples to clarify:

1. A young boy lost the use of his legs in an automobile accident 25 years ago. He has used a wheelchair since being discharged from the hospital. Today, he is an active member of society, working and supporting a family. Since his independence is facilitated by the wheelchair, his scores on certain elements in the matrix will be high: he cannot move about easily without assistance. At the same time, this person has become accustomed to life in a wheelchair, and in his current environment, he is able to get around with little hindrance - he will score lower on the scale of participation restrictions.

2. Consider two individuals, 20 years old, both of whom are blind. One was born without the benefit of sight and the other became blind 6 months ago, as a result of a work-related accident. Both have identical impairments and their activity limitations will, for the most part, be the same - but the person who was born blind has had the benefit of 20 years to become accustomed to living with that condition - and in fact, has never experienced living with sight. That person may be able to carry out all or most of his/her activities of daily living with little or no problem. The person who has been experiencing blindness for only six months may be quite helpless in his/her current environment.

We find that if disability is measured according to some pre-defined societal norm (based on impairments), then we neglect to take into account the individual's own experiences (interacting with their social and physical environment) with respect to their particular disability. Measurements should, rather be based on an individual's experience and capability in their environment.

This paradigm shift has been supported through the research results from the study conducted by SINTEF (Loeb and Eide, 2004, 2006). From the data analysis perspective, the research challenge, we believe, lies in a shift in the dependent variable from a dichotomous outcome measure (disabled, not disabled) to a continuous measure of activity limitation/participation restriction - mirroring the range of disability we see in society. The figures that follow present such scenarios.

A relatively small sub-sample of those in our sample were identified as NOT having a disability (405 individuals). They were asked to complete the activities and participation matrix. Their responses are illustrated in the two following figures.

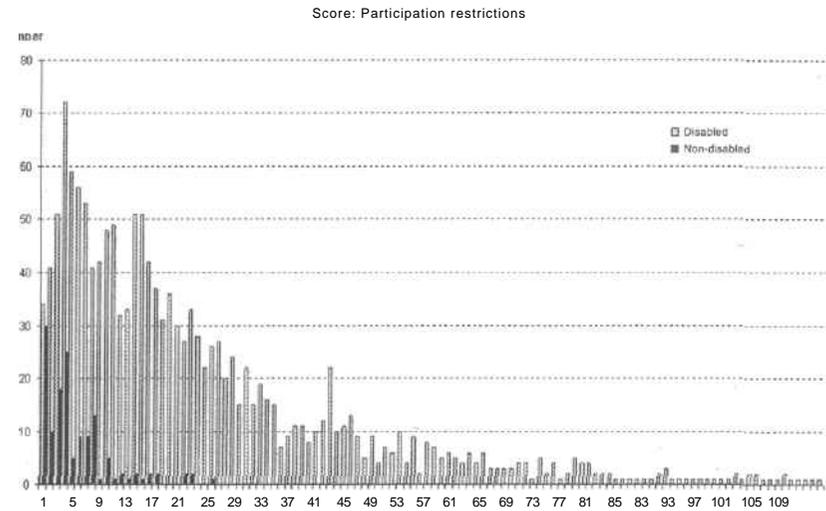


Figure 5. Participation restrictions among people with and without disabilities

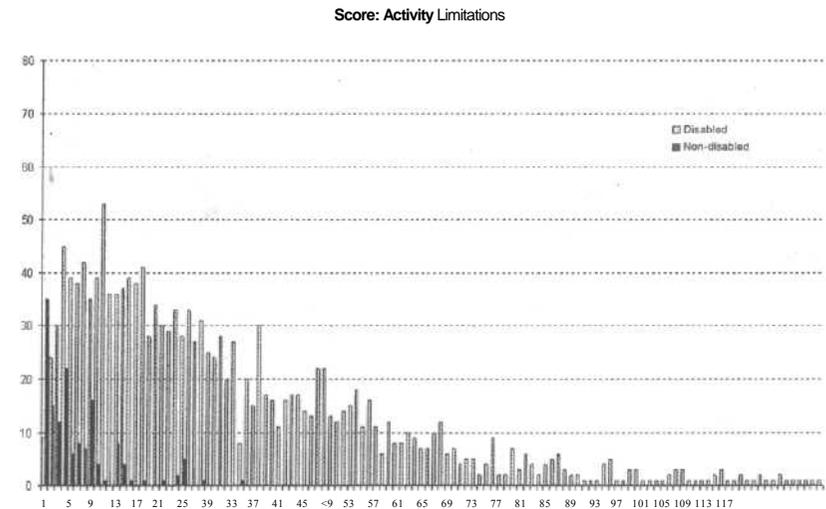


Figure 6. Activity limitations among people with and without disabilities

These figures clearly indicate that there is an overlap; that is, even people **without** disabilities live with certain limitations in their daily life activities and restrictions in their ability to participate in all levels of social interaction, and some people with disabilities are able to function in society with little or no problem. While only 10 (0.6%) of those with disabilities scored 0 on the activity limitation score as compared to 63% of those without disabilities, it is important to stress that some of those people identified with disabilities, are functioning well in society. Using the same reasoning, we found that 37% of those individuals who were identified as not having a disability, experienced at least a little problem in their capability to perform certain daily life activities.

Also, the range of scores on both activity limitations and participation restrictions, reflects the diversity of disability in society - and clearly indicates that being disabled is not a singular, two-dimensional phenomenon, but rather, a complex process that deserves to be understood as part of the human condition and not as something that represents a deviation from the norm.

Finally, these measures of activity limitations and participation restrictions must be interpreted as relevant to the environment, society and culture from which they are derived. This will require an expanded view of disability data and effect substantially greater measurement challenges. We have in this research, attempted to meet these challenges through the development of a matrix, based on the concepts inherent in the ICF and have thus taken a step in the direction of a new paradigm, defining a new concept. Disability research can no longer afford to be restricted to counting impairments, handicaps or even people with disabilities - but, using a better definition to identify a population based on activity limitations and participation restrictions and ensure that they are enfranchised.

OVERALL CONCLUSION

Good research practice in any domain requires the active participation of all the key players and nowhere could this be more important than in establishing the nature of disability, the effectiveness of CBR and how it

relates to community development. More research needs to be conducted and the evidence made available in the public domain, so that good practice can prevail. Without such work, CBR development will be slow and many programmes will continue to function in ways that others have already discarded.

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CHAPTER 10

Information Sharing and Community-based Rehabilitation

Stefan Lorezkowski

SUMMARY

Information technologies offer opportunities for improving community-based projects and programmes. Through the use of computers and access to the internet, information and experience can be located and exchanged more easily. However, the amount of information available on the internet grows every day and it becomes more and more difficult to identify what is relevant. Resource centres can help organisations or individuals in this process. This chapter explores how these new information technologies have developed and how they can help CBR workers become more informed. A list of useful web sites is presented at the end of the chapter.

INRODUCTION

Since the 1980s, community-based rehabilitation has been implemented in many countries in Africa, Asia and Latin-America. Despite the common name it developed in various forms appropriate for the local and regional conditions, probably due in part, to difficulties in communication between the communities concerned. Until some years ago the exchange of information and experiences between organisations in different continents was mainly limited to meetings, articles in journals and slow letters. Publications took a long time to reach people who were interested in them.