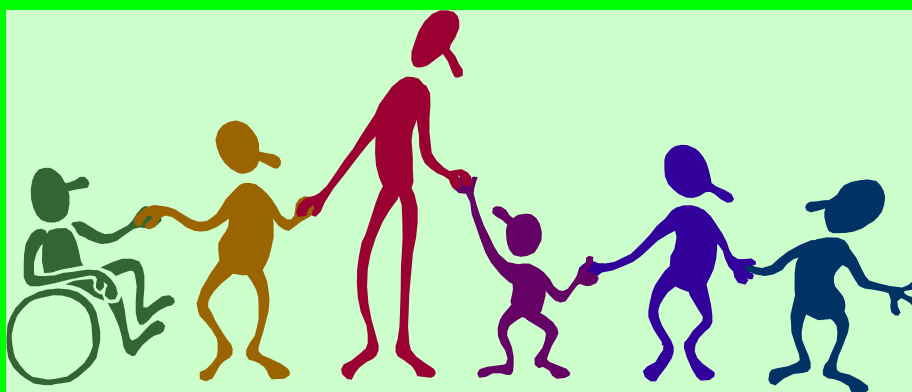


Part 1

Community-Based Rehabilitation as we have experienced it...



...voices of persons with disabilities



WHO
World Health Organization



SHIA
Swedish Organizations of
Disabled Persons International Aid
Association

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Foreword

This study on how persons with disabilities experience community-based rehabilitation (CBR) has been undertaken through the collaboration between the Swedish Organizations of Disabled Persons International Aid Association (SHIA) and the World Health Organization (WHO).

SHIA is a partner to the Disability and Rehabilitation Programme at WHO (WHO/DAR), and as such is very supportive of DAR activities in general, and the present study in particular.

Although there have been many previous evaluations of CBR carried out to a very high quality, this study is the first of its kind that is based on the experiences of the users of CBR themselves. In this respect it is unique and thus adds value to the other studies and evaluations of CBR.

The draft report was sent by WHO/DAR for comments to a selected number of professionals as well as WHO regional offices who expressed their appreciation. Based on these comments the text was revised by the authors. We wish to express our gratitude to Mrs Solveig Hargö Granér, who did the fieldwork that involved all interviews and compilation of data. Also, our thanks go to Mrs and Mr Annika and Lennart Nilsson who analysed the material and wrote the report. They have been exceedingly dedicated and committed in their efforts to complete this undertaking.

We hope that the report will be used as a source of inspiration and assistance to any CBR programme. It is through the participation and involvement of disabled persons in CBR programmes that their quality of life can be improved.

This report could also be used as an important background document for the International Consultation on Reviewing CBR in 2003.

Dr E. Pupulin
Coordinator
Disability and Rehabilitation Team
WHO

Mrs Malin Aldén
Secretary General
SHIA

Acknowledgement

We should like to extend our thanks to all persons in Ghana, Guyana and Nepal who have volunteered to express their most personal thoughts and feelings to help us understand the benefits and challenges of community-based rehabilitation (CBR). We have appreciated their frankness, openness and critical views. Without their willingness to contribute, this study would not have been possible. They have told their stories in the hope of being able to influence development and contribute to more efficient programmes in their country that will improve living conditions of persons with disabilities and their families. We hope that this report will do justice to what has been said and that it will lead to practical measures being implemented in many CBR programmes. As one person said "You spend so much time and so many resources quantifying and justifying what you are doing. But when is that going to help us?" We forward that question to the readers of this report.

Annika and Lennart Nilsson

TABLE OF CONTENTS

- [EXECUTIVE SUMMARY](#) 7
- [INTRODUCTION](#) 9
 - [Background to this study](#)..... 9
 - [Understanding CBR](#) 10
 - [Analysing the impact of CBR](#) 11
 - [Analysing quality of life](#)..... 11
 - [Using the Standard Rules to analyse CBR programmes](#) 14
- [AIM OF THE STUDY](#)..... 16
- [METHODOLOGICAL CONSIDERATIONS](#) 16
 - [Selection of CBR programmes for the study](#)..... 16
 - [Study of research and previous evaluations](#)..... 17
 - [Choice of methodology for data collection](#) 18
 - [Selection of interviewees](#)..... 19
 - [Use of inquiry groups to expand knowledge](#)..... 19
 - [Design of the interviews](#)..... 20
 - [Analysing the data](#)..... 20
 - [Limitations of the study](#)..... 21
- [FINDINGS](#)..... 21
 - [General observations](#)..... 21
 - [Quality of life analysis](#)..... 22
 - [Analysis of CBR programme initiatives](#)..... 29
 - [Main concerns](#)..... 35
- [CONCLUSIONS AND RECOMMENDATIONS](#)..... 36

- APPENDICES
 - [List of existing CBR programmes, studies and evaluations](#)..... 41
 - [List of acronyms](#) 45

EXECUTIVE SUMMARY

Background and aim

Community-based rehabilitation (CBR) has been advocated internationally for more than 20 years as the core strategy for improvement of the quality of life of persons with disabilities. Despite emphasizing that disabled persons should be active partners in the planning and implementation of all measures affecting their civil, political, economic, social and cultural rights, persons with disabilities have not yet become sufficiently involved in evaluations and impact assessments. Based on these observations of gaps in previous evaluations, the Swedish Organizations of Disabled Persons International Aid Association (SHIA) and the World Health Organization (WHO) have concluded that it is timely to study the impact of the CBR strategy, after its 20 years of existence, from the perspective of persons with disabilities, including both children and adults.

The aim of the study is to examine the impact of CBR programmes on the quality of life of disabled persons and to identify the CBR initiatives perceived as being the most useful. The study is **not** attempting to evaluate the different programmes in relation to their particular objectives and strategies. Instead, it attempts to give voice to the experiences of persons with disabilities in some programmes with different aims, structures and strategies.

Method

Three countries, Ghana, Guyana and Nepal, were selected because they represent different approaches, regions and organizational models. In-depth interviews were held with 33 individual persons with disabilities — or their parents in 12 cases. In addition to the individual interviews, inquiry groups were created in all three communities in each country — nine groups in total. Through the group interviews an additional 80 persons with disabilities and their parents were reached and had their views recorded. Altogether 150 hours of interviews were taped and transcribed. The answers were organized into categories according to

- the quality of life domain to which they referred
- the particular type of CBR initiative to which they referred

Given the limited sample and the nature of qualitative enquiry, one must be careful about making broad generalizations on the findings of the study. However, as the answers given by the interviewees show a great congruence despite differences in background and organization of the CBR programmes, and despite differences in the political and cultural contexts, general conclusions may still be drawn.

Findings

The stories told by the interviewees in this study give evidence of many positive effects of the CBR programmes, but they also express concerns about the efficiency and sustainability of the programmes. CBR programmes seem to have initiated change processes in social norms and values, which are essential for the further development of quality of life of persons with disabilities.

This study indicates that CBR has **impacted positively** on the following aspects of quality of life:



- Self-esteem
- Empowerment and influence
- Self-reliance
- Social inclusion

However, **impact is limited** concerning:



- Physical well-being
- Confidence and trust in society to fulfil its human rights obligations

The number of communities reached remains very small and the expectation that the community (or district government), once awareness was raised, would provide the necessary resources, basic services and simple assistive devices, etc., has not been fulfilled.

Looking at the different CBR programmes it can be concluded that the initiatives perceived as the most useful by persons with disabilities were (in order of priority):



- social counselling
- training in mobility and daily living skills
- providing or facilitating access to loans
- community awareness-raising
- providing or facilitating vocational training/apprenticeships
- facilitating formation of local self-help groups, parents' groups and DPOs
- facilitating contacts with different authorities
- facilitating school enrolment (school fees and contacts with teachers)

It was noted that CBR programmes largely continue to regard persons with disabilities as beneficiaries and not as participants with a voice and a choice. Any influence by disabled persons and their organizations in the CBR programmes is limited. The number of persons with disabilities engaged at different levels in CBR programmes is still negligible even after 20 years of these programmes being realized.

Conclusions and recommendations

The study outlines a number of recommendations by persons with disabilities suggesting how CBR programmes could be improved in the areas of awareness-raising, medical care, rehabilitation, education and income generation. It especially indicates that, in all these areas, participation of disabled persons as role models, self-advocates and employed experts would increase quality and efficiency of the programmes.

CBR programmes must recognize that social change and fulfilment of human rights will not occur by targeting the community level alone. Neither will they occur by targeting only central policy-makers and legislators. Improved conditions for persons with disabilities depend on the combined efforts of a number of stakeholders. Persons with disabilities and their families need to be empowered, disabled people's organizations (DPOs) and parents' organizations need to be strengthened and duty bearers (such as government officials and professionals) need to build their capacity. This means that future CBR programmes should ensure support to these three spheres and facilitate input and collaboration between many stakeholders and sectors.

Donors and CBR implementing agencies should consider reviewing programmes and develop capacity in the light of the findings in this report. Complementary CBR training material and handbooks should be developed to meet the new needs and challenges.

Finally, it should be noted that CBR as a title no longer reflects the nature of the programmes implemented because

- they target many levels of society — not only the community level
- they address all issues affecting the quality of life of persons with disabilities — not only rehabilitation

INTRODUCTION

Background to this study

Community-based rehabilitation (CBR) has been advocated internationally for more than 20 years as the core strategy for improvement of the quality of life of persons with disabilities. CBR has been included in the policy agendas of several governments internationally and has been used by nongovernmental organizations (NGOs) and United Nations (UN) agencies as a programme approach. Managerial workshops have been conducted and special instruments have been created for the monitoring and evaluation of its practicality and effectiveness. Evaluations of CBR programmes have been performed in several countries — most using quantitative impact assessment methods with a focus on service provision levels.

The CBR strategy has also been discussed with the UN Special Rapporteur on Disability and his Panel of Experts, as well as with international nongovernmental organizations (INGOs). In these discussions it has been emphasized that, according to the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities¹, disabled persons should be active partners in the planning and implementation of all measures affecting their civil, political, economic, social and cultural rights. Based on these consultations and observations of the gaps in previous evaluations, SHIA and WHO have concluded that it is timely to study the impact of the CBR strategy, after its 20 years of existence, from the perspective of persons with disabilities, including both children and adults.

SHIA and WHO have taken their initiative to a joint project to study the impact of CBR programmes on the quality of life of persons with disabilities. The study includes the following steps:

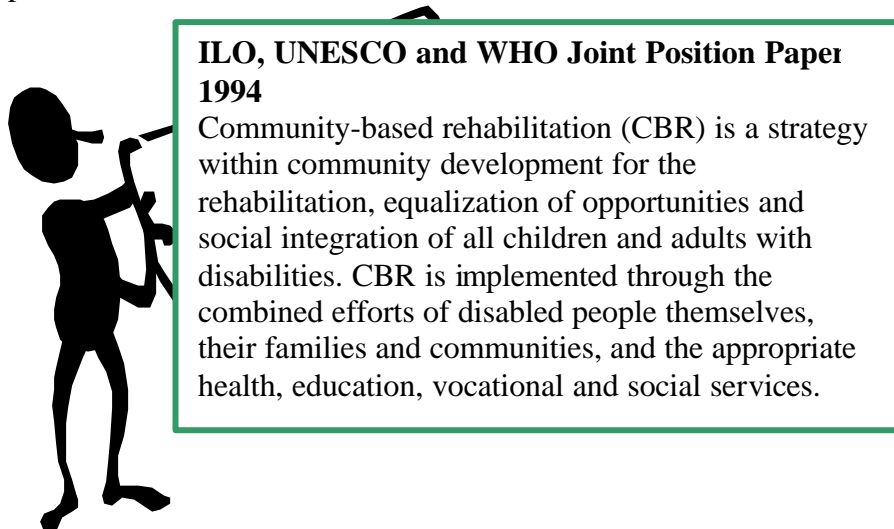
- Collect information in order to select relevant CBR programmes for the study.
- Identify three countries to participate in the study.
- Draw experience from previous CBR evaluations in these countries.
- Make field studies in three countries in order to enquire about the changes in the quality of life and perception of persons with disabilities.
- Support the undertaking of a self-assessment by the communities where a CBR programme has been implemented.
- Prepare a consolidated report and recommendations on how the participation and quality of life of persons with disabilities in CBR could be increased and strengthened.
- Translate, publish and distribute the consolidated report.



¹ Referred to in the following text as the “UN Standard Rules”.

Understanding CBR

CBR is a concept that has been interpreted in different ways by the various agencies and NGOs. The concept has also developed gradually and at times there has been great confusion about the meaning of “community-based rehabilitation”. CBR started as a strategy for delivery of primary rehabilitation services to persons with disabilities in their communities. The current understanding is that CBR is a community development programme, which is multi-disciplinary and addresses **all** areas that are central for the improvement of quality of life of persons with disabilities:



In a 1997 Economic and Social Commission for Asia and the Pacific (ESCAP) statement called “Understanding CBR”, it was concluded that CBR programmes should be based on the following criteria²:

1. Persons with disabilities are included at all stages and levels and have distinct decision-making roles.
2. The primary objective is the improvement of the quality of life of persons with disabilities. In order to achieve this, CBR programmes focus on
 - eliminating stigma and increasing the recognition of disabled persons as resourceful members of family and society;
 - making the environment and existing service delivery systems accessible to persons with disabilities;
 - supporting persons with *all* types of disabilities (physical, sensorial, psychological and mental, leprosy, epilepsy, etc.) according to their specific needs.

The same ideas are reflected in the revised joint position paper on CBR from the UN Agencies³. In this paper increased emphasis is given to aspects on human rights and community participation. CBR is seen as a strategy to achieve equal opportunities and full participation of disabled persons, addressing a wide range of obstacles to their participation in society. The word “rehabilitation” is seen as too medical and narrow and no longer reflects the CBR concept. CBR is seen as a strategy to promote the rights of persons with disabilities to enjoy health and well-being and to participate fully in educational, social, cultural, religious, economic and political activities. CBR benefits all people in the community because an accessible and human rights sensitive environment makes life easier for everyone. The position paper introduces the term “inclusive communities” meaning that the focus is on the human rights of all citizens, including those with disabilities.

² Authors’ interpretation of Appendix 1 of document ST/ESCAP/1761.

³ CBR with and for people with disabilities: draft joint position paper. ILO, UNESCO, UNICEF, WHO, 2001.

The position paper also recognizes the UN Standard Rules as an important tool for promoting the rights of persons with disabilities. The participation and influence of disabled persons on the individual level as well as on the organizational level are emphasized and are seen as a precondition for the successful planning, implementation and monitoring of CBR programmes. Rehabilitation is viewed as a process in which persons with disabilities or their advocates make decisions about the services they need to reduce limitations in their activities.

Finally, the position paper examines the lessons learnt from implementing CBR programmes and concludes that the following factors are essential for sustainability of CBR programmes:

- recognition of the need for a CBR programme based on a human rights approach
- willingness of the community to respond to the needs
- availability of resources and support, from outside the community
- multisectoral collaboration, including collaboration with DPOs and NGOs
- presence of community workers
- integration of CBR within government with allocation of adequate resources

Most CBR programmes do not operate in an environment where all these preconditions are fulfilled. In order to achieve better results there is a need to review strategies and to increase commitment and collaboration among all sectors and levels of government and civil society.

Analysing the impact of CBR

It is difficult to find a standard model or approach to assess impact as the concepts in CBR have evolved. Often there has been no baseline study, and no indicators for input, process or output have been established. Most of the CBR programme evaluations to date have been quantitative and have measured changes in service levels as perceived by staff and volunteers in the programmes. However, this study attempts to examine the impact of CBR programmes as perceived by disabled persons themselves. It is a mainly qualitative study which analyses the perceived improvements in quality of life of the persons with disabilities who are participating in the CBR programmes and their views on the usefulness of various CBR initiatives. The study has been using a qualitative participatory research approach (PRA) method.

The study is **not** attempting to evaluate the different programmes in relation to their particular objectives. Instead it attempts to compile and analyse the experiences of persons with disabilities in some programmes with different aims, structures and strategies. The experiences of the persons participating in the study have been analysed in two ways:

- according to the perceived improvements in quality of life
- according to the perceived usefulness of different CBR initiatives

Analysing quality of life

Defining and measuring quality of life have been the subjects of much research^{4 5 6}. Discussions have included the extent to which quality of life is subjective and related to culture and personal perceptions, and the extent to which objective, general indicators can be used to measure quality of life across cultures and individual situations. Even without

⁴ World Health Organization quality of life assessment (WHOQOL): development and general psychometric properties, 1998.

⁵ Quality of life: its conceptualisation, measurement and application. A consensus document by the International Association for the Scientific Study of Intellectual Disabilities (IASSID), August 2000.

⁶ Turnbull A et al., Family quality of life outcomes: a qualitative inquiry launching a long term research program. Kansas: University of Kansas, to be published in 2002.

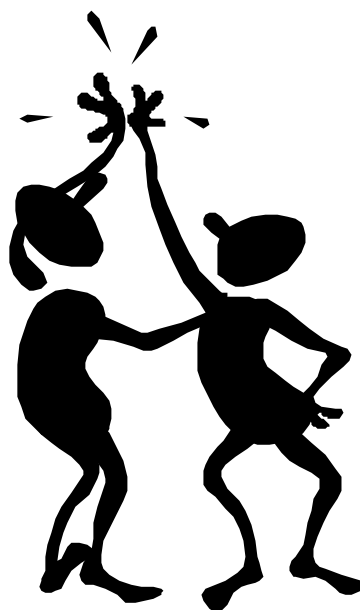
studying the research it seems obvious that many of the indicators of quality of life must be subjective and that quality of life will be perceived differently by individuals according to their age, personality and individual experience.

In addition, “equal opportunities and full participation”, which is the overall goal of the UN Standard Rules and many other disability programmes, is not easy to measure as it can be interpreted according to local cultural norms and values. In many developed countries, for example, people are equal and can participate when they achieve the status of being independent individuals, free to make decisions about their own lives. In many African and Asian rural communities, people are equal and participate when they are an integral, contributing member of the family and community, able to play a role in the social and economic development of these entities.

The question then arises as to whether it is possible to measure quality of life at all. In the Consensus Document⁵ prepared by IASSID for WHO, the core ideas that have emerged in the international literature are summarized and a framework for how quality of life could be understood and measured is provided. These ideas include (authors’ interpretation):

Domains of well-being. Quality of life is described as an aggregate of different, interrelated aspects of life. These aspects can be organized into domains. Researchers use various classifications. In this document eight domains of well-being are suggested:

- Emotional well-being
- Interpersonal relations
- Material well-being
- Personal development
- Physical well-being
- Self-determination
- Social inclusion
- Rights



Inter- and intra-personal variability. Variability means that the domains of well-being will apply to, or be experienced by individuals and cultural groups to varying degrees. A good quality of life means different things to different people.

Personal context. People are best understood within the context and environment important to them — where they live, work and play. Environments should be adaptable so as to accommodate personal interests and needs. Interventions should be directed towards people, places and surroundings that can promote and enhance a full life.

Life span perspective. Quality of life includes a life span perspective. Support and services denied during childhood can affect quality of life later in life and thus have cumulative effects.

Holism. This means that all the domains of well-being are interrelated. Particular aspects or domains of an individual's life may dramatically influence other domains. These inter-linkages must be carefully taken into account when designing programmes.

Values, choices and personal control. Quality of life recognizes different value systems and accepts that choices and personal control over activities, interventions and environment have major implications for self-image, motivation, self-expression and health.

Perception. An individual's perception about his or her own quality of life is important. There is no correct or incorrect response. Sometimes it is important to take into account the perceptions of parents, spouses or service providers. However, it should be noted that these perceptions might differ appreciably from the perceptions of the individual. Thus, it is a challenge to develop methods to communicate directly with intellectually disabled persons and children who, in the past, have been unable to provide input themselves.

Self-image. The aims of all quality of life programmes must be to enhance the individual's self-image and to provide empowering environments, which enhance opportunities to control the personal aspects of life.

Empowerment. Quality of life assumes major control by the service user over services provided and interventions designed. Detailed examination is needed to discover who controls the programmes and interventions to ensure that this can happen.

The Consensus Document concludes that there are both objective and subjective quality of life indicators. Objective indicators can be reliably observed and measure, for example, material attainment, stability of human institutions, social connections and life opportunities. Such indicators can be measured in quantitative studies. Subjective indicators measure quality of life, as it is understood and valued from the individual perspective, and identify those specific aspects that become valued by individuals as they pursue their lives in their unique environments. These indicators are identified by qualitative studies.

The present study attempts to look at the improvements in quality of life that have been experienced as a consequence of the CBR programmes by persons with disabilities themselves. This study therefore focuses on the subjective, qualitative indicators. The framework presented in the IASSID Consensus Document has been used as a guideline in analysing and structuring the data.

Emotional well-being and personal development

In this study persons with disabilities have expressed and defined these two quality of life domains in the following way:

- ⇒ **Self-esteem.** This involves perceptions of emotional well-being, sense of value and personal development.
- ⇒ **Empowerment and influence.** This involves the perception of influence and control over their personal situation and the level of confidence felt when advocating their own rights and when supporting others.

Social inclusion and interpersonal relations

In this study persons with disabilities have expressed and defined these two quality of life domains in the following way:

- ⇒ **Social inclusion.** This involves perceptions of social belonging and acceptance, quality and quantity of relationships and communication.

Self-determination and material well-being

In this study persons with disabilities have expressed and defined these two quality of life domains in the following way:

- ⇒ **Self-reliance.** This involves perceptions of personal independence and the ability to contribute practically and financially towards their own and family maintenance.

Physical well-being

In this study persons with disabilities have expressed and defined this quality of life domain in the following way:

- ⇒ **Physical well-being.** This involves perceptions of physical health and the level of satisfaction with medical treatment, rehabilitation and support services.

Rights

In this study persons with disabilities have expressed and defined this quality of life domain in the following way:

- ⇒ **Confidence and trust in society.** This involves perceptions of the level of commitment shown by a society to fulfil its human rights obligations towards persons with disabilities.

Using the Standard Rules to analyse CBR programmes

The UN Standard Rules list a number of areas where states should take action in order to promote equal opportunities and full participation for persons with disabilities. The rules could be successfully used to plan and to monitor government (and CBR programme) input towards human rights for disabled persons, because they cover a comprehensive range of preconditions for change in quality of life concerning persons with disabilities. However, no common methodology has been developed to make quantitative or qualitative assessments of the level of adherence to these rules. To date, three major studies have been undertaken to evaluate how states are adhering to the UN Standard Rules:

- A study carried out by the UN Special Rapporteur considering the general implementation of the rules. Questionnaires were directed to governments and DPOs in all UN Member States.
- A study carried out by WHO in collaboration with the UN Special Rapporteur in 1999 by means of a questionnaire sent to all governments of Member States of the WHO and to 600 NGOs working in the disability field in the Member States of the WHO. The information focuses on issues related to four of the 22 Standard Rules on the Equalization of Opportunities for Persons with Disabilities: Rule 2 on Medical Care, Rule 3 on Rehabilitation, Rule 4 on Support Services and Rule 19 on Personnel Training.
- A study carried out by the Danish Council of Organizations of Disabled People (DSI) in 1995–1997 by means of establishing an index based on questionnaires to 600 DPOs in 150 countries. DPOs were requested to score the performance of their respective governments in relation to each rule on a scale of 1–6.

All three studies depend on the subjective answers given by authorities and DPOs to a number of questions related to specific rules. These studies could be used as a baseline to monitor the effects of ongoing social and human rights processes. They could also be used to put the findings of this study into a wider context.

As the Standard Rules cover a comprehensive range of **preconditions** for improved quality of life for disabled persons, they have been used as a reference guide when examining and organizing the reflections made by the interviewees on the usefulness of different CBR programme initiatives. The following clusters of Standard Rules have been specifically mentioned because the programmes studied have particularly addressed these areas:

- ⇒ **Awareness-raising.** This involves all measures aimed at eliminating stigma, increasing the knowledge of different disabilities and creating an inclusive social environment.
- ⇒ **Medical care.** This involves early interventions and access to medical treatments.
- ⇒ **Rehabilitation and support services.** This involves measures to enable persons with disabilities to reach their optimal physical, sensory, intellectual and social levels, and to provide tools, services and assistive devices that compensate for the loss or absence of a functional limitation.
- ⇒ **Education.** This involves access to basic education and literacy skills.
- ⇒ **Income maintenance and social security.** This involves employment, vocational skills training and loan facilities.
- ⇒ **Government and community commitment.** This involves the implementation measures taken by the authorities and the community to fulfil their obligations towards persons with disabilities, such as recognition of their responsibility, adoption of policies and plans, legislation, resource allocation, coordination and training, etc.
- ⇒ **Support to DPOs.** This involves **the empowerment** of persons with disabilities to form their own self-help and advocacy groups, **the capacity building** of these organizations to enable them to engage in development issues in general and disability issues in particular, and **the recognition** of the importance of these organizations as important stakeholders.

The clusters chosen also reflect most of the components and sectors that have been identified as essential for a CBR programme in the 1997 ESCAP document called “Understanding CBR” referred to above.

AIM OF THE STUDY

The overall aim of the study is to examine the impact of CBR programme initiatives on the living conditions⁷ of disabled persons.

Specific objectives of the study are the following:

- To review the involvement of persons with disabilities and their families in CBR programmes.
- To examine the change in living conditions of persons with disabilities after the implementation of CBR.
- To identify the CBR programme initiatives that are most helpful in improving living conditions of persons with disabilities.

This study does *not* attempt to evaluate the different CBR programmes according to their particular aims and strategies. Instead, it attempts to voice the perceptions, views and experiences of disabled persons and their families who are participating in a variety of programmes throughout the world.

METHODOLOGICAL CONSIDERATIONS

This study has been a process involving many steps and methodological considerations. These are described in detail below and include the following: selection of CBR programmes for the study, study of research and previous evaluations, choice of methodology for data collection, selection of interviewees, use of inquiry groups to expand knowledge, design of the interviews and analysing the data. Finally, the limitations of the study are discussed.

Selection of CBR programmes for the study

A global list of existing CBR programmes, studies and evaluations was prepared by Uppsala University to form the basis for selection of suitable programmes to be included in this study⁸. Criteria for selection of suitable programmes comprised:

- diverse geographical regions should be represented
- various approaches should be represented (e.g. NGO driven and government driven)
- several CBR sectors should be represented (e.g. education focus, rehabilitation focus, income generation focus, etc.)
- distinct disability groups should be represented
- both children and adults should be represented
- programmes should have a gender perspective
- programmes should include the participation of DPOs, parents and individual persons with disabilities
- programmes should be well known to SHIA and WHO and easily accessed

The three countries identified and selected for this study were Ghana, Guyana and Nepal. These countries were selected because they fulfil the criteria for selection; in particular they represent differing approaches to CBR.

1. Ghana's CBR programme is a national one, initiated by the government and driven by the Department of Social Welfare. UN agencies as well as Nordic DPOs have supported the project from its inception. Support to, and establishment of national and

⁷ "Living conditions" are defined as "quality of life" throughout this study.

⁸ Jennische B, List of existing CBR programmes, studies and evaluations. Uppsala University, 2000 (see the Appendix of the present document).

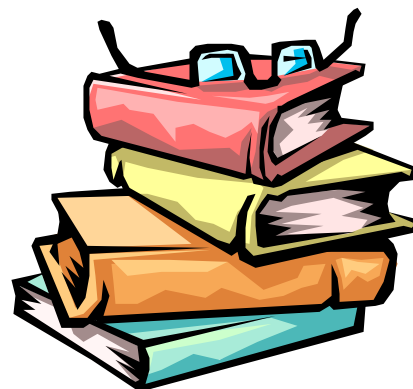
local DPOs have in recent years been an important part of the CBR programme. In Ghana the Association of the Blind has implemented its own CBR project parallel to the government initiative.

2. In Guyana the CBR concept was introduced by an NGO especially established for this purpose. Children with disabilities and their parents were the main target group for the programme.
3. In Nepal CBR is initiated and driven as a project by one of the national DPOs with support from SHIA and from the Nepalese Ministry of Women, Children and Social Welfare. Sign language training has been an important part of this CBR programme, partly because of a previous programme supported by SHIA and the Swedish Association of the Deaf. There are several other CBR programmes in addition to this one — all are implemented by different NGOs. One NGO has even established a National CBR Training Centre in Nepal.

Study of research and previous evaluations

In order to find an effective method for collecting evidence, measuring quality of life and assessing the usefulness of various CBR programme initiatives a number of desk studies were carried out:

1. Study of information gained through previous evaluations^{9 10 11} concerning the impact of CBR as perceived by persons with disabilities themselves.
2. Study of annual reports and monitoring reports from the three CBR programmes in Ghana, Guyana and Nepal.
3. Study of data obtained by WHO in collaboration with the UN Special Rapporteur on Disability in 1999 by means of a questionnaire sent to all governments of Member States of the WHO and to 600 NGOs working in the disability field in the Member States of the WHO. The information focuses on issues related to four of the 22 Standard Rules on the Equalization of Opportunities for Persons with Disabilities: Rule 2 on Medical Care, Rule 3 on Rehabilitation, Rule 4 on Support Services and Rule 19 on Personnel Training.
4. Study of the experience of using Participatory Research Approach (PRA) methods in qualitative studies (see below).
5. Study of “quality of life” research and literature to establish possible categories for systematization of evidence (as indicated on page 11).
6. Study of possible framework to systematize CBR programme initiatives, e.g. Standard Rules and CBR evaluation guidelines.



⁹ Krefting L, Krefting D, Evaluation report NDA/NHR/SHIA CBR program in Nepal, December 1998.

¹⁰ O'Toole B, Participatory evaluation, Ghana community-based rehabilitation program. Government of Ghana/NAD/SHIA/UNDP, April 1996.

¹¹ Miles J, Pierre L, Offering hope, an evaluation of the Guyana CBR program. AIFO, July 1994.

Choice of methodology for data collection

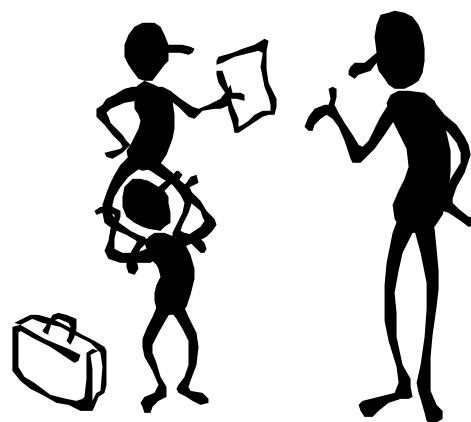
In order to determine how persons with disabilities and their families perceive the impact of CBR in changes to their own lives and living conditions it was necessary to find a method that involved active participation in the study by the individuals concerned. The PRA model was chosen as the best option because:

- Participatory research brings together researchers and participants in a dialogue that expands the knowledge and awareness of both¹². It is a learning process for all involved, and not just a process whereby some people accumulate information about others. Local people and professional researchers are equals in the research process — they are both researchers and learners¹³.
- In participatory research, all who participate are both co-researchers and co-subjects. Cooperative inquiry is therefore also a form of education, personal development, and social action¹⁴. Participatory research is a three-pronged activity, which integrates a research process (social investigation) into educational work through an action designed to deal with specific problems¹⁵.
- The goal of the research is political or social change derived from the information gathered. Knowledge gained in the process can be translated immediately into action for social change. Local people control the process of problem definition, information gathering and decisions about the action that might ensue from the information.

In accordance with PRA methodology this study was carried out as follows:

Studies were made in Ghana and Guyana in 2000, and Nepal in 2001. Representatives of SHIA and WHO introduced the project called “Impact assessment of CBR” to ministries, agencies, INGOs and DPOs in each country. After this introduction assessments were carried out in three communities within each country. The communities were selected by the respective CBR programme management to represent various geographical and demographic conditions.

In each community persons with disabilities (and in some cases also their parents) who had been involved in the CBR programme were invited to participate in the study. These persons first met as a group (inquiry group) with the researcher to discuss, to understand jointly and to agree about the aims and design of the study. Following this, the SHIA/WHO researcher met each individual for in-depth interviews. Before leaving the community the researcher met the group again to summarize and discuss the findings, to make additional comments and reflections and to learn from each other. As a result some of the groups also decided to take action to address some of the problems identified.



¹² Brown LD, Organizing participatory research: interfaces for joint inquiry and organizational change. *Journal of Occupational Behaviour*, 1983.

¹³ Couto R, Participatory research. *Methodology and Critique, Clinical Sociological Review*, 1987.

¹⁴ Reason P, Human inquiry in action. Thousand Oaks, CA: Sage Publications, 1988.

¹⁵ Hall B, Research, commitment and action: the role of participatory research. *International Review of Education*, 1984.

Selection of interviewees

In-depth interviews were held with 33 individuals: 12 were parents, 7 were men with disabilities and 14 were women with disabilities. All of them had been involved in the CBR programme for at least three years. These 33 persons represented the following disability groups: 16 persons with physical impairment, 8 with hearing impairment or deafness, 6 with intellectual disability persons and 3 with visual impairment¹⁶. When parents were interviewed the children were present and, in a few cases, they also volunteered to comment. However, it was mainly the viewpoint of the parents that was being sought. In order to obtain a picture of the viewpoint of children themselves, complementary studies would be needed.

The selection of interviewees was made by the local CBR programme staff. It can be assumed that the selected persons were those believed to have a positive view of the CBR programme. As the study attempts to find how quality of life had changed and what types of initiatives were most helpful to bring about that change, it was essential to take a starting point in the successful examples. Thus, the positive bias in the selection was not a problem.

How representative are the views of these 33 persons? From previous evaluations of the three CBR programmes it can be concluded that the number of persons benefiting from CBR programmes remains low. The number of communities reached is limited, even in government-supported programmes such as those in Ghana. Even in communities reached by the CBR programmes many persons with disabilities are not found or targeted. The Nepal evaluation gave evidence that less than 40% of the disabled population had been reached in some communities. The reason for this limited contact is not yet fully understood, but persons with severe and multiple disabilities are often seen as “too difficult”. Another reason may be lack of commitment or discrimination due to cast or socio-economic status.

Thus, the 33 interviewees are not representative of the disabled population of the countries studied. However, as their stories of successes and disappointments are very congruent, they can give us an enhanced understanding of the impact of CBR on quality of life for persons with different kinds of disabilities, as well as some ideas about which CBR programme initiatives have worked best.

Use of inquiry groups to expand knowledge

In addition to the individual interviews, inquiry groups were created in all three communities in each country — nine groups in total. The groups consisted of the persons individually interviewed, other persons with disabilities in the community, family members and local representatives of DPOs. Two group interview sessions were held with these inquiry groups, one session after the arrival of the SHIA/WHO researcher in the community and another before departure. Three group interviews with national DPOs in Ghana have also been made.

The outline of the study and the open interview guide were discussed at the first interview session. The participants contributed information about the local CBR programme, their own experiences, cultural and social knowledge of values. The recurrent session served to create a cooperative relationship, and the participants brought up additional subjects and questions. Through group interviews an additional 80 persons with disabilities and parents were reached and had their views recorded.

¹⁶ In this study no difference has been made between hearing impaired and deaf persons. As hearing aids are often inaccessible, persons with hearing impairments and deaf persons are expressing the same need for a sign language environment in order to develop communication, social and academic skills.

Design of the interviews

The interviews were taped and transcribed. An open interview guide was used, containing questions within the following areas:

- How has your own life changed as a result of CBR?
- What are the most important changes brought about by CBR in the community?
- Has CBR improved your access to health services, rehabilitation, assistive devices and equipment?
- Has CBR helped to improve your education? How?
- Has CBR contributed to your self-reliance/independence and income generation?? How?
- Have your communication skills and personal participation in family and community increased as a result of CBR?
- Have you been able to influence government policy-making and planning?
- How has CBR affected the role of DPOs?
- What is your view of the future?



The interviews were carried out as conversations lasting between one and two hours and the group interviews often more than two hours. The data analysed totalled approximately 150 hours of recorded interviews. An independent interpreter was engaged to translate the communication between the researcher and the interviewees. When interviewing deaf persons a sign language interpreter was engaged, except in two cases where the mother and husband served as interpreters because the sign language used was peculiar to these individuals.

All individual interviews have taken place in the home of the interviewed person and the researcher has taken part in some of each person's daily activity at home, at school or elsewhere.

Analysing the data

All statements made by individuals and groups have been transcribed and organized into categories according to

- the quality of life domain to which they referred
- the particular type of CBR initiative to which they referred

The statements have been used as evidence in this study and form the basis for the conclusions drawn on the impact of CBR programmes as perceived by persons with disabilities and their families. When statements from communities in all three countries give the same evidence a conclusion has been drawn regarding the effects on the particular quality of life domains and regarding the impact of different CBR programme initiatives. In the few cases when statements have given evidence of differing opinions this has been reflected in the conclusion.

To validate the conclusions in this study, comparisons have been made with findings on the perceptions of disabled persons reported in earlier evaluations. This has further strengthened the conclusions in this study, as the earlier findings were very similar.

Limitations of the study

As this study is of an explorative nature and aims at assessing perceptions of persons with disabilities concerning the impact of CBR programmes, it was decided to use a qualitative enquiry method. Given the nature of qualitative enquiry, we caution against broad generalizations of these findings. However, as the answers given by the interviewees show a great congruence despite the differences in background and organization of the CBR programmes and despite differences in the political and cultural contexts, general conclusions may still be drawn.

The limitations of the study include:

- The difficulty for a foreign person to establish a trustful relationship with the interviewees in the communities visited. This might lead to dishonest answers. However, at the same time, many of the interviews show signs of being open and critical. Some even used the researcher to send critical messages to the CBR programme leadership.
- The difficulty not to influence interviewees with your own feelings, ideas and suggestions in a PRA study.
- The difficulty to verify the translations to and from local languages.
- To date no confirmatory study has been undertaken to verify the conclusions. Originally it was planned to hold feedback discussions in the inquiry groups and to conduct a complementary quantitative study involving a larger number of persons with disabilities and CBR programmes. However, due to serious health problems of the researcher this part of the study had to be excluded.

FINDINGS

General observations

What is a successful CBR programme? Should it be measured by the quantity and quality of services provided? Or should it be measured in terms of the social change processes that it has managed to start? This study indicates that the strengths of the CBR programmes have mainly been found in the latter area. Whereas medical care and physical rehabilitation services are still inaccessible to most persons with disabilities in the targeted areas, processes of empowerment and social acceptance have been initiated.

This study gives evidence that CBR programmes have started change processes in the communities targeted and brought about improvements in the quality of life of persons with disabilities in a range of areas. However, the number of communities and persons with disabilities that have been reached is still very small. Also, the expectation that the community (or the district government), once awareness was raised, would provide the necessary resources, basic services, simple assistive devices, etc., has not been fulfilled. It is obvious that CBR programmes need to be combined with other efforts and measures in society, integrated into mainstream community development programmes and supported by governments on a large scale, in order to bring about lasting and comprehensive improvements. DPOs and international organizations can play an important advocacy and capacity building role in order to achieve this.

It is encouraging that national policies on disability and new legislation are being discussed or have been adopted in all three countries under study. In Ghana there are new options to influence political priorities and resource allocation through the District Assemblies, in

Guyana the Ministry of Health has recently entered into a new agreement with the CBR Programme, and in Nepal increasing media attention is being given to disability issues.

Stories told by the interviewees in this study illustrate many positive effects of the CBR programmes, but they also bring forward concerns about the efficiency and sustainability of the programmes.

Quality of life analysis

CBR programmes seem to have started change processes in social norms and values, which are essential for the further development of quality of life of persons with disabilities. This study indicates that CBR has impacted positively on the following aspects of quality of life:

- Self-esteem
- Empowerment and influence
- Social inclusion
- Self-reliance

However, impact is limited when it comes to

- Physical well-being
- Confidence and trust in society to fulfil its human rights obligations

Self-esteem

The study shows that CBR programmes have increased self-esteem as reported by persons with disabilities and parents of children with disabilities. Disabled people have become visible; they have shown that they can contribute to family life and in the community, irrespective of the type of disability. Typical statements were:

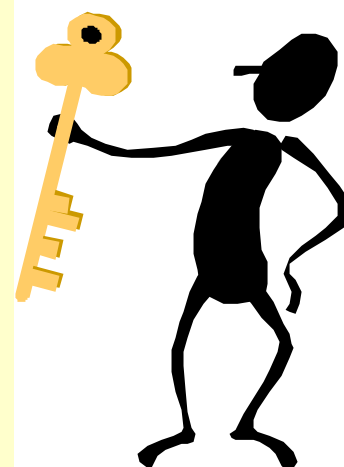
“Previously, I felt very inferior but after I joined the CBR programme...I have been able to overcome that feeling... I can now assess myself with others and say that I can perform certain activities and tasks better than the able bodied.”

“I used to be a very shy girl and felt hesitant to speak a word in front of 2–3 persons. This was because of the discrimination and the way non-disabled persons looked upon me. Since the programme was launched in this village we came to know about disability and learn to support ourselves through different trainings. Now I have confidence in me and I’m able to introduce myself in mass and speak my mind.”

“I see myself as a role model for other persons with disabilities.”

“Since I started CBR, I am not depressed as I used to be — Oh, I have a child like this. By seeing other children and being involved my daughter has learnt a lot. I am proud of her.”

“This programme not only helps to uplift the economic background of disabled persons but also helps them to grow strong inside.”



When analysing the reasons that could have brought about this change some conclusions can be drawn, though they differ for each group:

Parents become proud when their children improve their social behaviour, develop new skills and communicate better. In addition, they become proud when they are able to use their experience to help other parents.

Persons with disabilities increase their self-esteem when they are able to

- contribute to the well-being of their family, practically or financially
- maintain themselves independently
- contribute to the development of the community
- play an active social role
- prove their ability to perform well in school, develop useful vocational skills and earn an income

Being able to assist non-disabled people is highly motivating for self-esteem. One woman in Ghana has used her loan from the CBR programme to assist a whole group of women to purchase raw materials on credit. This has considerably increased her self-esteem as well as her social status.

For **deaf and hearing impaired persons** self-esteem and social inclusion are also connected to the ability to communicate. Access to a common and recognized sign language and to interpreter services is a precondition for recognition and inclusion in society as well as for enhancement of self-esteem and self-confidence. Hearing aids will not be affordable and accessible for the majority of hearing impaired persons in the countries studied in the foreseeable future.

Empowerment and influence

Most CBR programmes continue to be weak in these aspects despite the fact that CBR policy documents indicate the necessity of involvement and influence of persons with disabilities and their organizations. DPOs and persons with disabilities are seen as beneficiaries and not as participants with a voice and a choice. However, CBR programmes have empowered many individuals to challenge this situation. The following describes how disabled persons and their families regard the impact of CBR programmes on their empowerment and influence.



This is the feeling in Ghana:

“Before, we hardly knew each other. This has changed. When I got to know about the Association I realized there were others like me. I am always happy to attend meetings because of the companionship. I have been able to get advice, companionship and play an advocacy role.”

“CBR has assisted the Association immensely since it has enabled us to get funds, and mobilize members. The three Associations (of the blind, the deaf and the physically disabled) work hand in hand in our district. The CBR programme has been able to encourage DPOs to form a common platform on which they present common issues and chart a common course.”

Parents in Guyana:

“Since I know about CBR I have learned a lot. I learn that there are many other disabled children so that mine is not the only one and with my experience I can advise other parents. Because for sixteen years I have had to deal with my child so I have a lot of experience. So that whatever I have learned from CBR I can share with younger parents on how to keep the child entertained and not to keep him home so that he can get to interact with others. Before that I usually kept my child at home for fear that someone would laugh at him, only his parents could have communicated with him. It is really nice to be associated with CBR.”

“I think that the policy-makers understand that they cannot make decisions for us without consulting us who are in the situations and knows exactly the way it feels.”



In Nepal:

“Before the CBR was launched in this village we didn’t know the number of disabled people living in this community. We only saw them and knew about their disabilities. But now we have a strong relationship among ourselves. We can do everything according to our desires. We came to know that my disability is different from hers or his, but in one way or another we support each other, which we have learned through the CBR Programme’s guidance and support.”

“We can do everything through this Disabled Organizational Development Group (DODG) unity. We can fight for our rights in this community. If anybody hampers our way of progress we can tackle them and stop them from doing anything negative on our part. If somebody says ‘you are this or that’ we can go through this DODG and convince them that you should not say that.”

When analysing the possible contributions to this increased empowerment the following was compiled:

- Creation of meeting places where persons with disabilities and parents of children with disabilities can share experiences.
- Sharing of common experiences of difficulties and discrimination as well as possible solutions to overcome these problems.
- Self-reliance that makes it possible financially and physically to attend meetings.
- Leadership training that has increased confidence and self-esteem.

Despite this empowerment there is a strong feeling of having a long way to go before influence is achieved. Many persons with disabilities give evidence that much is said verbally and in policy documents about the participation of persons with disabilities and DPOs but, in practice, persons with disabilities are seen as passive beneficiaries and are not considered for employment, appointments, study visits and training opportunities in the CBR programmes. Nor are they considered as resource persons or teachers. It was pointed out that persons with intellectual disabilities and deaf persons have an additional disadvantage owing to their communication problems.

“In the situation of the hearing impaired because they cannot verbalize their concerns, they are considered a disturbance. Often people make negative remarks: ‘The deaf people are coming’.”

“I am restricted because of my limited sign language. I would like more training. Because of the difficulty communicating with the authorities they have not taken it seriously about our needs.”

Social inclusion

Numerous stories illustrate how social inclusion and acceptance have improved for all disability groups as a result of the CBR programmes.

“The level of social understanding has improved; we are able to interact with people and they do not make fun of us.”

“Previously it was taboo for a person with disability to enter the Chief’s Palace; all this has changed now.”

“As you move in the community, assistance is provided willingly. The level of understanding of the blind has improved greatly.”

“I am now invited to family gatherings.”

“CBR is good in the sense that it brought out so many other persons that had children with disabilities to understand that they had a place in society and that they should not be locked away and be kept indoors. CBR brought them out.”

“There is not much of a problem with social recognition and acceptance since I am one of the recognized tailors in town.”



“Before the CBR Programme was launched in this village, the disabled persons were teased and humiliated by the local people. These activities made them hesitate to go outside so they had no choice other than to sit at home idly. But since the CBR Programme started in this village there has been drastic change in the life of persons with disabilities. They gave trainings of different skilful activities to disabled people and made them capable to earn money on their own. Now the disabled children go to school where non-disabled children study. They are not teased like before but it’s not completely gone either.”

When analysing the reasons for the changes in social acceptance the following emerges as the most important:

- Persons with disabilities become visible when the CBR programme starts asking questions about their situation.
- Persons with disabilities have shown the community that they have skills and can contribute to family life and earn an income.
- Persons with disabilities have attracted attention from NGOs and government authorities which benefits the community.
- Community leaders and members have been informed about disabilities, their causes and the way to support children and adults with disabilities.

It should be noted that the single most effective tool to change social norms and values is through successful role models. To be “successful” means performing well as regards income generation and practical, social or academic skills. This may put pressure on children and adults with disabilities who are pioneers in schools, training schemes or workplaces.

For children social inclusion is also about being accepted in school. No doubt CBR programmes have impacted on the number of children being enrolled in ordinary schools. However, parents and DPOs have mixed feelings about the impact of inclusive education. For some children it has meant humiliation, low self-esteem and social exclusion, while others have experienced benefits.

Deaf persons depend on a sign language environment in order to be able to enjoy social inclusion. This is seldom accommodated in CBR projects. The Associations of the Deaf can play an important role in the social life and development of sign language skills of deaf persons if given support to do so. In Ghana the CBR programme has been instrumental in facilitating the creation of local deaf associations. In Ghana and Nepal the CBR programmes have an important role in identifying and referring persons to these associations.

Self-reliance

CBR programmes have impacted positively on the self-reliance of many children and adults with disabilities. Firstly, training in daily living skills has been helpful. Some of the statements were:

“Initially, I found it difficult to socialize and did not have any personal skills, such as putting on shoes was difficult for me. With training from the CBR programme I am now able to take care of myself and interact with people in the community.”

“If I went outside people would stare at me and used to say that though I have a beautiful face and body it is just worthless, as I can't walk. So they just pitied me but my parents love me and supported me greatly. Now, I can go a longer distance with the help of a wheelchair. And I can change cloths for myself during the period. I can wash them. I can take a bath without support of my mother, sisters or sisters-in-law.”

“CBR has made a difference in all our families' lives. From the inception when the child could not do anything for himself, it was very frustrating not knowing what to do and where to go for help and this is where CBR came into our lives. It has worked tremendously for other families and us.”

When analysing the reasons for the positive impact on personal self-reliance it was noted that social counselling and advice on daily living skills and mobility were the most important factors. Provision of assistive devices or physical rehabilitation was not mentioned as a contributing factor to self-reliance. The woman in the example above who had a received a wheelchair is an exception. She received her wheelchair as a gift from Sweden — not through the CBR programme. Her wheelchair is now out of order because there are no spare parts in Nepal.

Secondly, self-reliance has been achieved through skills training and loan schemes as the following statements show:

“Now I'm benefiting from this business and feel proud that I'm not dependent on my husband. Because in our society all women are dependent on men but in my case I've my own business raising the children by myself and I feel very happy about that.”

“When I lost my sight I was worried about how I could get a husband and go to the farm like the others. My happiest day was when I learned to weave, which was the first step to earning an income. This was fulfilled when I received the first loan. Through the loan from the CBR programme I have been able to start a weaving trade and now I cater for my needs and assist others in my family.”

“If the CBR Programme were not launched in this area I would have never come this far. I mean I would be staying at home the whole day depending on my family for everything. I would be crawling on the ground, others staring at me and querying about my disability. But this programme has changed my life positively. Before this programme I had to depend on the family but now I can support them with my independent professions.”

When analysing the reasons for the positive impact on financial self-reliance the loan schemes were reported to be the single most important influence. Although many interviewees thought the loans to be too small they were appreciated even more than the skills training because:

- Even without a vocational skill, animal keeping is an option to improve socio-economic status. A loan to buy chickens or goats can be a turning point.
- Many disabled persons are able to find apprenticeships on their own but then fail to create a business owing to lack of starting capital.
- Some persons with disabilities also complain that the skills training given through the CBR programmes is not efficient and that there are preconceived ideas as to the type of skills training that is suitable for particular disabilities.

Physical well-being

The physical well-being of persons with disabilities has not been influenced much by the CBR programmes. Early interventions are rarely made and traditional medicine is still the first option in many cases, as indicated by the following statements:

“We did not know from the beginning. Our child was born at the Public Hospital Georgetown. There was difficulty in the birth period and we did have a problem in getting the doctor to explain to us. We were told it was related to jaundice but subsequently everything would be okay. As time went by there was no improvement by our observation. At the paediatric clinic the doctors still said everything would be okay, she would develop. It was not until some years after we knew she was disabled. She had difficulty moving, keeping her head up.”

“I went to the healer for one year. He used to put some locally made medicine on my legs and also asked us to give sacrifices of animals like goats and chickens in some temples. But nothing helped my condition. Then I went to a hospital but the medication didn't help me. I couldn't stand on my legs and I was not able to bend them either. I used to work by crawling and sitting because the doctors and sisters had suggested to me that I wouldn't be able to do anything and my condition would be degraded more if I sat idly. So I started doing things in whatever way I could.”

“I don't go to the hospital any more because I can't afford the medicine. That's why I am having the pains.”

When analysing the reasons for this situation it can be concluded that

- health professionals still have little knowledge about diagnosing or treating different conditions
- medical care is not accessible because of high costs

Positive reports come from Nepal where the CBR project actually pays the bills for hospital treatments and assistive devices. This has benefited some individuals. However, paying bills for individuals is not a sustainable method that can be brought to scale.



Furthermore, physical rehabilitation efforts and assistive devices offered at the community level seem to be either non-existent or of poor quality. Typical examples were:

“I was provided with callipers and trained on how to use them. However, when I got back home, the landscape was not good enough since I was experiencing great pains. I now use a stick for walking.”

“I was taken to the hospital, but was not able to recover. I was given a walking pen but it was not helpful. Due to financial problems I could not purchase one that would be suitable. I am now managing without a walking aid. The CBR agent gave me some training on an easier way to move about.”

“There is no support for technical aids. The limb fitting centre, which is under the Ministry of Health, has all the materials but they are very expensive and when we complain they tell us that it is the tax on the raw materials and that the rate of exchange is unfavourable.”

When analysing the reasons for this situation the following influences were mentioned:

- Physical rehabilitation and production of assistive devices seem to be more difficult than anticipated and are not handled easily by community volunteers.
- Referral units are inaccessible owing to distance or cost.

Confidence and trust in society

This has been one of the weakest points in the CBR programmes. Persons with disabilities (and their families) notice that, despite supportive words and new policies, in practice little is done as regards resource allocation, neither in families, communities and government bodies, nor in international development assistance. Persons with disabilities and their organizations have concluded “we have to help ourselves” and “without us nothing will happen”. They are no longer satisfied about depending on the goodwill of others. They have seen volunteers lose interest and commitment, CBR committees dissolve, and governments and international organizations break promises. It is not surprising that many interviewees are discouraged about the possibility of getting the support to which they are entitled from governments and communities. Most of them put their hope in INGOs. Here are some comments:

“The Community is very innovative with the social attitude. If I go to the District Chief Executive, he welcomes me wholeheartedly into his office and I am able to discuss a lot of issues with him. But when the discussion borders on financial commitment or support, the response is usually discouraging.”

“The CBR programme is supposed to be community-based but the response here has been very, very discouraging. Would you believe that after launching an appeal in church you may receive approx. USD 1.80, which cannot even cater for the cost of transportation incurred to undertake the appeal?”

“At first they indicated that they would join the project (authorities) but later on we realized their assistance was not forthcoming. So we decided to come together and help ourselves.”

“This is a CBR project but the very people who should support us disregard us. They used to attend meetings in the hope of obtaining some reward. Since that was not forthcoming they gradually withdrew their participation.”

When analysing the reason for little improvement in confidence the following has emerged:

- Many communities are extremely poor and there are no resources available to guarantee everybody their rights.
- The few businessmen who can afford to donate become exhausted.
- Moral support is easy to give. It does not cost and it makes you popular. When resources are requested it becomes clear that the commitment had its limits and that other issues have higher priority.

Analysis of CBR programme initiatives

Looking at the different CBR programme initiatives used to achieve the positive impact on quality of life it can be concluded that the initiatives perceived as the most useful by persons with disabilities were (in order of priority):

- social counselling
- training in mobility and daily living skills
- providing or facilitating access to loans
- community awareness-raising
- providing or facilitating vocational training/apprenticeships
- facilitating the formation of local self-help groups, parents' groups and DPOs
- facilitating contacts with different authorities
- facilitating school enrolment (school fees and contacts with teachers)



If these views are put into the context of the Standard Rules the following can be concluded about different CBR programme initiatives.

Awareness-raising

Awareness-raising is perceived as an important and successful part of the CBR programmes that has impacted on the quality of life of disabled persons.

“The most important thing is to bring changes in their (community members) attitudes towards persons with disabilities (PWD). We have to make them aware of the things that PWD can do to support themselves. We have to counsel them, giving examples of disabled people who are doing well in life.”

“The most valuable was when CBR representatives gave inspirational speeches in front of the village office. I don't remember them all except one thing: they told us that disabled persons could do anything if they had good skills and financial support. They can be independent and can stand in competition with non-disabled persons in every field if they are given the opportunity and if the disabled themselves are confident and determined on what they are doing. At that moment I promised to myself that I would show my husband that there isn't anything that I can't do to support and bring up my children. Though I didn't tell this to anybody I felt a strong determination within me that I can do everything, whether it be men's work or anything else.”

It is mainly the following awareness-raising methods that have brought about change:

- social counselling to families and individuals
- exposure of role models, e.g. persons with disabilities, who are seen to be socially and materially “successful”
- dialogue and information dissemination at community meetings
- empowerment workshops for persons with disabilities and their families

Some of the interviewees point out that:

- The best awareness is created by persons with disabilities themselves.
- Drama is a powerful tool to make people see prejudices.

- Traditional workshops and seminars are not always efficient. Seminars for government staff seldom lead to changes if not combined with practical on-the-job training and rewards for improved practices.
- Media is a new avenue for information dissemination as increasingly more people access radio and television.
- Pop stars and sport stars are under-utilized as advocates.

Medical care

CBR programmes seem to have failed to bring on board the health authorities and few tools remain to provide medical assistance. Only in Nepal, where the CBR programme has paid medical bills, do persons with disabilities report increased access to medical treatment. However, traditional practitioners still remain the first option for most persons with disabilities, which also hampers early detection. The following statements give voice to the view of disabled persons and their families:

“Due to financial problems I have not been able to undergo medical treatment.”

“When he was born with his foot was turned in. He (a doctor) said that he would operate on him, to help him to walk. He did more damage. He made three (operations), one at the Georgetown Hospital and two at St. Joseph Mercy Hospital (private). We did get help (financial) from the Women’s United Group (NGO). The CBR programme could not help with funding. They explained that CBR is about training of parents and guidance to assist the child with the disability, especially at home.”

Medical health care systems are reported to have the following problems:

- Primary health care lacks competence to make correct diagnoses and treatments.
- Treatment is not free.
- Referral specialists are inaccessible owing to distance or cost.

The Ministries of Health are responsible for these shortcomings and should address the training needs as well as the issue of subsidizing treatment. As long as the modern health care system offers no satisfactory options, traditional healers will continue to be the first option in the communities, meaning that early interventions will not be made. It should be recognized that medical care requires resources and knowledge that are not normally available at the community level.

Rehabilitation and support services

Physical rehabilitation and provision of assistive devices are not perceived to be successful initiatives of CBR programmes. It was not foreseen that there would be such difficulty in providing these services at community level and the referral systems are still inaccessible or non-existent in most places. As one DPO representative in Ghana put it:

“Initially, under the CBR programme, that was the expectation; that logistic support and all other things would have to come from appropriate technology in the community. But like my sister was saying, it takes a bit of expert knowledge to be able to produce the appropriate thing. At the community level for example, if you want to develop crutches, you can easily develop them, but at the end of the day, because there might not be any cushion for the armpit area, the user may develop some lumps in the armpit. It might not be up to the measurement, so eventually the user might develop some curvature instead of straightening up. There has to be a measure of training in the provision of these services. Talking about passive exercises, such as physiotherapy in the house, if the person does not know a few things, the exercise might be more harmful than helpful. So there has to be some know-how in providing these services.”

Local production of assistive devices or physiotherapy equipment has not been an original part of the CBR programmes. It sometimes takes more skill to improvise and design the right device from local material than to produce the technically advanced device. In general, devices continue to be produced in only a few centres in the country or they are imported. This makes them too expensive for most persons with disabilities.

In addition, skill is required to design physiotherapy exercises and to use equipment. Without professional back-up and referral systems it has been difficult to keep pace. Few CBR workers have sufficient skills to provide relevant, quality advice on physiotherapy or rehabilitation techniques, or to design assistive devices. A few days of training without follow-up are not enough. As some parents indicated:

“We had a two-day workshop (with professionals) but that alone cannot profit anything; there needs to be an ongoing effort. And because they (physiotherapists, etc.) will have to come from New Amsterdam it will incur a lot of cost and they will have to be paid for their services.”

However, in all three CBR programmes **social rehabilitation and counselling** were mentioned among the most important and successful of the CBR programme initiatives that achieve improved quality of life of persons with disabilities and their families. The most appreciated initiatives were

- social counselling
- practical daily living skills training
- mobility training

Unfortunately, counselling and training are frequently limited to persons who can communicate. Intellectually disabled and deaf persons may be neglected. CBR workers generally do not know how to communicate or to learn about their needs. However, the sign language classes in Ghana and Nepal, organized in collaboration with the Associations of the Deaf, are reported to be contributing greatly to quality of life of deaf and hearing impaired persons, especially perception of self-esteem and social inclusion.

Education

Facilitating access to education in ordinary schools has been an important part of all CBR programmes studied. School fees, books and uniforms have been subsidized and teachers have been trained. In Ghana there are peripatetic teachers to support the ordinary schoolteachers. For many children this has contributed greatly to their quality of life, but not for all. Success is reported mostly for children with physical disabilities or minor impairments. The views on inclusive education among persons with disabilities and their families vary. Although the concept of inclusive education is well accepted its implementation is a controversial issue.



The stories told in this study give evidence of how inclusive education can be either helpful or harmful, depending on the disability of the child and the resources of the school. The reality that most parents and children face is a school where classes are big, material scarce, the syllabus inflexible and teachers insufficiently trained in learning methods and styles. In order to cope in such an environment the child requires a supportive home environment, good communication skills and little need of special measures from the teacher; otherwise the risk is great that schooling will increase exclusion and low self-esteem.

Persons with disabilities and parents were concerned about the situation of blind and deaf children, as shown by the following statement:

“Teachers should be trained specifically for students who are blind and deaf. At the moment we don’t have blind children because the teacher must know their way of reading and writing. If she doesn’t know about Braille then it’s worthless that any blind child goes to school. He won’t learn anything; it will only be like going and coming from school. Similarly in the case of deaf children, teachers should also know about their sign languages. Then, only the deaf students can learn things well.”

Some parents, especially parents of children with intellectual disabilities, feel that their children should rather learn a skill that can be used for income generation, while the majority feel that formal education is even more important for a child with a disability:

“Educating a child is very important whether he is disabled or non-disabled. Moreover, a disabled child should be educated even more than a non-disabled one because a disabled person cannot do field and other labouring work. So the easiest way for him to live independently is by being educated.”

“There are some parents of disabled children who don’t send them to school. Such parents should be counselled in the programme that your children should be educated, that’s the only way of making them a respected man in the society.”

The interviewees in this study emphasized the need for

- sign language classes for deaf children and for family members
- parent-driven community centres for intellectually disabled children focusing on skills training and care
- activities of daily living (ADL) and Braille training for blind children

It was suggested that these initiatives be strengthened in the CBR programmes.

Income maintenance and social security

According to the findings in this study income generation is the most appreciated CBR programme initiative, together with awareness-raising. Income generation positively impacts on almost all aspects of quality of life identified in this study; self-esteem, social inclusion, self-reliance, physical well-being, empowerment and influence. Some statements illustrate this:

“Disabled persons ideally should not sit, instead they should be engaged in skilful activities so that they become independent and show to non-disabled that disabled persons are also no less than them.”

“When CBR was introduced we received a lot of support from the loans and training in activities of daily living. I used the first loan to buy raw materials. The second loan I used to buy a goat and some chickens. They have already reproduced. I am saving to buy a cow. It is customary to give the family of the bride a cow when you want to marry.”

The CBR programmes have provided skills training, organized apprenticeships and access to revolving loan schemes. This study clearly indicates that the loans are considered to be the most essential part of income generation initiatives. Access to finance is a common problem in the communities, but has been particularly difficult for persons with disabilities. The CBR revolving funds have been an opening, but the amounts provided are very small and in Ghana it can only be used for purchase of raw materials — not for tools and equipment. In all three countries credit schemes are also part of other ongoing NGO and poverty reduction programmes. Interviewees suggested that future CBR programmes should facilitate access to these loans in addition to the ones targeted especially to persons with disabilities. Collaboration with DPOs in accessing business ideas and monitoring the loan schemes was also suggested.

Vocational training has been an appreciated part of the CBR programmes as well. However, the following has been pointed out:

- Apprenticeships are often more useful and efficient than the training given in vocational training centres.
- Without starting capital for tools and material there is no means of creating a trade after the training.
- Employment is still not an option for most persons with disabilities because positions are few and prejudices still vivid.
- The training provided is not innovative but follows preconceived ideas about what disabled persons can do.

In Nepal women who had been trained in tailoring said:

“It’s better if we get other vocational training like fabric painting, knitting and candle making. Yes and it’s good if we get the training of incense making because people can benefit from this type of small business. There is nobody who is in this business at the moment in this community.”

It was noted that in Guyana, the income generation is geared towards the parents, which indirectly benefited the children. However, it has been a challenge to move on and address the needs of young adults to become self-reliant. A parents’ organization naturally looks at the programme from the parents’ perspective and primarily considers their particular needs. CBR programmes seem to have difficulty in addressing the needs and rights of persons with disabilities in a holistic and multisectoral manner if steered by a particular interest group or government sector.

Government and community commitment

This study shows that community and government involvement so far has been limited to moral support. Apart from a few examples where individual school fees and income generation initiatives have been subsidized there are no substantial contributions by communities or local/district government authorities. It is obvious from this study that CBR is a powerful strategy to start processes of change in communities. However, in order to make these processes sustainable governments need to take responsibility and to play their part.

The stories told by persons with disabilities in the three countries show that there is a limit to what attitudes, goodwill and voluntary efforts can do.

“Generally contributions come from individuals. We have not received any funds from the community or district bodies. Our needs are not a priority. Our plans of action are made known to the authorities but are always cut out of the budgets.”

“The Local Supervisors (volunteers) cannot work under the existing financial situation. There are no incentives and no funds for travelling, meetings and training.”

“Even though we recognize the responsibility of parents and communities, the CBR programme should complement these efforts as a last resort. Our community is not economically strong.”

“There is a limited number of persons and organizations that donate locally so they are worn out of giving.”

There is an urgent need for CBR programmes to ensure that governments:

- Include persons with disabilities in ordinary community development programmes and poverty reduction schemes.
- Provide community workers with back-up, continuous training opportunities and incentives.
- Support a referral system at district level.
- Provide training and resources for education and health systems.
- Provide assistive devices free of charge.
- Support sign language development and interpreter training.

Support to DPOs

In general, the CBR programmes have been weak in supporting the capacity building of DPOs. Only in Ghana have strategic efforts been made to build capacity of the DPOs, but still the CBR programme is criticized for not doing enough. In Guyana the CBR programme is focusing on the parents of children with disabilities. In Nepal the support is confined to the community self-help DODGs that have no formal links to the disability movement in the country.

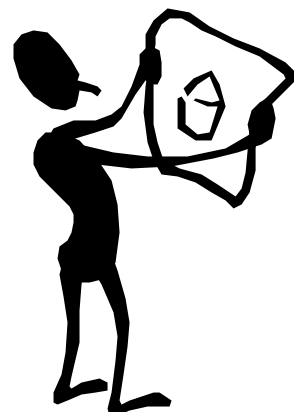
Strong DPOs are essential for realization of the rights of persons with disabilities. The importance of involving DPOs as key stakeholders will increase as CBR develops from being mainly a programme for provision of rehabilitation services to being a programme that promotes human rights of persons with disabilities and an inclusive community.

DPOs can play the dual role of advising and pressurizing the government authorities and empowering their members. However, many DPOs need strengthening to develop a wider support base, a democratic and transparent structure and a more strategic approach so that they can effectively take on this role. Presently, DPOs often promote the specific needs and rights of a particular disability group rather than an inclusive community for all citizens. This study has shown that there is a need for cross-disability collaboration to ensure effective work. Organizations of the physically disabled, the visually impaired and to some extent the deaf are strong advocates for their own groups, but persons with disabilities that do not fall within these categories, especially the intellectually disabled, do not have any spokespersons. Furthermore, it is mainly the issues defined by adult men that are given priority. Therefore, women’s organizations and parents’ organizations must also be assisted to build capacity and to have a voice. Joint platforms are thus needed at community, district and national levels to promote issues of common interest.

CBR programmes should take these findings into consideration and include a comprehensive empowerment package for DPOs as part of their programme initiatives.

Main concerns

Although the CBR programmes studied show that impact of the CBR programmes on quality of life of persons with disabilities has been substantial in the communities targeted there are some concerns:



1. The three CBR programmes studied here have managed to reach very few communities and people during their 10–15 years of existence. To date, only a few thousand people have been reached by the three programmes, out of an estimated population of persons with disabilities of more than two million in the three countries. Even in Ghana where the programme is a national government supported initiative, the number of disabled persons reached is very small.
2. Even in communities reached by the CBR programmes it seems that only half of the disabled population have benefited from these programmes. In Ghana and Nepal the huge majority of persons benefiting are those with moderate physical disabilities, while persons with intellectual or communication difficulties are poorly represented. The Guyana study, where parents have been targeted, gives a different picture: children with intellectual disabilities and hearing impairment seem to be the major group that has benefited from the programmes.
3. On average approximately 45% of the persons reached by the CBR programmes are physically disabled, 20-25% are visually impaired, 15-20% are deaf or hearing impaired and 5% intellectually disabled. The rest have other types of disabilities. Only in Ghana have persons with other types of disabilities such as epilepsy or psychiatric problems been specifically targeted. CBR programmes understandably start by approaching persons where communication is easy and where special educational measures and expensive medical treatment are not needed. This creates frustrations among the groups of persons with disabilities who are not prioritized — often those who have the greatest needs for support.
4. CBR programmes largely continue to regard persons with disabilities as beneficiaries and not as participants with a voice and a choice. Any influence by persons with disabilities and their organizations in the CBR programmes is limited. However, in Ghana where support has been given directly to the capacity building of DPOs (from the CBR programme as well as from Action on Disability and Development - ADD - and other NGOs) the situation has improved.
5. The sustainability of CBR programmes is of major concern. This study has shown that:
 - Voluntary community workers are difficult to sustain without support and incentives.
 - Specific committees formed for the sole purpose of managing and supporting CBR programmes seem to die when the committee members do not benefit from the programme.
 - Anticipated community resources have not been forthcoming to support the programmes.
 - Government authorities have seldom allocated resources in support of CBR programmes and referral systems.

CONCLUSIONS AND RECOMMENDATIONS

Based on the analysis of the different CBR programme initiatives in this study the following recommendations are made:

Awareness-raising

CBR programmes have been successful in raising awareness. However, improvements can be made. Awareness-raising initiatives should:

- Systematically engage persons with disabilities themselves as advocates because the most powerful advocacy tools are living examples of success and personal stories about discrimination and how to overcome it.
- Evaluate the local situation and target the most influential people (those who have power and/or money). In many cases key change agents in the community are schoolteachers, religious leaders, community leaders, elders, etc.
- Always be specific about the tasks of the change agents.
- Use media as a tool — especially radio.
- Use drama as a tool to make prejudices visible.

Medical care

CBR programmes have not yet been able to make a difference concerning medical care for persons with disabilities. CBR programmes should give more priority to influence health authorities to take their responsibility as stipulated in the Standard Rules on medical care. CBR programmes should increasingly challenge and support the health authorities:

- To improve competence and capacity of primary health care to make early interventions, correct diagnoses, treatments and referrals.
- To make referral specialists accessible at regional or district levels.
- To provide subsidies for medical care.
- To engage with traditional healers to increase their knowledge about disabilities, their causes and suitable early intervention measures.

Rehabilitation and support services

Rehabilitation and support services have not been provided by the CBR programmes, as was originally expected. CBR programmes should consider developing the following aspects:

- Social counselling, ADL and mobility training can be effectively carried out in communities but they could be more effective if peers (or parents of disabled persons) who have practical experience from solving various problems were systematically used as resource persons.
- Physical rehabilitation and production of assistive devices require a level of expertise that is not available in most communities: government funded referral centres at the districts level should be promoted as well as district budgets for assistive devices.
- Sign language training and training of interpreters should also be the responsibility of the resource centre — in collaboration with the Association of the Deaf.
- The district referral centre should also play an important role in supporting vocational training initiatives and apprenticeships.

Education

CBR programmes have had a positive impact on education opportunities for children with physical disabilities and minor impairments. For other children the options remain limited to a few special schools. CBR programmes should increase efforts to influence education

authorities to take their responsibility as stipulated in the Standard Rules on education. CBR programmes should also consider supporting:

- Special sign language medium classes for deaf children in collaboration with education authorities and the Association of the Deaf: deaf persons should be offered appropriate training and given priority when employing teachers in these classes.
- Parent-driven community centres for intellectually disabled children focusing on skills training and care: these parent self-help groups should be supported to develop community-based care facilities as a complement to family care.
- ADL and Braille training for blind children in collaboration with the education authorities and the Association of the Blind as a complement to the ordinary curricula.

Income maintenance and social security

This has been a successful CBR programme initiative that has impacted on all aspects of quality of life. It could be further strengthened by:

- Facilitating access to loan schemes outside the CBR programme such as the poverty reduction programmes, NGO programmes and commercial bank initiatives.
- Involving DPOs in identification of viable business ideas among their members and in monitoring and back-up of loan schemes.
- Finding new innovative areas for skills training; leaving traditional preconceived ideas behind regarding suitable trades for different groups of persons with disabilities; involving persons with disabilities in the identification of suitable trades.
- Facilitating apprenticeship and participation in ordinary vocational training schemes.

Government and community commitment

CBR programmes have not yet succeeded in ensuring the anticipated government and community commitment. In general, this commitment has been moral support, but improved quality of life for persons with disabilities requires resources as well. CBR and the fulfilment of human rights of persons with disabilities cannot depend on volunteers and goodwill from NGOs. CBR programmes need to revise their implementation strategies and build on structures that can be sustained, such as:

- Structures that are mandated and financed by the government: the change of ownership in Ghana seems to be a step in this direction.
- DPOs and self-help groups that will not lose their commitment because they have self-interest in development of inclusive communities.

CBR programmes must recognize that sustainable change requires government support — both in policy and practice. There is an urgent need for CBR programmes to ensure that governments:

- Include persons with disabilities in ordinary community development programmes and poverty reduction schemes.
- Provide community workers with back-up, continuous training opportunities and incentives.
- Support a referral system at district level.
- Provide training and resources for education and health systems.
- Provide assistive devices free of charge or at a low cost.
- Support sign language development and interpreter training.

Support to DPOs

During the 10–15 year period that the three CBR programmes studied here have been in operation, adjustments have been made which are based on the lessons learnt. The importance

of involving persons with disabilities and their organizations has been increasingly stressed. The revised joint position paper discusses human rights for persons with disabilities, inclusive communities and “CBR with and for persons with disabilities”. This is a positive development from the viewpoint of persons with disabilities but it also raises questions, such as:

- How will DPOs be involved in this work?
- Will sufficient resources be allocated for capacity building of DPOs nationally and locally?
- What will be the roles and responsibilities of the CBR programme and the DPOs, respectively, as the advocacy and empowerment components of CBR become more important?

Although positive trends are noted in some countries, DPOs and persons with disabilities continue to have limited influence in CBR programmes because of

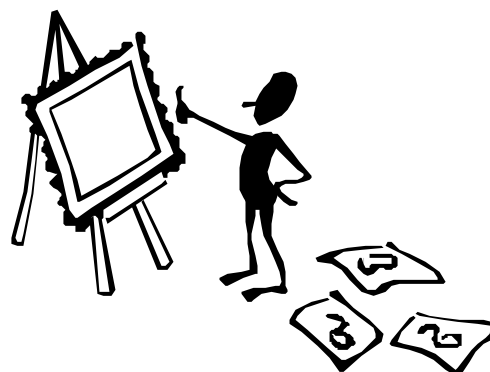
- limited self-confidence on the part of individuals owing to the discriminatory treatment they have experienced
- limited capacity and coordination within the disability movement nationally and locally
- limited recognition as useful resources by the CBR programmes owing to prejudices

CBR programmes should be instrumental in breaking this vicious circle by addressing all three problems. Strong DPOs that can monitor government performance, advocate the rights of their members, advise development programmes and provide peer counselling are a precondition for a successful change process. CBR programmes should therefore make it a priority to support capacity building of DPOs and parents’ associations, and to promote and facilitate the formation of self-advocacy groups. Many DPOs need support to overcome shortcomings and to become effective stakeholders with a wide support base, a democratic and transparent structure, a strategic approach and a skilled leadership at all levels. CBR programmes need to collaborate with DPOs to develop practical empowerment tools to achieve this.

It should be noted that parents and family members have different perspectives and rights to persons with disabilities themselves. Therefore, parents and persons with disabilities need to form their own separate advocacy groups. DPOs tend to give too little attention to children’s issues and to parental problems, while parents’ organizations sometimes focus too much on strengthening the family situation, leaving the disabled family member to continued dependence.

General recommendations

The concept of CBR has changed and is now aiming at addressing all areas that are essential for the quality of life of persons with disabilities and the building of inclusive societies. Thus, CBR programmes need to seek alliances and facilitate collaboration among a wide range of stakeholders.

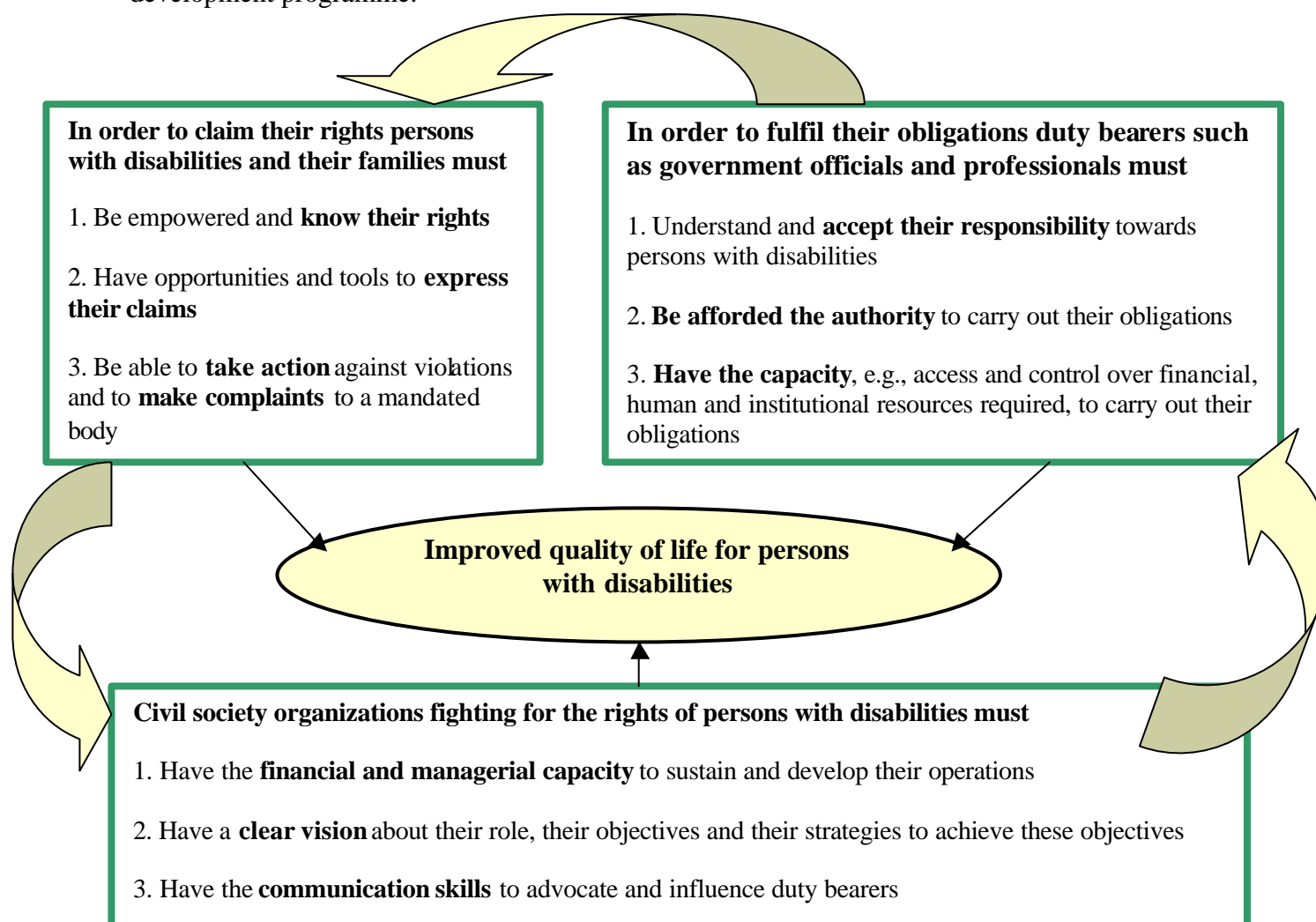


Firstly, it is essential to recognize that social change and fulfilment of human rights will not occur by targeting the community level alone. Neither will they occur by targeting only central policy-makers and legislators. For sustainable change to happen there is a need to combine bottom-up and top-down approaches in a “pincer movement”. Without policy and legislation to support development there is no direction and commitment; without community awareness and empowerment there is no acceptance or

drive for change. The district level is emerging as a strategic level because decentralization of power is an ongoing process in many countries. This is the level where the community demands and central directives meet and priorities have to be made.

Secondly, it is important to recognize that development depends on the combined efforts of a number of stakeholders. In “rights-based programming” that has been introduced as a planning tool in the UN system, and by NGOs working in various areas of human rights, stakeholders are divided into three distinct spheres: rights holders, duty bearers and civil society. These spheres have different roles and responsibilities in the change process but they are equally important prerequisites for the success of the process.

Duty bearers have to fulfil their obligations as stipulated in the Standard Rules. In doing so, they will create the preconditions for disabled persons to be empowered. Yet, duty bearers will not move and prioritize disability issues unless monitored and advised by a strong disability movement. The disability movement, on the other hand, will not be strong unless its members have been empowered. Hence, the change process depends on these three events happening. Therefore, it is essential to consider all three spheres when designing a development programme.



Consequently, CBR programmes should address all three spheres. As a rule of thumb a programme should invest one-third of its efforts and resources in initiatives aimed directly at disabled persons and their families; one-third in influencing and building capacity of duty bearers; and one-third in the strengthening of NGOs, particularly DPOs and parents’

organizations. CBR programmes should identify the most strategic stakeholders within each sphere, set measurable targets for the tasks that these stakeholders should perform as a result of the programme and choose the most efficient ways and means to enable them to carry this out.

Thus, a major role of future CBR programmes will be to facilitate input and collaboration among many stakeholders and sectors. CBR programmes that are run by particular interest groups or government sectors run a risk of not achieving the necessary holistic and multisectoral approach. It will be a challenge to find appropriate mechanisms to guide and to steer these CBR programmes. Three guiding principles should be followed:

- Existing political and administrative structures should be used.
- Government at various levels is responsible for fulfilling the human rights of its citizens to the best of its ability and should be encouraged to take that responsibility.
- DPOs should have a major influence on priorities and design of programmes.

CBR programmes must prove themselves efficient in order to obtain government support and community commitment. Therefore, it is important to liaise with ongoing development programmes, to make strategic alliances and to cover a whole district rather than spreading resources throughout the country.

Donors and CBR implementing agencies should review their programmes and develop their capacity in the light of these findings — and complementary CBR training material and handbooks should be developed to meet the new needs and challenges.

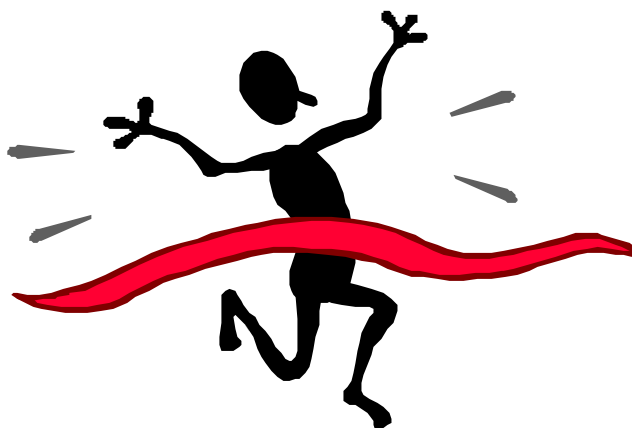
Finally, it should be noted that Community-based **Rehabilitation** as a title no longer reflects the nature of the programmes implemented because

- they target many levels of society — not only the community
- they address all issues affecting the quality of life of persons with disabilities — not only rehabilitation

It will be a challenge to find a new title that better describes the complexity of this approach.

Follow-up of this study

This document is a qualitative study based on a relatively small number of in-depth interviews. Explicit conclusions have been made because the CBR programmes chosen represent a variety of approaches and cultural settings and because the views of the interviewees were extremely congruent. It is however recommended that a follow-up study be made in order to examine further the findings and to compile more quantitative data concerning the issues raised.



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List of acronyms

ADD	Action on Disability and Development
ADL	Activities of Daily Living
ADRA	Adventist Development and Relief Agency
AIFO	Italian Association Raoul Follereau's Friends
CBR	Community-based Rehabilitation
CBRP	Community-based Rehabilitation Programme
GCBRP	Guyana Community-based Rehabilitation Programme
CRU	Community Resource Units (Guyana)
CWD	Children with Disabilities
DAR	Disability and Rehabilitation Programme at WHO
DODG	Disabled Organizational Development Group (Nepal)
DPO	Disabled People's Organization
DSI	Danish Council of Disabled People
ESCAP	Economic and Social Commission for Asia and the Pacific
HRDC	Hospital and Rehabilitation Centre for Disabled Children (Nepal)
IASSID	International Association for the Scientific Study of Intellectual Disabilities
ILO	International Labour Organization
INGO	International Non-governmental Organization
NAD	Norwegian Association of the Disabled
NDA	Nepal Disabled Association
NHR	The Swedish Association of Neurologically Disabled
NGO	Non-governmental Organization
NTV	National Television (Nepal)
PRA	Participatory Research Approach
PWD	Person with Disability
SHIA	Swedish Organizations of Disabled Persons International Aid Association
UN	United Nations
UNDP	United Nations Development Fund
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNICEF	United Nations Children's Fund
USD	US Dollar
VDC	Village Development Committees (Nepal)
WHO	World Health Organization
WHOQOL	World Health Organisation Quality of Life Assessment

She got my foot in and I did the rest

“She” in the heading above is referring to this young informant’s mother. The quotation gives emphasis to the importance of the parents’ role for a good start in life for children with disabilities.

“Well, since I was small I could always vividly remember I was always a part of the family. If reading was done I was required to read too. If there was speaking they would tell me to watch my tone of voice. They tried to discipline and guide me in the area of social skills. Not because I had a disability I was spoilt and allowed to do what I wanted. That was not the point. The emphasis was always on my achievement. If I wanted to open a bottle my family would say ‘Don’t open it for her! Let’s see how she will figure it out on her own.’ So I grew up in an environment of always figuring out things, which has been able to take me through life. What will this child be able to do for herself? And that’s one of the unique things about my mother. She always thought about the future and now she’s deceased. A future without her I am able to.

I know him (my father) but he has never been a part of my life. I don’t know. I can only speculate. There was never anyone born with disability in either family. Maybe they acquired it through an accident or somehow but no one was born with it. So I think... I don’t know if mentally he could have coped with it. He probably saw it as something with himself. Something wrong with him that caused me to be born this way. He left when I was seven days old and never returned to our family.

I always had a dream to acquire an education, to become an accountant. I resented the fact that in school some teachers limited me to do vocational training courses or skills training courses with no emphasis on academic achievement. I had to do self-advocacy telling them ‘No, I want to do accountancy not home-economics or craft or whatever.’ That was a revolution to their mind. I got a lot of resistance as I wanted to go into the business stream of high school. I know its breaking barriers actually. The first is always the hardest. But going through the system, very few persons with physical disabilities, severe ones like mine, have gone through the system and have come out at the tertiary level of education.

With the work CBR has done it has become easier. There are a lot of teachers who are sensitized about what persons with disabilities can do. CBR’s emphasis really has been on sensitization of the rights of persons with disabilities, knowing your rights. They give you advocacy skills. But in terms of advocating and lobbying on the whole that has not really been the emphasis of CBR.

I self-advocate for many jobs in different fields. Most times people will call me for an interview because they have seen my qualification on paper and when I turn up for the interview they will see that it’s someone with a disability, and it has never occurred to them that if I can acquire the qualification that I can also work. They always see obstacles that can prevent me from working.

A lot of the young persons with disabilities feel that their life has no meaning because they do not work. They see themselves as not having a job and see themselves as depending upon society, but some of them are also “sweet skin”, not wanting to get their hands dirty. Some people have had so many bad experiences of quite callous professionals who think that, if too many persons with disabilities shine they will be out of a job. Also, too many parents cannot see behind the disability of the child so they refuse to fight for that child’s needs and support that child when that child wants something. A lot of them get crushed by that. They see no hope for them. Our country is tough for young people generally and it’s ten times tougher for you with a disability. I think that a lot of people have lost their fighting spirit.

What maybe you need in Georgetown is a meeting place, a social meeting place where persons with disabilities hang out, share their ideas and come up with groups themselves. CBR in Georgetown would be good in one sense that you will have a structured organization. An organization and environment where persons with disabilities can meet and receive training but there’s no such one that I know of in Georgetown.

I’m part of a Sports Club and through the Sports Club I meet other persons with disabilities. And that group has just started meeting at the national park where they meet and do exercises. And practice. I play wheelchair basketball with a group of young men so that gives me an opportunity to meet young people outside CBR. Through my interaction with them a lot come to the CBR office.”