



World Health Organization



MINISTRY OF
SOCIAL AFFAIRS AND HEALTH

International Consultation on Reviewing Community Based Rehabilitation (CBR)

Organized by WHO

In collaboration with UN Organizations, NGOs and DPOs

Hosted by the Government of Finland

Helsinki 25-28 May 2003

THEME PAPER
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1. Introduction

About 600 million people in the world experience disabilities of various types and degrees. If families of people with disabilities are taken into account, then the number of persons experiencing disability is estimated to represent up to 25% of the world population. An estimated 80% of the world's disabled people live in low-income countries and the majority of them are poor. Basic survival is one of the greatest challenges of many people with disabilities, particularly those with severe and multiple disabilities, in low-income countries

Despite the incremental progress made in the past 25 years, even today, the vast majority of people with disabilities cannot access even basic rehabilitation services. The majority also cannot exercise their Human Rights which is the "...right to a standard of living adequate for the health and well-being of individuals and their family, including food, clothing, housing and medical care and necessary social services..."

As an aftermath of the declaration of Alma-Ata in 1978, there was a realisation about the need for, and benefit of a shift in emphasis from city-based institutions/hospitals to the community. Community based rehabilitation (CBR) developed as a natural consequence of this initiative. It was seen as an alternative or complimentary approach for reaching members of the community who would otherwise have no access to even basic services. It was also to build on existing resources of local communities to assist people with disabilities to become equal members of their communities. Rehabilitation does not mean only "cure or treatment" – it has a much deeper meaning "dignity, equal opportunities and equal rights". Naturally it is difficult for one UN organization or one department of the Government to meet the need.

It is more than twenty years since the concept of CBR was introduced. Accordingly, it is timely to review past experiences and evaluate the impact of the CBR approach in order to provide direction for the development of CBR in this new millennium.

Perhaps this is the first time in the history of CBR that so many of the different stakeholders in CBR have come together to conduct a review. This event includes representatives of the various governments, United Nations (UN) organisations, non-governmental organisations (NGOs), people with personal experiences of disabilities, parents and organisations of people with disabilities from all over the world who will discuss the impact of CBR and provide the necessary impetus to promote it. This event will provide a valuable opportunity to engage the active participation of all stakeholders in frank and open discussions with one goal in mind - how to ensure a better quality of life for people with disabilities for the future.

2. Evolution of CBR

Many positive changes have taken place since the CBR approach was first introduced in the early eighties. Now CBR has been adopted as national strategy for reaching persons with disabilities in many countries. Along with the quantitative growth in CBR services, there have been major changes in the way

CBR has been conceptualised. There has been the influence of many factors including that of different national/international declarations such as the ILO proclamation (Convention No. 159) which views disability as a condition of occupational disadvantage, and the UNESCO Salamanca Conference document which advocates for inclusive education. The UN Standard Rules on the Equalization of Opportunities for People with Disabilities has played a major role in influencing the conceptualization of CBR to be more effective as a development strategy. The evolution of the CBR concept could be summarised as follows:

- ❖ All communities are different because of socio-economic conditions, terrain, cultures and political systems. Therefore, there cannot be one model of CBR for the whole world. It may not be the same even within the same country. This is the uniqueness and at the same time, the challenge of CBR.
- ❖ The focus of CBR has expanded from medical rehabilitation towards more comprehensive multi-sector approaches such as access to total health care, access to education, vocational training, income generation programmes and participation/inclusion.
- ❖ CBR is being viewed as an essential part of community development with the goal of empowerment of the whole community. This approach is important for ensuring successful and sustainable CBR programmes.
- ❖ There has also been a shift in focus from service delivery to management issues that influence the effectiveness and the quality of services.
- ❖ CBR has been increasingly seen as a means to realize the human rights and equal opportunities of people with disabilities as defined in the intentional legal instruments and particularly in the UN Standard Rules on the Equalization of Opportunities for People with Disabilities.
- ❖ The International Classification of Functioning Disability and Health (ICF), has refocused attention on the abilities of disabled persons. The ICF conceptualization may provide a systematic framework with a greater focus on social inclusion.

Government is responsible for addressing the needs of all citizens of its country, including people with disabilities. There is evidence that people with disabilities are among the most marginalised groups in most societies, especially women and girls. Besides the common challenges of poverty, illiteracy, infectious and chronic illnesses, and poor living conditions there are also new problems such as HIV/AIDS, accidents, and the rapid increase of mental health conditions in a number of communities. To overcome this situation, all the stakeholders need to collaborate, discuss strategies and assume responsibility for priority strategic actions which would have a significant impact on improving the citizenship of disabled persons in the coming years.

3. Key issues related to CBR for consultation

The main purpose of this background paper is to facilitate and focus this Consultation on some key issues to promote CBR as a strategy for offering a wide range of activities which ensures that persons with disabilities are equal members of their society. To have a consultation on all the issues related to CBR in a short time span is not possible. As a result, WHO initiated a process for identifying key issues which can make a significant impact in existing CBR programmes while, at the same time, assisting in scaling up CBR for nationwide coverage.

In the past few years, WHO organised a series of inter-country meetings with its member states to identify the key issues. Representatives from ministries of health, ministries of social welfare and disabled peoples organisations (DPOs) were invited to these meetings. As health is only one of the sectors involved in CBR, WHO decided to invite the participation of all other involved stakeholders to Geneva including UN organisations, international NGOs and international DPOs. All participants approved the proposal of calling an International Consultation on reviewing CBR and agreed on the main issues to be discussed, which are **community involvement/ ownership, multi-sector collaboration, role of DPOs in CBR and scaling up CBR**. All stakeholders supported this consultation in various ways, particularly by identifying and sponsoring some of participants, who are involved in CBR. On request, the Government of Finland kindly agreed to host and support this International Consultation and a local organising committee was established to facilitate the consultation process.

3.1 Community involvement and ownership

The term community may have many meanings. For this Consultation, however, 'community' refers to the smallest administrative area where people live. This implies that there is a formal structure or administrative body and there is an elected or appointed administrative chief/mayor/leader responsible for the wellbeing of all citizens of the community, including people with disabilities. Within the community, there can be a number of more or less organised people's movements/organisations such as women's movement, youth movement, sports clubs, religious organisations, artisans, labour unions, the business community, welfare organisations, and sometimes organisations of disabled people. There is a need to find ways for involving these local stakeholders to have an active role in CBR, which would eventually lead to community participation and ownership.

During the inter-country consultations, the involvement of communities was seen as a major issue requiring attention. From the experiences of CBR practice, in many parts of the world, it has become evident that community involvement is a necessary condition for the success of CBR. It would be ideal if communities own the CBR Programme. This may not always be possible, especially when CBR ownership is perceived as outside the community and belonging to one particular ministry or NGO. It is important to devise strategies that creates bridges and partnerships among people with disabilities, communities and government.

In order to create an equal partnership between the community and government, there are a number of issues to be addressed, including but not limited to the following:

- ❖ Raising awareness of the community about the need for, and benefit of CBR and ensuring that resources will be committed for the benefit of persons with disabilities.
- ❖ Empowering communities to take responsibility for planning, implementation and to be involved in monitoring and evaluation of CBR programmes.

- ❖ Identifying mechanisms for decentralising government CBR programmes and for transferring decision making power from central level to communities and people with disabilities.
- ❖ Promoting inclusion of CBR in the community development agenda as there are a number of competing urgent needs.

Significant effort is required to enable communities to take control of CBR programmes. It requires the real devolution of actual decision making powers to people with disabilities and communities.

3.2 Multi-sector collaboration

Basic needs of people with disabilities are the same as those of other citizens and include opportunities to access food, health care, education and shelter. Following this, the majority of people with disabilities do not require medical rehabilitation for life long. It is not disability but society's attitude towards disabled people and an unfriendly environment and barriers, which prevents people with disabilities from equal opportunity and participation. It is difficult for one ministry or one NGO to solve the needs of people with disabilities, especially those who are poor. It needs multi-sector collaboration with the support of an established national policy.

In order to create multi-sector collaboration and to ensure that CBR is effectively included in general community development, the following issues need to be addressed:

- ❖ Ensuring participation of all ministries especially of health, education, social welfare, labour, development and finance in responding to the need of the people with disabilities.
- ❖ Ensuring that INGOs, NGOs and private service providers respond to the needs of people with disabilities in an integrated manner.
- ❖ Identifying a strategy for the coordination among all the stakeholders mainly government, NGOs, DPOs and communities
- ❖ Ensuring that government will implement the UN Standard Rules through appropriate country legislation/acts.

Time has come to explore the possibilities of extending CBR's mandate beyond disability to ensure it plays an active part in total community development. An analysis of this issue could provide strong arguments for justifying the investment in CBR.

3.3 The Role of DPOs

People with disabilities know their own needs better than others. "Nothing about us without us" is a legitimate claim. Historically, people with disabilities have been seen as only "passive receivers". Many CBR programmes do not involve people with disabilities or DPOs in planning, implementing and monitoring the work of CBR which threatens its relevance and impact. In many places, CBR implementers and DPOs (where they exist) do not work together. One of the outcomes of CBR is to develop strong partnerships with DPOs. Where DPOs do not exist CBR should encourage the formation of DPOs. The formation of self-

support groups by parents and people with disabilities can be a mechanism for the development of strong DPOs.

This background paper advocates for a broad approach for developing CBR programmes that involves people with disabilities, family members and DPOs. Besides, the formulation and implementation of national policies to ensure equal rights, people with disabilities also need to take an active part in service provision and to be role models.

To have a better understanding of the need for, and benefit of DPO involvement in CBR, the following areas require attention:

- ❖ Facilitating the participation of people with disabilities especially when people have restricted mobility and access.
- ❖ Promoting representation of all types of disability among DPOs participating in CBR, which could help to ensure that CBR programmes are accessible to all disabled persons.
- ❖ Enabling people with disabilities to form their own community level organizations which also should include parents or care-givers of people with disabilities.
- ❖ Ensuring that CBR programmes have good representation of people with disabilities among the CBR workers, especially women with disabilities.
- ❖ Promoting people with disabilities to be represented in decision making and political systems at different levels.

Disabled people's organisations often work only in major towns and may not have representation from all communities. The fundamental principles of full and equal participation of people with disabilities have not materialized. The DPO network from the community to the national level is crucial and once it happens it can become a significant force for ensuring equal rights for people with disabilities. The inclusion of people with disabilities remains a challenge for professionals, donors and other stakeholders.

3.4 Scaling up CBR

In many countries, CBR has been initiated by external assistance as a pilot project covering a limited geographical area and often to address the need of one group of people with disabilities. Many CBR projects have been restricted to the same geographical area for the last 10-15 years.

Reasons for this are many and they need to be identified and addressed. There might have been an unrealistic expectation that enough experts will be available one day to meet the needs of communities. In reality, that has proven to be impossible – most of the countries do not have enough resources to produce so many specialised professionals or to employ them. Besides, specialised professionals prefer to live in cities and few want to work in rural areas. There is a need to mainstream specialised services into regular programmes such as rehabilitation in health care, inclusive education in schools. Specialised professionals need to guarantee an effective referral system and to enlarge their roles from “service provider also to trainer and counsellor”. Some ministries have the interest and resources but do not have either the expertise or the network to

link with the community. In this kind of situation it is more effective for resources to be shared.

Governments do not view the needs of people with disabilities as a priority issue and often consider interventions in favour of person with disabilities as very expensive and with a low cost-effectiveness benefit. Governments sometime do not have enough funds to meet all the need of people with disabilities especially in low income countries. Even international and national NGOs experience similar problems. Alternatives have to be explored – such as using local resources as much as possible and ensuring people with disabilities are included in various government development programmes not specifically addressed for people with disabilities.

The common issues linked to scaling up of CBR could be as follows:

- ❖ Governments consider that their services be provided to all citizens with particular attention to people more in need and among them people with disabilities.
- ❖ Community resources be mobilised to scale up pilot projects.
- ❖ The different support structures, resources and services be identified to enable mainstreaming of services to accommodate people with disabilities.
- ❖ CBR be supported to strengthen the referral system in every sector and among sectors.
- ❖ CBR play an important role in nation-wide poverty alleviation programmes.
- ❖ Services provide evidence of the cost-effectiveness of CBR.

Support from national planning/policy and resources from governments are essential for scaling up CBR. To ensure effectiveness and sustainability of CBR, the community needs to be involved. Scaling up of effective CBR depends a lot on how strong the link is between the government, the community and people with disabilities.

4. Conclusion: Recommendations to different stakeholders

This Consultation is an opportunity for policy makers, NGOs, DPOs and CBR implementers to learn from each other. The optimal result of this Consultation will be achieved when each and every one of the four key stakeholders focus on how their constituency can best improve their own performance in this joint effort to give the desired push to promote CBR. Thus the basic question to each participant is “what shall I and my organization do in the near future to advance CBR, especially to reach more people with disabilities with an aim of an inclusive society”. The task is huge, so there is a great need for collaboration among the stakeholders” – this Consultation could be a first major step in the right direction.