

International Consultation on Reviewing CBR  
25-28.5.2003 Helsinki, Finland

# COMMUNITY-BASED REHABILITATION CONSTRAINTS AND CHALLENGES

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## 1. To the participants

In accordance with the Terms of Reference of the International Consultation on reviewing CBR, it will explore various CBR themes or strategies: community involvement/responsibility, DPO empowerment/ participation, multi-sectoral collaboration, mainstreaming/inclusion, top down/bottom up organizational structures, content etc. Working group sessions on these strategies will attempt to reach a consensus on the essential elements of each. The results of the working groups will be published in a Report of the Consultation, which will include recommendations for the future implementation of CBR for use by the various stakeholders. (Background document).

This paper is based on inputs received. Some inputs were specifically requested, some have been sent to the organizers more spontaneously. This paper does not intend to "summarize" and produce a shopping list of all points that have been put forward.

There is a great number of examples of good practice. These examples can be studied on the web based database that is at the AIFO website for easy reference.

The purpose of this paper is to facilitate and focus the discussion at the working groups of the Consultation. It constitutes the platform for the issues to be addressed by the working groups. The working groups and the plenary of the Consultations will then elaborate the outcome of the consultations, which will be finalized by the rapporteurs.

The working language of the Consultation is English. However, many English words and phrases may have quite different meanings and connotations in various parts of the world and particularly when translated to other languages. In this material the phrases "People with disabilities" and "disabled people/persons" are used interchangeably with the understanding that there are differences in which one is considered to be the standard or preferred usage.

## 2. Objectives

The objective of the consultation is to bring together the different stakeholders in CBR in order to improve the further development of the CBR strategy and its implementation. The basic elements essential for effective CBR strategy will be identified through the review of current practices and experiences in a variety of settings. The International Consultation will explore various CBR themes or strategies: community involvement/responsibility, DPO empowerment/participation, multi-sectoral service provision, mainstreaming/inclusion, top-down /bottom-up organisation structures, contents etc. Working group sessions on these strategies will attempt to reach consensus on the essential elements of each.

## 3. Introduction - the challenge

According to recent estimations, about 600 million people in the world experience disabilities of various types and degrees. This corresponds to 10 % of the world population. The obstacles to participation and the challenges of daily living experienced by people with disabilities affect directly, however, many more people. If families of people who experience disabilities are taken into account, at least 25 % of people are directly affected.

While their living conditions vary, they all have the same common experience: being exposed to various forms of discrimination and social exclusion, which prevent them from exercising their basic rights and fundamental freedoms and make it difficult for them to participate fully in the activities of their societies.

People with disabilities are under-served by most societal agencies and service systems. Only a tiny proportion of people with disabilities in developing countries have access to rehabilitation services. This is not only due to the limited number of qualified professionals and restricted resources but it also reflects the choices and priorities of governments and decision-makers at various levels - people with disabilities are not at the top of the agenda.

CBR was founded with the intent to make rehabilitation services available to a larger proportion of previously unserved persons (Helander, Legris & Opplestrup, 1989), thus making up for a lack of suitably qualified and trained personnel and material resources.

## 4. The policy context

There are several intergovernmental initiatives and processes that constitute the policy context of this Consultation. The outcome of this Consultation is also expected to have relevance and support the objectives and targets of those established initiatives.

The Health-for-All initiative of the WHO is one of the central building blocks of CBR. The HfA remains fundamentally a call for social justice based on the principles that everyone is of equal worth, everyone is entitled to respect and personal autonomy, and, everyone is entitled to have her/his basic needs met. In this respect, health should be seen as a basic human right. This standpoint is also supported by the Alma-Ata Declaration (1987\*\*), as well as by the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993). The UN Standard Rules on the Equalization of Persons with Disabilities<sup>1</sup> is the principal document, which forms the basis for the rights-based approach to disability.

Recently, an initiative was tabled at the UN by the Government of Mexico to further strengthen the rights based perspective regarding people with disabilities. This proposal has led to the establishing of an open-ended Ad Hoc Committee *"to consider proposals for a comprehensive and integral international convention to protect and promote the rights and dignity of persons with disabilities, based on the holistic approach in the work done in the field of social development, human rights and non-discrimination, taking into account the recommendations of the Commission of Human Rights and the Commission for Social Development."*

The empowering and rights-based approach is also supported by the recent conceptual developments.

The International Classification on Functioning, Disability and Health (ICF, 2001) has turned the focus from disabilities to abilities. The ICF conceptualization may provide a systematic framework for designing a broad-based community-based rehabilitation approach that is built on the idea of a service continuum. The objective of the intervention is to enable the person and his/her family to

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<sup>1</sup> UN Resolution 48/96, 20 December 1993: [gopher://gopher.un.org/00/sec/dpcsd/dspd/disabled/ar48-96.en](http://gopher://gopher.un.org/00/sec/dpcsd/dspd/disabled/ar48-96.en)

limit the impact of disability in their lives so as to enable them to achieve equal opportunities and full participation and inclusion in their communities.

The essential strategy of CBR is to build on the existing service system of the community and to promote an inclusive society for all people. A helpful instrument towards a society for all is the Design for All (DfA). The DfA approach recognizes that one size does not necessarily fit all. Rather a three pronged approach is needed:

The DfA principle implies that environments, technology and services should be designed so as to

- a) be usable by all or most of people without any modification ,or
- b) be flexible enough so that they can easily and with reasonable costs be adapted to different user needs, or
- c) have a slot where an additional component can be fitted to accommodate specific user needs)

The applications of DfA planning principles offer practical models to achieve inclusion of people with various abilities and user requirements, cost- effective solutions and socially sustainable development.

The consultations take place in a situation where there are, for the first time, a clear set of jointly agreed development goals. The Millenium Development Goals have been endorsed by the whole international community. Furthermore, there is a widening and deepening coherence regarding the policy frameworks. An increasing number of developing countries and their partners have committed themselves to the poverty reduction strategy (PRS) framework. ON this basis, the Development Assistance Committee of the OECD has also agreed on the Guidelines on Poverty Reduction. These guidelines emphasize the importance of putting countries themselves to the driver's seat and the participation of the poor. Furthermore a call for policy coherence and collaboration between all donors is strongly expressed.

## 5. Community ownership

There have been evolutions in the debate on CBR and its relationships to its operating environment. An emerging theme is to integrate CBR with broader community development initiatives. Community development in more general terms and poverty reduction in particular are seen as the umbrella objectives that create the prerequisites for the lives of people with disabilities. On the other hand, many stakeholders may expect that CBR has an impact on these general development objectives as well.

The broadened approach has been adopted by a number of agencies active in the field.

There are a number of essential elements of such a broad strategy to CBR. These can be summarized as follows:

- using a multi-sectoral approach: use of agencies and service providers in an integrated one-stop manner, to respond to the needs of involved disabled people
- decentralising resources, functions and managerial responsibilities: to various agencies and actors such as people with disabilities themselves, families, communities, local organisations and referral systems
- adopting a comprehensive and empowering conceptual framework to disability

- becoming an integral part of community development strategies that consist of several components
- integrating rehabilitation services: with various health, education, employment and social services
- involving non-professionals in simple rehabilitation techniques
- introducing appropriate technology: such as assisting devices widely available and produced in the community from local material
- raising awareness and mobilising communities as a key component of the programme
- involving the private sector in supplying credits, employment and technology
- giving people with disabilities and their families as users a central role in the design and follow-up of the programme

While community involvement and community ownership of CBR activities is seen as a necessary element it remains difficult to reach in many countries. This is a particular challenge when CBR is seen as a programme belonging to one particular ministry, or when it is being managed nationally top-down.

In situations where there are many sectors and actors involved the managing of CBR programmes faces particular challenges. For instance, the government partner has a tendency to follow the culture of top-down management. The community and the NGO sector, on the other hand, is usually oriented bottom-up

The top-down ideology assumes that professionals know best what the patients and the community need and prescribe the treatment and seek acceptance from the patient and community to comply to the prescription.

*In the bottom up approach it is acknowledged that people with disabilities, their families, and communities are in the best position to know what is needed, and, after gaining appropriate skills, can and should control how rehabilitation is to be implemented (Pupulin, 1995). On the other hand, Strictly bottom-up programs are frequently not sustainable because they tend to alienate governments.*

Enabling communities to climb on the driver's seat of CBR programmes requires the real devolution of actual decision making powers to the level of the community, the full involvement of disabled people and their families and the necessary resources to exercise those powers. Sustainability, on the other hand calls for the policy support and full involvement of governments.

## 6. Multisectoral collaboration

The joint position paper of 2002 by WHO, ILO, UNICEF and UNESCO of 2002 defines CBR in a rather flexible and broad manner:

*CBR is a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities.*

*CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services.*

(Ref.: 1)

The perspective reflected in this consensus definition calls for a broad collaboration of various sector agencies at all levels. While different sectors have specific missions and respective capacities to make them suitable to lead interventions related to specific components, a functional CBR programme needs to be cross sectoral and involve all existing service structures in the community. Such a complex collaboration requires the support of an established national policy.

CBR programmes not only need the support from other sectors. CBR can be a facilitator to other sectors and community development at large. In short, CBR programme may help organize the community for development.

The issue is to clarify the roles and responsibilities of international organizations, partner governments, as well as national sector agencies in CBR and in the efforts to promote coherently the objectives of CRR in the context of broader development objectives and operations.

## 7. The role of DPOs

The position paper advocates for a broad approach for developing CBR programmes, that involves the following elements

- *the participation of people with disabilities and their representatives at all stages of the development of CBR;*
- *the formulation and implementation of national policies to support the equal participation of people with disabilities;*
- *the establishment of a system for programme management;*
- *and the multisectoral collaboration of governmental and nongovernmental sectors to support communities as they assume responsibility for the inclusion of their members who experience disabilities.*

A culture of equal partnership of all relevant public and private stakeholders and disabled people's organizations is a vital element in efforts to improve the lives of people with disabilities. It is being reported that this principle has, however, still too often remained a distant vision, only.

A platform for collaboration with the actual customers as well as their families and disabled peoples organizations is an essential component of all CBR programmes. At best this collaboration leads to sustained empowerment.

It should also be recognized that people with disabilities share with all community members the common challenges of poverty, infectious and chronic illnesses, and poor living conditions. There are also new challenges such as HIV/AIDS and the rapid increase of mental health problems in a number of communities.

A successful and sustainable CBR initiative requires a serious effort of identifying and pooling community resources commanded by various stakeholders, including the resources of disabled people and their organizations to meet the priority needs of disabled people in the context of the challenges the community as a whole is tackling.

The lack of mechanisms for the involvement of people with various disabilities and their organizations in the planning, implementation and evaluation of CBR programmes threatens the relevance of the outcomes of CBR programmes. Furthermore, there is the gender dimensions, cultural factors and regional differences that need to be reflected while respecting the agreed general objectives of CBR.

The fundamental principle of full and equal participation of disabled people and their organizations has not materialized. Awareness, knowledge and conducive attitudes and practices (AKAP) regarding disability and the inclusion of people with disabilities remains a challenge for professionals, donors and other stakeholders, including disabled people themselves and their organizations.

## 8. Scaling up CBR

There are various origins of CBR programmes. In some cases they are initiated and led by NGOs supported by international partners. In other cases the lead agency is one Government ministry. The NGO led option faces difficulties in securing appropriate support and resources by public authorities at all levels. The challenges for the ministry led alternative is the commitment and involvement of the organizations of the necessary partner ministries, local governments and the civil society at various levels.

CBR programs are still often separate operations supported by donors rather than being standard policies included in the national and local government plans and budgets. An externally funded donor-push, or government- push, seldom results in sustainable programmes as the ownership remains undeveloped.

Sustainability, and eventual expandability, requires that the programme is soundly rooted in its social, cultural, administrative and financial environment.

The joint position paper has identified six prerequisites for sustainability.

*Countries' approaches for implementing CBR have varied a great deal, but their experiences have identified some common factors that affect the sustainability of CBR programmes. These include:*

- 1) the recognition of the need for a CBR programme based on a human rights approach;*
- 2) the willingness of the community to respond to the needs;*
- 3) the availability of resources and support, from outside the community;*

- 4) *multisectoral collaboration, including collaboration with DPOs and NGOs;*
- 5) *the presence of community workers; and*
- 6) *the integration of CBR within government with allocation of adequate resources.*

Furthermore, the twinning national and local disabled people's organizations with partner countries and international organizations of disabled people can be a powerful means for capacity building and empowerment.

The expandability, the potential for a good programme to be rolled out to other communities would require, in addition to the above, evidence on what works and why. Information on the cost-effectiveness of CBR is seldom available as evaluation has not been a standard practice in CBR programmes.

The following standard evaluation criteria and practices are applicable in evaluating CBR programmes:

- relevance: does CBR meet its objectives
- effectiveness: does CBR produce intended results
- efficiency: is CBR good value for money
- impact: has it made an impact on wider society
- participation of stakeholders
- sustainability

Evidence-based practice would require clarity of objectives, concrete targets, as well as specification of activities and inputs. The challenge for CBR is to speak the language of policy priorities. The CBR objectives are not well connected to the mainstream of the development dialogue. There is lack of systematic application of the language and logic of the current development talk. There is a urgent need to integrate the CBR approach and objectives to the current development policy debate at all levels, particularly at the national level where those internationally agreed policy frameworks are applied.

## **9. Cross cutting issues**

### **9.1. Human rights**

There are a number of universal human rights instruments that are, by definition, intended to be applied to all people. The opportunities for people with disabilities to exercise their basic rights and fundamental freedoms is restricted by factual and hidden discrimination. The existing international human rights instruments may provide much more "tools for power" than what is actually utilized.

Most of the contributing organizations recognize the importance and potential of the human rights framework in advancing the opportunities and inclusion of disabled people. While poverty and lack of access to basic services is one of the major phenomenon interfering with human rights of disabled people, only a few organizations explicitly connect the objectives of CBR into the context of the MDGs and the mainstream development policies.

### **9.2. Gender**

Women and girls with disabilities encounter multiple discrimination, due to their gender, disability, and their poverty in all its dimensions and forms. This is still too seldom reflected in the CBR program priorities and design.

There are obligations embedded in the international legal instruments as well as in national legislation of donors and partner countries that imply an improved recognition of gender issues in all arenas of life.

## Background papers

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### A. REQUESTED PAPERS

1. **Community Based Rehabilitation CBR with and for people with disabilities. Draft Joint Position Paper 2002** (ILO, UNESCO, UNICEF, WHO) (email 7.1.2003)
2. **Guiding Principles for Evaluating and Reporting on World wide Community Based Rehabilitation Programs** by Margaret GH. Stineman, August 2002, (email 7.1.2003)
3. **The Relationship between Prosthetics and Orthotics Services and Community-Based Rehabilitation.** A joint ISPO/WHO statement, October 1999. (email 7.1.2003)
4. **Equal Opportunities for All: Promoting Community-Based Rehabilitation (CBR) among Urban Poor Populations. Initiating and Sustaining CBR in Urban Slums and Low-Income Groups** - WHO/DAR and AIFO
5. **Disability and Rehabilitation status review of disability issues and rehabilitation services in 26 African countries.** Disability and Rehabilitation Team WHO-Geneva, December 2001
6. **Reports:**
  - Part 1. Community-Based Rehabilitation as we have experienced it...voices of persons with disabilities. Part 1. WHO and SHIA
7.
  - Part 2. Community-Based Rehabilitation as we have experienced it.... voices of persons with disabilities in Ghana, Guyana and Nepal. Part 2 - Country reports. WHO and SHIA
8. **WCPT Community Based Rehabilitation Consultation**  
Summary of responses to survey and discussion paper (Fax/Eva 27.1.2003)
9. **The Human Rights Dimension of Disability.** Paper prepared by the Office of the High Commissioner for Human Rights. (email 27.1.2003)
10. **Disabled Peoples' International (DPI) Position Paper on Community Based Rehabilitation (CBR)** by Venus M. Ilagan (email 28.1.2003)
11. **Community-Based Rehabilitation for the Visually Handicapped - a Second-rate solution or the real way to independence** by John Heilbrunn, Danish Association of the Blind, and Arne Husveg, Norwegian Association of the Blind and Partially Sighted, sent by Tomas Lagerwall, RI (email 7.1.2003) together with
12. **International CBR Consultation by WHO. Comments** by Tomas Lagerwall, RI, (email 7.1.2003)
13. **IDDC Position Paper on CBR.** Paper produced as a result of the IDDC CBR Task Group Meeting October 2002 by Sue Stubbs (email)

## B. NON-REQUESTED PAPERS

1. **Community Based Rehabilitation (CBR) in perspective. Past, present and future directions.** 11 October 2002 Symposium Report by Dutch Coalition on Disability and Development, Mark Raijmakers (email 16.1.2003)
2. In the name of God. **Performance of Community-Based Rehabilitation planning (CBR) in Rural Areas of Iran.** (By Dr. Nahvinejad) (email 7.1.2003)
3. **Disability, Rehabilitation and HIV,** 26.12.2002 by Geert Vanneste, CEO CCBRT, Tanzania, (email 27.1.2003)
4. **CBR A participatory Strategy in Africa,** based on the Proceedings of a Conference Uganda, September 2001. Editor Sally Hartley (sent by Sunil Deepak email 30.1.2003)
5. **Critical Issues Related to Policy and Planning of Community-Based Rehabilitation in South Asia,** by Maya Thomas, M.J.Thomas (email 17.2.2003)
6. Meeting the Needs of People with Disabilities - New Approaches in the Health Sector. A technical Note by Ronald Wiman, Eoinar Helander and Joan Westland. The World Bank, June 2002