

The participatory development of international guidelines for CBR†

CHAPAL KHASNABIS* & KAREN HEINICKE MOTSCH**

**Disability and Rehabilitation (DAR), Department of Violence and Injury Prevention and Disability, World Health Organisation, 20 Avenue Appia, Geneva, Switzerland*

***CBR Adviser and Working Group Coordinator CBM, Nibelungenstr. 124, D-64625 Bensheim, Germany*

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Summary

Purpose The CBR Guidelines are being developed by UN Agencies and civil society groups including disabled people's organisations (DPO). The aim of the CBR guidelines is to enhance the quality of life of people with disabilities including those affected by leprosy. Strong linkages between leprosy programmes and CBR will optimise the benefit of medical care and ensure leprosy-affected people access all relevant services that promote inclusion and participation.

Background The World Health Organisation introduced the concept Community Based Rehabilitation (CBR) in the early 1980s. CBR was designed to enhance the quality of life for people with disabilities through community initiatives. To facilitate this, WHO published a CBR Manual 'Training in the community for people with disabilities' in 1989. Since then there have been many developments within and outside the disability sector.

Based on these global developments and as a result of stakeholder consultation, ILO, UNESCO and WHO updated the CBR Joint Position Paper (2004) and restructured CBR as a strategy for rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of people with disabilities. The purpose of this Joint Position Paper was to describe and support the concept of CBR as it is evolving, with an emphasis on human rights and a call for action against poverty. The Convention on the Rights of Persons with Disabilities aims to ensure that they enjoy human rights on an equal basis with others. Guidelines on how to implement CBR respond to the demands created by the publication of the Joint Position Paper and The Convention on the Rights of Persons with Disabilities.

Results The CBR Guidelines are being developed by three UN agencies: WHO, ILO and UNESCO. It is being actively supported by 13 International Non

†The views expressed are those of the authors alone and not necessarily those of the organisations they represent.

Correspondence to: Chapal Khasnabis, Disability and Rehabilitation (DAR), Department of Injuries and Violence Prevention, World Health Organisation, 20 Avenue Appia, Geneva, Switzerland (Tel: +41 22 791 3499; Fax: +41 22 791 4874; e-mail: khasnabisc@who.int)

Governmental Organisations (NGO) including Disabled People's Organisations (DPO). Over 150 experts from across the globe have contributed to the draft guidelines which are being field tested in 25 countries. The guidelines have five major components: health, education, livelihood, social and empowerment. Beside these five components, the Guidelines also focus on management of some special scenarios including CBR and HIV/AIDS, CBR and leprosy, CBR and mental health and CBR in crisis situations. The CBR guidelines also underline that people with leprosy-related disability are seen as members of the disability community in the wider context given the shared experiences and challenges.

Conclusions The CBR guidelines are an important step forward in promoting CBR as a community based inclusive development strategy. The guidelines focus on meeting basic needs, reducing poverty, accessing benefits of mainstream developmental initiatives, inclusive community and empowering people with disabilities and their families. It also focuses on implementing the Convention on the Rights of Persons with Disabilities using community-based initiatives. People with leprosy are often neglected by traditional CBR programmes. These guidelines make the case for including people with leprosy in CBR programmes and in the community.

Introduction

In light of the principles of the Alma Ata Declaration¹ 'Health for All' in 1978 and given the lack of specialised medical rehabilitation services in the developing world, the World Health Organisation (WHO) articulated the concept of Community Based Rehabilitation (CBR). The aim was to ensure that rehabilitation services are provided to all people with disabilities, whether they live in an urban or rural setting and whether they are rich or poor. This approach involves measures taken at community level to use and to build upon the resources of the community as well as drawing on specialised services such as surgical intervention, assistive devices, and advanced skill training – usually available at higher levels. WHO has recognised that most basic rehabilitation activities can be carried out in the disabled person's own community using the community resources and benefiting from the primary health care system. From the beginning, the focus of CBR was on training a person with disability to carry out daily activities such as going to school, playing, joining in family and community activities and making a living – mainly by using local resources. In many countries, Ministries of Health and Non Governmental Organisations have come to play a vital role in promoting CBR in developing countries.

CBR Manual

To support the implementation of CBR, in 1989 WHO published the CBR Manual² entitled 'Training in the community for people with disabilities'. It took 10 years of hard work, including the field testing of three earlier versions in 1979, 1980 and 1983. The manual consists of 34 modules: four guides and 30 training packages. The guides are for local supervisors, community rehabilitation committees, people with disabilities and schoolteachers. The training packages are aimed at assisting family members who support people with different kinds of impairments. The manual played an important role in the promotion of CBR and in changing the quality of life of people with disabilities in developing countries. It has been translated into more than 50 languages, and is still being used regularly in many countries.

Changing disability scenario

The disability scenario is constantly evolving. Many lessons have been learnt since CBR was introduced, most notably the shift in ways of understanding disability from a purely medical approach, to a social approach that is rights-based. The introduction of The United Nations' Standard Rules on the Equalisation of Opportunities for Persons with Disabilities³ played a significant role in promoting equal opportunities and dignity. Other national and international instruments and legislation contributed to this evolving scenario. The disability movement continues to gain strength. The motto 'Nothing about us without us' symbolised the momentum. Starting by getting people with disabilities involved in the planning of strategies and policies that affect their lives, the current Disabled People's Organisations (DPO) are now steering a global movement to achieve the full participation and equalisation of opportunities for, by and with people with disabilities. Policy makers have also started to recognise the important role people with disabilities, their families and organisations can play in the drive to equality for all.

The wider global context is also going through dramatic changes. Globalisation, privatisation and the information technology revolution all present new challenges and opportunities to people with disabilities and their family members. Various global developmental initiatives such as the Millennium Development Goals (MDG)⁴ and Poverty Reduction Strategies Papers (PRSP)⁵ create opportunities to connect disability and poverty. According to the World Bank, people with disabilities in developing countries are over-represented among the poorest people. They have been largely overlooked in the development agenda so far. The recent focus on poverty reduction strategies is a unique opportunity to rethink and rewrite that agenda.⁶

The recent UN Convention on the Rights of Persons with Disabilities (CRPD)⁷ boldly reinforces the fact that disability is a human rights issue. The Convention promotes, protects and ensures the full and equal enjoyment of all human rights and fundamental freedoms by all people with disabilities, and promotes respect for their inherent dignity. According to Kofi Annan (past United Nations Secretary-General), the UN Convention on the Rights of Persons with Disabilities represents the 'dawn of a new era' for around 650 million people worldwide living with disabilities.⁸

CBR must also change. Increasingly, it needs to operate in terms of a rights-based and inclusive development strategy in order to ensure that the benefits of development initiatives reach people with disabilities and their families. Poverty is often the major barrier in improving quality of life, accessing health care, education, housing and other services. Accordingly, CBR will need to increasingly focus on reducing poverty, facilitating the fulfilment of basic needs such as food, healthcare, education, and housing while at the same time working for inclusion and participation. People who implement CBR programmes are also seeing the need to reach out specifically to groups like people with leprosy, psychosocial difficulties and HIV/AIDS as well as women with disabilities who have been particularly marginalised in order to ensure they are included in CBR.

Changing CBR scenario

INTERNATIONAL CONSULTATION TO REVIEW CBR

In 2003, the Government of Finland hosted a global consultation to review CBR.⁹ The main purpose of the consultation was to review CBR in its 25th year. The Helsinki review brought

together stakeholders from across the globe. It was organised and attended by WHO, ILO, UNESCO, international organisations of people with disabilities and international non-governmental organisations working in the CBR field. Among many recommendations, the most notable ones are to promote CBR as a part of poverty reduction strategies, multisectoral approach and involvement of DPOs in CBR.

CBR JOINT POSITION PAPER (2004)¹⁰

To highlight the Helsinki recommendations, ILO, UNESCO and WHO updated the CBR Joint position paper and redefined CBR: 'CBR is a strategy for rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of people with disabilities.' The purpose of the Joint Position Paper was to promote human rights and the call for action against poverty. It defined CBR as a strategy within the scope of general community development, one that focuses on the rehabilitation, equalisation of opportunities and social inclusion of all people with disabilities. It recognised that CBR is an effective strategy to meet the needs of people with disabilities (Evidence for the effectiveness of CBR is reviewed in another paper in this issue of leprosy review¹¹). The paper noted that CBR needs to be implemented through the combined efforts of people with disabilities themselves, their families, organisations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services. It also acknowledged the role of DPOs as a resource to strengthen CBR programmes. Publication of the CBR joint position paper created a demand for developing Guidelines to implement the CBR joint position paper and will bring the Convention on the Rights of Persons with Disabilities to community level especially in the developing world.

The CBR Guidelines Initiative

Though CBR is practised in more than 90 countries and is part of many national strategies, most CBR programmes continue to follow a vertical approach, focusing on one or at most two domains of life. For example, many strategies focus on health alone or exclusively on physical rehabilitation. Others focus on education or on income generation activities. The single domain approach does not adequately address the multi-dimensional needs and interests of human beings, whether or not they are disabled. In order to ensure that CBR continues to be relevant to the needs and interests of people with disabilities, their families and the communities in which they live, it must adopt a multi-sectoral comprehensive approach addressing the key domains (or components) of well-being.

The CBR joint position paper promoted multi-sectoral and rights-based approach, and at the same time focused on poverty reduction within an inclusive community. Putting the policy into practice requires guidelines. Good guidelines help people understand the benefits of and approaches to working together across domains and sectors. WHO, ILO and UNESCO agreed to develop guidelines, with full stakeholder participation which would provide a framework for CBR, and would highlight best practices in the field, so as to make CBR an effective multi-sectoral strategy. Many of the principles and key concepts inherent to what has now become the CBR Guidelines mirror, or are drawn from, the provisions of the UN Convention on the Rights of Persons with Disabilities. There are enough reasons to believe that these Guidelines could become an important tool for implementing the Convention.

People with disabilities, including people with leprosy, experience common challenges: stigma, prejudice, poverty, discrimination, lack of access to healthcare (including rehabilitation services), education and decent work. Though there has been a shift from the medical model to the social model in the disability sector, for historical reasons, leprosy and mental health still focus very much on the medical model. People with psychosocial disability are now part of the disability movement and their voices have been heard in the Convention and other national and international instruments. The International Disability Alliance (IDA) in particular is an important campaigner for equal rights, participation and inclusion. Though the treatment or management of leprosy has been generally mainstreamed in the recent past, people with leprosy are still struggling to be seen as fully participating members of their communities and their organisations do not form a part of the disability movement. The ultimate success of medical care in managing leprosy needs to be measured with an inclusion and participation scale. The CBR guidelines would help to achieve this by mainstreaming leprosy and by dedicating a chapter exclusively to promote the inclusion of people with leprosy in CBR programmes.

The Guidelines development process as an exercise in multi-stakeholder cooperation

As a first step towards developing the Guidelines, a concerted effort was made to develop a multi-stakeholder consensus on CBR, its various components (domains) and elements (sectors).¹² Various stakeholders including UN Agencies (ILO, UNESCO and WHO), representatives from Member States, from academia, from NGOs, DPOs, professionals' organisations and CBR experts including pioneers in the field came together to finalise the outline of the CBR Guidelines and agree upon a common agenda called 'Inclusive development to promote inclusive society.' It was agreed that if it is going to live up to this agenda, CBR must use the principles of community action to ensure equality of access to health, education, livelihood opportunities, life in family and community, social mobility and political empowerment. Special efforts have been made to ensure sufficient participation of people with disabilities and CBR practitioners from developing countries in developing the guidelines.

It was acknowledged that all communities are different – in terrain, culture, their political systems, socio-economic conditions and many other factors. Therefore there is no single model of CBR appropriate for the whole world. There are many models for CBR programmes reflecting unique situations and conditions. However CBR programmes have commonalities and there is a need for some common norms to guide all CBR programmes and a common framework or 'CBR Matrix' which will truly reflect a comprehensive multisectoral approach.

The guidelines framework: CBR matrix

The CBR Guidelines focus on the key domains that make up the universe of well-being: health, education, livelihood, social life and participation. The CBR guidelines focuses on empowerment of people with disabilities and their families as a key approach to achieve the universe of wellbeing. Considering this, the universe of CBR consists of five key components: health, education, livelihood social and empowerment as shown in Figure 1.

CBR guidelines focuses on mainstream local means and initiatives to promote well-being and life with dignity, such as healthcare from existing health facilities, education form regular school or college, livelihood through traditional skills, income generation programme, micro credit, inclusion and participation through local cultural initiatives and community life. Formation of Self-help groups (SHG) or disabled peoples organisations needs to be the core of a CBR strategy to access mainstream opportunities and to sustain it. These all together will promote and reinforce the concept of community-based inclusive development as shown in Figure 2.

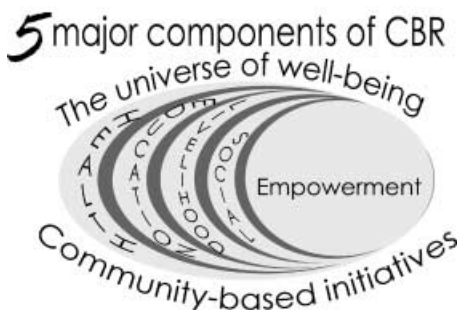


Figure 1. Components of CBR.



Figure 2. The universe of CBR.

To promote the universe of CBR, further work has been done to identify the key elements or sub-domains of the five key components, which resulted in the development of the CBR matrix. This matrix provides a framework for a coherent CBR programme. The matrix illustrates the areas which combine to form a CBR strategy. It consists of five components (domains), each divided into five elements (sub-domains) – Figure 3. Each of these elements has a dedicated chapter in the Guidelines. The matrix represents the topic areas which an effective CBR programme may contain, depending on local circumstances.

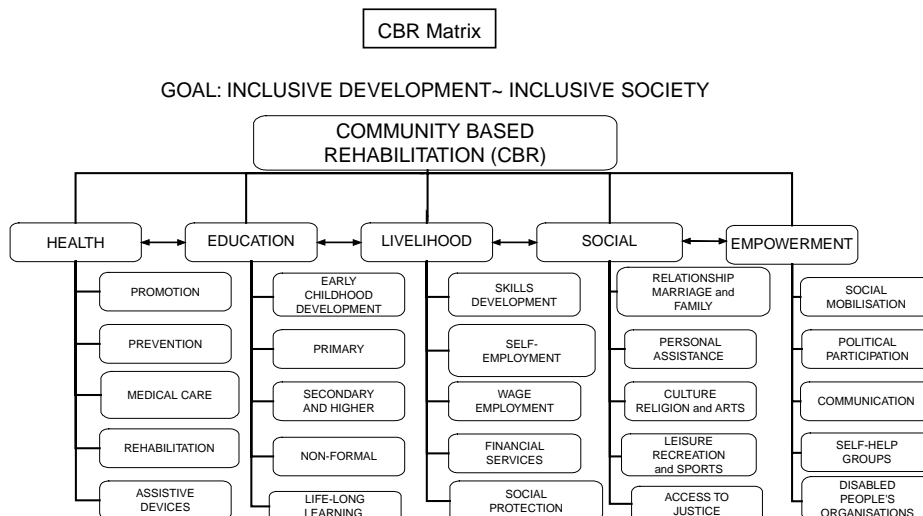


Figure 3. CBR matrix.

To use this matrix the practitioner may choose:

- the most practical entry point for the programme, for example an initiative on primary schooling or organising parents of children with disabilities;
- the next logical step to build up the programme, for example an initiative on health promotion or prevention of all avoidable disabilities and its impact
- the next could be assisting in skills training or self-employment
- and so on until a coherent programme of appropriate components and elements is formed, supported by a strong set of cross-sector alliances and partnerships.

The matrix should not be seen as sequential. It is a ‘pick and mix’ series of options, a set of components and elements from which the practitioner can select, so any one programme may choose to address only some of the components and elements. At the same time, the implementer will need to be in touch with other organisations or groups which will take care of the other elements. It is to be noted that CBR programmes need to be designed and implemented based on need and availability of resources.

How the Guidelines are written

The CBR Guidelines are not prescriptive – they contain different ideas, different experiences and examples to promote and illustrate an up-to-date, practical strategy. The Guidelines suggest ways to achieve these aims through community based initiatives focussing on inclusive development.

The Guidelines contain four sections:

1. Introductory Chapters
2. Core Components (domains)
 - 2.1. Health
 - 2.2. Education
 - 2.3. Livelihood
 - 2.4. Social
 - 2.5. Empowerment
3. Management
4. Supplementary Chapters

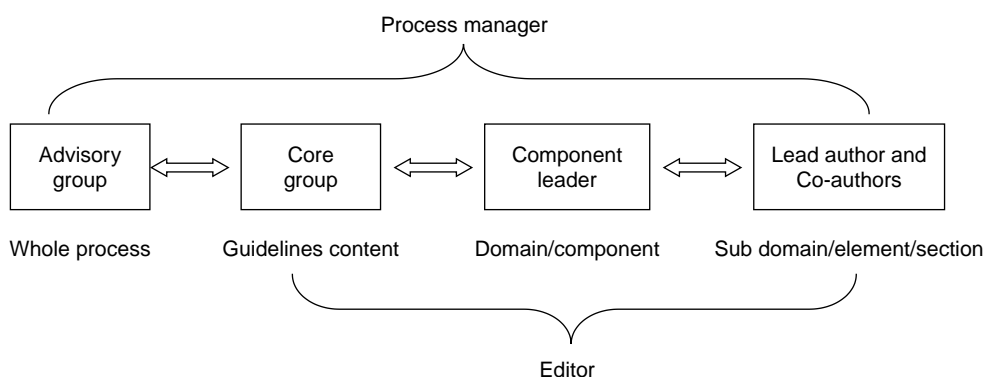
The key approaches are to:

- Meet basic needs and reduce poverty
- Build capacity
- Create opportunities for livelihood, health, rehabilitation, education and social life
- Involve disabled peoples organisations [DPOs] or organize disabled people where it does not exist
- Collaborate across sectors – partnership
- Involve the whole community
- Involve local government and leaders
- Use the legislation, judicial and political systems

One of the major focuses of the guidelines is reducing poverty. Poverty is not simply lack of income; it has many facets. According to the Office of the High Commissioner for Human Rights (OHCHR),¹³ ‘Poverty is a human condition characterized by the sustained or chronic deprivation of the resources, capabilities, choices, security and power necessary for the enjoyment of an adequate standard of living and other civil, cultural, economic, political and social rights.’ People with disabilities have various needs created by their impairment. These are in addition to the basic human needs of food, shelter, clothing, livelihood, healthcare, education, relationships, and so on. Meeting basic needs is often the stepping stone for removing poverty and achieving human rights. Hence, the Guidelines focus on meeting the basic needs and reducing poverty. ‘Wherever we lift one soul from a life of poverty, we are defending human rights. And whenever we fail in this mission, we are failing human rights.’ – Kofi Annan, Immediate past United Nations Secretary-General.¹⁴

To ensure that the guidelines are a useful document for practitioners, special efforts have been made to incorporate evidence, experts’ opinions and good practices from all over the world. The participation of people with disabilities and their families, especially from the developing countries, has been an important aspect in the development of the Guidelines. Over 150 authors from around the globe have been involved in the writing process.

To develop the guidelines with a such a wide participation needed very strict planning and committed people to coordinate. Four key groups have been formed: i) An advisory group to give overall direction and maintain a focus on the principles; ii) Core group – the main leading force for the content development, drafting the preambles of the components and selecting the component leader; iii) Component leaders identify the lead authors for every element or section, guiding lead authors and compiling all the elements to complete the whole component and cross check with other component leader and iv) the authors group – headed by a leader who is responsible for completion of the section/elements, to identify co-authors, to write the sections and have them validated by experts. Beside these, a process manager was nominated to complete the whole process from conceptualization to publication and an editor to complete the content matters and editing the whole document.



Although the first draft was produced in English, contributions were also obtained in different regional languages which were translated and accommodated in the original draft. Author’s guidelines, common principles and cross cutting themes were given to lead authors to assist them in drafting their sections.

Component leaders with constant interaction with the lead authors, completed all the chapters. A SharePoint website was created for the lead authors, component leaders and core group members to review the chapters as they were developing. Each version is maintained on the website. WHO engaged an Intern to do a systematic literature review and collect evidence which has also been used to develop the guidelines. After two years of hard work from all the groups, the first draft was completed and sent for field testing in more than 25 countries.

The principles

This wide range of authors has contributed to the creation of CBR guidelines which are rich in diversity and approach but with a commonly held set of basic and important principles. These are inclusion, participation, sustainability, empowerment, self-advocacy and a barrier free environment. These principles are overlapping, complimentary and inter-dependent.

INCLUSION

Inclusion refers to any act or practice that ensures including people with disabilities in community life. It is being welcomed, valued and embraced as an equal member of the community. Inclusion also means placing disability issues and people with disabilities in the mainstream of activities, rather than as an after-thought. Inclusion also means including people with all forms of impairment irrespective of cause or nature.

PARTICIPATION

Participation means the involvement of disabled people as active contributors to the CBR programme from policy-making to implementation and evaluation, for the simple reason that they know best what they need. Participation also means people with disability being a critical resource within any CBR programme – providing training, making decisions etc. It principally covers the participation of women in all processes and decision-making, and other groups who are typically not included.

SUSTAINABILITY

Firstly, the benefits of the programme must be lasting. CBR activities must be sustainable beyond the immediate life of the programme, that is being able to continue beyond the initial intervention and thrive independently of the initiating agency. Sustainability usually have three core components: technical, financial and organisational.

EMPOWERMENT

Empowerment means that local people – and specifically people with disabilities and their families make the programme decisions and control the resources. It means people with disability taking leadership roles within programmes. The empowerment of women is central to any programme.

SELF-ADVOCACY

Self-advocacy means the central and consistent involvement of people with disabilities defining for themselves the goals and processes for poverty alleviation. Family members will also play a key role as advocates. Self-advocacy is a collective notion and not an individualistic one. It means self-determination, mobilization, organisation, representation, creation of space for interaction and demands.

BARRIER FREE ENVIRONMENT

Barriers are factors in a person's environment that, through their absence or presence, limit functioning and help to create disability. These include factors such as the physical environment that is inaccessible as well as the negative attitudes of society or community towards people with disabilities and even towards their families. The commonest examples of physical barriers are steps or inaccessible buses and trains for people with mobility impairments.

People's attitudes influence behaviour and social life at all levels, from interpersonal relationships and community associations to political, economic and legal structures. For example, the stigma and abuse of people with disabilities which leads to their marginalization and stereotyping. Environmental factors are a major obstacle in inclusion.

CBR and leprosy

There are lot of commonalities in the medical treatment and rehabilitation between people with leprosy and people with neuromuscular impairments. Traditionally, leprosy treatment was delivered by means of a centre-based delivery system or outreach program. Leprosy treatment and rehabilitation programmes are often vertical and segregated programme usually delivered by a specialized group of professionals. Leprosy colonies or in a separate isolated settlements of people with leprosy are still a reality in many parts of the world. There is a growing trend to mainstream leprosy treatment or allow leprosy treatment facilities to take expand their services to include treatment related to other impairments but much work needs to be done to eradicate stigma, fear, negative image and enable people with leprosy to participate as equal members of the community with equal opportunities and equal rights. While people with disabilities are increasingly accepted in the community due to greater community awareness, action by the disability movement and national and international rules and instruments, efforts need to be made to ensure that people with leprosy also have full and equal enjoyment of all human rights and fundamental freedoms and gain respect for their inherent dignity.

The CBR guidelines provide useful strategies and activities for promoting the inclusion of people with disabilities, including people with leprosy in all key domains of life. Additionally the dedicated chapter on CBR and leprosy was added to ensure people with leprosy are not excluded from CBR programmes. It is hoped that the CBR Guidelines will contribute to the inclusion of people with leprosy in the disability movement and in their communities; empowered to join and benefiting from mainstream development initiatives including medical or rehabilitative care.

The purpose of the dedicated chapter on leprosy in the guidelines is to:

- show why many people affected by leprosy may need rehabilitation and should be able to benefit from mainstream CBR programmes;

- highlight the particular characteristics of leprosy to people working in CBR programmes who may not be familiar with the disease and its consequences;
- ensure that (rehabilitation) experts and programme managers in the field of leprosy understand the need to integrate their services and programmes into mainstream CBR developments.

Beside the CBR guidelines, WHO and ILEP are also producing a technical guide on *Community-Based Rehabilitation and Leprosy* which will further promote the linkage between CBR and existing leprosy programmes.

Who are these Guidelines for?

Stakeholders involved in disability, development and CBR have come to a common understanding of CBR and committed to working together to produce the guidelines which would provide much needed technical support to CBR managers based on common norms and best practice in the field. The guidelines are a supplement to the available tools for CBR. For example, it will be a complimentary to WHO/ILEP technical guide on community based rehabilitation and leprosy. The purpose of the Guidelines is to provide support for initiating and strengthening CBR programmes. They are designed as a practical guide to assist in the development and delivery of CBR and the day-to-day practice in the field. Special efforts have been made to ensure the benefit of the Guidelines address the needs of further marginalized groups such as women with disabilities, people with HIV/AIDS, people with psychosocial difficulties and people with leprosy.

Conclusion

Since its inception, the development of the Guidelines has been a participatory process. Over 150 experts from all over the world and from a wide range of organisations such as UN agencies, DPOs, INGOs and professional organisations have contributed in various ways – as authors, as financial supporters, and as advisers. Currently about 30 CBR programmes in 25 countries are contributing by reviewing the draft Guidelines. Feedback from this field validation process will be incorporated into the Guidelines which will then be sent to cooperating universities for peer review. CBR Guidelines are expected to be published in December of 2008. A concerted effort has been made to ensure larger ownership and partnership and to develop a practitioners document for CBR managers. The momentum that has been created through the process of developing the Guidelines will continue to grow. Further occasions for cooperation and knowledge sharing and additional opportunities for working in alliance across the spectrum are already being discussed and considered. People with leprosy are mostly from low income countries where CBR is the most common strategy for rehabilitation and inclusion of people with disabilities. The CBR guidelines open a new door for people with leprosy to be in the mainstream, to be empowered, to have full and equal enjoyment of human rights and fundamental freedoms and to promote respect for their inherent dignity. The success of any guideline depends on its scale of implementation and that invites YOUR participation.

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List of countries where CBR is in practice

| CBR atlas | America | Asia | Europe |
|---------------|--------------------|------------------------------------|-----------------------|
| Africa | | | |
| Algeria | Argentina | Afghanistan | Azerbaijan |
| Angola | Aruba | Bangladesh | Estonia |
| Botswana | Belize | Bhutan | Israel |
| Burkina Faso | Bolivia | Cambodia | Latvia |
| Cameroon | Brazil | China | Romania |
| Congo | Chile | Democratic Republic of Timor-Leste | Russian Federation |
| Côte d'Ivoire | Colombia | India | Serbia and Montenegro |
| Egypt | Costa Rica | Indonesia | |
| Eritrea | Cuba | Iran | |
| Ethiopia | Dominica | Jordan | |
| Gambia | Dominican Republic | Lao People's Democratic Republic | |
| Ghana | Ecuador | Lebanon | |
| Kenya | El Salvador | Malaysia | |
| Lesotho | Guatemala | Maldives | |
| Liberia | Guyana | Mongolia | |
| Malawi | Honduras | Myanmar | |
| Mali | Jamaica | Nepal | |
| Mauritania | Mexico | Pakistan | |
| Mauritius | Nicaragua | Palestine | |
| Mozambique | Panama | Papua New Guinea | |
| Namibia | Paraguay | Philippines | |
| Niger | Peru | Sri Lanka | |
| Nigeria | Uruguay | Syria | |
| Senegal | Venezuela | Thailand | |
| Sierra Leone | | Viet Nam | |
| Somalia | | Yemen | |
| South Africa | | | |
| Sudan | | | |
| Tanzania | | | |
| Togo | | | |
| Tunisia | | | |
| Uganda | | | |
| Zambia | | | |
| Zanzibar | | | |
| Zimbabwe | | | |