



World Health Organization

Meeting Report on the development of guidelines for Community Based Rehabilitation (CBR) programmes (1st and 2nd November 2004, Geneva, Switzerland)

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1. **Preamble**

Community-based rehabilitation (CBR) is community action to ensure that people with disabilities have the same rights and opportunities as all other community members. This includes, for example, equal access to health care, education, skills training, employment, family life, social mobility and political empowerment.

For more than two decades CBR has been talked about, implemented and evaluated. Throughout that time, it has evolved and shifted from an emphasis only on medical or educational services to a concern with equal rights and poverty reduction for people with disabilities. Today it is a strategy that is promoted by people with disabilities, as well as government and non-governmental agencies and organizations interested in promoting the rights of people with disabilities. Many of the people who are using, or planning to use this strategy are calling for more guidance to initiate and sustain CBR programmes. These guidelines are a response to their requests.

Twenty five years ago the World Health Organization, in collaboration with other United Nations agencies, published a CBR manual that could be used by community leaders, people with disabilities and their families, as well as healthcare workers and school teachers. Based on the first experiences with CBR, people from many countries provided feedback on the manual, which was revised and published in 1989 with the title, *Training in the Community for People with Disabilities*. As more CBR programmes were initiated, and more people with disabilities were empowered, they expressed their need for a focus on meeting their basic needs and at the same time rights and equal opportunities.

During the 1990s, U.N. agencies worked together to promote and support CBR programmes. A joint position paper was issued in 1994 and revised in 2004: "*The ILO, UNESCO and WHO Joint Position Paper on CBR*". This paper provides an update on the concept of CBR and its future directions. It has identified CBR is a strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities. A guidelines were thought to be an idea tool for those who wish to start or strengthen an existing CBR following new joint position paper (2004).

Poverty is a root cause of many disabilities and disability enhances poverty further. About 400 million people with disabilities live in low income countries, often amidst poverty, isolation and despair. Poverty further limits access to basic health services, including rehabilitation and accessing education. Community Based Rehabilitation is a strategy for socio-economic development. It is essentially about human rights. Its key principles need to be poverty alleviation, education, health and rehabilitation. and enabling people with disabilities participation in the whole range of human activities.

- Poverty is the critical issue for people with disabilities, and within the category 'people with disabilities', some groups of people are considerably more likely to be poor than others. For example, women with disabilities are not just more likely to be poor but also due to marginalization and exclusion, more likely to experience extreme poverty.
- Mainstream approaches to poverty alleviation frequently marginalize or ignore the rights of people with disabilities. They remain marginalized or absent from initiatives such as the Millennium Development Goals. Such initiatives may contribute to poverty alleviation but fail to affect those living in chronic poverty – most likely to be people with disabilities and their families.
- One of the key objectives of any CBR strategy is the inclusion of people with disabilities in the civil, social, political and economic structures of the community. This means people with disabilities playing a full part as citizens of their society with the same rights, entitlements and responsibilities as others, while contributing tangible benefits to the whole community.
- Poverty alleviation strategies which target people with disability also bring socio-economic benefits to the whole community and ultimately to the country.
- Poverty is a structural issue which has been exacerbated in recent years by globalization and environmental damage, due to recent policies of liberalization and privatization without ensuring social protection for all.
 - For example, the effects of global warming on a farmer in the low income countries may pitch him into a cycle of increased poverty: arid land, failed crops, loans, debts, rural migration, urban poverty and disease. A policy which in effect damages the ecology of sustainable farming has a dramatic effect on rural poverty. An example is the replacement of traditional crops with cash crops for export.

In 2003, the Government of Finland hosted an International Consultation to Review Community Based Rehabilitation which was organized by WHO along with other UN agencies and International Disabled Peoples Organizations. People with disabilities and others working with CBR programmes stressed the importance of focusing on the persistent poverty that affects the majority of disabled people. Participants at the meeting also pointed out that it is essential to include all people who have disabilities in the programmes concerned with poverty reduction and eradication. It was acknowledged that people with mental impairments or conditions are particularly excluded.

The participants identified the following aspects of CBR that need to be strengthened to make programmes more effective:

- Community Involvement and Ownership
- Multisectoral Collaboration in CBR programmes
- Involvement of Disabled People's Organizations in CBR programmes
- Scaling up CBR programmes
- CBR programmes to be used as an effective tool for poverty reduction
- Evidenced based practice to promote CBR programmes

It was also acknowledged that all communities are different in terrain, culture, their political systems, socio-economic conditions and many other factors. Therefore, there cannot be one model of CBR for the whole world. It may not be the same even within the same country. There are many models of CBR programmes; each is unique to its own situation. This is the uniqueness and at the same time the challenge of CBR programmes. However, from experience, it has been realized that there need to be some basic norms for a valid CBR programme. Evidence is needed that the particular CBR strategy being used is the most effective and efficient approach to enhance the quality of life for people with disabilities and their family members.

Those who took part in the review of CBR stressed that better guidance is needed for CBR programmes, and cautioned that new guidelines must take into consideration the great variety in the programmes that exist, each of which was developed to meet special needs in a specific setting. Capitalizing on 25 years of CBR programmes, the aim is to develop Guidelines on CBR to ensure that "CBR is a strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities", while acknowledging the fact that good guidelines must be flexible enough to accommodate different realities and different cultures.

In response to the expressed need for better guidance, WHO called the Meeting on the Development of Guidelines for Community Based Rehabilitation Programmes, which took place in Geneva in 1st and 2nd November, 2004. WHO asked the participants to develop an outline of the information needed to describe the components of a CBR. WHO proposed the major topics of health, education, income, empowerment and inclusion. Based on individual expertise, each participant was assigned to a group related to one of the major topics. To initiate the discussions, and to recognize the variation in CBR programmes, some of the participants in this meeting presented analyzes of their experiences with CBR. Through the discussions, an outline of the programme content for the new guidelines was developed. The outline is summarized in the matrix and described in the body of this report.

The **purpose of the guidelines** is to provide a step-by-step guide to the implementation of Community Based Rehabilitation programmes. These guidelines are for use by CBR programme implementers who may be policy makers, programme managers or project workers. They are designed as a practical guide to strengthen the delivery of CBR and the day-to-day practice in the field. One of the key challenges is *'Can they be used by a CBR team working in the city slums or rural areas of the low income countries? Are they practical, easy to understand and helpful?'*

The guidelines will contain examples of **good evidence-based practice** to help practitioners build on others' experiences. The guidelines will be produced in accessible formats and plain language. They will be available in various languages, Braille, on audio cassette and electronic format.

In producing the guidelines, we recognize too that all those working on a CBR programme – be they people from the community, paid practitioners or managers - are engaged in one of the most complex forms of community change. They all need a high level of skill.

The training of practitioners and the capacity building of local groups needs to acknowledge this wider context of the causes of poverty and the contribution that a CBR programme can make to alleviate the effects of poverty on people's lives.

Policy makers may also be interested in learning more about how CBR programmes work, so a summary chapter will be provided for them in the guidelines.

The issues to be presented in the new guidelines are of concern worldwide. Poverty is a concern for people with disabilities in almost all countries. Their access to education, income generating programmes and employment is markedly lower than national averages. As a result, most people with disabilities have far less than average incomes within their countries. Nonetheless, it is well recognized that the situation in low income countries is worse for people with disabilities because they have greater restrictions in access to education, health care, assistive devices and personal assistance than people with disabilities in higher income countries. Hence, these guidelines will focus more on the low income countries. However, with modification to accommodate different socio-economic conditions, they can also be used globally.

The headings (components) in the matrix are: Health, Education, Livelihoods, Empowerment and Social. Each heading has five sub-headings (elements). For each of these, one or more authors will be identified to draft the text. Participants at the meeting have been invited to contribute to the formulation of the new guidelines. In addition to the topics identified on the matrix, there will be information and good evidence that will help managers to initiate and to strengthen CBR programmes. A draft of the complete outline for the guidelines is presented below. WHO will form a advisory/core group to monitor the development of the new guidelines.

Draft of Content for CBR Guidelines:

1. Background and Purpose
2. Evolution of disability scenario
3. Evolution of CBR
4. *Programme Content: Principles**
5. *Programme Content: Health**
6. *Programme Content: Education**
7. *Programme Content: Livelihoods**
8. *Programme Content: Empowerment**
9. *Programme Content: Social**
10. Examples of starting CBR
11. Examples of sustaining and expanding CBR
12. Evidences of poverty alleviation through CBR
13. Monitoring and Evaluation
14. Guide to Policy Makers

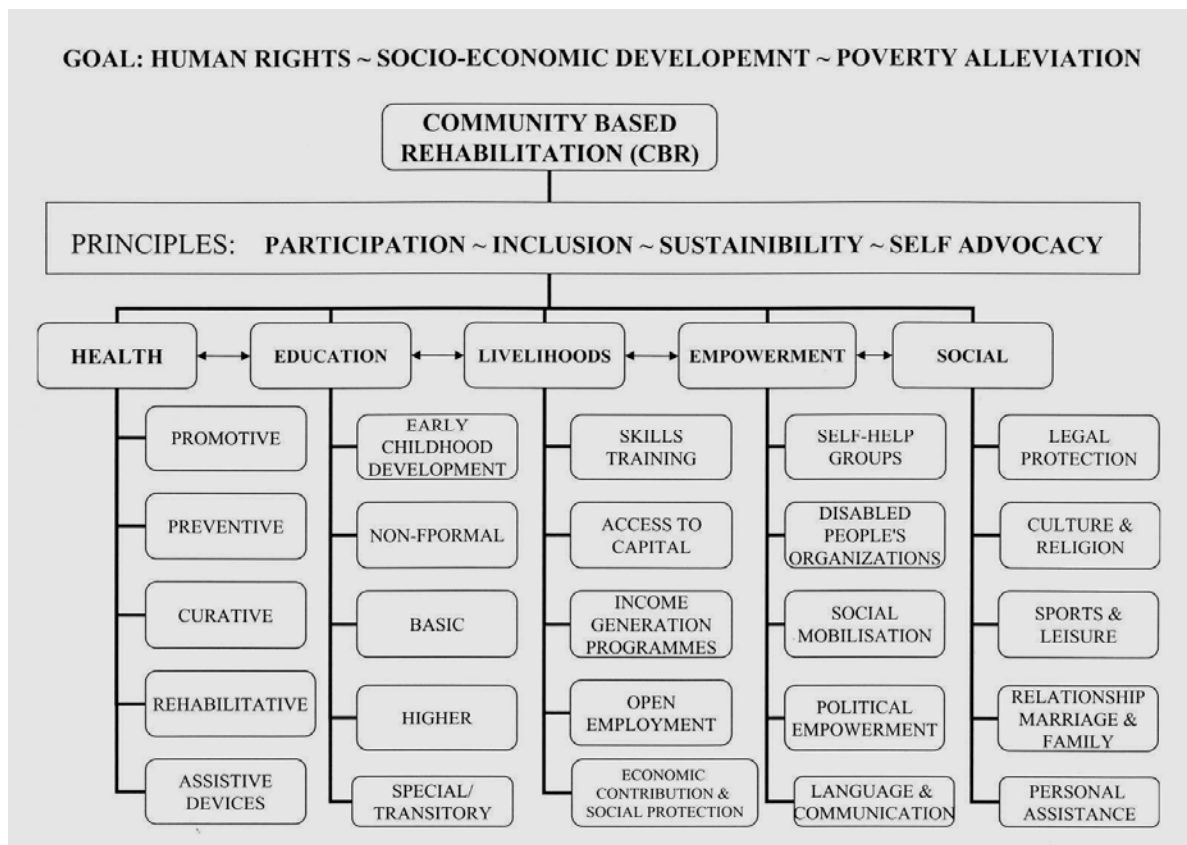
2. The matrix

The matrix illustrates the topic areas which can make up a CBR strategy. It consists of five components, each divided into five elements. Each of these elements will have a dedicated chapter in the guidelines. The elements are sub-divided into content headings. Each element has between four to eight key content headings. The components and elements are underpinned by a number of principles which inform all the work. These principles are in no way just theoretical or abstract but intended to be translated into tangible ways of working and should be observable in programme activities.

The matrix represents the topic areas which an effective CBR programme may contain depending on local circumstances. The practitioner may choose:

- The most practical entry point for the programme, for example, an initiative on primary schooling or organizing parents of children with disabilities
- The next logical steps to build up the programme, for example, an initiative on anti-natal and primary health care;
- 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, Implementer needs to be in touch with other key organizations who usually take care of other components/elements.



2.1 The principles

The principles are overlapping, complimentary and inter-dependent – they cannot be separated one from the other.

Principles

Inclusion

Participation

Sustainability

Empowerment

Self-advocacy

Inclusion

Inclusion means the removal of all kinds of barriers which block people with disabilities from access to the mainstream. Inclusion means placing disability issues and people with disabilities in the **mainstream** of activities, rather than as an after-thought or ‘bolt-on’.

Inclusion also means ‘**convergence**’ – that is, the involvement of people with disabilities in the campaigns, struggles and activities of other oppressed groups which are not centred exclusively on disability issues, such as children living on the streets, farmers, land rights and environment, women’s groups,

It means including **all forms of impairment** – physical, sensory, communicative, mental health and illness, and intellectual and developmental disabilities. It means including people with multiple and/or severe disabilities.

It embraces young people – particularly children, their care and protection from violence and abuse, and it includes older people and their care and protection from abuse too.

It means the inclusion of those groups in society who are traditionally excluded and discriminated against – women, people with multiple and severe disabilities, , people of particular religious beliefs, ethnic, caste or community background, refugees, and people who are HIV+ or have AIDS.

It includes also people with disabilities living in extreme poverty, and people suffering from conflict and war and its aftermath.

Inclusion also means **access**, that is, the removal of any barriers which disable people.

These barriers are:

- Environmental and physical
- Attitudinal
- Technological

They debar people with disabilities from participation in:

- Political and civic activity
- Social and cultural activity
- Economic activity

Environmental barriers - for example, steps for people with mobility impairments.

Attitudinal barriers - for example, the stigma and abuse of people with disabilities, leading to their marginalisation and stereotyping.

Technological barriers caused by language and medium of communication - for example, the non-provision of Braille or sign language.

Economic barriers - for example, the prohibitive cost of a bus fare to the nearest hospital.

Barriers at a polling booth may prevent the civic right to political participation.

Barriers to a school may prevent the social right to participation in education.

Barriers to a place of worship may prevent cultural and religious rights.

The discrimination against people with disabilities is structural and institutionalised – at state, organisation and individual level. It is legitimized in laws and regulations; woven into an organisation's policies, practices and procedures and the way officials use their discretion; strengthened by the broader attitudes within society, and the sanctioned behaviour of individuals.

Inclusion means the removal of all these barriers.

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 covers the participation of women in all processes and decision-making, and that of other groups who are typically not listened to or excluded. Likewise children and young adults can and should be part of the processes and decision-making.

It requires the imaginative and flexible use of language and communication: for example ways around the barriers of illiteracy; the right to use your own language without discrimination or stigma.

Sustainability

Firstly, the benefits of the programme must be lasting. This means an approach to poverty alleviation where the socio-economic gains last beyond the short-term and benefit not just the present but future generations too.

Secondly, the CBR activity must be sustainable beyond the immediate life of the programme itself – able to continue beyond the initial intervention and thrive independently of the initiating agency.

Strong links between government organizations, NGOs, community based / development organizations and disabled peoples organizations will contribute towards sustainability. This means that disabled people's organizations and self-help groups – are the hub of any CBR activity.

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. It means ensuring that CBR workers, service providers and facilitators are people with disabilities and all are adequately trained and supported.

The empowerment of women is central to any programme.

Empower means drawing strength from solidarity and guarding against ways in which institutions and individuals may work to ‘divide and rule’ between groups within the community. These splits may be fostered along ethnic, religious or gender lines. Such divisions only serve to disempower.

Empowerment necessitates capacity building – that is, the developing and using of the skills necessary to act with authority and responsibility, independent of the initiating agencies and CBR programme managers.

The skills of CBR workers and their managers are crucial too. They need to be empowered by ensuring they have a range and depth of skill appropriate to the complexities of the work. Their training should include an understanding of the causes and effects of poverty, and the contribution the CBR programme can make to poverty alleviation. CBR workers are themselves often poor and have many other responsibilities. Training and support needs to acknowledge this reality.

Technical staff – prosthetists and orthotists, therapists etc. – also need specialist training to work within the context of poverty and in a style which is empowering rather than patronizing or intimidating. The assistive devices must also be empowering – designed appropriately for the user’s needs and context of their life.

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 not an individualistic one. It means self-determination. It means mobilizing, organising, representing, creating space for interaction and demands. It may mean posing a threat, making a challenge. These are the self-advocacy tools used in any CBR strategy.

These five principles will inform and affect the activities within each of the components and elements of the matrix.

2.2 Methods of working

The key methods of CBR working are:

- Meeting basic needs
- Building capacity
- Creating opportunities for livelihood, health, rehabilitation and education
- Organizing disabled people and involving disabled people’s organisations [DPO’s]
- Collaborating across sectors
- Involving the whole community
- Involving local government and leaders
- Using the legislation, judicial and political systems

The components and the elements should be seen as inter-related – not discrete and separate boxes.

2.3 Components and elements

2.3.1. Health

Some points for the preamble

- Health care needs of people with disability are often the same as those of non-disabled people – needing and entitled to the same range of treatments – particularly those not related to their impairment.
- The range of access and assistive devices – prosthetics, orthotics, mobility aids, hearing aids, accessible environment etc
- An emphasis on all relevant settings, not just health and rehabilitation e.g. school, home, social, work
- Differentiate between ‘community’ and ‘referral’ level
- Disability should not be seen as a medical issue but within a wider social context

Elements and their contents

➤ Promotive

- Access to information and promotion of personal and public health
- Promotion of knowledge on health and staying healthy
- Health of personal assistants, parents and siblings of children with disabilities
- Healthy environment
- Recognition of people with disability as a peer resource

➤ Preventive

- Primary prevention - Immunization
- Early detection and intervention [especially children under 3 years’ old]
- Prevention of secondary conditions [e.g. depression, deformities, pressure sores, respiratory infections etc]
- Sexually transmitted diseases and appropriate preventive education and provision of protection

➤ Curative

- Health care for people with disabilities [e.g. flu, high blood pressure, HIV/AIDS]
- Referral to specialized services
- Corrective surgery and medical intervention

➤ Rehabilitative

- Medical intervention
- Daily living skills support
- Therapeutic intervention
- Referral to specialist services
- Family and community support
- Return to work programmes

➤ Assistive devices

- Access to devices inc. mobility, vision, hearing etc
- Access to prosthetic and orthotic devices
- Education on their use; access to after-care

- Access to Information and Communication Technology
- Environmental adaptations
- Promotion of appropriate technology

2.3.2 Education

Some points for the preamble

- Include child labour
- Include parents' groups
- Note the links between water and sanitation at home and school – especially for girls
- Note use and importance of technology
- Need of transport and personal assistance
- Importance of mainstream education and role of some specific or special educational provision

Elements and their contents

➤ **Early childhood development**

- Early identification
- Parent and family support
- Play and development
- Child development
- Transition and readiness for formal education

➤ **Non-formal education**

- Home-based learning
- Adult literacy
- Community-based alternatives to formal education
- Community-based day care centres
- Links with formal education
- Flexibility and adjustments/ adaptations within formal education settings
- Religious-based supplementary education [e.g. Sunday schools, Madrasahs]
- Individual educational planning
- Creativity and sports

➤ **Basic education**

- Access to curriculum, technology and medium and method of instruction
- Home / community / school links
- Child-to-child activities
- Orientation of school personnel
- Access to resources and learning materials
- Educational and technical support

➤ **Higher education**

- Advice, guidance and enrolment
- Access to materials, methods, communication and ICT
- Individual and family support
- Distance learning

- Flexible examination and assessments methods
- Special provision for some people with disabilities

- **Special and transitory**

- Special education
- Identification of work options
- Linkages to working life
- Peer counselling
- Survival needs training -
- Citizenship and political awareness

2.3.3 Livelihoods

Some points for the preamble

- Issue of typical vocational rehabilitation
- Importance of traditional skills
- Decent and fair employment / work
- Importance of commercial market analysis
- Focus on service sector

Elements and their contents

- **Skills training**

- Vocational – formal and informal/traditional
- Skills transfer from home to work
- Life and work skills and orientation
- Vocational guidance
- Mainstream skills training

- **Access to capital**

- Savings inc. group savings
- Guarantors and collateral
- Micro credit
- Access to mainstream capital and grants
- Knowledge of resources and sources of capital
- Linkage and possible merging with other mainstream groups

- **Income generating activities**

- Co-operatives
- Enterprises
- Protected [sheltered] schemes
- Focus on service sector
- On-going guidance and support

- **Open employment**

- Active lobbying
- Legal obligations on employers inc. affirmative action and quotas
- Diversity awareness within organizations
- Equality of treatment at work for people with disabilities

- ‘Reasonable adjustments’ by an employer e.g. adaptations to working environment, ways of working etc
- Supported employment [inc. job coaching, mentoring etc.]
- Social capital and enterprise

➤ **Economic contribution and social protection**

For those working:

- As resource person e.g. peer support, counselling
- Skills training and role models
- Employment creation – services and goods to the community
- Contribution to the household
- Consumer role – services and goods

For those who cannot get employment nor have a decent income:

- Social security
- Mutual assistance in community
- Micro insurance schemes i.e. pensions, health, funeral expenses
- Support from family or official carer / guardian

2.3.4 Empowerment

Some notes for the preamble

- Inclusion in the political processes and participation in political leadership
- Self-help groups to have a broader perspective on poverty reduction processes
- People with disabilities and their carers need to have involvement in overall social development
- Enabling people with disabilities to understand their rights and potential power
- Strong linkage with local government if the CBR programme is not being run by local government

Elements and their contents

➤ **Self-help groups**

- Organizing people with disabilities and their family members
- Peer counselling and support e.g. child to child, mother to mother
- Facilitate groups’ leadership role in CBR processes
- Capacity-building
- Promote group activities for access to resources

➤ **Disabled peoples organizations [DPO’s]**

- Organizing people with disabilities
- Strengthening existing DPO’s
- Promoting self-determination
- Capacity building
- Networking inc. agencies
- Umbrella organizations
- Resource to educate both people with disabilities and non-disabled people
- Partnership with local government

- **Social mobilization**
 - Alliance building with representatives of society
 - Campaigns - led by people with disabilities
 - Campaigns on general issues to include people with disabilities
 - Access to local and community resources
 - Involvement in any local committees

- **Political empowerment**
 - Reservations, quotas and affirmative action for elected and non-elected bodies at national to local level
 - Access to voting and right to a secret ballot
 - Monitoring
 - Lobbying
 - Training political leaders and policy makers

- **Language and communication**
 - Specific language issues inc. literacy and translation
 - Communication needs inc. sensory and communication impairments
 - ICT – Internet, mobile phones etc.
 - Tactile signing for deaf – blind communication

2.3.5 Social

Notes for the preamble

- Legislation
- Commitment to implement UN standard rules and outcome of UN Convention
- Judiciary activism
- Access to places of worship
- Removal of discriminatory laws and regulations e.g. right to open bank account, insurance coverage

The following need to be included in some way:

- Protection of people with disabilities, especially children caught up in conflicts and emergencies
- The need to add ‘volunteers’ as an element and list its contents.
- ‘Personal assistance’ [not ‘Care giver’] includes sign language interpreters
- Clear definitions of independent living, self determination and freedom of choice – from the perspective of the Low income countries

Elements and their contents

- **Legal protection**
 - Independent living
 - Home working
 - Sexual and reproductive rights
 - Land and inheritance rights
 - Protection of disabled children
 - Financial support for legal advice

- Enforcement laws
- Protection from negative cultural beliefs
- **Culture and religion**
 - Participation in cultural and religious activities
 - Society's attitudes to disability
 - Religious attitudes to disability
 - Resources and support from cultural and religious groups
 - Using religious and cultural activities to remove stigma
- **Sports and leisure [social activities]**
 - Integrating young people and adults into mainstream provision
 - Physical activity for people with disabilities
 - Parallel sports activities for people with disabilities
 - Promotion of sports as a therapeutic measure
 - Spectator roles in a range of sports
 - Inclusion in public and family social gatherings
 - Access to recreation facilities e.g. cinema
 - Technological – used for equipment adaptation and modification
- **Relationships, marriage and family**
 - Marriage and family
 - Diverse relationships and sexualities inc. lesbian, gay, same-sex
 - Sex education and HIV/AIDS preventive education
 - Sex and reproductive health issues
 - Emotional issues
 - Peer counselling among married and non-married people with disabilities
 - Support for single mothers and mothers neglected and deserted by husbands after birth of child with disabilities, or after mother acquires disability
 - Counselling and capacity building for women with disabilities
 - Awareness work with religious communities on disability and relationships / marriage / sexual relations between people with disabilities and between a person with a disability and a non-disabled person
 - Compensation in cases of divorce or separation
 - Trauma and psycho social counselling
- **Personal assistance**
 - Daily living skills
 - Protection of the young, older people, and those with severe communication impairments from exploitation and abuse
 - Persons with disabilities using the programmes have a decisive influence
 - Interpretation services
 - Access to information
 - Training – supervised / provided by people with disabilities

3. Processes

It has been acknowledged that developing CBR guidelines needs time but effort needs to be made from all the stakeholders to make it within two or three years.

The process stages are:

- Finalization of the CBR Guidelines Meeting report
- Identification of key stakeholders who would support the development of guidelines
- Identification of needs, research and data collection
- Project planning and costing
- Developing the Guidelines
- Training and development - both awareness raising and skills
- Support for field testing
- Monitoring, review and evaluation

To realize the various components and elements described in the matrix, the same principles will be followed – that is, *inclusion, access, participation, sustainability, empowerment and self-advocacy*

4. Next steps for production of guidelines

The next steps in the drafting of these Guidelines for CBR are:

4.1 Drafting

- Formation of an e-group.
- Finalization of Contents under each element by the e-group
- Finalization of format for writing on different contents of the elements.
- Identification of volunteers to write on each component, and the elements and contents of the matrix [volunteers could choose to collaborate with others especially with people with disabilities and their organizations].
- Identification of an advisory group to guide the overall development and advise the core group
- Identification of a Core Group to write the preamble, the overall context of development including the principles contained in the guidelines, legislative context, etc., and to edit the final document.
- Meeting between ILO, UNESCO and WHO
- Two or three meetings of the Core Group and one or two meetings of Core Group plus Volunteers to finalize the manual.
- Regional Workshops
- Professional editing of Guidelines.
- Publication in different languages and formats, and dissemination
- Training.

4.2 Support

- Formation of Support Group
- Fund raising

5. List of the participants

- 1 Dr Alaa Sebeh
SC UK regional office
Flat 9, 12 A, Hassan Sabry Street
Zamalek, Cairo
EGYPT"
T: 0020 (02) 735 0558 or 0020 (02) 735 8619
F: 0020 2 735 0558"
a.sebeh@scuk-mena.com
- 2 Dr Alice Nganwa
Disability and Rehabilitation Section
Ministry of Health
P.O. Box 8
Kampala
UGANDA"
T: 00 256 756 48920
dparmoh@yahoo.co.uk
- 3 Dr Ann Goerdts
Physical Therapy Department
New York University
380 Second Ave. - Fourth Floor
New York, NY 10010
U.S.A.
T: 001 212-998-9401
F: 001 212-439-6310
ag89@nyu.edu
- 4 Ms Anna Lindström
"Swedish Handicap Institute &
Rep. of Rehabilitation International
P.O. Box 510
SE-16215 Vallingby
SWEDEN"
T: 0046 8 620 17 12
F: 0046 8 739 2152
anna.lindstrom@hi.se or ri@riglobal.org
- 5 Ms Ariam Gebremariam
"Swedish Organization of Disabled Persons International Aid Association (SHIA)
Liljeholms torg 7A
SE-117 63 Stockholm
SWEDEN
T: 0046 8 462 3367
F: 0046 8 714 59 22
ariam@shia.se

- 6 Mr Axel Hardenberg
"Christoffel-Blinden Mission
Nibelungentrasse 124
64625 Bensheim
GERMANY
T: 0049 6251 131 247
F: 0049 6251 131 165
axel.hardenberg@cbm_i.org
- 7 Mr Balakrishna Venkatesh
"Timbaktu Collective
C.K. Palli - 515101 Ananthapur District
Andhra Pradesh
INDIA
T: 0091-94406-86839
F: 0091-80-25588098
dearvenky@yahoo.com
- 8 Mrs Birgitta Andersson
"Swedish Organization of Disabled Persons International Aid Association (SHIA)
Liljeholms torg 7A
SE-117 63 Stockholm
SWEDEN
T: 00 46 8 7600895
F: 0046 8 7615552
birgitta.mats@telia.com
- 9 Mr Bob Ransom
Disability Programme
ILO
4, Route des Merillons
CH-1211 Geneva 22
SWITZERLAND
T: 0041 22 799 66 47
F: 0041 22 799 63 10
ransom@ilo.org
- 10 Ms Bruce Lissen
Norwegian Association of the Disabled
Schweigaardsgate 12
0134 Oslo
NORWAY
T: 0047 24 102400
F: 0047 2 410 2499
lissen.bruce@nhf.no
- 11 Mr Chiwaya Clement
Hon'ble Minister of Social Development and Persons with Disabilities

- P.O. Box 30390
Private Bag 257
Blantyre
MALAWI
T: 00265 (01) 622 420
F: 00265 (0) 1 635 306
chiwacle@yahoo.com
- 12 Mr Derek Hooper
Director, Equality Works Ltd
Shepherdess Walk Buildings
1, Underwood Row
London N1 7LQ
UK
T: 0044 207 251 4939
F: 0044 208 883 5337
derek.hooper@equalityworks.co.uk
- 13 Dr Donald J. Lollar
Senior Research Scientist
National Center on Birth Defects and Developmental Disabilities
1600 Clifton Rd., E87
Atlanta, GA 30333
USA"
T: 001 404 498 3041
F: 001 404 498 3050
dlollar@cdc.gov
- 14 Dr Einar Helander
Rua Vasco da Gama 11
7520-21 Lisboa
PORTUGAL
T: 00 351 936 465 665
F: mop58158@mail.telepac.pt
- 15 Ms Eleanor Cozens
Sight Savers International
Head of Programme Development
Grosvenor Hall
Bolnor Road
Haywards Health
West Sussex RH 16 4BX
UK
T: 0044 1444 446600
F: 0044 1444 44 66 77
ecozens@sightsavers.org
- 16 Dr Enrico Pupulin
Consultant, Disability and Rehabilitation

- 648, Guy de Maupassant
Divonne-les-Bains
FRANCE
T: 0033 450 202 432
penrico@aol.com
- 17 Ms Eva Falkenberg
Disability Adviser - SIDA
SE-105 25 Stockholm
SWEDEN
T: 0046 8 698 55 89
F: 00 46 8 698 56 47
eva.falkenberg@sida.se
- 18 Ms Eva M Sandborg
"Senior Advisor
Office of the Disability Ombudsman
P.O. Box 49132
SE-100 29 Stockholm
SWEDEN
T: 0046 8 693 03 66
F: 0046 8 20 43 53
eva.sandborg@ho.se
- 19 Ms Farhat Rehman
RCPD
Ummeedabad 2, P.O.Box 201 Swatgante
Peshawar
PAKISTAN
T: 0092-91-277663 or 285911
F: 0092-91-5260258
fht_rehman@hotmail.com or fht_rehman2000@yahoo.com
- 20 Ms Francesca Ortali
Associazione Italiana Amici di Raoul Follereau (AIFO)
Via Borselli 4-6
I-40135 Bologna
ITALY
T: 0039 051433402
F: 0039 051 434046
francesca.ortali@aifo.it
- 21 Dr Francisco José Posada Rodriguez
Colonia La Sultana Calle los Lirios # 11 Antiguo Cuscatlan
EL SALVADOR
T: 00 503 243 0685
F: 00503 262 280 2024
cim@isri.gob.sv

- 22 Dr Frank Kronenberg
World Federation of Occupational Therapy
Eindstraat 21
5801 CP Venray
THE NETHERLANDS
T: 0031 478-581670
F: 0031-478-512317
tulipan.rubio@worldonline.nl
- 23 Ms Garance Upham
Peoples Health Movement
86 Chemin
Pre de Planche
01280 Prevevin
France
T/F: 0033 (450) 428226
g_uham@club-internet.fr
- 24 Mr Geert Vanneste
International Training Programme - CBR
CCBRT Headquarters
Dar-es-Salaam
UNITED REP. TANZANIA
T: 00255 22 - 260 1543
F: 00255 22 - 260 1544
geertvanneste@ccbrt.or.tz
- 25 Ms Geraldine M Halls
National CBR Committee
107 Carmichael Street
North Commingsburg
Georgetown
GUYANA
T: 00592 (2) 225 0701-3
F: 00592 220 5432
halls@networksgy.com
- 26 Prof Gerold Stucki
Interantional Society of Physical and Rehabilitation Medicine
C/O University Hospital Munich
Marchioninstr, 17
81337 Munich
Germany
T: 0049 (89) 7095 4051
F: 0049 (89) 7095 8836
Gerold.Stucki@phys.med.uni-muenchen.de
- 27 Dr Giampiero Griffo
Chief of DPI-Europe

- Via De Simone 45
81038 Trentola-Ducenta (Caserta)
ITALY
T: 0039 348 320 8071
F: 0039 081 814 0692
giabudda@tin.it
- 28 Mr Harry Finkenflugel
Erasmus Medisch Centrum
Institute for Health Care Policy and Management
P.O. Box 1738
3000 Rotterdam
THE NETHERLANDS
T: 0031 10 408 9701
F: 0031 10 408 9094
finkenflugel@bmg.eur.nl
- 29 Ms Ibrahim Asindua Shaya
Training & Development Officer
Leonard Cheshire
Eastern and Northern Africa Region Office
P.O. Box 38748 - 00600
Nairobi
KENYA
T : 00254 20 572 178
F : 00254 20 572 249
encheshire@iconnect.co.ke
- 30 Ms Judy Heumann
World Bank
1818 H Street MS G8-802
Washington DC 220433
USA
T: 00 1 212 458 9045
jheumann@worldbank.org
- 31 Ms Kamala Achu
Jaipur Limb Campaign
404 Camden Road
London N7 0SJ
UK
T: 0044 207 700 7298
F: 00 44 207 700 1091
mail@jaipurlimb.org
- 32 Ms Karen Heinicke-Motsch
MIUSA
Project Manager, International Development & Disability
PO Box 10767

- Eugene, Oregon 97440
USA
T: 001 (541) 343-6812 or 001 (541) 343-1284
F: 001 (541) 343-6812
khmotsch@miusa.org
- 33 Mr Lawrence Ofori-Addo
Department of Social Welfare
P.O. Box MB 230
Accra
GHANA
T: 00233 21 684 538
F: 00233 21 663 615
oforiaddo@yahoo.com
- 34 Dr Lily Pinguz Vergara
Instituto Especiaizado de Rehabilitacion
Jiron Vigil N°535
Bellavista-Callao-02
PERU
T: 00 511 4290611
oei@inr.gob.pe
- 35 Ms Liz Carrington
International Development Adviser
The Chartered Society of Physiotherapy
14 Bedford Row
London WC1R 4ED
T: 0044020 7306 6694 or 0044 20 7306 6611
F: 0044 20 7306 6666
carrington@csp.org.uk
- 37 Dr Maya Thomas
Editor - Asia Pacific Disability Rehab. Journal
J - 124, Ushas Apartment
16th main, 4th Block
Jayangar, Bangalore - 560011
Karnataka
INDIA
T: 0091 80 26633762
F: 0091 80 26910193
thomasmaya@hotmail.com
- 38 Mr Mike Davies
CBM Unit
604 Alabang Business Tower
1216 Acacia Avenue, Alabartg
1780 Munitinlupa
THE PHILIPPINES

T: 0063 (2) 8078586 or 87
F: 0063 (2) 8078292
mike.davies@cbmseapro.myip.org

39 Dr Nan Dengkun
Professor and Director
WHO Collaborating Center for Training & Research in Rehabilitation
Tonji Hospital
1095 Jiefang Dadao
Wuhan 430030
CHINA
T: 0086 27 8364 3633
F: 0086 27 8364 3633
nandk@public.wh.hb.cn

40 Mr Nzimande Louis
Member of Parliament, South Africa
Mpumalanga Province
Private bag X 11285
Nelspruit, 1200
SOUTH AFRICA
T: 00272 1 4032011
F: 00272 1 4032070
lnzimande@parliament.gov.za or milaniw@social.mpu.gov.za

41 Mr Paul Caswell
Christoffel Blindenmission
Wuse-Abuja
NIGERIA
T: 00234 9 314 0330
F: 00234 9 314 4082
cbmabuja@hotmail.com

42 Mr Peter Coleridge
Technical Consultant to ILO
Cwmlerwyn
Hundred House
llandrindod Wells
Powys LD1 5RU
UK
T: 00 44 1982 570412
F: 00 44 1982 570412
petercoler@yahoo.co.uk

43 Mr Philippe Chervin
Handicap International
Mobilisation & political actions Div
Disability rights and policies Unit
14 Avenue Berthelot

F- 69361 Lyon Cedex 07
FRANCE
T: 0033 4 72 76 12 58 or 0033 4 78 69 79 79
F: 0033 4 72 76 12 67
pchervin@handicap-international.org

- 44 Mr Ronald Wiman-Rapporteur
Development Manager
STAKES
P.O. Box 220
FIN-00531 Helsinki
FINLAND
T: 00358 9 3967 2464
F: 00358 9 3967 2054
ronald.wiman@stakes.fi
- 45 Ms Roselyn Wabuge-Mwangi
Early Childhood and Inclusive Education
UNESCO ED/BAS/EIE
7, Place de Fontenoy
F-75352 Paris
FRANCE
T : 0033 1 45 68 21 57
F : 0033 1 4568 5626
R.Wabuge-Mwangi@unesco.org
- 46 Mr Salil Shetty
Director, Millennium Campaign
Millennium Development Goal
United Nations, New York
USA
T: 001-212-906-6324
F: 001-212-906-6057
salil.shetty@undp.org
- 47 Dr Sally Hartley
Institute of Child Health.
Honorary Senior Research Scientist
Great Ormond Street Hospital
30 Guilford Street
LONDON WC1N 1EH
UK
T. 0044 207 404 2062
F: 0044 207404 2062
s.hartley@ich.ucl.ac.uk
- 48 Mr Sepp Heim
International Society for Prosthetics & Orthotics(ISPO)
78337 öhningen/Wangen

- IM Haggarten 5 e
GERMANY
T: 00 49 7735 2332
F: 0049 7735 1499
ot-heim@t-online.de
- 49 Dr Servious Dube
International Training and Development
Leonard Cheshire International
30, Millbank
SW1P 4QD
London
UK
T: 0044 207 802 8222
F: 0044 207 802 8275
S.Dube@lc-uk.org
- 50 Ms Sue Stubbs
International Disability and Development Consortium (IDDC)
Flat 3, 24 Adelaide Crescent Nove
E Sussex BN3 2JH
London
UK
T: 0044 1273 727289
F: 0044 8 70 70603 87
suekali@yahoo.co.uk
- 51 Mr Sulemana Abudulai
"International Grants
Comic Relief
89 Albert Embankment
London SE1 7TP
UK
T: 0044 207 820 5528
F: 0044 207 820 5500
s.abdulai@comicrelief.org.uk
- 52 Dr Sunil Deepak
Associazione Italiana Amici di Raoul Follereau (AIFO)
Via Borselli 4-6
I-40135 Bologna
ITALY
T: 0039 051 43 34 02
F: 0039 051 40 40 46
sunil.deepak@aifo.it
- 53 Mr Svein Brodtkorb
Norwegian Association of the Disabled
Schweigaardsgate 12

0134 Oslo
NORWAY
T: 0047 2 410 2481
F: 0047 2 410 2499
svein.brodtkorb@nhf.no

- 54 Ms Valérie SCHERRER
Handicap International
14 avenue Berthelot - 69361
LYON cedex 07
FRANCE
T: 0033 478 69 67 44
F: 0033 4 72 76 12 67
vscherrer@handicap-international.org
- 55 Ms Venus B Ilagan
International Disability Alliance and Disabled Peoples' International
701 Merchant Square Condominium
1386 E. redriguz Ave. corner
Mobolo Street, 1112 Quezon City
THE PHILIPPINES
T: 00 632 411 9655
F: 00632 412 0506
bbc701@surfshop.net.ph
- 56 Ms Wolmarans Milani
Rehabilitation & Disability Services
Mpumalanga Province, Private Bag X 11285
Nelspruit 1200
SOUTH AFRICA
T: 0027 13 7663293
F: 0027 13 7663472
milaniw@social.mpu.gov.za