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CBR Guidelines

Empowerment component

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Preamble

Empowerment is the final component of the community-based rehabilitation (CBR) matrix and is a cross-cutting theme. While the first four components of the matrix relate to key development sectors (i.e. health, education, livelihood, and social sectors), the empowerment component focuses on the importance of empowering people with disabilities, their family members and communities to facilitate the mainstreaming of disability across each sector and to ensure that everybody is able to access their rights and entitlements.

The word empowerment has different meanings in different contexts and is not easily translated into all languages (*1*). Simple descriptions of empowerment include: having a say and being listened to, self-power, own decision-making, having control or gaining further control, being free, independence, being capable of fighting for one's rights, and being recognized and respected as equal citizens and human beings with a contribution to make (*1,2*).

Many CBR programmes have focused on the medical model, i.e. on the provision of rehabilitation to people with disabilities without asking for anything in return. While this has resulted in positive changes for many people with disabilities, it has also promoted a dependency model – a mindset of giver and receiver. Empowerment begins to happen when individuals or groups of people recognize that they can change their situation, and begin to do so. It is a process that involves things like awareness and capacity-building leading to greater participation, to greater decision-making power and control, and to action for change (*2*).

People with disabilities, their family members and communities are central to CBR. These guidelines encourage and promote a move away from the traditional model of CBR to a community-based inclusive development model. The starting point of any CBR programme should be to facilitate the empowerment of disabled people and their families and communities as this will lead to achievement of goals, outcomes and sustainability.

BOX 1   Malawi

Visible, vocal and active

The Malawi Council for the Handicapped (MACOHA), a subsidiary of the Ministry for Persons with Disabilities and the Elderly (MPWDE), is responsible for implementing the national CBR programme in Malawi. MACOHA works in partnership with other ministries, e.g. those of health, education, finance, economic planning, gender, child development and community development, and also with the Federation of Disability Organisations in Malawi (FEDOMA), Christoffel Blinden Mission (CBM), Sight Savers international, and the Norwegian Association of the Disabled.

The draft CBR guidelines provided the main framework for developing the national CBR programme, along with the Convention on the Rights of Persons with Disabilities and the mandate of the African Decade for Persons with Disabilities. The government of Malawi has endorsed CBR as the preferred approach for reaching people with disabilities across the country. MACOHA is directly responsible for implementing the health, education, and livelihood components of the CBR matrix, while it works with FEDOMA and other nongovernmental organizations, government ministries and disabled people's organizations to implement the social and empowerment components of the matrix.

MACOHA, FEDOMA and partners work directly with people with disabilities at the district and subdistrict levels to empower them. Empowerment begins with a community awareness programme, mobilization of the community, and the organization of disabled people and formation of a disabled people's committee. Representatives of the committee then attend a training workshop to gain greater understanding of the concepts of CBR and mainstreaming, enabling them to negotiate with local authorities and access the benefits of development initiatives. Thus people with disabilities are enabled to access health, education and livelihood opportunities; they are becoming visible, vocal and active, so promoting their participation and equal opportunities, and enhancing their self-confidence.

A recent evaluation by the Norwegian Association of the Disabled indicated that while MACOHA works on all five components of the CBR matrix, its main focus and starting point is "Empowerment of people with disabilities, especially political and economic empowerment". The evaluation found the Malawi CBR programme to be effective and useful because it brings together different ministries, nongovernmental organizations and disabled people's organizations.

Goal

People with disabilities and their family members make their own decisions and take responsibility for changing their lives and improving their communities.

The role of CBR

The role of CBR is to contribute to the empowerment process by promoting, supporting and facilitating the active involvement of people with disabilities and their families in issues that affect their lives.

Desirable outcomes

- People with disabilities are able to make informed choices and decisions.
- People with disabilities are active participants and contributors in their families and communities.
- Barriers in the community are removed and people with disabilities are accepted as people with potential.
- People with disabilities and their families are able to access development benefits and services in their communities.
- People with disabilities and their family members come together, form their own groups and organizations, and work towards addressing their common problems.

Key concepts

Disempowerment

Many people with disabilities experience disempowerment both in the family and the community. They are often strongly supported by their families however they may also be over-protected whereby family members do most things for them, and they may be rejected and excluded from community life because of stigma and discrimination. This means that people with disabilities have very limited opportunities and choices; they become victims and objects of pity, not agents able to make a difference. The negative attitudes and low expectations lead people with disabilities to feel disempowered – to feel unable to do anything or to change their own lives, to feel worthless and incapable, and to have low self-image and low self-esteem. It is this experience of disempowerment that starts the search for empowerment.

Empowerment and motivation

Empowerment is a complex process; it is not something that happens immediately, or that can be given to someone (*2*). Change must start with people with disabilities shifting their mindset from being passive receivers to active contributors. This shift in thinking is important for overcoming the attitudinal, institutional and physical barriers that may be present in the community. CBR programmes can facilitate this process by e.g. raising awareness, providing information, building capacity, and encouraging participation, which can lead to greater control and decision-making. All these components are mentioned throughout these CBR guidelines.

Awareness

Awareness is the level of understanding that individuals have of themselves, their situation and the society in which they live. Raising awareness assists people to recognize that there are opportunities for change (*3*). Raising awareness in families and communities about disability issues and human rights can also help to remove barriers for people with disabilities so they have greater freedom for participation and decision-making.

Information

Information is power, and one of the key activities of CBR programmes is to disseminate information. The poorer the people, the less access they have to basic information about their rights/entitlements; providing information ensures that people are better equipped to take advantage of opportunities, to access services, exercise their rights, negotiate effectively, and hold duty-bearers accountable. It is impossible for people with disabilities to take effective action and bring about change unless they have information that is relevant, timely and presented in forms that they can understand (*1*).

Capacity-building

People with disabilities need a range of skills and knowledge to enable them to participate and contribute meaningfully to their families and communities. Gaining skills and knowledge can lead to increased confidence and self-esteem, which is an important part of the empowerment process.

Peer support

Many people with disabilities feel they are the only ones facing a particular problem, but when they meet people with similar problems they may find that their problems are shared and that there are common solutions. Being together helps to minimize isolation and to increase mutual support (see Self-help groups and Disabled people's organizations, below).

Participation

Being a contributor brings social recognition and is important in the empowerment process. People with disabilities can participate and make positive contributions at many different levels. For example, at a household level they can participate in activities such as caring for family members, herding animals, fetching water, cooking, cleaning; at a community level they can provide peer support to people who have recently experienced disability and participate as members of a group or organization.

Alliances and partnerships

Because their numbers are limited, people with disabilities form alliances and partnerships with others who are working towards the same goals of inclusion and development. Inclusion works well when other groups are involved too – with collective action there is greater community ownership.

BOX 2 Philippines

Myla sets a good example

Myla is from the Philippines and was born with spina bifida. As a young girl she found it difficult to cope with the impact of her impairments on her life. She says "My self-esteem and self-confidence were very low. I always used to ask 'why me?' and even thought about committing suicide. As time went by I learnt to live with my impairments and make use of my abilities. With the assistance of the CBR programme and a scholarship from Simon of Cyrene, I finished high school and an accounting course (in 2007). Then I did a training course on self-enhancement and leadership. Since then my life has changed. I am the core leader of the Albay chapter of disabled people's organizations. My self-confidence and changed way of thinking allowed me to face the reality of my disability. I am now out of my shell and work to motivate others by setting an example. The first great gift we can bestow to others is a good example – disability is not a hindrance in reaching one's goal."

Elements in this component

Advocacy and communication

This element is about self-advocacy, which means people with disabilities speaking out for themselves, and also communication, i.e. the way messages are sent and received, which is important for self-advocacy. Both should be considered when facilitating the empowerment of people with disabilities – they connect disabled people to their families and communities, giving them the power to make choices, express opinions and make

decisions which in turn builds their confidence and self-esteem. CBR programmes play a key role in working with people with disabilities to improve their ability to communicate and engage with others, ultimately leading to their gaining the ability to self-advocate.

Community mobilization

Community participation is critical to the success of CBR programmes, and community mobilization is a strategy which aims to engage community members and empower them for change and action. The strategy is often used in low-income countries to address community development problems, and can be used by CBR programmes to ensure that communities are empowered to address the needs of people with disabilities and their family members.

Political participation

Promoting the participation of people with disabilities in politics is an important approach to empowerment. Decision-making is central to politics, so political participation enables people affected by issues to be at the centre of decision-making and to influence change. There are many different ways in which people can participate in politics, including formal participation (e.g. national and local party politics) and informal participation (e.g. political discussions with friends and family). This element explores practical ways of ensuring people with disabilities and their families are able to influence decision-making and attain equal rights and opportunities.

Self-help groups

Self-help groups are informal groups where people come together to pursue a range of activities and resolve common problems. CBR programmes need to focus their activities beyond the individual, on encouraging people with disabilities and their families to form, join and participate in self-help groups. Participating in self-help groups can improve the visibility of people with disabilities within their communities, provide them with mutual support, encourage them to share resources and find solutions together, and improve their confidence and self-esteem. It is through self-help groups that CBR can achieve some of its goals and facilitate the process of empowerment. This element focuses on how CBR programmes can support and facilitate the formation of self-help groups.

Disabled people's organizations

Just as workers come together in many parts of the world to promote and protect their interests at work, people with disabilities also come together to form "disabled people's organizations" to promote and protect their interests. Disabled people's organizations exist at the regional, national and international level, usually have a formal structure, and engage in a wide range of activities including advocacy and representation. Supporting these organizations is one way to promote the empowerment of people with disabilities. In communities where CBR programmes and disabled people's organizations coexist, they need to work together. Where disabled people's organizations do not exist, CBR programmes are encouraged to support their formation at the community level; this element covers how they can do this effectively.

Advocacy and communication

Introduction

Advocacy has been mentioned as a suggested activity throughout the CBR guidelines. Advocacy can be undertaken in different ways and by different people, e.g. self-help groups or disabled people's organizations might advocate as a group to influence decision-makers to create change and ensure inclusive policies and programmes for people with disabilities. This element however focuses on self-advocacy, meaning individuals speaking up for themselves.

Successful advocacy depends on important messages being communicated and heard. However many people with disabilities experience barriers to communication, so frequently their voices are not heard and they have few opportunities to influence decisions on the issues, policies and services that affect their lives (*4*). The Convention on the Rights of Persons with Disabilities highlights the importance of communication for people with disabilities. Article 9 calls on States parties to ensure that persons with disabilities have access on an equal basis with others to "… information and communications, including information and communications technologies and systems …", and Article 21 confirms the right to "… freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice …" (*5*).

Self-advocacy and effective communication are an important part of the empowerment process for people with disabilities. This element highlights the important aspects of each of these and provides basic suggestions for activities which can be carried out by CBR programmes.

BOX 3 India

Hansa's journey towards a productive life

Hansa was born into a rural family in the remote village of Dhanki in Gujarat, India. Her family were labourers, earning wages on a daily basis. Profoundly deaf, with low vision and an intellectual impairment, Hansa was labelled the "Lord's curse" by the villagers. The family was shunned and their mere presence in the fields or other people's homes was seen as bad luck. As Hansa's family was dependent on the work they found each day for their daily food, this stigma and discrimination became a heavy burden that affected the whole family.

Things began to change for Hansa and her family when a CBR worker trained by Sense International began providing support. During regular visits to Hansa's home, the CBR worker assisted Hansa to begin exploring her environment through games and activities. With time, Hansa began responding and making progress. She learnt how to communicate with sign language, count with beads and do simple arithmetic. She began to help her mother with household chores. A previously unkempt and reclusive Hansa transformed into a well-groomed and confident adolescent.

It took a while for the villagers to change their attitudes, but slowly things began to change. Farmers began to employ Hansa's parents again and they took notice of Hansa's skills and abilities. Hansa is now a farm hand and contributes to her family's income. The family is again invited to social and community events and Hansa has formed a group of friends of her own age.

Goal

People with disabilities are able to speak out for themselves.

The role of CBR

The role of CBR is to assist people with disabilities to develop advocacy and communication skills, and to ensure that their environment provides appropriate opportunities and support to allow them to make decisions and express their needs and desires effectively.

Desirable outcomes

- People with disabilities and their families have improved access to information and communication resources.
- Communication barriers for people with disabilities are reduced and/or eliminated.
- People with disabilities and their families represent themselves in their respective communities.
- CBR personnel are effective communicators and share information with all stakeholders including those who have communication difficulties.

Key concepts

Self-advocacy

What is self-advocacy?

Most people use self-advocacy every day to fulfil their personal needs. Self-advocacy is about people having a voice of their own. It means knowing about their rights and responsibilities, speaking up for their rights, and being able to make choices and decisions about their lives.

Why is it important?

Self-advocacy is an important part of empowerment. Many people with disabilities spend much of their lives not being listened to and being told what to do. Decisions are usually made for them by others. By learning self-advocacy skills, people with disabilities can learn to assert their rights, take control of their lives, and make the best decisions for themselves. Self-advocacy can be as simple as people with disabilities making choices about what to eat and what to wear, or at another level, it may mean that they speak out publicly about issues which are important to them such as commenting about a service they have used.

Effective self-advocacy

Children with disabilities played an important role in negotiations during development of the Convention on the Rights of Persons with Disabilities. In January 2006, during the sixth round of negotiations, a group of children from Bangladesh, China and the United Kingdom went to New York to present their perspectives on why the Convention needed to include specific measures to protect their rights. In a widely circulated written statement, they highlighted the need for recognition of the importance of ending institutionalization, challenging violence and abuse, ensuring access to services and information. At the Convention's signing ceremony in March 2007, two young disability advocates from Nicaragua and Armenia reminded delegates of the need to pay special attention to the situation of children with disabilities in the implementation of the new Convention. The participation of these young people affirmed that children with disabilities can be effective advocates for their own rights and are entitled to be involved in decisions that affect them (*6,7,8,9*).

What support is required?

In many settings people with disabilities experience stigma and discrimination, and it can be very difficult to voice their opinions, wants and needs. Often people with disabilities will need support to learn self-advocacy skills (see Suggested activities). While self-advocacy is the ultimate goal for people with disabilities, in some situations they may request or need the support of an advocate. An advocate might be a family member, friend, member of a disabled people's organization, an advocacy volunteer from the community, or a CBR staff member. An advocate might assist a person with a disability to access information, provide support at appointments and meetings, write letters about important issues and speak on their behalf in difficult situations.

Communication

What is communication?

Communication is the way information and messages are transferred from one person to another and are the means by which social relationships between individuals and communities are built and maintained. There are three key ingredients for effective communication: means, reason, and opportunity.

- The means: refers to how a message is sent. This may occur via spoken or written words, sign language, and/or assistive communication devices. People require access to the means of communication that best suits their needs (see Health component: Assistive devices).

- The reason: refers to why communication takes place. The many reasons include: expression of practical needs, e.g. asking for a drink; expression of thoughts, opinions and feelings; to ask someone their name, to make friends or tell a joke.
- The opportunity: people need frequent opportunities to communicate with others. Many people with disabilities do not have the opportunity to communicate, e.g. children with disabilities are often hidden when visitors come to the family home, an adult who cannot speak after a stroke may be excluded from family decision-making, a deaf person is unable to participate in a council meeting because a sign language interpreter is not available. Limited opportunities can affect the learning and development of communication and other skills.

Even without a voice people can communicate

While the concept of self-advocacy for people with disabilities is about having a voice of their own, it does not necessarily mean literally having a voice. Some people with disabilities cannot talk or communicate easily with others. Physical, auditory, visual and intellectual impairments can affect the way people communicate and the ease with which others are able to understand them. However, it is important to understand that everyone has the ability to communicate even if they do not have the ability to speak – communication does not just include the spoken word.

A person with a disability can still express his/her likes and dislikes, wants and needs, in ways other than words. Communication also includes "… display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology" (*5*) (see Health component: Assistive devices).

BOX 5 Viet Nam

Trang learns to communicate

Trang is 14 years old and lives with his family in a remote hill village. Trang has cerebral palsy, which has resulted in a communication impairment. His family and friends are unable to understand his speech and he is unable to use sign language as his motor movements are uncoordinated. Most people think Trang has an intellectual impairment because of his limited communication skills. Trang's aunt approached the CBR programme and asked for help. CBR personnel helped create a communication board, which contained pictures of the most important activities and items in Trang's life. Trang now uses this board as well as pointing with his eyes to express his needs and exchange information and converse with his family and friends. CBR personnel have also encouraged his family to start teaching Trang to read.

Communication barriers

Self-advocacy also means that people with disabilities need to be listened to, and it is important to identify barriers to communication. There are four major barriers: physical barriers, e.g. long distances or environmental distractions, barriers of meaning, e.g. the use of complex words and specialized vocabulary, attitudinal barriers, e.g. avoidance of communicating with someone who has difficulty expressing her/himself, due to impatience and arrogance, and positioning of information e.g. inappropriate timing or too much information. For communication to be effective, it is important to identify those barriers which are present and take steps to overcome them.

Suggested activities

To support self-advocacy and develop effective communication to empower people with disabilities, CBR personnel need to address not only the individual and the environment, but also their own ability to communicate.

Carry out a basic communication assessment

Resources, such as *Let's communicate: A handbook for people working with children with communication difficulties* (*10*), can provide comprehensive information about communication assessment. Some basic considerations when assessing the quality of communication are as follows.

- What method/s of communication is/are currently being used?
- How well are they being used? (consider the skills of people both with and without disabilities).
- Is the communication system understood by everyone?
- Does the nondisabled person really understand the needs of the person with disability?
- Who does the person with disability usually communicate with?
- Why is the person with disability communicating? Is it to join in, express a practical need, and/or express his/her feelings?
- What kinds of opportunities to communicate does the person have? Does he/she have many people to talk to or is he/she left alone?
- Are there any other barriers to good communication?
- Does status, power and role influence communication? For example, does the woman with disabilities talk in front of the man? Is the family embarrassed to let their disabled family member communicate?

Provide support to develop communication skills

CBR personnel will need to work closely with people with disabilities and their families to ensure that they are able to develop communication skills. Support will be based on individual needs and circumstances and may be provided directly by CBR personnel or by others. Again resources, such as *Let's communicate,* will provide many helpful suggestions. Following the identification of people with communication impairments, CBR personnel may:

- facilitate referrals to specialist services where they exist, e.g. speech and language therapy;
- ensure families are aware that speech may not be possible for some people and provide information about other forms of communication, e.g. sign language, communication boards;
- ensure access to assistive communication devices where required; this may involve showing families how to make devices (see Health component: Assistive devices);
- ensure that people who require hearing aids are provided with appropriate information about availability, fitting, care and use;
- teach sign language or provide information about where to access sign language instruction;
- encourage inclusion of people with communication difficulties in everyday activities and experiences (e.g. visits to the market, cooking, cleaning, fetching water) and teach simple words, phrases and gestures that can be used in the community;
- link people to groups/clubs which provide opportunities for social interactions, e.g. deaf clubs, stroke clubs, sports clubs for people with disabilities, inclusive playgroups.

BOX 6

Stephanie hears a new world

Children who have hearing impairments may need hearing aids to help them communicate with their families, friends and teachers. CBR programmes can provide assistance in accessing aids, and provide instruction in how to use and maintain them. CBR programmes may also find out whether low-cost batteries are available and promote the use of sign language if appropriate.

Stephanie's hearing impairment went undetected for many years. She lived in virtual isolation, communicating only with her mother. A volunteer doctor from a local CBR programme identified that her hearing loss was the result of a chronic ear infection. She was provided with treatment for the infection and later fitted with a hearing aid. Stephanie started going to primary school, which opened up many new horizons for her. She is no longer isolated, and interacts with her friends on a daily basis.

Address communication barriers

CBR programmes can help reduce or remove communication barriers in the environment by:

- encouraging positive attitudes in the home environment to maximize communication opportunities for children and/or adults with disabilities;
- identifying key people with whom people with disabilities can communicate, and who are interested in what people with disabilities have to say;
- sharing information with others about people's preferred means of communication; it is important to develop a means by which people with disabilities can do this independently, e.g. a CBR programme could develop a "my communication sheet" for a person with a disability which tells others about the best way to communicate with him/her;
- teaching family and community members communication strategies that may be useful for people with disabilities, e.g. allowing extra time for communication, and using simple language, gestures, signs, drawings or Braille;
- providing suggestions about how the environment might be adapted to maximize communication, e.g. a quiet space to talk for a person with a hearing impairment, adequate light for a person who lip-reads;
- promoting the development of a pool of trained sign language interpreters – it may be helpful to partner with a disabled people's organization to do this;
- using public meetings or the media to increase community awareness about the challenges faced by people with communication problems;
- together with disabled people's organizations, promoting the need for and use of accessible information and communication formats in all activities, such as training, community events and development programmes.

Philippines

Signing for a better future

On the island of Bohol in the Philippines, the local CBR programme introduced basic sign language training for people with hearing impairments, their families and community members. In 2008, over 200 community members, ranging in age from eight to 68 and from all walks of life, learned to sign, and have now gone on to teach sign language to their families and friends. This initiative aims to raise awareness about deaf culture and encourage people to respect and communicate with deaf people.

At the end of one of the four-week training courses, the trainers (mostly deaf adults) were invited to conduct similar sign language training programmes at the local university. The university paid them to conduct these training programmes. Three of the most outstanding university students have now joined the CBR project as teachers of deaf high-school students.

Provide support for self-advocacy

CBR programmes should:

- remember to ask people with disabilities what they want;
- provide people with information about their disability;
- teach people about the social model of disability;
- provide information to people with disabilities about their rights and responsibilities;
- include people with disabilities in decision-making for the CBR programme;
- provide people with information about the services that exist in their communities;
- link people with disabilities to self-help groups and disabled people's organizations where they exist in the community.

Ensure CBR personnel are effective communicators

To support people with disabilities through advocacy activities, CBR personnel need to be effective communicators. CBR personnel are required to interact with people from many different backgrounds and walks of life, and need to be able to communicate information clearly, especially when topics are difficult or sensitive, where there are class or status differences, where a common language is not shared, or where there are differences in literacy level. CBR personnel need to:

- encourage a communication-friendly environment and support people with communication difficulties to express themselves;
- speak the same languages and dialects as the local communities;
- know the local sign language, and how to use alternative ways of communicating;
- understand and respect local cultural, class and caste differences, and be a good role model by communicating respectfully with people with disabilities, women and other marginalized groups;
- communicate regularly with various stakeholders in the health, education, livelihood and social sectors, and facilitate dialogue during stakeholder meetings;
- know how to use the media for communicating with the public.

Community mobilization

Introduction

Community mobilization is the process of bringing together as many stakeholders as possible to raise people's awareness of and demand for a particular programme, to assist in the delivery of resources and services, and to strengthen community participation for sustainability and self-reliance. A lot can be achieved when people from different parts of the community share a common goal and actively participate in both identifying needs and being part of the solution. Community mobilization helps to empower communities and enable them to initiate and control their own development.

Little progress will be made towards mainstreaming disability until community support is built up and the different sectors of society become actively involved in the process of change (*11*). CBR programmes can use community mobilization to bring together stakeholders in the community, e.g. people with disabilities, family members, self-help groups, disabled people's organizations, community members, local authorities, local leaders, decision- and policy-makers, to address barriers within the community and ensure the successful inclusion of people with disabilities in their communities with equal rights and opportunities.

This element focuses on how CBR programmes can bring people together to act and bring about change in the communities in which they operate.

Fig 1: Four steps of community mobilization

1. Bringing people together

Self-reliance and Sustainable programme

4. Facilitate and strengthen community participation

2. Raise people's awareness

3. Assist in the delivery of resources and services

BOX 8 Colombia
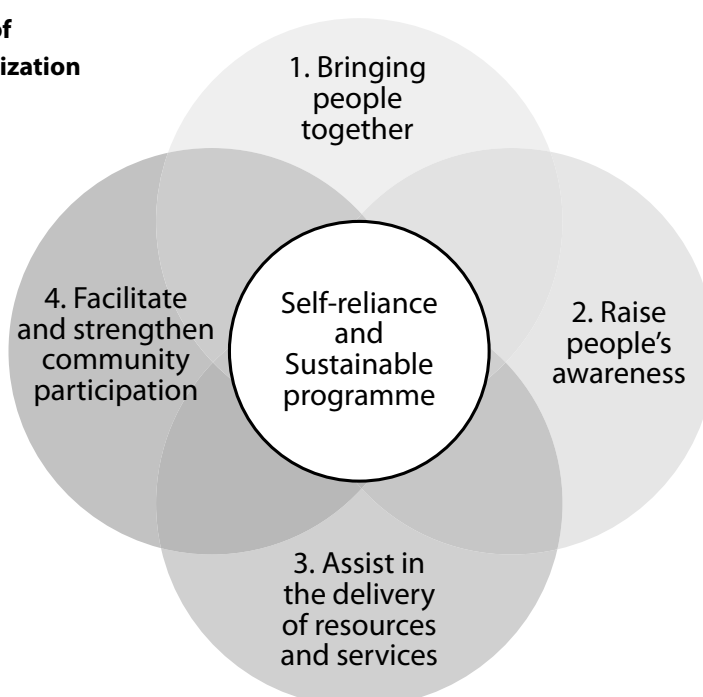
Empowerment through leadership roles

In Colombia, many municipalities run CBR programmes which are funded and managed by local government. In 2002, after a few years of experience, one local government, realizing that many of its programmes were not sustainable and lacked community ownership, helped to establish a pilot project, FUNDISCA (Foundation of the Disabled – Caucasian), in the municipality of Caucasia, north of Colombia.

The key objective of FUNDISCA was to facilitate the empowerment of people with disabilities by allowing them to assume leadership roles within the CBR programme and to play an active role in planning and controlling their own lives. FUNDISCA mobilized many people in the community to come together and support the programme, including people with disabilities, parents, caregivers, displaced individuals, indigenous people, community members and community leaders.

FUNDISCA now has 218 members and has engaged 20 volunteers who work as CBR personnel. These CBR personnel are primarily responsible for identifying people with disabilities and providing them and their families with the necessary support. They work to promote self-esteem, family inclusion, and access to services in the health, education, labour and employment sectors.

FUNDISCA has experienced several setbacks, e.g. some members putting their own interests before the group's interests, limited availability of resources for addressing disability issues at municipality level, and institution/service providers often demonstrating limited sensitivity regarding disability issues.

However, with time and effort FUNDISCA has overcome these difficulties and has become a dynamic and well-established foundation. Because of its continuous community mobilization strategy, FUNDISCA has stimulated the community to become interested and involved in disability activities. It has brought people with disabilities and their communities closer together, and encouraged community leaders to become advocates for disability issues with the local authorities.

Goal

Local communities are empowered to remove barriers for people with disabilities and their families, and play an active role in facilitating the inclusion of people with disabilities and their families in community activities.

The role of CBR

The role of CBR is to mobilize the community to ensure that negative attitudes and behaviours towards people with disabilities and their families change, that the community is supportive of CBR programmes, and that disability is mainstreamed across all development sectors.

Desirable outcomes

- Communities are aware about the needs, and motivated to improve the quality of life, of people with disabilities and their family members.
- Barriers in the community are reduced or removed for people with disabilities and their family members.
- Communities are knowledgeable about CBR and how community resources can be used to develop and sustain CBR programmes.
- Communities participate in planning, implementing and managing CBR programmes.

Key concepts

Definition of "community"

The title *community-based rehabilitation* already suggests that the community plays a key role in any CBR programme. A "community" can be described as people living together in some form of social organization and cohesion. However, generally communities are not homogeneous, and their members often have different political, economic, social and cultural characteristics, interests and aspirations (*12*). For example, in a "traditional" rural community, members may belong to different ethnic groups, speak different languages, have different religious beliefs and engage in different cultural practices.

Community stakeholders

Communities consist of different people, groups and organizations, many of whom are important stakeholders for CBR programmes. These include people with disabilities and their family members and neighbours and friends, schoolteachers, self-help groups, disabled people's organizations and local authorities. The Management chapter (introduct-

ory booklet) provides more detailed information on stakeholders, including a summary of their key roles and responsibilities. Note that within each community, some stakeholders are more influential than others (e.g. tribal, religious or political leaders) and have more power to make decisions about issues that concern the community.

Disability as a community issue

Community development issues that relate to health, education, water and sanitation, housing, transportation and the environment, all have an impact on the incidence and prevalence of disability (see Health component). So disability is an important issue within communities, yet it is most often ignored.

In many communities there are barriers which impact on the quality of life of people with disabilities and their family members. These include physical/environmental, attitudinal, cultural, and services, system and policy barriers. More detailed accounts of the different types of barriers that people with disabilities and their family members may encounter are given in the different components of these guidelines. It is important that CBR programmes are able to identify and understand the barriers in each community which impact most on people with disabilities and their families.

Community mobilization

Within the development sector there is a strong focus on communities taking a lead role in development activities rather than just being the receivers of grants and services. The community is seen as the best judge of its own problems, and to have the ability to undertake appropriate action to solve these problems. CBR is a strategy for community-based inclusive development so the importance of community participation is acknowledged, e.g. communities are listened to and directly involved in decision-making and activities that affect their lives (see Introductory booklet).

Community mobilization is a strategy that CBR programmes can use to help make disability everyone's business, and not only that of disabled people. It is a strategy that can be used by CBR programmes to engage community stakeholders in CBR activities towards inclusive development. When CBR programmes involve communities in their work it is more likely that the benefits for people with disabilities and their family members will continue even after funding and support may have ended.

BOX 9 Ethiopia

Building bridges to motivate communities

In the Adaama province of Ethiopia, a CBR worker noticed a bridge across a river was broken. It was difficult for people with disabilities to use this bridge, and many others also experienced difficulties, for example, a young boy broke his arm while trying to pass over the river. The CBR person contacted the school and the local government authority, and formed a committee to improve accessibility of the area. This committee mobilized the community to contribute money and also physical labour. A new bridge was eventually built in partnership with the local government, which facilitated the construction process. After the new bridge was completed, the local government was motivated to do more for people with disabilities and decided to make improvements to the local school to provide increased access for children with disabilities. The CBR programme realized that the community is a great resource and can be encouraged and motivated to improve their living conditions. Even with few resources, many things can be achieved, especially when the community owns the idea.

Suggested activities

As community mobilization is a continuous process, this element does not provide a step-by-step guide, but suggests activities that are very broad and organized around key headings. Many of the activities are common to other sections of these guidelines, particularly the Management chapter.

Find out about the community

To mobilize a community to address disability issues and support the development and implementation of CBR, it is necessary to become knowledgeable about the community. The CBR programme must develop an understanding of the context in which people live, e.g. of the physical, economic, social, political and cultural context, and the issues and problems faced by the community. A situation analysis is an effective way to do this, and a detailed description of a situation analysis is provided in the Management chapter.

Identifying power structures in the community is an important activity for community mobilization. People in official positions of power, e.g. local government leaders, leaders of community groups and organizations (self-help groups, disabled people's

organizations) need to be identified, as well as others in the community who may have influence in the different development sectors (such as teachers in the education sector). It is important for CBR programmes to learn about these power structures because people with power and influence have the ability to mobilize others to support initiatives in the community.

It is also important when learning about the community to find out about the current attitudes and behaviours directed towards people with disability and their family members. People's behaviour towards others often reveals their attitudes; by observing their behaviour, it is possible to perceive whether they are disrespectful, patronizing, oppressive, or neglectful.

Build trust and credibility within the community

It is important that CBR programmes take the time to establish trust and credibility with stakeholders in the community. CBR programmes should:

- ask permission from local leaders to work with the community;
- be visible and active in their communities and support the activities of other stakeholders;
- make contact with many different stakeholders in the community in order to get to know them, begin to understand their problems, and work out the best ways to work with them;
- regularly share important information and updates about the CBR programme;
- be honest and transparent and not make promises to the community that cannot be met.

Raise awareness in the community

To successfully mobilize a community and gain support for disability initiatives, community members must first develop awareness about disability and begin to understand why it matters and what action they can take. Many community members will have limited knowledge about disability and as a result will have negative attitudes and behaviours towards people with disabilities; disability may merely be perceived as a health issue, and approached with pity and stigma.

There are many different ways to teach and create awareness about disability in the community. For example CBR programmes could use group discussions, roleplays, flashcards, storytelling and songs, drama, puppet shows, posters, films and radio.

There are important things to remember when raising awareness about disability in the community, such as:

- messages must be simple;
- the methods used should be appropriate to the local culture;
- awareness-raising activities will have a greater impact when people with disabilities are directly involved in implementing them;
- attitudes and behaviours take time to change and is an ongoing process.

Kenya

Changed attitudes

Kalume is a young boy with epilepsy who lives with his family in a rural Kenyan community. Kalume has a mobility impairment as a result of leg contractures that developed after he had a seizure near a fire and was burnt. Many of his skills, e.g. communication skills, were delayed because he was hidden and isolated. Kalume's family were considered outcasts in the community because of his disability and as a result they found it very difficult to meet even their basic needs.

Kalume was identified during a disability survey conducted in the district. A CBR worker took Kalume to a health centre so he could get medication to control his seizures. Arrangements were made by the Kenya Medical Research Institute (KEMRI) in collaboration with the Association of People with Disabilities Kenya (APDK) to access surgery for Kalume so his contractures could be corrected. Kalume also received basic therapy to improve his skills. Follow-up with Kalume and his family was conducted every month in the community by KEMRI fieldworkers.

The community was also sensitized on disability including the possible causes, through the chief's *barazas* (gatherings). KEMRI staff helped the community to understand that epilepsy is not contagious and that witchcraft does not bring disability, and that it is the responsibility of every community member to support children with disabilities and their families. Regular communication with community members helped to change attitudes towards people with disabilities and their families, and some members of the community even made a house for Kalume's family.

Motivate the community to participate

It is important that CBR programmes motivate community stakeholders to address disability issues and work towards inclusive development. Different stakeholders within the community will need to be approached and motivated to encourage their participation in community action and change. CBR personnel need to convince stakeholders that CBR is a strategy which can ultimately benefit the whole community, not just people with disabilities. Sensitizing and orienting community members to the CBR strategy (concept, philosophy, goal, purpose) and to how it can assist the community is therefore an important activity.

Understanding what motivates community stakeholders is critical. In the early stages of community mobilization it may be necessary to provide incentives to increase the interest and motivation of stakeholders (*11*). However, it is suggested that CBR programmes work to ensure that people understand the value of their participation and the satisfaction they can gain through participating, rather than provide incentives or rewards. CBR programmes could, for example, invite key stakeholders in the community (community leaders) to observe CBR activities or organize field visits to other communities where CBR activities are working well.

Create opportunities for community participation

Communities consist of many different stakeholders, with different opinions, ideas, priorities and agendas. For community mobilization, it is not necessary to approach all the stakeholders at the same time; different sections of the community can be mobilized at different times to participate in different aspects of the CBR programme.

Stakeholders can be invited to participate in different CBR activities in the community, e.g. in a situation analysis to help raise awareness about community needs, rights, resources, capacities and roles (see Management chapter).

CBR programmes need to identify barriers that may prevent community stakeholders from participating, and to work with these stakeholders to overcome the barriers. Barriers to participation may include time constraints, cultural limitations, family responsibilities, work responsibilities or low self-esteem.

Bring relevant stakeholders together

It is important to bring stakeholders together to initiate the discussion and negotiation required for action and change. Organizing regular meetings with the different stakeholders in the community is a good way to do this. The balance of power must be taken into account in the meetings, to ensure that vulnerable groups are not excluded and disempowered.

Build capacity in the community

Community members play a vital role in CBR programmes and it is necessary to consider what training they might need to upgrade their skills and knowledge. Capacity-building is not discussed in detail here as it is included in the Management chapter.

Celebrate achievements

To ensure the continued motivation and participation of community stakeholders, it is necessary to recognize their contributions and achievements. Celebrations can re-energize the community, attract further interest from both within and outside the community, and build support for CBR programmes and inclusive development.

Political participation

Introduction

A narrow definition of politics refers to the activities of governments, politicians, or political parties. A broader definition includes the interrelationships between people – between men and women, parents and children, people with and without disabilities – and the operation of power at every level of human interaction.

Political participation includes a broad range of activities through which people develop and express their opinions on the world and how it is governed, and try to take part in and shape the decisions that affect their lives. These activities range from developing thinking about disability or other social issues at the individual or family level, joining disabled people's organizations or other groups and organizations, and campaigning at the local, regional or national level, to the process of formal politics, such as voting, joining a political party, or standing for elections.

Ordinary people can participate in politics, and every individual has the right to participate, including people with disabilities. The Convention on the Rights of Persons with Disabilities, Article 29 on participation in political and public life, mandates that "States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others" (*5*).

People with disabilities face many barriers to political participation, and many choose not to participate in politics because the issues that concern them are often ignored and/or they feel they have limited power to influence change and decision-making. Promoting political participation for people with disabilities is an important part of the empowerment process. Until more people with disabilities participate, their voices will not be heard and their right to equity and access to the health, education, livelihood, and social sectors will be restricted.

BOX 11 Uganda

The Gulu experience

The National Union of Disabled Persons of Uganda (NUDIPU) was formed in 1987 to advocate for the equalization of opportunities for people with disabilities, and for their involvement and participation in the policy, planning and implementation of disability programmes in close partnership with the government, civil society and the general public. After many years of political lobbying by NUDIPU, people with disabilities are now represented by five parliamentarians, and also by many councillors in local governments at district and subcounty levels.

Like many countries, Uganda has laws which relate to people with disabilities including the: Council for Disability Act 2003, Policy on Disability 2003, Persons with Disabilities Act 2006, and Equal Opportunities Act 2007. The Act of 2006 outlines provisions for accessibility and penalties for those who do not adhere to the law.

Similar laws exist in many countries, but often implementation is poor and the public unaware of the existence and implications of the laws. NUDIPU believes that "If users don't come out to claim/demand their rights, then the related acts may remain on paper and the intended users may never benefit".

The Centenary Rural Development Bank Ltd in Gulu, Uganda, was not accessible for people with disabilities. The building had several steps which made it difficult for people with mobility impairments, particularly wheelchair users, to enter. NUDIPU discussed this issue with the bank, but the bank refused to modify the building entrance to make it accessible.

The Persons with Disabilities Act 2006 states that "It shall be the responsibility of all organs in public and private institutions to provide suitable access for persons with disabilities and universal standard designs for toilets". NUDIPU took the matter to court and, after a series of hearings, the judge ruled in favour of NUDIPU, directing the Bank to make their building accessible and cover all the court expenses incurred by NUDIPU. As a result of the court case, Centenary Bank management directed all branches throughout the country to ensure their premises were accessible for people with disabilities.

The Gulu experience sets a good example for the disability movement. People with disabilities and their family members need to have political awareness to achieve their rights. It has also proved that people must be mobilized and organized in order to advocate for their rights and bring about change in their communities.

Goal

People with disabilities participate in political and public life on an equal basis with others.

The role of CBR

The role of CBR is to ensure that:

- people with disabilities and their families have the information, skills and knowledge to enable them to participate in politics, and have access to opportunities to participate;
- disability issues are visible so that they are integrated into political decision-making and are at the centre of development policies and programmes.

Desirable outcomes

- CBR personnel have increased awareness of the political system.
- People with disabilities and their family members have increased political awareness.
- Governments and civil society are aware of disability issues and the rights of persons with disabilities and their families to participate in political processes.
- Barriers which prevent the participation of people with disabilities and their families in political processes are reduced or removed.

Key concepts

Power and decision-making

Power is the ability to make informed choices and the freedom to take action. Decisions are made by people with power, and in all societies there are some people who are more powerful than others because of factors, such as age, gender role, ethnicity, political affiliation, economic situation (*13*). Power is present at every level of society, from the family through to government level – understanding who has the power to make decisions and why they have this power is an important first step in political participation.

Barriers to political participation

The barriers to political participation that people may face are similar to the barriers mentioned in other components of the CBR guidelines. In summary they include the following.

- Poverty – poor people are mostly focused on survival activities; their basic needs often need to be met first before they can participate, so they may have limited time or interest.
- Education – without information and knowledge, meaningful participation in politics can be difficult.
- Social isolation – there is a limited network to support and encourage political participation.
- Personal factors – people may have limited confidence or motivation to participate.
- Stigma and discrimination – majority groups may have prejudices, fears and discomfort towards people with disabilities and therefore may not support their participation.
- Lack of disability-friendly processes – access barriers can make it difficult for people with disabilities to participate, e.g. inaccessible voting booths.
- Lack of role models – in many countries or communities there are few examples of people with disabilities in high profile political positions.
- Legal barriers – in many countries people with disabilities are not permitted to vote, e.g. people with mental health problems.

It is essential that CBR programmes are realistic about the level of participation that is practically possible for people with disabilities living in poor communities, and that activities are designed taking potential barriers into account.

Disability as a political issue

Many of the disadvantages that people with disabilities and their family members face are because governments and policy-makers do not address some of the main problems of disability, e.g. the social barriers and discrimination. The needs of people with disabilities are rarely at the top of the policy agenda, especially in places where resources are limited. As a result, there are very few inclusive mainstream programmes and disability-specific services. Where disability is addressed in policies, implementation is often poor and as a result there are still many barriers in society for people with disabilities.

Government

A practical understanding of how the government works, e.g. knowledge about political structures and processes, knowing how power flows through them, and an understanding of how to influence them can be useful for advocacy to build alliances and influence change. There are generally three branches to government: the legislative branch (i.e. parliament/assembly), the executive branch (i.e. government and civil service), and the judicial branch (i.e. the courts). Countries are divided into administrative areas and there are different levels of government, e.g. at local, district, regional and national levels. At each level these branches may have democratically elected legislative bodies who pass laws. The legislative branch is elected by local people. At the most local level, this may be the village council, then the district or regional assembly, and then the national assembly/parliament.

Political quotas

To ensure political representation, many countries have reserved a percentage of seats on elected bodies at the local, regional and national levels and/or a percentage of government jobs for marginalized groups, e.g. women, ethnic minorities, people with disabilities. These are referred to as "quotas", "affirmative action" or "positive discrimination".

Suggested activities

Ensure CBR personnel develop awareness of the political system

CBR programmes need to have a practical understanding of how the government works to enable them to build partnerships and influence change. They could develop this awareness by:

- identifying key legislation and policies that are related to disability and the development sectors;
- researching the role of the government and the responsibilities of each department – which department is responsible for what and who has the power to make decisions;
- finding out about the political structure at the local level, how government decisions filter down to this level and if there is local power for decision-making;
- meeting with political representatives regularly, including representatives of the opposition, regardless of personal affiliations; CBR programmes need to be nonpartisan, i.e not subscribe to, or be thought to subscribe to a particular party or power-base.

Facilitate development of political awareness

Many people, including people with disabilities, and especially the poor, may have low levels of political awareness, e.g. they may not know how to vote or may be unaware of the existence of national laws regarding disability rights or international conventions, such as the Convention on the Rights of Persons with Disabilities. To encourage political participation, CBR programmes can:

- encourage adults with disabilities to join literacy programmes (see Education component);
- ensure people with disabilities have access to advocacy and rights-based training;
- link people with disabilities to self-help groups and disabled people's organizations, where they can learn useful skills for political participation, e.g. public speaking, problem-solving, campaigning;
- ensure children and adolescents are included in activities where they have the opportunity to express their opinions, think and make decisions, and understand the consequences of their actions.

Raise disability awareness within the political system

Quite often discrimination and exclusion of people with disabilities is due to ignorance and lack of knowledge at government level. Therefore another part of the strategy towards enabling people with disabilities to participate in politics is to develop disability awareness within political systems. Suggested activities include:

- making local political representatives and bureaucrats aware that legislation related to disability exists;
- conducting disability-awareness training with local councils – it is important that people with disabilities take leadership roles in this training;
- involving political leaders and representatives in activities carried out by CBR programmes and people with disabilities, e.g. invite them to attend the inauguration of a new CBR programme or events celebrating the International Day of Persons with Disabilities – political leaders and representatives will want to be seen as contributors to the well-being of their constituents, and CBR programmes need to take advantage of this.

Facilitate access to political processes

CBR practitioners need to understand the numerous barriers to political participation, and in partnership with self-help groups, disabled people's organizations and others, can work to ensure that these barriers are reduced and/or removed. Suggested activities include:

- providing recommendations to local authorities about making voting sites and procedures accessible to people with disabilities when elections are being planned – this includes ensuring buildings are physically accessible and voting materials are easy to understand and use by people with a range of impairments;
- encouraging national electoral commissions and advocacy organizations to inform voters with disabilities about their voting rights and what assistance is available to enable them to participate;
- encouraging political leaders and parties to develop accessible propaganda material and to depict voters with disabilities on these materials;
- investigating transport options for people with disabilities, particularly those with mobility impairments, to enable them to reach voting venues;
- identifying the political seats/government jobs that are reserved for marginalized groups and encourage people with disabilities to take advantage of these positions.

BOX 12 Ghana

Enabling the blind to vote

The International Foundation of Electoral Systems (IFES) was awarded a grant from the Finland Ministry for Foreign Affairs to design and pilot-test a ballot in Ghana that would enable blind voters to vote secretly and independently. As in most low-income nations, Ghanaian voters who are blind rely on assistants to help them vote. The ballot that was pilot-tested did not use Braille, but instead relied on tactile cues, as less than 1% of blind adults in Ghana are literate. The ballot was tested in elections in 2002, and was designed in collaboration with the Ghana Electoral Commission, the Ghana Federation of the Disability Associations, and Action on Disability and Development of Ghana (*14*).

Self-help groups

Introduction

Self-help groups are informal groups of people who come together to address their common problems. While self-help might imply a focus on the individual, one important characteristic of self-help groups is the idea of mutual support – people helping each other. Self-help groups can serve many different purposes depending on the situation and the need (*15*). For example, within the development sector, self-help groups have been used as an effective strategy for poverty alleviation, human development and social empowerment (*16*), and are therefore often focused on microcredit programmes and income-generating activities (see Livelihood component).

Over the past 20 years, self-help groups have been used in various forms in the disability sector, and self-help groups of people with disabilities and their families are engaged in a whole range of activities including health care, rehabilitation, education, microcredit and campaigning. Self-help groups can facilitate empowerment; belonging to a group (or organization) is one of the principal means through which people with disabilities can participate in their communities (see Disabled people's organizations), and it is through the involvement in groups that they can begin to develop their awareness and the ability to organize and take action and bring about change (*2*).

While many CBR programmes focus their activities at the level of the individual, e.g. on providing direct assistance, such as basic therapy, they are encouraged to bring people with disabilities and their family members together to form self-help groups to address and resolve their own problems. Self-help groups are a key element of the CBR matrix and can be a means to achieving the newly emerging CBR goals of inclusion of and ownership by people with disabilities, and to enhance their participation in development processes (*15*). This element mainly focuses on how CBR programmes can facilitate the formation of new self-help groups, but it also looks at the linking of CBR programmes with existing self-help groups of people with disabilities and their families, including mainstream self-help groups.

BOX 13 Viet Nam

Self-help groups for landmine survivors

The Landmine Survivors Network (LSN) started working in the Quang Binh Province of Viet Nam in 2003, where the network has helped establish 15 self-help groups for landmine survivors. Many of these survivors have injury related impairments but a unique characteristic of the groups is that they also include people with disabilities unrelated to conflict. These groups aim to facilitate the process of self-empowerment by overcoming social exclusion, enhancing participation in decision-making processes and improving quality of life. The ultimate goal of LSN-Viet Nam is to have a self-help group in each commune.

Outreach workers from LSN-Viet Nam, many of whom have a disability, are responsible for supporting communes that have expressed an interest in forming a self-help group. These workers start by fostering collaborative relationships with the local authorities as well as with major representative organizations such as the Farmers' Association, the Women's Union and the Veterans' Association. They provide training on the concept of self-help groups for the organizing group and guidance on the legal steps associated with registration of the group with the local authorities, and arrange initial stakeholder meetings.

Once groups are formally registered and formed, they are run independently by the members. Outreach workers provide ongoing support where required. For example, they may provide training for group members on disability issues and/or group facilitation (e.g. how to chair meetings). Group members are responsible for directing activities which may include: inviting representatives from local authorities to discuss health services for people with disabilities, working with local authorities to improve the quality and accessibility of health services for people with disabilities, organizing local sports events, participating in national sports events, providing peer education on health care and treatment, creating small business ventures and work opportunities, and promoting a positive image of people with disabilities in the local community. Many self-help groups have assumed responsibility for the National Day of People with Disabilities in Viet Nam by setting the agenda for the day and leading public celebrations.

One of the greatest achievements of the self-help groups is the impact they have had on raising the awareness of local authorities about the needs of people with disabilities and the important participatory role people with disabilities can play in addressing their needs. The next step is to bring all self-help groups together under one umbrella.

Goal

People with disabilities and their family members participate in groups to resolve common problems, enhance their individual strengths, and improve their quality of life.

The role of CBR

The role of CBR is to provide support and assistance to people with disabilities and their families to form new self-help groups or sustain existing ones. Where mainstream groups exist within communities, e.g. women's groups and microcredit groups, the role of CBR is to promote the inclusion of people with disabilities and their family members in these groups.

Desirable outcomes

- Self-help groups exist within local communities for people with disabilities and their family members.
- Self-help group members develop knowledge and skills that enable them to become contributors in their families and communities.
- People with disabilities and their family members are able to access mainstream self-help groups that are available to other members of the community.
- Self-help groups promote CBR, and members become involved in the planning and implementation of CBR programmes.
- Self-help groups join together to form federations and become self-sufficient.

Key concepts

Self-help groups

Characteristics

Some common characteristics of self-help groups that are associated with CBR programmes include their:

- voluntary nature – they are run by and for group members, have regular meetings, and are open to new members (*17*);
- generally being formed in response to a particular issue, e.g. no access to education for children with disabilities, limited income-generating opportunities;
- clear goals, which originate from the needs of group members and are known and shared by all members (*15*);
- informal structure and basic rules, regulations and guidelines to show members how to work effectively together;

- participatory nature – involving getting help, sharing knowledge and experience, giving help, and learning to help oneself (*18*);
- shared responsibility among group members – each member has a clear role and contributes his/her share of resources to the group;
- democratic decision-making;
- governance by members, using an external facilitator only if necessary in the formation of the group (*15*);
- evolution over time to address a broader range of issues;
- possibility of joining together to form a federation of groups across a wider area.

BOX 14 Ghana

Self-help groups provide livelihoods

In Kodobeda, Akwapim South District of the Eastern Region, Ghana, four people with disabilities decided to form a self-help group to improve their economic situation. At a meeting with the chief and elders of the village, they asked to be given three female goats to help them start an animal husbandry initiative. It was agreed, and the group started their initiative. The goats soon gave birth. The young goats were given to one member to rear, whilst the original goats remained with the first member of the group. When the goats gave birth again, the kids remained with the member and the original goats were sold, and the money used to buy another goat for the next member. The process went on until all the members had goats to rear and were able to earn enough to sustain themselves.

Membership

Group members are volunteers, in the sense that they are not paid, but they work systematically and regularly to change their own situation through mutual support. Within the context of CBR, self-help groups usually comprise people with disabilities and their families. These groups are usually small, consisting of only a few people, but over time may grow and include 7–30 members. Small groups enable effective participation of all members in discussions and decision-making, whereas larger groups may have more power and influence.

Facilitation and leadership

CBR personnel may be required to take on a facilitator role, particularly when new self-help groups are being formed. CBR personnel can provide guidance to ensure chosen leaders do not dominate the group; they can prevent the hijacking of benefits by some

individuals, keep the group motivated, and provide training on different aspects of group functioning (*15*). It is not necessary to be a person with a disability to work with people with disabilities, but the shared experience of discrimination may strengthen understanding and empathy between an external facilitator and a group. A facilitator with a disability may also be a role model for people with disabilities in the group.

Promoting self-help groups

The CBR project in the Tibet Autonomous Region, People's Republic China, works with parents of children with disabilities to discover new ways of responding to their children's needs. These parents identified that prejudicial attitudes and discriminatory behaviour directed towards their children was a priority issue because it prevented their children from attending school, and it was uncomfortable taking their children into the community. CBR personnel, who had previously been introduced to the concept of self-help groups, saw the potential benefit that a self-help group would have for this group of parents.

A couple of parents decided to create a self-help group and started by focusing on raising public awareness about disability. They held these awareness sessions in local tea houses. As the parents came to rely upon one another, and drew increasing comfort from sharing their similar experiences, the group grew from two to 12 members. The community was positive and slowly their attitudes began to change, with many community members offering support, e.g. through donating wheelchairs, during these awareness sessions. This was a great source of encouragement. Many children with disabilities also started attending schools and families are now accepted and included in community activities.

The self-help group has slowly branched into other activities with the support of the CBR programme. It has opened a teahouse, dedicating the profits to poorer families who have members with disabilities. The CBR programme provided the initial grant and business training. The self-help group has also started visiting families at home to provide assistance when they are finding it difficult to follow their child's rehabilitation plan, due to low educational levels or work obligations. The CBR programme provided training for self-help group members on simple rehabilitation activities to promote child development and CBR personnel accompany them on home visits, to slowly build their capacity and confidence levels. The success of this self-help group has inspired others to form similar groups.

Challenges of organizing self-help groups

Rural vs. urban self-help groups

CBR experience shows that it is often easier to facilitate the formation of self-help groups in rural areas. Formation of self-help groups in urban settings can be particularly difficult (*15*) because of frequent migration and difficulties in building trust and a sense of belonging among group members. Although it should be noted that, in rural areas, geographical isolation and the long distances group members may need to travel, and the limited means of communication, may make it difficult to hold regular meetings.

Women and men

The CBR experience indicates that women's groups are generally easier to form than groups for men. Women tend to have a stronger sense of solidarity towards one another and work more easily in a collaborative way. Where groups have both male and female members, it is important to ensure that women are represented, their voices heard and their issues discussed.

Levels of education

Within self-help groups, members may have varying levels of education. It is likely that people with disabilities will have lower levels of education and therefore may be disadvantaged. It is important that self-help meetings are not monopolized by those people who may have a higher level of education, and for those self-help groups that are based around microcredit, it is important that there is not an uneven distribution of benefits. To prevent inequalities from arising within groups, time needs to be dedicated in the early stages of group formation to building a sense of cohesion and empowerment among the less literate or vocal members.

Single-impairment groups

Many groups have been formed for and by individuals with similar impairments. While single impairment groups have a clear and well defined purpose, often cross-disability groups are more practical in small communities where there are few people with one particular type of impairment. The basic needs of people with disabilities, irrespective of their impairments, are the same, e.g. food, shelter, health care, education. Single-impairment groups can often divide people with disabilities and set up competition for scarce resources.

Dependency

Disability is often associated with dependency, e.g. with doing things for people with disabilities rather than doing things with them. As a result, people with disabilities who are used to being recipients rather than contributors may lack the motivation and confidence to participate in self-help groups and activities.

Suggested activities

Provide assistance to form new self-help groups

CBR programmes need to play an active role in cre-
ating self-help groups of people with disabilities
and their family members. The process of form-
ing a self-help group will vary according to the
local situation, with different levels of support
required for each group. A general outline of
suggested activities is provided below.

Getting started

CBR personnel usually start working with people with disabilities and their families in
their homes, identifying their needs and providing basic information about disability
and the types of support available. As trust and confidence strengthens over time, they
can be encouraged to meet with others who share similar experiences. At this stage CBR
personnel can:

- provide information to people with disabilities and their family members about the
  concept of self-help groups and encourage them to form a group in their community
  – this may include talking about the advantages of being in a group and the types of
  concerns that can be addressed, e.g. concerns about forming a group when the pri-
  mary focus is to generate income to sustain the family – people may want to know
  how the group can help them directly by providing regular work and income;
- encourage people with disabilities and their family members to identify and talk with
  other people in their communities who may be interested in joining;
- organize a formal planning meeting in an accessible location, if there is enough inter-
  est and motivation.

Planning

- Discuss what the shared concerns are and establish what the initial focus of the group
  will be, e.g. sharing feelings and experiences, raising awareness, exchanging informa-
  tion and resources.
- Ask people what resources they are willing to contribute for the benefit of the group.
- Identify a group leader or coordinator – it may be necessary to have more than one.
- Allocate tasks as early as possible to help promote ownership and responsibility.
- Establish a group identity by adopting a name for the group.
- Decide who can join the group – try to keep the group small to begin with as this will
  provide everyone with a chance to participate.
- Decide on how often to meet, setting a date and time for the first meetings. Ensure
  meetings are arranged in accessible locations and not too far from where the group
  members live. Consider holding meetings in community locations, e.g. schools, to
  ensure visibility of the group and the CBR programme.

- If necessary, decide how to publicize the group to encourage people to attend the first meeting. This might include talking to people, putting up a poster or advertising on the local radio station or in the newspaper.

Running the meetings

While CBR personnel are encouraged not to be in charge of running meetings, they need to be aware of the basic structure for a self-help group meeting so they can support and assist groups where necessary. The basic structure involves:

- welcoming people to the meeting as they arrive;
- opening the meeting and encouraging members to introduce themselves;
- establishing the rules for confidentiality – for keeping private what is discussed and what happens during a meeting – different cultures may interpret confidentiality in different ways, so it is important to decide what the group wishes to keep confidential;
- carrying out the main activities of the meeting;
- taking minutes of the meetings, making a record of attendance, key topics of discussion and decisions made;
- dealing with administrative matters, e.g. date and time of next meeting;
- closing the meeting.

Facilitating

CBR programmes should fulfil a facilitative role in self-help groups, enabling them to work cooperatively and effectively. For example, CBR programmes can:

- provide support and assistance for group leaders when requested;
- ensure meetings are run so that all members understand what is going on and are able to take part;
- encourage the rotation of roles and responsibilities within the group;
- assist the group to see how they can provide mutual support to one another, e.g. companionship, taking children to school, starting group saving activities;
- check to see that there are fair and transparent methods for sharing the benefits of group activities;
- assist with drafting group rules and regulations once the group is well established;
- provide financial contributions, e.g. seed money or matching grants to enable self-help groups to expand their activities, and to open bank accounts.

Building capacity

Groups often need considerable support and capacity-building before they can function effectively and independently. Important skills for group members include: preparing agendas, conducting meetings, speaking in public with confidence, writing minutes, resolving conflicts, problem-solving, democratic decision-making, delegation of tasks, monitoring progress. Sometimes self-help groups will benefit from the development of specific skills, and sometimes the skills may already exist within the group. Self-help group meetings in themselves provide a good opportunity for members to practise new skills.

New self-help groups can learn from already established groups in the community. New groups may benefit from inviting members from existing self-help groups within the community – a new self-help group will value most the experience of people in circumstances similar to their own. Early contact between self-help groups of people with disabilities is important for learning, future links and mutual help.

Groups may be hesitant about getting involved in social or political action at first because they feel they lack the know-how or ability. But with time, patience and encouragement, group members will begin to discover their ability to understand, plan and implement the activities needed to change their situation, e.g. mobilizing the community in the form of a petition to local authorities as a first step towards safe drinking water and improved sanitation.

BOX 16 Dominican Republic

A mothers' self-help group improves the lives of their children

A self-help group for mothers of children with disabilities was formed in the slums of Santiago, in the Dominican Republic, with the assistance of an international nongovernmental organization. The common interest among the group members was to access services for their children. The government was unresponsive to their children's needs in both the health and education sectors. In the absence of government support, the mothers made a decision to undertake basic rehabilitation and education services themselves. They received training from the nongovernmental organization, and in time extended their services to include other children in the slum areas of Santiago. The mothers' group has continued to grow and has developed support services for adolescents with disabilities and a revolving loan fund. The mothers sought the expert help of the Government's Institute for Co-operatives in forming and managing their revolving fund. The mothers' group continues to grow as it identifies further areas of need; it now organizes social events, awareness-raising opportunities and income generation. The mothers are proud of their success and proud of the success of their children and teenagers.

Develop partnerships with existing self-help groups

In many communities, self-help groups for people with disabilities and their family members already exist and operate independently of CBR programmes. These groups might be for people with a specific condition or impairment, e.g. for people who are blind or deaf, have leprosy, or are victims of landmines. Some groups may focus on a specific topic or issue, e.g. disability rights, income generation, women. Other terms that may be used for "self-help groups" include: local disability groups, parents groups, social groups, peer groups, clubs or mutual aid groups.

The objectives of these groups and the self-help groups initiated by CBR programmes are often similar. Therefore it is important that CBR programmes identify and make contact with any groups that currently exist in the community and work towards developing partnerships to share knowledge and resources and ensure that more people with disabilities and their family members are reached.

Encourage inclusion of people with disabilities in mainstream self-help groups

While self-help groups specifically for people with disabilities and their families play an important role, CBR programmes should also encourage people with disabilities and their families to become members of mainstream self-help groups, e.g. women's groups, youth groups, microcredit groups, farmers' groups. The following activities are suggested:

- encourage mainstream self-help groups to include people with disabilities as regular members with equal rights, e.g. ensure they meet in accessible venues;
- highlight common issues faced by people both with and without disabilities, e.g. facilitate a discussion about gender discrimination with a women's group and highlight how this issue is shared by all women – this may provide an incentive for mainstream self-help groups to work in alliance with disability self-help groups and/or include people with disabilities in their groups;
- identify existing members of mainstream self-help groups who are either disabled or have a family member who is disabled and encourage them to talk about the issues and problems they face and to put disability on the agenda of their self-help group for discussion and debate;
- ensure people with disabilities and their families have the necessary skills and knowledge before linking them to mainstream self-help groups, as otherwise they may be vulnerable to discrimination.

Encourage self-help group members to participate in CBR programmes

Self-help group members (from both disability specific and mainstream self-help groups) have the potential to be important resources for CBR programmes, and thus need to be well informed about CBR. Self-help groups can play an important role in creating

awareness about disability and promoting inclusive development. Self-help group members may also be able to volunteer their time and contribute to CBR activities, e.g. by identifying people with disabilities in the community, supporting people with rehabilitation activities, and providing follow-up. Disability-specific self-help groups should be particularly encouraged to gradually play a bigger role in CBR programmes. Their participation in the management (e.g. planning, implementing and monitoring) of CBR programmes can make programmes more appropriate, credible and sustainable.

Encourage self-help groups to join together

While self-help groups for people with disabilities and their family members may be able to make a difference at the local level, their members may be limited in capacity to make changes at higher levels. Greater numbers of people can bring about change and therefore the next step is to encourage self-help groups (both those which have been started by CBR programmes and those which exist independently) to come together under one "umbrella" – this is commonly known as a federation. CBR programmes can facilitate the formation of a self-help group federation by bringing together one or two elected representatives from each self-help group. Self-help group federations need to ensure that people of different groups (e.g. of different age, impairment, gender, socio-economic status) are equally represented. A self-help group federation can also take on greater responsibilities and one day may become a formal organization in its own right.

BOX 17 Bangladesh

Strength in numbers

Azgar became one of the first members of the Belgachi self-help group in Bangladesh. His enthusiasm and hard work led to his election as chairman. Today the group has 21 members and meets on a weekly basis to discuss problems and possible solutions. Azgar's physical difficulties, together with his limited access to land, meant that he found it very difficult to support his family. He normally had work for only 10 or 12 days each month. He applied to the Government for permission to farm on nearby wasteland. Although his application was opposed by some villagers, the self-help group continued to support him. After Azgar was awarded an acre of land, a nongovernmental organization provided him with training in agricultural techniques. Today, Azgar grows and sells vegetables and has raised his family's standard of living. Azgar stood for election in the Poradha federation of self-help groups and was elected vice-chairman. He persuaded a Government official to allocate a small piece of wasteland to the federation and inspired members to collect bamboo to build a meeting hall. His continuing task is to establish rights for people with disabilities and ensure their acceptance by the community.

Disabled people's organizations

Introduction

Throughout the world, people with disabilities have united in organizations as advocates for their own rights to influence decision-makers in governments and all sectors of society (*18)*. These organizations are known as disabled people's organizations.

Disabled people's organizations have arisen in response to societal barriers that have prevented the equal participation of people with disabilities, and as a reaction against the control of people with disabilities by others. For a long time, people with disabilities have been spoken for by health professionals, family and others without regard for their needs, priorities or choices. People with disabilities are their own best spokespersons and representatives, as they know best their needs and aspirations (*19*).

Disabled people's organizations usually exist at the regional and national levels e.g. in major cities. They may be "single-disability" organizations and represent individuals with a particular type of impairment, such as a hearing or visual impairment (e.g. country branches of the World Blind Union), or they may be "cross-disability" organizations and inclusive of all people with disabilities (e.g. the National Union of Physical and Mental Handicapped (UNHPM) in Mauritania). In many countries there are also networks of disabled people's organizations, e.g. the Federation of Persons with Disabilities in Burundi. Disabled people's organizations also exist at the international level, e.g. the World Federation of the Deaf, the World Blind Union, Disabled Peoples International; many of these have joined together to form an international network known as the International Disability Alliance (IDA).

Historically CBR programmes and disabled people's organizations have not worked closely together. Disabled people's organizations may be hesitant about working with CBR programmes for a number of reasons, including the fact that, in the past, most CBR programmes were based on a medical model of disability and were run by nondisabled people and professionals, without the active participation of people with disabilities. Also, many CBR programmes have failed to include people with particular impairments, e.g. people with visual or hearing impairments who are priority groups for many disabled people's organizations.

While disabled people's organizations and CBR programmes have differences in their origins and strategies they do share similar goals, e.g. ensuring equal opportunities and social inclusion of disabled people. It is important that both disabled people's organizations and CBR have mutual respect for each other and work towards developing successful partnerships to meet these common goals and ensure the implementation of the Convention on the Rights of Persons with Disabilities (*5*).

BOX 18 India

A real hero

Ladakh is a Himalayan region located in the north of India, where people live in small towns and villages at very high altitudes and in harsh conditions. Life is hard for everyone but particularly for people with disabilities. While development initiatives are not new to the region, disability had never been considered in any development programme until the year 2000, when the Namgyal Institute for People with Disabilities (NIPWD), a nongovernmental organization, was established. The focus of NIPWD was to ensure that disability was mainstreamed into development programmes and that the needs of people with disabilities were met.

People with disabilities have been at the forefront of many of the changes that have occurred in Ladakh. One of them is Mohammed Iqbal, president of PAGIR – the People's Action Group for Inclusion and Rights, which was formed by people with disabilities in Ladakh in 2006. Iqbal spent the first 30 years of his life in an unproductive way, in bed at home, listening to music and chatting with friends, but by the time he was 45 years old (in 2008), had become a successful business man and leader of PAGIR. He had had the courage to move away from the image of a "poor disabled person" to one of a person in control of his environment. Iqbal and his lobby group called the People's Action Group for Inclusion and Rights (PAGIR) is a positive outcome of a seven-year community development process in Ladakh.

One of the key projects of PAGIR is a community managed garbage programme which creates income opportunities for more than 200 disabled people. Mohammad Iqbal says "Our garbage management programme, "Jungwa Shungskyob" in Ladakhi, started as a livelihoods initiative for disabled persons, but has now moved on to handle a serious garbage problem in the city. We collect garbage in huge quantities, reuse, recycle them and give the cleaner environment back to the community. We still have a long way to go in handling the problem to its entirety, but have made a beginning … a beginning where disabled people are leading a garbage drive and generating employment for the larger community."

NIPWD, DDRC and PAGIR continue to work in the Ladakh region. PAGIR is now the key stakeholder in organizing people with disabilities, empowering them and building their capacity in overcoming poverty through its various income-generation activities. Mohammad Iqbal recently received the CNN-IBN "Real Hero Award", in Mumbai on 20th March 2010, for PAGIR's outstanding work towards creating an inclusive society.

Goal

CBR programmes and disabled people's organizations work together to ensure the implementation of the Convention on the Rights of Persons with Disabilities and community-based inclusive development.

The role of CBR

The role of CBR is to work in partnership with disabled people's organizations where they exist, and where they do not exist, to provide assistance when requested to support their formation.

Desirable outcomes

- CBR programmes and disabled people's organizations work together to plan, implement and monitor new or existing CBR programmes.
- Disabled people's organizations support CBR programmes to become more representative and inclusive of people with disabilities.
- Disabled people's organizations are motivated to develop and implement CBR programmes in communities where they do not exist.

New disabled people's organizations are formed at the local/community level where they do not exist and are linked to regional and/or national disabled people's organizations.

Key concepts

Disabled people's organizations

Characteristics

Disabled people's organizations are mostly advocacy organizations which work at the regional, national and/or international levels to change policies and ensure equal rights and equal opportunities for people with disabilities. They are formally registered and structured, and usually function like any other organization or establishment. Initially a few people with disabilities come together and form a group of disabled people who work to:

- increase membership
- draw up a constitution and register as legal entity
- form the general body of the organization from the membership
- elect a governing body (through the general body)
- elect office bearers for the governing body
- become part of national or international affiliations and movements.

Membership

Disabled people's organizations promote the "Nothing about us without us" slogan – they are organizations "by", "for" and "of" people with disabilities. Therefore they are organizations that are controlled by a majority of people with disabilities at the board and membership levels (*19*). Membership varies depending on the type of organization. "Single-disability" organizations restrict membership to those with a specific impairment, e.g. an association of blind people is a single-disability organization, while "cross-disability" organizations have more inclusive membership, e.g. an association which includes people with hearing, visual, physical and mental impairments.

Depending on the needs, context and opportunity, there may be scope for different types of disabled people's organizations. Deaf people often prefer to have their own organizations rather than joining a cross-disability organization. People with intellectual disability may lack a voice in cross-disability organizations, and therefore prefer to form their own self-advocacy groups, sometimes with appropriate support from people without disabilities. Whatever the form and format of the disabled people's organization, it is important for people with disabilities to set the agenda, and for the organization to be respectful of differences within the disability community, e.g. the need to hear voices of women with disabilities, older people with disabilities.

Self-help groups and disabled people's organizations

The characteristics of self-help groups and disabled people's organizations vary among countries and at times it can be difficult to distinguish the two. For example, in many countries self-help groups are also known as disabled people's organizations, especially where they have joined together and become umbrella organizations. In these CBR guidelines, self-help groups are identified as groups which are established locally, operate on an informal basis, and are focused on addressing the needs of their own members, who may include people both with and without disabilities, e.g. family members. Disabled people's organizations are identified as organizations that are more formally structured, and have majority control by people with disabilities. They usually work on a larger canvas, advocating for human rights and influencing policy and resource allocation.

Partnerships between disabled people's organizations and CBR programmes

Many national and international disabled people's organizations in partnership with United Nations organizations, Member States and civil society organizations played an important role in the development of the Convention on the Rights of Persons with Disabilities (CRPD). While a great achievement, the Rights are meaningless for people with disabilities unless they can be implemented and enforced through meaningful activities and programmes (*20*). Currently many people with disabilities in low-income countries, especially those living in urban slums and in rural/remote communities, are not receiving the benefit of the Convention.

These CBR guidelines highlight the strong focus CBR has on community-based inclusive development to ensure people with disabilities have equal access to services and opportunities – CBR is a strategy/tool which can contribute to the implementation of the CRPD at community level. While CBR has been viewed in the past as a top–down strategy, new approaches recognize that the participation of people with disabilities is of vital importance to the success of CBR. And while disabled people's organizations have historically focused on disability as a human rights issue, they are now recognizing that disability is also a development issue – in fact many disabled people's organizations have started CBR programmes (*21*), e.g. in China, India Malawi and Nepal. These developments provide new opportunities for strong and effective partnerships between CBR programmes and disabled people's organizations.

It is possible for CBR and disabled people's organizations to work together to ensure that the benefits of their knowledge, skills and resources reach all people with disabilities, their families and communities. In this way CBR programmes suggest a "Nothing about us without all of us" slogan whereby all stakeholders are involved to ensure that communities become inclusive of people with disabilities. Partnerships will also ensure that both disabled people's organizations and CBR programmes are effective and sustainable in the long term.

Suggested activities

Work together with disabled people's organizations

Both CBR and disabled people's organizations have similar goals and knowledge, experience and resources that they can share for the benefit of people with disabilities and their families. While joint activities have been included in other sections of these CBR guidelines, in summary these activities may include:

- CBR programmes involving disabled people's organizations in CBR planning, implementation and monitoring, respecting the concept of "Nothing about us without us" e.g. disabled people's organizations could be involved in the recruitment of CBR personnel;
- CBR programmes using disabled people's organizations' representatives and members as resources when providing CBR training and sensitization for government officials, local leaders and service providers in the health, education, livelihood and social sectors;
- disabled people's organizations providing training for CBR personnel and self-help group members about the importance of policy, disability rights, and the need for and benefit of advocacy activities;
- working together to create joint resources, e.g. training materials and community resource directories for people with disabilities and their family members;

- working towards the empowerment of people with disabilities by advocating for the implementation of the Convention on the Rights of Persons with Disabilities.

Ensure access to CBR programmes for members of disabled people's organizations

Many CBR programmes have experience in delivering a range of services. Many members of disabled people's organizations may require these services to enable them to access their basic needs, enjoy their human rights and overcome poverty. CBR programmes can provide support to members of disabled people's organizations by providing access to all CBR activities based on their needs.

Encourage disabled people's organizations to support CBR as a strategy

Disabled people's organizations can support CBR by:

- promoting CBR at national and international levels as a strategy to mainstream development and ensure the benefits of the Convention on the Rights of Persons with Disabilities and the Millennium Development Goals reach more people with disabilities;
- lobbying for inclusion of the CBR strategy in government policies and programmes and lobbying for the necessary budgetary support;
- mobilizing communities by raising awareness about disability and the importance of CBR and encouraging them to participate in all aspects of CBR programmes;
- encouraging the formation of self-help groups for people with disabilities in urban slums and rural villages, and assisting in building the capacity of these groups – self-help groups can be the basic building blocks for the formation of disabled people's organizations at the community level;
- directly implementing CBR programmes using the CBR matrix.

Support the formation of community-based disabled people's organizations

In many countries, disabled people's organizations are based in big cities and often do not have adequate representation at grass-roots level; however, there are exceptions, including in Bangladesh, El Salvador, South Africa and Uganda. The strength of CBR programmes is that they have direct contact with people with disabilities at the grass-roots level and therefore can play a supportive role for people with disabilities who are interested in forming disabled people's organizations. People with disabilities should themselves lead the development of the disabled people's organization, but CBR personnel can play a vital role in supporting their efforts by:

- identifying people with disabilities who are interested in forming their own organization, and ensuring that there is representation from women and children with

disabilities, all impairment groups (especially people with severe or multiple impairments), and people from different socioeconomic groups;

- providing information about the benefits of forming a disabled people's organization – it is important that a clear distinction is made between the roles and responsibilities of CBR programmes and those of disabled people's organizations, while highlighting how the two can work together;
- working in partnership with disabled people's organizations at the national or regional level to organize training workshops to build the capacity of potential local members of disabled people's organizations;
- assisting them to: develop their organizational structure, mission, objectives, and plan of action; register with the local authorities; open bank accounts; and complete any other necessary legal formalities;
- providing ongoing assistance once the disabled people's organization is formed, e.g. inviting local members to training sessions carried out by CBR programmes so that they can observe how stakeholders (e.g. local leaders) are oriented to disability issues.

References

1. *Empowerment and poverty reduction: a sourcebook*. Washington, DC, World Bank, 2002 (http://web. worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTPOVERTY/EXTEMPOWERMENT/0,,contentMDK:2026 0036~menuPK:543261~pagePK:148956~piPK:216618~theSitePK:486411,00.html, accessed 10 June 2010).

2. Karl M. *Women and empowerment: participation and decision making*. London/New Jersey, Zed Books Ltd, 1995.

3. *Guidelines for the social and economic rehabilitation of people affected by leprosy*. London, International Federation of Anti-Leprosy Associations (ILEP), 1999 (www.ilep.org.uk/fileadmin/uploads/Documents/ Technical_Guides/sereng.pdf, accessed 10 June 2010).

4. *Giving voice to the voiceless: A communicating for advocacy learning publication*. London, Healthlink, 2007 (www.healthlink.org.uk/PDFs/cfalearningpublication.pdf, accessed 10 June 2010).

5. *Convention on the Rights of Persons with Disabilities*. New York, United Nations, 2006 (www.un.org/ disabilities/, accessed 30 March 2010).

6. *Disabled youth plead for inclusion at UN meeting on disability rights treaty*. London, Child Rights Information Network, 2006 (www.crin.org/resources/infodetail.asp?ID=6973&flag='news', accessed 10 June 2010).

7. *Children's statement at the 7th meeting*. London, Child Rights Information Network, 2006 (www.crin. org/resources/infodetail.asp?ID=6970&flag='news', accessed 10 June 2010).

8. *With participation of disabled youth, UN treaty on the rights of the disabled signed*. New York, United Nations Children's Fund (UNICEF), 2007 (www.unicef.org/infobycountry/usa_39285.html, accessed 10 June 2010).

9. *Be in the know: Convention on the Rights of Persons with Disabilities*. New York, United Nations Children's Fund (UNICEF) (undated) (www.unicef.org/voy/explore/rights/explore_3742.html, accessed 10 June 2010).

10. *Let's communicate: a handbook for people working with children with communication difficulties*. Geneva, World Health Organization, 1997 (www.who.int/disabilities/publications/care/en/index.html, accessed 10 June 2010).

11. *Training manual for community-based initiatives: a practical tool for trainers and trainees*. Cairo, WHO Regional Office for the Eastern Mediterranean, 2006 (www.emro.who.int/cbi/pdf/cbi_training_manual.pdf, accessed 10 June 2010).

12. Helander E. *Prejudice and dignity: an introduction to community-based rehabilitation*. New York, United Nations Development Programme, 1993 (www.einarhelander.com/PD-overview.pdf, accessed 10 June 2010).

13. *A community-based approach in UNHCR operations*. Geneva, Office of the United Nations High Commissioner for Refugees, 2008 (www.unhcr.org/47ed0e212.html, accessed 10 June 2010).

14. *Finnish grant awarded to IFES' disability project*. Washington, DC, International Foundation for Electoral Systems, 2009 (www.electionaccess.org/publications/news/02_01_04_Finland_Release.htm, accessed 10 June 2010).

15. Thomas M, Thomas MJ. *Manual for CBR planners*. Bangalore, Asia Pacific Disability Rehabilitation Journal Group Publication, 2003 (www.aifo.it/english/resources/online/apdrj/Manual%20for%20cbr_planners.pdf, accessed 10 June 2010).

16. Das M. *Karnataka human development report 2005: investing in human development*. Bangalore, Government of Karnataka, 2006 (http://planning.kar.nic.in/khdr2005/English/Main%20Report/Prelims.pdf, accessed 10 June 2010).

17. *Starting a self-help group*. Toronto, Self Help Resource Centre, 2009 (www.selfhelp.on.ca/start.html, accessed 10 June 2010).

18. *World Programme of Action concerning Disabled Persons, 1982* (www.un.org/disabilities/default.asp?id=23, accessed 10 June 2010).

19. Enns H. *The role of organizations of disabled people: a disabled peoples' international discussion paper*. Stockholm, Independent Living Institute (undated) (www.independentliving.org/docs5/RoleofOrgDisPeople.html, accessed 10 June 2010).

20. Cornielje H. The role and position of disabled people's organizations in community based rehabilitation: balancing between dividing lines. *Asia Pacific Rehabilitation Journal*, 2009, 20(1):3–14 (www.aifo.it/english/resources/online/apdrj/apdrj0109/dpo_cbr_cornielje.pdf, accessed 10 June 2010).

21. *International consultation to review community-based rehabilitation*. Geneva, World Health Organization, 2003 (www.aifo.it/english/resources/online/books/cbr/reviewofcbr/Report.Helsinki.CBR.May.pdf, accessed 10 June 2010).

Recommended reading

Carter I. *Mobilising the community and building the capacity of local groups. A Pillars Guide*. London, Tearfund, 2001 (available at: http://tilz.tearfund.org/Publications/PILLARS/, accessed 10 June 2010).

Charlton J. *Nothing about us without us: disability, oppression and empowerment*. Berkeley, CA, University of California Press, 1998.
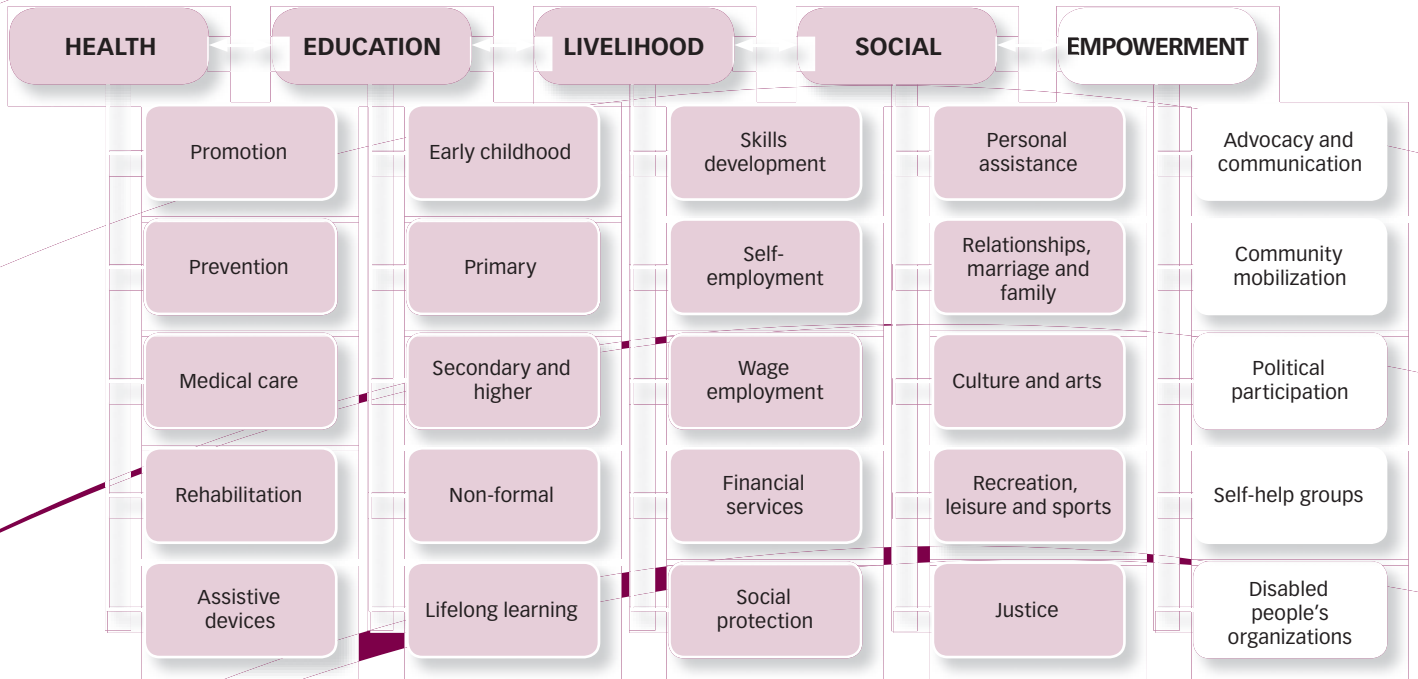
Community mobilization and capacity building: key facets. Washington, DC, World Bank, 2009 (http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTSOCIALDEVELOPMENT/EXTCDD/0,,contentMDK:20384443~menuPK:608222~pagePK:148956~piPK:216618~theSitePK:430161~isCURL:Y~isCURL:Y,00.html, accessed 10 June 2010).

Hartley S. *CBR: a participatory strategy in Africa*. London, University College London Centre for International Child Health, 2001 (www.asksource.info/cbr-book/cbr.pdf, accessed 10 June 2010).

Lynton RP, Pareek U. *Training for development*. New Delhi, Vistar Publications, 1990.

Notes

Notes

HEALTH	EDUCATION	LIVELIHOOD	SOCIAL	EMPOWERMENT
Promotion	Early childhood	Skills development	Personal assistance	Advocacy and communication
Prevention	Primary	Self-employment	Relationships, marriage and family	Community mobilization
Medical care	Secondary and higher	Wage employment	Culture and arts	Political participation
Rehabilitation	Non-formal	Financial services	Recreation, leisure and sports	Self-help groups
Assistive devices	Lifelong learning	Social protection	Justice	Disabled people's organizations