



# INTEGRATING PEOPLE WITH DISABILITIES



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# CBR Guidelines

## **Health component**

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# Preamble

The right to health without discrimination is captured in various international instruments. The Constitution of the World Health Organization (WHO) states that “enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition” (1).

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) addresses the right to health for people with disabilities. Article 25 requires States to “recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination of disability” and, together with Articles 20 (accessibility) and 26 (habilitation and rehabilitation), outlines measures States Parties should undertake to ensure that people with disabilities are able to access health services that are gender-sensitive, including health-related rehabilitation (2).

Unfortunately, evidence shows that people with disabilities often experience poorer levels of health than the general population (3) and face various challenges to the enjoyment of their right to health (4).

The right to health is not only about access to health services; it is also about access to the underlying determinants of health, such as safe drinking water, adequate sanitation and housing. The right to health also contains freedoms and entitlements. These freedoms include the right to be free from nonconsensual medical treatment such as experiments and research and the right to be free from torture or other cruel, inhuman or degrading treatments. The health-related entitlements include the right to a system of health protection; the right to prevention, treatment and control of diseases; access to essential medicines; and participation in health-related decision-making (4).

Community-based rehabilitation (CBR) programmes support people with disabilities in attaining their highest possible level of health, working across five key areas: health promotion, prevention, medical care, rehabilitation and assistive devices. CBR facilitates inclusive health by working with the health sector to ensure access for all people with disabilities, advocating for health services to accommodate the rights of people with disabilities (5) and be responsive, community-based and participatory (6).

Although CBR has historically focused on the health sector, as health is influenced by many factors, there is a need for multisectoral collaboration and inclusion (7) and for CBR programmes to work across many different sectors, such as education and employment. Given the size of the topic of health, this component focuses primarily on those CBR activities that take place within the health sector.

## Taking health services to the community

Thailand has a long and successful history of primary health care which, over time, has evolved through many innovative strategies and activities. In many provinces, primary health care is based around networks of satellite units called primary care units, which are connected to and supported by large central hospitals. In 2006, one of these hospitals, Sichon Hospital, introduced community-based rehabilitation (CBR) to their network of primary care units. The Tha-Hin primary care unit is part of this network. It is located in a rural area and has a team of health personnel including a family doctor, a pharmacist, nurses and health workers. Before CBR was introduced, this team mostly carried out general health promotion and prevention activities. However, with the addition of CBR, the team also became responsible for identifying people with disabilities and addressing both their general and their specific health-care needs.

The major focus of CBR was to provide health services for people with disabilities on their “doorsteps”. A home health-care scheme was established (which is also for older people and people with chronic health conditions), providing a direct link to Sichon Hospital. Home visits are conducted on a regular basis by members of the Tha-Hin team and a physical therapist from Sichon Hospital, enabling people to avoid unnecessary and costly travel. A protocol was also established for home-based rehabilitation. Local volunteers and family members were trained to provide basic rehabilitation (i.e. daily living skills training) to people with disabilities and were encouraged to promote inclusive education for children with disabilities. The multidisciplinary approach has ensured that all people with disabilities are able to access health care and rehabilitation services in their communities as well as referral services at Sichon Hospital when needed.

A 2008 evaluation concluded that the CBR programme had been effective in providing a range of health-care services for people with disabilities and their families, including early identification of people with disabilities and early intervention, health promotion and rehabilitation including functional training and provision of assistive devices. Overall, quality of life has been enhanced for all people with disabilities with improvements in their independence, mobility and communication skills. Parents of children with disabilities have also been provided with better support. Good working relationships have been established between all key stakeholders (Sichon Hospital, the primary care unit and the community) and inclusion of local volunteers and mobilization of other resources have created a sense of community empowerment and ownership.



## Goal

People with disabilities achieve their highest attainable standard of health.

## The role of CBR

The role of CBR is to work closely with the health sector to ensure that the needs of people with disabilities and their family members are addressed in the areas of health promotion, prevention, medical care, rehabilitation and assistive devices. CBR also needs to work with individuals and their families to facilitate their access to health services and to work with other sectors to ensure that all aspects of health are addressed.

## Desirable outcomes

- People with disabilities and their family members have improved knowledge about their health and are active participants in achieving good health.
- The health sector is aware that people with disabilities can achieve good health and does not discriminate on the basis of disability and other factors such as gender.
- People with disabilities and their family members have access to health-care and rehabilitation services, preferably in or close to their communities and at affordable cost.
- Health and rehabilitation interventions enable people with disabilities to become active participants in family and community life.
- There is improved collaboration across all development sectors, including education, livelihood and social sectors, to achieve good health for people with disabilities.

## Key concepts

### Health

#### *What is health?*

Health has traditionally been defined as the absence of disease and illness. However, as defined by WHO, it is a much broader concept – it is “a state of complete physical, mental and social well-being and not merely the presence of disease or infirmity” (1). Health is a valuable resource that enables people to lead individually, socially and economically productive lives, providing them with the freedom to work, learn and engage actively in family and community life.

## Khurshida

Khurshida was born deafblind in a small village of Barabanki District, in Uttar Pradesh, India. When Satyabhama, a CBR worker trained by Sense International India, met her, Khurshida was 10 years old and had spent most of her life lying in a dark corner of the family home completely isolated from her community. She was completely dependent on her mother for all her needs and was unable to communicate. Satyabhama worked hard with Khurshida to teach her daily living and communication skills. Khurshida began to respond positively by sitting up, eating meals with her family and playing with toys. She began to learn the language of touch, discovering that by pulling at her mother's sari it would make her stay a little while longer. With time, Satyabhama was able to take Khurshida by the hand and encourage her to take her first steps outside the family home. She may not have heard the birds sing or seen the sun, but the expression on her face showed that she loved the feel of the gentle fresh breeze against her face. The CBR programme was able to help Khurshida's family obtain a disability certificate for her, which enabled access to a wide range of services. The programme also assisted Khurshida's mother to access treatment for tuberculosis. Satyabhama continues to work with Khurshida and is now teaching her sign language. It will be a long journey for Khurshida and her family, but with the support of the CBR programme they are working towards the full inclusion of Khurshida in the life of her community.

### *Determinants of health*

A person's health status is influenced by a wide range of personal, economic, social and environmental factors. These factors are commonly referred to as determinants of health and are outlined below (adapted from (8)).

- Genetics – inheritance plays a part in determining the lifespan, healthiness and the likelihood of developing certain illnesses.
- Individual behaviours and lifestyle – diet, activity, smoking, drinking and how we deal with life's stresses all affect health.
- Income and social status – the greater the gap between rich and poor people, the greater the differences in health.
- Employment and working conditions – people in employment are healthier, particularly those who have more control over their working conditions.
- Education – low education levels are linked with poor health, more stress and lower self-confidence.
- Social support networks – greater support from families, friends and communities is linked to better health.
- Culture – customs and traditions and the beliefs of the family and community all affect health.
- Gender – men and women suffer from different types of diseases at different ages.



- Physical environment – safe water and clean air, healthy workplaces, safe houses, communities and roads, all contribute to good health.
- Health services – access to and use of services influence health.

Some of these factors can be controlled, e.g. a person can choose healthy or unhealthy behaviour. However other factors, such as genetics, cannot be controlled.

## **Disability and health**

Health for All was a global health objective set by WHO during the 1978 primary health care conference in Alma-Ata. Thirty years later, communities globally have yet to achieve this objective and many groups of people, including people with disabilities, still experience poorer states of health than others.

To ensure that people with disabilities achieve good levels of health it is important to remember that:

- people with disabilities need health services for general health-care needs (e.g. health promotion and prevention services and medical care) like the rest of the population, including different needs in different phases of life;
- while not all people with disabilities have health problems related to their impairments, many will require specific health-care services, including rehabilitation, on a regular or occasional basis and for limited or lifelong periods.

## **Health care**

### ***Health-care provision***

Health care within each country is provided through the health system, which comprises all those organizations, institutions, resources and people whose primary purpose is to promote, restore or maintain health. While ultimate responsibility for the health system lies with the government, most health care is provided by a combination of public, private, traditional and informal sectors (9).

The 2008 World Health Report emphasizes the essential role of primary health care in achieving health for every person (10). Primary health care is essential health care made universally accessible to individuals and families at a cost they can afford. It is the first level of contact with the national health system for individuals, families and communities and brings health care as close as possible to where people live and work (11).

### ***Barriers to health-care services for people with disabilities***

The poor health that people with disabilities may experience is not necessarily a direct result of having a disability. Instead it can be linked to difficulties in accessing services and programmes (12). It is estimated that only a small percentage of people with disabilities in low-income countries have access to rehabilitation and appropriate basic

services (5). The barriers to health-care services that people with disabilities and their family members may face include:

- absent or inappropriate policies and legislation – where policy and legislation do exist, they may not be implemented or enforced and can be discriminatory and/or obstructive regarding the provision of health services to people with disabilities;
- economic barriers – health interventions such as assessments, treatments and medications often require out-of-pocket payments, presenting difficulties for people with disabilities and their families who are likely to have limited income for health care (see Introduction: Poverty and disability);
- physical and geographical barriers – lack of accessible transport and inaccessible buildings and medical equipment are examples of common barriers, as well as the limited health-care resources of rural areas (where many people with disabilities live) and the long distances to reach services in big cities;
- communication and information barriers – communicating with health workers may be difficult, e.g. a person who is deaf might find it difficult to communicate his/her symptoms to a doctor and health information is often not available in accessible formats, such as picture formats for people with intellectual impairment;
- poor attitudes and knowledge of health workers about people with disabilities – health personnel may have inappropriate attitudes, be prejudiced or insensitive and lack awareness and often lack the knowledge, understanding and skills to manage health issues for people with disabilities;
- poor knowledge and attitudes of people with disabilities about general health care and services – people with disabilities may be reluctant to use health services; many also have limited knowledge about their rights and health issues and about what health services are available.

Some people with disabilities may be more vulnerable to discrimination and exclusion than others. They may suffer double or multiple disadvantages, for example due to the type of disability they have, their age, gender and/or social status (13) and so find it more difficult to access health-care services. CBR programmes should be particularly mindful of the following groups: women, children and older people with disabilities; people with multiple impairments e.g. those who are both deaf and blind, or who have intellectual impairments, disabilities and HIV/AIDS, mental health problems, leprosy, or albinism (see Supplementary chapters).

### ***Inclusive health***

“Inclusive education” has become a widely recognized concept and is increasingly being implemented in education systems throughout the world. It refers to education that welcomes all people, including those with disabilities, to participate fully in regular community schools or centres of learning (14) (see Education component). Similarly, the concept of inclusive health is now being promoted by CBR programmes to ensure health

systems recognize and accommodate the needs of people with disabilities in their policies, planning and services delivery. It builds on the primary health care “Health for All” concept, that health care should be “... accessible to individuals and families in the community through their full participation and at a cost that the community and the country can afford...” (11).



Inclusive health means that all individuals can access health care irrespective of impairment, gender, age, colour, race, religion and socioeconomic status. To ensure this, health-care service providers need to have positive attitudes towards disability and people with disabilities and have appropriate skills, e.g. communication skills to accommodate the needs of people with different impairments. The whole environment needs to change so that nobody is actively, or passively, discriminated against; one way of achieving this is by ensuring that people with disabilities and disabled people’s organizations (DPOs) are active participants in the planning and strengthening of health-care and rehabilitation services.

### BOX 3

## Pakistan

### The courage to overcome barriers

Muhammad Akram is from Sindh Province, Pakistan. He became deaf as a teenager due to an illness. The following anecdote describes his experience of visiting a doctor with his family. “Being deaf I was always unaware of what they were talking about. If I asked the doctor a question he usually replied that he had told my family everything. And if I asked my family a question they always said “don’t worry, nothing special” or “we will tell you later”. Nobody really told me anything – I just had to take the tablets. No-one used sign language and nobody had the time or willingness to communicate with me using pen and paper. Over time I began to lose my confidence and became very dependent on others. After joining a CBR programme I slowly gained confidence and developed the courage to face the challenges myself. I started refusing to take a family member with me to the doctor. This forced the doctor to communicate with me directly in writing. Some doctors still ask me to bring someone with me on my next visit but I always tell them that I am an adult. I feel good as I have developed self-confidence and have also helped to raise the profile of disability by educating medical professionals.”

## **CBR and the health sector**

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CBR programmes can facilitate access to health care for people with disabilities by working with primary health care in the local community, providing the much needed link between people with disabilities and the health-care system. In many countries, e.g. Argentina, Indonesia, Mongolia and Viet Nam, CBR programmes are directly linked with the health-care system – they are managed by the ministry of health and implemented through their primary health care structures. In other countries, CBR programmes are managed by nongovernmental organizations or other government ministries, e.g. social welfare, and in these situations close contact must be maintained with primary health care to ensure that people with disabilities can access health care and appropriate rehabilitation services as early as possible.

## **Elements in this component**

CBR programmes recognize, support and advocate a number of key aspects of health care for people with disabilities. These are consistent with best practice (5,15) and are outlined below.

### **Health promotion**

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Health promotion aims to increase control over health and its determinants. The wide range of strategies and interventions available are directed at strengthening the skills of individuals and changing social, economic and environmental conditions to alleviate their impacts on health.

### **Prevention**

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Prevention is very closely linked with health promotion. Prevention of health conditions (e.g. diseases, disorders, injuries) involves primary prevention (avoidance), secondary prevention (early detection and early treatment) and tertiary prevention (rehabilitation) measures. The focus of this element is mainly on primary prevention.

### **Medical care**

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Medical care refers to the early identification, assessment and treatment of health conditions and their resulting impairments, with the aim of curing or limiting their impacts on individuals. Medical care can take place at the primary, secondary or tertiary level of the health-care system.

### **Rehabilitation**

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Rehabilitation is a set of measures which enables people with disabilities to achieve and maintain optimal functioning in their environments; it is relevant both for those who

acquire disabilities during their lifetime and for those who have disabilities from birth. Rehabilitation services range from the basic to the specialized and are provided in many different locations e.g. hospitals, homes and community environments. Rehabilitation is often initiated by the health sector but requires collaboration between all sectors.

## **Assistive devices**

A device that has been designed, made or adapted to assist a person to perform a particular task is known as an assistive device. Many people with disabilities benefit from the use of one or more assistive devices. Some common types of assistive devices are: mobility devices (e.g. walking sticks, wheelchairs), prostheses (e.g. artificial legs), orthoses (e.g. hand splint), visual devices (e.g. glasses, white canes) and hearing devices (hearing aids). To ensure that assistive devices are used effectively, important aspects of their provision include user education, repair, replacement and environmental adaptations in the home and community.



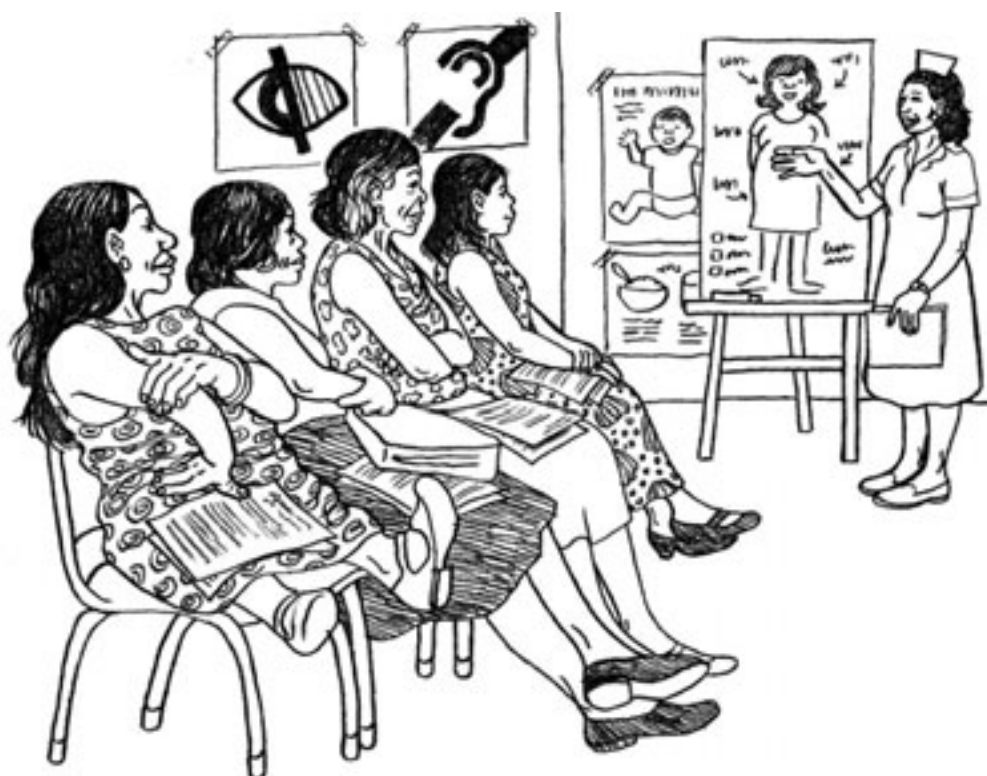
# Health promotion

## Introduction

The Ottawa Charter for Health Promotion (1986) describes health promotion as the process of enabling people to increase control over and to improve, their health (16).

Health promotion focuses on addressing those determinants of health that can potentially be modified, such as individual health behaviours and lifestyles, income and social status, education, employment and working conditions, access to appropriate health services and the physical environment (17). Health promotion does not require expensive drugs or elaborate technology; instead it uses social interventions, which, at the most basic level, require a personal investment of time and energy (18), e.g. health promotion campaigns.

The health potential of people with disabilities is frequently overlooked and as a result they are often excluded from health promotion activities. This element is about the importance of health promotion for people with disabilities. It provides suggestions for CBR programmes on how to facilitate access to health promotion activities for people with disabilities and how to implement basic activities where necessary. It is important to remember that as health promotion focuses on changing a wide range of determinants of health, it involves many different sectors, and not just the health sector.



## Overcoming stigma and prejudice

In some African cultures, albinism is believed to be a result of a mother having a “sexual relationship” with evil spirits during pregnancy. Having a child with albinism is considered immoral, and both the family and child are subject to discrimination and stigmatization within their communities. Children with albinism remain hidden and their fundamental human rights are denied, including their right to health.

Kwale District Eye Centre (KDEC) in Kenya has a CBR programme which focuses on alleviating discrimination and stigmatization towards children with albinism in their homes, schools and community environments. To ensure these children achieve their highest attainable standards of health, the CBR programme uses a variety of health promotion activities and interventions including:

- sensitizing community members and community leaders, village health committees, school teachers and women’s groups, to bring about changes in perceptions, attitudes and treatment of people with albinism;
- educating parents so that they are able to promote and protect their child’s health, e.g. as people with albinism are at risk of sun damage, KDEC provides education about the importance of using sunscreen and protective clothing, such as long-sleeved shirts and trousers;
- forming partnerships with local hotels to encourage guests to donate sunscreen and unwanted items of clothing before they leave, which can be given to those in need;
- conducting eye assessments to detect visual impairments, which are common among people with albinism, and providing glasses and low-vision devices where required.

The success of this CBR programme is linked to the strong working relationship that KDEC has developed with both the health and the education sectors. Children with albinism are now integrated into mainstream schools.





## Goal

The health potential of people with disabilities and their families is recognized and they are empowered to enhance and/or maintain existing levels of health.

## The role of CBR

The role of CBR is to identify health promotion activities at a local, regional and/or national level and work with stakeholders (e.g. ministries of health, local authorities) to ensure access and inclusion for people with disabilities and their family members. Another role is to ensure that people with disabilities and their families know the importance of maintaining good health and encourage them to actively participate in health promoting actions.

## Desirable outcomes

- People with disabilities and their families are reached by the same health promotion messages as are members of the general community.
- Health promotion materials and programmes are designed or adapted to meet the specific needs of people with disabilities and their families.
- People with disabilities and their families have the knowledge, skills and support to assist them to achieve good levels of health.
- Health-care personnel have improved awareness about the general and specific health needs of people with disabilities and respond to these through relevant health promotion actions.
- The community provides a supportive environment for people with disabilities to participate in activities which promote their health.
- CBR programmes value good health and undertake health-promoting activities in the workplace for their staff.



## Key concepts

### Health promotion for people with disabilities

Health promotion is often viewed as a strategy to prevent health conditions; it is not often associated with people with disabilities because disability is viewed as a consequence of not utilizing health promotion (19). A person with paraplegia as a result of spinal cord injury, for example, may not be considered a good candidate for health promotion as her/his health has already been affected by injury.

Many people with disabilities have as much need for health promotion as does the general population, if not more (3). People with disabilities are at risk of the same health conditions as people in the general population but they may also have additional health problems due to greater susceptibility to health conditions (related or not to their disabilities) (20). Often, people with disabilities and their family members have very little awareness of how to achieve or maintain good health.

### Barriers to health promotion

People with disabilities often experience poorer levels of health than the general population because of the many barriers they face when trying to improve their health (see above: Barriers to health-care services for people with disabilities). Dealing with these barriers will make it easier for people with disabilities to participate in health promotion activities.

### Health promotion for family members

Many people with disabilities require support from others, particularly family members. Family members may experience problems related to the care of people with disabilities including stress-related physical and emotional illness, reduced ability to care for other children, reduced time and energy for work, reduced social interaction and stigmatization (21). Maintaining the health of family members is essential (see Social component: Personal assistance).

### Health promotion action

The Ottawa Charter for Health Promotion outlines five areas for action which can be used to help develop and implement health promotion strategies (16).

#### 1. Build healthy public policy

Develop legislation and regulations across all sectors which protect the health of communities by ensuring safer and healthier goods and services, healthier public services and cleaner, more enjoyable environments.

## 2. **Create supportive environments for health**

Make changes in the physical and social environments to ensure that living and working conditions are safe, stimulating, satisfying and enjoyable.

## 3. **Strengthen communities**

Adopt community approaches to address those health problems that have strong environmental, socioeconomic and political components. Empower communities to set priorities, make decisions and plan and implement strategies to achieve better health.

## 4. **Develop personal skills**

Develop people's skills by providing information and health education to enable them to exercise more control over their health and environment and make better choices to improve their health status.

## 5. **Reorient health services**

The health sector must move increasingly towards health promotion, beyond its responsibility of providing clinical and curative services.

Health promotion strategies can be applied to different:

- population groups, e.g. children, adolescents, older adults
- risk factors, e.g. smoking, physical inactivity, poor diet, unsafe sex
- health or disease priorities, e.g. diabetes, HIV/AIDS, heart disease, oral health
- settings, e.g. community centres, clinics, hospitals, schools, workplaces.

Individuals have enormous potential to influence their own health outcomes and participatory approaches in health promotion are important as they allow people to exert greater control over the factors which affect their health. Health issues need to be addressed through working with others rather than by doing things for them.

## **Suggested activities**

Health promotion activities are very dependent on local issues and priorities, so the activities outlined here are general suggestions only. CBR programmes need to develop a good understanding of the communities in which they work by making contact with community members and groups already working towards increased control over the factors which affect their health.

## **Support health promotion campaigns**

Health promotion campaigns can positively influence the health of individuals, communities and populations – they can inform, encourage and motivate behaviour change. CBR programmes can promote better health for people with disabilities by:

- identifying existing health promotion campaigns operating at community, regional or national level and ensuring that people with disabilities are actively targeted and included in these campaigns;

- actively participating in health promotion campaigns and associated events, raising the profile and awareness of disability;
- encouraging health promotion campaigns to show positive images of people with disabilities, e.g. by depicting people with disabilities on posters and billboards for messages intended to reach the entire population;
- ensuring existing health promotion campaigns utilize appropriate formats for people with disabilities, e.g. that public service announcements are adapted for the deaf community with text captioning and sign language interpretation;
- identifying existing resources within the community (e.g. community spokespersons, newspapers, radio, television) and encouraging them to increase their coverage of disability-related health issues – it is important to ensure that any coverage is respectful of the rights and dignity of people with disabilities;
- supporting the development of local health promotion campaigns to address disability-related issues that are not covered by existing campaigns.



## Strengthen personal knowledge and skills

Health information and education enables people with disabilities and their families to build the knowledge and life skills necessary for maintaining and improving their health. They can learn about disease risk factors, good hygiene, healthy eating choices, the importance of physical activity and other protective factors through structured sessions (individual or small group). CBR personnel can:

- visit people with disabilities and their families in their homes and talk about how to maintain a healthy lifestyle, giving practical suggestions;
- collect health promotion materials (e.g. booklets, brochures) and distribute them to people with disabilities and their families;
- adapt or develop health promotion materials to make them accessible to people with disabilities, e.g. people with an intellectual disability will require materials that are simple and straightforward with basic language and relevant pictures;
- inform people with disabilities and their families about local health promotion programmes and services that will enable them to acquire new knowledge and skills to remain healthy;
- develop specific education sessions, if necessary, for people with disabilities whose needs are not being met by those targeting the general community;
- ensure that a wide range of teaching methods and materials are used in education sessions to reinforce learning and understanding, e.g. games, role plays, practical demonstrations, discussions, storytelling, problem-solving exercises;
- focus on assisting people with disabilities and their families to become assertive and confident in the presence of health-care providers to enable them to ask questions and make decisions about their health;
- provide training for individuals with disabilities, in partnership with the health sector, to enable them to become health promotion educators.

## Link people to self-help groups

Self-help groups enable people to come together in small numbers to share common experiences, situations or problems with each other (see Empowerment component: Self-help groups). For many people the opportunity to receive support and practical advice from someone else who has a similar problem is more useful than receiving advice from a health worker (22). Self-help groups are mentioned throughout this component because they can contribute to better health for people with disabilities and their family members. CBR programmes can:

- connect people with disabilities and their families to existing self-help groups in their communities to meet their specific health needs, e.g. groups of people with spinal cord injuries, or affected by leprosy, or living with HIV/AIDS, or who are parents of children affected by cerebral palsy;
- encourage people with similar experiences of disability to come together to form new self-help groups where suitable groups do not already exist – in small villages, it may be difficult to establish such a group and 1:1 support from a peer may be more appropriate;
- encourage self-help groups, in partnership with others, to participate actively in health-promoting activities in their communities, e.g. by organizing health camps and observing World Health Day, World Mental Health Day and the International Day of Persons with Disabilities.

### BOX 5

## Colombia

### Managing health through self-help groups

With the support of a CBR programme in Piedecuesta, Colombia, a group of people with spinal cord injuries formed a self-help group. They felt they had been given inadequate health information – regarding self-care, prevention of ulcers and urinary problems – in the hospitals where they were treated. Experienced members of the group were supportive of new members who had recently acquired a spinal cord injury and helped them to develop ways of coping by showing them how to use their residual abilities and assistive devices. The CBR programme organized an interactive session with hospital specialists during which group members could ask questions to clarify their doubts.



## Educate health-care providers

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Health-care providers are a trusted source of health-related information and have the potential to positively influence the health of others. CBR programmes need to work with these providers to ensure they have adequate knowledge about disability and include people with disabilities in all their health promotion activities.

It is suggested that CBR programmes:

- orient health workers (e.g. primary health care personnel) towards disability and inform them of the challenges faced by people with disabilities and their families;
- help health workers understand the importance of communicating with people with disabilities in a respectful and nondiscriminatory manner and provide them with practical demonstrations to facilitate learning;
- show health professionals how they can make simple adaptations to interventions to ensure that their health messages are understood;
- encourage health professionals to use a variety of media and technologies when planning and developing health information and programmes for people with disabilities.

### BOX 6

## Africa

### Train the trainer

CBR programmes can work with disabled people's organizations to develop appropriate education materials and methods to inform people who are blind or who have low vision about HIV/AIDS and to inform health-care services about the specific needs of this group. For example the African Blind Union produced a "train the trainer" manual on HIV/AIDS to facilitate the inclusion and participation of blind and partially sighted persons in HIV/AIDS education programmes.

## Create supportive environments

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CBR programmes can work with community health centres, hospitals, schools, worksites and recreational facilities and with key stakeholders to create supportive physical and social environments for people with disabilities, as well as to enable them to achieve optimal health by:

- ensuring that environments promote healthy lifestyles and that specific health promotion programmes and services are physically accessible for people with disabilities;
- creating partnerships between urban, social and health planners and people with disabilities to create and improve physical and architectural accessibility;
- creating opportunities to enable people with disabilities to participate in recreational activities, e.g. support wheelchair users to organize a wheelchair football match at a local sports facility (see Social component: Recreation, leisure and sport);

- ensuring accessible and safe public transport, because problems with transport can cause people with disabilities to face isolation, loneliness and social exclusion;
- addressing, through education and training, any misconceptions, negative attitudes and stigma that exist within the health sector and community towards people with disabilities and their families;
- organizing cultural events to address problematic health issues within the community through dance, drama, songs, films and puppet shows.

## BOX 7

## Egypt

### Healthy lifestyles

A CBR programme in Alexandria (Egypt) organizes an annual summer camp where children with disabilities, their families and community volunteers go together for group holidays. The emphasis is on spending leisure time together, improving health status, playing and enjoying being together as a larger family or group of friends. The CBR programme also collaborates with the local Paralympics committee, parents' organizations and disabled people's organizations to organize an annual sports day in the city stadium.



### Become a health promoting organization

Health promotion within workplaces has the capacity to improve staff morale and skills, job performance and, ultimately, health. Organizations that implement CBR programmes should focus on promoting the health of their staff by:

- providing training and education to all staff, regardless of the level at which they work, on ways to improve and maintain their health;
- providing a safe and healthy environment, e.g. a nonsmoking environment, healthy meals, safe water and sanitary facilities, reasonable working hours, safe transport options;
- developing policies and practices within the organization which promote health, e.g. policies against discrimination, prejudice and stigma, harassment, as well as tobacco, drug and alcohol use;
- encouraging staff to be good role models in their communities, setting good examples for others by adopting healthy behaviours.





# Prevention

## Introduction

The main focus of prevention in health care is to stop health conditions from occurring (primary prevention). However, prevention also involves early detection and treatment to stop the progression of a health condition (secondary prevention) and management to reduce the consequences of an existing health condition (tertiary prevention). This element mainly focuses on *primary* prevention.

Primary prevention may include: primary health care; prenatal and postnatal care; education in nutrition; immunization campaigns against communicable diseases; measures to control endemic diseases; safety regulations; programmes for the prevention of accidents in different environments, including adaptation of workplaces to prevent occupational injury and diseases; and prevention of disability associated with pollution of the environment or armed conflict (23).

It is estimated that, through better use of primary prevention and health promotion, the global burden of disease could be reduced by as much as 70% (10). Even so, it is commonly believed that prevention (as for health promotion) has little, if any, role in the management of health for people with disabilities.

Health care for people with disabilities usually focuses on specialized medical care and rehabilitation. However, as previously mentioned, people with disabilities are at risk of other health conditions and also at risk of secondary conditions resulting from their primary health conditions (24).

Just like health promotion, prevention requires the involvement of many different sectors. Within the health sector, primary health care plays an important role and since CBR programmes are most closely linked with primary health care, they can play a significant role in promoting and supporting preventive health care for people with disabilities.



## Living with dignity

In Chamarajnagar, one of the poorest districts of Karnataka, India, the quality of life is very poor, particularly for people with disabilities. While Mobility India (MI), a nongovernmental organization, were carrying out a CBR project with the support of Disability and Development Partners UK, they discovered that many community members did not have access to basic sanitation facilities. Most people travelled far from their houses to use open fields. This was very difficult for people with disabilities, and more so for women with disabilities.

The Indian Government offered grants to families to construct toilets and MI assisted people with disabilities and their families in Chamarajnagar to construct accessible toilets. Using existing community-based networks and self-help groups (SHG) to assist with this new project, MI organized street plays and wall paintings to raise awareness about hygiene and the role proper sanitation plays in preventing health problems. As people became interested and motivated, MI agreed to work with them to facilitate access to basic sanitation.

The total cost to construct one toilet was an estimated US\$ 150. While the Indian Government offered a grant to each family, funding the remaining amount was difficult for most people, particularly people with disabilities. With financial support from MIBLOU, Switzerland and local contributions, MI was able to construct 50 good quality accessible toilets. SHG members were asked to select poor households with disabled family members who had the greatest need for a toilet. They also coordinated the construction work in partnership with families and ensured proper use of funds.

Many people with disabilities no longer need to crawl or be carried long distances for their toileting needs. They have become independent and, importantly, have been able to reclaim their dignity. Their risk of developing health conditions associated with poor sanitation has also significantly reduced. Seeing the success of the MI project, the Indian Government has since increased the amount of the grant and directed local authorities to release these funds immediately.

People with and without disabilities are benefiting from this project, and it is gradually being scaled up to become a district-level project. Chamarajnagar will soon become a district where people have toilets in their houses, or at least near to their homes.



## Goal

People with disabilities are less likely to develop health conditions, related or unrelated to their impairments, that affect their functioning and overall health and well-being; and family members and other community members are less likely to develop health conditions and impairments associated with disability.

## The role of CBR

The role of CBR is to ensure that communities and relevant development sectors focus on prevention activities for people both with and without disabilities. CBR programmes provide support for people with disabilities and their families to ensure they can access services that promote their health and prevent the development of general health conditions or secondary conditions (complications).

## Desirable outcomes

- People with disabilities and their families have access to health information and services aimed at preventing health conditions.
- People with disabilities and their families reduce their risk of developing health problems by taking up and maintaining healthy behaviours and lifestyles.
- People with disabilities are included and participate in primary prevention activities, e.g. immunization programmes, to reduce their risk of developing additional health conditions or impairments.
- All community members participate in primary prevention activities, e.g. immunization programmes, to reduce their risk of developing health conditions or impairments which can lead to disability.
- CBR programmes collaborate with the health and other sectors, e.g. education, to address health issues and provide support and assistance for prevention activities.

## Key concepts

### Risks to health

Risk factors influence a person's health and determine the likelihood of injury, illness and disease. People everywhere are exposed to many health risks throughout their lives. Some of the leading risk factors include: being underweight; unsafe sex; high blood pressure; tobacco consumption; alcohol consumption; unsafe water, sanitation and hygiene; iron deficiency; and indoor smoke from solid fuels (25).

Prevention activities reduce the risks to health of individuals and communities. While some risk factors, e.g. family history, are beyond a person's control, others, e.g. lifestyle and physical and social environments can be altered, potentially maintaining and

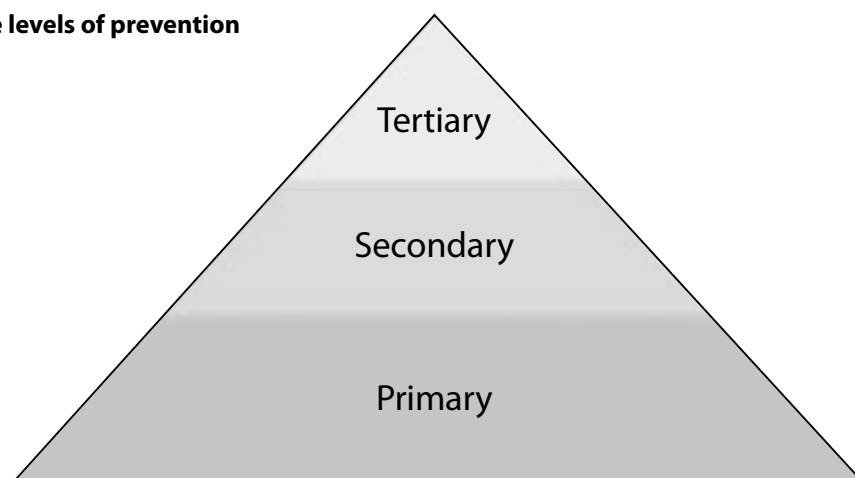
improving health status. The health sector can play a significant role in addressing these risk factors.

## Three levels of prevention

Prevention interventions can be at one of three levels.

1. **Primary prevention** – the phrase “prevention is better than cure” is one that many people are familiar with and is the focus of primary prevention. Primary prevention is directed at avoidance and uses interventions that prevent health conditions from occurring (17). These interventions are mainly aimed at people (e.g. changing health behaviours, immunization, nutrition) and the environments in which they live (safe water supplies, sanitation, good living and working conditions). Primary prevention is equally important for people with and without disabilities and is the main focus of this element.
2. **Secondary prevention** is the early detection and early treatment of health conditions, with the aim of curing or lessening their impacts. Examples of early detection include mammograms to detect breast cancer and eye examinations to detect cataracts; examples of early treatment include treatment of trachoma with antibiotics to prevent blindness, multidrug treatment of leprosy to prevent disease progression and appropriate handling of a fractured bone to promote proper healing and prevention of deformity. Secondary prevention strategies for people both with and without disabilities are discussed in the Medical care element below.
3. **Tertiary prevention** aims to limit or reverse the impact of already existing health conditions and impairments; it includes rehabilitation services and interventions that aim to prevent activity limitations and to promote independence, participation and inclusion. Tertiary prevention strategies are discussed in the elements on Rehabilitation and Assistive devices.

**Fig 1: Three levels of prevention**



## Anita stands tall

Anita is a 50 year-old woman who lives in Khandale village, situated in a hilly area of Raigad District, Maharashtra, India. One day Anita sustained a small injury to her right foot. She quickly developed pain in her leg and after a few days it turned black. Her son took her to Alibaug Hospital, 15 km away, where they advised her to go to a specialized hospital in Mumbai, 100 km away. Health personnel in Mumbai immediately diagnosed Anita with diabetes and amputated her right leg below the knee as it had developed gangrene. Immediately following surgery, Anita's family took her back to their village as they could not afford to stay in the city. Anita was unable to walk so her son had to carry her on his back.

The village health worker informed Anita and her family about a CBR programme that provided free health services for people who had lost a limb. Anita visited the CBR programme at the health centre close to her village. Her amputated stump was checked to ensure proper healing and her left leg/foot was assessed to check for early sensory and circulation changes. Anita learnt about diabetes and how to control the condition with medicine, regular exercise and diet. She has also learned about proper foot care to prevent her left leg from being amputated in the future. Anita was given crutches and trained in how to use them.

Later a team of health professionals visited the health centre and fitted Anita with a prosthesis and a good pair of shoes to ensure her left foot was protected from injury. She was given gait training to ensure she could walk properly with her prosthesis and CBR personnel constructed parallel bars outside her hut so she could practise walking with her prosthesis at home. Gradually Anita's confidence improved, until she was able to walk independently with her prosthesis and return to household tasks and work in the fields. She continues to take her medication on a regular basis and has regular health check-ups. Anita says that her quality of life has improved and with the help of the CBR programme and others she has succeeded in preventing further health complications as a result of her diabetes.

## What does prevention mean for people with disabilities?

Like everybody, people with disabilities are exposed to risk factors for which they require routine preventive health care, e.g. immunizations. However, they may also require targeted and specialized interventions because often they are more vulnerable to the health risks present in the community. For example, in situations of poverty people with disabilities have the least access to safe water and sanitation facilities. Poor access to these facilities can force them to follow unhygienic practices, putting their health at risk and contributing to keeping them poor and unable to improve their livelihoods

(26). In these situations, special facilities or modifications may need to be provided for people with disabilities.

People with disabilities are also at risk of secondary conditions (i.e. health problems or complications which are related to their primary health condition). Examples include: pressure sores, urinary tract infections, joint contractures, pain, obesity, osteoporosis and depression. These secondary conditions can be addressed with early intervention and many of them can be prevented altogether. For example, a person with paraplegia can prevent pressure sores with good skin care and prevent urinary tract infections with good bladder management.

## BOX 10

## Viet Nam

### Making home environments accessible

Handicap International supported the establishment of a Spinal Cord Injury department at a rehabilitation hospital in Ho Chi Minh City, Viet Nam. CBR personnel working in this department were responsible for following up discharged patients, with the aim of preventing secondary conditions and ensuring their home environments were wheelchair-accessible. CBR personnel tried to ensure follow-up for all patients, but due to limited human resources and the large coverage area, only 25% of individuals were seen and often those in greatest need were missed. Medical and CBR personnel decided to implement a new system whereby patients were prioritized – home visits were provided for high-risk individuals and telephone calls and education booklets were provided for low-risk individuals. As a result, the rehabilitation hospital has seen a decrease in readmissions. This initiative has also proved to be more cost-effective and less stressful for CBR personnel.

### What does prevention mean for people without disabilities?

Prevention is just as important for people without disabilities as it is for those with disabilities. Many health conditions associated with impairment and disability can be prevented, e.g. 80% of all blindness in adults is preventable or treatable and approximately half of all childhood blindness can be avoided by treating diseases early and by correcting abnormalities at birth, e.g. cataract and glaucoma (27). The Fifty-eighth World Health Assembly resolution on *Disability, including prevention, management and rehabilitation* (WHA58.23) (28) urges Member States to increase public awareness about the importance of the issue of disability and to coordinate the efforts of all sectors to participate in disability prevention activities.

Sensitivity is required when promoting programmes or initiatives that are focused on preventing health conditions and impairments associated with disability because many people within the disability community may find this threatening or offensive and view it as an attempt to prevent people with disabilities from existing. There should be no

conflict between prevention interventions that try to reduce disability-related health conditions and those that maintain and improve the health of people with disabilities (29).

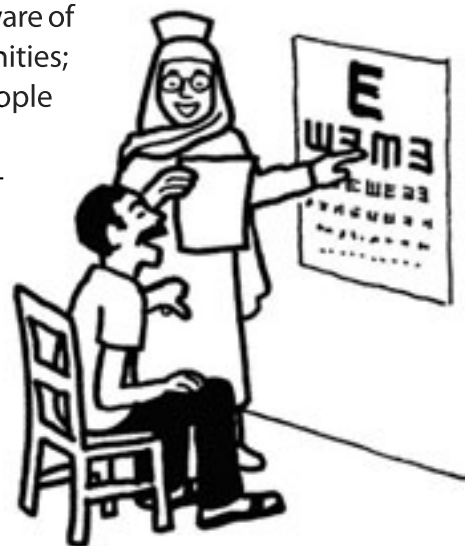
## Suggested activities

As prevention is closely associated with health promotion and medical care, it is important to note that there is overlap between the suggested activities mentioned in all three elements and it is suggested that all three be read together. The main focus here is on primary prevention activities; violence and HIV are not included, as they are addressed in the Social component and the Supplementary chapter on CBR and HIV/AIDS.

### Facilitate access to existing prevention programmes

CBR programmes can gather information about existing prevention activities in their communities and work with prevention programmes to include people with disabilities, thus ensuring greater coverage. CBR programmes can:

- ensure that people with disabilities and their families are aware of the types of prevention activities available in their communities;
- ensure that health personnel are aware of the needs of people with disabilities;
- ensure that information about prevention activities is available in appropriate formats and in a variety of locations close to where people live;
- determine if locations where prevention activities take place are physically accessible and if not, provide practical ideas and solutions to make them accessible;
- determine whether prevention services can be provided in alternative locations, e.g. in home environments, when access is difficult.



#### BOX 11

## Kenya

### Meeting the needs of wheelchair users

A health centre run by a nongovernmental organization in the Korogocho area of Nairobi, Kenya, was not wheelchair-accessible owing to a number of steps. As a result, vaccination programmes were not accessible for people with physical disabilities (e.g. children with cerebral palsy), so health workers would direct families to a rehabilitation centre in the city. The CBR programme organized a meeting to discuss the issue with health workers and a simple solution was identified whereby the health centre agreed to vaccinate children with disabilities on the ground floor of the building.

## Promote healthy behaviours and lifestyles

Healthy behaviours, such as not smoking, drinking only small amounts of alcohol, healthy eating, exercising regularly and wearing condoms during sex, can reduce the risk of developing health problems. Prevention programmes often use health promotion strategies to encourage healthy behaviours, e.g. awareness campaigns to communicate prevention messages within communities and education for individuals. See element on Health promotion for suggested activities to promote good health behaviours.

## Encourage immunization

Within each community, immunization programmes should be available for specific diseases and for high-risk groups, e.g. poliomyelitis, diphtheria, tetanus and measles vaccinations for infants and young children and tetanus vaccination for pregnant women. CBR programmes can:

- become actively involved in awareness campaigns to promote immunization for all community members including people with disabilities;
- make contact with primary health care workers to educate them about the importance of immunization for people with disabilities, especially children with disabilities, despite existing impairments;
- work with primary health-care services to ensure that people with disabilities and their family members are able to access vaccination programmes in their communities;
- ensure that people receiving support and assistance from CBR programmes have received the recommended immunizations, e.g. children with disabilities, their brothers and sisters, pregnant mothers of children with disabilities;
- provide information about the location of safe and reputable services for people who have not received recommended immunizations and support them to access these services as necessary;
- work with primary health-care services to make alternative arrangements for people who are unable to access vaccination programmes, e.g. children with disabilities who are not attending school.

### BOX 12

## Malaysia

### Saving young lives

The national CBR programme in Malaysia works very closely with primary health-care services to ensure that people with disabilities are able to access those activities conducted by primary health care personnel, including rubella immunization for young mothers and immunization programmes for children.



## Ensure proper nutrition

Poor nutrition (malnutrition) usually results from not getting enough to eat and poor eating habits and is a common cause of health problems. Ensuring adequate food and nutrition in communities is the responsibility of many development sectors with which CBR programmes need to collaborate. In relation to the health sector, some suggested activities for CBR programmes include the following:

- ensure that CBR personnel are able to identify people (both with and without disabilities) with signs of malnutrition and provide referral to health workers for proper assessment and management;
- encourage the use of iron-rich and vitamin-rich foods that are locally available, e.g. spinach, drumstick leaves, whole grains, papaya fruit – demonstrating low-cost, nutritious recipes is one way to encourage people to eat nutritious foods;
- ensure that children with disabilities get sufficient and appropriate food to eat – children with disabilities are often neglected, especially those with feeding problems;
- identify people with disabilities who have feeding difficulties, e.g. children with cerebral palsy who have chewing and swallowing problems, and provide referrals to speech and language therapists where possible;
- provide simple suggestions to families about ways to assist people with disabilities to eat and drink, e.g. proper positioning to make feeding safer and easier;
- identify nutrition initiatives available in the community and ensure that people with disabilities can access these, e.g. children with disabilities are actively included in programmes which monitor growth and provide micronutrients and supplementary food;
- promote breastfeeding and encourage pregnant women to attend antenatal care for iron and folic acid supplements (see Facilitate access to maternal and child health care, below).



## Gaining strength through nutrition

The Sanjivini Trust in Bangalore, India, has been working with women and children for over a decade. One of its main interventions has been to address the issue of malnutrition in children, especially those below five years of age. Convinced that in many children belonging to poor families malnutrition occurs during the transition from breast milk to semi-solid foods to solid foods, due to nonavailability of suitable food, the Trust provides a nutritional supplement – an energy-protein-rich powder – to all malnourished children once a month. Volunteers are trained to prepare the supplement and distribute it to needy children after identifying them. Mothers are given nutrition education and shown how to prepare low-cost nutritious meals using locally-available grains and vegetables. Sanjivini also works in collaboration with other organizations that provide rehabilitation for children with disabilities, by providing them the nutritional supplement. Children with special needs, e.g. those with feeding problems, have used the supplement consistently and have benefited enormously from it.

Afreen is nine years old and has cerebral palsy. She lives with her parents and two sisters in Illysnagar slum, Bangalore. Her parents work for a daily wage of Rs 70 in a local factory. Her family migrated to Bangalore when Afreen was six years old. Due to a complication during her delivery, Afreen developed cerebral palsy. She was fed only on liquid foods and as a result was malnourished and bedridden, poorly developed and had frequent diarrhoea and seizures. The CBR worker was unable to give Afreen any form of therapy due to her condition, so she was given the nutritional supplement and over a period of one year Afreen gradually improved in health and developed strength. Afreen now goes to the coaching centre for therapy and stimulation; her family is overjoyed at her improvement and her mother is able to introduce her to other foods.

## Facilitate access to maternal and child health care

Antenatal care, skilled care during delivery and postnatal care reduce the risk of mothers and babies developing health conditions and/or impairments that may lead to disability. CBR programmes should:

- identify maternal health services available in the community, e.g. antenatal care;
- provide all women with information about maternal health services and encourage them to access these;
- provide additional support for women with disabilities when access to maternal health-care services might be difficult, e.g. provide advocacy where discrimination is present within the health-care system;
- refer women and their families for genetic counselling where they have specific questions or concerns related to current or future pregnancies, e.g. a couple with a disabled child might ask if their next child will inherit the same condition/impairment;

- advise health services about access issues for pregnant women with disabilities, e.g. provide suggestions about appropriate communication methods and how to make hospitals/delivery rooms accessible;
- find out if there are training programmes for traditional birth attendants operating in the local communities and ensure that these programmes include information on disability and early recognition of impairments;
- encourage families to register children with disabilities with the local authorities at birth.

## BOX 14

## Mongolia

### Easing the stress of pregnancy

In some villages of north-west Mongolia, many women have hip dislocation. When these women become pregnant, they find that the additional weight puts extra stress on their hips, worsening their pain and disability. The National CBR programme in Mongolia works with these women, providing advice regarding planned intervals between pregnancies and adequate rest during the later stages of pregnancy.

### Promote clean water and sanitation

Water and sanitation measures contribute to improving healthy living and minimizing disability. CBR programmes can help to ensure that the needs of people with disabilities are considered by:

- talking to people with disabilities and their family members about the barriers they face when accessing and using water and sanitation facilities, e.g. people with disabilities may be unable to access water sources because they live too far away, the terrain is too rough and/or the method for obtaining water from the wells is too difficult;
- making local authorities and water and sanitation organizations aware of these barriers and providing suggestions and ideas for ways to overcome the barriers in partnership with people with disabilities and their family members;
- lobbying and working with local authorities to adapt existing facilities and/or build new facilities, e.g. installing raised toilet seats and handrails to provide support for people who are unable to use a squat latrine;
- encouraging community members to support and assist people with disabilities where needed, e.g. encourage neighbours to accompany a person with a disability when fetching water.



## Help to prevent injuries

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Many disabilities are caused by accidents at home, at work or in the community. Often adults and children with disabilities are also at higher risk of injury. CBR programmes can play a role in injury prevention in their communities by:

- identifying the major causes of injury in the home and community (e.g. burns, drowning, road accidents) and identifying those groups most at risk (e.g. children);
- creating awareness in the community about the common causes of injuries and how to prevent these; this might include a health promotion campaign (see Health promotion element);
- working with local authorities and community groups regarding actions to take to reduce the occurrence of injuries in the home and community, e.g. to prevent injuries during big festivals;
- providing suggestions for families about how to prevent injuries in the home, e.g. watching children when they are near water or open fires, keeping poisons locked away and out of reach of children, keeping children away from balconies, roof edges and stairs and not allowing children to play with sharp objects;
- providing education for employers and workers about how to prevent injuries in the workplace, e.g. wearing appropriate safety equipment on construction sites (shoes, helmets, gloves, earplugs);
- providing education for schoolchildren about road safety, e.g. on how to cross roads safely, wearing seatbelts in motor vehicles and wearing helmets when riding bicycles and motorbikes.

## Help to prevent secondary conditions

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People of all ages with disabilities are at risk of secondary conditions. CBR programmes can promote primary prevention strategies to reduce the likelihood that people with disabilities will develop these conditions. It is suggested that CBR programmes should:

- ensure that people with disabilities and their family members are aware and knowledgeable about the secondary conditions commonly associated with their disabilities, e.g. people with spinal cord injuries or spina bifida (and their families) should be aware that they are at a high risk of developing urinary tract infections;
- assist people with disabilities and their families to identify strategies to prevent secondary conditions from developing, e.g. adopting healthy lifestyle behaviours such as exercise and good nutrition, having regular health check-ups, maintaining good hygiene and joining self-help groups;
- ensure that any assistive devices provided to people with disabilities do not create risks for secondary conditions, e.g. that prostheses fit properly and do not cause red marks which can lead to pressure sores.

# Medical care

## Introduction

Medical care can be defined as the identification, assessment and treatment of health conditions and/or resulting impairments. Medical care can: provide a cure (e.g. treatment of leprosy or malaria), reduce the impact (e.g. treatment of epilepsy), and prevent avoidable impairments (e.g. treatment of diabetes to prevent blindness). Access to quality medical care, when and as often as needed, is critical for maintaining good health and functioning (30), particularly for people with disabilities who may experience poor levels of health.

In the Preamble, we referred to the Convention on the Rights of Persons with Disabilities, Article 25, and the measures States Parties are required to undertake regarding health services for people with disabilities, including: providing people with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other people; providing those health services as needed by people with disabilities specifically because of their disabilities, including early identification and intervention as appropriate; and providing services as close as possible to people's own communities (2).

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (23) also outline a list of responsibilities for States regarding medical care and highlight medical care as a precondition for equal participation in all life activities.

With guidance from the Convention and Standard Rules, CBR personnel can work within their communities to ensure that people with disabilities are able to access inclusive, appropriate and timely medical care.



## Adnan's big change

Irene and Mohammed live in the United Republic of Tanzania. They were overjoyed when Adnan was born as they already had a six-year-old daughter and had waited a long time for another child. When Adnan was approximately two months old they noticed that his head appeared to get smaller. Irene and Mohammed took Adnan to the local hospital for medical care. An X-ray was taken after which the doctors told Irene and Mohammed that there was nothing to worry about. However as Adnan grew older it became obvious that he was unable to perform simple tasks or follow basic instructions and his behaviour become increasingly challenging. He also experienced regular convulsions. Irene explains, "He never spoke or made much sound so I never thought he understood anything and I didn't really talk to him. What was the point? But his behaviour got worse and worse."

Adnan only started walking at the age of four and when he was playing in the street one day, a passer-by, recognizing that Adnan had an intellectual impairment, told Irene and Mohammed about the local CBR programme run by a nongovernmental organization called Comprehensive Community Based Rehabilitation in Tanzania (CCBRT). Adnan's parents contacted CCBRT and requested support and advice. Mama Kitenge, a CBR worker, started visiting their home regularly, providing education and therapy. She also helped the family access medical care to manage his convulsions. As a result, Adnan now takes regular medication to control his epilepsy.

Irene said "Before I joined the programme, Adnan was unable to do anything himself. He couldn't eat or dress himself or wash his hands. He was not a settled, happy child. He just walked around all day and often got lost. I did not know what to do with him. The training has been really helpful, especially in instructions. Now I talk to him all the time and he understands what I say. He can carry water, feed himself and wash his face. I have shown him the way back home from the water point many times, always pointing out the same things to look for, so now he knows his way back home if he gets lost. He takes his epilepsy medicines regularly and does not have fits. It is a big change from before."



## Goal

People with disabilities access medical care, both general and specialized, based on their individual needs.

## The role of CBR

The role of CBR is to work in collaboration with people with disabilities, their families and medical services to ensure that people with disabilities can access services designed to identify, prevent, minimize and/or correct health conditions and impairments.

## Desirable outcomes

- CBR personnel are knowledgeable about medical care services and able to facilitate referrals for people with disabilities and their families for general or specialized medical care needs.
- People with disabilities and their families access activities that are aimed at the early identification of health conditions and impairments (screening and diagnostic services).
- Medical care facilities are inclusive and have improved access for people with disabilities.
- People with disabilities can access surgical care to minimize or correct impairments, thus contributing to improved health and functioning.
- People with disabilities and their families develop self-management skills whereby they are able to ask questions, discuss treatment options, make informed decisions about medical care and manage their health conditions.
- Medical care personnel have increased awareness regarding the medical needs of people with disabilities, respect their rights and dignity and provide quality services.

## Key concepts

### Types of medical care

Many health systems in low-income countries have three levels of health care: primary, secondary and tertiary. These are usually linked to each other by a referral system, e.g. primary health care workers refer people to secondary care when needed. While there is often overlap between each level, e.g. primary health care might be provided in a place that normally provides secondary health care, it is important for CBR personnel to understand the basic differences between the levels so they can facilitate access for people with disabilities and their family members.

**Primary level of care** refers to basic health care at the community level. It is usually provided through health centres or clinics and is usually the first contact people have with the health system. Medical care provided at primary level includes short simple treatments for acute conditions (e.g. infections) and routine management of chronic conditions (e.g. leprosy, epilepsy, tuberculosis, diabetes). CBR programmes work at the community level and so work closely with primary health-care services (14).

**Secondary level of care** refers to more specialized medical services that are provided by large clinics or hospitals which are usually present at the district level. Primary health care provides an important link to secondary care through referral mechanisms.

**Tertiary level of care** is highly specialized medical care. It is provided by specialized medical professionals in association with nurses and paramedical staff and involves the use of specialized technology. These services are provided by large hospitals usually located in major cities at the national or regional level. Medical care provided at the tertiary level might include brain surgery, cancer care or orthopaedic surgery.

## **Medical care for people with disabilities**

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Medical staff often refer people with disabilities to rehabilitation services for general medical care instead of treating them at primary health care facilities. This is because they lack the awareness that, like the general population, people with disabilities may acquire a general health condition at any stage throughout their life for which they will need medical care, particularly primary health care. For example, medical care may be needed for respiratory infections, influenza, high blood pressure, middle ear infections, diabetes, tuberculosis or malaria.

Health-care personnel have an important role to play in the early identification of conditions that can lead to impairments. It is important that all health conditions are identified and treated early (secondary prevention). Some health conditions, if left untreated or uncontrolled, can lead to new impairments or exacerbate existing impairments in people with disabilities. Early intervention is less traumatic, is cost-effective and produces better outcomes.

Many people with disabilities also have specific medical care needs for limited or lifelong periods of time, e.g. people with epilepsy or people with mental health problems may require drug regimens over a long period of time. Some people with disabilities may also require surgery to address their impairments.



## BOX 16

### Epilepsy

Epilepsy (seizures) is a chronic neurological disorder which commonly leads to disability, particularly in developing regions. People with epilepsy and their families often suffer from stigma and discrimination. There are many misconceptions and myths regarding epilepsy and its appropriate treatment. Recent studies in both high-income and low-income countries have shown that up to 70% of newly diagnosed children and adults with epilepsy can be successfully treated (i.e. their seizures completely controlled) with anti-epileptic drugs. After two to five years of successful treatment, drugs can be withdrawn in about 70% of children and 60% of adults without relapses. However approximately three fourths of people with epilepsy in low-income countries do not get the treatment they need (31).

### Surgery

Surgery is a part of medical care and is usually provided at the secondary or tertiary levels of the health-care system. Some types of surgery can correct impairments or prevent or limit deformities and complications that may be associated with impairments. Examples of surgery include removal of cataracts that are causing visual impairment, orthopaedic surgery to address fractures or spinal deformities and reconstructive surgery for cleft lip and palate, burns, or leprosy.

There are many things to consider before surgery is undertaken. Families may have limited knowledge and understanding regarding surgery, so they must be informed properly about the benefits and consequences. Surgical care is often very expensive and, without social security or health insurance, it will be difficult to access for poor people. Successful outcomes from surgery are dependent on comprehensive follow-up – following surgery, people may require further medical care, therapy and assistive devices, so close links are required between medical and rehabilitation professionals. It is important to remember that surgery alone cannot address all problems that may be related to impairment and disability.

## Learning about possibilities

Patrick, from Kyenyojo District in Kenya, was born in 1987 with clubfeet. His sister Sara was also born with clubfeet. Patrick says that he stayed with the disability until 17 years of age when he heard a radio announcement asking children with disabilities to go to Kamwengye town. “For all these years, I was always isolated among my peers. When I heard the radio announcement I had mixed feelings, I was not sure that something could be done about my feet. But finally I went to the Kamwengye Outreach Centre. I found lots of other children with disabilities there as well. I never knew that other people were going through similar experiences. After two surgeries my feet were corrected and above all I am happy that I can put on regular shoes now, something that was a dream. Walking is easier each passing day. My younger sister, who is now 14 years, also had surgery. It is very important to know for all communities, that medical and rehabilitation services for children with disabilities are available and possible. People in our area were not aware of these services. Sara and myself, we are doing our best to inform our families, friends and community about such services. We, together with other people with disabilities, are part of the society and want to be engaged in normal activities in churches, schools and other groups. Ever since my sister and I were operated on, many people now believe that it is possible that other children with disabilities can regain their lost hope.”

## Self-management

Self-management (also commonly referred to as self-care or self-care management) does not mean managing your health without medical intervention. Self-management involves people taking control over their health – they are responsible for making informed choices and decisions about medical care and for playing an active role in carrying out care plans to improve and maintain their health. It requires a good relationship between individuals and their health-care personnel to ensure that good health outcomes are achieved. People who self-manage their care:

- communicate regularly and effectively with health personnel;
- participate in decision-making and care planning;
- request, obtain and understand health information;
- follow a treatment regimen that has been drawn up with health personnel;
- perform appropriate self-care activities, as agreed with health personnel.

Self-management is important for people who experience a lifelong disability, e.g. paraplegia, or a chronic condition such as diabetes. Health workers may ignore the role which people with disabilities and their families can play in self-management. Equally, individuals may lack the skills to ensure they take increased responsibility for their own health.

Self-help groups can provide a good opportunity for people with disabilities to learn about self-management through the sharing of knowledge and skills with others. Often valuable information is learnt regarding available medical-care resources, how to negotiate the health-care system effectively and how to manage existing health conditions.

## BOX 18

# El Salvador

## Strength in numbers

The Italian association Amici di Raoul Follereau (AIFO/Italy) together with the Disability and Rehabilitation team at the World Health Organization and Disabled People International, carried out research across several countries to determine whether people could learn self-management skills and play a more active role in improving their own medical care if they got together as a group of people with disabilities with similar medical care needs. Pilot projects were asked to: identify and create groups of people with disabilities with similar medical care needs; identify the main medical care needs; in collaboration with health professionals, provide knowledge and skills for self-care for addressing the identified needs; assess if the quality of self-care and medical care by people with disabilities and/or family members had improved; and determine if the knowledge and skills of people with disabilities was recognized and given some role within the medical care system.

A pilot project in El Salvador focused on spinal cord injury. AIFO/Italy, in partnership with Don Bosco University and Instituto Salvadoreño Para La Riabilitación de Inválidos, worked with 30 people with spinal cord injuries and their families from the areas of San Salvador and the village of Tonacatepeque. Four self-help groups were formed and regular meetings were held. Members of these groups identified their major medical care needs which included: urine, bladder and kidney issues; pressure sores; joint stiffness; and sexuality and parenthood-related issues. Health professionals involved in the project provided self-management skills training to address the issues that had been identified. Over time, members of the self-help groups and health professionals involved in the project began to change their thinking. They realized that with proper support and training, people with spinal cord injury could manage their health and achieve a better quality of life. They also realized that health professionals needed to look beyond their traditional medical roles and facilitate and promote self-management/care – a concept of shared responsibility. Members of the self-help groups went on to form their own association called ALMES (Asociación de Personas con Lesión Medular de El Salvador).

## Suggested activities

CBR programmes can carry out the following activities to promote access to medical care for people with disabilities.

### Gather information about medical services

Knowledge of the medical services available at primary, secondary and tertiary levels of the health system is essential for assisting people with disabilities and their families to access medical care and support. CBR programmes can:

- identify existing medical services at the local, district and national levels, ensuring that government, private and nongovernmental service providers are identified, including providers of traditional medicine, if relevant;
- initiate contact with the service providers and gather information regarding the type of medical care provided, accessibility, costs, schedules and referral mechanisms;
- compile a service directory to ensure that all information is accessible for CBR personnel, individuals and communities – ensure service directories are available in local languages and accessible formats and made available in places where health care is provided.

### Assist with early identification

CBR programmes can:

- establish a mechanism for the early identification of health conditions and impairments associated with disability in partnership with primary health care personnel;
- identify screening activities aimed at the early identification of communicable or noncommunicable diseases, e.g. tuberculosis, leprosy, filariasis, river blindness, diabetes, cancer;
- provide information to people with disabilities and their families about the timing and location of screening activities and ensure they are able to access these;
- ensure members of families that have a history of genetic or hereditary conditions, e.g. muscular dystrophy, are referred to appropriate medical facilities for assessment and counselling;
- be aware of secondary conditions, e.g. pressure sores that are associated with particular disabilities and check for these when working with people with disabilities;
- identify people with impairments in the community who may benefit from surgery.



## Joining forces to provide care

CBR programmes run by two nongovernmental organizations in the Mandya District of India collaborate with the national leprosy programme. They are involved in awareness-raising activities providing information about the early signs and symptoms of leprosy and encouraging people with suspected lesions to visit their nearest primary health care service. People who are diagnosed with leprosy commence a 6–12 month treatment regimen, which is provided free by the primary health care service. If people fail to attend treatment, the primary health care service requests the CBR programme to follow up these individuals.

### Ensure access to early treatment

CBR programmes can promote and encourage collaboration between people with disabilities, their families and primary health care workers to increase access to medical care services at all levels. Suggested activities include:

- checking with health workers to make sure people with disabilities who have been included in screening activities are provided with follow-up medical care if required;
- checking with health workers to make sure referrals have been made for people with disabilities who require access to secondary and tertiary levels of health care;
- advocacy, e.g. CBR personnel who know sign language may accompany deaf persons to health facilities to ensure that they are able to communicate their needs and understand the information being provided and support them to access appropriate treatment;
- raising awareness about the barriers that prevent access to medical care and working with others to reduce or eliminate these barriers – innovative mechanisms may be required to address some barriers, e.g. the costs associated with medical care;
- identifying gaps in service provision for people with disabilities and exploring, with others (e.g. people with disabilities, family members, medical staff, policy-makers), ways in which these gaps can be reduced or eliminated.



## Building on success

Clubfoot or congenital foot deformities are birth defects that often lead to disability in low-income countries. The Community Agency for Rehabilitation and Education of Persons with Disabilities, Belize (CARE-Belize), recognized that it was a significant issue for children in Belize. In partnership with the International Hospital for Children and the Ministry of Health, CARE-Belize developed a programme to ensure the early identification and treatment of children with clubfoot.

Local doctors, therapists and rehabilitation field officers were trained to embrace the Ponseti method, a nonsurgical method to correct clubfoot deformities at a very early age using gentle manipulation, serial casting and splinting. Through its CBR personnel, CARE-Belize identified children at a very early age and referred them to medical care services for correction of clubfoot. Although this was originally a local nongovernmental organization initiative, its success has led to the development of a national clubfoot programme.

## Facilitate access to surgical care

Some people with disabilities may require surgical care. When combined with follow-up care and rehabilitation, surgery can correct impairments, prevent them from becoming worse and contribute to improved functioning. CBR programmes can:

- explore what surgical options are available for people with disabilities and particularly whether funding options are available;
- before surgery takes place, check to ensure that people with disabilities and their family members have been well informed of the possible risks and benefits of surgery and that they are aware of the costs and duration of the entire surgical/treatment plan;
- following surgery, check to ensure that people are receiving appropriate follow-up from surgical and nursing teams and rehabilitation professionals (e.g. physiotherapists, occupational therapists, prosthetists/orthotists) to maximize the benefits of surgery – CBR can assist in ensuring a smooth transition from medical care to rehabilitation.

## Promote self-management of chronic conditions

CBR programmes can assist people with disabilities and their families to become aware of their right to medical care and to learn skills that enable them to manage their chronic health conditions. It is suggested that CBR programmes:

- work directly with people with disabilities to encourage them to take responsibility for their own health by seeking appropriate medical care and making healthy lifestyle choices and to ensure they are able to understand and follow medical advice;

- develop or adapt existing materials/publications that provide medical information about health conditions into formats that are appropriate for people with disabilities and their family members, e.g. in simple language, with simple sketches or pictures and translated into local languages;
- link people with disabilities to self-help groups to enable them to learn about self-management through the sharing of knowledge and skills with others – they can learn valuable information about what resources are available for medical care, how to effectively negotiate the health-care system and how to manage existing health conditions.

## BOX 21

# Nicaragua

## Partnerships to create change

In Nicaragua, there are “clubs” for people with chronic conditions, e.g. high blood pressure or diabetes. These clubs, or support groups, add to the efforts of the health-care system by ensuring that people are able to take responsibility for the management of their own health and prevent the development of further conditions and impairments. In the meetings, people talk about their problems, learn how to self-monitor their health conditions and explore solutions such as developing healthy lifestyles. Club management committees carry out fundraising activities to help cover the costs of medicines and laboratory tests, which are not usually provided by the health system. The CBR programme collaborates with these support groups to ensure that people with disabilities are included.



## Build relationships with medical care providers

Medical personnel often have limited knowledge about disability and how best to enable access for people with disabilities to medical care services. By making contact with these services and building relationships with staff, CBR programmes can develop a network which facilitates referrals and comprehensive medical care for people with disabilities. CBR programmes can:

- promote awareness among medical personnel about the health needs of people with disabilities and their families;
- organize interactive sessions between individuals and groups of people with disabilities, family members (where relevant) and medical personnel to enable discussion of key issues related to disability, e.g. access issues and sharing of experiences;

- encourage medical personnel to involve people with disabilities and their family members in the development of medical treatment/care plans;
- request medical services to provide education and training for CBR personnel so they are able to assist with early detection, provide referrals to appropriate services and provide follow-up in the community;
- work jointly with community health programmes to ensure that people with disabilities can access the benefits of these programmes.

## BOX 22

## Indonesia

### Awareness raising in Indonesia

A CBR programme in South Sulawesi, Indonesia, has a multisectoral team including village health workers, primary-school teachers and community volunteers, many of whom have disabilities or are family members of a person with a disability. The CBR team has regular training sessions with personnel from all levels of the health system. These training sessions provide great opportunities for networking, promotion of the medical care needs of people with disabilities and promotion of the role of CBR and medical care services.



# Rehabilitation

## Introduction

As highlighted in the Preamble, access to rehabilitation is essential for people with disabilities to achieve their highest attainable level of health. The Convention on the Rights of Persons with Disabilities, Article 26, calls for “appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life...” (2).

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities state that rehabilitation measures include those which provide and/or restore functions, or compensate for the loss or absence of a function or a functional limitation (23). Rehabilitation can occur at any stage in a person’s life but typically occurs for time-limited periods and involves single or multiple interventions. Rehabilitation may range from more basic interventions such as those provided by community rehabilitation workers and family members to more specialized interventions, such as those provided by therapists.

Successful rehabilitation requires the involvement of all development sectors including health, education, livelihood and social welfare. This element focuses on those measures to improve functioning that are offered within the health sector. It is important to note however that health-related rehabilitation services and the provision of assistive devices are not necessarily managed by the ministry of health (see Rehabilitation services).



## Forging public–private partnerships

The Association for the Physically Disabled of Kenya (APDK) has been providing comprehensive rehabilitation services in Kenya for the past 50 years, reaching over 500 000 people with disabilities. As a result of several partnerships, APDK has been able to establish a national rehabilitation network consisting of nine main branches, 280 associated outreach centres and many community-based rehabilitation programmes; these provide services such as therapy, assistive devices and support for surgical interventions.

One of APDK's successful partnerships has been with the Ministry of Medical Services (formally the Ministry of Health). Over the past 30 years, APDK has worked closely with this Ministry to ensure that quality rehabilitation services are accessible to as many people as possible. Six of the nine APDK branches are located within government hospitals and the Ministry of Medical Services has provided over 50 health workers, mostly therapists and technicians, to work in these branches. The Ministry provides the salary for most of these health workers while APDK funds the programme costs.

APDK established their first CBR programme in their Mombasa branch in 1992. Since 2000, they have extended these programmes to the major slums in Nairobi in order to reach those people with disabilities who are most vulnerable. CBR programmes provide home-based rehabilitation and are an important referral link to APDK outreach centres and branches. With financial support from CBM and Kindernothilfe, APDK has employed 32 CBR personnel to work in these programmes while the government has funded several therapy positions.

APDK is a successful example of a public–private partnership and demonstrates how centre-based rehabilitation and community-based rehabilitation can work together to provide rehabilitation services for people living in both urban and rural areas. In 2008 alone, approximately 52 000 Kenyan people received rehabilitation services from APDK.



## Goal

People with disabilities have access to rehabilitation services which contribute to their overall well-being, inclusion and participation.

## The role of CBR

The role of CBR is to promote, support and implement rehabilitation activities at the community level and facilitate referrals to access more specialized rehabilitation services.

## Desirable outcomes

- People with disabilities receive individual assessments and are involved in the development of rehabilitation plans outlining the services they will receive.
- People with disabilities and their family members understand the role and purpose of rehabilitation and receive accurate information about the services available within the health sector.
- People with disabilities are referred to specialized rehabilitation services and are provided with follow-up to ensure that these services are received and meet their needs.
- Basic rehabilitation services are available at the community level.
- Resource materials to support rehabilitation activities undertaken in the community are available for CBR personnel, people with disabilities and families.
- CBR personnel receive appropriate training, education and support to enable them to undertake rehabilitation activities.

## Key concepts

### Rehabilitation

Rehabilitation is relevant to people experiencing disability from a broad range of health conditions and therefore the CRPD makes reference to both “habilitation” and “rehabilitation”. Habilitation aims to assist those individuals who acquire disabilities congenitally or in early childhood and have not had the opportunity to learn how to function without them. Rehabilitation aims to assist those who experience a loss in function as a result of disease or injury and need to relearn how to perform daily activities to regain maximal function. Habilitation is a newer term and is not commonly used in low-income countries, therefore these guidelines use the term “rehabilitation” to refer to both habilitation and rehabilitation.

## Rehabilitation interventions

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A wide range of rehabilitation interventions can be undertaken within the health sector. Consider the examples below.

- Rehabilitation for a young girl born with cerebral palsy might include play activities to encourage her motor, sensory and language development, an exercise programme to prevent muscle tightness and development of deformities and provision of a wheelchair with a specialized insert to enable proper positioning for functional activities.
- Rehabilitation for a young boy who is deafblind might include working with his parents to ensure they provide stimulating activities to encourage development, functional mobility training to enable him to negotiate his home and community environments and teaching appropriate communication methods such as touch and signs.
- Rehabilitation for an adolescent girl with an intellectual impairment might include teaching her personal hygiene activities, e.g. menstrual care, developing strategies with the family to address behavioural problems and providing opportunities for social interaction enabling safe community access and participation.
- Rehabilitation for a young man with depression might include 1:1 counselling to address underlying issues of depression, training in relaxation techniques to address stress and anxiety and involvement in a support group to increase social interaction and support networks.
- Rehabilitation for a middle-aged woman with a stroke might include lower limb strengthening exercises, gait training, functional training to teach her to dress, bath and eat independently, provision of a walking stick to provide support for balance difficulties and exercises to facilitate speech recovery.
- Rehabilitation for an older man who has diabetes and recently had both legs amputated below the knee might include strengthening exercises, provision of prostheses and/or a wheelchair and functional training to teach mobility and transfer skills and daily living skills.

## Rehabilitation services

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Rehabilitation services are managed by government, private or nongovernment sectors. In most countries, the ministry of health manages these services; in some countries, however, rehabilitation services are managed by other ministries, e.g. by the Ministry of Labour, War Invalids and Social Affairs in Viet Nam and by the ministries of social welfare in India, Ghana and Ethiopia. In some countries, services may be managed through joint partnerships between government ministries and nongovernmental organizations, e.g. in the Islamic Republic of Iran, Kenya and China.

Services are provided by a broad range of personnel including medical professionals (e.g. nurses, psychiatrists), therapy professionals (e.g. occupational therapists, physiotherapists, speech therapists), technology specialists (e.g. orthotists, prosthetists) and rehabilitation workers (e.g. rehabilitation assistants, community rehabilitation workers). Rehabilitation services can be offered in a wide range of settings, including hospitals, clinics, specialist centres or units, community facilities and homes; the phase during

which rehabilitation occurs (e.g. the acute phase following an accident/injury) and the type of interventions required usually determine which setting is appropriate.

In low-income countries and particularly in rural areas, the range of rehabilitation services available and accessible is often limited. There may only be one rehabilitation centre in the major city of a country, for example, or therapists may be available only in hospitals or large clinics. Therefore community-based strategies such as CBR are essential to link and provide people with disabilities and their families with rehabilitation services.

### ***Community-based services***

Historically, CBR was a means of providing services focused on rehabilitation to people living in low-income countries through the use of local community resources. While the concept of CBR has evolved into a broader development strategy, involvement in the provision of rehabilitation services at community level remains a realistic and necessary activity for CBR programmes.

Rehabilitation at specialized centres may not be necessary or practical for many people, particularly those living in rural areas and many rehabilitation activities can be initiated in the community. The WHO manual on *Training in the community for people with disabilities* is a guide to rehabilitation activities that can be carried out in the community using local resources (32).

Community-based services may also be required following rehabilitation at specialized centres. A person may require continued support and assistance in using new skills and knowledge at home and in the community after he/she returns. CBR programmes can provide support by visiting people at home and encouraging them to continue rehabilitation activities as necessary.

Where rehabilitation services are established in the community, close links must be maintained with referral centres that offer specialized rehabilitation services. The needs of many people with disabilities change over time and they may require periodic support in the long term. Successful rehabilitation depends on strong partnerships between people with disabilities, rehabilitation professionals and community-based workers.



## Li's journey to independence

Li, a middle-aged widow, lives with her elderly mother and three children in the Qing Hai province of China. Her whole family depended on her before an accident in October 2003. Li fell from a height while repairing her house and sustained a spinal fracture, resulting in weakness and sensory loss in both legs. After she was discharged from hospital, she stayed in bed all day and night. Swelling quickly developed in both her legs and she required full assistance from her children to turn in bed, bathe, change her clothes and use the toilet. Li soon lost her confidence and tried to commit suicide several times; fortunately, she was unsuccessful.

A village rehabilitation officer from a local CBR programme came to visit Li and provided her with home-based rehabilitation. Li was taught new ways of completing daily living activities using her residual abilities. She was given information about her disability and learnt how to prevent bed sores and urinary tract infections. Her family and friends were taught how to make a simple walking frame for her to practise standing and walking. They also made a simple toilet bowl to solve the problem of going to the toilet. The County Rehabilitation Centre provided crutches and a wheelchair. With time and practice Li was able to stand and walk independently with crutches and use a wheelchair for longer distances.

Step by step, Li built up her confidence. She was soon able to manage her own daily activities, which included cooking for her family, an activity she really enjoyed. Li also opened a mill, providing her with a source of income which, together with a small monthly living allowance from the County Ministry of Civil Affairs, allows her once again to care for her family and be confident about the future.

## Rehabilitation plans

Rehabilitation plans need to be person-centred, goal-oriented and realistic. When developing a plan, a person's preferences, age, gender, socioeconomic status and home environment need to be considered. Rehabilitation is often a long journey, and a long-term vision is required, with short-term goals. Valuable resources can be wasted when rehabilitation plans are not realistic.

Many rehabilitation plans fail because people with disabilities are not consulted; it is important to ensure that their opinions and choices influence the development of the plan and that the realities of their lives, in particular the issue of poverty, are considered. For example, a plan that requires a poor person living in a rural area to travel frequently to the city for physiotherapy is likely to fail. Rehabilitation personnel need to be innovative and develop appropriate rehabilitation programmes which are available as close as possible to home, including in rural areas.

Rehabilitation needs may change over time, particularly during periods of transition, e.g. when a child starts school, a young adult starts work, or a person returns to live in her/his community following a stay in a rehabilitation facility. During these transitions, adjustments will need to be made to the rehabilitation plans to ensure the activities continue to be appropriate and relevant.

## Suggested activities

### Identify needs

Before making a rehabilitation plan and starting activities, it is important for CBR personnel to carry out a basic assessment with an individual and his/her family members to identify needs and priorities. Assessment is an important skill, so CBR personnel should receive prior training and supervision to ensure competency in this area. To identify a person's needs it can be helpful to consider the following questions.

- What activities can they do and not do?
- What do they want to be able to do?
- What problems do they experience? How and when did these problems begin?
- What areas are affected? e.g. body, senses, mind, communication, behaviour?
- What secondary problems are developing?
- What is their home and community situation like?
- In what way have they adjusted to their disability?

Accurate information can be obtained by reviewing past medical records, observing the individual, performing a basic physical examination of the individual and through discussions with the individual, family members and involved health professionals/services. It is important to keep a record of the initial assessment and future consultations, so an individual's progress can be monitored over time. Many CBR programmes have developed assessment forms and progress notes to make this easier for their staff.

### Facilitate referral and provide follow-up

If, following the basic assessment, CBR personnel identify a need for specialized rehabilitation services, e.g. physiotherapy, occupational therapy, audiology, speech therapy, they can facilitate access for people with disabilities by initiating referrals. The following activities are suggested.

- Identify rehabilitation referral services available at all levels of the health system.
- Provide information regarding referral services to people with disabilities and their families, including location, possible benefits and potential costs.
- Encourage people with disabilities and their families to express concerns and ask questions about referral services. Help them to seek additional information if required. Links can be made with other people in the community who experience similar problems and have benefited from the same or similar services.

- Ensure people with disabilities and their family members give informed consent before any referral is made.
- Once a referral is made, maintain regular contact with the services and individuals involved to ensure that appointments have been made and attended.
- Identify what support is required to facilitate access to services (e.g. financial, transport, advocacy) and how this can be provided. For example, if advocacy is required, CBR personnel can accompany people to their appointments.
- Provide follow-up after appointments to determine whether ongoing support is needed, e.g. rehabilitation activities may need to be continued at home.

Specialized rehabilitation services are often based in large urban centres and this can restrict access for people living in rural/remote areas. Consideration must be given to the costs associated with a visit to the city, including transport, food, accommodation and loss of daily wages; many services also require out-of-pocket payments. CBR programmes should be aware of financial constraints and ensure that a wide range of options are investigated including government and/or nongovernmental organization schemes, bank loans and community support.

## BOX 25

## Iran

### No place too far from services

The CBR programme in the Islamic Republic of Iran encourages village health workers and CBR personnel to identify people with disabilities early and refer them to the primary health-care services in the community. Following referral, a mobile team of rehabilitation personnel visit the home to provide home-based rehabilitation. If specialized interventions are required, referral is made to a tertiary-level care centre, usually in the provincial headquarters or capital city. Following rehabilitation at a specialized centre, people are referred back to the primary health-care services, which work with the CBR programme to ensure that rehabilitation activities are continued, if necessary. The mobile team provides follow-up to monitor progress and provide further assistance when required.

### Facilitate rehabilitation activities

CBR programmes can facilitate home and/or community-based therapy services and provide assistance to people with a wide range of impairments, enabling them to maintain and maximize their function within their home and community.

#### *Provide early intervention activities for child development*

Every child goes through a learning process enabling him/her to master important skills for life. The major areas of child development include: physical development, speech and language development, cognitive development and social and emotional development.



Delays in development occur when a child is unable to reach the important milestones suitable for his/her age group. Through early intervention, children at risk of, or with, developmental delay are identified as early as possible and provided with focused rehabilitation interventions to prevent or improve this delay.

The presence of a disability, e.g. cerebral palsy, blindness or deafness, can result in developmental delay and restrict a child's ability to participate in regular activities such as playing with other children and going to school. CBR personnel can provide early intervention activities, usually home-based, to encourage simple and enjoyable learning opportunities for development. CBR programmes can also encourage parents to meet together to share ideas and experiences and facilitate playgroups, so their children learn to play with other children, learn new skills and improve in all areas of development.

## BOX 26

## Egypt

### Fun for families

The CBR programme in Alexandria, Egypt, has several clubs that meet weekly in different parts of the city, including in a local stadium and a mosque. Parents come with their children who have disabilities to participate in activities organized by the CBR programme and community volunteers. There is a range of fun activities for children, e.g. singing and dancing contests, and parents are given the opportunity to talk and share their experiences with one another and to attend training sessions.

### *Encourage functional independence*

Functional interventions aim to improve an individual's level of independence in daily living skills, e.g. mobility, communication, bathing, toileting, dressing, eating, drinking, cooking, housework. Interventions are dependent on a person's age, gender and local environment and will change over time as she/he makes a transition from one life stage to another. CBR personnel can provide:

- training for people with disabilities and their families about the different ways to carry out activities;
- education for families on how to best assist people with disabilities in functional activities to maximize their independence;
- training in the use of assistive devices, e.g. walking/mobility devices to make activities easier;
- education and instruction on specific techniques used to address impairments, e.g. muscle weakness, poor balance and muscle tightness, which impact a person's ability to carry out activities; this might include strengthening, stretching and fitness programmes.



## Learning to view life differently

Shirley lives in a village in Guyana. She is blind and because of this her mother was afraid to allow her to go outside the house alone, fearful that she would hurt herself. When CBR volunteers visited Shirley's house, they talked to her mother and said that it was possible to teach Shirley how to move outside independently. It was difficult to convince Shirley's mother. The CBR volunteer asked Pauline, a CBR regional coordinator, to visit the house. As Pauline was blind herself, the CBR volunteer thought that she would be a good example and motivator for both Shirley and her mother. Shirley's mother agreed and a rehabilitation plan was made to facilitate greater functional independence for Shirley. Shirley made rapid progress and is now able to move around her community independently with the help of a white cane. She has become an active member of the local CBR committee and a member of the disabled people's organization.

### *Facilitate environmental modifications*

Environmental modifications may be necessary to improve the functional independence of a person with a disability. CBR personnel may facilitate environmental modifications at an individual level (in the home), e.g. ramps for wheelchair access, handrails near steps, toilet adaptations and widening doorways, or at community level, e.g. modification of the school environment, public buildings or work places (see Assistive devices element).

## A grandmother finds her way

An elderly grandmother in the village of Thai Binh, Viet Nam, had diabetes and low vision. She needed to go to the toilet frequently, especially during the night, and as the toilet was outside in the courtyard she had to wake a family member to accompany her. A volunteer from the local CBR programme advised the family to fix a cord from her bed to the toilet, so that during the night she could follow the cord to the toilet without waking her family. A simple environmental modification ensured this grandmother's independence.



### *Link to self-help groups*

CBR programmes promote self-help groups where people with similar impairments or similar rehabilitation needs come together to share information, ideas and experiences. CBR programmes can encourage interactions between these groups and rehabilitation professionals to enable mutual understanding and collaboration.

#### **BOX 29**

## India

### **Recognising the support of hospitals**

A CBR programme in a poor area of Greater Mumbai, India, often involves staff from rehabilitation institutions as trainers and teachers for CBR personnel. The CBR programme found that many families with people with disabilities were afraid of going to referral hospitals for e.g. ear, nose and throat (ENT), or ophthalmology care. So visits to referral hospitals were organized for small groups of people with disabilities and their family members, to explain how these hospitals worked and how people could access the different services. Some professionals from the hospitals were invited to cultural events organized by the CBR programme and given community recognition for their support. Many specialized hospitals agreed to charge subsidized fees for people referred by the CBR programme.

### **Develop and distribute resource materials**

Disability booklets and manuals can be a useful tool for rehabilitation. These resources can be used by CBR personnel and by people with disabilities and their family members to guide rehabilitation, particularly where access to rehabilitation professionals is limited. These resources may also provide valuable information for the wider community as well as the many different services and sectors involved in rehabilitation activities. The following CBR activities are suggested.

- Locate existing resource materials. These may be available through government ministries, United Nations bodies, disabled people's organizations or national and international nongovernmental organizations, and many can be accessed from the Internet, e.g. *Training in the community for people with disabilities* (32) and *Disabled village children* (33).
- Adapt materials to suit local requirements, giving special consideration to cultural differences.
- Translate existing materials into national and/or local languages.
- Where existing resources are not available, develop new materials in simple language to suit local needs.
- Distribute resource materials to all CBR personnel to carry with them when visiting people with disabilities for rehabilitation.

- Create resource units where materials for people with disabilities, family members and other members of the community are available. The units may be located in the local development office, community health centre, or specific centres for people with disabilities.

## BOX 30

## Viet Nam

### Translating resources into Vietnamese

A CBR programme in Viet Nam translated several existing publications, including the WHO CBR manual, into Vietnamese to use for local purposes. In addition they developed their own materials on specific concerns for people with disabilities and their caregivers. Health workers are always provided with two copies of any resource material – one copy for themselves and one copy for the people they are visiting.

### Provide training

CBR personnel need training to ensure they are able to facilitate access to rehabilitation services and provide appropriate services at community level. Many organizations have developed suitable training programmes. CBR personnel require a good understanding of the role of rehabilitation personnel, e.g. physiotherapists, occupational therapists, speech therapists, audiologists, mobility trainers, prosthetists/orthotists, medical and paramedical personnel and of how they can be of benefit to people with different impairments. CBR can also provide education to rehabilitation personnel to raise their awareness of the role of CBR and how it can help them optimize their services (see Management).

# Assistive devices

## Introduction

Assistive devices are external devices that are designed, made, or adapted to assist a person to perform a particular task. Many people with disabilities depend on assistive devices to enable them to carry out daily activities and participate actively and productively in community life.

The Convention on the Rights of Persons with Disabilities, Articles 4, 20 and 26, asks States to promote the availability of appropriate devices and mobility aids and provide accessible information about them (2). The Standard Rules on the Equalization of Opportunities for Persons with Disabilities also call upon States to support the development, production, distribution and servicing of assistive devices and equipment and the dissemination of knowledge about them (23).

In many low-income and middle-income countries, only 5–15% of people who require assistive devices and technologies have access to them (34). In these countries, production is low and often of limited quality, there are very few trained personnel and costs may be prohibitive.

Access to assistive devices is essential for many people with disabilities and is an important part of any development strategy. Without assistive devices, people with disabilities may never be educated or able to work, so the cycle of poverty continues. Increasingly, the benefits of assistive devices are also being recognized for older people as a health promotion and prevention strategy.



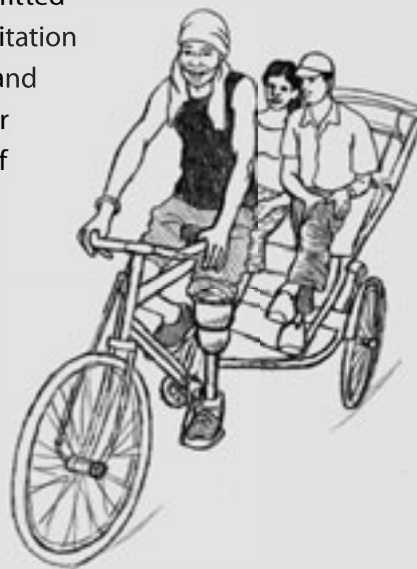
## Being able to work again

Community Based Rehabilitation Biratnagar (CBRB) is a nongovernmental organization that has been working in the eastern region of Nepal since 1990. Currently it is working in 41 villages of the Morang District and in Biratnagar Submunicipality, providing rehabilitation services to more than 3000 children and adults with disabilities.

In 1997, CBRB started a small orthopaedic workshop to carry out minor repairs of assistive devices, as many people with disabilities had to travel to the capital or neighbouring India for repairs. Over time, CBRB worked towards establishing a fully equipped orthopaedic workshop. Working in partnership with Handicap International (Nepal) they developed a comprehensive service which included the fabrication, provision and repair of assistive devices. Local people (women and men, with and without disabilities) were trained as technicians in Nepal and India and integrated into the existing CBRB team. CBRB now provides quality orthoses (e.g. calipers, braces, splints), prostheses (e.g. artificial legs and hands) and mobility devices (e.g. crutches, tricycles, wheelchairs) to people living with disabilities in 16 districts of eastern Nepal. CBR personnel, therapists and workshop technicians all work hand-in-hand to enhance the quality of life of people with disabilities.

One of the people to have benefited from the orthopaedic workshop is Chandeswar. He is a rickshaw-puller who worked hard until he suffered an injury and had his left leg amputated. He lost his income because he was no longer able to work as a rickshaw-puller and he lost his savings because he needed to pay for his medical care. Chandeswar was identified by the CBRB team working in his village, who fitted him with a below-knee prosthesis and provided rehabilitation to ensure he was able to walk well with his artificial leg and learn how to pedal his rickshaw again. Now Chandeswar is back pedalling his rickshaw around the busy streets of Biratnagar and making a reasonable living.

Seeing the benefit to people such as Chandeswar, the President of CBRB says: "We were carrying out CBR for many years but since we started providing quality assistive devices we have become more effective, our credibility has gone up and now we have a great acceptance in the community".



## Goal

People with disabilities have access to appropriate assistive devices that are of good quality and enable them to participate in life at home and work and in the community.

## The role of CBR

The role of CBR is to work with people with disabilities and their families to determine their needs for assistive devices, facilitate access to assistive devices and ensure maintenance, repair and replacement when necessary.

## Desirable outcomes

- CBR personnel are knowledgeable about assistive devices, including the types available, their functionality and suitability for different disabilities, basic fabrication, availability within communities and referral mechanisms for specialized devices.
- People with disabilities and their families are knowledgeable about assistive devices and make informed decisions to access and use them.
- People with disabilities and their families are provided with training, education and follow-up to ensure they use and care for their assistive devices appropriately.
- Local people, including people with disabilities and their families, are able to fabricate basic assistive devices and undertake simple repairs and maintenance.
- Barriers preventing access to assistive devices, such as inadequate information, financial constraints and centralized service provision, are reduced.
- Environmental factors are addressed to enable individuals to use their assistive devices in all locations where they are needed.

## Key concepts

### Common types of assistive device

Assistive devices range from simple, low-technology devices (e.g. walking sticks or adapted cups), to complex, high-technology devices (e.g. specialized computer software/hardware or motorized wheelchairs). It is helpful to consider this wide variety of assistive devices under different categories.

## ***Mobility devices***

Mobility devices assist people to walk or move and may include:

- wheelchairs
- tricycles
- crutches
- walking sticks/canes
- walking frames/walkers.

Mobility devices may have specialized features to accommodate the needs of the user. For example, a person with cerebral palsy may require a wheelchair with trunk/head supports to ensure he/she is able to maintain a good sitting position. The WHO guidelines on *Provision of manual wheelchairs in less resourced settings* (35) are a useful reference for those people involved in the design, production and distribution of wheelchairs.

## ***Positioning devices***

People with physical impairments often have difficulty maintaining good lying, standing or sitting positions for functional activities and are at risk of developing deformities due to improper positioning. The following devices can help overcome some of these difficulties:

- wedges
- chairs, e.g. corner chairs, special seats
- standing frames.

## ***Prosthetics, orthotics and orthopaedic shoes***

These are usually custom-made devices which replace, support or correct body parts. They are designed, manufactured and fitted in specialized workshops or centres by trained prosthetic/orthotics personnel and include:

- prostheses, e.g. artificial legs or hands
- orthoses, e.g. spinal braces, hand/leg splints or callipers
- orthopaedic shoes.

## ***Daily living devices***

These devices enable people with disabilities to complete the activities of daily living (e.g. eating, bathing, dressing, toileting, home maintenance). There are many examples of these devices, including:

- adapted cutlery and cups
- shower seats and stools
- toilet seats and frames
- commodes
- dressing sticks.



### ***Vision devices***

Low vision or blindness has a great impact on a person's ability to carry out important life activities. A range of devices (simple to complex) can be used to maximize participation and independence, including:

- large print books
- magnifiers
- eyeglasses/spectacles
- white canes
- braille systems for reading and writing
- audio devices, e.g. radios, talking books, mobile phones
- screen readers for computers, e.g. JAWS (Job Access with Speech) is a screen reader programme.

### ***Hearing devices***

Hearing loss affects a person's ability to communicate and interact with others; it can impact on many areas of development, e.g. speech and language and restricts educational and employment opportunities, resulting in social discrimination and isolation. Devices include:

- hearing aids
- headphones for listening to the television
- amplified telephones
- TTY/TTD (telecommunication devices)
- visual systems to provide cues, e.g. a light when the doorbell is ringing.

#### **BOX 32**

## Papua New Guinea

### **Top of the class**

Anna is a mother who lives in East Sepik province of Papua New Guinea. Her daughter Koris was born deaf. Anna was very determined to send her daughter to school and, through a CBR worker trained by Callan Services for Disabled Persons (a national nongovernmental organization), Anna became aware of a nursery school for deaf children. Before attending this school, Callan Services arranged for the provision of hearing aids; ear mould impressions were taken for Koris and when the hearing aids were ready to be fitted she was sent to an audiologist in Port Moresby. Koris started attending school and also began learning sign language. With the help from assistive devices and with the support of her teachers, Koris soon became one of the top pupils in her class.

## ***Communication devices***

Augmentative and alternative communication devices can assist individuals who have difficulty understanding and producing speech. They are provided to support speech (augmentative), or to compensate for speech (alternative). Devices include:

- communication boards with pictures, symbols or letters of the alphabet
- request cards
- electronic speech output devices
- computers with specialized equipment and programmes.

## ***Cognitive devices***

Cognition is the ability to understand and process information. It refers to the mental functions of the brain such as memory, planning and problem-solving. Brain injuries, intellectual impairment, dementia and mental illness are some of the many conditions that may affect an individual's cognitive ability. The following devices can assist individuals to remember important tasks/events, manage their time and prepare for activities:

- lists
- diaries
- calendars
- schedules
- electronic devices, e.g. mobile phones, pagers, personal organizers.

## **Selection of assistive devices**

### ***Appropriate technology***

Many types of technology are not suitable for rural/remote areas and low-income countries. However, "appropriate technology" is designed with consideration given to the environmental, cultural, social and economic factors that influence communities and individuals. Appropriate technology meets people's needs; it uses local skills, tools and materials and is simple, effective, affordable and acceptable to its users. Assistive devices are technologies that must be carefully designed, produced and selected to ensure they meet these criteria.



## Wearing the same shoes

The Assisi Leprosy and CBR programme in Andhra Pradesh, India provided sandals made of black microcellular rubber to people with leprosy who had lost sensation in their feet and were at risk of foot ulcers. It became obvious that many people who were provided with these sandals did not use them. After talking with these people, it was discovered that by wearing the sandals they were subject to social stigma – the black sandals had become easily identifiable in the community as shoes that only people with leprosy wore. As a result the programme decided to use sandals available from the local market, modifying them as necessary to suit the requirements of people with leprosy. People began wearing the footwear as there was little visible difference between their sandals and those that other community members wore.

### *Assessment*

Assistive devices need to be carefully selected and often specially made and fitted to ensure they meet the individual's needs. Poor selection and design can lead to many problems including frustration, discomfort and the development of secondary conditions. For example, it may be common practice in some countries to distribute donated or second-hand wheelchairs on a large scale. While this may have benefits, it also has the potential to cause harm to users, e.g. the provision of a wheelchair without a cushion to a person with a spinal cord injury may cause a potentially life-threatening pressure area (see Prevention element).

Comprehensive assessment is necessary to ensure assistive devices meet the needs of individuals within their homes, schools and work and community environments. A comprehensive assessment might include a medical history, a review of current function, individual goals, an evaluation of existing assistive devices and a physical examination. The approach to assessment should be multidisciplinary where possible and include a wide variety of people, such as people with disabilities, family members, therapists, technicians, teachers and CBR personnel.

## Use of assistive devices

### *Barrier-free environments*

Many people use their assistive devices in different places and it is important to ensure that all environments are barrier-free in order for someone to achieve maximum function and independence. For example, a young woman using a wheelchair must be able to use it to enter/exit her home, move freely within her home and access important areas (e.g. the bathroom), travel within her community and access her workplace.

Adaptations/modifications to the physical environment include installing a ramp where there are steps, widening a narrow doorway, reorganizing furniture to increase the amount of space for movement. It is also important to consider other aspects of the environment, e.g. attitudes and support systems, which can also influence a person's ability to use the device. For example, a young boy who uses a communication board instead of speech will need to use his board both at home and at school, so it is important that family members, schoolteachers and friends are positive, willing and able to use this device with him.

When considering environmental modifications, particularly within the community, it is helpful to consider "universal design" (36). Universal design means designing products, environments, programmes and services to be usable by all people (2), both with and without disabilities.

### **BOX 34**

## Viet Nam

### **Bridging the community**

In a village in the Thai Binh district of Viet Nam, CBR volunteers motivated community members to improve the local bridge so that people using wheelchairs as well as others could pass over it comfortably.

## Suggested activities

### Train CBR personnel

CBR personnel require training on assistive devices to ensure that they are able to provide accurate information, referral and education. Training may be specific, or it may be part of a course on rehabilitation. CBR personnel need knowledge about:

- the common types of assistive device;
- the purpose and function of assistive devices;

- which basic devices can be prepared in the community, e.g. crutches;
- where specialized devices, e.g. prostheses and hearing aids, are available;
- referral mechanisms, to enable access to specialized devices;
- the funding options available for people who are unable to afford devices.

Practical training is also essential, particularly for CBR personnel who work in rural/remote areas, to ensure they can produce basic assistive devices and develop the skills and confidence to work directly with individuals who need the devices. For example, CBR personnel may need to:

- show a family how to build a wooden chair with a strap to enable a child with poor balance to sit upright;
- show a family how to build parallel bars to enable walking practice at home;
- show a family how to make a simple walking stick for a person recovering from a stroke to assist her/him in walking;
- teach a child with cerebral palsy, with no speech or coordinated hand movement, how to use a pictorial communication board using her/his eyes;
- provide instruction to a blind person on the use of her/his white cane.

### BOX 35

## Indonesia

### Information where it's needed

The CBR programme in South Sulawesi, Indonesia, prepared an Assistive Device Resource Sheet listing the main service providers in the province who are able to supply and repair devices. This resource sheet is distributed to all CBR personnel, ensuring accurate information is always available for people with disabilities living in villages.

### Build capacity of individuals and families

CBR personnel need to work closely with people with disabilities and their family members to ensure that they are:

- aware of the different types of assistive device and how these can assist individuals to achieve independence and participation;
- involved in decision-making regarding the selection and design of assistive devices – providing opportunities for people to see and try assistive devices will assist them to make informed decisions;
- able to use their assistive devices properly and safely and are able to perform repairs and maintenance to ensure long-term use;
- able to give feedback to referral services about any difficulties experienced so that adjustments can be made and different options considered.

This health component highlights the fact that self-help groups enable people to share valuable information, skills and experiences. Self-help groups can be particularly beneficial when someone has limited access to rehabilitation personnel. Self-help groups can support individuals to adjust to newly acquired assistive devices, educating them on their care and maintenance and can provide advice on self-care, e.g. prevention of secondary complications and how to achieve optimum function.

## Train local artisans

It is unrealistic to expect people living in rural areas to travel to specialized centres to have their devices repaired and many people stop using their devices when they experience problems. Local artisans can be trained to make small repairs to assistive devices such as orthoses, prostheses and wheelchairs, e.g. repair orthoses by replacing straps, screws or rivets. CBR programmes can identify local artisans and facilitate this training in partnership with technicians.



Assistive devices such as walking sticks, crutches, walking frames, standing frames and basic seating can also be produced by local artisans because they are simple to make using locally available materials. CBR programmes can identify local artisans who are interested in producing them and facilitate training.

### **BOX 36**

## Mongolia

### **Learning how to make assistive devices**

In 2000, the National CBR programme in Mongolia organized a training course for staff working at the National Orthopaedic Laboratory in Ulaan Baatar, to teach them how to make simple splints, seating devices and mobility devices using local materials and appropriate technology. Now, whenever a CBR programme starts in a new province of Mongolia, two local artisans are identified and trained at the National Orthopaedic Laboratory.

## Facilitate access to assistive devices

Access to assistive devices may be limited by inadequate information, poverty, distance and centralized service provision. CBR personnel need to work closely with people with disabilities and their families to facilitate access to assistive devices by:

- identifying existing service providers – local, regional and national – who produce and/or supply a wide range of assistive devices (basic and specialized);
- compiling detailed information on each service provider, including referral mechanisms, costs and processes, e.g. administrative procedures, assessment procedures, number of visits required for measurements and fittings and time for production;
- ensuring this information is available in an appropriate format and is communicated to people with disabilities and their families;
- identifying funding options for people who are unable to afford the costs associated with assistive devices – CBR programmes can facilitate access to existing government or nongovernmental schemes and can raise their own funds and/or empower individual communities to donate resources;
- assisting people to complete relevant administration processes so they can obtain a disability certificate, which in many countries will enable them to access free devices;
- partnering with referral centres, local authorities and other organizations to discuss ways to decentralize service provision, e.g. mobile facilities;
- providing transport for small groups of people from rural/remote areas to travel to referral centres, ensuring prior arrangements are made with these centres.
- providing home or community-based repair services for people living in rural/remote areas, e.g. establish a mobile service or regular meeting point in the community for people needing repairs to their devices.

### BOX 37

## Lebanon

### Accessing assistive devices

The national disabled people's organization in Lebanon launched a production unit for wheelchairs and other assistive devices such as crutches, walkers, toilet chairs, orthopaedic shoes and specialized seating systems. They also created five distribution, repair and maintenance workshops around the country to facilitate access to these devices. The production unit and repair workshops employ people with disabilities. The disabled people's organization has also ensured an adequate national budget for assistive devices. CBR programmes can now refer people who need assistive devices to these centres to access assistive devices.

### *Set up small-scale workshops*

When referral services are not available, or barriers such as cost and distance cannot be overcome, CBR programmes can consider setting up and/or supporting a small

workshop to meet local needs. Simple devices can be produced by locally trained people. Both the WHO *CBR manual* (32) and *Disabled village children* (33) provide information about making assistive devices in the community using local resources.

### BOX 38

## Guinea-Bissau

### Finding local solutions

Cumura Hospital in Guinea-Bissau has a small workshop for preparing orthoses and two people with disabilities have been trained as orthopaedic technicians to work here. Finding appropriate materials is often a problem and importing materials is very costly, therefore the technicians try to find local solutions for designs from other workshops. For example they have started to make a leather and plastic splint for persons with foot-drop.

People with disabilities can also be trained to make assistive devices. This can generate income and lead to their recognition as active contributors to their communities, to the development of social networks and ultimately to empowerment.

### BOX 39

## India

### Making a small business work

Several CBR programmes in Bangalore, India, identified a group of 10 young women with disabilities. All of these women faced disadvantages and discrimination because they were poor, uneducated, female and disabled – they were all seen as liabilities within their families and communities. In 1998 the 10 women trained as orthopaedic technicians and were provided with a loan from one of the CBR programmes to open a commercial workshop. Life has changed for the women since they started their business (Rehabilitation Aids Workshop by Women with Disabilities). The workshop started making a profit from the second year and by the end of the fourth year they had repaid the whole loan. They extended their business by becoming agents for several major companies that manufactured assistive devices and health-care products and by establishing links with major private hospitals in the city. The women are now earning good incomes, have good quality of life and are seen as active contributors to their communities. They are married, are assets to their families and are role models for many people with disabilities.





## Network and collaborate

In some countries it may not be feasible to establish services that provide a wide range of assistive devices. This may be due to government priorities, limited resources, or small populations. But many assistive devices will be available in neighbouring countries, where they are likely to be cheaper and easier to access than importing them from high-income countries. CBR programmes need to determine what resources are available in neighbouring countries and collaborate with these countries where possible. In addition, CBR programmes need to develop strong links with international and national nongovernmental organizations who are often active in producing and providing assistive devices with a view to the development of sustainable service provision.

## Address barriers in the environment

Very often there are barriers in the home, school, work or community environments that make it difficult for people to use their assistive devices. CBR personnel require practical knowledge regarding these barriers so they can work with individuals, family members, communities and local authorities to identify and address them.

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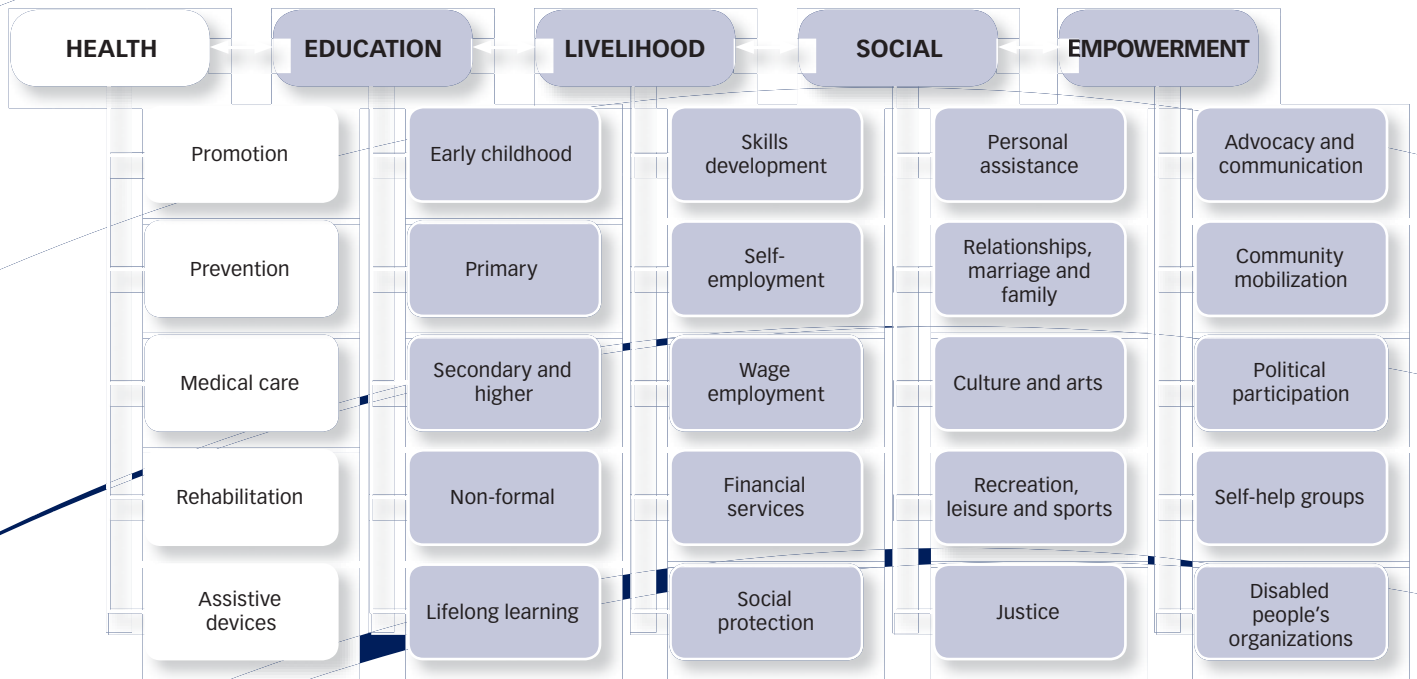
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