



WHO/ILEP

Technical guide on community-based
rehabilitation and leprosy

*Meeting the rehabilitation needs of people
affected by leprosy and promoting quality of life*

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The text is based on information drawn from a survey of 31 projects providing community-based rehabilitation services in 15 countries across Africa, Asia and South America.

Cover photograph : Georgina Cranston/TLMI.

Abbreviations

AIDS	acquired immunodeficiency syndrome
CBR	community-based rehabilitation
CIOMAL	Comité International de l'Ordre de Malte
COMBRA	Community Based Rehabilitation Alliance
GLRA	German Leprosy and TB Relief Association
HIV	human immunodeficiency virus
ILEP	International Federation of Anti-Leprosy Associations
ILO	International Labour Organization
NLR	Netherlands Leprosy Relief
TB	tuberculosis
TLMI	The Leprosy Mission International
UNESCO	United Nations Educational, Scientific and Cultural Organization
WHO	World Health Organization

Introduction

Until recently, rehabilitation was understood as a complex task requiring specialized rehabilitation services provided by professionally qualified staff working from specialized rehabilitation centres. The services addressed disability-related needs arising from a diversity of conditions, and were based in cities and urban centres with little community involvement. Historically, people with leprosy-related disability rarely accessed such services, preferring the services offered by dedicated leprosy centres. This institution-centred approach and the stigma surrounding leprosy meant that communities had little involvement in the rehabilitation process of people affected by leprosy.

Following the Declaration of Alma-Ata (1978) (1) that stated that health is a fundamental human right, and considering the limitation and constraints of specialized medical rehabilitation services, the World Health Organization introduced the strategy of community-based rehabilitation (CBR). This strategy was intended to enhance the quality of life for people with disabilities through community initiatives. The intention was to promote the concept of the “inclusive community”, local resources being used to support the rehabilitation of people with disabilities in their own communities. However, due to stigma and lack of knowledge, the specialized rehabilitation services and many CBR programmes failed to recognize people with leprosy-related disability as equal members of the community requiring rehabilitation.

In recent years there has been a change in attitude towards leprosy. Stigma has reduced. People affected by leprosy now often remain within their families and communities. As a result, involving the family and community members is now seen as a key strategy to empower people affected by leprosy, encouraging them to play an active role in their rehabilitation, and to further reduce stigma. The central strategy of CBR is to facilitate community action to ensure that people with disabilities have the same rights and opportunities as all other community members. This includes, for example, equal access to health care, education, skills training, employment, family life, social mobility and political empowerment. It applies equally to people affected by leprosy. CBR is therefore a legitimate strategy for meeting the needs of people affected by leprosy and promoting their quality of life.

The Joint Position Paper of the International Labour Office (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO) and the World Health Organization (WHO) on CBR (2004) (2) defines CBR as follows:

“CBR is a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities”.

Due to the stigma and disabilities resulting from leprosy, people affected have suffered reduced opportunities and experienced many forms of social exclusion – all in the context of a poverty-related disease. It is easy to see, therefore, that CBR, according to its current definition, is highly relevant to the rehabilitation of people affected by leprosy.

In addition, as leprosy control activities have been integrated into general health services, so rehabilitation of people affected by leprosy should be integrated into general CBR programmes. In leprosy-endemic areas where only a leprosy-related programme is available, these programmes are encouraged to introduce CBR strategies and to open up their services to people with other disabilities.

How to use this technical guide

This technical guide is a reorientation and familiarization tool for managers of leprosy projects and programmes. It describes the strategies and tasks of CBR as the appropriate response to the needs of individuals, families and communities affected by leprosy. Throughout the text, “Case studies” and “Experience in the field” are presented in shaded boxes. The case studies illustrate particular principles and processes described in the text. The experience in the field material is the direct experience of individual contributors to this guide.

The guide has been prepared for use by managers, trainers and supervisors in leprosy control or rehabilitation programmes responsible for introducing and managing CBR. It may also be used by CBR managers to include people affected by leprosy in their programmes. It describes the broad objectives of CBR, the roles and tasks of programme managers, and the responsibilities of community workers (these can also be former leprosy workers) who have daily contact with people affected by leprosy, their family and community members.

The contents may be used for training of field-level staff and, in this case, should be supplemented by the published training courses listed in Annex 1, and the CBR guidelines (to be published by December 2008).

The needs of people with disability are best met through interventions that are specific to individuals and their family members, and are sensitive to the communities in which they live. Interventions that benefit the whole community, either directly or indirectly, will further develop community participation and ownership.

The guide recommends approaches reported to be effective, but avoids prescribing these methods in all situations. Programme managers need to be selective and cautious in applying the procedures described here, testing their potential and suitability in each situation.

The guide is compatible with the new CBR matrix (see Annex 2), which was adopted in 2005 by WHO, ILO, UNESCO, and major leading international disability nongovernmental organizations, including disabled people’s organizations. The matrix presents a comprehensive overview of CBR components based on the principles of participation, inclusion, sustainability and self-advocacy. The guide is complementary to the new ILEP Learning Guide (No. 4) on preventing disability in leprosy (3), and the WHO CBR guidelines, which are in preparation.

1 The need for rehabilitation

1.1 How leprosy affects people's lives

Leprosy affects people's lives in a number of ways. Most obviously, it can lead to physical disabilities that make it difficult to perform routine activities of daily living, to work or to earn an income. This may diminish the status of the affected person within their family and community and lead to psychosocial problems. Stigma resulting in discrimination and social exclusion can have a major impact on quality of life. Quality of life may be further affected where self-stigma causes people to attempt to hide their condition or to withdraw from normal social contacts, from income-earning activities or from their family responsibilities.

The disabilities associated with leprosy are not unique. Many different conditions are stigmatized. The community-based approach to rehabilitation recognizes the importance of responding to needs, irrespective of the person or their form of disability. Any person affected by disability has the right to play a full part in the life of their community – as an equal member with equal citizenship.

1.2 Principles of CBR

CBR is recognized as best practice in addressing the needs of people with disabilities, including those affected by leprosy. The definition recognized by the ILO, UNESCO and WHO describes CBR as follows:

“CBR is a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities.

CBR is implemented through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and nongovernmental health, education, vocational, social and other services”.

The basic needs of all people, including people with disability and people affected by leprosy, are the same – food, health, education, shelter, and so on. CBR facilitates access to basic needs, and at the same time promotes equal opportunities and equal rights. It is therefore a multisectoral strategy with some key principles to enable people with disabilities to participate in the whole range of human activities.

The principles outlined below are overlapping, complementary and inter-dependent.

Inclusion

CBR works to remove all kinds of barriers which block people with disabilities from access to the mainstream of society. Inclusion means placing disability issues and people with disabilities in the mainstream of activities.

Participation

CBR focuses on abilities, not disabilities. It depends on the participation and support of people with disability, family members and local communities. It also means the involvement of people with disabilities as active contributors to the CBR programme, from policy-making to implementation and evaluation, for the simple reason that they know what their needs are.

Empowerment

Local people – and specifically people with disabilities and their families, ultimately may make the programme decisions and control the resources. This requires people with disability taking leadership roles within programmes. It means ensuring that CBR workers, service providers and facilitators include people with disabilities and that all are adequately trained and supported. Results are seen in restored dignity and self-confidence.

Equity

CBR emphasizes equality of opportunities and rights – equal citizenship.

Raising awareness

CBR addresses attitudes and behaviour within the community, developing understanding and support for people with disabilities and ensuring sustainable benefits. It also promotes the need for and benefit of inclusion of disability in all developmental initiatives.

Self-advocacy

CBR consistently involves people with disabilities in all issues related to their well-being. Self-advocacy is a collective notion, not an individualistic one. It means self-determination. It means mobilizing, organizing, representing, and creating space for interactions and demands.

Facilitation

CBR requires multisectoral collaboration to support the community and to address the individual needs of people with disability, with the ultimate aim of an inclusive society.

Gender sensitivity and special needs

CBR is responsive to individuals and groups within the community with special needs.

Partnerships

CBR depends on effective partnerships with community-based organizations, government organizations and other organized groups.

Sustainability

CBR activities must be sustainable beyond the immediate life of the programme itself. They must be able to continue beyond the initial interventions, and be independent of the initiating agency. The benefits of the programme must be long-lasting.

Box 1 shows how community workers in different countries put these principles into practice.

Box 1. Putting CBR principles into practice: examples in the field

Inclusion: example from Senegal

“Since 95% live in very poor conditions it is very difficult to ask for contributions and guarantees from clients. Therefore, where possible, we encourage clients to join a group or look for somebody who is able to provide support and do some follow-up. In resettlement projects local families have to clearly state that the client is welcome among them, and prove it by accepting him or her over a certain period of time, before any action is taken. The client has to be ready and willing to make the move.”

Participation: example from Nepal

“Each intervention is a partnership requiring contributions from the organization, the client, the family and the community. All participate in making decisions. We encourage self-help. What the clients do for themselves is increasing all the time. Where this policy is not applied we find interventions are often less successful.”

Empowerment: example from China

“As a people’s organization, HANDA (a Chinese charity that helps sufferers of leprosy) expects our own people to work for each other. We empower and motivate our members. Our role is to help people to organize and plan their activities. We give advice and provide financial or technical support where needed.”

Equity: example from India

“The expectations of people with disabilities are very high, while the CBR programme has to manage with limited resources. We make it clear that we cannot give anything freely, but only as a loan which has to be repaid. If it is not repaid we are unable to help others.”

Facilitation: example from Egypt

“We believe in self-reliance. We help support patients to look after themselves and carry out their own activities independently. We initiate discussions with them so they can reflect on the problems and become partners in their solution.”

Facilitation: examples from Nigeria and Paraguay

“For financial reasons, some clients’ families refuse involvement. Some families consider rehabilitation as the sole responsibility of nongovernmental organizations. We work among family and community members, encouraging them to get involved. This has facilitated the acceptance of clients, eased their adaptation, and increased their chance of survival in the communities. It has created a sense of love and belonging.”

“We are just facilitators. We expect clients to manage interventions themselves. We encourage family members to support the individual during the intervention. We try to involve the community. Though it is demanding on the client, we want to extend this approach because it has been found to work. It has potential to help all clients.”

1.3 The scope of CBR

In its wider sense, disability arises because people are denied equal access to opportunities within their families and communities. The barriers may be cultural, social, institutional, environmental or economic, with attitudinal barriers being especially important. Since disability is not only about impairments, it follows that the best way to address disability is to work with the community. CBR has therefore emerged as a key strategy for social inclusion, aimed at overcoming activity limitations and participation restrictions, and improving the quality of life of people with disabilities (4).

Rehabilitation services commonly required by people with leprosy-related disability include physiotherapy, orthopaedic services, occupational therapy, and reconstructive surgery. Also included are so-called “socioeconomic rehabilitation” (SER) activities, including vocational training, integrated education of children affected by leprosy, micro-finance and business creation schemes, provision or improvement of appropriate housing, and advocacy at various levels involving a variety of media. The preferred strategy for implementing most of these services is CBR.

CBR recognizes the importance of activities to prevent all kinds of avoidable disabilities, through health education, medical interventions or physical rehabilitation, and enhancement of functioning through therapeutic interventions and assistive devices.

The CBR approach assumes that people with disabilities are able to work together to organize their own lives and their own development, drawing on the active involvement and support of their families and local community. It ensures that those affected are accepted in the community. It follows that rehabilitation programmes serving people affected by leprosy need to be fully integrated with existing CBR programmes. Where these programmes do not already exist, leprosy-oriented CBR programmes should be extended to include people with disabilities irrespective of their cause.

Poverty is both a cause and a consequence of disability. Poverty limits access to basic health services, including rehabilitation, and to education. Reducing poverty through access to livelihood opportunities and empowerment is therefore a key strategy both for prevention of disability and for rehabilitation. CBR will be most effective if it leads to poverty alleviation of people with disability, their family and the wider community.

The scope and complexity of CBR activities requires close cooperation and communication between those involved with the community, those concerned with the prevention of disability, and those involved in promoting social and economic well-being. The lines of communication are summarized in Figure 1.

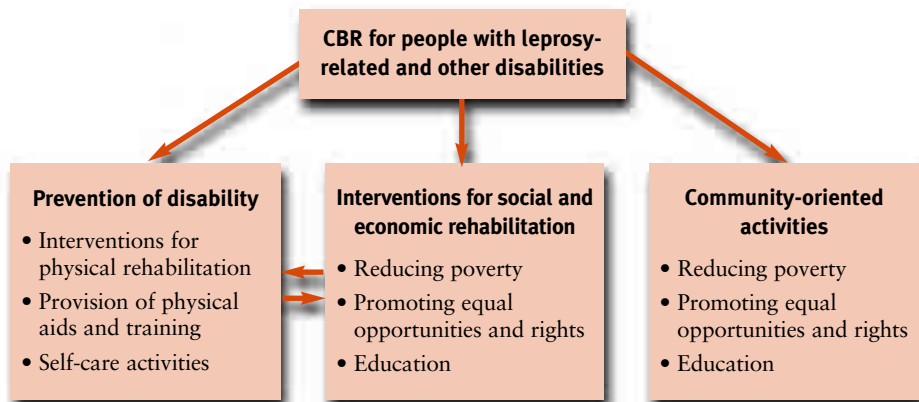


Figure 1. The inter-relationships between prevention of disability, social and economic rehabilitation, and community-oriented activities within CBR

1.4 Arrangements for the delivery of CBR services

Arrangements for the delivery of primary-level CBR services vary according to the local situation. Depending on which organizations exist, CBR services may be delivered through some or all of the following:

- community-based organizations;
- organizations of people affected by leprosy or other disabilities;
- voluntary, nongovernmental organizations;
- government services.

The work may be further supported by networks of community-based, local government and nongovernmental organizations combining to provide resources, to develop skills or to conduct interventions that contribute to a comprehensive rehabilitation service for people with disabilities.

The success of the programme is largely dependent on the skills of community and CBR workers. They need to be effective motivators, encouraging the commitment and involvement of affected people and their family and community members working as a team. They facilitate the contacts between people with disabilities and the community: in particular, the principal service providers within the community – local employers, local health services, schools, markets, training centres and production units. Much relies on their ability to gain access to local resources, including expertise, goodwill, knowledge, skills and financial support. Their commitment and motivation are essential for success. Figure 2 describes how the many potential sources of help may combine to deliver rehabilitation services to those in need.

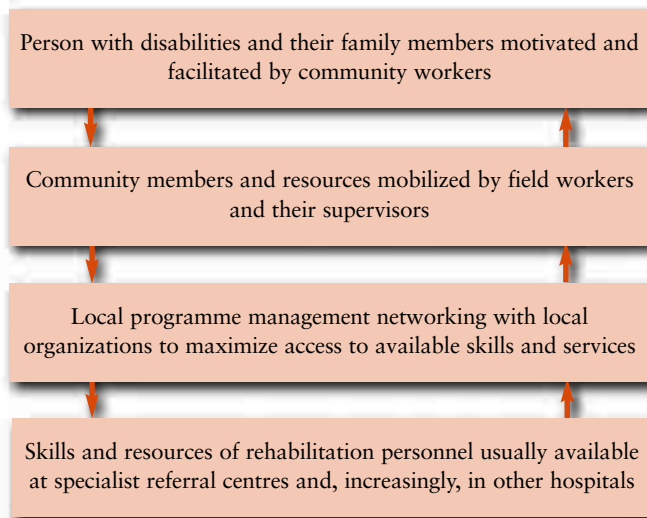


Figure 2. Sources of help in the delivery of CBR services

Case study 1 from Tamil Nadu describes the experience of one young girl who benefited from the care and concern of community workers and visiting specialists. Together their inputs transformed her life.

Case study 1: Tamil Nadu, India

Ms Karpagam is the first child of her parents. She lives with her family in a village in Trichirapalli. Her father has a spinal deformity. Karpagam herself has cerebral palsy. Her parents work as farm labourers. They own no land of their own but rely on others to give them work and earn some income.

Until she was seven years old, Karpagam was left alone at home all day while her parents went in search of work. When her younger sister was born, her parents showed great interest in the child, causing Karpagam to long for her parents to show the same love and concern for her.

When she reached the age of seven, community workers heard about Karpagam and began to visit her home. Her condition was diagnosed and her parents were taught how to manage and care for her. Because of his own disability, her father was quick to respond.

In the following months, community workers helped Karpagam to learn to walk, using parallel bars made out of bamboo. A physiotherapist made several visits and taught her many skills. She learnt how to use her hands to recognize colours, to tell the time and to handle money. Through training in activities of daily living she learnt toilet skills, hair brushing and dressing. She can now bath herself and wash her own clothes, and helps her mother in household activities such as cutting vegetables, cooking and cleaning. She can collect water from the tubewell, and can make garlands of jasmine flowers. Having observed this great change and development in their daughter, her parents shower grace and affection on her. Now she has completed training in raising goats and hopes to earn some income for her family. For the first time, she has also started to attend school, so her story is only just beginning.

2 Working with the community

2.1 The potential of the community

It is important to recognize communities and individuals and their family members within the community as the primary resource available for rehabilitation. Communities understand the problems that arise. They have access to resources and can provide long-term support. Developing community support and participation in the rehabilitation process is essential for effective rehabilitation. Even the poorest community has resources that can facilitate inclusion and participation. To achieve this, community and CBR workers need a good understanding of the community and its potential.

Objectives for work with the community

One of the key objectives of CBR is to create an inclusive environment in which people with disabilities play a full role in the civil, social, political and economic structures of their community.

To achieve this objective, community workers seek to develop respect and promote the dignity of people with disabilities so that they have equal rights, entitlements, responsibilities and opportunities, and are able to participate in everyday social and economic activities and to contribute to the community.

Strategies to achieve these objectives

A detailed understanding of the community should first be developed, identifying attitudes and beliefs that may slow the rehabilitation process, and resources and support that may speed its progress. Only when this is done can work start on creating an enabling, inclusive environment for rehabilitation by building channels of communication, raising awareness, changing attitudes and encouraging participation.

Tasks of programme managers

Programme managers facilitate an enabling environment and assemble skills and resources for the rehabilitation process by:

- identifying and building working relationships with local politicians, local administrative authorities, local industries/workshops, opinion leaders, teachers, and other key individuals who may become key stakeholders in the rehabilitation process;
- developing networks and identifying services provided by local organizations or government – health, education, shelter, savings and credit programmes, skills training, welfare or pension payments (see section 2.4);
- preparing an agenda for promoting awareness, participation and advocacy in the community (see section 2.2).



Source : Jean Plateau/DFB

Tasks of community workers

Community workers collect essential information about the community by identifying:

- local beliefs and practices towards disability and leprosy;
- vulnerable groups – women, elderly people, poor people, people with severe disabilities, those living in settlements;
- constraints relating to language, communication and transport;
- local resources;
- resources outside the community, and how to access them.

Experience in the field

Understanding and involving the community is an essential first step in creating awareness and promoting participation. Community members who participate in the rehabilitation process give a strong message that the person with disabilities is accepted and valued.

2.2 Promoting community awareness and participation

Experience has shown that impairment is only one limiting factor in the life of a person with disability. Attitudinal, institutional and other barriers have a strong influence on the level of disability experienced, and limit the opportunities of people with disabilities. While the first step for many people with disabilities is a fundamental change in their mindset – from passive receiver to active contributor – removal of the barriers that deny them full participation in their communities is a key step in the rehabilitation process.

Community-oriented interventions are needed that increase knowledge, change attitudes, mobilize resources, and encourage participation in rehabilitation activities.

Tasks of programme managers

Programme managers help to promote community awareness and participation by:

- identifying the focus for each health education campaign;
- planning and implementing health education and health promotion activities, relying on available expertise and specialist skills;
- identifying local opportunities to arrange meetings – in public places, schools or groups;
- planning CBR programme activities with active participation of people with disabilities, their families and other important community members.

Much of this work relies on the information provided by community workers and people with disabilities and their families.

Tasks of community workers

Community workers need to identify local service providers and to recognize the barriers that restrict access for people with disabilities. They may then be involved at each stage of an intervention.

At the planning stage they may contribute by identifying:

- the vulnerable or “at risk” groups;
- the providers of a range of services;
- the opinions of community leaders;
- the normal channels of communication within the community;
- the opportunities to communicate through local media, street theatre, traditional drama groups and schools;
- the barriers to participation and exclusion;
- the opportunities to gain the support of village/local leaders.

They may facilitate community participation by:

- sensitizing the community to the need to remove barriers to participation;
- creating awareness of the benefits that might arise from including people with disabilities in the community;
- encouraging community members to provide appropriate care and support to people with disabilities.

They may contribute directly to interventions by:

- working to change attitudes among people with disabilities and their family and community members;
- promoting role models, drawing attention to the success of individuals who have overcome physical, social or economic problems;
- encouraging people with disabilities to become active contributors, motivators and advocates;
- responding to stigmatizing behaviour by presenting appropriate information and persuading people to change their behaviour;
- helping to organize the interventions;
- developing new skills among participants.

Advice

- ✓ Keep it simple – give an appropriate and clear message.
- ✓ Be innovative – take every opportunity to present the message.
- ✓ Be persistent – keep repeating the message.

The two case studies below are from Nepal. Case study 2 illustrates how, with encouragement, groups can develop their own solution to a problem. Case study 3 illustrates how empowerment is effective against social exclusion.

Case study 2: Nepal

The Sundari Community Forestry Committee manages forest production in the Sundari community. One of the community members had been affected by leprosy. As a part of his assessment a social worker visited the Forestry Committee and the members of the Committee decided to join the rehabilitation process. Through this partnership the Forestry Committee realized that people with disabilities are the most underprivileged and neglected group in the community and decided to initiate a rehabilitation programme in their community, mobilizing all available resources. They formed a rehabilitation committee and sent one community worker for a month-long training.

Elsewhere in Nepal community members have donated money, written references, provided training at no cost, agreed welfare budgets or developed rehabilitation plans for people with disabilities.

Case study 3: Nepal

A stigma elimination programme in Nepal adopted a unique approach to reducing leprosy-related stigma in the community. The idea was to encourage self-help groups to pursue a development agenda for the benefit of their wider communities. Ten people affected by leprosy were appointed as facilitators and asked to develop self-care groups in their villages. All these individuals had completed self-care training and were chosen on the basis of character and perceived potential as organizers and facilitators. They were issued with the names of people affected by leprosy in their villages and were asked to contact these people and to encourage them to initiate self-care groups.

Within one year these groups had developed and began to function as self-help groups. They were conducting small projects and managing loans. They recruited new members, including other marginalized and disadvantaged people.

Next, the groups took initiatives to pursue a development agenda for the benefit of their communities. The groups organized and supervised non-formal education. They worked to obtain wells and water pumps and to improve the local environment (hygiene and access). They were also involved with old people and in advocacy.

Evaluation of the programme found that the groups had gained recognition and respect in their communities. Local people appreciated all their activities on behalf of the community and especially their efforts to overcome the impact of leprosy impairments. The Director of the District Education Office considered the groups to be the best-functioning community partners in the District. An assessment of participation restrictions found that individuals involved in the groups reported much reduced participation restrictions compared with individuals affected by leprosy who were not included in the programme. The evaluation concluded that, when individuals marginalized through leprosy are transformed into positive-change agents, the stigma associated with leprosy in their communities is negated.

2.3 Advocacy

Advocacy means promoting or speaking out for a cause. Since people with disabilities have the best understanding of their situation and needs, it is important that they take a lead in advocacy. If they do not do this their situation and needs will not be effectively expressed. The act of expression itself is empowering and can motivate action.

Rehabilitation workers become involved in advocacy on behalf of people with disabilities. This involves speaking out against injustice and working for equality of rights. Communities and governments are encouraged to accept and take up their responsibilities towards people with disabilities. Where disabilities result in loss of rights or social exclusion, advocacy draws attention to these injustices and seeks to correct them.

Involving more people, speaking with a united voice, and working in alliance with other interest groups all contribute to successful advocacy.

Activities commonly associated with advocacy include large-scale education programmes or lobbying for changes in society to address injustice. Advocacy begins when individuals or groups contact the relevant authority and raise a specific issue, such as the need to enrol a disabled child in a local school, to access credit, to access housing benefit, etc.

Tasks of programme managers

Programme managers plan programme activities that ensure that people with disabilities become aware of their rights – the right to access services, to own land, to marry, to have children, to work, and to participate in social and religious festivals – and that they enjoy these rights. This involves:

- facilitating joint meetings between local authorities and people with disabilities and their families to address examples of prejudice and discrimination;
- networking and building alliances with like-minded organizations;
- encouraging the participation of community leaders and other interest groups in advocacy;
- promoting self-advocacy, encouraging people with disabilities to speak out for themselves, perhaps through self-help groups (see section 4.5);
- encouraging local media to report achievements of people with disabilities or to increase awareness of their rights.

Tasks of community workers

Community workers seek to ensure the rights of people with disabilities and to help them gain access to available services. They seek to address local issues or assist clients to overcome specific problems by:

- making people with disabilities aware of their rights and opportunities;
- facilitating group formation – encouraging people with disabilities and their families to come together (group advocacy is more powerful than solitary efforts);
- encouraging groups to speak out against injustice and discrimination;
- arranging legal representation for land purchase, inheritance, citizenship, etc.;
- participating with clients in addressing injustice, e.g. to gain access to schools, to access training courses, to work or to marriage;
- promoting self-help and other groups that represent the rights of people with disabilities (see section 4.5);
- identifying and promoting role models who have overcome injustice and discrimination arising from their disabilities.

Experience in the field shows that it is important to concentrate on one issue at a time, as illustrated in the example below.

- ✓ What is the issue? What is being violated?
- ✓ Is it widely recognized as a problem? Where and when does it occur?
- ✓ How might it be solved?
- ✓ What resistance might there be?
- ✓ What actions will address the problem?
- ✓ Build a team to address the problem. Assign responsibilities.
- ✓ Take action.

Forming a Rehabilitation Advisory Committee has proved to be an effective way to guide advocacy activities. Members can be drawn from local communities, partner organizations, self-help groups, governmental and nongovernmental organizations.

Case studies 4 and 5 show the importance of advocacy in Bangladesh and Senegal.

Case study 4: Bangladesh

Life for people with disabilities is particularly hard in Bangladesh. A community worker began to visit people with disabilities in their own homes, entering into dialogue and learning from their experiences. He gave them advice and stimulated them to join forces and to discuss among themselves all kinds of matters that needed to be improved. One issue was the difficulties experienced in gaining access to schools for many children with disabilities. Schools did not know how to deal with these children and often refused access.

At the start, self-help groups were formed in twelve villages. Each had around ten members who met regularly to discuss matters such as transport, assistive resources, neglect and oppression. The groups worked for improvements in their village environment...and it worked. People with disabilities became more and more aware of their rights and of their ability to change things. In villages where there are self-help groups many children with disabilities now go to school.

Recently, a national campaign was started to induce the government to fund assistive devices that will enable greater participation in society for people with disabilities. There is an increase in awareness of the benefits to all of greater participation.

Another issue to which these self-help organizations have devoted much time and energy is access to buildings for people with disabilities. Since few public buildings are accessible, the number of people with disabilities who have paid jobs is very small. The government is now working on policies to create jobs for people with disabilities and there is a growing awareness that mobility is very important. In many districts, buses now have reserved seats for persons with disabilities, who travel at half the normal fare.

Case study 5: Senegal

In Senegal, a seminar was organized that made a clear recommendation to change the discriminating laws of the leprosy villages. The information reached the Prime Minister and discussions with the government continued. The village chief and the village development committees in some villages are now legally recognized by the administration. Lobbying for citizenship showed results. People now have identity cards and are able to vote – but they are now also registered to pay taxes.



Source : Georgha Cranston/TLMI

2.4 Networking with community and other organizations

Being aware of the services available in the community to people with disabilities is important information for the rehabilitation process. Networking among potential partner organizations provides the opportunity to share information on local services, reduce duplication, and open new ways to respond to rehabilitation needs. It ensures that rehabilitation programmes and their clients gain access to the services they need.

Any local group or organization may join the network. Organizations may represent the community or groups within the community. They may represent the interests of people with disabilities. They may provide resources or services such as loans, vocational/skills training, marketing opportunities or other services or expertise.

Networking in Pakistan and Uganda

In Pakistan, referral options encourage people with disability to use their right to approach the appropriate services, and use resources in the community. Since networking with health clinics has been established, clients are becoming accustomed to mixing with other community members.

In Uganda, networking has led to the development of national policies concerning CBR, and to national recognition for approved CBR training programmes.

Tasks of programme managers

Programme managers develop networking through formal or informal meetings with representatives of other organizations. These meetings offer many different opportunities by:

- recognizing shared interests and concerns;
- learning about the work of other programmes and organizations;
- identifying duplication or gaps in services;
- identifying local issues or problems;
- reviewing working arrangements, for example, referral routes or training programmes.

Regular meetings sustain networking – ensuring regular communication, developing awareness and promoting participation.

Tasks of community workers

Community workers benefit from increased awareness of skills and resources available within the community by:

- networking with key individuals in the community, e.g. school teachers, religious or community leaders, or women's groups, and encouraging their participation in the rehabilitation process;
- networking with local organizations, community representatives or government departments that may provide access to designated funds, e.g. for the training of clients, community workers or others involved in providing CBR.

2.5 Facilitating the work of other service providers at community level

Some organizations choose not to have their own field programmes but to help other service providers develop their services. This approach requires regular communication with field partners and effective networking. Case study 6 shows how a group of local nongovernmental organizations provide CBR services in Uganda.

Case study 6: Community Based Rehabilitation Alliance, Uganda

The Community Based Rehabilitation Alliance (COMBRA) was started in 1990 by a group of Ugandans whose vision was to create an enabling environment for persons with disability to enjoy equal opportunities as other Ugandans through capacity-building. COMBRA's mission is to empower and advocate for and with persons with disabilities for their sustainable development. Through CBR, COMBRA aims to enhance the quality of life of people with disabilities, providing equitable opportunities and promoting and protecting human rights. Objectives are set in five areas as follows:

- developing CBR programmes;
- training rehabilitation workers at different levels;
- strengthening linkages and networking;
- advocating and lobbying for equal opportunities;
- developing research and documentation.

The organization develops training materials and provides training for CBR workers at different levels. It maintains communications by networking with partners in the government ministries as well as with organizations representing people with disabilities, and with nongovernmental organizations.

3 Responding to the rehabilitation needs of individuals

Sustainable interventions must match individual needs and skills. Active involvement of the affected person in the intervention is essential. To be fully effective, interventions require the active support and participation of the community.

3.1 Screening to match needs and resources

People affected by leprosy or disabilities may be referred to rehabilitation services by health or social services, or by community workers or local leaders. Some may self-refer.

It is important to identify individuals who can enhance their functional capabilities through vocational training or credit schemes. Some may have significant needs that they can manage themselves. Some may respond to simple counselling or encouragement. Other others may have needs that are no different from those of the local community. Many programmes use a screening process to identify individuals in need of rehabilitation services (see Figure 3).

Access to the programme may be further restricted by policies that recognize individuals with priority needs or limited resources. Priority may be given to individuals from recognized vulnerable groups, e.g. relating to gender, age or marital status, having severe psychological, social, economic or physical problems, or by severe participation restriction.

Through screening, some individuals may be referred to the services available from other local organizations. Those selected for rehabilitation begin a period of assessment and motivation that leads to a commitment to an individual rehabilitation plan (see Annex 3) aimed at developing new life skills, social integration and restoration of dignity.

Immediate family members – husband/wife, parents, grandparents, children, brothers or sisters – are often valuable resources to the process. This family focus is central to CBR.

Individuals enrolled into rehabilitation programmes are referred to as clients rather than patients.

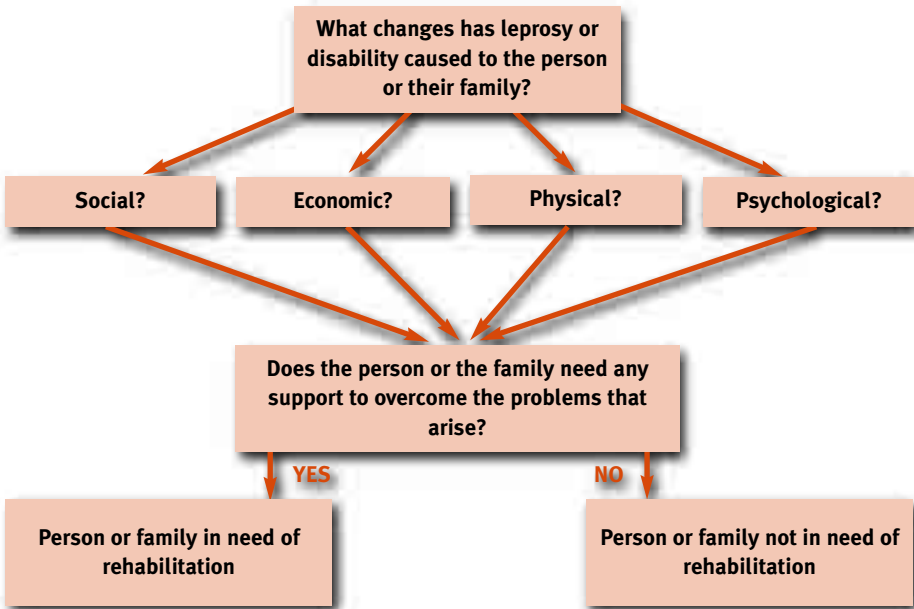


Figure 3. Steps in identifying people in need of rehabilitation services

3.2 Assessing needs and skills

Through needs and skills assessments, rehabilitation workers develop a good understanding of each new client, the changes leprosy has brought to their lives, and the skills and resources that may be required for their rehabilitation.

Tasks of programme managers

Programme managers identify and develop the tools and documentation systems needed to monitor overall progress of the programme. He or she may need to modify the tool to meet specific local requirements, or in response to feedback from community and CBR workers.

Tasks of community workers

To collect complete and accurate information requires meeting at a place where an individual is most comfortable to talk, and working through a needs and skills assessment form. Annex 3 includes the outline of the form. Using guiding questions, such as “Why...?” and “How...?” clients are encouraged to speak freely about their situation and experiences. Suggested questions are listed below.

- What physical changes has the client observed, including loss of sensation or weakness?
- Have the disabilities affected activities of daily living? (Annex 3 provides a reference to the SALSA Scale that may be used to make this assessment.)
- How has the disability affected relationships with family and community?
- How has the disability changed the person’s ability to work and support family members or to complete their education?
- What problems occurred because of gender, age or ethnic group, or because of multiple disabilities or the severity of the disability?
- What skills and resources are available to the person?

In addition, information should be collected from listening to the views of family members and others, encouraging their participation in the rehabilitation process from the start.

It is also important to gather as much information as possible related to the following:

- educational background;
- economic background;
- security, such as family support, land, housing, etc.;
- “saleable” skills and knowledge;
- responsibilities for family members;
- support from community or other sources;
- facilities which can be accessed within or outside the community;
- the client’s future possibilities, according to his or her consideration.

Quantifying the participation restriction experienced by the client draws attention to specific problems and provides a baseline for assessing future changes. Annex 3 provides a reference to the Participation Scale (P Scale) that can be used to assess participation restrictions resulting from leprosy or other conditions.

Obtaining complete information about the client’s situation may require a series of meetings.

It is also important that community workers manage their work and keep careful records by:

- keeping a field diary containing a summary of what is said at each meeting, while respecting confidentiality;
- submitting a report of findings to supervisors or managers;
- identifying and referring individuals with complex needs for further assessment or specialist help.

Advice

- ✓ Accept each client as he or she is.
- ✓ Have respect for individuals and their families.
- ✓ Listen carefully to everything they have to say.
- ✓ Do not be critical.
- ✓ Recognize that assessing the needs and skills of clients is ongoing, but over time the emphasis moves on to motivation.

3.3 Developing motivation

Many people affected by leprosy may find it difficult to talk about their experiences and the impact of leprosy on their lives. For some, the experience will have been traumatic. Others may be in a depressed state. It is important therefore to take time, perhaps organize several brief meetings, before beginning to discuss the rehabilitation process. As this process begins, community and CBR workers have an important role to play in developing motivation, and encouraging each client to participate in rehabilitation activities from the beginning.

Clients are likely to be very knowledgeable about their current situation, their needs, and their problems, and many will be aware of potential solutions. For a successful rehabilitation process it is important therefore to listen to what the client has to say and to encourage them to develop their own plans for the future.

As motivation develops, some programmes encourage clients to participate in preparing an individual rehabilitation plan. Over time these are developed to describe a series of agreed rehabilitation actions and responsibilities (see Annex 3). For some clients, developing a rehabilitation plan may provide all the motivation and confidence needed for their rehabilitation.

Tasks of programme managers

Programme managers direct the process of developing motivation by:

- promoting methods of working that encourage clients to share their experiences;
- monitoring the attitudes and activities of community and CBR workers and assessing the quality of communication with clients;
- assessing the relationship between all stakeholders in the rehabilitation process.

The quality of the relationships between stakeholders is vital to the success of the rehabilitation process (see Figure 4).

Tasks of community workers

Through listening, reassuring, counselling and coaching, community workers can encourage

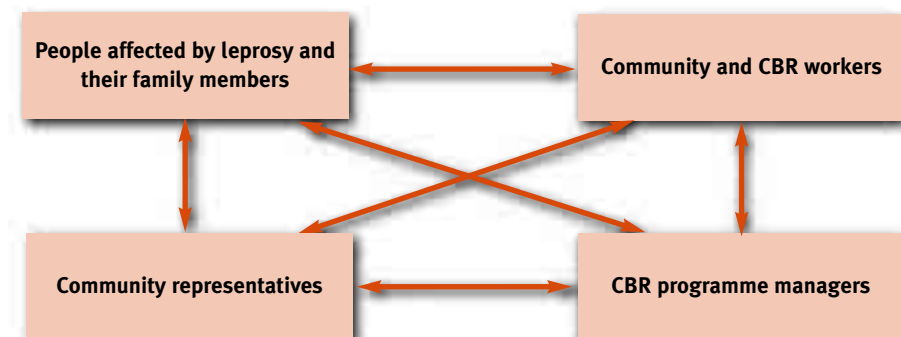


Figure 4. Relationships between stakeholders within the CBR process

the development of self-confidence and motivation in their clients. Specific tasks to help to achieve this include:

- meeting regularly to develop trust and communication;
- developing an understanding of the cause of disability, including the need for continuing self-care;
- developing an understanding of the rehabilitation process;
- involving family members in the rehabilitation process as and when needed;
- linking clients to self-help groups;
- encouraging clients to participate in educational programmes, e.g. functional literacy, developing new life skills;
- introducing other successful clients as role models.

The quality of the relationship between the client and the community worker is the key to success.

Case studies 7 and 8 illustrate the importance of counselling when stigma or self-stigma is present.

Case study 7: India

Beeramma is 40 years old. When she was young she was a good singer and villagers used to ask her to sing devotional songs at festivals and other special occasions. Nearly 20 years ago she noticed patches on her neck, and doctors told her she had leprosy. She began the lengthy treatment, but the tablets made her feel sick so she stopped taking them. Over the years she lost sensation in her hands and legs and began to develop disabilities.

When CBR workers visited her village they noticed that Beeramma kept away from other people. When they asked her why she did not join with others, she explained that she was afraid that people might tease her because of her disabilities and leprosy. She said “When people tease me, I am really hurt”. The workers counselled and encouraged her to join a new self-help group in the village.

Beeramma agreed to join the group and became one of its leading members. She learned how to protect her hands and feet and is now busy with household chores and caring for sheep. There is no stigma towards her in the community. Looking back she says “For a long time I lived within four walls. I kept myself apart. Now I realize that people do not think badly of me. I was the one who had an inferiority complex. Now I realize that no one is without value”. These days, Beeramma is active in telling people about leprosy and assuring them that it is curable if they receive treatment in time.

Case study 8: Thailand

Some clients have severe psychological problems due to stigma, or because they have difficulty accepting their disabilities. Others begin to hate themselves or experience feelings of hopelessness and guilt. In such cases they are not ready to start work on an intervention. The time to start is when there is trust between the client and key people in the community, a community worker, or a friend or neighbour. Without this trust there is insufficient back-up or support for a new challenge.

The clients should come up with the proposal for an intervention. This takes time. Those people who come up with their own ideas are ready. If there is no suggestion then more motivation and background work is needed. To just say “You can do it!” doesn't work with someone who has no hope or no future perspective. It is better to give a few words of encouragement and to encourage cooperation with family and friends. The client could be asked to think about it and to continue discussions at a later meeting.

When the client is ready to become involved in an intervention, it is important to involve family and community members in a supportive way and not to treat the client as a “poor leprosy patient” who needs help.

4 Planning and implementing interventions

4.1 What is an intervention?

Interventions are activities agreed between CBR workers and clients that seek to address an agreed need or problem related to individuals or communities. They take many different forms, such as:

- supplying information to clients or communities about resources and opportunities available in and around the community;
- counselling or social work to address psychological or social problems.
- formation and development of self-help groups or advocacy groups;
- educational activities to enhance social harmony or to promote an inclusive society;
- advocacy to promote equal opportunities and equal rights in the society;
- negotiating access to local government services, schools, pensions or benefits;
- promoting the participation of people with disabilities in community development activities;
- small projects that provide income without the risk of aggravating disabilities;
- developing home-based care programmes – preferably self-care;
- providing assistive devices to overcome physical disabilities;
- encouraging people with disabilities to join mainstream self-help groups;
- skills training and income-generating activities.

As can be seen by the interventions listed above, income generation is just one of many types of intervention. Clients and community workers may identify other forms of intervention that are appropriate to the specific needs of the client.

Some or all interventions may be arranged through referral to services provided by other organizations.



Source : TLMII

4.2 Choosing an intervention

The choice of intervention is central to the client's individual rehabilitation plan. The intervention should match the needs, skills, expectations and resources of the client and other family and community members involved.

The objective is to identify an appropriate activity to meet an agreed priority need, whether physical, psychological, social or economic.

The result may be an intervention with the community, the family or the client.

In choosing an intervention it is important that clients recognize the risks and costs as well as the opportunities and benefits.

Tasks of community workers

Community workers play an important role in facilitating the client's choice of intervention, helping him or her to understand the implications involved. A list of questions that might be used to match interventions to the skills and needs of individual clients is given below.

Questions relating to physical status, dexterity and mobility

- Is the client able to travel to a workplace?
- Will the proposed activity pose a risk to insensitive hands or feet or to other forms of disability?
- Will the disability prevent precision work?
- Will the activity allow the client to work in his or her own home?
- Will there be sufficient space for the client to work effectively?

Questions relating to work experience and training requirements

- Is the training affordable and of limited or manageable duration?
- Does the client have relevant and adequate work experience?

Questions relating to employment, production and marketing

- Does the intervention develop locally available skills?
- Is there relevant local experience?
- Can products be marketed locally?
- Is there a reliable, year-round market?
- Are there competing, quality products already available?
- What is the cost of consumables, raw materials, tools and equipment? Do these threaten sustainability?
- Are there issues relating to gender, caste or social status?
- Will negative attitudes towards disability threaten sales?
- Would the intervention be more successful as a group or cooperative activity?
- Does the intervention require access, rent or purchase of land?
- Is the agricultural, livestock or fisheries intervention susceptible to local disease, annual monsoon or flooding?
- Is there adequate and affordable local transport to move raw materials and products?
- Is the intervention reliant on high-cost specialist skills, e.g. veterinary skills?

Working with the client and their family members, and guided by managers, community workers can facilitate the choice of intervention by:

- identifying interventions that develop existing knowledge, skills and work experience of the individual or their family members;
- identifying interventions that rely on skills, resources and opportunities available in the community;
- encouraging involvement of family and community members;
- discouraging interventions that pose a risk to insensitive hands or feet;
- assisting in the mobilization of resources needed for training and capacity building;
- facilitating a choice of intervention that allows support by the programme;
- confirming with managers that policy and resources will allow the programme to support a particular intervention.

To be successful, it is important that community workers maintain good communication with their managers, with rehabilitation professionals, and with local leaders or entrepreneurs.

The factors that contribute to making an intervention effective are summarized below.

Factors that contribute to making an intervention effective

Community workers

- Responsiveness to suggestions from clients and others.
- Careful planning, monitoring and evaluation.
- Ownership, enthusiasm and commitment of community workers.

Community

- Shared responsibility for supervision.
- Commitment of resources by community members.

Client and family

- Ownership of the intervention.
- Motivation, as seen in the family's involvement and encouragement, and the commitment of family resources.
- Shared responsibility for supervision, perhaps also involving a self-help group.
- Appropriate knowledge and management skills.
- Management of risks associated with severe disabilities.

Income-generating interventions that produce items for sale

- Skills in managing a business.
- A realistic business plan including information about:
 - production costs – raw materials, labour and transport;
 - marketing issues – demand, design, quality, durability, flexibility;
 - funding issues – loan, seed money, pricing and fund management, including banking.

4.3 Preparing for an intervention

Once the client, family members, community worker and manager commit to an intervention, it is important that detailed plans are included in the individual rehabilitation plan, resources are allocated, and all those involved have a clear understanding of what is expected of them.

Tasks of programme managers

The programme managers ensure effective planning, by:

- making the client aware of the implications of the chosen intervention, including the availability and cost of technical support;
- defining the role of family members as essential partners, committed to providing resources and supporting the client;
- preparing a written plan covering all aspects of the intervention, including:
 - a description of the intervention;
 - defining an end-point for the intervention;
 - stating a schedule, noting possible changes;
 - predicting impact and how it will be assessed;
 - identifying risks or assumptions that may affect the outcome;
 - specifying arrangements for supervision, monitoring and reporting, including who will provide monitoring information;
- explaining the roles and responsibilities of client, family, and programme staff.

Experience in the field

- ✓ It is very important that people are fully committed to an intervention and enjoy the support of family and community members.
- ✓ Community workers may have to make special efforts to ensure support from community members.
- ✓ Clients will need varying levels of support, some more, some less.
- ✓ Over time, clients gain the capacity to organize new initiatives, and need less support from the programme.

4.4 Implementing an intervention

Interventions may involve the use of new skills, taking difficult decisions and exposure to risk. Careful planning and attention to detail ensures that interventions are correctly implemented and risk is reduced. Monitoring provides information about the progress of the intervention and identifies any problems that may arise. Evaluation assesses the impact of the intervention.

Managers take responsibility for all these processes, depending on community workers to collect the data and report on progress.

Tasks of managers

Managers commit resources according to the agreed schedule by:

- supporting the assigned community worker;
- holding regular review meetings with all the staff concerned to review the progress they are achieving and to understand any difficulties they may be experiencing;
- meeting regularly with community workers and clients to identify when the intervention has reached its agreed end-point;
- identifying and documenting lessons learnt and any need for further interventions.

Tasks of community workers

Community workers help to implement the intervention by:

- encouraging clients, families and communities to commit agreed resources;
- reviewing progress with clients;
- assisting with problem-solving;
- providing progress reports based on agreed monitoring procedures, including baseline assessments (see section 6.2);
- reporting the client's own assessment of progress and impact together with those of family and community members (see sections 6.2 and 6.3).

Case study 9 illustrates the implementation of an income-generating intervention.

Case study 9: Bangladesh

Babu was just 16 years old when he was diagnosed with leprosy. He worked as a farm labourer, but he had severe loss of sensation in his right hand, which was the cause of serious ulcers. He needed several periods of in-patient treatment before his ulcers healed. His right foot was also deformed. After his time in hospital he decided he needed to find a new job with reduced risk of damaging his hands. First Babu took a small loan from the CBR programme that allowed him to buy a cow and earn income from selling milk. When he had repaid the loan in full he asked for a new loan to finance a business repairing cycles. He took training and started his own business and earns a small income each day.

As a result of the CBR activities, Babu's daily income is now three times what it was before. He has married and lives in a new house near his place of work. His customers value the quality of his work. Previously, other members of the community neglected him. Now they accept him and he plays a full part in community life and attends the mosque.

4.5 Forming and supporting self-help groups

Assisting the formation and development of self-help groups can be an important activity for rehabilitation programmes. Rather than including only people affected by leprosy, these groups should bring together people from a broad disability background or include affected people in mainstream self-help groups. Groups dedicated to the general needs of women are to be preferred to those having a membership that is exclusively for women affected by leprosy.

Self-help groups have proved effective in many different ways as listed below.

- Members meet regularly to discuss and share problems. They learn to support, understand and encourage one another, so building confidence and self-esteem.
- Group meetings provide opportunities to share information and to learn from others. Existing members assist in needs and skills assessments with new members. Members may review rehabilitation plans of others.
- Increased visibility of group members within the community helps to change attitudes and encourage acceptance.
- Local people and authorities are more likely to listen when members speak as a group.
- Formal registration of groups gives a legal status and may facilitate access to government or financial services.
- Once a group becomes strong and active, its inclusion with mainstream self-help groups becomes easier. In turn this promotes inclusion and participation as equal members of the community.

Forming and supporting self-help groups – experience in the field

Early stages

- Limited mobility, cultural issues and poor local communications may make it impractical to form self-help groups.
- It is important to provide mentoring and a high level of support during the early stages.
- Motivation develops through shared learning and increased awareness of the experiences of others.
- developing and working with self-help groups has provided opportunities for capacity-building (Nepal), needs assessments (Ethiopia), developing training materials (Uganda), and planning and monitoring rehabilitation activities (Nigeria).
- Groups need to be allowed to develop in their own way.

Later stages

- Self-help groups have proved very effective in developing motivation and self-confidence – important contributions to the rehabilitation process.
- Group members learn how to identify priorities for interventions among their members and how to monitor the progress of interventions.
- At group meetings, community workers have the opportunity to learn from the experience of group members and to promote new ideas or challenges.
- Respect for group members by the community workers is very important.
- Group members may challenge the assumptions and priorities of the programme, but this is part of the empowerment process.

Forming a self-help group

Early stages

Community workers facilitate the process, building capacity and encouraging group members to function jointly. Their tasks include:

- identifying the geographical area for recruitment;
- defining the objectives of the group in consultation with potential members;
- explaining the purpose of the group to the community;
- identifying and recruiting members from the agreed locality;
- facilitating initial meetings to discuss local issues and promote unity;
- encouraging the group to identify physical, economic or social needs;
- guiding the group in the election of a leader/committee;
- identifying capacity-building needs and arranging training;
- encouraging groups to grow and mainstream;
- teaching group members how to manage funds, how to set up a bank account and how to set up a savings scheme.

Criteria contributing to making a self-help group effective

Criteria can be identified under the following categories.

Membership

- Members share common values, concerns and experiences.
- The group has shared goals and objectives.
- Membership is homogeneous. (Where necessary – to ensure a level of literacy or provide required expertise – one or two people without disability may be included in the group.)
- All members commit resources (time, finances, etc.).
- All members are clear about their roles and responsibilities and develop ownership of the group.
- Optimum size of group: 10–15 members.

Leadership and capacity-building

- Annual elections are planned to select a group leader.
- Training is provided to develop leadership skills, secretarial skills, and skills in maintaining accounts.

Development of the group

- Regular saving is encouraged.
- Involvement in small-scale projects is encouraged.
- The group is motivated to review and set new aims and objectives.
- Concern for self-care is maintained.
- Understanding and mutual support are developed.
- The group is encouraged to lobby for equal opportunities.
- Awareness of key issues is raised, e.g. advocacy, functional literacy, family planning.
- Time spent in managing loans is reduced.
- Formation of federations of self-help groups is encouraged.

Case studies 10 and 11 show how starting a self-help group of people with different disabilities encouraged the persons affected by leprosy to be involved with their own self-care.

Case study 10: Nepal

The programme in Nepal encourages people to form self-help groups. Training is provided in micro business, agricultural skills, basic account keeping, and other subjects according to the requirements of the group. When the members have developed trust and understand the importance of mutual help, they start saving. Every member is provided with a pass book and each contribution is entered in their pass book and also in a ledger.

From time to time, group members take loans from the group, either from savings or from seed money provided to the group by the programme. The group itself decides about the interest rate and duration of the loan. Half the members may get a loan at the same time. The other members encourage them to repay their loans on time. Of the 14 self-help groups who received seed money, 13 are doing well.

Case study 11: Tamil Nadu, India

In Pallathur we tried to form a self-help group with eight people affected by leprosy. We told them and their families about self-help groups and their advantages, but the families refused to cooperate. They did not understand how it would work. Their concept was that people with leprosy-related disabilities have to be cared for throughout their lives. We held regular meetings, but there was always the question “What do we get out of it?”. Then we identified eight other people with different forms of disability. One had a physical disability, some were blind, and some had speech or hearing problems. We encouraged all 16 people to join in an integrated self-help group. They all agreed, though it took one year for the clients and their families to understand the concept. They called the group *Sakti*, meaning power. Now they meet every two weeks and there is no stigma among them. They try to understand one another’s difficulties. When the group was recognized by the government, it was awarded RS 25 000 as a revolving fund, so it is now financially secure.

4.6 Micro-credit programmes

Since many people with disability live in poverty, poverty reduction is an important CBR activity. Where banks are reluctant to give loans, many people with disabilities borrow money from private lenders at high interest rates. When they fail to make the repayments they are forced to borrow more and so their financial state deteriorates further and they become more marginalized.

Providing access to micro-credit loans with a fair and affordable rate of interest has proved to be an effective means to generate income and promote empowerment. In the context of CBR, such loans provide access to financial resources that might otherwise be denied. In some CBR programmes, self-help groups run micro-credit programmes among their members.

It is common practice for clients of CBR programmes embarking on income-generating activities to request a small loan. The following sections describe recommended procedures for the issue and recovery of loans. (Note that formal accounting procedures and legal requirements relating to credit programmes are beyond the scope of this guide, but need to be understood by managers.)



Source : Georgina Cranston/TLMI

Key principles for credit programmes

- A micro-credit programme should not be started alongside a programme that is making grants or charitable gifts. The two do not go together. It is unrealistic to think that one individual will repay the money he or she was given while another is allowed to keep it.
- Where local organizations provide credit on acceptable terms there are many advantages in referring clients to those organizations.
- A credit programme needs to be run on business terms with very clear conditions and simple accounting procedures that are understood by all participants.
- All those involved must be fully committed to the principle of repayment.
- It is preferable to offer credit through self-help groups, with group members involved in decision-making, supervision and collecting repayments.
- Monitoring of repayments should be included among agreed procedures.



Source : TLMI

Tasks of programme managers

Programme managers establish links with partner organizations or local banks to provide micro loans.

Case study 12 lists the problems experienced with micro-credit programmes in Senegal.

Case study 12: Senegal

- For cultural reasons people do not express their ideas. Instead they say “Whatever you do for me is fine”. In contrast, demands can be excessive. The process of deciding how and where to help is mostly rather slow.
- Increasing poverty has a negative influence on micro-credit projects – people find it difficult to maintain repayments.
- Working with individuals requires good knowledge of the client and his or her environment, regular follow-up, etc. Very often this is impossible and as a result the system of guarantees does not work.
- The normal size of loans is too small to generate sufficient income. Giving large loans is not possible.
- Pressure from family members is very high. A person who earns just a little money has to contribute towards the cost of food, family events (e.g. funerals, marriages, etc.) or the care of elderly family members. Often the loan is used for these additional purposes.
- Management of small businesses is inadequate, leading to an inability to renew stock.
- The choice of financially attractive activities is extremely limited for people who are illiterate.
- Some people fail to respect the rules and contracts relating to loans.

Tasks of community workers in support of credit programmes

Community workers play an important role in informing clients about how they may benefit from the credit programmes by:

- ensuring clients are aware of all aspects of the programmes, the costs as well as the benefits;
- facilitating access to loans from partner organizations or forwarding applications for approval by the managers;
- involving family members or other group members in interventions with clients who would otherwise experience difficulty in making repayments;
- encouraging regular repayments;
- identifying and seeking to address situations where repayments may be delayed.

The factors below have been identified as being important for running a successful micro-credit programme.

- Approval of loans should be conditional on regular savings over a 12-month period.
- Clients and groups should learn to manage their loans.
- A schedule, usually of one to two years, should be agreed upon for repayments that match the capabilities of the client.
- Frequent repayment of small amounts helps to achieve higher repayment rates.
- Group and family members provide motivation and supervision.
- Selected community members or leaders should be invited to motivate and monitor recipients of loans.
- Where literacy is an issue, other people from the community should be involved to keep records or to facilitate literacy classes.
- Any problems that arise should be dealt with promptly.

Case study 13 illustrates how a small loan initiated long-term improvements.

Case study 13: Ethiopia

Ato Tsega Birle is 38 years old. He is married and has six children. He lives in a smart new house and has a healthy bank account. Outside his house there is a line of transport carts waiting for work. But Ato Tsega has not always been so well off.

He was born in Gondar. When he was 10 years old both his parents died. As if this was not hard enough to bear, soon after, he was diagnosed with leprosy. Instead of caring for him, his remaining relatives isolated him. He was forced to move away to live in a leprosy colony in a distant town. He became a member of that community and after some time he heard that there was a cure for leprosy. He found the place where he could be treated and he started working so that he could buy food and pay for somewhere to live. He found that work in a factory caused him to injure his hands. Later he worked in a flour mill and managed to start saving. Eventually he saved enough money to buy a mule and cart and to earn money by carrying goods to and from the local market.

All Ato Tsega's hard work and careful saving seemed to promise a happy future, but then, within just a few weeks, disaster struck. His mule died and his business collapsed. He did not know what to do and considered ending his life. Thankfully his friends and neighbours persuaded him that there was still hope. Within a few days he heard of a rehabilitation project that might help him to restart his business.

He applied for a loan that would allow him to start a new business. The loan was given and he began work maintaining transport carts. This proved to be profitable and the business grew rapidly, allowing him to repay his loan quickly. Soon he purchased his own carts and transported goods to and from Addis Ababa. He was able to buy a house and got married. Through hard work he achieved many things in his life.

By providing assistance when it was most needed, the CBR programme played an important role in the life of Ato Tsega. He admits that before he got help he had a feeling of inferiority that came from his time living in the colony. Now he has developed self-confidence and dignity and is well on the way to being the most important merchant in his town. He is a member of social and religious groups. Financially he is totally independent and able to support other social groups.

5 Contextual issues regarding interventions

5.1 Working in settlements

In many places there are settlements of people affected by leprosy. These are commonly referred to as colonies. Many were created through historical policies of isolation or resettlement and a lack of understanding about the merits and demerits of such colonies.

Some of those living in settlements may be long-term residents with no contact with family members or former family homes. Those with severe disabilities may be dependent on begging or charity. In some cases the community may have developed an attitude of entitlement, considering it their right to receive grants and unconditional gifts from charitable organizations or individuals.



Source : Livio Semigallies/World Health Organization

The objective for rehabilitation activities in settlements is to enable and empower communities through a process of awareness raising and facilitation. In long-term settlements this includes working to develop self-reliance and improve quality of life, assisting residents to gain normal rights and privileges. Reverse integration – encouraging people without disabilities to move into the settlements – may also be encouraged.

Tasks of managers

Managers negotiate with local authorities and decision-makers to clear the way for field work that assists residents to:

- register as land owners;
- access government benefits such as pensions or allowances;
- access health services and local amenities;
- access schools, higher education and vocational training;
- earn an income and support family members;
- develop new awareness among community leaders.

Through networking, managers encourage other organizations to extend their programmes to the settlement, e.g. programmes of employment creation, vocational training or credit programmes.

In overcrowded settlements, rehabilitation programmes may encourage families and individuals to consider resettlement elsewhere. They follow-up families who choose to relocate, report their experiences, and encourage others to do the same. Settlement land can then be reallocated for community use, resource centres, rehabilitation centres or recreation centres.

Where settlement land is under threat from developers, rehabilitation programmes develop alliances of residents and partner organizations to engage in advocacy, together with and on behalf of the residents. Where this proves successful, they work to normalize the situation of

the settlement. Where the settlement is required to relocate, this should ideally be to existing communities. They should seek to ensure that the new land is properly designated and that housing and basic amenities are provided.

Tasks of community workers

Community workers play a key role in all this work. They:

- represent or encourage representation of the community at meetings discussing the future of the settlement;
- work to motivate individuals and families;
- support individuals and families in decision-making and problem-solving;
- identify groups with special needs – by age, gender or disability status;
- collect and report information and monitor progress.

5.2 Gender Issues

Disabilities affect both men and women. In the case of leprosy, the evidence is that women experience more social and economic problems.

Young, newly married women are particularly at risk. Disability or leprosy may spoil marriage prospects. Women with disabilities may be more vulnerable to exploitation. Giving special attention to the needs of women acknowledges their wide-ranging roles within the family and within the community.

Tasks of community workers

It is important that programmes seek to appoint female workers. Their role is to help women identify and solve problems. They:

- assist women to join women's groups;
- form and develop self-help groups for women;
- assist women to gain access to loans and run their own income-generating activities;
- educate women about their rights and provide information about avoiding exploitation and obtaining legal help.

Experience in the field

- Field work is found to be more successful where support is available from client's family members or the community.
- Advocacy issues on behalf of women include reproductive rights, HIV prevention, family planning and sexual exploitation. Government ministries have programmes in many of these areas.
- Complex family situations may require the input of professional social workers or counsellors.
- Priority should be given to women with special needs or severe disabilities, as well as to women with large families, those without children, and widows.
- Role models should be identified and promoted.

Case study 14 from Ethiopia illustrates the potential of women's work, either through individuals or groups.

Case study 14: Ethiopia

A self-help group for women in Bisidimo began saving a few cents each week. As their savings grew, the women began investing in income-generating activities. They began by keeping chickens. Then they purchased goats, and then cows and oxen. Finally they began vegetable farming using an irrigation system.

Field workers in Ethiopia have found that women are highly motivated. They are ready to travel long distances to attend group meetings. As soon as they complete one piece of work they begin planning something bigger. They set strict working rules for their self-help group and keep to them. Their hard work is seen as the main success factor. These women are mostly housewives with little opportunity to participate in political or social affairs. The project provides training in assertiveness, establishes women's associations, gives opportunities, and encourages them when opportunities occur. These women's groups receive support from women's organizations at national, regional and district level.

Case study 15 from Bangladesh illustrates the influence that effective CBR can have on psychological health as well as financial improvement.

Case study 15: Bangladesh

Shanti has had leprosy for 20 years. When she was just 10 years old her uncle recognized the symptoms. Because of serious nerve involvement she had several hospital admissions. During one of these, just six months after her marriage, her new husband divorced her. She returned to live with her parents and younger brother. The CBR programme began to work with her and encouraged her to take a sewing course at the Vocational Training Centre. Shanti learnt how to use a sewing machine and soon she was able to earn an income and help support her parents and sisters. There was some gossip and avoidance among local people, but the rehabilitation workers were able to encourage people to accept her. Now she has a reputation for high-quality work and has become the main breadwinner in her family. New clients of the CBR programme come to her home to learn from her. She has purchased land and the family home has its own tube well and latrine.

There has also been a change in Shanti's psychological state. Before, she was depressed and used to worry about her physical problems. Now she is confident, physically well, and is respected. After several years, her former husband wanted to remarry her but she refused. Since then her father has found a more suitable husband for her. She is now happily married and has a child.

5.3 Working with children

Children may be directly affected by disability or suffer because their parents or relatives are affected by leprosy. As a result, they may:

- be denied access to school;
- be forced to drop out of school;
- be isolated from former friends;
- be hidden away by their families;
- be withdrawn from school and be required to work and earn an income;
- have additional emotional needs or difficulties.



Source : Georgina Cranston/TLM

The objective for rehabilitation activities is to ensure that children enjoy equal rights and opportunities. The objective is to ensure that children complete their education in a regular school and go on to develop a skill with an income-earning potential. Typical programme activities include:

- lobbying and facilitating access to schools;
- counselling children, other family members, teachers and sometimes school or local authorities;
- market-oriented vocational training – where appropriate, building on traditional skills;
- participation in other interventions, e.g. after-school tutorial groups.

Care is needed to avoid positive discrimination, i.e. giving preferential privileges to children affected by leprosy, as this may increase stigma.

Tasks of community workers

Community workers ensure that children enjoy equal rights and opportunities, by:

- meeting with teachers and working to ensure access to schools;
- discussing the need for and benefit of education with parents and family members – facilitating families to consider the future, as they are only used to dealing with day-to-day issues or, at the most, the very near future;
- working with children beyond school age to identify opportunities for vocational training and adult education.

5.4 The needs and opportunities of urban areas

Towns and inner cities often have areas with high population density, high mobility, widely varying socio-cultural backgrounds and extreme poverty. These areas may have poor housing and sanitation and limited access to water, electrical power and other amenities. Diseases such as malaria, TB and HIV/AIDS may be the primary health concerns, but disability or leprosy can still have a major impact. Stigmatizing attitudes may encourage people affected by disability or leprosy to seek the anonymity of urban areas, where it may be difficult to provide rehabilitation services. There may also be little or no support available from extended families or the local community.

However, the difficulties experienced in providing rehabilitation services in urban areas are balanced by the opportunities offered by government agencies and various organizations and local nongovernmental organizations. This access to local organizations, local transport and communications may assist the delivery of services, including those unrelated to leprosy.

Tasks of programme managers

Programme managers identify the needs and opportunities of urban areas by:

- collecting information about the poorest urban communities (size, cultural background, health status and disability-related needs);
- finding out about the services offered by local government and voluntary organizations;
- identifying partner organizations and developing networking and referral arrangements (see section 2.4);
- giving special attention to areas where there is stigma towards people with disabilities and leprosy.

Tasks of community workers

The priorities for community workers are similar to those described in Chapters 2 -to 4. Community workers are involved in contacts with community representatives, and work with individual clients to assess their needs and skills, motivate them and help them to choose the most appropriate intervention.

5.5 Working with other groups

Groups in the community with special needs, in addition to those relating to leprosy, may include elderly people, people with severe disabilities, those living in extreme poverty, and other minority groups.

Tasks of community workers

Additional priorities for working with such groups are identified below.

- Elderly people
 - Access to pensions and travel concessions should be negotiated.
- People with severe disabilities
 - Opportunities need to be found for them to participate in decision-making and social events within the family or community.
 - Opportunities should be identified for vocational training for their family members.
 - Situations where some form of welfare or pension arrangement may be required should be identified.
 - Access to assistive devices should be facilitated.
- People living in extreme poverty
 - Families should be helped to address one need at a time.
 - Access to poverty alleviation programmes should be negotiated.
 - Functional literacy training should be provided.
- Individuals set apart because of social status or disease (e.g. HIV/AIDS)
 - Priority should be given to identifying specific needs, sharing in advocacy, and facilitating access to health care services.



Source : Peter Lemieux/TLMI

6 Providing an effective rehabilitation service

This guide describes ways in which rehabilitation programmes can endeavour to ensure that their work is effective. This chapter provides extra detail to some key topics – the motivation of community workers, and procedures for their monitoring and evaluation. The *Guidelines for social and economic rehabilitation for people affected by leprosy* discuss organizational structure, decision-making, training requirements, and monitoring and evaluation procedures in detail as do publications targeted at community workers, such as the WHO publication *Training in the community for people with disabilities* (5).

6.1 Developing staff motivation

The most effective community workers are those who are highly motivated, committed to the programme and have a positive attitude towards people who are poor, marginalized and disabled. In many situations, people with leprosy or disability have proved to be effective workers.

Tasks of programme managers

Programme managers help staff to become motivated by:

- organizing training programmes to develop new skills – for example, in facilitation, in listening, in motivating, in promoting participation of family or community members, or in identifying and utilizing resources available within the community;
- ensuring that workers have a good understanding of all programme activities and of their individual work responsibilities;
- meeting regularly with staff to review progress, discuss experiences and learn from situations where rehabilitation plans have failed, including dealing with shortcomings in a constructive way;
- encouraging innovation and local decision-making;
- recognizing and acknowledging their achievements.

6.2 Monitoring the progress of an intervention

Monitoring an intervention involves collecting data on programme activities and the associated changes in people's lives. Managers are interested in the impact of interventions, the benefit to the clients, and the lessons learnt by the organization. Monitoring provides answers to important questions for all those involved in an intervention. Examples of such questions are given below.

- How is the intervention progressing?
- What problems have arisen?
- What difference has the intervention made?
- How does the client, family or community assess the process?

Allocating sufficient time and energy to monitoring the progress of an intervention shows a commitment to understand all aspects of the problems faced by people with disabilities, and to learn from negative as well as positive outcomes.

Tasks of programme managers

Programme managers are responsible for planning and implementing monitoring procedures for each intervention, by:

- making everyone aware of the benefits of monitoring and evaluation – that this is not aimed at finding faults in an individual's performance, but for improving the programme using the experiences gained so far;
- facilitating a participatory approach and conducive environment where people are encouraged to assess the strength and weakness of an intervention;
- preparing plans for monitoring based on the individual rehabilitation plan (see Annex 3);
- identifying who needs monitoring information, when to collect data, and including a baseline assessment;
- identifying how the expected changes will be measured, using locally relevant indicators, designing a monitoring form (see section 6.3), and training staff in their use;
- holding regular meetings with field staff to review the progress of the intervention;
- collating information to meet reporting requirements.

The participatory approach

The participatory approach to monitoring requires that everyone who has an interest in the outcome of an intervention contributes to its evaluation. In addition to programme managers, this includes individual clients and their family members, friends or near neighbours, technicians and/or other rehabilitation professionals, participating individuals in the community, and community workers themselves.

Tasks of community workers

Community workers assist in the implementing of monitoring procedures by:

- attending scheduled meetings with clients and others;
- completing the monitoring form prepared for the intervention, including a baseline assessment;
- using guiding questions to collect more information – asking “Why...?” and “How...?”
- recording observations and problems arising, in a field diary;
- reporting findings and participating in review meetings;
- discussing progress with clients and others involved.

Experience in the field**Later stages**

Field work is found to be more successful where support is available from client's family. Monitoring involves monthly follow-up visits to homes and working areas. These identify problems, failures, and success. The resulting information is organized and tabulated for reporting to identify problems, failures and successes. Through regular follow-up, people learn from the experience of others.

India

Information is monitored to decide whether the client and his or her family have received the best possible use of the services provided. Is there a need for further social work interventions? Has he or she made improvement and if not, what has gone wrong and why? What are the various factors that led to the failure of the intervention process? Future action will be decided based on the information collected from monitoring. This helps the worker to adopt new techniques or strategies to help the patient to solve his problems.

Nepal

Monitoring information is presented at a quarterly review meeting. The meeting identifies the need for new activities with each client, and any further training needed. The information is used to make further plans with the community members supporting the clients. Information is shared with others about the success or failure of certain assistance and the reasons for it. The lessons learnt provide guidance when preparing new plans and budgets for work with new clients.

Pakistan

Staff assess each client's progress. Family members and neighbours also give feedback. Progress is monitored on routine visits and changes are noted. When clients visit staff, they are asked about their progress. The information is used to guide and encourage the clients. The success of one client is shared with others to motivate them. Sometimes a demotivated client is taken to visit a successful one, so that he or she might become encouraged.

6.3 Using indicators

Indicators provide a way to measure an attribute that cannot be measured directly. They are used to estimate change or to measure progress resulting from an intervention.

Where an indicator is needed, it is important that managers identify an appropriate indicator or indicators. Examples of impact indicators are given below.

Indicators based on objectives

- Able to participate in social events or to access schools.
- Increase of income by 50% compared with some baseline.

These might be assessed and reported as "Achieved" or "Not achieved".

Qualitative indicators based on client's statements

- "I drink tea/coffee with my neighbour."
- "We walk to the market together."
- "Our children play together."

These might be reported separately or as a count of positive responses reflecting quality of life.

Indicator to assess behaviour in the community

- The number of referrals for rehabilitation services by community members.

Indicators to assess the long-term impact of rehabilitation activities on clients

- The client's ability to express a vision for the future – for example, in terms of involvement in social activities, future family events or prospects of future employment.
- The Participation Scale may be used to assess changes in response to an intervention.

Indicators must accurately reflect what they are meant to measure. They must be:

- sensitive to change;
- based on data that is readily available;
- understood by those collecting and assessing data.

It is good practice to evaluate indicators as well as interventions. Initially indicators may be selected from published lists. Later they may be developed in the light of local experience. (See references to published lists of indicators in Annex 1.)

Tasks of programme managers

Programme managers are expected to:

- identify one or more appropriate indicator for each intervention;
- train community workers, so that they:
 - understand what the indicator is measuring;
 - know how and when to collect the necessary data;
 - know how to report changes based on the indicators.

References

1. *Declaration of Alma-Ata. Adopted at the International Conference on Primary Health Care, Alma -Ata, Kazakhstan, 1978.* Geneva, World Health Organization, 1978 (http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf accessed 10 October 2007).
2. ILO, UNESCO, WHO. *CBR: a strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities. Joint Position Paper, 2004.* Geneva, World Health Organization, 2004 (http://whqlibdoc.who.int/publications/2004/9241592389_eng.pdf , accessed 17 August 2007).
3. *How to prevent disability in leprosy.* London, International Federation of Anti-Leprosy Associations, 2006 (Learning Guide No. 4).
4. *International Classification of Functioning, Disability and Health (ICF).* Geneva, World Health Organization, 2001 (<http://www3.who.int/icf/icftemplate.cfm> , accessed 17 August 2007).
5. Helander E et al. *Training in the community for people with disabilities.* Geneva, World Health Organization, 1989.

Annex 1

Additional resources

Information on disability indicators

Boyce W, Broers T, Paterson J. CBR and disability indicators. *Asia Pacific Disability Rehabilitation Journal*, 2001, 12:3–12.

Velema J, Cornielje H. Reflect before you act: providing structure to the evaluation of rehabilitation programmes. *Disability and Rehabilitation*, 2003, 25:1252–1264.

Wirz S, Thomas M. Evaluation of community based rehabilitation programmes: a search for appropriate indicators. *International Journal of Rehabilitation Research*, 2002, 25:163–171.

A wide range of resources on CBR and health and development can be found at the web site of Enablement, Langenhorst 36 2402 PX, Alphen aan de Rijn, The Netherlands (<http://www.enablement.nl>), and Source International Information Support Centre, 2nd Floor, Institute of Child Health, 30 Guilford Street, London WC1N 1EH, England (<http://www.asksource.info>).

Centres offering courses in CBR and related subjects

The ILEP web site lists courses on CBR and related subjects (<http://www.ilep.org.uk>).

Degree and Masters Courses are available in Australia, Canada, the Philippines, the United Kingdom, USA, and elsewhere. Search the Internet for “community based rehabilitation”, “community disability studies” or similar.

Recommended reading

Periodicals

Asia Pacific Disability Rehabilitation Journal

Available from Dr Maya Thomas, Editor, APDRJ, J-124, Ushas Apartments, 16th Main, 4th Block, Jayanagar, Bangalore 560011, Karnataka, India (<http://www.aifo.it/english/resources/online/apdrj/journal.htm>).

Target audience: managers, policy-makers, researchers and rehabilitation professionals.

Disability Dialogue (formerly CBR News)

Published by regionally based partners of Healthlink Worldwide (<http://www.healthlink.org.uk/resources/newsletter.html#disa>).

Target audience: community workers.

Disability World

<http://www.disabilityworld.org>

Footsteps

Available from Tearfund, 100 Church Road, Teddington, Middlesex, TW11 9AA, England (<http://tilz.tearfund.org>).

Leprosy Review

Published by the British Leprosy Relief Association (LEPRA), 28 Middleborough, Colchester, Essex, CO1 1TG, England (<http://www.leprosy-review.org.uk>).

Partners Magazine

Published by the Leprosy Mission International, 80 Windmill Road, Brentford, Middlesex, TW8 0QH, England (<http://www.leprosymission.org>).

Regional arrangements for mailing.

Available in Bengali, Chinese, English, French and Hindi.

Target audience: paramedical workers assisting people affected by leprosy.

Nonserial publications

Abbat F, McMahon R. *Teaching health care workers: a practical guide*, 2nd rev. ed. Basingstoke, Macmillan Education Ltd, 1993.

Chambers R. *Challenging the professions. Frontiers for rural development*. London, Practical Action Publishing (formerly Intermediate Technology Publications), 1993.

Chambers R. *Rural development. Putting the last first*. Harlow, Longman, 1983.

Chambers R. *Whose reality counts. Putting the first last*. London, Practical Action Publishing (formerly Intermediate Technology Publications), 1997.

Frist T. *Don't treat me like I have leprosy*. London, International Federation of Anti-Leprosy Associations, 2003.

Guidelines for social and economic rehabilitation of people affected by leprosy. London, International Federation of Anti-Leprosy Associations, 1999.

Helander E. *Prejudice and dignity – an introduction to community-based rehabilitation*, 2nd ed. Geneva, United Nations Development Programme, 1999.

The end of isolation. A handbook for the social and economic reintegration of persons affected by leprosy. Geneva, International Labour Office, 1999.

Thomas M, Thomas MJ. *Manual for CBR planners*. Bangalore, Asia Pacific Disability Rehabilitation Group Publication, 2003.

United Nations Convention on Rights of Persons with Disabilities. Geneva, United Nations, 2007 (<http://www.un.org/disabilities/convention> accessed 17 August 2007).

Werner D. *Disabled village children. A guide for community health workers, rehabilitation workers and families*. Berkeley, CA, The Hesperian Foundation, 1987.

Werner D. *Nothing about us without us. Developing innovative technologies for, by and with disabled persons*. Paulo Alto, CA, HealthWrights, 1998.

Werner D, Bower B. *Helping health workers learn. A book of methods, aids and ideas for instructors at the village level*. Berkeley, CA, The Hesperian Foundation, 1982.

Many of the above publications can be obtained by mail order or from the publishers listed below.

DevelopmentBookshop.com. ITDG Publishing, The Schumacher Centre for Technology and Development, Bourton-on-Dunsmore, Rugby, Warwickshire, CV23 9QZ, England (<http://www.itdgpublishing.org.uk>).

Teaching Aids at Low Cost (TALC). PO Box 49, St Albans, Herts, AL1 5TX, England (<http://www.talcuk.org>).

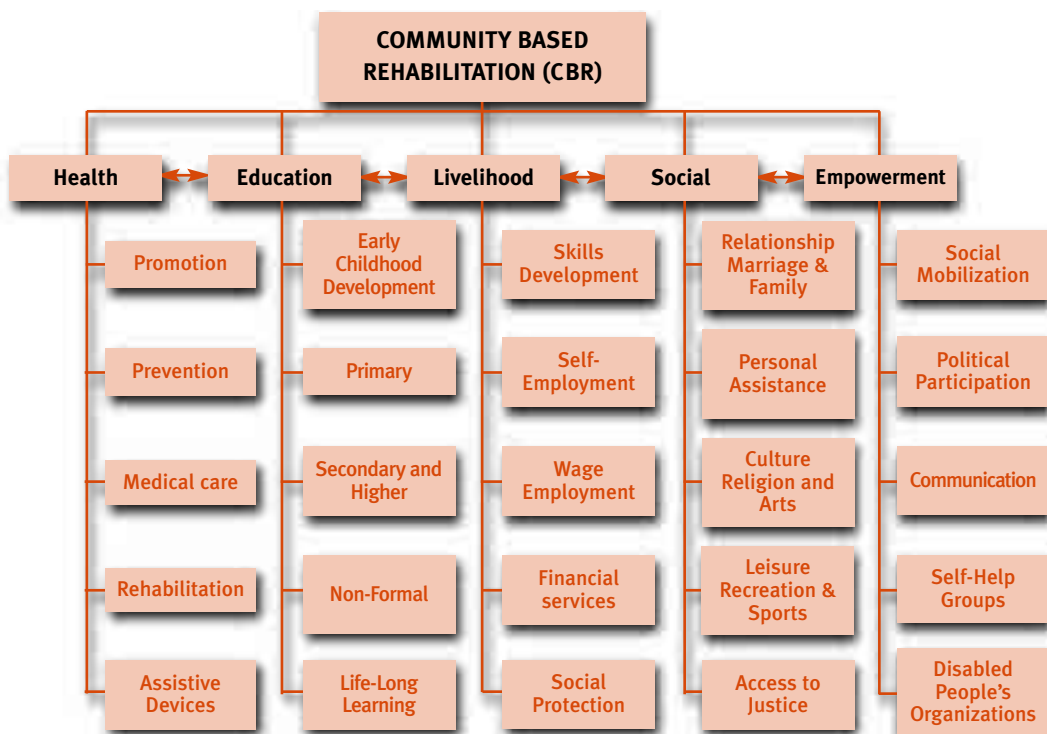
ILEP, 234 Blythe Road, London, W14 0HJ, England (<http://www.ilep.org.uk>).

INFOLEP Leprosy Information Service, Wibautstraat 137, 1097 DN Amsterdam, The Netherlands (<http://www.infolep.org>).

CBR matrix

This matrix gives an overall visual representation of CBR, indicating the topic areas which can make up a CBR strategy. The matrix consists of five major components: health, education, livelihood, social and empowerment, each of which is divided into five key elements as described below. CBR needs to develop a truly intersectoral approach by building bridges between the five major components.

Goal: Inclusive Development – Inclusive Society



Annex 3

Data collection forms

The range of forms used in CBR programmes is listed here. Specimen forms are available on the ILEP web site (<http://www.ilep.org.uk>).

Needs and skills assessment forms

These forms describe the physical, psychological, social and economic impact of disability and draw attention to skills and resources that may guide the choice of intervention. They may also be used to collect information from family members and representatives of the local community. An outline form is shown below. Note that the listed questions all need careful testing. It may be that, in any given situation, some questions are not needed while others need to be added.

Needs and skills assessment form – suggested questions

Demographic and physical status

1. Client number, name, age and sex
2. Father's/husband's name – or that of nearest relative, and postal address
3. Education, religion and marital status
4. Diagnosis, where registered, treatment status
5. Physical impact of disease, impairment status and disabilities

Economic status

6. Previous occupation, years of experience, special skills acquired, normal monthly earning
7. Present occupation, years of experience, special skills acquired, normal monthly earning
8. Reason for unemployment
9. Number of family members working, current total income of family
10. Other vocational skills possessed by the client or available in the family

Social status

11. Size of family: spouse, other adults, children, total number
12. Type of house: construction, owned personally, owned by family member, rented, temporary house on common ground
13. Arrangement for water supply, latrines
14. Family assets: house, land, animals and savings

Other information collected by community worker

15. Community's opinion
16. Worker's observation
17. What problems does the client have?
18. What does the community know and understand about the disability and problems of the client?
19. What ideas does the community have about how they can assist the client?
20. In what ways do community members feel their lives are affected by the client?

Individual rehabilitation plan

This form describes the chosen intervention, the commitments and responsibilities of all stakeholders, the details of any intervention, the arrangements for follow-up and supervision, the choice of indicators, and other information specific to the intervention.

Other forms used in the context of CBR are given below.

- **Monitoring forms** – used to record information produced by the monitoring system.
- **Field diaries** – used to record details of daily activities of community workers, events of special interest, questions and problems, and issues arising.
- **Intervention outcomes** – used to record the outcome of interventions and develop a history of field experience.
- **The Participation Scale (P scale)** – used to assess participation restrictions resulting from leprosy or other conditions. (Available from the leprosy information service of Netherlands Leprosy Relief (INFOLEP) (<http://www.infolep.org>), and from The Leprosy Mission International (TLMI) Research Resource Centre, Delhi. (Email contact: rrc@tlmi.india.org)).
- **The SALSA Scale** – used to assess activity restrictions resulting from leprosy or other conditions. (Available from TLMI Evaluation and Monitoring Services, Apeldoorn, the Netherlands. Email contact: ems@ems.tlmi.nl)).

The disabilities associated with leprosy are not unique. Nor are they only about physical impairments. In its wider sense, disability arises because people are stigmatized and denied equal access opportunities within their families and communities.

Community-based rehabilitation (CBR) is recognized as a key strategy for social inclusion, aimed at overcoming stigma, activity limitations and participation restrictions, and improving the quality of life of people with disabilities. As such, it is an approach which is highly relevant to the rehabilitation of people affected by leprosy.

This technical guide describes the strategies and tasks of CBR as the appropriate response to the needs of individuals, families and communities affected by leprosy. It will prove a useful re-orientation and familiarization tool for managers, trainers and supervisors in leprosy control or rehabilitation programmes responsible for introducing and managing CBR. It may also be used by CBR managers to include people affected by leprosy in their programmes. It describes the broad objectives of CBR, the roles and tasks of programme managers, and the responsibilities of community workers who have daily contact with people affected by leprosy, their families and community members. The guide recommends approaches reported to be effective, but avoids prescribing these methods in all situations.

