CBR Guidelines

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CBR Guidelines

Supplementary booklet

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Introduction

These community-based rehabilitation (CBR) guidelines are applicable to all disability groups. However, the need was identified for a supplementary booklet to highlight a number of issues which CBR programmes have historically overlooked, i.e. mental health problems, HIV/AIDS, leprosy and humanitarian crises. These issues may have been overlooked for a number of reasons. Originally, CBR programmes focused on issues that were seen as high priorities at the time, e.g. poliomyelitis and other communicable diseases, while the involvement of many professional groups, e.g. physical therapists in the implementation of CBR programmes resulted in a strong focus on physical impairment. Today however the focus and concerns are different; CBR managers may lack knowledge and confidence about how best to address new issues in their programmes, while stigma and discrimination continue to be associated with many of the issues.

As these CBR guidelines highlight, much more is known about disability today as over the past 30 years CBR has undergone a significant evolutionary process. CBR is a strategy for community-based inclusive development which takes into account the principles of the Convention on the Rights of Persons with Disabilities, e.g. non-discrimination and the need to include all people with disabilities in development initiatives. Therefore, it is important that CBR programmes take steps to address issues which they have traditionally excluded, such as mental health problems, HIV/AIDS, leprosy and humanitarian crises. While these four issues have been chosen for inclusion in this booklet, CBR programmes are encouraged to think broadly about other issues (e.g. CBR and children, CBR and ageing) that are particularly relevant in their communities and which may be included in future editions of the guidelines.

CBR and mental health

Introduction

Mental health is a state of well-being in which a person realizes his/her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his/her community (*1*). Mental health is an inseparable part of general health, essential for the well-being and functioning of individuals, families, communities and societies (see Health component).

Mental health has a low priority on the development agenda and for society in general. There is a lack of knowledge about mental health issues, with widespread stigma, prejudice and discrimination. In every community, there are people living with mental health problems who are likely to be isolated, abused and deprived of their fundamental human rights. The Convention on the Rights of Persons with Disabilities (*2*) highlights that persons with disabilities include those who have "mental impairments" and emphasizes the need to: (i) ensure their full and equal enjoyment of all human rights and fundamental freedoms; and (ii) promote their participation in civil, political, economic, social and cultural spheres with equal opportunities.

People with mental health problems have extremely limited access to support and health services particularly in low-income countries and historically have also been excluded from community-based rehabilitation (CBR) programmes. However an evaluation of a CBR programme for people with chronic schizophrenia in rural India shows that CBR programmes can achieve positive outcomes for people with mental health problems, particularly in resource-poor settings (*3*).

These CBR guidelines are relevant to all people with disabilities, including people with mental health problems – many of the issues affecting people with mental health problems are similar to those affecting any other impairment group and therefore other components should be referred to. However this section provides additional guidance regarding inclusion of people with mental health problems in CBR activities, as it is acknowledged that many CBR programmes have limited experience in working in this area.

The language used when referring to people with mental health problems can be confusing because many different terms are used, e.g. mental illness, serious mental illness, mental disorders, mental impairments, mental health condition, behavioural disorders, madness, mental ill-health, users and survivors of psychiatry, psychosocial disability. This section uses "people with mental health problems" as this is easy to understand and translate; it includes people with conditions such as chronic depression, schizophrenia, bipolar disorder and substance abuse disorders.

BOX 1 Japan

Cocoron

In 2002, Cocoron, a non-profit-making-organization, was established in the Fukushima Prefecture of Japan by local community members, including the mayor and a community mental health specialist. The name Cocoron, meaning heart and/or mind, was selected by the wider community. The focus of Cocoron was on community development, given that poverty was an issue of concern in the region, aiming to develop and support the community as a whole so that people with and without disabilities could live with equal rights, security and dignity.

In the beginning, Cocoron raised awareness and developed capacity among community members, its staff and board members, by running a series of workshops over a three-year period. With the support of the provincial authority and local community, resource people were invited from different development sectors to run these workshops.

Cocoron then worked towards establishing a number of income-generating activities in the community. Since a major source of income in the local area is agriculture, Cocoron decided to develop many of its activities around this industry. Cocoron opened shops and a café called Cocoroya to sell local products such as vegetables, mushrooms, fruits and saki, and to serve lunches and sweets. Cocoroya soon become a very popular meeting place for local people, particularly after being publicized in the newspaper and on television.

In March 2004, Cocoron opened a community centre in Izumizaki village to support people living with mental health problems. Cocoron had become aware that people with disabilities, particularly people with mental health problems, were marginalized from mainstream development initiatives. Cocoron has established a number of supports for people with mental health problems and their families, including a counselling service, residential accommodation, and work-based education, training and support.

Many people with mental health problems are now integrated into Cocoron's various income-generating activities – they are the major workforce of Cocoroya – and also other businesses within the community. Their lives have changed; they no longer experience the social isolation that is associated with living in psychiatric facilities, they are able to work in welcoming and accommodating environments, their health and socioeconomic conditions have improved, and they now experience feelings of satisfaction and independence.

Cocoron is a good example of community-based inclusive development, where people with disabilities, particularly people with mental health problems, form an integral and inseparable part of the community and community life.

Goal

People with mental health problems are supported to enable their inclusion and participation in all aspects of community life.

The role of CBR

The role of CBR programmes is to promote and protect the rights of people with mental health problems, support their recovery and facilitate their participation and inclusion in their families and communities. CBR also contributes to the prevention of mental health problems and promotes mental health for all community members.

Desirable outcomes

- Mental health is valued by all community members and recognized as a requirement for community development.
- People with mental health problems are included in CBR programmes.
- Communities have increased awareness about mental health, with a reduction in stigma and discrimination towards people with mental health problems.
- People with mental health problems are able to access medical, psychological, social and economic interventions to support their recovery process.
- Family members receive emotional and practical support.
- People with mental health problems are empowered, with increased inclusion and participation in family and community life.

BOX 2 India

Involving local communities in CBR

In a very disadvantaged part of rural India, Chatterjee and coworkers (3) adapted the principles of CBR, specifically the use of local resources and involvement of people with mental health problems, families and local communities, to complement the specialist mental health services and thus improve access, equity and acceptability of the interventions.

Local members of the community were trained as CBR workers to deliver comprehensive, home-based services, such as identifying people with chronic schizophrenia and ensuring access to the clinical team in outreach clinics, regular follow-up and monitoring, education for people and their families, and planning of rehabilitation interventions.

In addition, concerted efforts were made to promote awareness, address stigma and facilitate economic and social rehabilitation. In most villages, families of people with mental health problems and other concerned members also formed self-help groups to promote the social and economic reintegration of local members with severe mental disorders.

The clinical and disability related outcomes for clients within the CBR programme were better than those of clients who received outpatient care alone. This approach to service delivery focused on empowerment of clients, mobilization of existing community resources, intersectoral linkages (welfare, local government and health sectors) and a human rights perspective.

The success of CBR programme has prompted the health committee of the district government, in partnership with a nongovernmental organization, to include mental health services in its planning and budgeting exercise, with a view to scaling up the programmes to the entire district (4).

Key concepts

Mental health and community development

Poverty is associated with mental health problems (see Introductory booklet and Health component) – it can be both a cause and a consequence. People and communities living in poverty face a high burden of environmental and psychological stress (e.g. violence, limited access to resources, unemployment, social exclusion, insecurity), and are at increased risk of mental health problems (5). Poverty may worsen an existing mental health problem and increase feelings of hopelessness and powerlessness. People with mental health problems face poverty because they are more likely to encounter barriers to education, employment, housing and inclusion – a vicious circle that is difficult to escape.

Community and economic development can be used to restore and enhance mental health. Community development programmes that aim to reduce poverty, achieve economic independence and empowerment for women, reduce malnutrition, increase literacy and education, and empower the underprivileged will contribute to the promotion of mental health and the prevention of mental health problems (*5*). Communities whose members enjoy good mental health are better equipped to solve their problems, establish social networks and promote mutual support. CBR, as a part of community development, should take into account the mental health needs of all community members, involving community leaders and members in this process. People with mental health problems can contribute to the development of their communities.

Common myths about mental health problems

There is often very limited understanding within society about mental health problems, and many myths have developed. Common myths include the following.

- *Mental health problems are uncommon.* Mental health problems are actually found in people of all ages, regions, countries and communities. It is estimated that approximately 450 million people have mental health problems, and that one in four people will be affected at some stage during their life (*6*).
- *People with mental health problems, particularly those with psychosis, such as schizophrenia, are violent and endanger the safety of others if they are allowed to live in the community.* Actually, the majority of people with mental health problems are not violent. In a small proportion of people, mental health problems are associated with increased risk of violence (*6,7*). Often increased risk of violence is associated with additional factors, such as substance abuse and personal history and environmental stressors (*8*). Rather than being violent, people experiencing psychosis are more often frightened, confused and in despair.
- *Mental health problems are difficult to treat and people will never get better.* Actually, there are many effective interventions available for mental health problems; these can enable a person to recover fully or to keep their symptoms under control.
- *Mental health problems are brought on by weakness of character*. Actually, mental health problems are a product of biological, psychological and social factors.

Stigma and discrimination

Stigma and discrimination against people with mental health problems is widespread and affects all areas of life including personal, home and family life, work, and even people's ability to maintain a basic standard of living. People with mental health problems often describe the stigma and discrimination they face as worse than their main condition. Family members of people with mental health problems are also subject to limited understanding, prejudiced attitudes and discriminatory behaviour (*7*).

Stigmatization may lead to self-stigma, whereby people with mental health problems and their family members internalize society's negative attitudes towards them (*9*); they

may actually start to believe what others say and think about them, often leading to self-blame and a decrease in self-esteem.

Anticipation of rejection due to stigma may result in many people reducing their social networks and not taking advantage of life's opportunities. This, in turn, may lead to isolation, unemployment and lowered income (*9*). Experienced or anticipated discrimination is the main reason why many people hide their mental health problems and do not seek help.

Human rights

In many countries, people with mental health problems routinely experience human rights violations. These violations frequently occur in psychiatric institutions through inadequate, degrading and harmful care and treatment, as well as unhygienic and inhuman living conditions. Violations also occur within society, where people with mental health problems are unable to exercise their civil liberties and have limited access to education, employment and housing (*10*).

Every person, including people with mental health problems, has human rights. All general international human rights conventions are applicable to people with mental health problems and protect their rights through the principles of equality and non-discrimination (*7*), e.g. the Universal Declaration of Human Rights. In addition there are also more specific conventions that are applicable to people with mental health problems, e.g. the Convention on the Rights of Persons with Disabilities (*2*).

While policy and legislation are needed in countries to ensure international human rights standards are met for people with mental health problems, all communities can take action now and work towards protecting, promoting and improving the lives and well-being of people with mental health problems.

Health care

People with mental health problems may require access to specialized health care and/or general health care.

For mental health problems

There is a range of health-care interventions available that can promote the recovery of people with mental health problems. Medical interventions may include the prescription of psychotropic drugs (antipsychotics, antidepressants, mood stabilizers) and treatment of associated physical health conditions. Psychological interventions can include one or more of the following: education about the condition and treatment options, counselling, individual or group psychotherapy, and family interventions.

In many cultures, the concept of mental health is associated with religious, spiritual or supernatural beliefs. Therefore faith leaders and traditional healers are often consulted

first. It is important to be aware that the practices of traditional healers, such as certain conventional practices, can vary widely – some treatment methods may be harmful, while others are not. Culturally sensitive approaches to health care are required with consideration of local healing traditions, exchanges of experience and development of mutual understanding.

BOX 3 Ghana

Partnering with traditional healers

In Ghana, over 75% of people with mental health problems consult traditional healers as their first point of treatment. Therefore working with traditional healers is essential to ensure the well-being of people with mental health problems and their family members. BasicNeeds Ghana works together with traditional healers to ensure positive change and progress in the mental health situation in Ghana. The organization hosts a forum for the Traditional Healers Association and provides training and orientation on various mental health issues, including recovery.

While effective interventions have been identified for mental health problems, there is very limited availability of specialized health care. Shortages of psychiatrists, psychiatric nurses, psychologists and social workers are among the main barriers to providing treatment and care in low and middle-income countries (*11*). Where available, prices of medicines and professional fees are often very high, and therefore many people in low-income countries have limited access.

Where specialized health care is available for people with mental health problems, it is often inappropriate. Human rights violations of psychiatric patients are routinely reported in most countries, and include physical restraint, seclusion and denial of basic needs and privacy (*11*). Many people with mental health problems are reluctant to seek health care for fear of being admitted and treated in mental health facilities against their will (*12*). Users and survivors of mental health care services often feel patronized and humiliated by mental health professionals; they often do not receive information about their condition and are assumed to be unable to take responsibility for their lives or make decisions.

General health care

People with mental health problems often have increased rates of physical illness compared with the general population. They are more likely to have major health problems, such as obesity, high blood pressure and diabetes (*13*). People with schizophrenia have been shown to have higher morbidity and mortality rates from cardiovascular disease than the general population and also have higher than expected rates of infectious diseases, respiratory diseases, some forms of cancer and HIV infection. The reasons for this may include factors related to the specific mental health problem (including the

effects of medication), health behaviours such as smoking and physical inactivity, and the health system (*14*).

Reduced access to health care for people with mental health problems is a global phenomenon and results in increased likelihood of significant health risks and major health problems. The reasons for limited access to health care are complex but include social deprivation, difficulties with physical access, underdiagnosis of physical illness, unmonitored treatment, and poor organization of health services (*13*).

Recovery

Recovery is a concept that has emerged from people who have first-hand experience of mental health problems (*15*). There is no universal definition of recovery, as it is a personal process that has different meanings for different people. While many health professionals consider "recovery" to mean "cure", the concept of recovery goes beyond this and considers all aspects of functioning. Recovery is a process of personal growth and transformation beyond suffering and exclusion – it is an empowering process emphasizing people's strengths and capabilities for living full and satisfying lives. Recovery may be described by people with mental health problems as enjoying the pleasures life has to offer, pursuing personal dreams and goals, developing rewarding relationships, learning to cope with mental health problems despite symptoms or setbacks, reducing relapses, becoming free of symptoms, staying out of hospital, or getting a job (*7*).

BOX 4

A personal account of recovery

To me, being recovered means feeling at peace, being happy, feeling comfortable in the world and with others, and feeling hope for the future. It involves drawing on all my negative experiences to make me a better person. It means not being afraid of who I am and what I feel. It is about being able to take positive risks in life. It means not being afraid to live in the present. It is about knowing and being able to be who I am (*16*).

Specific issues related to mental health

Children and adolescents

Like adults, children and adolescents also experience mental health problems, but their problems are widely neglected and/or often wrongly diagnosed as an intellectual impairment. Around 20% of the world's children and adolescents are estimated to have mental health problems, with similar types of problems reported across cultures (*17*). The lack of attention to child and adolescent mental health may have lifelong consequences.

The mental health status of children and adolescents is influenced by the family, and social and cultural environment. Experience of poverty, violence, physical and sexual abuse, neglect and lack of stimulation may all have an impact. There is evidence for a link between a mother's mental health and the cognitive, social and emotional development of her child (18). Children who care for parents with mental health problems are also vulnerable, as they may not receive adequate attention and care and, in contrast, often assume a level of responsibility for their parents that is beyond their capacity.

While it is important to address mental health problems in children and adolescents, care must be taken not to overdiagnose and apply psychiatric labels to problems that are associated with normal living and development during this period, as this can have negative consequences for both children and families.

Gender

Although the overall prevalence of mental health problems is similar between men and women, there are gender differences when considering specific problems, e.g. women are more likely to experience common mental health problems, such as anxiety and depression, while men are more likely to develop alcohol dependence (19) and be successful in any suicide attempts.

There are gender-specific risk factors for common mental health problems that disproportionately affect women. In many societies, women have lower social status than men, which may lead to submissive behaviour and feelings of inferiority, low self-esteem and helplessness, depriving them of the necessary coping skills. Women generally have less power than men, less access to resources, and less control of their lives. Gender-based physical and sexual violence against women leads to humiliation, subordination and feelings of being trapped. Sexual abuse is quite common for women with mental health problems. Moreover, women experience greater discrimination than men in their interaction with health services.

Crisis situations

In the aftermath of crisis situations, the mental health needs of survivors need to be considered, as the experience of war and other major disasters is associated with increase in mental health problems (11). Often, existing resources are insufficient and the time needed for coping with severely traumatizing events is underestimated. People with mental health problems related to trauma may need nonintrusive emotional support, education and encouragement of positive ways of coping.

Some groups, such as people with disabilities, including those with pre-existing mental health problems, are more at risk of developing social and/or psychological problems following crisis situations (20). People with mental health problems may not present for support during crisis situations owing to isolation, stigma, fear, self-neglect, disability or poor access. Social supports that previously sustained them may have been lost as a direct result of the crisis, or they may be at increased risk of abandonment by families stressed by the additional burden of care (20). It is important that CBR programmes focus

on people with mental health problems during crisis situations, as without special attention they may be neglected or forgotten (see CBR and humanitarian crises).

Suggested activities

Promote mental health

In promoting mental health, the cultural, socioeconomic and political determinants of mental health, such as poverty, violence, neglect and sexual abuse, are addressed in partnership with relevant sectors. CBR programmes can promote mental health in their communities in the following ways.

- Create inclusive environments that respect and protect the basic rights of everyone, including people with mental health problems.
- Strengthen community networks and encourage collective responsibility for preventing alcohol/drug abuse, gender discrimination and community and family violence.
- Develop partnerships with other stakeholders that are involved in promoting mental health and well-being, e.g. working with women's clubs on gender issues or with a local nongovernmental organization focusing on early interventions with children.
- Promote positive interactions between parents and their children to enhance childhood development.
- Promote evidence-based programmes in schools that enhance the social and emotional competencies of students to help prevent substance abuse and violence.
- Work with the media to change the negative image of people with mental health problems.

(See Health component: Health promotion.)

BOX 5 Jamaica

Promoting positive interactions

A regular home-visiting programme helping socially disadvantaged mothers to provide early stimulation for infants in Jamaica showed long-term beneficial effects – including enhanced self-esteem, and reduced school dropouts and antisocial behaviour – on the mental health of adolescents.

Facilitate inclusion in CBR programmes

The following activities are suggested to facilitate the inclusion of people with mental health problems in CBR programmes.

- Ensure that CBR personnel have received accurate training regarding mental health problems and have a positive attitude towards supporting and including people with mental health problems.
- Consult and involve people with mental health problems and their family members in the planning, implementation and monitoring of CBR programmes.
- In collaboration with people with mental health problems and their families, identify barriers and possible solutions in meeting basic needs, including access to health services, education, livelihood and social security.
- Identify mental health personnel, users of mental health services and/or family members who could be involved as resource persons for training of CBR personnel.

Overcome stigma and discrimination in the community

Public knowledge about mental health problems and the possibility of recovery is very limited. To enable people with mental health problems to participate actively in society, common myths, prejudices and discrimination need to be addressed. CBR programmes can play a key role in doing this. Suggested activities include the following.

- Ensure CBR personnel treat people with dignity and respect at all times.
- Identify key people in the community who can assist CBR programmes to deliver positive messages and images about mental health. These people may include influential people, such as local political or religious leaders.
- Make contact with the identified key people and provide them with information about mental health issues in their community, e.g. invite them to be guests of honour at events that CBR programmes have organized.
- Discuss ways in which the key people can deliver key messages about mental health problems, e.g. religious leaders can deliver messages when addressing their followers.
- Identify community members and groups that would most likely have contact with people with mental health problems and are likely to have developed negative assumptions and attitudes, e.g. police officers, health-care personnel, traditional healers.
- Make arrangements to provide education and training for community members and groups. Provide accurate information about mental health problems to dispel myths (e.g. that people with mental health problems are violent) and make people aware that there are effective interventions, e.g. medical and psychological interventions that can help people to recover from mental health problems.

- Promote human rights and challenge, when it happens, discriminatory behaviour that occurs in the community towards people with mental health problems and their family members. Be a good role model and demonstrate positive behaviours.

Changing perceptions of mental health through personal contact

Direct personal contact between people with mental health problems and the general population is known to be very effective in changing negative attitudes. Invite people with mental health problems to meetings with community members or students where they can relate their experiences. Those people who have overcome mental health problems and have fulfilling family, work and community roles are powerful advocates in the fight against discrimination.

Support the recovery process

Recovery focuses on the strengths of people and their capacity to lead fruitful and satisfying lives. The recovery process is a holistic process and may involve a combination of medical, psychological, social and economic interventions.

Facilitate access to medical care

People living with mental health problems in low-income countries find it difficult to access medical care owing to poverty, distance and scarcity of specialized services. CBR programmes need to work together with the primary health care system and existing local mental health resources to facilitate access to both specialized and general medical care. The following activities are suggested.

- Identify existing structures, locations, staffing and resources for specialized mental health care, e.g. clinics, hospitals, residential institutions, community centres, non-governmental organizations. This can be done at community, regional and/or national level.
- Visit mental health services to build a good relationship with them. Ensure information exchange by asking about their services (including availability of psychotropic medication), policies, referral mechanisms, hours of opening and costs, and by providing information about CBR and how CBR can assist them with their work.
- Make a list of traditional healers and faith leaders in the community and visit them to exchange experiences, share ideas, and develop mutual understanding and respect.

- Ensure CBR and primary health care personnel are able to facilitate referrals to mental health professionals where necessary – provide training as required.
- Ensure people with mental health problems and their family members have been informed about the side-effects of psychotropic drugs and make certain that they understand this information.
- Promote the collaboration of traditional healers with health-care staff as a source of help for people with mental health problems.
- Assist people with mental health problems to access general health care through the primary health care system by raising awareness and providing relevant information to primary health care workers.
- Where community mental health programmes exist, develop partnerships and promote collaborative working – community mental health programmes could address health/medical needs, while CBR programmes could address other needs, such as livelihood opportunities.

(See Health component: Medical care.)

BOX 7 Belize

A holistic approach to mental health

In Belize, nurses working in the area of mental health meet with traditional healers to share knowledge and skills. The nurses have discovered that developing relationships with traditional healers in their communities can be an effective way to meet the mental health needs of the community. Both conventional and traditional approaches are acknowledged to ensure a holistic approach to mental health care.

Facilitate access to psychological support

In low-income countries, access to specialized psychological support may be very limited; however, basic interventions can be carried out by CBR personnel. Suggested activities include the following.

- Organize or provide training for CBR and primary health care personnel in basic psychological care. This training should be culturally sensitive and may include emotional support (basic counselling skills), reassurance, information and relaxation methods.
- Build positive relationships with people who have mental health problems and their family members based on open communication and trust. Make regular visits to people with mental health problems and their family members to ask how they are feeling and coping, taking time to listen to them.
- Work closely with people who have mental health problems, providing support to solve problems, manage stress and develop coping skills.

- Find out what psychological interventions traditional healers and spiritual leaders can offer people with mental health problems and their family members, and the best way to access this support.
- Encourage the formation of self-help groups for people with mental health problems and/or their family members, to enable mutual support and empowerment. If self-help groups are already available in the community, facilitate the inclusion of people with mental health problems where appropriate.

Facilitate access to social support

CBR programmes can facilitate access to social support in the following ways.

- Identify relevant social services available within the community.
- Identify social needs and make a plan with possible solutions, together with people with mental health problems and their family members.
- Work with families to address the rights of people with mental health problems, ensuring their basic needs (e.g. food, hygiene, clothing, shelter) are met.
- Provide suggestions to family members about ways to include people with mental health problems in everyday family activities.
- Encourage people with mental health problems and their families to continue socializing with relatives and friends and to rebuild relationships where necessary. It may be necessary to help people to educate their relatives and friends about their mental health problem.
- Identify activities in the community that people with disabilities and their family members can participate in – it may be necessary to accompany them into the community if they have little confidence and there are significant barriers.
- Establish regular contact with those people who have no social support networks, live on the streets and/or face severe stigmatization.
- Develop partnerships with different development sectors to ensure that the needs of people with mental health problems – including food, decent shelter/housing, education and work – can be met.
- Where access to medication is difficult owing to cost factors, explore ways to overcome this.

(See Social component.)

Facilitate access to livelihood opportunities

Participation in livelihood activities is an important part of the recovery process. In addition to generating income, livelihood opportunities promote independence, autonomy, improvement in self-esteem, establishment of social networks, achievement of valued social status and control over one's life. Suggested activities to increase access to livelihood opportunities include the following.

- Identify development initiatives in the community that are focused on income generation. Make contact with these initiatives and work with them to ensure that they have the capacity to include people with mental health problems.

- Identify other livelihood opportunities available within the community for people with mental health problems. This may include assisting people to return to their previous jobs or making contact with local businesses which are positive about employing people with mental health problems.
- Where people are able to return to their previous jobs, work with the employers to make the necessary adjustments to the work environments, e.g. recommend quiet working spaces if concentration and noise sensitivity is a problem, flexible working hours, gradual extension of working hours.
- Inform employers of their legal obligations towards people with disabilities, referring to the relevant legislation of the country.

(See Livelihood component.)

BOX 8 Tanzania

Leading meaningful lives

The Mtwara Mental Health Programme in Tanzania started working in partnership with five district health departments to set up accessible, affordable and consistent treatment options in the community for people with mental health problems. During the first phase of the pilot project, 1026 people received treatment within walking distance of their homes and later this number increased to 4711. Access to treatment and psychosocial support has enhanced the quality of life for many people with mental health problems. Their lives have become more stable – a number of people have returned to their former jobs, while others have taken up new jobs in their communities. According to the programme manager: "as people with mental health problems are relieved of their symptoms and start participating in meaningful activities, immediately, social attitudes towards them change too. This is the comparative advantage of a community approach over an institutional approach".

Support family members

In low-income countries, the family can be the most important mental health resource. The following activities are suggested.

- Provide information for family members about mental health problems and coping strategies. Remember to obtain permission from the person with the mental health problem before sharing the information.
- Help families caring for people with many needs to avoid burn-out by encouraging them to share their care burden with other family and community members.
- Encourage family members to join self-help groups to share their experiences with others.

Mothers sharing experiences

A group of mothers in Uganda belong to an organization for parents of children with disabilities. They regularly go to the local maternity hospital to visit other mothers who have given birth to children with disabilities. They listen to these mothers, acknowledge feelings of grief and loss that may be associated with the birth, and share positive experiences, providing hope for the future

Contribute to the empowerment process

Recovery from mental health problems is very closely linked to empowerment. As a detailed overview of the empowerment process and a comprehensive list of activities are provided in the Empowerment component, only a small selection of activities are listed here.

- Ensure that CBR personnel are respectful in the way they approach and communicate with people with mental health problems and their family members.
- Recognize that people with mental health problems and their family members have personal knowledge and skills. Ensure there is a focus on people's strengths, and encourage them to play an active role in the recovery process.
- Provide information to people (and, if appropriate, to their family members) about their mental health problems without imposing unnecessary labels. Ensure that they are aware of their human rights and how to exercise these rights.
- Make people aware of the available treatment and support options in their community to enable them to make informed decisions about actions they want to take.
- Link people with mental health problems and their family members with self-help groups.
- Encourage and support self-help groups to advocate for the development of accessible, affordable and acceptable community mental health services.
- Raise awareness about the Convention on the Rights of Persons with Disabilities in partnership with others and address local and national laws to enable people with mental health problems to exercise their rights.

(See Empowerment component.)

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CBR and HIV/AIDS

Introduction

Responses to human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) are often targeted at key populations that are believed to be at increased risk, such as migrant workers, sex workers, men who have sex with men, injecting drug users and indigenous people (*1*). However, one of the world's most vulnerable populations – individuals who live with permanent physical, mental, intellectual or sensory impairments – has almost been entirely overlooked (*2*). It is commonly assumed that people with disabilities are not at risk of HIV infection because it is believed that they are not sexually active, are unlikely to use drugs and are at less risk of rape and violence (*3*).

The recent Joint United Nations Programme on HIV/AIDS (UNAIDS), World Health Organization (WHO) and Office of the High Commissioner for Human Rights (OHCHR) joint policy brief on Disability and HIV recognizes that people with disabilities is a key population at high risk of exposure to HIV (*4*). However, governments and policy-makers rarely consider disability issues in HIV/AIDS policies and plans. This issue and a number of other barriers make HIV prevention, treatment, care and support programmes and services unavailable and inaccessible to people with disabilities.

While this section mainly focuses on disabled people, and their vulnerability to HIV/AIDS and limited access to mainstream programmes and services, CBR programmes also need to consider that people living with HIV/AIDS may experience disability as a result of the disease and its treatments. People living with HIV may be considered to have a disability when they develop impairments which, in interaction with their environment, restrict their full and effective participation in society on an equal basis with others (*5*).

The issue of disability and HIV/AIDS has been overlooked in many CBR programmes. However, as a strategy for community-based inclusive development, CBR can be effective in raising the profile of disability in HIV/AIDS programmes and services. CBR ensures that the needs of people with disabilities are addressed, and responds to the needs of and supports the social inclusion and equalization of opportunities for people living with HIV/AIDS who may come to experience disability.

BOX 10 Namibia

Alexia pushes for laws for people with disabilities

Alexia Manombe-Ncube, Namibia's first-ever Member of Parliament with a disability, has commented that in many African countries people with disabilities have a higher rate of HIV infection than non-disabled people.

She asserts that the general exclusion of disabled people from mainstream society is to blame. Visually impaired people, for instance, cannot read health education posters or advertisements. People with hearing impairments miss television and radio programmes on how to prevent the spread of infection. Those with mobility problems sometimes cannot get into health centres for advice or testing. Health education materials are rarely available in alternative formats such as Braille or sign language. Disabled people are sometimes even directly targeted. Women and girls with intellectual impairments may be easily persuaded into having unsafe sex.

Yet how many health service providers genuinely consider these issues in their programmes? Ms Manombe-Ncube is using her position to push for new laws on disability in the Namibian Parliament. Without including access to both prevention and treatment of HIV/AIDS for people with disabilities, it will be impossible to meet Millennium Development Goal 6: combat HIV/AIDS and other diseases.

Adapted from (5)

Goal

There is universal access to HIV/AIDS prevention, treatment, care and support programmes and services for people experiencing disability.

The role of CBR

The role of CBR is to: (i) ensure that people with disabilities and their families are aware of the HIV/AIDS programmes and services in their communities; (ii) ensure that HIV/AIDS programmes and services are accessible for people with disabilities and their families; and (iii) include in its programmes people living with HIV/AIDS who may be experiencing temporary or permanent disability.

Desirable outcomes

- People with disabilities are able to access mainstream HIV/AIDS programmes and services.
- People experiencing disability associated with HIV/AIDS are included in CBR programmes.
- Relevant stakeholders are knowledgeable about disability and HIV/AIDS.
- Networks and partnerships are created between disability and HIV/AIDS stakeholders.
- Key development sectors include people living with HIV/AIDS.
- Workplace policies are in place to reduce the risk of CBR personnel becoming HIV-positive and to provide support for those with HIV/AIDS.
- National HIV/AIDS policies and plans include people with disabilities.

Key concepts

HIV/AIDS

HIV is the virus that causes AIDS. It can be transmitted through direct contact with the blood or body fluid of someone who is infected with the virus, e.g. people may get HIV infection when they have unprotected sex or share an injection needle with an infected person. Babies can also get HIV before, during or after birth if the mother is infected.

AIDS is the final stage of HIV infection. AIDS affects the body's immune system, making it difficult for the body to fight off diseases. AIDS can result in life-threatening infections, some forms of cancer, and deterioration of the nervous system. Not everyone who is HIV-positive has AIDS – it may be many years before people with HIV get sick with AIDS. Antiretroviral treatment (ART) can help slow down the progress of the HIV virus, but they cannot cure HIV/AIDS. At the moment, prevention is the best and only cure.

People living with HIV/AIDS and disability

Many people living with HIV/AIDS may experience disability. Antiretroviral medications help many people to live longer lives; however, this also means that they live their lives with a chronic condition characterized by cycles of illness and wellness (*6*). People living with HIV/AIDS may experience a range of temporary or permanent impairments (physical, mental or sensory) which result from treatment or from the progression of HIV. For example, fatigue, digestive problems, skin problems and/or neuropathy (nerve damage) are common side-effects of treatment which may lead to functional problems (difficulties walking, showering, driving) and disability for people living with HIV/AIDS.

Many people living with HIV/AIDS also experience stigma and discrimination. HIV/AIDS is associated with behaviours that are often considered socially unacceptable and are therefore widely stigmatized. People living with HIV/AIDS are frequently subject to discrimination and human rights abuses; many have been thrown out of jobs and homes, rejected by family and friends, and some have even been killed (*7*).

People with disabilities and HIV/AIDS

Sexuality

Sexuality is the way that people experience and express themselves as sexual beings, and it is an important topic when addressing HIV/AIDS. In many societies, cultural taboos limit the free discussion of sexuality issues and, in particular, many people are uncomfortable discussing them in relation to disability. However, such issues are very real in the lives of many individuals with disabilities and cannot be ignored (*8*). People with disabilities are often perceived as asexual individuals because they are viewed as being innocent or childlike, are thought to be unable to have intimate relationships, and/or are considered to have fewer sexual needs. However, this is a myth, as many people with disabilities are as sexually active as people without disabilities (*9*) and therefore they are also at risk of being infected with HIV.

Risk factors

The Global Survey on HIV/AIDS and Disability has shown that almost all known risk factors for HIV/AIDS are increased for people with disabilities (*10*). Some of these risk factors are as follows.

Illiteracy – Literacy is important for understanding HIV messages and using these messages to change HIV risk behaviours (*8*). The Education component highlights that people with disabilities generally have lower levels of education than the general population, which suggests that they could be at increased risk of HIV (see Education component).

Limited HIV awareness and knowledge – People with disabilities have low levels of sexual knowledge (*9*) and are less informed about HIV (*11*). This may be a result of missing out on HIV education at home and school because of false beliefs about their

sexuality and because HIV information and messages are often not presented in accessible formats. For example, when prevention campaigns are conducted only by means of newspapers and billboards, blind people are excluded; when they are only on the radio, deaf people are excluded; and when campaigns use detailed and complex information, people with intellectual impairments may be excluded (*3*).

BOX 11 Mozambique

Acknowledging sexuality

Research conducted in Mozambique on disability and HIV found that one reason people with disabilities are routinely excluded from HIV and AIDS policies and programmes is a refusal or reluctance to regard people with disabilities as sexual beings. The report shows this to be a further dimension of the stigma and discrimination directed towards people with disabilities (*12*).

HIV risk behaviours – Behaviours, such as unprotected sex, injecting drug use and sex work increase the risk of HIV infection. Research has shown that many people with disabilities also engage in these behaviours (*10*). Low self-esteem and feelings of being unattractive or undesirable might lead to risky sexual behaviours (*9*). For example, disabled adolescents are often pressured into sex because of their need for social acceptance and inclusion, and therefore have a limited ability to negotiate safe sex (*3*).

Sexual abuse – Disabled people around the world are more likely to be victims of sexual abuse and rape than their non-disabled peers (*4*), which places them at greater risk of HIV infection. Many factors make people with disabilities more vulnerable to abuse, such as their dependence on other people for care, institutional living and lack of access to legal rights (*10*) (see Social component).

Barriers to HIV/AIDS prevention, treatment, care and support

People with disabilities have limited access to HIV services, e.g. testing and counselling, medication, care and support (*10,13*). The barriers that people with disabilities face are similar to those outlined in the Health component*,* and include the following.

Policy – Because many people think that people with disabilities have a lower quality of life and cannot contribute productively to society (*14*), it is not unusual for policy-makers to suggest that time, energy and resources should first be given to non-disabled populations (*8*). Where antiretroviral medications are scarce and services and support are limited, people with disabilities often report being placed last on the list of those entitled to care (*2,8*).

Environmental and communication barriers – Services offered at clinics, hospitals and in other locations may be physically inaccessible (e.g. they have no ramps for people

using wheelchairs), lack sign language facilities or fail to provide information in alternative formats, such as Braille, audio or plain language (*5*).

Negative attitudes and knowledge of health workers – Many people with disabilities are ridiculed or dismissed by health workers when requesting sexual and reproductive health information (*14*). In many countries, they report being turned away even when they are able to reach HIV testing centres or AIDS clinics by staff who indicate, incorrectly, that disabled people cannot get HIV/AIDS (*8*).

Health-seeking behaviour – There are many reasons why people with disabilities might not use HIV/AIDS services: negative attitudes from health workers might make them reluctant to seek help when they are concerned about their sexual health (*11*); the stigma associated with HIV/AIDS causes secrecy and denial and prevents some people from seeking HIV testing (*9*); many disabled people rely on family members or friends for support to access health services and may therefore not use those services because they are embarrassed, ashamed or fearful that these people will find out about their HIV/AIDS status.

Impact of HIV/AIDS on families

People with disabilities are affected when family members have HIV/AIDS. As people with disabilities often require assistance from family members for daily activities and have extra medical, educational or rehabilitation needs, they may be neglected where there is a loss of family income, resources and time due to HIV/AIDS. It has been estimated that 4–5% of children who have lost one or both parents to AIDS also have disabilities (*5*). In these situations, they are more likely to be malnourished, neglected, placed in institutions or abandoned (*10*). Children with disabilities who are also HIV-positive are also more likely to experience exclusion and discrimination in all areas, particularly in the field of education (*5*).

Reaching disabled populations

Inclusion of people with disabilities in HIV/AIDS programmes and services

Many disabled people may not be included in mainstream HIV/AIDS programmes and services because it is often believed that is it too expensive or too difficult. However, there are many ways in which CBR programmes, disabled people's organizations, HIV/AIDS advocates, educators and policy-makers can support their inclusion. Many practical ideas are provided under Suggested activities but, in general, these involve the following:

- facilitating access to mainstream HIV/AIDS programmes and services which target the general population;
- adapting mainstream HIV/AIDS programmes and services to enable inclusion and participation;

- developing and implementing disability-specific interventions for people who cannot be reached by mainstream HIV/AIDS programmes and services.

It is important to remember that combinations of these measures will be required to reach all people with disabilities.

Rehabilitation

Rehabilitation becomes increasingly important for people who may be experiencing disability as a result of HIV/AIDS. Rehabilitation related to HIV/AIDS can slow down deterioration and enable people to achieve and maintain independence (*5*). Rehabilitation will not be covered in detail here as it is addressed in the Health component; however, it is important to understand that, at the community level, CBR can play a key role in addressing the functional problems that people living with HIV/AIDS may experience. In addition, it is important to consider other support and other aspects of rehabilitation, e.g. vocational rehabilitation, which may help a person with HIV-related disability to maintain a healthy and productive lifestyle.

Suggested activities

Facilitate access to HIV prevention, treatment, care and support

CBR should work towards addressing the barriers that limit the full participation of people with disabilities in HIV/AIDS prevention, treatment, care and support in the following ways:

- making people with disabilities and their family members aware of the HIV/AIDS programmes and services being offered in their communities and making sure that they are aware that they have a right to attend;
- ensuring HIV/AIDS programmes and services are physically accessible, e.g. CBR programmes can encourage HIV/AIDS programmes and services to move to accessible meeting places or provide advice and assistance regarding adaptations;
- encouraging HIV/AIDS programmes and services to show disabled people in posters, billboards or other materials designed for the general public, e.g. showing a wheelchair user or a blind person with a cane alongside people without disabilities;
- working together with disabled people's organizations to advise HIV/AIDS programmes and services on ways of making simple adaptations to their interventions to ensure that messages are understood by people with disabilities, e.g. passing condoms around during education sessions so that blind participants can feel what they are like and how they work;

- giving information and education materials on HIV/AIDS to people with disabilities who are at risk, to ensure they are being reached;
- working together with disabled people's organizations to advise HIV/AIDS programmes and services on ways of adapting existing materials to make them accessible, e.g. deaf people may require text captioning or sign language interpretation, blind people may require Braille or tapes, people with intellectual impairment may require pictures;
- working together with disabled people's organizations to develop new programmes, services and materials for people with disabilities who cannot be reached by those designed for the general population, e.g. developing education sessions specifically for people with disabilities;
- providing practical assistance, e.g. transport, to improve access for people with disabilities and their families to mainstream services;
- ensuring people with disabilities and their families are provided with appropriate follow-up, e.g. treatment, care and support, after becoming aware of their HIV-positive status.

BOX 12 Uganda

A young woman manages HIV with timely help

In Uganda, a young woman who was deaf had a sexual relationship with a HIV-positive man. She became pregnant, and the man took no responsibility for the relationship or the child. Family members became concerned that she might have contracted HIV, and took her to an HIV/AIDS counsellor. She tested positive, and arrangements were made for her to receive antiretroviral drugs. Now she and her baby (who did not test positive) are doing well; she takes her medication regularly, is working and is also helping out at home. Her family now encourages other families with disabled family members to access HIV/AIDS information and services.

Include people living with HIV/AIDS in CBR programmes

As CBR communicates a strong message of inclusion, programmes should address the needs of people living with HIV/AIDS who may experience disability. Some people living with HIV/AIDS may require access to specialized services, such as rehabilitation and assistive devices. CBR can facilitate this.

Build capacity

A number of different stakeholders can benefit from capacity-building, including people with disabilities and their family members, CBR personnel, disabled people's organizations, health workers and members of the community. CBR programmes can take the following actions:

- promote activities and support initiatives that strengthen the roles of women in decision-making about HIV and disability in communities;
- ensure that people who provide support and assistance for people with disabilities and HIV/AIDS (e.g. family members) receive adequate training and support;
- strengthen their own programmes to ensure that HIV/AIDS and related issues, such as sexuality, reproductive health and sexual abuse are addressed and, where necessary, provide additional training for CBR personnel;
- involve disabled people's organizations and people with disabilities in HIV/AIDS activities, e.g. people with disabilities could be trained as HIV/AIDS educators for their communities or for particular groups of people with disabilities;
- in partnership with disabled people's organizations, train HIV/AIDS educators, outreach workers and health personnel about disability issues;
- educate community and religious leaders about disability and HIV/AIDS issues, and encourage them to take action to challenge negative attitudes and promote inclusion in their communities;
- educate people involved in law enforcement, e.g. police officers, lawyers and judges, about disability and HIV/AIDS issues and the need to protect the safety and human rights of people with disabilities.

BOX 13

HIV programmes by the deaf community

In some countries, local deaf groups run HIV prevention programmes. These programmes raise awareness among the deaf community and teach safer lifestyle practices. They also bring greater awareness to HIV organizations and government programmes about the need to broaden the ways in which HIV information is communicated to the public.

Create networks and partnerships

Because of the relationship between disability and HIV/AIDS (i.e. people with disabilities are at risk of HIV/AIDS and people living with HIV/AIDS may experience disability), strong networks and partnerships need to be built between disability and HIV/AIDS stakeholders. It is suggested that CBR programmes should take the following actions:

- attend events and meetings in the community on HIV/AIDS to ensure that disability issues are considered; equally, CBR programmes can invite representatives from the HIV/AIDS community to events and meetings on disability;
- work closely with disabled people's organizations, where available, to develop local strategies to reach people with disabilities with HIV/AIDS information and education, identify training needs in the community and educate HIV/AIDS workers about disability;
- share the disability and rehabilitation expertise of CBR programmes with HIV/AIDS networks by providing education and training about disability and the benefits of rehabilitation and raising awareness that people with disabilities are also at risk of HIV;
- invite HIV/AIDS programmes and services to share their specialist skills and knowledge with CBR programmes and disabled people's organizations to help them respond to the needs of their staff, members and clients;
- set up referral systems between CBR programmes and HIV/AIDS programmes.

Promote a multisectoral approach

Both disability and HIV/AIDS are development issues. They share many common links, including poverty, stigma and discrimination, violence and other inequalities, such as reduced access to education and opportunities for making a living. Therefore, it is important that CBR programmes consider the involvement of all sectors when developing strategies to address both disability and HIV/AIDS. A review of the Health, Education, Livelihood, Social and Empowerment components will provide a comprehensive overview of suggested activities, some of which are to:

- address disability and HIV/AIDS-related stigma and discrimination that may be present in communities and across each sector;
- promote the right to education for people with disabilities, including sex education, and ensure that environments are inclusive and accessible (see Education component).
- ensure that people with disabilities and HIV/AIDS, and their family members, are able to access livelihood opportunities (see Livelihood component).
- ensure that people with disabilities and HIV/AIDS are able to access formal and informal social protection schemes (see Livelihood component).
- ensure that people with disabilities are able to access programmes and mechanisms that are designed to prevent/address sexual assault or abuse (see Social component: elements on Relationships, marriage and family, and Access to justice).

Implement workplace HIV/AIDS policies

HIV/AIDS is a workplace issue; in many countries, CBR personnel and their family members may be at risk of or affected by HIV/AIDS. Therefore CBR programmes should have appropriate workplace policies in place to:

- minimize the possibility that CBR personnel become infected with HIV;
- ensure that CBR workers who have HIV, or are affected because family members have HIV/AIDS, are well supported;

- eliminate any stigma and discrimination that may be present in the workplace.

HIV/AIDS policy should cover the following areas: protection of the rights of those affected by HIV/AIDS; prevention through information, education and training; and care and support for workers and their families (*15*).

Promote inclusive national policies and programming

As people with disabilities are often left out of HIV/AIDS policies and programming, CBR programmes should join with other groups to advocate and lobby for change. For example, the Africa Campaign on Disability and HIV and AIDS, launched in 2007, is a unifying umbrella organization under which disabled people's organizations, organizations of people living with HIV/AIDS, nongovernmental organizations, HIV and AIDS services, researchers, activists and other citizens work collectively to promote equal access to HIV programmes and full participation in AIDS policies and strategic plans for people with disabilities (*16*).

BOX 14 South Africa

New milestones

South Africa first included disabled people in the National AIDS strategic plan in 2007–2009. This was prompted by a combination of leadership from champions within the Government, the strong organization of the disability sector and self-representation in the South African National AIDS Council (*5*).

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CBR and leprosy

Introduction

Leprosy is a chronic infectious disease that has existed for a very long time. Leprosy is caused by bacteria and, if left untreated, can cause progressive and permanent damage to the skin, nerves, limbs and eyes (*1*). Approximately 249 000 new cases were reported in 2008 (*1*). While there is an effective cure for leprosy, it has been estimated that approximately 3 million people are living with leprosy-related disabilities (*2*).

Before there was an effective treatment and cure for leprosy, societies were very fearful of the disease, and people affected by it faced much stigma and discrimination (*3*). Many were forced to leave their families to live in colonies or settlements, where they were isolated from the community and had no access to services and support. This isolation further contributed to their stigma. With advances in treatment and surgery, these institution-based approaches have become outdated (*3*) – people affected by leprosy now often remain within their families and communities, and leprosy activities are being integrated into general health services (*4*).

However, despite effective leprosy treatment, public awareness campaigns and the integration of leprosy work into general health services, stigma is still a major issue for people affected by leprosy (*5*). Many people continue to face social exclusion, and experience difficulties accessing mainstream services such as CBR programmes, e.g. many thousands of people affected by leprosy may be in need of rehabilitation services, but only a few have access to these services (*5*).

CBR is a strategy that applies equally to people affected by leprosy (*4*). The suggested activities that follow provide practical ideas on ways of including people affected by leprosy in CBR programmes and in the wider community. It is hoped that this section will also raise the awareness of people working in leprosy services about the importance of including people with other disabilities in their activities.

BOX 15 India

Shivrao

Shivrao lives in a small village in the Mandya subdistrict in Karnataka state in the south of India. Three of his family members had leprosy and experienced disabilities as a result. In 1999, when he was 15 years old, he developed a round red mark on his face. Ambuja, a leprosy worker from the Maria Olivia Bonaldo (MOB) rural health programme, visited Shivrao's house one day and noticed this mark. She suspected that it was due to leprosy and therefore took him to the Mandya Civil Hospital where he was diagnosed and started on treatment. Somehow the news that Shivrao was receiving treatment for leprosy reached his school, and his teachers told him that he should no longer attend.

When Ambuja carried out a follow-up visit to Shivrao's home, she found out what had happened and decided to talk to his schoolteachers. She explained to them that Shivrao was receiving treatment and that there was no risk of infection to the other children. She asked them to allow Shivrao to come back to school. However, his teachers were not convinced and asked for a certificate from the hospital. Ambuja went with Shivrao to the Civil Hospital and got this certificate from a doctor, and finally Shivrao was allowed to go back to school.

In 2001, the MOB rural health programme decided to start a CBR programme, and Ambuja was trained as one of the first CBR workers. After her training, Ambuja decided to start a self-help group for people with disabilities. She went to Shivrao's house to ask if one family member would like to join the group. Shivrao's family was afraid of joining the self-help group because they thought that they would not be accepted by others. However, after many discussions, Shivrao's mother decided to go along to the self-help group meetings. She joined the savings activity, where each member saved a small sum of money every week.

Ambuja continued to provide regular follow-up for Shivrao. She gave advice to Shivrao about taking good care of his feet, because she discovered that his feet had become numb because of the leprosy. She also gave him a pair of sandals from the Leprosy Programme to protect his feet from becoming damaged. In 2003, Shivrao decided to join the local CBR programme as a CBR worker. His experience in that job has given him a lot of confidence, and he has learned more about the different opportunities available for people with disabilities. He went on to study at university through distance learning. Today he is a schoolteacher, is married and has a baby girl. He also continues to be an active supporter of CBR in his village.

Goal

The rights of people affected by leprosy are recognized and they are able to access local support and services to improve their quality of life and ensure that they are able to participate as equal members in society.

The role of CBR

The role of CBR is (i) to include people affected by leprosy in their activities, and (ii) to encourage leprosy programmes and services to include people with disabilities in their activities.

Desirable outcomes

- People affected by leprosy have their rehabilitation needs met through CBR programmes and/or relevant referral services.
- Leprosy-specific rehabilitation centres and programmes offer their services to other disabled people, including those involved in CBR programmes.
- Stigma and discrimination in communities towards people affected by leprosy and their family members is reduced.
- All relevant stakeholders have increased skills and knowledge to address problems and issues related to leprosy.

Key concepts

Understanding leprosy

What is leprosy?

Leprosy is a disease caused by the bacterium *Mycobacterium leprae,* which mainly affects the skin and nerves. Leprosy is often called Hansen's disease, after the person who discovered the bacterium. It can affect people of both sexes and of all ages. It progresses very slowly, and it can therefore take many years before noticeable signs and symptoms appear. One common sign of leprosy is "skin patches", which are pale, reddish or copper-coloured. These areas of skin may be flat or raised and have no feeling (sensation). They may appear anywhere on the body; they do not itch and usually do not hurt (*6*).

Common myths about leprosy

While awareness and knowledge about leprosy have improved over time, there are still some common myths. These include the following.

- *Leprosy is incurable.* This is false. Treatment with multidrug therapy (MDT) can cure leprosy. Over the past 20 years, more than 14 million people have been cured (*1*). WHO provides MDT for any country that needs it as part of the Organization's ongoing efforts to eliminate leprosy. Treatment is available free of charge at health centres (*6*).
- *Leprosy is highly contagious.* This is false. While leprosy can be transmitted to other people (via droplets from the nose and mouth), it is not highly contagious. Only people with large numbers of bacteria can pass the disease on to others; therefore, many people with leprosy are not considered contagious. It is also estimated that 95% of the world's population has a natural resistance to leprosy, which makes transmission unlikely. MDT is very effective in killing the bacteria; therefore once people start MDT, they are not contagious (*7*).

Leprosy reactions

Some people with leprosy may experience "leprosy reactions". These are part of the body's response to leprosy, and do not mean the disease is becoming worse or that the treatment is not working (*6*). They are rather like an allergic reaction – the body reacts against the presence of leprosy bacteria, and in doing so can cause damage to its own tissues. Because leprosy bacteria target nerves, these are often damaged during leprosy reactions. Nerve damage can occur very quickly, and therefore early detection and referral to appropriate health services for treatment is important to prevent irreversible damage. Early detection and treatment of nerve damage are the great challenges of leprosy control programmes. Up to 30% of persons affected by leprosy are at risk of reactions and nerve damage (*8*).

Impairments associated with leprosy

Nerve damage associated with leprosy can lead to a wide range of impairments (*9*). Nerve damage can result in sensory impairments, e.g. people affected by leprosy may lose feeling in their hands and feet. Nerve damage can also result in motor impairments, e.g. a person's hands, feet and/or eye muscles may become weak or paralysed. Leprosy also often causes the skin to become very dry, because of damage to the nerves which control sweating. For many people, these impairments can then lead to further problems and complications.

For example, people who lose sensation in their hands and feet often injure themselves without noticing. Because they do not sense the pain from the injuries, they do not necessarily seek treatment, and this may lead to infections, tissue and bone damage and the potential loss of limbs. Muscle weakness and paralysis in the hands and feet often lead to joint stiffness and deformity. Loss of strength in the eye muscles can eventually lead to blindness, as without regular blinking and complete closure of the eye at night the eye becomes dry and easily damaged (*10*). Dry skin can crack; this creates openings for infection that can quickly spread into the joints and bones, causing the loss of an infected finger or toe (*10*).

The impact of leprosy

Functional impact

The impairments associated with leprosy can make it very difficult for people to carry out daily activities. For example, people who lose feeling or strength in their hands will have more difficulty with simple tasks, such as threading a needle or holding a spoon; and people who are unable to lift their foot ("foot drop") will have difficulty walking. An estimated 20–25% of people affected by leprosy experience disability (*9*). Early detection of leprosy and proper treatment combined with regular checkups are key to preventing disabilities (*11*).

Social impact

Often, it is not the physical impairments or even the functional limitations that cause the greatest problems for people affected by leprosy. Instead, it is stigma and social exclusion that have the greatest impact. People who are visibly affected by leprosy are often unable to find work or marry, and are therefore dependent on others for financial support and care. Self-stigma is also common – people start blaming themselves for their disease, which results in feelings of worthlessness and loss of self-esteem, hope and purpose. Often, even people who have been cured of leprosy will continue to experience the ongoing effects of stigma and discrimination.

These guidelines have highlighted elsewhere that women with disabilities are often more vulnerable and disadvantaged in society. This is also true for women with leprosy. A general lack of awareness and knowledge within communities about leprosy, e.g. whether it is inherited, infectious or curable, has an impact on relationships, marriage and family. Many women have been abandoned by their spouses, particularly if they were only recently married, and for many unmarried women leprosy can severely restrict their marriage prospects.

Economic impact

Leprosy can have a considerable economic impact on individuals and their families. People may be unable to work, or may not be able to continue working, owing to impairments associated with leprosy. People may also lose their jobs because of the stigma related to leprosy. For example, people are often reluctant to buy goods, such as food products from a person affected by leprosy, for fear of contamination. There are also treatment-related costs. While drug treatment is free, access to health care in low-income countries is often associated with travel costs and loss of wages. There may also be additional treatment costs, e.g. hospital admissions or the purchase of protective footwear, orthoses or prostheses. Many people may be discouraged from accessing services because of these costs. As a result, they may develop secondary conditions and the impact of their disability may increase.

Leprosy colonies

Until a few decades ago, there was no effective cure for leprosy, and therefore people affected by the disease were usually isolated in leprosy colonies or leprosariums. This segregation was often enforced by law. As effective treatment and cure became available, many of these colonies were closed; however, they still exist in some countries. Some people living in these settlements may be long-term residents with no contact with family members from their former family homes. Those with severe disabilities may be dependent on begging or charity (*4*).

India

Leprosy colonies

India has always had the largest population of people affected by leprosy. In 2005, an organization of people affected by leprosy conducted a national survey of leprosy colonies in India. This study revealed that 700 leprosy colonies still existed and approximately 200 000 people affected by leprosy and their family members were living in these colonies. Of these, around 25 000 people were making a living by begging. In many colonies, there were no toilet facilities, drinking water, approach roads or education facilities. Surrounding communities avoided people living in these colonies, and as a result they had difficulty accessing public transport and other public facilities.

It is important that governments and nongovernmental organizations support the integration of people affected by leprosy into their local communities, making them aware of their rights and working with them to remove stigma and discrimination. CBR can also play a role in this process. Where resettlement in the community is not an option, e.g. if people are unwilling to leave leprosy colonies, CBR can assist them to live in harmony with surrounding communities and gradually open up their own colonies to accommodate other people. There are examples around the world where leprosy colonies have gradually evolved into ordinary villages.

Integration of leprosy and CBR activities

Even though leprosy may continue to be a disease of low prevalence, and may even be rare in many areas, leprosy services – diagnosis, treatment, the prevention and care of disabilities, and rehabilitation – will need to be maintained far into the 21st century (*9*).

In the past, these services have been specialized and segregated, but now integration into the general health system is seen as the most appropriate strategy (*9*). This also has an impact on the way rehabilitation services are being delivered.

The provision of rehabilitation for people affected by leprosy has often developed in parallel with "mainstream" rehabilitation services. For example, many international and national nongovernmental organizations have set up rehabilitation services (both health-related and socioeconomic rehabilitation) specifically for people affected by leprosy while, on the other hand, mainstream rehabilitation services, such as CBR programmes exclude people affected by leprosy. It has been suggested that the stigma related to leprosy and the existence of specific leprosy programmes are the main reasons why CBR programmes do not include people affected by leprosy (*12*).

Rehabilitation services specifically for people affected by leprosy are now being encouraged to offer their services to other groups of disabled people, as they have many skills and resources that may be of benefit to this wider group. They may be very useful referral centres for CBR programmes; for example, a CBR programme could refer a person with a physical impairment to an orthopaedic workshop usually reserved for people affected by leprosy. CBR programmes are also being encouraged to offer their services to people affected by leprosy because it has been recognized that the CBR strategy is highly relevant to this group (*4*). Recently, it has been suggested that CBR should be the strategy of choice for people affected by leprosy and in need of rehabilitation (*12*).

Suggested activities

As CBR is a strategy that is applicable to all people experiencing disability, many of the suggested activities in these guidelines also apply to people affected by leprosy. Therefore it is suggested that this section should be read alongside the other major components of the CBR matrix – health, education, livelihood, social and empowerment. In addition, publications such as the *WHO/ILEP technical guide on community-based rehabilitation and leprosy* provide a detailed overview of suggested activities for both CBR programme managers and workers (*4*).

Include people with leprosy in CBR programmes

Solutions to the problems experienced by people affected by leprosy should be considered from a development perspective (*2*). Therefore CBR programmes need to work across all sectors to ensure that people affected by leprosy can access mainstream development programmes and activities. As women with leprosy-related disabilities are even more vulnerable to exclusion and poverty, CBR programmes need to make sure they also have the opportunity to participate in and benefit from CBR activities.

Health

People experiencing impairments related to leprosy will require health interventions to 1) preserve nerve function, 2) preserve joint mobility, 3) preserve vision, 4) learn self-management/self-care, 5) access protective footwear, and 6) access assistive devices. CBR programmes can support appropriate health-related interventions by:

- ensuring people affected by leprosy and their family members are aware of the health services available in their communities and are able to access them;
- motivating people on MDT to take their medicines regularly until their treatment is complete, and ensuring that people have information about leprosy reactions so that they are able to identify them and seek treatment immediately;
- supporting the development of self-help groups where people affected by leprosy can meet regularly to share experiences and learn about self-management/self-care activities to prevent and manage their impairments (see Health component: Prevention);
- providing advice to people experiencing sensory loss about protecting their hands, feet and eyes, e.g. using cloth gloves when holding hot objects, such as cooking pots; manuals, such as *Training in the community for people with disabilities* (*13*), provide more detailed information about preventing injuries and deformities in people experiencing sensory loss;
- facilitating access to assistive devices where required, e.g. special shoes, and ensuring their repair and maintenance (see Health component: Assistive devices).

BOX 18 Ethiopia

Self-respect and dignity through self-help groups

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ALERT is a medical facility on the edge of the city of Addis Ababa, Ethiopia, specializing in leprosy. In 1995, ALERT staff expressed concern about the increasing number of people who continued to use the ALERT hospital and field clinics for the management of wounds (e.g. foot ulcers), despite having received many years of health education. This was placing increasing pressure on ALERT, as they had limited financial resources for wound healing supplies. In response to this problem, ALERT developed self-care groups to encourage people to take responsibility for managing and monitoring their own wounds. By 1999, there were 72 established groups and a number of positive outcomes were reported, e.g. the number of wounds decreased and group members reported improved self-respect and dignity and increased participation in society (*14*).

Education

Children may be directly affected by leprosy, or may suffer because their parents or relatives are affected by leprosy. As a result, they may be denied access to school, forced to drop out, isolated from former friends, hidden away by their families, or required to work and earn an income (*4*). There are many ways whereby CBR programmes can ensure that children (and also adults) are able to access education opportunities in their communities, e.g. CBR workers can meet schoolteachers and parents to raise awareness about leprosy to change attitudes towards students affected by leprosy. For a detailed list of activities, refer to the Education component.

Livelihood

People with leprosy are often very poor; additional issues, such as stigma, discrimination and disability associated with leprosy often restrict opportunities for work, which increases their poverty. Skills training and decent work can provide a strong entry point for integration into society, and are a mechanism for breaking the cycle of isolation, dependency and poverty commonly associated with disability. When people with disabilities are able to make financial contributions to their families, they often report increased participation in family activities such as decision-making (*15*). There are many ways CBR programmes can support people in making a living, e.g. they may need to act as mediators and provide information for prospective employers who may be concerned about employing people affected by leprosy. For a detailed list of activities, refer to the Livelihood component.

BOX 19 Ethiopia

Tapping potential to end stigma and poverty

The Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) is committed to improving the livelihood of its members to enable them to regain dignity and self-esteem. Currently, the association has 20 000 members distributed across 54 local associations in the seven regions of Ethiopia. It has implemented awareness, advocacy and livelihood projects in partnership with national and international agencies. The livelihood projects demonstrate that people affected by leprosy have the potential to be productive just like any other citizen. ENAPAL uses revolving funds for members to enable them to engage in income-generating activities. It also provides education opportunities for members' children, empowering families to break the cycle of stigma and poverty. With the same aim, the association organizes self-help groups for women affected by leprosy. These strategies have proved successful.

Social

Stigma, discrimination and misconceptions about leprosy often result in people being unable to access mainstream services and participate in the life of their communities. CBR personnel can play a very important role in reducing stigmatizing attitudes and practices in the community by:

- working with others, e.g. community leaders, teachers and religious authorities, to spread positive messages about leprosy;
- developing or participating in public awareness-raising campaigns about leprosy – these may involve drama, exhibitions or distribution of leaflets and can be carried out in a variety of places, e.g. local markets, public meeting places, health centres, schools;
- developing joint activities, such as sports or cultural programmes, where people affected by leprosy, people with disabilities and nondisabled people can come together – this will help convince the whole community about the ability of people with disabilities to participate as equal members of the community and their right to do so.

Empowerment

It is important that people affected by leprosy are aware of their rights and how to speak up for themselves so that they can gain access to services and resources. Self-organization can be an effective way to do this, and around the world, people affected by leprosy have organized themselves into local groups and associations. Examples include the Movement for Reintegration of People Affected by Hansen's Disease (MORHAN) in Brazil, the Association for the Reintegration of People Affected by Leprosy (ARPAL) in Angola,

and the National Forum in India. Some of these groups have "federated" (joined together) as the International Association for Integration, Dignity and Economic Advancement (IDEA). Some people have also joined local disabled people's organizations. These associations have been active in organizing empowerment workshops and other meetings on themes, such as the International Convention on Rights of Persons with Disabilities (*16*). CBR programmes can support people affected by leprosy in accessing self-help groups and disabled people's organizations in their local areas (see Empowerment component: Self-help groups, and Disabled people's organizations).

Encourage leprosy programmes to become inclusive

CBR programmes should encourage leprosy rehabilitation programmes to make their services available to other people with disabilities. This could have many benefits; it could help reduce the stigma associated with leprosy, facilitate the integration of leprosy services into mainstream sectors and ensure that more people are able to benefit from existing services. In areas where only specialized leprosy programmes and services exist, they should be encouraged to introduce the CBR strategy as a way of opening up their services to people with other disabilities (*4*). While networking with these programmes, it is essential to share information, reduce duplication of services and explore new ways to respond to rehabilitation needs.

Build capacity

CBR programmes should be particularly focused on building the capacity of all stakeholders to enable them to move towards an inclusive CBR approach (*17*). Stakeholders may include CBR personnel, personnel from leprosy programmes and services, people affected by leprosy, people with disabilities, family members and disabled people's organizations. Suggested activities include the following.

- Provide training/retraining for CBR personnel to enable them to include people affected by leprosy in CBR programmes – ensure that people with leprosy expertise are involved in these training programmes.
- Encourage leprosy programmes and services to provide training for their personnel on the CBR strategy – ensure that CBR personnel are involved in these training courses.
- Increase the awareness of leprosy among disabled people currently involved in CBR programmes – ensure that they are accepting of people with leprosy joining CBR programmes.
- Facilitate education and training for people affected by leprosy and their family members to ensure that they take responsibility for managing their disease and associated impairments.
- Encourage local disabled people's organizations to learn about leprosy and accept people affected by leprosy as members with equal rights and opportunities.

BOX 20 Sudan

Accepting people affected by leprosy

In Nyala, Sudan, the Society for the Disabled did not include people affected by leprosy. Staff from the Leprosy Mission organized training sessions for members of the Society to educate them about leprosy, e.g. explaining that people are no longer infectious when they are receiving MDT. Following the training, the Society for the Disabled decided to start providing MDT in addition to its already wide variety of services and to accept people affected by leprosy as members.

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CBR and humanitarian crises

Introduction

A humanitarian setting is one in which an event (e.g. armed conflict, natural disaster, epidemic, famine) or series of events has resulted in a critical threat to the health, safety, security and well-being of a community or other large group of people. The coping capacity of the affected community is overwhelmed and external assistance is required (*1*).

Humanitarian crises can have an enormous human impact by causing injury, loss of life and a decreased ability to meet basic needs, such as food, water, shelter and sanitation. They also have an economic impact by causing damage to infrastructure, crops and housing and increasing unemployment (*2*). Humanitarian crises are relevant to the field of disability and to community-based rehabilitation (CBR) because they can disproportionately affect people with existing disabilities and also create a new generation of people with disabilities who will require support and assistance (*3*).

There have been many changes in the humanitarian sector over the past few years to ensure that humanitarian action and response are more effective and efficient. This section of the supplementary booklet highlights some of these changes, explores the role of CBR programmes in humanitarian crises and provides suggestions on how to ensure the inclusion and participation of people with disabilities and their family members in humanitarian action.

BOX 21 Sri Lanka
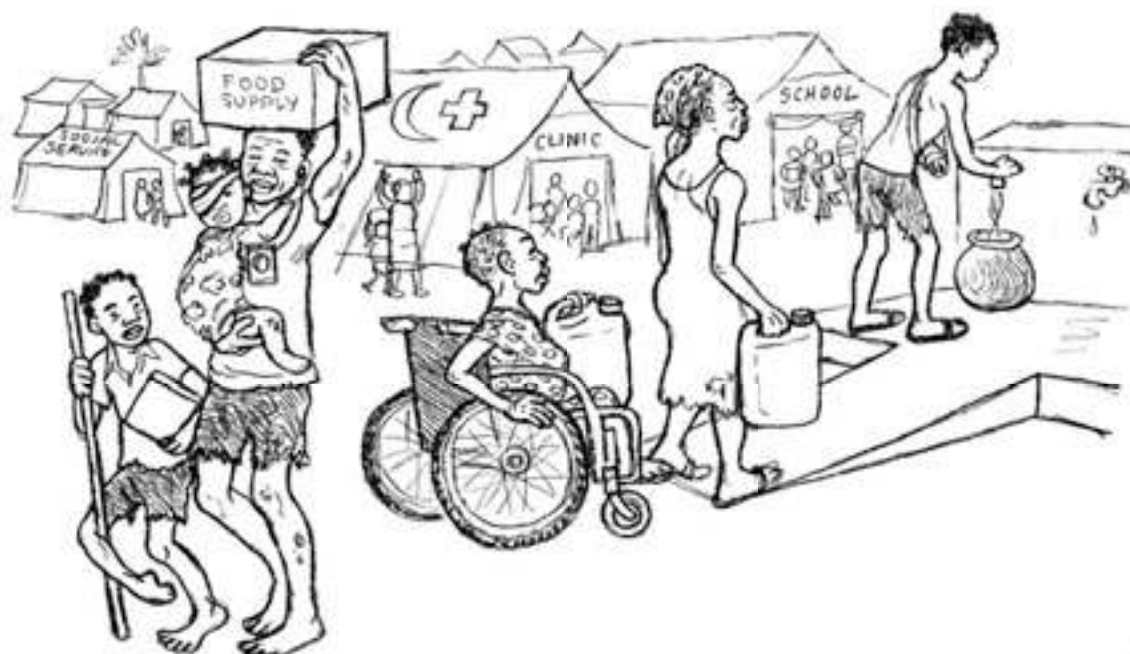
Access for All

The Access for All campaign was launched immediately after the tsunami that devastated large parts of the coastal areas of Sri Lanka on 26 December 2004. It was founded by Disability Organizations Joint Front (a national umbrella group of 18 local disability organizations), Spinal Injuries Association, Motivation, CBM, John Grooms, Handicap International and the Ministry of Health (Youth Elderly Disabled and Displaced Persons Unit).

The aim of the campaign was to promote the inclusion of all disabled people and their needs in the tsunami relief, reconstruction and rehabilitation work in Sri Lanka. In particular, it has focused on rebuilding an accessible Sri Lanka – ensuring that all public buildings, transport, places of employment, services and infrastructure are accessible to people with disabilities. Access was never particularly easy for people with disabilities living in Sri Lanka even before the tsunami; however, the extensive reconstruction that was required afterwards was a good opportunity to ensure that their needs were considered and addressed.

The Access for All committee started holding meetings two weeks after the tsunami, inviting people responsible for rehabilitation and reconstruction, including governmental authorities, international and Sri Lankan nongovernmental organizations and the public sector, to attend. The purpose of these meetings was to make everybody aware of the need for accessibility for people with disabilities (including the need for accessible distribution processes and temporary shelters) and to offer technical advice, resources and support.

As a result of the Access for All campaign, there has been a great willingness among organizations involved in reconstruction and rehabilitation work to acknowledge and address disability issues. Accessibility regulations are in place – construction of all new buildings must consider access issues and all inaccessible buildings must be made accessible within a stipulated period. The Access for All campaign continues in Sri Lanka and now focuses on the inclusion of people with disabilities in the wider context, by promoting their rights and equal opportunities for education and employment.

Adapted from (*4*)

Goal

People with disabilities and their family members are involved and included in humanitarian action including preparedness, emergency response and recovery activities.

The role of CBR

The role of CBR is to (i) assist people with disabilities, their family members and communities to prepare for potential humanitarian crises; (ii) ensure that humanitarian response and recovery is inclusive of people with disabilities; and (iii) link people with disabilities and their family members to services and assistance provided through humanitarian channels.

Desirable outcomes

- People with disabilities and their families are prepared to respond during humanitarian crises.
- People with disabilities and their families are identified and their needs addressed during humanitarian response.
- People with disabilities are included in planning and implementation of humanitarian and recovery programming.
- Infrastructure that is rebuilt following a humanitarian crisis is physically accessible to people with disabilities.
- Services and support that are re-established or developed following a crisis are accessible and respond to the needs of people with disabilities.

Key concepts

Disability and humanitarian crises

People with disabilities are one of the groups that are most frequently at risk in humanitarian crises (5). The following is a list of some of the factors which may make people with disabilities more vulnerable.

Exclusion – inappropriate policies and practices by communities and the agencies involved in providing humanitarian aid and intervention may result in the exclusion of people with disabilities (6,7).

Lack of awareness – information about hazards and risks, warnings of approaching events and advice on the action to take during and after a crisis are often not presented in accessible formats for people with disabilities. Therefore it may be difficult for them to see warning signals, and understand and follow instructions about what to do, where to go and where to turn for help (7).

Disruption of social support networks – social networks are particularly important for people with disabilities, who often rely on family members, friends and neighbours for assistance and support (see Social component: Personal assistance). These networks are often affected during a crisis situation, e.g. people with disabilities may be separated from caregivers or their caregivers may be injured or killed.

Physical barriers – physical environments are often transformed in crisis situations, exacerbating existing barriers or creating new ones for people with disabilities. Many people with disabilities may also lose their assistive devices, such as artificial limbs, crutches, hearing aids and spectacles (*4*). As a result many people with disabilities have greater difficulty in seeking assistance and support in crisis situations, e.g. they may be unable to access food, water, shelter, latrines and health-care services (*4*).

Inclusion of people with disabilities in humanitarian action

Despite evidence showing that people with disabilities are disproportionately affected during crises, they are often excluded from humanitarian activities (*8,9*). Disability issues should be addressed in all humanitarian action as highlighted in Article 11 of the Convention on the Rights of Persons with Disabilities.

"States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters" (*10*).

Participation of the affected population is an important aspect in humanitarian crisis (*5*). It is critical that people with disabilities and their representative organizations are not just included as beneficiaries, but are also included as partners in humanitarian action and response. This means involving them in the assessment, design, implementation, monitoring and evaluation of assistance programmes.

The cluster approach

Since 2005, there have been efforts to improve the effectiveness of international humanitarian response to crisis. The overall goal is to ensure that comprehensive needs-based relief and protection reaches more people in a more effective and timely manner. One of the major changes to humanitarian response is the development and implementation of the cluster approach.

The cluster approach strengthens coordination within and between sectors of humanitarian assistance (e.g. health, education, emergency shelter) by clearly defining their roles and responsibilities during a crisis. The cluster approach aims to make the international humanitarian community more structured, accountable and professional, so that it can be a better partner for governments, local authorities and local civil society.

At the global level, there are 11 clusters (see Table 1). Each cluster is led by an agency, e.g. the global health cluster is led by the World Health Organization (WHO), which is responsible for setting standards and policies, building response capacity and providing operational support. Within each cluster, there are a number of agencies and organizations which must work together to ensure a coordinated response during a humanitarian crisis, e.g. the global health cluster consists of over 30 agencies and organizations, such as the United Nations Children's Fund (UNICEF), the International Federation of Red Cross and Red Crescent Societies (IFRC) and Handicap International.

At the country level, when a humanitarian crisis occurs, some or all of these clusters may be activated; however, it is important to note that they may be called by different names, e.g. the clusters may be called sectors and led by different agencies. Membership at the country level is also open to all stakeholders supporting or providing services in the affected area, including donors. At the country level, clusters are responsible for ensuring inclusive and effective coordination to enable:

- needs assessment and analysis
- emergency preparedness
- planning and strategy development
- application of standards
- monitoring and reporting
- advocacy and resource mobilization
- training and capacity-building

The cluster approach is relevant to CBR programmes working in areas experiencing humanitarian crisis. CBR focuses on many different development sectors, i.e. the health, education, livelihood and social sectors to ensure that they are inclusive of and accessible to people with disabilities and their family members. The role of CBR programmes is no different during a humanitarian crisis. However, instead CBR programmes should focus on working together with each humanitarian cluster/sector at the national, regional and/or community level to ensure that the needs of people with disabilities and their family members are met. The cluster approach also provides opportunities for CBR programmes to access additional resources (e.g. financial or technical resources) for activities they wish to carry out in a crisis to support people with disabilities.

Table 1: Global humanitarian clusters

Cluster/area	Corresponding organization(s)
TECHNICAL AREAS:	
Health cluster	World Health Organization (WHO)
Nutrition cluster	United Nations Children's Fund (UNICEF)
Water, sanitation, and hygiene cluster (WASH)	UNICEF
Emergency shelter and non-food items cluster	Office of the United Nations High Commissioner for Refugees (UNHCR) for conflict situations and the International Federation of the Red Cross (IFRC) for disaster situations
Education cluster	UNICEF and Save the Children
Agriculture cluster	Food and Agriculture Organization of the United Nations (FAO)
CROSS-CUTTING AREAS:	
Camp coordination and management cluster	UNHCR and the International Organization for Migration (IOM)
Protection cluster	UNHCR
Early recovery cluster	United Nations Development Programme (UNDP)
COMMON SERVICE AREAS:	
Logistics cluster	World Food Programme (WFP)
Emergency telecommunications cluster	Office for the Coordination of Humanitarian Affairs (OCHA), UNICEF and WFP

Moving from crisis to development

In a humanitarian crisis, there is usually an influx of external organizations, as a result of which some people with disabilities may actually find themselves receiving better services than they did previously (*7*). Disability is a long-term development issue, therefore it is important that external organizations work in partnership with communities to ensure that there is capacity for continued action and sustainable development after they leave. As a strategy for community-based inclusive development, CBR programmes have an important role to play.

Suggested activities

The following activities have been structured around three broad areas: preparedness (activities and measures carried out in advance of a potential crises with the aim of reducing their impact), emergency response (the provision of assistance to meet the life preservation and basic subsistence needs of the people affected) and recovery (restoring or improving the living conditions that existed prior to the crisis).

Prepare people with disabilities for potential crises

There are many activities that CBR programmes can carry out to ensure that people with disabilities, their families and communities are prepared for a potential crisis, such as a natural disaster. These include the following:

- raising awareness in the community about the importance of including people with disabilities in preparedness activities, e.g. organize disability awareness training for local officials, disaster management committees, emergency personnel and community members;
- informing people with disabilities about preparedness planning processes in their communities and encouraging their participation, e.g. in disaster management committees;
- identifying and registering people with disabilities living in the community, noting where they live and what their needs will be during a crisis situation;
- ensuring copies of the above databases are kept in different locations (e.g. at the head office or with a partner organization) as information can often go missing in a crisis;
- informing people with disabilities about preparedness activities in their communities and encouraging their participation, e.g. in evacuation exercises/drills;
- providing advice to relevant stakeholders on making preparedness measures accessible, e.g. warning systems, evacuation procedures and emergency shelters;
- encouraging and supporting people with disabilities and their families to develop preparedness measures at home:
  - identify trusted people who can provide support during an emergency;
  - store extra essential medicines, e.g. epilepsy medication, equipment/materials (such as urinary bags for people with spinal cord injury, and assistive devices);
  - develop and keep updated information sheets on individual needs, e.g. medication and communication needs;
  - practise evacuation procedures, e.g. practise using evacuation roads to shelters.

Ensure emergency response is inclusive of people with disabilities

Find out about the current situation in the community

- Update the database of people with disabilities and make it available to relevant stakeholders involved in emergency response.
- Determine whether the services that existed in the community before the crisis are operational.

Establish partnerships with new humanitarian stakeholders

- Identify and make contact with new humanitarian stakeholders in the community.
- Determine their roles and responsibilities and what services and resources they can provide.
- Share information about the local context and current situation with a focus on people with disabilities.
- Assist them to identify and analyse the needs of the community, particularly people with disabilities.
- Assist them to identify and analyse the capacities of the community, particularly people with disabilities.
- Provide information about the capacity of the CBR programme, e.g. infrastructure, personnel available, existing partnerships, activities, etc.
- Establish referral mechanisms to make it easy to link people with disabilities to their services and supports.
- Discuss ideas with them about possible CBR activities and submit proposals to them to access resources through the relevant clusters/sectors.

Ensure people with disabilities and their families are well informed

- Provide outreach for people with disabilities to ensure that they are kept well informed and up to date regarding the situation.
- If possible, set up an accessible place in the community to provide information for people with disabilities and their families about the relief activities taking place and the support available.
- Ensure the participation of people with disabilities in developing and transmitting key information/messages.
- Ensure that all information and communication methods are accessible.

Suggested activities relevant to specific clusters/sectors

CBR programmes, together with people with disabilities and their family members, can ensure relevant stakeholders at the local, national and international level consider the needs of people with disabilities and include them in planning and implementation of humanitarian activities. Some suggested activities for CBR programmes that are relevant to each cluster/sector include the following.

Health cluster/sector

- Prioritize which people need health services (e.g. trauma care, basic first aid) and refer to appropriate services.
- Where people with disabilities need personal assistance, accompany them to health services.
- Organize replacement of lost/damaged assistive devices and provide new ones for people with newly acquired injuries/impairments.
- Provide follow-up and basic care and rehabilitation for people with injuries and disabilities.

Nutrition and logistics cluster/sector

- Assign volunteers to assist people with disabilities to access food distribution.
- Provide advice and assistance to humanitarian stakeholders to make food distribution processes accessible, e.g. separate queues, specific distribution locations, installation of makeshift ramps at distribution points.
- Ensure that appropriate food rations are available for people with disabilities who may have particular food needs, e.g. provision of foods that are easy to mash or puree for people who have difficulty chewing or swallowing.

Emergency shelter and non-food items cluster/sector

- Provide advice and assistance to humanitarian stakeholders to make temporary shelters accessible to people with disabilities.
- Provide advice and assistance to humanitarian stakeholders to ensure that people with disabilities are able to access blankets, tarpaulins, hygiene supplies, clothing and sanitary supplies.
- Take supplies directly to people with disabilities and their family members where necessary.

WASH cluster/sector

- Provide advice and assistance to humanitarian stakeholders to ensure that temporary latrines and toilet facilities are appropriate for people with disabilities.
- Provide advice and assistance to humanitarian stakeholders to ensure that water distribution points, wells, hand pumps, etc. are accessible for people with disabilities.
- Inform people with disabilities and their family members about when and where water sources and sanitation facilities are available.
- Provide information in accessible formats on the prevention of water- and sanitation-related diseases.

Education cluster/sector

- Ensure that education programmes are inclusive of children with disabilities.
- Support teachers and activity leaders with ways of including children with disabilities in activities.

Protection cluster/sector

- Raise awareness among all humanitarian stakeholders about disability and protection issues, including violence, exploitation and abuse, and discrimination especially regarding people with intellectual impairments and women and girls with disabilities.
- Provide advice and assistance to humanitarian stakeholders to maximize the safety of people with disabilities in temporary shelters, e.g. fence off areas that are unsafe, ensure sufficient lighting and reunite people with their families/caregivers as quickly as possible.
- Identify child-friendly spaces and other child protection measures and facilitate the inclusion of children with disabilities.
- Develop peer-to-peer activities and support creation of self-help groups (see Empowerment component: Self-help groups).
- Identify services offering psychosocial support and ensure they are inclusive of and accessible to people with disabilities and their families.

Early recovery, agriculture and protection clusters/sectors

- Provide means of livelihood (e.g. tools and seed capital) as soon as possible to enhance people's self-reliance.

Assist people with disabilities to restore and/or enhance their quality of life during the recovery phase

When a humanitarian crisis begins to stabilize, infrastructure gradually begins to be rebuilt and services start to be delivered through the normal processes or channels. A crisis can provide new opportunities for development (*11*) and CBR programmes should take advantage of these opportunities to ensure inclusive communities are "rebuilt". It is suggested that CBR programmes take the following actions.

- Continue to sensitize relevant stakeholders in the community, e.g. local authorities and mainstream development organizations, about disability and the needs of people with disabilities and their families.
- Provide information and resources about accessibility issues relating to housing, water and sanitation, schools, public buildings, transport, etc. to stakeholders involved in reconstruction – minimum standards, practical guidelines, examples of good practice and universal design principles will be useful.
- Work with the education sector to assist children with disabilities to return to school (see Education component).

- Work with relevant stakeholders to assist people with disabilities and their families to return to previous livelihood activities, and help identify new livelihood opportunities where necessary (see Livelihood component).
- Work with relevant stakeholders to ensure that people with disabilities and their families receive the necessary social support to rebuild their relationships with family and friends and make certain they are able to participate in community activities (see Social component).
- Support self-help groups organized by people who have experienced a crisis situation (see Empowerment component: Self-help groups).

BOX 22

Creating work opportunities through cooperatives

After a disastrous earthquake in Indonesia, many people became disabled or developed post-traumatic stress disorders and lost their sources of income. They decided to work together to change their situation. With assistance from the CBR programme, they established a cooperative society. A nongovernmental organization provided capital as well as technical assistance to the group. The cooperative provides loans and business advice for its members, who are involved in enterprises, such as brick-making, batik cloth-making and food selling. The cooperative has gradually expanded work opportunities in the community and increased members' income.

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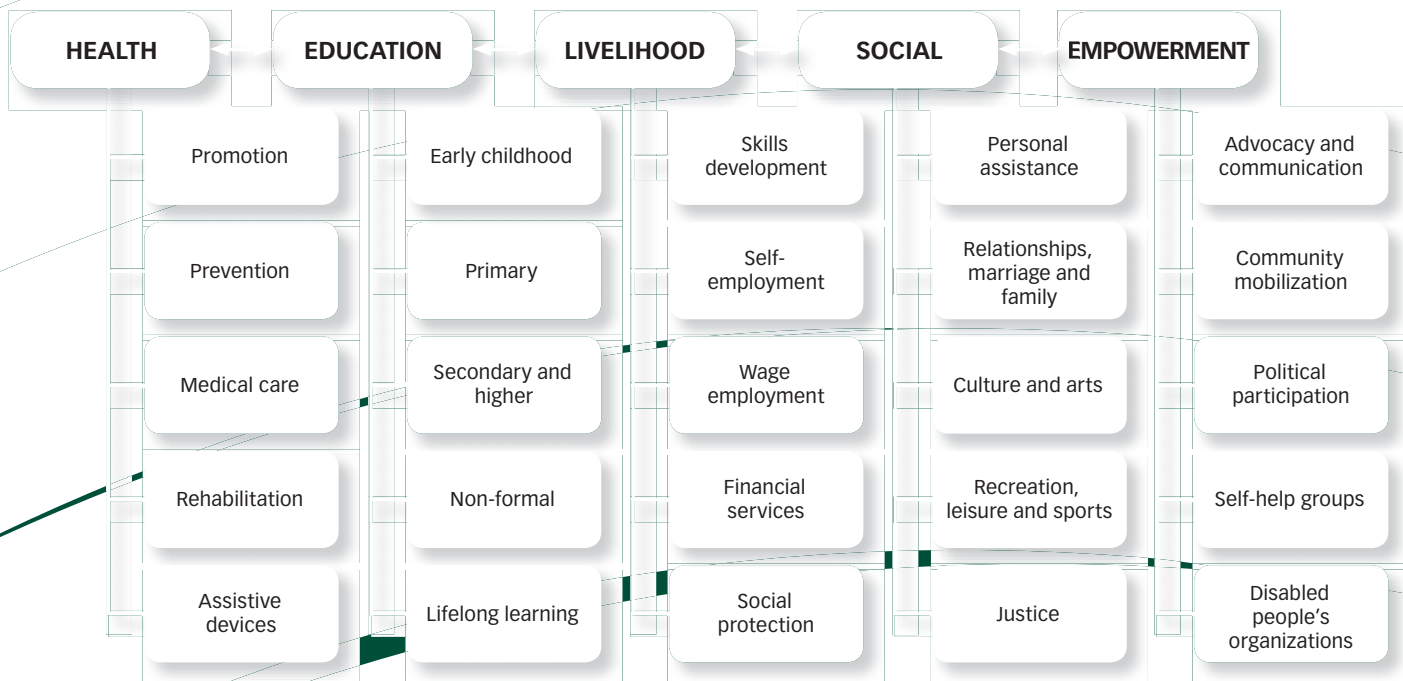
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HEALTH	EDUCATION	LIVELIHOOD	SOCIAL	EMPOWERMENT
Promotion	Early childhood	Skills development	Personal assistance	Advocacy and communication
Prevention	Primary	Self-employment	Relationships, marriage and family	Community mobilization
Medical care	Secondary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