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CBR Guidelines

Social component

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Preamble

Being actively included in the social life of one's family and community is important for personal development. The opportunity to participate in social activities has a strong impact on a person's identity, self-esteem, quality of life, and ultimately his/her social status. Because people with disabilities face many barriers in society they often have fewer opportunities to participate in social activities.

In the past, many community-based rehabilitation (CBR) programmes focused on health issues and rehabilitation activities, often ignoring the social needs of people with disabilities. Even today, topics such as relationships, marriage and parenting may be seen as too sensitive or too difficult to address, while access to cultural, sporting and recreation activities, and to justice, is seen as unnecessary. This component highlights the importance of these issues in the lives of people with disabilities and therefore the need for CBR programmes to address them.

Goal

People with disabilities have meaningful social roles and responsibilities in their families and communities, and are treated as equal members of society.

The role of CBR

The role of the CBR is to work with all relevant stakeholders to ensure the full participation of people with disabilities in the social life of their families and communities. CBR programmes can provide support and assistance to people with disabilities to enable them to access social opportunities, and can challenge stigma and discrimination to bring about positive social change.

Desirable outcomes

- People with disabilities are valued as members of their families and have a variety of social roles and responsibilities.
- People with disabilities and their families are encouraged and supported to contribute their skills and resources to the development of their communities.
- Communities recognize that people with disabilities are valued members, and can make positive contributions to the community.
- Barriers that exclude people with disabilities and their families from participating in social roles and activities are challenged and addressed.
- Local government authorities respond to the needs of people with disabilities and their family members and provide effective social support and services where required.

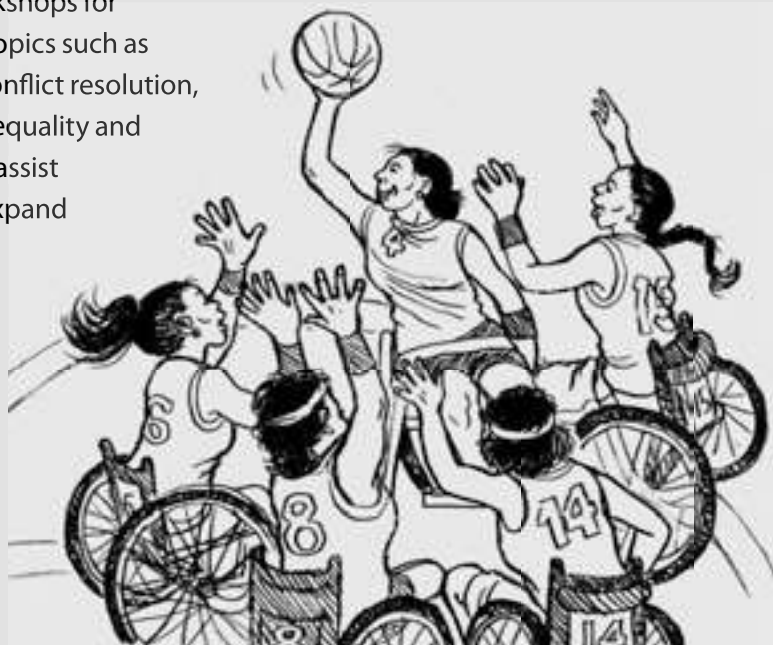
Ensuring participation from the whole community

Piña Palmera is a non-governmental organization working on the south coast of Oaxaca, Mexico. Piña Palmera started community-based rehabilitation activities in 1989, and today is active in seven rural communities and works closely with people with disabilities and their families to address their day-to-day needs. The organization also works closely with local authorities, teachers, public transport operators and local medical professionals to remove barriers and facilitate the social inclusion of people with disabilities in their communities.

Piña Palmera undertakes a number of activities which highlight elements of the CBR Social component. Piña Palmera provides personal assistance to people with disabilities, particularly children with disabilities and people with severe or multiple impairments. This assistance is provided by staff members or volunteers and includes assistance with personal hygiene, travel in the community and social activities. Where needed personal assistance is also available for staff members with disabilities to enable them to carry out their work activities.

Piña Palmera encourages people with disabilities to participate in recreation, leisure and sports activities. The organization works in collaboration with people with disabilities and local sports people to provide resources and organize local community activities and events where both disabled and non-disabled people participate. Assistive devices and adapted sporting equipment are provided where necessary to enable people with disabilities to participate. Several people with disabilities have gone on to participate in the national wheelchair basketball team.

Piña Palmera organizes workshops for people with disabilities on topics such as effective communication, conflict resolution, teamwork, respect, gender equality and sexuality. These workshops assist people with disabilities to expand their social networks. When needed Piña Palmera also provides advice regarding legal rights in simple language to ensure that people with disabilities are able to defend themselves against any acts of injustice.



Key concepts

Social roles

What are social roles?

Social roles are the positions people hold in society which are associated with certain responsibilities and activities. Different types of social roles include those related to relationships (e.g. husband, wife, mother, father, brother, sister, friend), work (e.g. teacher, community worker, farmer), daily routine (e.g. cleaner, cook), recreation and sport (e.g. football player, card player), and community (e.g. volunteer, community leader). The social roles people hold are influenced by factors such as age, gender, culture and disability. People's social roles change throughout their lifespan, and many communities mark these transitions with important rituals and practices.

Why social roles are important

Social roles are important as they give identity and meaning to life. A person's social status is influenced by the different social roles he/she has within the community. For example being a husband/wife, parent and/or wage earner may be highly valued and therefore will have a positive impact on social status, whereas being unmarried, childless and/or unemployed may be less valued and have a negative impact on social status. When people with disabilities have the opportunity to fulfil positive social roles in their communities, attitudes towards disability can change. For example, the successful inclusion of a child with disability in school, or an adult with disability in work, can be a powerful means to change social attitudes towards people with disabilities.

Supporting people with disabilities to secure valued social roles

There are many different ways in which people with disabilities can be supported to achieve valued social roles. Assisting people with disabilities to improve their skills and abilities, promoting positive images of people with disabilities in the community, and working to change negative attitudes are all helpful (see Empowerment component).

Barriers to social participation

A wide range of barriers may restrict the social participation of people with disabilities. For example:

- people with disabilities may have poor self-esteem and think that they do not deserve or have the ability to take part in activities and events;
- family members may feel that having a member with a disability brings shame, and so they do not encourage or allow this person's social participation;
- community members may have irrational thoughts and beliefs about disabilities, e.g. that holy places are defiled by a person with a disability, that people with disabilities

are cursed and need cleansing, that people with disabilities have supernatural or evil powers;

- physical barriers to social participation include inaccessible transport and buildings, e.g. community centres, sporting venues and cinemas.

BOX 2

Physical barriers to participation

“Once in a while we’d like to see a movie in the theatre, but there is no access for wheelchairs. We cannot sit in the given seat, as there is no space in front of it. If we ask, nobody listens to us” (1).

Gender equality

Women with disabilities in low-income countries often have limited opportunities to participate in certain social roles, e.g. parenting. Some families may be over-protective and prevent the woman with disabilities from participating in any social activities outside the home. In addition, while gender equality is an important aspect of development, women and girls with disabilities are often excluded from mainstream development programmes. Women with disabilities are seldom actively involved in decision-making processes, and are underrepresented, e.g. in women’s groups, where their concerns may be mistakenly believed to be different from those of other women. Girls with disabilities are also less likely to be included in youth or recreational programmes.

Children with disabilities

Safe and loving environments are essential for all children, including those with disabilities, who need to receive love and affection, stimulation and opportunities for learning and development. CBR programmes can play an important role in promoting the rights of children with disability and supporting families to challenge stigma and discrimination that may prevent children with disabilities from participating in family and community life.



Elements in this component

Personal assistance

Some people with disabilities require personal assistance to enable them to participate in family and community life. In low-income countries where there are limited social services and benefits, families are often the main or only means of this support. While formal options are often very limited, this element shows how CBR programmes can utilize community resources to ensure people with disabilities and their families are able to access a range of different options for personal assistance which are appropriate to their individual needs and preferences.

Relationships, marriage and family

Relationships are as important for people with disabilities as for everyone else. This element looks at the ways in which CBR programmes can support people with disabilities to enjoy a variety of social roles and responsibilities associated with relationships. By working closely with a range of stakeholders in the community, CBR programmes can help to increase awareness about disability, challenge negative family and community attitudes, and prevent and address violence against people with disabilities.

Culture and arts

Participation in cultural and arts activities is important for personal growth and development. It helps to establish personal identity, and to provide a sense of belonging as well as opportunities for people with disabilities to contribute. This element identifies and addresses barriers that exclude people with disabilities from participating in the cultural and artistic life of their families and communities. It also explores the role that culture and arts can play in challenging stigma and discrimination directed towards people with disabilities, and in promoting diversity, inclusion and participation.

Recreation, leisure and sport

Recreational, leisure and sporting activities are important for health and well-being and for strengthening the cohesion of the community. This element looks at the benefits these activities can have for people with disabilities and provides practical suggestions about how CBR programmes can work with a range of stakeholders to increase opportunities for the inclusion and participation of people with disabilities. The value of working directly with stakeholders to plan and develop programmes and activities that are appropriate and responsive to the local community is highlighted.

Justice

All community members may need to access justice at some point in time. At a local level it is important to be aware of existing laws that can be used to ensure people with disabilities are able to access their rights and entitlements as outlined in the Convention on the Rights of Persons with Disabilities (2). This element focuses on how CBR programmes can support people with disabilities to claim their rights by raising their legal awareness and facilitating their access to a range of legal processes to challenge injustices.



Personal assistance

Introduction

Some people with disabilities may require personal assistance to facilitate their full inclusion and participation in the family and community. Personal assistance may be necessary because of environmental factors (e.g. when the environment is inaccessible), and because people with disabilities may have impairments and functional difficulties that prevent them from carrying out activities and tasks on their own.

Personal assistance may enable a person with disability to get up and go to bed when he/she wants, eat what and when he/she wants, complete household tasks, attend social events outside the home, access education, earn an income, and care for the family.

Personal assistance can be provided through informal means, such as family members and friends, or through formal means, such as private employees or social services. While funds for formal support systems are often limited in low and middle-income settings, more governments are developing social protection schemes, e.g. in Brazil, India, South Africa, and more recently Bangladesh. As these systems develop it is hoped there will be greater opportunities for CBR programmes to support people with disabilities to access personal assistance (see Livelihood component: Social protection).

BOX 3

Convention on the Rights of Persons with Disabilities, Article 19: Living independently and being included in the community (2)

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Assistance when needed

Jae-Hwan is a 13-year-old boy from Seoul, Republic of Korea. He lives with his grandmother, sister and two cousins. He was diagnosed with muscular dystrophy when he was four years old. By the time he was nine he was unable to walk independently and unable to attend school, and had become depressed.

The CBR programme first made contact with Jae-Hwan Kim when he was 13 years old. They referred him to the National Rehabilitation Hospital where he was able to access medical rehabilitation and therapy. He also received a powered wheelchair with special seating from the Assistive Technology Research and Assistance Centre (ATRAC). Once his condition became stable he wanted to go back to school. However, he was not able to do this without personal assistance.

A social worker from the hospital linked Jae-Hwan with a volunteer from a university who provided assistance to enable him to complete the elementary school curriculum. He was also linked to a local nongovernmental organization who organized volunteers to read books with him every week and assist him to draw and sketch. Assistance was provided to modify the family home so it was wheelchair accessible and a volunteer was also sent on a regular basis to assist Jae-Hwan's grandmother with household tasks such as cleaning. Jae-Hwan also became a member of a self-help group run by the Korea Muscular Dystrophy Foundation (KMDF).

Jae-Hwan's situation improved because of cooperation between the CBR programme, the National Rehabilitation hospital, KMDF, ATRAC and other local nongovernmental organizations. Social workers and local volunteers also played an important role in ensuring he was able to access support for his personal assistance needs.



Goal

People with disabilities are able to access personal assistance which meets their needs and enables them to lead active and fulfilling lives.

The role of CBR

The role of CBR programmes is to support people with disabilities to access and actively manage the personal assistance necessary to live their lives with self-determination and dignity.

Desirable outcomes

- CBR programmes and disabled people's organizations work together to ensure personal assistance options of an appropriate quality and standard are available in the local community.
- People with disabilities have individual support plans in place.
- People with disabilities have access to training to enable them to manage their personal assistance needs.
- Training is available for both informal and formal personal assistants.
- Support is available for families who provide personal assistance on an informal basis.
- Mechanisms are in place in the family and community to respond to crisis situations and prevent people with disabilities being sent into institutional care.
- Local communities support and provide community-based personal assistance options for people with disabilities.

Key concepts

Institutional care vs. independent living

Over a number of decades, high-income countries have moved away from "institutional care" to "independent living". Independent living does not mean that people with disabilities do everything by themselves. It means they live their lives with the same choices and control as people without disabilities. People with disabilities are seen as the best experts regarding their needs and therefore should be in charge of their lives, and think and speak for themselves, as does everybody else. Personal assistance is one of the keys to moving away from institutional care towards independent living for people with disabilities.

BOX 5

Personal assistance for independent living

The Independent Living Movement (ILM) is an international movement that advocates that people with disabilities need to enjoy the same degree of interdependence within the family that is common for non-disabled siblings, friends and neighbours in a given culture. This applies particularly to people with high support needs whose survival depends on the practical assistance of other people for activities of daily living, such as getting dressed, going to the toilet, eating, communicating and structuring the day.

The term “personal assistance” is used by the ILM for the activities mentioned above only if the individual user has the power to decide what tasks are to be delegated, and to whom, and when and how they will be carried out. This control is only possible if users have the financial means to buy services from service provider(s) of their choice and/or to employ people of their choice (including family members) as assistants. As people with disabilities and their families typically do not have the necessary economic resources, government payments are required. Some people, e.g. children with disabilities or people with intellectual impairments, may require support to exercise this control.

Personal assistance tasks

Personal assistance is not only about supporting people with intimate personal tasks. It may also involve supporting them with a variety of tasks in different environments – in homes (assistance with parenting and caregiver tasks), schools, workplaces, community settings (e.g. travelling, shopping, banking) and emergency/respite services. Regardless of whether personal assistance is provided through informal or formal means, it is important that it is of a quality and quantity that appropriately supports the person with disabilities to fully participate with dignity in family and community life.

Understanding the “personal” in personal assistance

The word “personal” in personal assistance is used to reflect that each person is different and has a unique set of needs. Personal assistance is about finding solutions which suit the individual. Different levels of assistance (i.e. no assistance, partial assistance or full assistance) may be required for different tasks and at different times, as needs will change depending upon individual circumstances, e.g. changes in social roles or changes in health status. It is important that the right balance is achieved for each individual.

The importance of control

Personal assistance is often viewed as something that is done to and for a person with disability, such that the person becomes a passive recipient. This thinking is no longer acceptable; it is now understood that people with disabilities must have the freedom to control the direction of their lives and therefore they need to be at the centre of decision-making about their personal assistance needs (see Box 5).

Support options

Informal assistance

Worldwide, most support to people with disabilities takes the form of informal assistance (3). Family members, friends, neighbours and/or volunteers may provide this informal assistance.

Formal assistance

Personal assistance may also be provided on a formal basis. Many different types of formal support services are offered in high-income countries, and increasingly also in low-income countries (3). These services may be provided by governmental and nongovernmental organizations and the private sector. As more budgets become decentralized, funds for support services may become available through local authorities, such as ministries of social welfare. Allowances, such as disability pensions, guardianship awards or caregiver allowances, may be available to fund personal assistance.

Challenges

Limited options in low-income countries

Different challenges are associated with the provision of personal assistance in high-income and low-income countries. When trying to ensure that people with disabilities are able to access personal assistance options in low-income countries, CBR programmes may face challenges, such as:

- little awareness about and demand for personal assistance by people with disabilities, their families and disabled people's organizations;
- scarcity of programmes that provide training and support for personal assistants;
- no social protection policies and programmes in place to support personal assistance, e.g. disability allowances, grants or pensions (only in a few low-income countries);
- few nationally agreed definitions and standards of personal assistance and procedures to monitor.

Crisis situations

When support systems break down, people with disabilities can be faced with a crisis situation. In some cases it may mean they are sent to an institution, often against their will. In low-income countries where personal assistance is most often provided by families, there are many reasons why support can break down. For example, if a family member dies, there may be conflict within the family or financial problems. In some situations, families may simply be too exhausted due to the burden and stress associated with providing personal assistance with little access to support and training. Given the role of informal support for people with disabilities, and the central place of the family in many cultures, the services provided to families with members with disability are of considerable importance (3).

Vulnerability and the risk of abuse

People who need support services at any point in their lives are usually more vulnerable than those who do not (3). It is particularly difficult for people who are being abused to report or change their situation when their abuser is also their personal assistant (see Relationships, marriage and family).

Suggested activities

Work in partnership with disabled people's organizations

In many situations it can be difficult for people with disabilities to advocate on their own to ensure their personal assistance needs are met. However, when people with disabilities work collectively it is often easier for them to bring about change. It is important that CBR programmes recognize the role of disabled people's organizations in establishing options for personal assistance and work with them to:

- promote and develop agreed standards for personal assistance;
- ensure that local information is available on personal assistance options for people with disabilities;
- create options for personal assistance where services do not exist in the community;
- support the development and monitoring of appropriate personal assistance services for people with disabilities;
- ensure people with disabilities, particularly those with severe and/or multiple impairments, are linked to disabled people's organizations and self-help groups.

Transforming lives with customized personal assistance

In Serbia, after a consumer-controlled personal assistance service was established for the first time, the lives of many individuals were transformed on a personal level, and people with disabilities were mobilized to act collectively. As a result of the service, for example, one user has become an active disability leader. Whereas previously his life was limited to reading at home with only sporadic visits outside, now, with the support of his personal assistant, he travels three times a week to lead a disabled people's organization in planning and activities. This disabled people's organization has successfully advocated and mobilized the community to establish a local branch office for independent living for people with disabilities. The office space has been provided by the local municipality.

Assist people with disabilities to develop individual support plans

It is important to ensure that personal assistance is appropriate to the social and cultural context and sensitive to gender and age-related needs. CBR programmes can assist people with disabilities to:

- identify which tasks require assistance, being careful not to make assumptions about what these might be;
- review the different personal assistance options available in the local area – it might be a good idea to trial the different options available to see what works best;
- communicate to their personal assistants which tasks require assistance, when these tasks need to be completed, and how they need to be performed;
- put in place written agreements regardless of whether personal assistance is provided by paid staff or volunteers;
- review personal assistance needs at regular intervals and make modifications to plans where there have been changes in health status, daily activities or environment.



Planning for personal assistance

In the Philippines, a national disabled people's organization has developed a multisectoral programme in partnership with the Department of Education and a parents association. A major role of this programme is to provide training to parents and teachers in the provision of personal assistance to children with severe impairments to enable them to attend local mainstream primary schools. The programme works with over 13 000 children in rural areas and undertakes joint training workshops with pre-school children, parents and teachers to ensure that there are agreed support plans for each child. The programme was successful in preparing and including children with high support needs to attend mainstream primary schools alongside their peers.

Support training opportunities

People with disabilities may need training to assist them to gain the confidence and skills to identify and manage their personal assistance needs. Personal assistants may need training to assist them to develop the skills to meet their roles and responsibilities.

For people with disabilities

To ensure people with disabilities receive personal assistance of good quality they need to be able to express their needs and expectations. CBR programmes can support people with disabilities to:

- access appropriate training to develop communication and assertiveness skills (see Empowerment component: Advocacy and communication);
- access information about personal assistance;
- learn the best ways to identify, arrange and manage their personal assistance requirements;
- learn how to effectively negotiate their personal assistance needs within their families, communities, schools and workplaces.

Opportunities for training may be available through a number of sources including disabled people's organizations, local government services, training institutes, non-governmental organizations, CBR programmes and/or other experienced personal assistants. Disabled people's organizations and self-help groups are often the best source of support, information and training for people with disabilities regarding the management of personal assistance. Where disabled people's organizations or self-help groups do not exist in communities it may be helpful for CBR programmes to link people with disabilities and their family members with other people in similar situations.

For personal assistants

It is important for personal assistants to be confident and competent in their roles and responsibilities. In many situations personal assistants, particularly those who provide support on an informal basis, will not have received any training for the tasks they carry out. Training is important for personal assistants to assist them to:

- understand the importance of their role;
- develop an awareness of their boundaries;
- effectively listen and respond to the needs of the person they are assisting;
- develop the skills necessary to carry out tasks as requested;
- manage their time and tasks, especially when they have other roles and responsibilities.

People with disabilities may need support to train their assistant; CBR programmes, disabled people's organizations and self-help groups can be a good resource in these situations. Other training programmes may also exist in the community and should be investigated.



Ensure families are supported in their roles as personal assistants

Family members who provide personal assistance often do so in addition to their other roles and responsibilities. This often leaves them exhausted with little time for their own needs. Often too, family members have no means of support for themselves. CBR programmes can provide support for family members by:

- identifying options for emergency back-up or respite support;
- linking them with other families who are in a similar position, e.g. through self-help groups, disabled people's organizations, parents' or family organizations;
- listening and talking with them about their concerns, and working with them to find solutions to better manage their personal assistant roles;
- including families in training opportunities so they can learn coping strategies;
- ensuring that younger members of the family who carry out personal assistance roles are still able to attend school and have time for recreation.

Prepare for and manage crisis situations

When support systems break down, the needs of people with disabilities must continue to be met. It is essential that CBR programmes plan in advance with other stakeholders to ensure they are prepared to respond to a crisis. Communities are a rich source of support and can provide resources and flexible options especially during times of crisis. Community solutions will usually be the most appropriate and effective in both the immediate and longer term. It is helpful if CBR managers can work with disabled people's

organizations and local authorities to agree upon strategies for managing a crisis in advance. Some possible options to explore before a crisis happens are:

- Is there a response team that can be called? This team might include a social worker from a local authority, a trained representative from a disabled people's organization, a local law enforcement officer, and a CBR staff member.
- Are there temporary facilities in the community that can be used? Options might be available in facilities that offer respite care or rehabilitation.
- Is there a safe hostel in the community for supporting women or girls who have experienced sexual abuse or domestic violence? These facilities need to be modified if necessary to ensure access for women and girls with disabilities.
- Do social workers who support families in crisis situations also have training in disability? If not, can disabled people's organizations and CBR programmes support this training?
- Can members of the extended family provide temporary support until long-term solutions are found?
- Can disabled people's organizations and CBR programmes identify families who are willing to provide support and care for other families experiencing a crisis?
- Are self-help groups available for both people with disabilities and family members?

During a crisis situation, families and people with disabilities may need the assistance and support of an external facilitator. CBR programmes can fulfil this role directly or indirectly by providing links to, for example, disabled people's organizations, self-help groups or social welfare programmes. When an agreeable solution cannot be found, and especially where an individual is in danger of personal risk, it is important to defuse the crisis and find alternative living solutions.

Encourage a move away from institutional care

Traditionally people with disabilities who needed a high level of support for personal assistance were sent to institutions. While this situation is changing, institutions do still exist in many countries, and for some people with disabilities they may be their only option. It is important that CBR programmes and disabled people's organizations work together to explore the best future options for people with disabilities with these institutions and the relevant government departments.

Countries that have moved away from institutional care have successfully converted their institutions into alternative facilities, such as:

- vocational training and resource centres;
- rehabilitation centres;
- independent housing where people with disabilities can live independently with some support available as needed;
- respite accommodation where people with disabilities stay for short breaks while family members take a break from their roles as personal assistants;
- emergency accommodation for all members of the community, and not just for people with disabilities, who are vulnerable to violence.

Relationships, marriage and family

Introduction

Relationships, marriage and family are at the core of every community. Families are universally recognized as an important source of support and security. They can provide safe and stable environments which nurture the growth and development of each member throughout the different stages of life, from birth to old age.

Families are diverse and influenced by a range of factors including cultural, traditional and religious practices. Families may be classified as nuclear, extended, single-parent, child-headed, foster, or adoptive. It is important to recognize this diversity and also to recognize that people with disabilities have a right to establish their own families. Article 23, from the Convention on the Rights of Persons with Disabilities, highlights that “States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others” (2).

This element highlights the importance of supporting people with disabilities to establish relationships, marry and become parents if they choose. It also highlights the issue of violence that people with disabilities may experience within their relationships, marriages and families, and the importance of recognizing and addressing this issue.



A courageous journey to motherhood

“I am over forty years now and I am proud that I have fought every inch to become what I am. While growing up, I kept on dreaming that I would have a baby of my own because all my sisters were married and had their own. They used to send their children to assist me doing daily chores but could not let them sleep at my house. I was working and staying in my own house as an independent person, but was still treated like an infant. At night I used to feel so lonely, had no one to talk to, no one to bring me water, no sharing of food. That was horrible!!

At the age of 25 I got pregnant. This news brought shock to my sisters, aunts and uncles, because that was the last thing they ever expected of me...I was told delivering a child was another horrible thing that I could not face due to my disability....The sad news I got was that I should abort the pregnancy because all my sisters had gone through child delivery and they thought I could not manage to go through the process. They frightened me by saying that ‘if able-bodied women die during delivery, who are you to try that?’ They even sent a message to the man who was responsible for my pregnancy and threatened to take him to the police. I told them that the gentleman admitted he did not follow the right procedure but accepted to take me as a wife.

Arrangements were done by my sisters together with my aunt to take me to the hospital for abortion, but what they did not know was that I had made up my mind to keep the pregnancy and that I was eager to see a child of my own. I privately went to see a doctor for counselling and advice on the pregnancy. I was assured by the doctor that it was possible for me to deliver a healthy baby.

Time came when I gave birth to a beautiful baby girl. This became the time of joy and reconciliation to the whole family. They were all happy and became very supportive. Few years later I got married to the man and had a handsome baby boy. I am a happy mother of these two children. The girl is now 18 years old and the boy is 14 years old. My children are very accepting and comfortable that I am their mother.

This is a personal experience on how I struggled to become a parent with disability. All one needs is courage! I made up my mind and became strong. According to my personal experience, I have seen that motherhood for a woman with disability is undesirable to the non-disabled society. What everyone needs to know is that the decision to have a child or not, or adopt a child is the right and responsibility of every person including a person with disability.

— Julian Priscilla Mabangwe, Malawi Council for the Handicapped (3).



Goal

People with disabilities fully realize their positions and roles within their families and communities.

The role of CBR

The role of CBR is to support people with disabilities to have fulfilling relationships with members of their families and communities.

Desirable outcomes

- Community members are aware and accept that people with disabilities can have meaningful relationships, marry and have children.
- Parents with disabilities and parents of people with disabilities have access to appropriate services and programmes to support them in their parenting roles.
- Families encourage and support their members with disabilities to socialize and develop relationships outside the home.
- People with disabilities are protected against violence, and all relevant stakeholders work together to address the issue.
- People with disabilities who have limited social networks are well supported in their communities.

Key concepts

Relationships

Fulfilling personal relationships are important to everyone and are essential for personal growth and development. Stimulating, lasting and satisfying relationships with family, friends and partners are a high priority for most people, including people with disabilities.

Family

Belonging to a family

The word “family” can mean different things to different people. Families come in many shapes and sizes but something that they all have in common is that they provide a sense of belonging. Families can also provide an environment for learning and development and provide safety and security for children and vulnerable family members including people with disabilities.

Family responses to disability

Every family responds differently to disability. One family may find it difficult to accept the birth of a child with an impairment, but another may simply be afraid and need more information about what the future holds, while a third may celebrate the birth of their child.

Families can be effective advocates and powerful agents of change to ensure the inclusion of people with disabilities. They can have a positive influence on the expectations of family members with disabilities and also influence the attitudes of the community.

Sexuality

Sexuality is an important part of health and well-being. However, in many societies discussion of the subject is sensitive and even taboo, particularly as it relates to disability, around which myths and misconceptions may go unchallenged. For example, people with disabilities are often viewed as being asexual, infertile, or as having overly high sex drives; these views may not only be held by community members but also by medical professionals and in some case people with disabilities themselves. It is important to be aware that people with disabilities have sexual needs, as does everyone else. The unfortunate reality is however that these needs are either ignored or denied (see Supplementary booklet on CBR and HIV/AIDS).

BOX 9

Uganda

Misconceptions

A female youth member of a disabled people's organization in Uganda, the National Union of Disabled Persons of Uganda (NUDIPU), noted "We are not invited to these community outreach programmes which are always held at health centres....in fact, people think that we are not sexually active because we are disabled".

Marriage and parenthood

It is often assumed that people with disabilities will automatically have children with disabilities. There is also a common belief that people with disabilities will not be able to care for and support their children independently. In extreme cases, people with disabilities, particularly adolescent girls and women with intellectual impairment, have been sterilized without their knowledge or consent. The Convention on the Rights of Persons with Disabilities, Article 23, refers to marriage and parenthood, to the rights of persons with disabilities to: marry and found a family, decide freely and responsibly on the number and spacing of their children, have access to age-appropriate information, reproductive and family planning education, and to retain their fertility (2).

BOX 10

Wanting a family

“I have a dream of getting married, having a home with children, but my parents told me that marriage is not for me because I would not be able to look after a family. I was shattered with disbelief” (5).

Violence

Violence can occur in every part of society, within families and institutions, and in schools, workplaces, and the community; many different people are responsible. People with disabilities are disproportionately susceptible to violence, particularly because of stigma, negative traditional beliefs and ignorance; they are at increased risk of becoming victims of physical, sexual, psychological and emotional abuse, neglect, and financial exploitation. Women with disabilities may be particularly exposed to forced sterilization and sexual violence (6).

Suggested activities

Challenge and address stigma, prejudice and discrimination

Negative attitudes, perceptions and practices towards people with disabilities are present in many communities. CBR programmes can challenge and address these by:

- working with the media to promote positive images and role models of people with disabilities;
- supporting disability awareness training for health professionals to ensure that sexual and reproductive health services, e.g. family planning, are accessible to people with disabilities;
- working with leaders in the community, e.g. religious leaders, to encourage them to create awareness about disability, challenge stigma and discrimination, and create opportunities for community discussions about sensitive issues.

Exploring sexuality and disability issues

A CBR programme managed by a local nongovernmental organization in Liberia realized they had never addressed issues related to sexuality and disability. The programme set out to learn about these issues by holding discussions with people with disabilities. Discussions with women with disabilities showed that being able to express their sexuality was important; however, they were often fearful of doing this. They also thought that sex was important for them so they could become mothers, which was a valued social role in their communities. In some instances non-disabled men had sexually abused women with disabilities. It was perceived that this abuse was caused by negative attitudes towards disability that resulted in men thinking that a public relationship with a woman with disabilities would stigmatize them.

Provide support for parents

To enable parents to make good parenting decisions, access to information and support is needed. CBR programmes should consider both parents with disabilities and parents of people with disabilities. They can provide support by:

- identifying local services that can provide support to parents, e.g. in sexual and reproductive health, maternal and child health, and family support;
- advocating with disabled people's organizations and other organizations for the inclusion of parents with disabilities, and parents of people with disabilities, in mainstream services and programmes;
- developing and supporting referral systems to facilitate access for people with disabilities, especially women and adolescents, to services and programmes;
- working with service providers to distribute accurate information on sexual and reproductive health in accessible formats through CBR networks.



Work with families to promote independence

Sometimes families overprotect their members with disabilities by sheltering them in the home and preventing them from socializing in the community, thus limiting their opportunities to develop relationships with others or to develop various skills and abilities. CBR programmes can work with families to:

- provide information and support to address their concerns regarding their members with disabilities, as well as for their own position and status within the community;

- help families to recognize the negative consequences of overprotection;
- encourage family members to become advocates for changing negative attitudes within the community;
- support people with disabilities to effectively communicate and self-advocate for their own needs and wants.

Help to prevent violence

Violence of any type can be a challenging issue for CBR personnel. As CBR programmes work across different environments (e.g. homes, schools, workplaces, communities) they are in a good position to ensure that strong social networks and supports are in place to protect people with disabilities from violence (see also Justice). CBR programmes can:

- build the capacity of CBR staff to recognize the signs and symptoms of violence, ensuring they know where to access appropriate legal advice and support for people with disabilities;
- raise awareness within communities about violence and disability and about actions that can be taken to protect people with disabilities;
- establish links with relevant stakeholders (e.g. families, disabled people's organizations, health-care/education personnel, law enforcement officers, community leaders, local authorities), and talk to them about their role in protecting people with disabilities from violence;
- develop procedures with stakeholders which enable people with disabilities to report episodes of violence in confidence;
- provide information about violence to people with disabilities and ensure they know how they can report episodes of violence confidentially;
- ensure people with disabilities have opportunities to participate in community life to increase their self-esteem and confidence, and develop social networks which will help protect them from violence;
- support people with disabilities who have experienced episodes of violence by talking with them, assisting them to access health-care services, and assisting them to develop solutions and take action;
- ensure that programme and organizational policies are in place to check that CBR staff and volunteers have no criminal history of violence.



Support people with limited social networks

Some people with disabilities may not have families, or their families may not be able to provide them with the support and assistance they need. So some people with disabilities live in residential institutions, hostels, religious communities or sheltered housing, or are homeless. In these situations, CBR programmes can:

- link people with disabilities to appropriate support networks in the community, e.g. disabled people's organizations and self-help groups;
- work with residential institutions to ensure people with disabilities are still able to participate and be included in community life;
- support people with disabilities to access their preferred living arrangements;
- support people with disabilities who are homeless to find appropriate accommodation, preferably in the community;
- watch for any indications of violence in the settings in which people with disabilities live.



Culture and arts

Introduction

The word “culture” has many different meanings. In this element however, it is used to refer to the way of life of a group of people. Culture therefore includes many things, such as dress, food, language, values and beliefs, religion, rituals and practices. The arts are also closely associated with culture and include painting, music, dance, literature, film, photography.

Some may believe that including people with disabilities in the cultural and artistic aspects of their community and supporting them to take part is unnecessary. Creativity, self-expression and spirituality are often seen as unimportant for people with disabilities. For example, while many families may make an effort to take a relative with disabilities to the health services, they may not think it is important to take him/her to local cultural events.

The opportunity to participate in cultural life is a human right (see box below) which benefits individuals, families, communities and societies as a whole.

BOX 12

Convention on the Rights of Persons with Disabilities, Article 30: Participation in cultural life, recreation, leisure and sport (2)

1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities enjoy access to a) cultural materials in accessible formats; b) television programmes, films, theatre and other cultural activities, in accessible formats; c) places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services.
2. States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential.
3. States Parties shall take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access.
4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

Using art to make rehabilitation fun for children

FANDIC (Friends of Children with Disability for their Integration into the Community) is a foundation in Bucaramanga, Colombia that works with children with disabilities. Their mission is to integrate children with disabilities into society through CBR. One of their projects, a dance project for children with disabilities, aims to:

- provide opportunities to develop physical and artistic abilities
- encourage team work and integration
- increase awareness about disability at various levels including the individual, community, organizational and governmental.

Twelve children, aged 5–21 years, with physical and intellectual impairments participate in the dance group. Their brothers and sisters are also encouraged to participate to promote family involvement and integration. Once a week a professional dancer is contracted to teach the children, and throughout the remainder of the week, volunteers practice with them. The children are taught simple dances, which with time, progress to more complicated ones. In addition to dancing, the children also perform stretching and strengthening exercises and participate in other social activities. The children are always encouraged with love, enthusiasm and positive feedback so they develop confidence in their own abilities.

FANDIC has found that dance has proved to be an excellent strategy for:

- making rehabilitation a fun activity for children with disabilities
- improving the function of children with disabilities
- creating opportunities for communication and socialization
- improving relationships between children with disabilities, family members and others
- breaking down attitudinal barriers.



Goal

People with disabilities contribute to and participate in the cultural and artistic lives of their families and communities.

The role of CBR

The role of CBR programmes is to work with relevant stakeholders to enable people with disabilities to enjoy and participate in cultural and arts activities.

Desirable outcomes

- Stigma and discrimination towards disability is challenged and addressed through culture and art.
- People with disabilities and their family members participate in a range of cultural and arts events and activities.
- Mainstream organizations and groups support the inclusion of people with disabilities in their cultural and artistic programmes and activities.
- People with disabilities are able to access mainstream cultural/arts media and venues.
- Spiritual and religious leaders and groups include people with disabilities in their activities.

Key concepts

Types of participation

There are many ways in which people with disabilities can be included in the cultural and artistic life of their families and communities. They can be active participants, e.g. directly involved in producing, directing, writing and performing, or they can be passive participants, e.g. enjoying a drama, watching a film, or wearing traditional dress.

Benefits of participation

Participation in cultural and arts activities not only entertains but also teaches individuals about who they are. The process of participating can be empowering for individuals, it can help them find their own voice and be heard by others. It also has many health benefits. For some people with disabilities, cultural and arts based activities may be the only means through which they can fully represent themselves on their own terms and on an equal basis with others.

The presence of cultural and arts activities in the community contributes significantly to the well-being of its members. These activities can develop and strengthen relationships

within and across communities, build capacity within the community, and promote community development and regeneration. The involvement of people with disabilities in the cultural and artistic aspects of their communities is often a good indicator that community members have positive attitudes towards disability.

Culture and art as a means to promote social change

The arts have traditionally been seen as a non-violent way for people to challenge and question oppressive or discriminatory practices. Often it is one of the few safe avenues where marginalized people can find a voice and highlight sensitive or taboo subjects. People with disabilities have often used the arts to challenge mainstream representations of disability issues. Art can be a means for people with disabilities to portray a more inclusive way of looking at the world.

BOX 14

Bangladesh

Seeing in the dark (7)

The successful *Seeing in the Dark* art exhibition took place at the Dhruvad Gallery in Dhaka, Bangladesh, December 2003. The exhibition was a joint collaboration between Social Assistance and Rehabilitation for the Physically Vulnerable (SARPV) and Healthlink Worldwide as part of a communicating-for-advocacy project. A working group of 25 people with visual impairments and five people with physical impairments and an international artist were also involved in creating the exhibition. It was more than just an art exhibition; it simulated the barriers faced by people with disabilities in their daily lives. The Gallery was plunged into complete darkness and Dhaka life was recreated through sound and touch, complete with rickshaws, gardens, sidewalks and shops. Visitors were invited to move around as blind guides led the way. After experiencing the exhibition visitors were encouraged to write their impressions, thoughts and feedback on a graffiti wall. The positive outcomes of the exhibition were: increased awareness about disability among visitors; collaboration between project participants and visitors; and a promise from the Bangladesh Bank to consider the issue that people with visual impairments found it difficult to distinguish between banknotes because they were all the same size.

Disability arts

In many countries, people with disabilities have turned to the arts as a way of developing self-esteem, raising awareness of disabling barriers, and building solidarity among their community. Theatre, dance, literature and the visual arts have all been used to promote the human rights approach to disability. Signed song, wheelchair dance and other innovative forms have sprung up from creative individuals and groups in the community.

Among people who experience mental health problems, writing, performance and the visual arts can be powerful tools for expressing feelings and sharing experiences.

Role models

Many artists with disabilities have achieved national and international recognition, and in doing so have created greater awareness about disability and become inspirational role models. Many artists also invest their talents and energy in supporting inclusive community development.

BOX 15

Messengers of Peace help spread awareness

On 3 December 2009 (International Day of Persons with Disabilities), the United Nations named well known singer-songwriter Stevie Wonder a United Nations (UN) Messenger of Peace with a special focus on people with disabilities. Messengers of Peace are individuals who possess widely recognized talents in the fields of art, academia, literature, sports and entertainment, helping to raise awareness of the UN's ideals and activities. Through their public appearances, contacts with international media and humanitarian work, they expand public understanding of how the UN helps to improve the lives of people everywhere (8).

Suggested activities

Promote the use of culture and art for social change

Disability advocacy and awareness campaigns are often more effective when based on locally relevant cultural and artistic media. Therefore CBR programmes should consider using these media to achieve social change for disability. Programmes can:

- work with artists and organize drama, arts and music events to challenge disability, stigma and discrimination that may be present in the community;
- explore the use of comedy, cartoons and popular art as a light and non-threatening way to address taboo subjects;
- support the positive portrayal of people with disabilities and disability issues through cultural and artistic media, e.g. drama, movies and theatre.

Investing in cultural training

Amadou and Mariam are two internationally recognized and influential mainstream musicians from Mali. They have used their talents to highlight disability issues and challenge stereotypes. They invest in cultural training programmes for youth with disabilities to ensure they have the opportunities to develop their skills and talents and follow their dreams and aspirations.



Support families to participate

It is important to remember that many families of people with disabilities may have lost the confidence to attend cultural events and venues through fear of stigma and discrimination. They may feel embarrassed, ashamed or unwelcome at weddings, religious services, restaurants, and cinemas. It is important that CBR programmes work with families and provide support by:

- listening to family members and encouraging them to express, recognize and challenge their fears;
- putting families in touch with others who share similar experiences and concerns;
- facilitating links to local disabled people's organizations to examine any misconceptions families may have and increase their confidence, expectations and aspirations.

Encourage people with disabilities to participate

CBR programmes can encourage people with disabilities to participate by:

- connecting them with groups and disabled people's organizations where they may find people who share similar interests in culture and the arts, and where they may develop the confidence to participate in a variety of activities;
- identifying artists with disabilities who have achieved recognition for their art and involving them in developing and implementing programme activities, if possible;
- working with stakeholders to develop specific disability arts projects;
- supporting and promoting examples of people with disabilities who have excelled and developed new art forms, e.g. silent theatre, and art forms which have been successfully adapted to reach wider audiences;
- promoting and supporting dance, drama and music as complementary types of therapy for people with disabilities.

Work with mainstream organizations and groups

CBR programmes have an important role to play in working with mainstream organizations and groups to develop their skills and confidence to include people with disabilities in their cultural and artistic programmes and activities. CBR programmes can:

- work with stakeholders to ensure that reasonable accommodation is made to enable inclusion of people with disabilities, such as modifying buildings to ensure physical access (e.g. community halls, places of worship, cinemas, tourist attractions), or producing information and promotional materials in accessible formats;
- develop alliances with women's groups to increase the inclusion of women with disabilities in mainstream cultural programmes;
- encourage inclusive art education in early childhood and school settings so that children with disabilities have opportunities to appreciate and participate in cultural and artistic activities from a young age;
- support people with disabilities and disabled people's organizations to develop and run diversity training with staff from a range of cultural and arts programmes to raise awareness about disability and inclusion;
- encourage apprenticeship and employment opportunities within cultural and arts programmes to ensure that people with disabilities actively participate in the management and administration of these programmes.

BOX 17

Palestine

Encouraging inclusion in mainstream cultural programmes

A small initiative started by CBR programmes in Palestine in 2000 was to include children with disabilities in summer camps. This initiative has become very successful and it is now standard practice to include children with disabilities in all summer camps. In addition, youth leaders of these camps have started to include children with disabilities in other mainstream programmes throughout the year. For example, a production of Cinderella (a popular children's story) cast a girl with a disability to play the lead role. This not only challenged stereotypes and increased awareness of disability in the community but also provided a positive role model for young people with disabilities.

Work with spiritual and religious leaders and groups

Spiritual and religious leaders can be powerful advocates for social change; however, they can also promote negative attitudes. So it is important for CBR programmes to work with religious leaders and members of all faiths within the community to promote the inclusion of people with disabilities in their activities. CBR programmes can:

- sensitize leaders about disability and the importance of including people with disabilities in religious and spiritual activities;
- encourage leaders to challenge discriminatory or harmful practices towards people with disabilities and their families in the community;
- ensure people with disabilities have access to personal assistance to enable them to attend religious/spiritual services and programmes;
- provide advice and assistance to leaders about making information accessible, e.g. making prayers, songs, chanting, and sermons accessible with signed translation, and making religious texts available in large print, audio and Braille;
- work with leaders to ensure that places of worship are physically accessible and that religious practices are modified to accommodate people with disabilities.



Recreation, leisure and sports

Introduction

Like culture and art, recreation, leisure and sports activities play an important role in communities. Their many benefits include improving the health and well-being of individuals, contributing to the empowerment of individuals, and promoting the development of inclusive communities. Recreation, leisure and sports activities may involve individuals, small groups, teams or whole communities and are relevant to people of all different ages, abilities and levels of skill. The types of recreation, leisure and sports activities people participate in vary greatly depending on local context, and tend to reflect the social systems and cultural values.

Participation in recreation, leisure and sports activities may be one of the few opportunities people with disabilities have to engage in community life beyond their immediate families. The right to participate in these activities is highlighted in the box below. As with culture and art, people with disabilities may choose to participate actively (e.g. as team members of a basketball team), or passively (e.g. as spectators at a football match).

BOX 18

Convention on the Rights of Persons with Disabilities, Article 30, paragraph 5: Participation in cultural life, recreation, leisure and sport (2)

With a view to enabling persons with disabilities to participate on an ongoing basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures to a) encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels; b) have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities; c) have access to sporting, recreational and tourism venues; d) ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities; e) have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities.

Using sport for social inclusion and personal development (9)

The project Sport as a Tool for Social Inclusion and Personal Development was launched by Handicap International in Morocco in 2007. A survey previously conducted (in 2004) by Handicap International had estimated that more than 1.5 million Moroccans had disabilities, and the purpose of the programme was to increase the opportunities for people with disabilities to be involved in sports and address inequalities in access to rehabilitation, health care and social integration.

The programme focused on three areas:

1. Capacity-building and networking of Moroccan institutions – programme staff worked closely with the Royal Moroccan Sports Federation (specialists in mainstream sports but with limited expertise in disability) and around 600 Moroccan disability associations specializing in health and education for people with disabilities, assisting them to develop strategic, national and international partnerships. Support was also offered to small projects and sports clubs for people with disabilities by offering training in management skills, project development, proposal writing and fundraising.
2. Provision of adapted sports equipment – including wheelchairs, appropriate clothing, and adapted equipment, e.g. balls which make noise for the blind.
3. Organization of inclusive sports events – a number of sporting events were held. These included an event to mark the International Day for Disabled Persons, and the Race for All, which attracted approximately 2000 runners both with and without disabilities. A high profile football tournament for players with disabilities was also held; it was sponsored by the King of Morocco and the final game was broadcast on national television to an audience of approximately 20 000 people.

The programme achieved a number of impacts:

- 1500 people with disabilities were reached through sporting clubs and regular sporting events;
- people with disabilities gained access to quality services, including appropriate technology and equipment and trained personnel who can advise them;
- people with disabilities gained access to opportunities to meet and interact with others of all abilities.



Goal

People with disabilities participate both actively and as spectators in recreational, leisure and sporting activities on an equal basis with others.

The role of CBR

The role of CBR programmes is to promote increased participation of people with disabilities in recreation, leisure and sports activities; and provide support to mainstream organizations and programmes to enable them to strengthen their capacity by offering appropriate and accessible recreation, leisure and sports activities.

Desirable outcomes

- People with disabilities participate in recreation, leisure and sports programmes available in the local community.
- Local, national and international authorities and associations include people with disabilities in their recreational, leisure and sports programmes.
- Families, teachers and community members recognize and actively promote the right and ability of people with disabilities to take part in recreation, leisure and sports activities.
- People both with and without disabilities are involved together in recreation, leisure and sports activities.
- People with disabilities are able to access recreation, leisure and sports venues.
- Equipment used for recreation, leisure and sports is adapted where needed to accommodate the needs of people with disabilities.
- Recreational, leisure and sports programmes and activities are developed specifically for people with disabilities where required.

Key concepts

Definitions

In this element:

Recreation refers to all those activities that people choose to do to refresh their bodies and minds and make their leisure time more interesting and enjoyable. Examples of recreation activities are walking, swimming, meditation, reading, playing games and dancing.

Leisure refers to the free time that people can spend away from their everyday responsibilities (e.g. work and domestic tasks) to rest, relax and enjoy life. It is during leisure time that people participate in recreation and sporting activities.

Sport refers to any type of organized physical activity, e.g. soccer, rugby, football, basketball and athletics.

Recreation, leisure and sports in the community

In many low-income countries where people work every day just to survive, the concept of leisure time is not always well understood and nor is it a priority. Indeed, many activities that are considered recreational in high-income countries are considered a means of livelihood in low-income countries, e.g. fishing and handicrafts.

In most communities the type of recreational and sporting activities people participate in are determined by age, gender, local context (e.g. rural vs. urban) and socioeconomic status. For example, children in poor communities are likely to play games using natural materials, such as sticks or stones or using discarded manufactured items like tyres and rope. Leisure time is also likely to be based around cultural activities, such as traditional dance, storytelling, religious festivals and events, and visiting entertainment troupes.

In many poor and rural communities there are no designated places for people to spend their leisure time, such as community centres and sports stadiums, so it is common for people to gather in places of worship, tea shops, houses and open spaces.

Communities in low-income countries often have pressing priorities and limited budgets. As a result the development of formal recreation and sports activities/programmes is usually dependent on donors. It is important that external funding is carefully managed to ensure that the programmes/activities introduced are appropriate to the local context.

The benefits of participation

Participation in recreation and sports activities can have many benefits for both the individual and community. These include:

- **health promotion and disease prevention** – recreation and sports activities are an enjoyable and effective way to improve health and well-being; they can relieve stress, increase fitness, improve physical and mental health, and prevent the development of chronic diseases, such as heart disease;
- **skills development** – physical and social skills are some of the many skills that can be developed through participation in recreation and sports activities;
- **awareness raising, reduction of stigma and social inclusion** – recreation and sports activities are a powerful, low-cost means to foster greater inclusion of people with disabilities; they bring people of all ages and abilities together for enjoyment, and provide people with disabilities the opportunity to demonstrate their strengths and abilities, and promote a positive image of disability;
- **international peace and development** – sport is a universal language that can be used as a powerful tool to promote peace, tolerance and understanding by bringing people together across boundaries, cultures and religions (10).

- **empowerment** – recreation and sports activities can empower people with disabilities by positively influencing their self-confidence and self-esteem.

BOX 20

Eritrea

War veterans become role models

In Eritrea, war veterans with disabilities received training to work as football team managers and trainers so they could play a key role in implementing children's football activities, involving more than 2000 children, in the capital city of Asmara. This involvement has changed the way the war veterans view themselves, and has positively influenced the way in which children view people with disabilities, while providing positive role models for other people with disabilities. Building on this success, the sports club is now providing football training to deaf children as a first step in the inclusion of children with disabilities in its sports activities.

Recreation and sport are complementary with other opportunities

While the many benefits of recreation and sporting activities have been highlighted, it is important to remember that they should not be used as a substitute for limited access to other opportunities, such as education or livelihood.

BOX 21

Afghanistan

Bicycle training

The Afghan Amputee Bicyclists for Rehabilitation and Recreation (AABRAR) programme in the Islamic Republic of Afghanistan is a bicycle training programme for people with amputations, to improve their functional mobility and independence and enable them to travel to and from work and save on transportation costs.

Enabling access to recreation, leisure and sport

Reasonable accommodation may be necessary for some people with disabilities to participate in recreation and sporting activities. With a little creativity and flexibility, activities and equipment can be adapted at minimal or no cost to ensure the inclusion and participation of people with disabilities.

Adapting sporting activities

Adapting the rules or point scoring systems of games can allow people of different abilities and ages to play together at no cost. Using local materials to make cheap adaptations of equipment, e.g. using a dried gourd with grains to make a ball that makes a sound, or pairing players to play together, can increase the participation of all community members.

Suggested activities

Identify local recreation, leisure and sports opportunities

A first step is to identify what recreation, leisure and sporting opportunities already exist in and around the community. CBR programmes should work closely with community groups, e.g. youth and women's groups, children's clubs, and people with disabilities, to identify these.

Facilitate the participation of people with disabilities

Activities are successful when they are: requested by individuals and communities, culturally appropriate, enjoyable and fulfilling for participants, and not too costly to develop and sustain. To facilitate the participation of people with disabilities in recreation and sporting activities, it is suggested that CBR programmes:

- provide information to people with disabilities about the recreation and sporting opportunities available in their local communities;
- link people with disabilities to mainstream recreation and sporting clubs/associations;
- ensure children with disabilities have the same opportunities as other children to participate in recreation and sports activities at school;
- explore options for personal assistance to enable people with disabilities to participate, whether actively or passively;
- facilitate positive media coverage of disability recreation and sports to encourage more people with disabilities to become involved.



Use recreation and sport to raise awareness about inclusion

Major events, such as the International Day of Disabled Persons, can provide opportunities for raising awareness, from national to local level, about the need for inclusive recreation and sporting activities. These events often attract positive media attention, which can raise awareness across a wide audience.

BOX 23

Pakistan

The Blind Cricket World Cup

Following successful local and national media coverage of the Blind Cricket World Cup in Pakistan, some CBR programmes saw an increase in the number of parents asking about educational and leisure opportunities for their visually impaired children.

Encourage mainstream programmes to become inclusive

Often mainstream recreation and sports programmes have not considered including people with disabilities. CBR programmes can work with these programmes to explore how to make their activities accessible to all. CBR programmes can:

- consult with national and international organizations to ensure that programmes are culturally and geographically specific, and available to people with disabilities of all ages, abilities, and genders living in urban and rural settings;
- provide ideas and suggestions on how to safely adapt activities, equipment and venues, emphasizing that many activities can be adapted at minimal or no cost;
- facilitate training for staff of mainstream programmes to develop their skills and confidence to include people with disabilities;
- advocate alongside disabled people's organizations to ensure that recreation and sporting opportunities become available and accessible for people with disabilities.

Publications such as the *Fun and inclusive handbook* (11) and *Sport, recreation and play* (12) provide further information and examples on how inclusion can be supported in low-income countries.

BOX 24

School sports days

CBR programmes can encourage and support school sports days that offer opportunities for inclusion. These sports days can increase awareness and understanding among school-aged children by offering opportunities for individuals with and without disabilities to play sports together. The events are a positive experience for everyone involved including the children, parents, teachers, volunteers and sports officials. They can positively challenge attitudes and beliefs about disability and increase awareness about the sporting abilities of children with disabilities.

Develop and support disability-specific programmes

Disability-specific programmes provide opportunities for people with disabilities to meet other people with disabilities, and enable them to compete against others who are at a similar skill level. CBR programmes can:

- ensure that people with disabilities are leaders and play a strong role in the decision-making process during programme development to make certain that recreation and sports programmes are suitable for their needs;
- provide appropriate training and resources to support people with disabilities who want to set up their own recreation and sports groups/clubs;
- link local disability recreation and sports groups/clubs to national and international organizations, e.g. the International Sports Federation for People with Intellectual Disability, the International Paralympic Committee, Special Olympics International, and the International Committee of Sports for the Deaf.

BOX 25

Bangladesh

Connecting through chess

One of the largest networks of visually impaired people in Bangladesh is a Braille chess club, which has a network of clubs that reaches throughout urban and rural areas. This network provides opportunities not only to compete and develop skills but also to socialize and link with people of similar interests.

Justice

Introduction

Access to justice is a broad concept which refers to people's ability to access the systems, procedures, information, and locations used in the administration of justice (13). All human beings are born free and equal in dignity and rights (14) and therefore everybody should have equal access to justice when their dignity and rights are infringed upon (15).

People usually turn to the justice system in their country when they have been wronged or mistreated in some way, e.g. when they have been the victim of a crime. While access to justice is a human right it is also of critical importance in the enjoyment of all other human rights, e.g. if a person with a disability has been denied the right to work they may wish to turn to the justice system to seek a remedy (solution) (13).

Many people from disadvantaged groups, including people with disabilities, face barriers to accessing justice (15). Without access to justice their voices are not heard and they are unable to exercise their rights, challenge discrimination or hold decision-makers accountable (16), and as a result they can become more vulnerable and marginalized (15).

This element provides information about some of the concepts related to access to justice for people with disabilities and provides suggestions on how CBR programmes can help to overcome the barriers that people with disabilities may face when trying to access justice. The participation of people with disabilities in the administration of justice, e.g. as witnesses, jurors, lawyers, etc. is also important but is not covered here.

BOX 26

Convention on the Rights of Persons with Disabilities, Article 13: Access to Justice (2)

1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.
2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

Netsanest's ordeal due to negative community attitudes

Netsanest is a 14-year old girl. She became blind when she was young, but does not remember exactly how and when it happened. Growing up as blind girl in her village she was made to feel useless and was often called names like "awer" (a name used for people who cannot see which also means stupid). When people visited the family home she often hid from view so she did not shame her family, and when there were festivities in her village she was never allowed to take part.

One day her aunt visited and told her family about a school for blind children in a nearby village. With her parents' permission, Netsanest started attending this school. She loved attending school and soon learned how to read and write, cook and move around the village by herself. She even began to rent a house with some of her new friends.

One evening a man from the village approached Netsanest and asked her to sleep with him in return for money to help pay for her education costs. Netsanest refused, telling him that she was not ready to marry and that she wanted to focus on finishing her education. A few days later when her friends were away from the house, the man came back and told her that being with him would make her life easier and that it would be their secret. Again she refused. However, this time he raped her. She screamed and shouted but no one came to help.

The next day at school the teachers heard about her story and took her to the police. Instead of helping her, the police started blaming her for what had happened. Several other blind girls had been raped in the village, and because of negative community attitudes and beliefs regarding disability it was often believed that it was their fault. News quickly spread throughout the village and the rapist's mother came to see Netsanest, shouting at her and accusing her "What do you think you are doing? You first seduce my son and make him do sinful things and now you are trying to disgrace his name..."

When news reached Netsanest's parents, they did not know what to do. On the one hand they were scared to do anything because they worried about Netsanest's safety and the shame this situation might bring for their family. However on the other hand they wanted justice for Netsanest.



Goal

People with disabilities have access to justice on an equal basis with others to ensure full enjoyment and respect of human rights.

The role of CBR

The role of CBR is to promote awareness of the rights of persons with disabilities and provide support to persons with disabilities and their family members to access justice where they face discrimination and exclusion.

Desirable outcomes

- CBR programmes are able to support people with disabilities to access justice when the need arises.
- People with disabilities are aware of their rights and the options and procedures for accessing justice.
- Relevant stakeholders in the justice sector are sensitive to the needs of people with disabilities and do not engage in discriminatory practices.
- People with disabilities are able to access informal mechanisms of justice when their rights are violated.
- People with disabilities are able to access formal mechanisms of justice when their rights are violated.

Key concepts

Rights holders and duty bearers

Understanding the relationship between rights holders and duty bearers is an important concept when considering the rights of persons with disabilities and enabling their access to justice.

Rights holders – people with disabilities are rights holders, i.e. they have both entitlements and responsibilities. As rights holders they are entitled to, for example, health, education, livelihood opportunities, land, housing, and political participation. These, as well as other entitlements, are all outlined in the Convention on the Rights of Persons with Disabilities (2).

Duty bearers – when a person has a right, someone else has a duty to respect, protect and fulfil that right. Duty bearers include both state (government) and non-state (e.g. nongovernmental organizations, religious leaders, parents) actors at national and local levels. The duties of states are outlined in the Convention on the Rights of Persons with Disabilities (2).

Barriers to justice

Access to justice is often limited to the wealthy, the politically connected, and people living in urban areas. People with disabilities, particularly those who live in low-income and middle-income countries, face a number of barriers to accessing justice. These barriers include:

- absence of adequate laws and policies to protect people with disabilities – in many countries there are no specific laws to protect their rights (15);
- physical barriers – people with disabilities may be unable to access police stations, courts, and other public buildings (13);
- barriers in communication – people with disabilities may be unable to communicate effectively with people in the justice sector if reasonable accommodations are not in place, e.g. sign language interpreters for people who are deaf;
- lack of accessible information – without accessible information people with disabilities may not be aware of how the justice system works and what their rights and responsibilities are (13);
- economic barriers – the cost of lawyer’s fees, court fees, etc. may be too high for people with disabilities;
- lack of awareness of needs – police and other officials may not understand the specific needs of people with disabilities in accessing justice and information on how to provide the necessary accommodations (13).

Legal capacity

Article 12 of the Convention on the Rights of Persons with Disabilities highlights: “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (2). Many people with disabilities are not allowed to exercise their legal capacity, e.g. they are prevented from participating in legal proceedings and from giving evidence in courts. This is because many people think that people with disabilities do not have the capacity to act. The Convention also recognizes that some persons with disabilities may require support in exercising their legal capacity. Such supported decision-making can take many forms, e.g. those assisting a person may communicate the individual’s intentions to others or help him/her to understand the choices at hand; they may help others to realize that a person with significant disabilities is also a person with a history, interests and aims in life, and someone capable of exercising his/her legal capacity (17).

Promoting access to justice

Legal protection

The rights of people with disabilities need to be recognized in national constitutions, legislation and policies. Once their rights are legally recognized then courts, administrative bodies, tribunals, and in some cases human rights institutions, can provide solutions

when the rights of persons with disabilities are violated. The type of remedy will depend on the wrong that needs to be corrected, e.g. requiring a school to admit a student, making a government building accessible, fining an employer for discrimination in hiring practices, obliging health authorities to issue a health insurance card, and punishing violence or abuse.

Informal mechanisms – unfair or unjust practices can often be effectively resolved at the community level. Informal mechanisms of legal protection may be accessible through, for example, religious and development organizations, tribal leaders, village leaders, unions and cooperatives, educational and health professionals, social workers and heads of households.

BOX 28

India

Informal justice paves a way

In Orissa, India, a community-based leprosy programme worked with elders and religious leaders to find a solution for a man who was forced to leave his home and village because he had leprosy. It was agreed that, after a religious renaming and re-birthing ceremony, the man would be able to return to his family with a new name and participate once again in community life.

Formal mechanisms – when a person cannot access their rights through informal means, then more formal processes of legal protection need to be used, such as legal action undertaken through the courts. Usually this is a last resort because it is expensive, slow, and requires professional legal advice. For people with disabilities living in low-income countries it is usually only possible with support from free legal aid centres or from human rights, disability or development organizations. It is important that any decision to undertake legal action must be made by the individuals or groups of people involved.



Finding justice through free legal assistance

A number of deaf employees working as money counters had their contracts terminated when the large Manila-based bank they worked for bought money-counting machines. The employees, with the support of KAMPI, the Philippine National Federation of Organizations of Persons with Disabilities, approached a group of lawyers who agreed to provide free legal assistance. After a number of years, the Supreme Court of the Philippines ruled, on the basis of national disability anti-discrimination law, that the termination was illegal and discriminatory. The bank was ordered to pay back wages to the employees for all the years they had been out of work, and further was ordered to reinstate them to their posts. Rather than choosing to return to their old jobs, the employees used the compensation money to set up small business activities.

Legal awareness

Legal awareness is the foundation for fighting injustice. People with disabilities cannot seek remedies for injustice when they do not know what their rights and entitlements are under the law (18). When people with disabilities and family members are aware of their rights, they are better able to defend those rights and speak out when they observe abuse of other people's rights.

Legal aid

Costs associated with formal legal processes are high and often discourage people from seeking justice. Legal aid support can help people from disadvantaged groups, including people with disabilities, to initiate and pursue justice (18). Legal aid schemes provide funding and support, for example, to advise people on their legal problems, assist people to understand their rights and the law, and represent people in court. Governments are usually responsible for providing legal aid; however, where governments have limited capacity to fulfil their responsibilities, nongovernmental organizations are an important source of assistance (18).

Community legal centres

One way to provide legal services for people with few resources who do not meet the eligibility requirements for legal aid is to use community legal centres (CLC) or law school clinics. CLCs are usually small non-profit organizations providing a range of legal services. They are an important resource; their work includes advice and assistance, referral, representation in court where appropriate, and provision of information about legal issues. They also play an important role in raising awareness, educating the community on legal issues, lobbying and developing policy (e.g. advocating for the development of a fair legal system), and working towards the reform of legal process and administration.

A key feature of community legal centres is their use of volunteers in the delivery of services. Thus the “community” refers to the unpaid time and expertise of practicing lawyers, students, para-legals and others. The centres can establish relationships with the private legal profession, i.e. they negotiate pro bono arrangements with private lawyers, and cooperative relationships with university law schools.

BOX 30

Ecuador

Helping children get back in school

A young girl in Quito, Ecuador was not allowed to study because her parents forced her to beg on the streets. The child’s grandmother was very concerned. After failing to resolve the matter within the family, the grandmother asked the CBR programme to help her gain custody of her grandchild. The programme contacted the legal aid society to support the grandmother with advice and assistance. They took on her case and now the grandmother has custody of her granddaughter, who is pleased to be back in school.

Suggested activities

CBR programmes can undertake a variety of activities, often in partnership with disabled people’s organizations and other civil society stakeholders, to support people with disabilities in gaining access to justice.

Develop an understanding of the local context

To effectively support people with disabilities to access justice, CBR programmes need to understand the local context in which they work. It is suggested that programmes:

- develop an awareness about the law (both general and disability-specific legislation) – disabled people’s organizations and legal aid services can be used as resources to help CBR personnel understand this legislation;
- develop an understanding about how laws are enforced – local enforcement officers, e.g. police officers can be used as resources to help CBR personnel understand how to report a crime and identify what protection mechanisms are in place for victims and witnesses;
- identify available resources (both non-formal and formal) in the local area which will be useful in assisting people with disabilities access justice, e.g. local leaders (local government, tribal, village and religious leaders), teachers, disabled people’s organizations, medical professionals, unions and cooperatives, law enforcement and court personnel, legal aid services and community legal centres.

Develop networks and alliances with relevant stakeholders

CBR programmes should work alongside disabled people's organizations and self-help groups to develop good relationships with influential community members and groups to prepare for and challenge any potential injustice or unlawful action against people with disabilities.

Raise awareness about rights

Strategies to promote legal awareness can be undertaken by CBR programmes; they can:

- work with disabled people's organizations to ensure that people with disabilities and their families are aware of their rights;
- disseminate information in accessible formats on disability rights and how to access these rights;
- participate in awareness raising activities along with disabled people's organizations, human rights organizations and self-help groups;
- support disabled people's organizations and human rights organizations to carry out disability training with key sectors and decision-makers at the community and district levels, e.g. law enforcement and court officers, legal and health professionals, teachers, religious and business leaders.



Promoting legal rights and empowerment

A three-year pilot project to promote the legal rights and empowerment of people with disabilities in Yeka Sub-city, Addis Ababa, Ethiopia, was implemented by Handicap International in partnership with the Ethiopian National Association on Intellectual Disability (ENAIID) and the Ethiopian Bar Association. The project worked to promote the legal rights of people with disabilities to reduce their vulnerability to sexual violence and HIV/AIDS.

A baseline survey on sexual violence against persons with disabilities found that 46% of respondents had been subjected to sexual violence, 83.5% had no access to any form of gender awareness education, and 88.3% had no access or were denied information on sex education, reproductive health education, as well as assertiveness training. Interviews with individuals and focus group discussions helped to provide further evidence and greater clarity on survey findings and define appropriate interventions to respond to the root causes of the abuse.

The project went on to support a review and analysis of the existing laws in Ethiopia; provide training for legal and law enforcement personnel, civil society and community members; develop a functional referral system; produce a user-friendly referral guide; and provide free psychosocial and legal counselling and representation in court.

Promote access to informal mechanisms where appropriate

Formal legal processes may not always be the most appropriate mechanism. Often informal mechanisms can be more effective and are usually quicker, less costly and more accessible for community members. Examples of ways in which CBR programmes can support access to informal methods of justice include:

- working with local schools to encourage them to enrol children with disabilities;
- approaching the local community and religious leaders to help resolve family disputes, e.g. a dispute about a couple's right to marry when one or both partners has a disability;
- working with farming cooperatives to ensure that farmers with disabilities have access to collective community resources;
- working with banks to enable clients with disabilities to manage their own accounts and access credit;



- supporting a local doctor to have a sign language interpreter so that deaf members of the community can access and use health-care facilities;
- working with tribal or religious leaders and heads of families to support people with disabilities to claim their inheritance rights.

BOX 32

Ghana

Accessing justice through community networks

A man from Ghana lived with his only daughter who happened to have a visual impairment. When he became sick his daughter supported him for years until his death. When the man's relatives heard of his death they came and took away all his belongings and threatened to eject the daughter from the house. The daughter sought legal advice from local community support networks and as a result was able to claim her father's pension benefit and get back belongings that were rightfully hers, including the full estate of her father.

Support legal action where appropriate

It is important for CBR programmes to:

- build strong relationships and alliances with trusted members of the legal community;
- seek legal advice to find out which legislation is appropriate for addressing the different types of discrimination, e.g. local agreements, national legislation or international conventions or treaties;
- respect the decision of the person with disability to seek legal action;
- review the risks involved in taking legal action, e.g. time, costs, and security considerations, particularly where effective legislation and protection mechanisms may not exist;
- ensure that people with disabilities and their families are involved in legal processes and are also aware of the risks involved;
- develop an awareness of, and work together with, organizations which address legal issues for poorer members of the community (e.g. community or legal aid centres, lawyers' collectives and/or international human rights and development organizations).

A successful fight for justice

A Nepalese disabled people's organization took the government of Nepal to the Supreme Court to argue that, under the Convention on the Rights of the Child, it was discriminatory to expect children using Braille to sit and complete public school exams in the same time as sighted children. They were successful and achieved a commitment which allowed children using Braille an extra 30 minutes in all exams.

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Recommended reading

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Notes

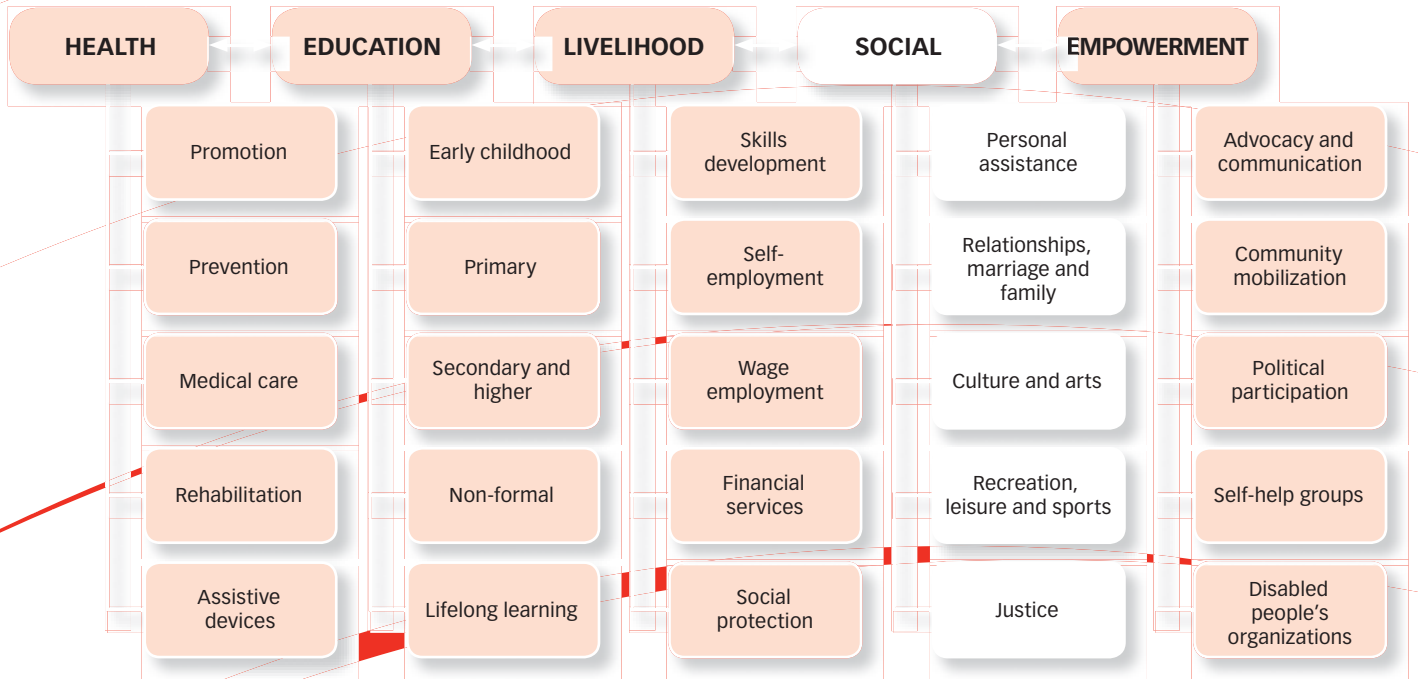


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