

Chapter one

Introduction

Community-based rehabilitation (CBR) is the strategy endorsed by WHO (WHO 2010a) for general community development for the rehabilitation, poverty reduction, equalization of opportunities, and social inclusion of all PWD. The concept was firstly introduced in an unpublished WHO report in 1976 (WHO 1976; Finkenflugel 2004) as a promising strategy to provide rehabilitation for people with disability in developing countries and part of the broader goal of reach 'Health for All by the year 2000' (WHO 1978). Since the first training manual published in 1980 (Helander 1980) and updated in 1989 (Helander 1989), the concept has evolved to become a multi-sectoral strategy. CBR is implemented through the combined efforts of PWD themselves, their families and communities, and the relevant governmental and non-governmental health, educational, vocational, social and other services. CBR is delivered within the community using predominantly local resources.

Today, CBR is practiced in over 90 countries and is increasingly seen as an effective strategy for inclusive development and, more recently, as a means of implementing the Convention on the Rights of Persons with Disabilities. The concept of inclusive development has gained momentum over the last few years, with more donor governments and development organizations committing to implementing programmes that include people with disabilities. The CBR strategy provides an important mechanism for ensuring that inclusive development policies have a positive impact at the local level and on the poorest and most marginalized people with disabilities

As a strategy, CBR seeks to further the inclusion and meaningful participation of people with disabilities in society by:

- Removing the barriers to development that people with disabilities face;
- Delivering quality services and programmes;
- Addressing the causes of disability; and
- Bringing persons with and without disabilities together on an equal basis

In achieving these aims, CBR helps reduce poverty and improve the lives of everyone in the community. As reflected in the CBR Guidelines, the foundation of CBR includes the eight core principles of the Convention on the Rights of Persons with Disabilities:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
2. Non-discrimination;
3. Full and effective participation and inclusion in society;
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
5. Equality of opportunity;
6. Accessibility;
7. Equality between men and women; and
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities. Two additional principles are central to CBR work: empowerment (including self-advocacy) and sustainability.

CBR matrix

In light of the evolution of CBR into a broader multi sectoral development strategy, a matrix was developed in 2004 to provide a common framework for CBR programmes. The matrix consists of five key **components** – the health, education, livelihood, social and empowerment components. Within each component, there are five **elements**. The first four components relate to key development sectors, reflecting the multi sectoral focus of CBR. The final component relates to the empowerment of people with disabilities, their families and communities, which is fundamental for ensuring access to each development sector and improving the quality of life and enjoyment of human rights for people with disabilities.

CBR programmes are not expected to implement every component and element of the CBR matrix. Instead the matrix has been designed to allow programmes to select options which best meet their local needs, priorities and resources. In addition to

implementing specific activities for people with disabilities, CBR programmes will need to develop partnerships and alliances with other sectors not covered by CBR programmes to ensure that people with disabilities and their family members are able to access the benefits of these sectors.

Community-based rehabilitation is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities.

CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services. “CBR was designed as a model by which cost-effective community / home-based rehabilitation could be provided in developing countries (Helander et al. 1989). As defined, it was not seen to equate to all rehabilitation that takes place outside an institutional setting, although it is easy to see how the term can be interpreted as such, and this is reflected in the feedback from WCPT Member Organizations. CBR, as internationally defined, is very much client-centric as opposed to profession-centric.

Characteristics of CBR

In trying to clarify what CBR is and to draw a distinction with any care that takes place in a community environment there are a few key points.

CBR is not:

- ✓ An approach that only focuses on the physical or medical needs of a person
- ✓ About delivering care to disabled people as passive recipients
- ✓ Only outreach from a centre
- ✓ Rehabilitation training in isolation
- ✓ An approach which is determined by the needs of an institution or groups of professionals
- ✓ Segregated and separate from services for other people (Stubbs 2002).

Conversely CBR involves:

- Partnerships with disabled people, both adults and children, their families and careers
- Capacity building of disabled people and their families, in the context of their community and culture
- An holistic approach encompassing physical, social, employment, educational, economic and other needs
- Promoting the social inclusion of disabled people in existing mainstream services
- A system based in the community, using district and national level services for referral

(Stubbs 2002; Vanneste 2001).

CBR has been described on the basis of component features such as:

- ❖ provision of functional rehabilitation services
- ❖ creating a positive attitude towards people with disabilities
- ❖ the creation of micro and macro income-generation
- ❖ vocational training
- ❖ The prevention of the causes of disabilities (United Nations Economic and Social Commission for Asia and the Pacific 1997).

Chapter two

Different models have been developed to define disability. In this course, disability is understood following the International Classification of Functioning, Disability and Health (ICF or International Classification hereafter) developed by WHO in 2001. According to the ICF, “disability is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition), and that individual’s contextual factors (environmental and personal factors)” (WHO 2001 p. 213). Thus, this model starts with a health condition (for example, diseases, health disorders,

injuries, and other health related conditions) which in interaction with contextual factors may result in impairments, activity limitations, and participation restrictions.

The ICF defines that *impairments* are problems in body function or structure such as a significant deviation or loss; *activity* is the execution of a task or action by an individual, *activity limitations* are difficulties an individual may have in executing activities; *participation* is involvement in a life situation; *participation restrictions* are problems an individual may experience in involvement in life situations' *environmental factors* make up the physical, social and attitudinal environment in which people live and conduct their lives; and *personal factors* are the particular background of an individual's life and living, including gender, race, and age (WHO 2001).

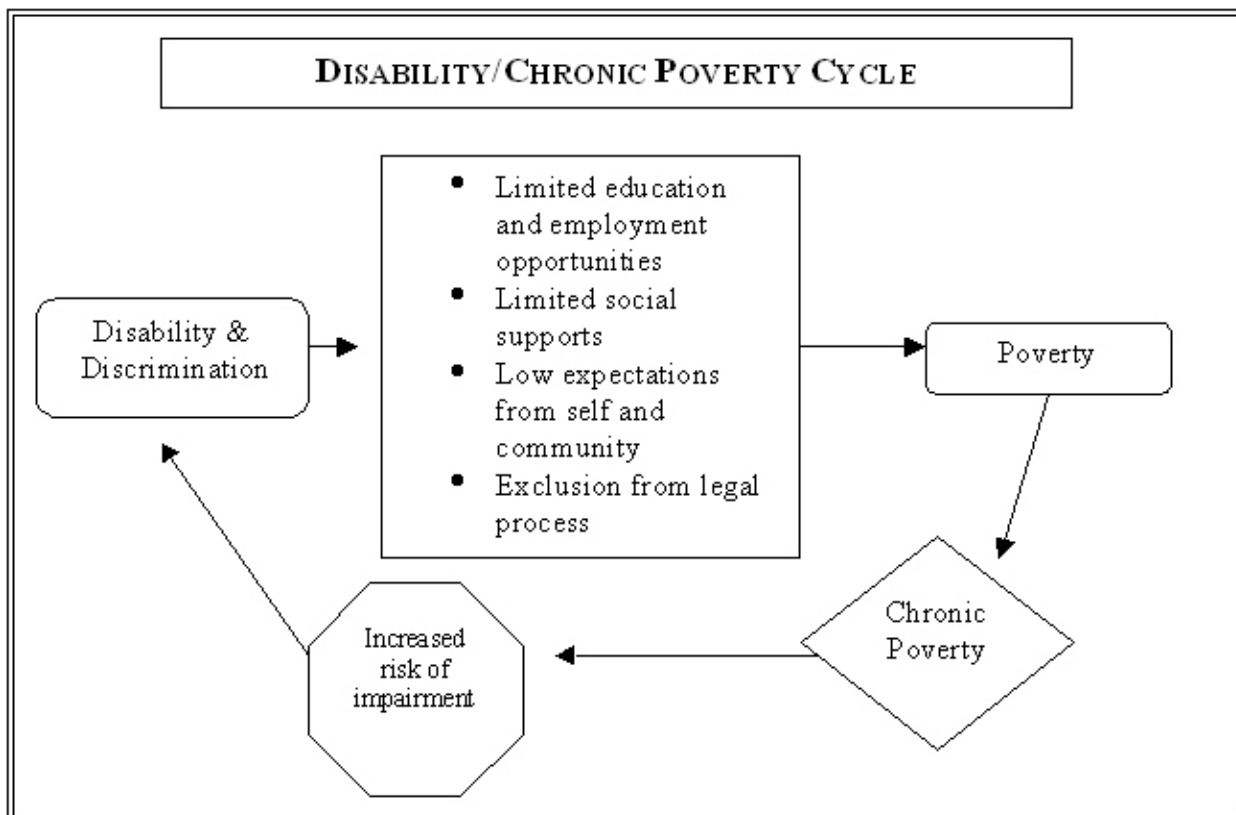
Despite numerous policies and statements regarding disability and poverty reduction, it is still estimated that 10,000, die every day because of extreme poverty. This is not an abstract theory, but a disastrous crisis. It would be deceptive to claim that this injustice is anybody's conscious intention. However, it can be argued that it is the inevitable and logical result of existing global relations. Earlier in 2005, many thousands of people took to the streets to protest against this injustice.

PWDs are among the most disadvantaged people in the world and are over-represented among the poorest of the poor. The relationship between disability and poverty has often been referred to as a vicious circle. It has been estimated that at least 10% of the world's population lives with a disability

(1), the majority in developing countries in conditions of poverty. People with disabilities are among the world's most vulnerable and least empowered groups. All too often they experience stigma and discrimination with limited access to health care, education and livelihood opportunities. Community-based rehabilitation (CBR) was first initiated by the World Health Organization (WHO) following the International Conference on Primary Health Care in 1978 and the resulting Declaration of Alma-Ata (2). CBR was seen as a strategy to improve access to rehabilitation services for people

with disabilities in developing countries; however over the past 30 years its scope has considerably broadened.

Poverty: a cause and consequence



The need for rehabilitation

This section gives a brief overview of international policy relevant to rehabilitation, specifically as it relates to primary health care and community-based rehabilitation (CBR). It is not designed to be exhaustive or to provide a detailed critique; rather it is intended to provide contextual information. Readers are referred to the documents referenced for more detailed information.

1.1 Prevalence of disability

Depending on how disability is defined there is a large variation in the reported prevalence figures. Estimates of the number of PWDs worldwide vary from 0.2% to 21% (Helander 1999; Thomas and Thomas 2002). The most frequently quoted international figure is 10% of the population (Helander et al. 1989; Leavitt 1995; Thomas and Thomas 2002; World Health Organization 1981). This stems from work undertaken in 1976 based on calculations which included a high proportion of people with slight and potentially reversible disabilities (Helander 1999).

A global estimate of moderate and severe disability has been given as 5.5% (Helander 1999). Based on population and survey data it is estimated that 70% of these 5.5% live in the developing countries (Helander 1999). In the developing countries it has been cautiously estimated that there were about 234 million moderately or severely PWDs in 2000 and that this will grow to about 525 million in 2035 (Helander 1999, 2000). Not all of these people would benefit from some form of rehabilitation nor perhaps be prepared to participate. It has been suggested that there are at least 70 million who would benefit now, rising to 149 million in 2035 (Helander 1999, 2000). At present only about 3% of those who need rehabilitation in the developing countries receive any meaningful service (Helander 2000).

It is estimated that 10% of children are born with or acquire a disability and of these no more than 10% receive appropriate rehabilitation (according to UNICEF cited in World Health Organization 2001a).

1.2 International policy

Health promotion, prevention, rehabilitation and the social integration and equalization of opportunities for people with disabilities have been accepted policy for the United Nations

(UN) and World Health Organization (WHO) for many years, with an increasing focus on primary health care and community services. Focusing on rehabilitation and primary health care, community-based rehabilitation (CBR) is one model of service provision, which WHO has advocated for over a decade (Helander et al. 1989; World Health Organization 1994, 1995a). The participation of people with disabilities, their careers and communities has long been a guiding principle for health care policy development, planning, implementation, monitoring and evaluation even if is not quite a reality worldwide.

International groups such as the United Nations Children's Fund (UNICEF) and WHO, along with international politicians and health planners, have called for greater self-reliance at the community level with increased attention on prevention. However, this could be considered to impose a top-down expectation that may not be matched with local ownership of the concept of self-reliance (van der Geest et al. 1990; Vanneste 1997). Some consider that self-reliance can appear to equate to people being left to fend for themselves (van der Geest et al. 1990) rather than gaining ownership and a sense of control. In addition, the aspirations of many developing countries for a health care system similar to that of developed countries may risk undermining self-reliance given the criticisms of the medicalization of health care in western society (van der Geest et al. 1990).

Disability incurs both economic and social costs for society which can be reduced by effective rehabilitation and support programmes (Hammerman and Maikowski cited in World Health Organization 1981). Generally, up until now, primary health care efforts have focused on family planning, childhood immunizations, nutrition and AIDS, all of which are important in the prevention of population health problems and disability (van der Geest et al. 1990). While for many communities primary health care initiatives that focus on preventative measures will pay dividends in the long-term, the priority needs of the people are more likely to be associated with treatment and rehabilitation where, if services were available, there is the potential for immediate effect. A balance therefore needs to be struck between prevention, health promotion, treatment and rehabilitation.

Rehabilitation has historically been seen as a low priority around the world due to a number of factors (Coleridge 1993; Leavitt 1995):

- Cost-benefit ratio of providing services to those with disabilities
- Under-estimation of disabled peoples' potential to achieve
- Negative societal attitudes towards disability
- Discriminatory practices

- Absence of urgency – rehabilitation tends to focus on the chronic, non-communicable diseases or illnesses that do not pose a risk to others
- Interest of biomedical practitioners focuses on improvement and cure, which is not always feasible or realistic for rehabilitation or the 'Cure or Care' model
- Public policy is not influenced by those with disabilities as they represent a relatively small marginalized minority.

Access to appropriate rehabilitation remains problematical. Where services do exist they are frequently centered on urban institutions (World Health Organization 1981). In addition care is Primary Health Care and Community Based Rehabilitation: Implications for Physical Therapy frequently driven by health care professionals rather than people with disabilities, their careers and communities, and therefore fails to address priorities and needs from their point of view.

There are many calls to increase the number of health care professionals available to provide services, including physical therapists, recognizing the significant shortfalls worldwide. However, there has been limited progress in maximizing the potential of that which is available for the benefit of the majority of people in need.

Human rights

Health for all and the equalization of opportunities, along with access to rehabilitation delivered in a culturally and socially sensitive manner, can be seen as basic human rights issues (Cole 1999; United Nations 1983, 1994). Cole argues that the essential human right is the right to progress, achieved through “the facility and ability to choose and participate in processes of social change” (Cole 1999, page 8 emphasis added). Ensuring that those with disabilities enjoy all aspects of human rights is embedded in international legislation and also widely at a national level. This means that the rights-based approach to disability is subject to law. The approach is designed to "...empower disabled persons, and to ensure their active participation in political, economic, social,

and cultural life in a way that is respectful and accommodating of their difference" (Office of the High Commissioner for Human Rights 2003, page 2). The extent to which national implementation makes this a practical reality is variable.

The human rights approach sees the problems of disability stemming from within society, not the individual. "The existing order of society, and the consequent allocation of scarce resources, necessarily engenders inequality, which reflects the power structure of society. This social status quo is ideologically justified, legitimating privilege. And hence any effective analysis of the social position and human rights of persons with disabilities in particular, and disadvantaged people in general, and the resultant questioning of the allocation of resources, will have to address the inadequacies of the extant institutional order.

In the context of international legislation there are a number of United Nations documents setting out international standards on human rights, along with a number of resolutions and declarations. For example see:

- Universal Declaration of Human Rights (United Nations 1948)
- International Covenant on Economic, Social and Cultural Rights (United Nations 1966)
- Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (United Nations 1984)
- Convention on the Rights of the Child (United Nations 1989a)
- The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations, 1994).

What is rehabilitation?

Rehabilitation as is set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments. A distinction is sometimes made between

habilitation, which aims to help those who acquire disabilities congenitally or early in life to develop maximal functioning; and rehabilitation, where those who have experienced a loss in function are assisted to regain maximal functioning (2). In this chapter the term “rehabilitation” covers both types of intervention. Although the concept of rehabilitation is broad, not everything to do with disability can be included in the term. Rehabilitation targets improvements in individual functioning – say, by improving a person’s ability to eat and drink independently. Rehabilitation also includes making changes to the individual’s environment – for example, by installing a toilet handrail. But barrier removal initiatives at societal level, such as fitting a ramp to a public building, are not considered rehabilitation in this Report.

Rehabilitation reduces the impact of a broad range of health conditions. Typically rehabilitation occurs for a specific period of time, but can involve single or multiple interventions delivered by an individual or a team of rehabilitation workers, and can be needed from the acute or initial phase immediately following recognition of a health condition through to post-acute and maintenance phases. Rehabilitation involves identification of a person’s problems and needs, relating the problems to relevant factors of the person and the environment, defining rehabilitation goals, planning and implementing the measures, and assessing the effects (see figure below). Educating people with disabilities is essential for developing knowledge and skills for self-help, care, management, and decision-making. People with disabilities and their families experience better health and functioning when they are partners in rehabilitation (Source: A modified version of the Rehabilitation Cycle from (10)).

Models of rehabilitation

Institution-based rehabilitation and outpatient services are models recognizable to most health care professionals and the ones that have historically influenced education provision. These services have been driven and developed by health care professionals. Health care reforms are seeing an increasing emphasis on service user involvement in

shaping future models of health service delivery. However, this remains a relatively new concept and one in development itself. In most countries institution-based rehabilitation is urban-based, making it relatively inaccessible and expensive to access, especially in poorer communities. How disability has been perceived has influenced health care service provision, including rehabilitation. The disability movement and the development of the social model of health have been influential in affecting change in recent years.

With a focus on community settings rather than institution-based centers, CBR is one model of providing rehabilitation. There are a number of different models of CBR that have been developed in response to local needs and a number of other programmes of interventions which share some common goals, but have fundamental differences. One such programme is that referred to as *out-reach*. These programmes are run by health care workers e.g. physical therapists, at a local level to provide complex professional care which directly addresses patients' pathology, impairments, and / or disabilities (Kay et al. 1994; World Health Organization 1994).

Such services are controlled from an institution and there may be a mismatch between what the people need and what the institution can provide (Stubbs 2002). CBR is not the only model in which community participation is emphasized on the development of the Independent Living (IL) movement. While their origin is different they both developed as a response to criticisms of then traditional rehabilitation model that was dependent on highly trained health care professionals. The essential difference between CBR and IL is that the CBR model is one of

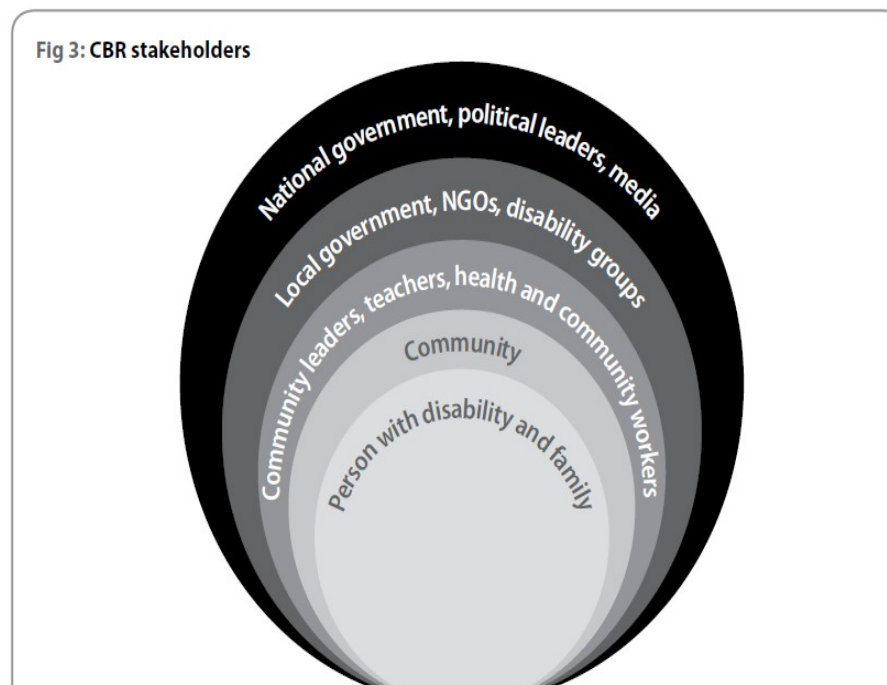
Primary Health Care and Community Based Rehabilitation: Implications for Physical Therapy partnership between the community and service providers, whereas control is seen as essentially being with disabled consumers in the IL model (Lysack and Kaufert 1994). In contrast to the IL movement it is often health care professionals who speak out in support of CBR and raise its profile, whereas in IL it is principally consumer

driven (Lysack and Kaufert , 1994). How well this is then translated through implementation is another matter.

Chapter Three

Roles and responsibilities of CBR key stakeholders

Many different stakeholders may be identified during a stakeholder analysis. These may include: people with disabilities and their family members, members of the community (including community leaders, teachers, etc.), civil society (e.g. nongovernmental organizations, religious organizations and women’s groups), disabled people’s organizations and government authorities (Fig. 3). It is important to remember that CBR workers and CBR programme managers are also stakeholders. Each stakeholder will bring skills, knowledge, resources and networks and will have specific roles and responsibilities regarding the development and implementation of CBR.



1. People with disabilities and their families

People with disabilities and their families play an extremely important role within CBR.

Their roles and responsibilities may include:

- playing an active role in all parts of the management of the CBR programme;
- participating in local CBR committees;
- being involved by volunteering and working as CBR personnel;
- building awareness about disability in their local communities, e.g. drawing attention to barriers and requesting their removal.

2. Community members

CBR can benefit all people in the community, not just those with disabilities. CBR programmes should encourage community members to undertake the following roles and responsibilities:

- ✚ participate in training opportunities to learn more about disability;
- ✚ change their beliefs and attitudes that may limit opportunities for people with disabilities and their families;
- ✚ address other barriers that may prevent people with disabilities and their families from Participating in the life of their communities;

3. Disabled people's organizations

Disabled people's organizations are a great resource for strengthening CBR programmes, and many currently play meaningful roles in CBR programmes. Their roles and responsibilities may include:

- ✓ representing the interests of people with disabilities;
- ✓ providing advice about the needs of people with disabilities;
- ✓ educating people with disabilities about their rights;
- ✓ advocating and lobbying for action to ensure that governments and service providers are responsive to these rights, e.g. implementation of programmes in compliance with the Convention on the Rights of Persons with Disabilities
- ✓ provision of information about services to people with disabilities;

4. Civil society

The roles and responsibilities of civil society organizations and groups will vary depending on their level – international, national, regional or community. Their roles and responsibilities will also be influenced by their level of experience and involvement in disability and CBR. Historically, many nongovernmental organizations have been at the centre of CBR work, so they may be the driving force behind any new or existing CBR programme. Generally, roles and responsibilities may include:

- ❖ developing and implementing CBR programmes where there is limited government

support;

- ❖ providing technical assistance, resources and training for CBR programmes;
- ❖ supporting the development of referral networks between stakeholders;
- ❖ supporting CBR programmes to build the capacity of other stakeholders;
- ❖ mainstreaming disability into existing programmes and services;
- ❖ supporting the evaluation, research and development of CBR

5. Government

Disability issues should concern all levels of government and all government sectors, e.g. the health, education, employment and social sectors. Their roles and responsibilities might include:

- taking the lead in the management and/or implementation of national CBR programmes;
- ensuring that appropriate legislation and policy frameworks are in place to support the rights of people with disabilities;
- developing a national policy on CBR, or ensuring CBR is included as a strategy in relevant policies, e.g. rehabilitation or development policies;
- providing human, material, and financial resources for CBR programmes;
- ensuring people with disabilities and their family members are able to access all public programmes, services and facilities;
- developing CBR as an operational methodology or service delivery mechanism for providing rehabilitation services across the country.

6. CBR managers

Management roles and responsibilities will depend on who is responsible for initiating and implementing the CBR programme and on the degree of decentralization, e.g. whether the programme is based at the national, regional or local level. In general, some of the roles and responsibilities of a CBR programme manager may include:

- ❖ facilitating each stage of the management cycle;
- ❖ ensuring policies, systems and procedures are in place for management of the programme;
- ❖ building and maintaining networks and partnerships both within and outside the community;
- ❖ ensuring that all key stakeholders are involved in each stage of the management cycle and are kept well informed of accomplishments and developments;
- ❖ mobilizing and managing resources, e.g. financial, human and material resources;
- ❖ building the capacity of communities and ensuring disability issues are mainstreamed into the development sector;

- ❖ managing day-to-day activities by delegating tasks and responsibilities;
- ❖ supporting and supervising CBR personnel, e.g. ensuring CBR personnel are aware of their roles and responsibilities, meeting regularly with CBR personnel to review their performance and progress, and organizing training programmes;
- ❖ managing information systems to monitor progress and performance.

7. CBR Workers

CBR personnel are at the core of CBR and are a resource for disabled people, their families and community members. Their roles and responsibilities will include:

- ✚ identifying people with disabilities, carrying out basic assessments of their function and providing simple therapeutic interventions;
- ✚ educating and training family members to support and assist people with disabilities;
- ✚ providing information about services available within the community, and linking people with disabilities and their families with these services via referral and follow-up;
- ✚ assisting people with disabilities to come together to form self-help groups;
- ✚ advocating for improved accessibility and inclusion of people with disabilities by making contact with health centres, schools and workplaces;
- ✚ raising awareness in the community about disability to encourage the inclusion of people with disability in family and community.