

## CHAPTER ONE: DEFINITIONS AND BASIC CONCEPTS

In discussing community-based rehabilitation it is necessary to carefully define disability, rehabilitation and community. It is important that the meaning of the main technical terms should be well understood and that these terms are used with consistency. This is not easy, as there are so many different definitions to choose from - and as most of these are compromises, worked out in committees.<sup>1</sup> Global efforts are being made at present to standardise the methods for undertaking disability surveys, and these may eventually lead to a harmonisation of concepts.<sup>2</sup>

### BOX 1.1. APPEARANCE AND DISABILITY

In Northern Mali, the most "disabling condition" for a woman is to be "ugly". This condition is defined in very clear terms. These women do not get married and consequently do not fulfill the normal parental role. If a man marries an ugly woman, it is commonly believed that the duration of his life will shorten by one day for each day of marriage.

In other countries, dwarfs, people missing an ear or an eye, a toe or a finger, or having an extra toe or finger, or with facial disfigurement or albinism, may have no functional limitations and yet be labeled disabled.

#### 1. *DISABILITY / DISABLED PERSON*

I will not try to introduce in this book all the complexities related to disability definitions. I will, however, point out a number of *cultural and developmental factors which will influence the concept of disability in the developing countries.*

"Disability" in the cultures of the Western countries is a cover term for many different conditions.<sup>3</sup> The idea of grouping together a number of very different conditions is a concept that is foreign to some cultures; instead, each condition may have its proper name. As that concept develops, it may follow the pattern described below:

##### *Phase 1. Concept based on local, traditional perceptions*

The simplest, and maybe the initial, definition of a disabled person appears to be the following:

"a person who in his/her society is regarded as disabled, because of a difference in appearance and/or behaviour". People "know" who is "disabled", and there are in all societies one or several terms to indicate this. There seems to be a tradition of what is and what is not "different".

In most instances, a disabled person has functional limitations or activity restrictions - two terms that will be defined later on. But this is not always true, as will be seen in the two examples presented in Boxes 1.1<sup>4</sup> and 1.2. The first example, illustrates the limits of what is considered "normal" appearance, and the second one, exemplifies the limits of "acceptable" behaviour.

### BOX 1.2. BEHAVIOUR AND DISABILITY

While visiting a CBR programme in Somalia I was shown a woman who had been identified as having a disability because of "strange behaviour". This woman, about 30 years old, had, during my visit, exhibited a perfectly normal appearance and behaviour, with no signs whatsoever of mental disorder. She lived with her married sister and assisted her in all household activities, helping the children, etc. The reason for considering her a disabled person was that her father had started arranging a marriage for her with an elderly, seemingly undesirable man when she was eleven years old. She had refused the marriage, and after this episode, she had been labeled a "fool". Her great difficulty was that whenever she stepped outside, the village children would shout abuse at her and throw stones.

Both examples show how, for cultural reasons, people will find themselves in a "state of disablement", facing negative reactions and prejudice from their community.

**BOX 1.3. THE CULTURAL ENVIRONMENT AND ITS INFLUENCE ON THE PERCEPTION OF DISABILITY**

A young man with a clubfoot (for which he underwent a successful surgical intervention) walks with a slight limp. The affected leg is somewhat shorter than the other, and he uses a shoe with a raised sole to compensate for the unevenness. In many developing countries, this man would be considered "disabled". Yet his impairment is slight, and he has no "activity restriction." In these countries, he might very well be denied vocational training, or if trained, be refused employment in spite of his qualifications for the particular job. This leaves him "handicapped" in his own country. In an industrial country, his physical condition would not be much of an obstacle to his entry in the labour market, and he would, in many countries, not be assigned to any "work disability" category.

A person with moderate mental retardation would, in a Western country, be "diagnosed" early on in life. Consequently, such a child is likely to be sent for special education. Given the high level of job requirements, such a person is unlikely to be employed in the open market later in life. Instead, at the age of 18 (or so), he or she would be given a disability pension for life. A similarly afflicted person in a developing country might not stand out, as there are so many other children suffering delays in their developmental milestones. When this child attends school, his or her learning problems might not cause much concern; perhaps he or she will drop out of primary school just like so many others. Such a child might conceivably be working in agriculture or performing household duties later on.

Two more examples (see Box 1.3) may serve to illustrate how social and cultural factor affect the perceptions of disability.

It should finally be pointed out that not all people - not even those with a visible disability - will be perceived as disabled. For instance, an adult who is amputated, receives a prosthesis and then continues his or her normal adult social role may not be seen as being "disabled".

*Phase 2. Concept based on difficulties experienced by the individual*

At this phase, the perceptions of disability will be oriented more toward identifying those people who are "different" because of functional limitations and/or activity restrictions.

A "functional limitation disability" may be defined as "specific reductions in bodily functions that are described at the level of the person". The main such limitations<sup>5</sup> may include difficulties that a person has, for instance, with

- *moving (including dexterity: fingering, gripping, holding);*
- *speaking, hearing (listening), understanding speech;*
- *feeling (reduced skin sensation);*
- *learning (acquisition of knowledge, skills and behaviour);*
- *location in time and space (memory);*
- *self-awareness (inappropriate interpretation of and response to, external events, confusion);*
- *decreased consciousness (including epileptic fits).*

The term "activity restriction disability" may be defined as "specific reductions in daily activities that are described at the level of the person". Examples of the main activity restrictions difficulties that a person has, for example, concern

- *personal care (e.g. dressing, bathing/washing, eating/drinking, toilet);*
- *being mobile (e.g. moving in bed, sitting, standing, walking, running);*
- *communicating;*
- *participating in education;*
- *work performance, including household duties;*
- *behaving and socializing;*
- *childcare.*

Some comments are needed:

- there are many degrees of functional limitation and activity restriction, from very slight to very severe. Most persons with disabilities who are dependent on others or who could improve their performance, will need rehabilitation. One of the problems with monitoring disability through statistics is the difficulty of drawing a clear line between disabled and non-disabled people;
- disabilities sometimes become apparent or more pronounced as a result of environmental factors, including restriction of human rights (such as denying a disabled child schooling).
- functional limitations and activity restrictions may be reversible, following e.g. curative treatment or rehabilitation.

### *Phase 3. Concept based on official recognition*

In many developing countries, efforts have started to provide services for certain recognized groups of disabled people.

At the very beginning, these groups often included injured freedom fighters or war heroes. Efforts focused frequently on providing rehabilitation, as well as on paying disability pensions to make up for the loss of income which such persons might have incurred as a result of a serious disability. Other groups, which have received official recognition, services and benefits, are traffic injury victims, military personnel and government civil servants. In many cases, an insurance system or a social security system has been set up for these categories of people.

Most social security systems begin with benefits awarded to employees suffering from impairments - not necessarily resulting in any disabilities - related to occupational injuries or diseases. In most developing countries, the coverage of such systems is as yet limited, typically not exceeding 5 to 15 per cent of the labour force and concentrating mainly on those working in the largest enterprises. In many industrialized countries, the process of providing social security benefits for disability is nearing complete coverage. It is very likely that the social security systems in the developing countries will undergo a similar expansion. With time and as a result of socio-economic development, persons with disabilities will be officially recognized as such and provided with the necessary services and compensatory benefits.

Disabled people receiving this kind of official recognition may not be easily perceived as "different". Their appearance and their behaviour may be totally "normal". Some suffer from chronic diseases, such as cardiovascular or lung conditions. Others may be afflicted by visible limitations following neurological or rheumatic disorders. Others may be mentally fragile, or suffer from chronic alcoholism or drug abuse.

Disability may be a "label" for people who are marginal on the labour market, for people who may be "slow" and lacking usable skills. Or they may be victims of the process of ever increasing demands at the workplace, where they are unable to compete. Finally there are those whose medical conditions may be insignificant, but who have been squeezed out of the labour market in times of growing unemployment. (See Box 1.4<sup>6</sup>.)

### *Phase 4. Concept of self-recognized disability*

After World War II, some affluent countries have been building extensive support systems for disabled people. Political decisions were taken to compensate for loss of income or quality of life through payment of lump-sum benefits and disability pensions. In many cases, such benefits used to be easily awarded to a person out of work, but on social rather than medical grounds.

Some of these benefits were initially related to wheelchair users, entitling them to free or subsidized transportation (e.g. by taxi). Eventually, large groups of people, in particular elderly persons who had trouble (even of a minor sort) using public means of transportation, were given transportation services. Another kind of assistance consisted in subsidized housing, originally devised to pay for the extra space

needed for a wheelchair user. Eventually, large groups of other "disabled people" were seeking - and receiving - this type of benefit.

In numerous countries, "disabled people" were encouraged (and given grants) to form their own associations or interest groups. This resulted in new organisations of people, grouping together, for example, people with chronic diseases such as psoriasis, allergies, diabetes. Each of these "self-recognized" groups of disabled people sought benefits for its members: allergen- and dust-free compartments on trains, annual trips abroad for medical care in a more temperate climate, to name a few. A recent study in USA showed that 15 per cent of all Americans over 15 years of age, considered themselves disabled.

Some critics feel that this development has produced a sort of "disability culture" and that the system was exploited. An example to illustrate this point is presented in Box 1.5. Austerity programmes are now under way in many countries. Politicians are cutting spending and hurdles are being put in the way of granting status as a "disabled person".<sup>7</sup>

When one compares the definitions based on traditional, local perceptions with those based on self-recognition, it is evident that they have little in common. Indeed, to find a common denominator for what is globally considered a "disability" is by no means an easy undertaking.

In this book, the *following operational definition of disabled person will be used*<sup>8</sup>:

*A disabled person is the one who in his or her society is regarded or officially recognized as such, because of a difference in appearance and/or behaviour, in combination with a functional limitation or an activity restriction.*

Most disabilities are caused by a health condition, such as a disease, a congenital malformation, a trauma, or by malnutrition.

Sometimes environmental factors and disadvantages, including restrictions of human rights which prevail where the disabled person lives, will lead to more pronounced consequences.

## 2. REHABILITATION

The original meaning of the term 'rehabilitation' is "to restore a person's dignity and/or legal status", and now as before this seems adequate.<sup>9</sup> The *scope of the term has changed*, a development that has been noticeable in the industrialized countries over the last 40 years, and we may follow the phases suggested

### **BOX 1.4. EARLY RETIREMENT ON DISABILITY PENSION AS A POLITICAL TOOL**

In a number of industrialized countries, labour supply exceeds labour demand, and a number of restrictions have been introduced to lower this supply. These include: prolonged schooling, restrictions on foreign labour immigration, repatriation of guest workers, reduction of working hours, increased paid leave, early retirement, and disability retirement programmes.

The number of disability pensioners and their proportion of the labour force have risen considerably during the last decades. In Australia, the number of "invalid or disability support pensioners was about 139,000 in 1972, and had increased to about 379,000 by 1992. This increase was especially noticeable among men: in 1972 there were 18.6 such pensioners per 1,000 population of working age; in 1987 the corresponding figure was 39.9. By contrast, there was no similar increase among women. In Canada, there were, in 1970, only 1,302 beneficiaries receiving disability pension; in 1992 their number had grown to 272,137. In Finland, 7.7% of the labour force were (in 1970) recipients of invalidity pensions; by 1992 this proportion had risen to 11.1%. In Holland there were, in 1971, 237,000 people receiving disability pensions - equivalent to 5.0% of the labour force; in 1992 the number of such pensioners had gone up to 915,000, or 12.6% of the labour force. About 15% were under the age of 35 years. In Sweden, some 167,000 received permanent disability pensions in 1970 (3.3% of the population aged 16-64). A noticeable increase has occurred since then, and in 1992 there were 327,000 such pensioners (or 6.0% of the population aged 16-64).

It should be noted that these changes appeared during a period when the needs for services, in particular for the disabled elderly, were increasing drastically and remained to a large extent unmet. In the near future, the industrialized countries will witness a contraction of their working-age populations, so the political tools for reducing the labour force may be modified.

below.

*Phase 1. Concept focusing on the disabled individual*

An example of a definition focusing on the individual is the WHO definition of rehabilitation (1969) offered by an expert group<sup>10</sup> "... the combined and co-ordinated use of medical, social, educational and vocational measures for training or re-training the individual to the highest possible level of functional activity".<sup>11</sup>

**BOX 1.5. TAKING ADVANTAGE OF THE WELFARE SYSTEM**

It is reported from Holland that about 13 per cent out of the labour force, or some 900,000 out of six million, are registered as unable to work for mental or physical reasons. In 1990, 116,000 people were recognised as disabled. For one third of those, the cause was stress.

The people at work in Holland support a large number of non-workers. For every 100 workers there are 86 others who receive disability pensions or other government grants because of unemployment.

The system is now under reform. The same is true of the Scandinavian countries. Sickness benefits based on self-declared inability to work, which amounted to 80-96 per cent of the take-home salary, are cut. In several countries in northern Europe, the average annual time on sick leave was about three weeks until a few years ago - the healthiest countries in the world had the most people off sick.

The welfare system has not only tempted workers to stay home when just feeling "tired." It has also been taken advantage of by employers who, when their profitability is somewhat close to the margin, have deliberately moved large groups of workers over to the benefit system.

*Phase 2. Concept recognising the importance of physical barriers in the environment*

Professionals early on recognised the role the environment plays in rehabilitation. This was of particular importance for people with moving problems. They encounter difficulties climbing stairs, passing through narrow doors or passages, using ordinary bathrooms and kitchens or public means of transportation, or moving outdoors on steep hills or in the terrain.

Other problems concerned people with impaired vision, having difficulties crossing roads, entering transport facilities, orientation in shops, receiving information via newspapers, etc. People with hearing difficulties were at a disadvantage in road traffic, communicating in shops, public offices and courts.

As these problems were realised, rehabilitation programmes in the industrialised countries started including interventions aimed at adapting the environment. New architectural norms for housing were issued. Buses, metros and trains and entrances to public buildings were specially designed. Special traffic signals were provided for people with poor vision. Braille signs were put in elevators and interpreters were provided for deaf people.

Until now only a few industrialized countries have more or less completed these changes. For others the main efforts are still to be made. But today these adaptations in the physical environment for each individual, as well as general changes, are considered an integral part of a rehabilitation programme.

*Phase 3. Concept related to equalisation of opportunities*

This term was introduced in 1981, and I quote the definition, which appears in the Manifesto of the Disabled People's International<sup>12</sup> :

*"Equalization of Opportunities means the process through which the general systems of society, such as the physical environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all. This involves the removal of barriers to full participation of disabled persons in all these areas, thus enabling us to reach a quality of life equal to that of others."*

Rehabilitation professionals had questioned the general access to society, many years before the above term was coined. Regulations or laws excluded disabled children from inclusive schooling, others barred adolescents and adults from access to vocational training and jobs.<sup>13</sup> There was reluctance to socially integrate disabled people into public services, housing, transportation, leisure, sports, workplaces, etc. Authorities often sought "special" solutions in terms of separate facilities for living, sheltered workshops for work, special medical, educational and vocational services away from the mainstream, and so forth.

The concept of equalisation of opportunities served to draw attention to the widespread discrimination experienced by all disabled people in all societies. The World Programme of Action Concerning Disabled Persons (U.N. 1982) and the U.N. Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1994) are now major global policy instruments.

#### *Phase 4. Concept focusing on human rights*

The term 'equalisation of opportunities' is cumbersome and is poorly understood by many people in the developing countries. It does not fully express the new orientation sought. Opportunities should be provided in any case on an integrated basis and not separate from the "mainstream." The term reflects the development debate during the 1970s and 1980s. At that time, more equitable opportunities and full participation were sought for many disadvantaged groups, such as women, minorities, special ethnic groups, the rural poor and slum-dwellers. The concept was applied also to disabled people.

Another important concept - which is not identical with the preceding one - relates to "equal access to and distribution of resources;" new mottoes were created, e.g. "new economic order," "health for all," "education for all."

We have already gone beyond these concepts to consider the vital question of human rights for disabled people. Compared to the terms mentioned above, "human rights" is a much more general term, and it is better known worldwide. Also, it expresses more fully the direction sought for development programmes in favour of disabled people. For what appears to be political reasons, the term human rights was for a long time not sufficiently promoted. But in the wake of constitutional reform and democratisation - many governments of developing countries have become more receptive to proposals that openly promote human rights.

Efforts to promote and protect the human rights of disabled people are seen as one of the corner stones of the CBR strategy. Such rights are described in the UN Universal Declaration of Human Rights, as well as in the constitutions of most countries. These legal instruments spell out a number of rights that apply to "all citizens."<sup>14</sup>

To conclude, I have chosen in this work to widen the term rehabilitation to encompass

- all interventions/training provided for the disabled individual,
- all changes/adaptations in his/her own local physical environment,
- all general changes needed in the environment in order to diminish or eliminate barriers for disabled people,
- equalisation of opportunities provided on the basis of integration and inclusion.
- promotion and protection of human rights and empowerment.

The operational definition of 'rehabilitation' is reproduced on page 8.

### *3. COMMUNITY*

As I will use the term "community" many times in this book, a short definition<sup>15</sup> may help to clarify its meaning.

*"A community consists of people living together in some form of social organization and cohesion.*

*Its members share in varying degrees political, economic, social and cultural characteristics, as well as interests and aspirations, including health. Communities vary widely in size and socio-economic profile, ranging from clusters of isolated homesteads to more organized villages, towns and city districts."*

We have to recognise that communities are not always homogeneous or static entities. A "traditional" rural community might have all its members coming from the same ethnic group, speaking the same language, sharing the same culture and religion in a community tightly knit through family connections, and its members accepting and following their leaders.

Only some of these conditions might exist in other rural or in marginal urban settlements, and as a consequence a "community spirit" might not be so easy to identify. In such an environment, it may take longer to get a community response to the call for an effort to show solidarity with the disabled members.

#### 4. COMMUNITY-BASED REHABILITATION.

The term community-based rehabilitation is defined on p. 8.

#### COMMENTS AND REFERENCES

<sup>1</sup>Definitions of the terms impairment, disability and handicap and of the disability process are offered by WHO in: WHO Document A29/INF.DOC/1, Geneva, Switzerland, 1976;

International Classification of Impairments, Disabilities and Handicaps, a manual published for trial purposes, WHO, Geneva, Switzerland, 1993, which includes the following most often cited definitions:

"an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function;

"a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being;

"a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual."

Technical Report Series No. 668, WHO, Geneva, Switzerland, 1981.

UN has definitions of "disabled people" and "handicap", appearing in: Declaration on the Rights of Disabled Persons, adopted by the UN General Assembly on 9 December 1975.

World Programme of Action Concerning Disabled Persons, UN 1985.

An ILO definition can be found in:

ILO Recommendation No. 168, ILO, Geneva, Switzerland, June 1983.

DPI has published definitions of disability and handicap in DPI "Manifesto", Singapore, 1985.

<sup>2</sup> A review of these efforts has been published in M. Chamie: Report of the Committee on the Conceptual Harmonization of Statistics for the study of disability-free life expectancy. Reves paper No. 41, INSERM, Montpellier, France, 1990, and M. Chamie: Harmonization and use of health expectancy indices, International Network on Health Expectancy, Ottawa, Canada, 1992.

<sup>3</sup> An interesting discussion on what counts as a person with a disability in USA appears in M.P. La Plante "The Demographics of Disability", published in (Ed. J. West): "The Americans with Disabilities Act", Milbank Memorial Fund, New York, USA, 1991.

<sup>4</sup> F.Q. Halatime and G. Berge: Perceptions of disabilities among Kel Tamnsheq of Northern Mali. In Bruun-Ingstad (Ed.): Disability in a Cross-Culture Perspective, Department of Social Anthropology, Oslo, Norway (1990).

<sup>5</sup> M. Chamie, *ibid.* The text in page 12 is adapted from the Manual TCPD and from Chamie.

<sup>6</sup> For a review, see: B.A. Mirkin: Early retirement: an international review, Monthly Labour Review 110, p.19, March 1987. The information in Box 1.4 has been supplied by the International Social Security Association, Geneva, Switzerland.

<sup>7</sup> U.S. Public Law 101-336 (Americans with Disabilities Act, 1990) excludes the following categories of self-recognised disabilities from the benefits of the Act:

"(a) HOMOSEXUALITY AND BISEXUALITY. ...are not impairments and as such are not disabilities under this Act.

"(b) CERTAIN CONDITIONS. - Under this Act, the term "disability" shall not include -

1) transvestitism, transsexualism, pedophilia, exhibitionism, voyeurism, gender identity disorders not resulting from physical impairments, or other sexual behavior disorders;

(2) compulsive gambling, kleptomania, or pyromania; or

(3) psychoactive substance use disorders resulting from current illegal use of drugs."

<sup>8</sup> Such disadvantages are causing "handicaps" as defined in the International Classification, etc. (see Comment 1). These include isolation, restriction in mobility caused by obstacles in the home/house, inaccessible transport, attitudinal barriers, lack of opportunities, etc. The term "handicap" is not used in this book.

<sup>9</sup> V. Finkelstein has written several articles criticising the use of "cure and care" language used by many rehabilitation professionals and suggests a terminological and conceptual framework that might take better account of the social aspects of disability. *Attitudes and Disabled People*, World Rehabilitation Fund, New York, USA, 1980. See also *World Health Statistics Quart.*, 42, WHO, Geneva, Switzerland, 1989.

<sup>10</sup> WHO Technical Report Series, No. 419, WHO Expert Committee on Medical Rehabilitation. WHO, Geneva, Switzerland, 1969.

<sup>11</sup> J.G. Greenwood points out that "rehabilitation for handicapping conditions ... implies not necessarily the restoration of maximum functional activity or independence, but the restoration of maximum social function, including work and family roles"; see "Disability dilemmas and rehabilitation tensions: a twentieth century inheritance", *Soc.Sci.Med.*:20:1241, 1985.

<sup>12</sup> DPI Manifesto, Singapore, 1981.

<sup>13</sup> The underlying idea is somewhat similar to what has happened to health services. At the time of their inception, the purpose was to cure individuals. With time, it was realised that the environment was a highly significant factor in all questions concerning health. So clean water, sanitation, health education, etc. began to be provided. Then the emphasis shifted to the general systems of society, with more attention being paid to the role of nutrition, exercise, tobacco, alcohol, stress, conditions at the workplace, etc., for health.

<sup>14</sup> L. Despouy: *Human Rights and Disability*, UN Economic and Social Council, Doc. E/CCN.4/Sub.2/1991/31. UN, New York, USA, 1991.

The U.N. "Standard Rules on the Equalization of Opportunities for Persons with Disabilities" was adopted by the General Assembly in 1993

<sup>15</sup> This definition is quoted from: World Health Organization: Resolution WHA 30/43 concerning primary health care; Geneva, Switzerland, 1977; The Alma-Ata Declaration, Geneva, Switzerland, 1978.