

CHAPTER EIGHT: PRINCIPLES, OBJECTIVES AND GENERAL APPROACHES RELATING TO COMMUNITY-BASED REHABILITATION

1. PRINCIPLES OF CBR

Community-based rehabilitation is founded on a set of principles described below.

To establish principles that are totally consistent and free from contradictions is not easy to do.¹ There is nothing new or eccentric about the five ideas of equality, social justice, solidarity and integration and dignity highlighted here. We should, however, note that these principles, for example, the one concerning equality, are not always part of the local or national culture. In others, nobody will object to them. However, they may not be applied.

Equality

All human beings are of inherently equal worth, are entitled to equal rights and share the same responsibilities. Human beings are born each a unique individual. Each develops along different lines. Each has different abilities. These differences do not make us unequal in worth.

It is a fact that disabled people in most or all societies are denied equality in rights. This reflects the prevailing social attitudes of our societies, which are biased toward admiring and rewarding certain abilities while disregarding many other qualities.

Disabled people face a situation similar to that of women in some societies, who, until recently, were denied the right to vote and earned lower salaries than men for the same work do. Some countries still will not let disabled people participate in political functions or give them a vote.

Disabled people are responsible neither for their situation nor for such attitudes. They are the victims. Disability is caused primarily by environmental factors – such as disease, trauma and lack of prenatal care. Involuntarily affected by such factors, people with disabilities may see their hope for a better life deteriorate in the face of social insensitivity to their needs for equality.

They may be denied the right to rehabilitation, education, employment and social integration. Insensitivity may lead to their rejection or even to the questioning of their right to life.

One of the most fundamental questions relative to equality is "Who has the power over a disabled person?" Is it the authorities and experts, or is it the disabled individual himself or herself? If there is one characteristic that is common to the group of disabled people - standing out over and above such others as poverty, lack of services, lack of access to education and employment - certainly that characteristic is powerlessness.

One of the aims of a rehabilitation programme should be to stress the abilities and competence of disabled people, to increase their responsibilities and rights, to apply more equal and more human standards to these fellow human beings, and to strengthen the process of empowerment.

In order to achieve this we have to overcome prejudice and reject arbitrary concepts of difference concerning disabled people, which have been reinforced over many centuries by tradition and dominant power structures, and which today represent formidable roadblocks on their way.

Social justice

Social justice implies that services and opportunities provided for disabled people should be at the disposal of all and not be reserved for a numerically small group among them. It stands to reason that the ultimate goal is to make individualised care, training, schooling, and access to employment and income-generation available to all disabled people. These are vital contributory factors to integration, independence and self-actualisation. Achievement of this objective is, however, many years away. In the meantime, guided by the principle of social justice, we should endeavour to build programmes that will eventually give *all disabled* people at least the *essential services*.

TEN BASIC RULES FOR INTEGRATED LIVING

1. *Family life:* As a person with a disability, you should have the freedom to find a partner, have children, and set up your own family. You should live with your family and be part of your community.
2. *Shelter:* You should have shelter and be able to move about freely at home and in your surroundings.
3. *Food:* As an infant, you should be breast-fed. As a child and as an adult, you should have a fair share of your family's food.
4. *Schooling:* As a child with a disability, you should go to school with the non-disabled. Your teacher should have learned how to take care of your special needs and to include you in all school activities.
5. *Education and training:* You should get the opportunities for education and training that you need in order to prepare yourself to work and to live independently.
6. *Leisure time:* You should be free to join others on social, cultural and religious occasions.
7. *Public services:* You should have access to all public services and all public buildings. Roads and public transport should be designed in such a way as to let you move and mix freely and independently in society.
8. *Association:* You should not be denied membership of any associations or organisations open to all, and you should be free to form or join an association of disabled people, should you so wish.
9. *Economic opportunities:* You should have the same opportunities to work as other people; any loss of income caused by your disability should be compensated.
10. *Political participation:* You should be allowed to vote and to participate in government as other citizens do. Your voice should be heard in matters of concern to you and regarding services provided for you.

Social justice further implies that one should not seek to accord disabled people privileges that go beyond what they would have been entitled to had they been able-bodied. It is true, disabled people today rarely enjoy their legitimate human rights. Positive discrimination is widely believed to be a means to remedy this situation. Rather than attempting to formulate yet another and another bill of rights - all of which eventually will fail for the same reasons - one should look into the underlying causes of the non-application of legitimate existing rights and remedy that situation.

Solidarity

The responsibility for fostering human life is shared by all. Solidarity should be shown toward those among us who are dependent and need help - children, the elderly, and those who have a disability. Solidarity of purpose and efforts toward this end should be seen as a privilege of all and not as charity for some.

In industrialised countries, it is common to have systems designed to transfer resources (cash, pensions, subventions, and services) from one group to another, for example, from the employed to the unemployed. Normally, disabled people should benefit from such transfers if they do not earn enough to enable them to live decent lives. In developing countries, the extended family, the tribe, or the clan plays a similar function. Dependency is not a characteristic limited to disabled people. On the contrary, all human beings are dependent on each other during many years of their lives. Solidarity is one of the main principles of our societies, without which none of us could survive.

Integration

All members of the society should join in the mainstream of community life.

Disabled people are often excluded from the activities of a particular society because they are looked upon as "special" or "strange." There is a clear correlation between the policy of providing special, segregated services and the attitudes of most non-disabled people in favouring the segregation of disabled people.

Segregation of services, housing, jobs, education transportation and so on, is mainly caused by social factors and cultural prejudice.

Segregation is a vicious circle. As long as disabled people are out of sight, nobody will get to know them, and fear and anxiety about meeting these hidden members of society will grow.

Integration of disabled people in all aspects of life will, in the long-term perspective, help them to achieve friendship with and esteem by others, and finally, to attain the degree of human dignity now denied to most of them. Ten basic rules for integrated living are suggested, which exemplify this principle. (Box 8.1.)

Dignity

The final guiding principle is dignity. All disabled people should live a life in dignity. The term "dignity" may be defined as follows: "the quality that earns or deserves respect."²(Box 8.2.³).

Box 8.2

DIGNITY for a disabled person is possible when:

- it is recognised that all human beings have equal worth and equal rights;
- all are willing - in the spirit of solidarity - to share the opportunities and means needed for self-actualisation;
- he or she is fully participating in the life of the community.

2. OBJECTIVES

Based on the above principles, the broad long-term objective - or goal - for rehabilitation is: ***"to promote a development that eventually will allow all disabled people to live a life in dignity."*** To achieve this end requires actions aimed at, among others:

- providing all the rehabilitation services needed;
- reducing or eliminating environmental barriers;
- compensating disabled people for any loss in their standard of living caused by disability;
- promoting social integration and self-actualisation;
- protecting and ensuring the security of disabled people;
- empower disabled people, so they can exercise their rights and have adequate representation and influence in the society where they live.

The realisation of these actions will depend on the willingness of society to provide the necessary resources and social means in a spirit of solidarity. This can only be brought about by a change of prevalent attitudes and behaviour. Sensitisation and education of the public at large are important means for reaching the ultimate aim of gaining equality for disabled people. Another requirement is that governments take over the leading role and assume the responsibility for disabled people in the same way as they do for non-disabled citizens.

Obviously it will take many years to translate this broad objective into practice, so we need to devise realistic, long-term, step-by-step approaches along with a strategy for their application.

3. GENERAL APPROACHES

Learning from the people

The first element in the approach to CBR⁴ is to learn from the people. In the conventional rehabilitation model, efforts had been made to transfer the technology, types of professionals and service systems existing in the industrialised world. This has largely failed. The essence of the CBR approach is to find out what is locally initiated, in terms of successful technology, service and management systems, in each developing country and to build on this experience. Not until the applied local approach builds on this general principle will the development be sustainable. Such a review of existing technology, service and management systems should not be confined to the disability area. There is a host of development projects initiated by local communities, and analysing their achievements as well as their failures will teach us a great deal. Such development projects may be concerned with, for example, community water supply, agriculture, primary health care and elementary schools.

We should therefore set out by looking for the inventive parents who have successfully trained their blind child to walk around in the village, or their mentally retarded adolescent to work in the fields. We should seek the advice of the schoolteacher who has included disabled children in the local school, as well as that of the artisan who has made crutches and wooden legs.

We should learn management from local community leaders, and principles of community work from existing co-operatives and development committees, and we should learn to respect the abilities and experience of the local people - and listen carefully to their views.

Hence, the principle is to look for what there is already and to learn from the people - this should be the point of departure of any development effort.

Building and upgrading the system from below

The conventional system often started off by providing a "national centre" or similar, in the belief that later on this centre would develop ramifications and decentralised services. In reality this has rarely been the case. National centres stayed national centres, and more often than not they turned into ivory towers.

The CBR system endeavours to start development from below, by first encouraging the establishment of community services and, at a later stage, linking them to a referral system. The referral system should be created once the community needs are known, preferably after a certain period of implementation.

In a system built from below, the educational objectives for professional staff working at referral centres will be formulated in response to local requirements while taking into consideration how existing resources could be restructured and decentralised.

At its inception, a CBR system will necessarily be simple. Over time it should be upgraded from below, by improving community workers' competence through in-service training programmes. Parents or other family members who act as trainers of disabled individuals will develop their abilities through experience. Local schoolteachers could learn more about how to integrate disabled children in the class, possibly with the assistance of a mobile resource teacher. Community leaders could start projects for integrated, informal ability training and help disabled people to an income-generating activity. Human rights could be

protected if the community provides mediation. And disabled people could obtain more say and better representation of their views.

CBR programmes owe much of their success to the principle of building and upgrading the system from below.

Do not look for instant or easy solutions

There are no quick or easy solutions. It will take years to adapt the technology to suit individual requirements, to inspire community involvement and organisation to train all the necessary personnel, to set up service systems to cover entire populations, to build up management resources, and to locate the necessary funds.

There is no such thing as a standardised CBR system, nor can this system be copied from country to country. Certain patterns can be duplicated, and experience can be shared, but each country has to make its own adaptations.

Other problems - such as those related to prejudice and application of human rights - will take even longer to resolve, given our very limited experience in how to apply awareness-building, sensitisation and public education programmes.

All governments seeking to improve the quality of life for their disabled citizens, should bear in mind that sustained, active efforts will be needed for a period of 15 to 25 years, if not more. The involvement of governments is necessary, for there is no other way to create a well-functioning network of services. But governments have limited funds and should not "promise to do everything". No nations have more resources than those, which can be mobilised through their own people; for rehabilitation services, a participatory approach is needed, involving people.

COMMENTS AND REFERENCES

¹The idea of e.g. equality is treated in an excellent and clarifying essay by I. Berlin in *Concepts and Categories*, Oxford University Press, Oxford, UK, 1980. T. Sowell in *A Conflict of Visions*, Quill-Morrow, New York, 1988 reviews the ideological origins of political struggle, the conflict between constrained and un-constrained visions are seen as the major influence.

²A.S. Hornby: *Oxford Advanced Learner's Dictionary of Current English*, Oxford University Press, Oxford, UK, 1987. A review regarding "Human Dignity, Respect and Consideration for Mentally Disabled Adults" was published as "Official Recommendations from the National Swedish Board of Health and Welfare" in Stockholm, Sweden, 1987. See also: *Human Dignity, Respect and Consideration for Mentally Disabled Adults*. Official Recommendations from the National Swedish Board of Health and Welfare, Stockholm, Sweden, 1987.

³Ethical issues have during the past 20 years or so become major preoccupations in the industrialised countries. See B. Duncan and D. Woods (Ed.): *Ethical Issues in Disability and Rehabilitation*, New York, USA, 1989, published by the World Institute on Disability, Rehabilitation International and World Rehabilitation Fund. Some examples of problems that arise are:

- (a) what is the appropriate action for disabled people who survive only through the use of expensive life-supporting systems? This problems occurs in affluent countries, but there may be insufficient means to finance this type of service for all who need it;
- (b) should professionals assist severely disabled people who do not want to live any longer in committing suicide?
- (c) should professionals, by withdrawing treatment, cause the death e.g. of infants born with a severe disability?

There is no lack of articles and documents dealing with these and similar subjects. Applying ethical principles is no doubt complex. In the developing countries, the issues mentioned above are not yet a subject of many debates.

⁴The most important principles and approaches of and to special education are described by T. Jönsson as follows:
"Special Education should be:

- * RECOGNIZED as a responsibility for all in the school system,
- * NATIONAL available to all who need it,
- * ACCESSIBLE by eliminating physical barriers,
- * DECENTRALIZED as part of the regular school system,
- * INTEGRATED allowing children with special educational needs to be educated in the "least restrictive environment", still meeting the child's special educational needs,
- * FLEXIBLE and child-centered with a content that is life-centered rather than subject-centred,
- * COMPREHENSIVE, looking at the total needs of the child during its entire childhood,
- * CO-ORDINATED at all levels,
- * PROFESSIONAL carried out by adequately trained and dedicated teachers,
- * REALISTIC by considering the actual economic, technical, social, cultural and political realities.

Source: T. Jönsson, *ibid*.