

## ***CHAPTER THIRTEEN: CBR AND THE ROLE OF PEOPLE WITH DISABILITIES AND THEIR ORGANISATIONS***

People with disabilities, their families and their organisations can and should play an extremely important role within a CBR system.<sup>1</sup>

### ***1. CARE PROVISION***

Adult disabled people have a role related to self-care and home-care. In the case of disabled children, it is the family who provides the bulk of home-based rehabilitation. Some disabled persons teach other disabled adults to read and write or contribute to ability/vocational training. For a certain proportion of disabled people rehabilitation may not be a realistic option. They will need care and the family should provide this.

There is evidence that recruiting disabled people as local facilitators for CBR gives excellent results. I am not advocating that all LFs should be disabled. Monopoly jobs should be avoided. The same applies to intermediate-level supervisors and specialists at referral levels.

### ***2. SENSITISATION, ANIMATION AND MANAGEMENT OF CBR AT THE COMMUNITY LEVEL***

Communities need to be sensitised to the fact that there are many disabled people in their midst - and that they have resources at their disposal to handle the major part of the disabled people's service needs.

Disabled people and their families should help in awareness building and stimulate animation locally, help mobilise resources and have an active part in the local management committee.

Successful disabled adults can play a particularly useful role: by meeting young people in the local schools, for instance. (See Box 11.5.). This might be one way of overcoming some of the negative images developed in the past.

As members of the rehabilitation committee, they can become actively engaged in home visits, in analysing the local situation, as well as in proposing ability training and jobs. They should play an active role in the management of the local project; planning and evaluation are important components.

Another area for action is drawing attention to environmental barriers and requesting their removal.

Disabled people should, at this level, also work toward ensuring that they will not be deprived of their human rights. If these rights are violated, they should approach those in the community responsible for legal protection and request them to take action.

### ***3. NATIONAL ORGANISATIONS OF PARENTS AND OF ADULT DISABLED PEOPLE***

The priority should be to build up local organisations. In our experience, the first one to be set up is often a parent organisation. Later on, disabled adults form their own groups - as a rule they do so at the end of their schooling.

Such groups are to be seen as having both social<sup>2</sup> and political functions. It is a place for getting together with others who have similar problems and needs. But an organisation can also act as an interest group to

voice their members' needs vis-à-vis local leaders and authorities. Where there exists more than one such special interest group, joining together in a local federation or in a union, as a more representative body, would give them more political weight.<sup>3</sup>

At a later stage, local groups may join provincial or regional ones and eventually form a national organisation. A union representing all groups of disabled people and their families could be set up and request formal recognition. Such a group would be a valuable partner for the government to consult in all matters concerning services for disabled people. This does not prevent each of the member organisations from keeping its specific profile and from continuing to carry out their social functions. A national federation or union or coalition can play a significant political role, making the public aware of the problems disabled people face and of the contributions they can make to society. Many such unions have approached political parties and other powerful groups to promote their ideas.

As pointed out with reference to the community level, disabled people's organisations have a crucial role to play when it comes to promoting environmental changes and seeking protection of their human rights. The authorities must be made aware of the fact that providing services and opportunities is not enough.

Regrettably, in most developing countries the development of organisations seems to start more often than not from the top and not from the grass-roots. It is also unfortunate that there should be such fragmentation and lack of cohesion, considering the adverse effects this has on the attention a government will give to these interest groups. Disabled people should not confine themselves to joining their own separate associations. Rather, they should strive to become members of groups of non-disabled people representing political, cultural, religious, social, environmental and other interests. Integrating themselves in this way will serve to sensitise all such groups to the special needs of disabled people.

#### 4. *INDEPENDENT LIVING*

The "independent living" movement started in USA about 20 years ago<sup>4</sup>, by groups of persons with moving disabilities. It is a broad concept to **free persons with disabilities from the physical, psychological and economic dependency on others**. Research<sup>5</sup> has been carried by several authors and resulted in the confirmation of a positive outcome regarding "living arrangements" (abilities of daily life to dress, feed, bathe by oneself, use public telephone and deposit money in a bank account).

Other studies concerned "productivity status" (employment, schooling, participation in a community organisation, participating in homemaking and in active leisure pursuits). De Jong in an early study proposed a weighting scale with 13 grades (reproduced in Tables 15.1. and 15.2)

The "Independent Living" movement has made great advances. It has brought awareness about abilities that disabled people were often discouraged from using. It has focused on the lack of public support and the important role that environmental barriers play for those with moving difficulties. But looking beyond the physical and economic factors, this movement has served to strengthen unmet needs of self-esteem, recognition by others and self-fulfilment.

There are now in developing countries, small groups of organisations for independent living. We are likely to see more of them in the future.

#### 5. *EMPOWERMENT*

Empower means "to give lawful power or authority to act."<sup>7</sup> This definition is used to describe the legal process, through which for instance a local authority will carry out an act decided at a higher level - a decentralisation process. Giving power also means transfer of responsibility and accountability.

The concept of “empowerment” started to be developed in the scientific literature, mainly as a result of the political activism seen in USA during the 1960s. It was related to the concerns about local influence on community development, activism, and mobilisation of minority groups.

Empowerment is a ‘new model’, different from the two that have until recently dominated the efforts to solve social problem: the ‘expert model’ and the ‘representation model’. The ‘expert model’ is built on the idea that people, who encounter social difficulties, cannot themselves find the way out of these. They are looked upon as children.

The ‘representation model’ claims that an outsider has to speak on behalf of the individual or group in order to bring about a change. In the context of persons with disabilities empowerment is seen as a process of mobilisation and activation

“Empowerment” has several definitions. One such is “the process by which individuals gain mastery over their lives and a better understanding of their environment”. Those, who use this definition propose that on the individual level one should consider three components: “a) the ability of the disabled person to cope within the family framework, b) the ability to fully utilise available services and resources, and c) the ability to develop a comprehensive perception of the structure of the services available at all levels”.

Others may see the term “empowerment” as a much broader paradigm. Perhaps a definition, specially applied to the situation of persons with disabilities could be :

**Empowerment is an ongoing process, which enables an individual to fulfil and be accountable for his or her duties and responsibilities and protect his or her rights in the society. Part of the process is to provide people with the resources, opportunities, knowledge and skills needed to increase their capacity to determine their own future, and fully participate in community life.**

*The goal of empowerment could in other words be to “enable the person with disabilities to exercise his/her political rights”.* A call for empowerment from an organisation of disabled people is reproduced in Box 13.1<sup>8</sup>.

#### **BOX 13.1 A DECLARATION FROM DISABLED PEOPLES INTERNATIONAL**

"WE DEMAND that all governments recognize our right to full and equal participation in society through the implementation of legislation in support of our human rights.

"WE DEMAND that the UN World Program of Action be used by all member states as a working document and as the basis for national strategies regarding disabled people.

"WE DEMAND that governments, statutory authorities and agencies, professionals and aid and development agencies recognize disabled people and our organizations as the true experts in disability and that they consult us and directly involve us in all issues that affect our lives, and that our organizations are properly resourced.

"WE DEMAND that the principles of Independent Living, as defined by disabled people, are applied and resourced.

"WE DEMAND that disability be defined within the framework of social change and not be seen as the problem of an individual.

"WE CALL UPON the world's media to recognize us as equal members of our own societies and to portray us as such and not as passive objects of charity.

"WE INVITE all organizations of disabled people to work with us at the national, regional and international levels to achieve human rights for disabled people.

"WE SUPPORT our brothers and sisters in the newly emerging countries in their efforts to define their own needs and solutions.

"WE CONDEMN all war and violence and DEMAND international peace.

"WE DEMAND that a proper monitoring and evaluation process, in which disabled persons are fully involved, is established to highlight any deviation from the World Program of Action and any violation of human rights and that appropriate action be recommended against the countries concerned."

The process of empowerment is to make sure that disabled persons like all other citizens have influence

on the national and local power structures and share in decision making, thus enforcing a political role. It is an effort to rid disabled people from the intimidation and patronising behaviour to which they are now subjected. The best way out of this - this is what all poor people need to do - is to get organised. Still there are countries where one can see examples of how the police will beat up peaceful blind demonstrators or overturn people in wheel-chairs, arresting some and giving them fines or prison sentences or abusing them at police stations. (Box 13.2)

**BOX 13.2. TAKE YOUR FATE IN YOUR OWN HANDS.**

In 1981, a group of 53 Nobel Prize recipients issued a manifesto to call attention to the “global holocaust” of hunger and underdevelopment. They appealed to all established authorities to enact laws and carry out the policies that would end this holocaust – and a means they reminded about the Gandhi legacy of non-violence. Their message is:

*“although the powerful on this earth bear the greatest responsibility, they are not alone. If the helpless take their fate into their own hands, if the increasing numbers refuse to obey any law other than the fundamental human rights, which is the right to life, if the weak organise themselves and use non-violent action... it is certain that an end will be put to this catastrophe in our time”.*

There is no doubt that in CBR the main goal for all the action proposed is “empowerment”. It is to provide persons with disabilities services and opportunities that will give the knowledge and skills to mobilise their capacities. With this preparation they should themselves actively fight for the restoration of all the human, civil, economical, social, development, cultural and political rights of they are now are deprived. The end of the road is the one that liberates everyone from the paternalism, apartheid, indifference and intimidation.

## 5. INTERNATIONAL ORGANISATIONS

No single international organisation is yet fully representative of all the interests related to disabled people. Maybe this will not be possible – or necessary - in the future. Globally, such organisations have already now an impressive size.

In spite of this, disabled people can play an important role together in international development. An example is expressed by Tambo Camara<sup>9</sup>: "Disabled people in the developing world, instead of taking a wait-and-see attitude and remaining passive, are getting organised to change public attitudes on the one hand and to demonstrate the role they can play in the development of their countries on the other."

One important area is common to all organizations: the *defence of their rights*. During and after the International Decade for Persons with Disabilities they have become engaged in important national and international efforts and established themselves as a force that is now included in all major decision-making: their right to development is now fully recognized. They have joined and succeeded in their efforts to establish a U.N. Rights Convention.

## 7. ASSISTANCE TO ORGANISATIONS OF DISABLED PEOPLE AND OF PARENTS

To carry out their political and organisational roles, many organisations in the developing countries would benefit from economic assistance. This is to some degree provided by sister organisations in the industrialised countries, or through donor/development agencies. One often-cited need is assistance in administrative and leadership training. There are examples of both special courses, held exclusively for disabled people or parents' groups, and general courses bringing together disabled people and members of other NGOs such as women's organisations, environmental groups, scouts and community development groups. Distance education should be useful in this context. More co-operation is called for in efforts to strengthen the role of these organisations.

## COMMENTS AND REFERENCES

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<sup>1</sup>For a review of the "role of the consumer of the rehabilitation service for the disabled", see F. Shah: Disability, Selfhelp and Social Change, ICIC Foundation, Karachi, Pakistan, 1990.

<sup>2</sup> Many studies show that organisations of disabled people or of parents, play a useful role in giving social support. For an example from a developing country, see V.C.B. Nwuga, *Int.J.Rehab.Research*, 8(1), p.61, 1985.

<sup>3</sup> See also "Guidelines for the Development of Organizations of Disabled Persons", UNCSDHA, Vienna, Austria, Document V.91-22597; and the Guide for Disabled People in TCPD, which describe how an organisation can be set up.

<sup>4</sup>For review: K.A. Boschen and J. Gargaro *Int. J. Rehab. Res.* 21,285, 1998. L. Friedem: *Am. Rehab.* 3 (6), 6, 1978.

<sup>5</sup>G. .De Jong and J. Hughes, *Arch. Phys. Med. And Rehab.* 63, 68, 1992. Boschen *ibid*.

<sup>6</sup>H.Itzhaky and C. Schwartz , *Int. J. Rehab. Res.*, 21, 301, 1998.

<sup>7</sup> Oxford Advanced Learner's Dictionary of current English, Oxford University Press, 1992.

Some of the early authors were Rappaport, who has publicised articles about mental health and social politics. Angela Davies used the concept in the Black power movement and P. Freire in the context of liberation pedagogy: conscientisation. It is also included in the Ottawa Charter of 1986 about Health Promotion. A review appears in G. Sen, A. Germain and L.S.Chen: *Population Policies Reconsidered – Health, Empowerment and Rights*, 1994

<sup>8</sup>The Vancouver Declaration. *Vox Nostra*, Vol. 5, No. 2, 1992, Winnipeg, Canada.

<sup>9</sup>Disabled People in International Development (Ed. D. Driedger), Coalition of Provincial Organisations of the Handicapped, Winnipeg, Canada, 1991.