

Einar Helander: Prejudice and Dignity.
An introduction to Community-based rehabilitation.

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Please note that this book has not been updated since its publication, thus it lacks references to events and literature after 1999. The principles remain unchanged.

Excerpts:

1. List of content
2. Introduction
3. What is Community-based rehabilitation
4. Chapters

SUMMARY

The book has three parts, preceded by an introduction.

The *Introduction* describes the reasons for proposing a change in the conventional service system for disabled people in the developing countries, which is seen as conceptually flawed, inadequate, ineffective, and costly. It is built on a strategy that has contributed to segregation of those few receiving rehabilitation, leaving the majority of the disabled population in these countries without much hope for the future.

It would be logical to seek a reorientation toward a reformed system built on coherent principles, taking into account the realities of those countries. It is imperative that families and communities, including disabled people themselves, should be involved in order to provide better quality of services, to mobilise local resources for rehabilitation, to give more equitable opportunities and better protection of human rights to the disabled people where they live. If this is to succeed, political commitment must be secured; such a change, in its turn, can be brought about only through a major sensitisation campaign. Yet another requirement is dissemination of knowledge on disability and rehabilitation-related skills on a large scale so as to reach all those in need. In addition, governments must commit themselves to provide the backbone of technical and administrative support through a network of organised public services. The new strategy has to be designed with a view of making the system economically maintainable, culturally appropriate, and sustained by grass-roots initiatives.

The Introduction ends with an operational definition of the term rehabilitation, and a detailed definition and description of the proposed alternative strategy for community-based rehabilitation.

PART ONE provides the terminological, statistical, and conceptual background for community-based rehabilitation, as well as an analysis of the situation disabled people in the developing countries find themselves in.

Chapter One shows how the definitions of disability/disabled person are strongly related to culture and socio-economic development. It reviews the development in the use of the term rehabilitation, and describes the concept of community. An operational definition of rehabilitation is used which widens the term considerably to include not only action directed toward the disabled person, but also action designed to meet the disabled person's needs in term of changes in the environment, in the general systems of society, etc. Moreover, it is suggested that one moves from the present emphasis on equalisation of opportunities to the broader concept of promoting and protecting the human rights of disabled people.

Chapter Two reviews the available statistics on the prevalence and incidence of disability. The purpose is to attempt to calculate service needs -information essential for planning national programmes. Based on available data, a "global operative prevalence rate of severe and moderate disability" by five-year age groups is proposed. Using this rate, the present prevalence of such disability is estimated at 8.5 per cent in the industrialised countries and at 4.8 per cent in the developing ones; the global rate comes to 5.5. per cent. In 2000, these rates correspond to a prevalence of about 100 million severely and moderately disabled persons in the industrialised world, and of about 235 million in the developing countries, bringing the world total to about 335 million. The prevalence is heavily influenced by excessive mortality rates among all disabled persons. In some countries, this is especially noticeable among females. This low survival is to the greatest extent related to neglect of the needs of persons with disabilities, which in its turn depends on negative attitudes and discrimination.

The present annual incidence of severe and moderate disability is estimated at about 50 million in the developing countries. Large increases are seen in the future, mainly due to a general population increase and to aging of the population. The 2035 estimate of the world total prevalence of moderate and severe disability is about 665 million. The annual incidence of such disability may increase from about 50 million in 2000 to reach about 125 million in the developing countries by the year 2035.

The causes of disability, the approaches to prevention, and the possible outcome of effective disability prevention are reviewed. A reduction of the annual incidence by about ten million people should be achievable in one decade. As at the same time non-preventable factors increase in importance, the resulting prevalence is calculated to increase to the extent mentioned above.

Based on these estimations, we may calculate that close to 10 million severely and moderately disabled people - almost all of them depending on others for help - will be added to the prevalence each year, or about 25,000 a day.

Chapter Three gives an account of the needs of disabled people. There are no systematic studies of such needs in the developing countries. However, it might be useful to distinguish between "felt," "expressed," and "assessed" needs. Cultural factors influence the perception of needs. The special needs of disabled women are reviewed.

Based on field studies, experience, and available statistics, an attempt is made to calculate service needs in the developing countries. Cautious estimates arrive at the prediction that, by 2000, permanent services to provide rehabilitation and follow-up will be needed for about 70 million disabled people. Within 35 years, these requirements will double, bringing the number of those in need to about 150 million, an increase by 2.3 million a year. With the aging of the population, the requirements of permanent services, which currently correspond to about 1.5 per cent of the population, will increase to 1.9 per cent, in 2035.

Active rehabilitation services now reach some two to three million people - the gap between needs and supply is enormous and grows rapidly.

Chapter Four reviews the existing, conventional system. National policies, plans and guidelines are largely lacking, or fail to be implemented. This explains in part the inefficiency, haphazard organisation, and lack of co-ordination of the services that do exist.

The service system is reviewed, both in terms of its achievements and of its problems. Its achievements consist mainly in demonstrating that, through rehabilitation, disabled people can become more independent, are enabled to take care of themselves, to learn, to work, to earn an income, and to be successfully integrated in their families and communities. Without the pioneers of rehabilitation, there would most likely have been little visible efforts in favour of disabled people in the developing countries.

The present services are mainly institution-based. A number of examples of these are given. Serious financial and staffing problems have contributed to the low quality associated with most services. The conventional system is afflicted with several main and, to a large extent, insurmountable problems. Among these are: the charity factor, the funding approaches, the unsuccessful transfer of technology and professions, vested commercial interests, the type of service delivery, the lack of parental and community involvement, the lack of representation of disabled people, the concentration on the intermediate level and neglect of the macro- and micro-levels, and the failure to include in the programmes legal protection and promotion of human rights. The gap between effective service provision and needs is about 97-98 per cent - in spite of the availability of handsome amounts of funds. The conventional services are built on a strategy that is inadequate to meet more than a fraction of the present needs, and they will certainly be incapable of meeting them in future, as well.

Chapter Five offers a historical perspective of the five main reactions to the presence of disabled people: elimination; the poorhouse approach; segregated institutional care; integration; and support aimed at enhancing self-actualisation. The development of these concepts is described. Based on past experience in the industrialised countries, it is proposed to include in future programmes for developing countries certain modern and humane features.

These are: greater emphasis on self-care and home-care, integrated schooling, efforts at economic and social integration, improved community awareness, more appropriate environmental interventions, less paternalistic and authoritarian attitudes among professionals, increased respect of human rights, and more efforts to promote self-actualisation and empowerment of disabled people.

Chapter Six deals with prejudice. It cites examples of beliefs, attitudes, and explanatory models concerning disability in various cultures around the world. This is followed by some reflections on how discriminatory behaviour increases the mortality and morbidity rates of disabled people, and how the policy-making process is influenced by attitudes among the political leaders. The chapter includes a review of the texts of the UN special declarations concerning the rights of mentally retarded and of disabled persons. These declarations reflect prejudice, the language used is partly condescending, and some of the formulations are totally unacceptable. More recent U.N. policies better reflect modern trends.

Then follows an analysis of some of the typical reactions people show when feeling powerless in the face of prejudice, authoritarianism, and injustice: resignation, seeking reform, or outright rebellion.

PART TWO presents the proposal for and the experience made to date with the alternative strategy of community-based rehabilitation.

Chapter Seven provides a summary of the problems disabled people encounter in developing countries. These problems are divided into four components: functional situation, organisational problems, environmental constraints, political concerns.

Chapter Eight establishes the ideological background for a rehabilitation programme built on the basic principles of equality, social justice, solidarity and integration. It incorporates "ten basic rules for integrated living," and describes what is needed to enable disabled people to live a life in dignity.

The objective of rehabilitation is defined as "to promote a development that eventually will allow all disabled people to live a life in dignity."

In addition, the chapter outlines several general approaches of importance: learning from the people; building and upgrading the system from below; and realising that there are no instant, or easy, solutions, nor a CBR system to copy from one country to another; that certain principles have to be maintained, that some patterns can be duplicated and experience can be shared, but that local adaptations are needed everywhere.

Chapter Nine reviews the conventional technology. It explains the origins of the CBR technology, building on a long series of field observations of "indigenous, spontaneous rehabilitation." In all societies, examples can be found of successful rehabilitation carried out by the family - by people who never had access to professionals. Such interventions include, for instance, training blind children to become mobile; teaching deaf people communication techniques invented at home; training in daily life activities, and mobility; making orthopaedic appliances; inclusive schooling; informal ability training, income generation and so on. This, already existing experience has been recorded. It has then been systematised and modified with a view of upgrading the quality of interventions.

The underlying idea has been to avoid as far as possible the transfer of Western technology - an approach associated with many pitfalls. The CBR technology encompasses a large number of components designed to meet the variety of needs seen among disabled people. The conventional medical model has been abandoned in favour of a direct problem-solving and people-oriented approach. Emphasis is placed on flexible, integrated solutions, with disabled people sharing education, informal and formal vocational training, jobs and social roles with the non-disabled population. Unlike the mystified approach of the highly structured conventional system built on professionals and imported procedures, simplified, local solutions are sought.

A wide range of issues related to technology are discussed, among others: problems related to low literacy, local identification, and assessment procedures. Others are: approaches to the multiply disabled child, mental health aspects, the integration in CBR of educational and income generation aspects, environmental factors, promotion and protection of human rights, etc.

The importance of the availability of referral-level technology is stressed.

Chapter Ten reviews the options for service delivery. The conventional, institution-based system (including programmes with outreach components) is inefficient, costly, and often leads to increased segregation. The CBR alternative built on service participation by the family and the community is described. There are various options for the distribution of tasks.

A model is presented. It builds on experience and comprises three different levels of service providers: (i) the family member (trainer), (ii) the community worker (local rehabilitation supervisor), and (iii) the professional (intermediate-level supervisor). The intermediate-level supervisor is proposed to provide the training of and technically supervising the personnel at the more peripheral levels and acting as liaison to the referral system. Options for recruiting, training and maintaining this personnel, including "volunteers," are outlined. Other requirements, e.g. transport and access to training material, are reviewed. The importance of creating a referral service system responding to grass roots' needs is emphasised; existing institutions/centres and other available resources should be included in such a system.

Whenever it is clear that the building of a CBR delivery system will take time, other approaches are recommended as a stopgap. An example is to try to reach disabled people and their families through distance education. There is no doubt that available mainstream community development programmes should be more effectively used for the benefit of persons with disabilities.

Chapter Eleven starts with an analysis of the process of decentralisation as a paradigm to be followed by a CBR programme. The government's role in development programmes is to encourage and to give local support to a

decentralised system in which communities will take their own decisions regarding priorities and resource allocation.

An example is given of a process through which community involvement, mobilisation of resources, and sustainable local management can be sought. A set of steps is described for how to develop a management system through which the government functions can be carried out effectively. It is stressed that long-term sustainability cannot be achieved unless there is both a clear community involvement and full government responsibility. Given the multi-sectoral character of the programme, it is necessary to establish a well-functioning national co-ordination mechanism.

Chapter Twelve deals with other aspects related to the role of the government in CBR. It starts with some proposals as to how to convince governments to become involved in public services for disabled people. Arguments are provided to show that disability is a large-scale problem - in fact, few other health problems attain this prevalence - that doing nothing has a high price, and that the CBR strategy facilitates its solution.

A few notes follow on how to prepare a policy review and formulate a detailed policy statement. An example of how to draw up a simple national plan for rehabilitation is described. Later in this chapter, detailed examples of cost calculations for a CBR programme are presented. A CBR programme is not a low-cost programme *per se*. It can be established at, or upgraded to, any programme cost level, with one qualification: that level should not be higher than the level maintainable by the particular country without outside assistance. A checklist for how to scale up small projects to large programmes is included.

Chapter Thirteen focuses on the role of disabled people and their organisations in CBR. Using their own experience, disabled people can participate in CBR training programmes and play an active role in providing care and rehabilitation for other disabled individuals.

Disabled people and parents of disabled children can contribute to sensitisation, animation and management at the community level by forming local interest groups. At the provincial and national levels, such groups should be set up. These should be recognised as partners to the authorities responsible for planning, implementation and evaluation of programmes for disabled people. This formal role will be easier to fulfil if all relevant organisations join together in a federation and seek a "political role" aiming at creating awareness and promoting changes that will lead to a better quality of life for disabled people.

A review of the concepts of "independent living" and "empowerment" and of their fundamental importance is included.

Chapter Fourteen reviews the principles of evaluation to be applied to a CBR programme: relevance, effectiveness, efficiency, sustainability, and impact. It is pointed out that the evaluation of the conventional system often is only anecdotal and/or reflects spending and compliance with the time/action plan, without giving a full account of the individual benefits, population coverage, and so forth.

This is followed by a review of a sample of the literature. There are a number of descriptions of the experience of CBR field programmes, with effective and culturally relevant technology. But scaled up, efficient service delivery systems are not easy to develop and require a great deal of attention in the future. The experience available to date on the management aspects of CBR programmes is limited, although there is evidence that the use of approaches similar to the ones described herein has been successful when applied to other development sectors.

More research should be encouraged with the aim of further developing culturally and socially appropriate systems for service delivery and management. Several research studies have been carried out. These confirm the effectiveness, low cost, and sustainability of CBR programmes. Finally the international debate over the CBR strategy is reviewed.

PART THREE deals with some future challenges.

Chapter Fifteen starts with the first challenge: quality and cost control. There are very serious problems at the present time because of the lack of monitoring of the results of all rehabilitation programmes (not just with CBR ones). The accountability, transparency and responsibility for quality use of available resources is hampered by the way evaluation results are presented by most organisations involved in service delivery.

Examples are given on how quality control can be carried out. Concerned factors are: quality of service delivery (measured in progress made by the beneficiaries), quality of community participation, quality of sustainability, quality of planning, quality of policymaking.

Methods for cost control and indicators for cost-effectiveness calculations are described.

In **Chapter Sixteen** it is pointed out that, apart from needs for rehabilitation, there are large unmet care needs among disabled people, in particular among the elderly. Some statistics from the industrialised countries are given to illustrate the extent of the problem. The conclusion is drawn that it is unlikely that any government will be able

to provide - using tax revenues - "services for all" - this conclusion applies to both industrialised and developing countries. This leaves but one alternative: to create a "caring society" - by the people themselves, in a reformed spirit of solidarity, organising and providing what is needed within the framework of a permanent system. Similar to what is proposed in the context of CBR, governments should provide the administrative backbone for this care system. They should accept responsibility for the training of personnel and for technical supervision, and operate the referral system. Such a strategic move from the approach of the "welfare state" to the "caring society" can only be achieved under certain preconditions. These are: a political commitment, a large-scale programme for sensitisation and education of the public and a reorientation of the use of the existing resources.

Chapter Seventeen contains a set of proposals concerning the priorities for the coming decades.

These are:

- (a) making services available to all disabled people who need them, improving their access to general development and mainstream programmes, and creating more equitable opportunities for disabled people;
- (b) increasing resources for development of programmes for disabled people so that all essential needs of disabled people can be met. It is proposed that, as soon as possible (and urgently), all development agencies make one per cent of their budgets available for this purpose. The co-ordination of the use of such resources should be improved;
- (c) strengthening all efforts aimed at sensitising the public and making it more aware of the abilities of disabled people;
- (d) developing an active local and national role for disabled people, their families and their organisations;
- (e) monitoring the human rights situation of disabled people, including equitable access to opportunities, protection against abuse and crime, and taking adequate corrective action when needed;
- (f) improving collection and dissemination of information.

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INTRODUCTION

The "conventional" system for rehabilitation of disabled people began to emerge in the 19th century. At the beginning, there were institutions - mostly quite small - which "took care" of various groups of disabled children or adults. There they were given food and shelter, education and some vocational training. Many were kept in "homes" for very long periods of time. I remember well how, as a young boy, I visited several such institutions where disabled people stayed for a lifetime.

World War II resulted in a significant increase in the disabled populations of most industrialised nations. For many countries, providing these people with a rehabilitation programme became a national priority. In the years that followed, other groups of disabled people shared the same services. The definition of disability has always been vague. Rehabilitation eventually came to include services for people afflicted by one or the other of a wide range of chronic diseases: rheumatic, lung, cardio-vascular, neurological, mental, skin, etc.; victims of accidents, alcoholics, drug abusers, and occasionally people released from prison. Many Western social security systems started to make the consideration of a rehabilitation programme mandatory for any person claiming a pension or other benefits before retirement age.

In response, systems of specific diagnostic and therapeutic resources were built up in the industrialised countries. Eventually - since there were a variety of needs among this widely differing group of people - large multiprofessional teams were set up. In 1969, an Expert Committee of the World Health Organization (WHO) recommended that the ideal team should consist of some 30 different specialists.¹

International cohesion was rather strong in this very small specialty, and where services were set up, they were fairly identical. An image emerged of a complex but coherent, logical and unbreakable system. The perception was that disabled people were difficult to treat, to train and to educate. No meaningful results could be expected unless competent and experienced professionals provided the rehabilitation.

When efforts were made to introduce this type of rehabilitation to the developing countries and to expand it (outside a few national centers or similar), many problems were encountered. Systems for medical rehabilitation, special education and vocational rehabilitation were all built on a medical model - a model not always appropriate for developing countries. Disabling conditions were diagnosed, the patient (pupil/client) was assessed, and interventions were prescribed. With time the system had become increasingly formalised, complex and mystified.

Furthermore, rehabilitation "had" to be provided in institutions. For this there were many rational explanations:

- (1) the number of professionals was limited, so they would be more effectively used if they all worked in a few centralised institutions;
- (2) disabled individuals needed a complete programme of training covering the whole day;
- (3) many of the components of rehabilitation were provided by different members of a rehabilitation team, and an institution was the only place where all these professionals could be expected to be available;
- (4) expensive equipment was needed, so again the most economical solution was to centralise such equipment in an institution, where it could be handled and maintained by competent staff.

These were the perceptions held by all experts, and they were prevalent in the early 1970s, as many publications and documents from the international organisations at that date confirm.

Where then lay the hope for developing countries? What was proposed for them was a slow expansion of the conventional system of institution-based rehabilitation, until eventually full coverage could be achieved. Perhaps not fully appreciating that the costs for such expansion would prove to be insurmountable in many developing countries, and that the necessary professional personnel would not be available for several generations, those same experts devised a strategy for rehabilitation, which had no chance of being implemented in our time.

Another obstacle to change was the fact that the governments of many countries had never committed themselves to providing public services for this large group of citizens. The rehabilitation sector was to a large extent managed and financed by charitable organisations. These organisations can reach only a small proportion of those in need. They tend to be staffed by expatriates and based in towns and cities, and in some cases they are selective in those they help.

At this point, it may be useful to make some comparisons with another development sector, namely that of education. Years ago, a high proportion of the (then existing) school system had been set up and financed by

charitable donors, such as missionary societies. No one denies the great importance of this effort - providing education where in many instances none was available. The reader is no doubt also aware of the criticism often heard: these schools were "elitist", "instruments of colonialism" and reached only a very small percentage of all children and adolescents; they were expensive, staffed by expatriates and so forth. So governments gradually took over, developing "education for all", centrally managed and supported by community involvement.

This development can to some extent serve as a pattern for rehabilitation. One obvious lesson is that the changes in the educational sector were almost nowhere "perfect". It is in the nature of development that changes take time, and meanwhile there is a lot of criticism. In the case of the education system there have been numerous problems concerning curricula, teacher competence, poor school performance, high drop-out rates, etc. But nobody now challenges the concept that education should be based on public services and set up for all. This is also the direction that should be sought concerning services for disabled people; some of the lessons learnt from the educational and other sectors could be applied.ⁱⁱ

The community-based rehabilitation (CBR) strategy is an effort to design a system for change - for improving service delivery in order to reach all in need, for providing more equal opportunities and for promoting and protecting the human rights of disabled people. It was clear that proposals for changes in the rehabilitation system should be preceded by a careful analysis to find out why and where it has succeeded or failed.

In this book I will argue, from the basis of long experience, that many services provided today are not efficient, that they are costly and insufficiently planned, and that there is a great lack of co-ordination. There are too many small initiatives, seemingly built on emotional rather than rational approaches. After a sudden burst of enthusiasm, many such projects are abandoned by the donors or sacrificed by governments during periods of "economic restructuring". This leads to victimisation of the "beneficiaries".

A large proportion of existing projects need re-orientation; donors could seek joint solutions, pool their funds and start working with governments and communities, using a coordinated plan.

The new strategy - community-based rehabilitation (CBR) - builds on several years of observations of existing and transferred technology, and on various approaches to service delivery and management. In the course of these observations, it became evident that the views held by the various experts on rehabilitation in the past had been based on incomplete knowledge of the conditions in and the resources of developing countries. Some of those working on solutions to the problems of disabled people had been preoccupied with designing strategies mainly based on macro-systems - such as ministries and national committees, etc. Others, mainly working for NGOs, had rarely tried to analyse any possible solutions beyond the isolated intermediate-level systems in the centers or institutions where they worked. And almost no one had been particularly interested in the microsystems of communities with a view to finding out how these were organised and what projects they were able to develop on the basis of their own initiatives and resources. Neither was it sufficiently understood that no serious sustainable community development would take place unless it were built on local, self-development initiatives.

In order to formulate a constructive programme, we need to thoroughly analyse the capacity of all these three managerial levels, assessing their potential use in a new system that could draw from their strengths and overcome their weaknesses.

There are presently about 230 million moderately or severely disabled people in the developing countries, most of them without services. It is evident that the mobilisation of the family and the community is the only credible basis for a programme of "rehabilitation for all". This implies that we must undertake a massive dissemination of knowledge and essential skills to this level, as well as developing the capacity to apply such technology in an appropriate way. Furthermore - since governments in the developing countries rarely can be counted on to finance the total cost of service delivery in all their communities - the basic services must be built on resources that are available locally.

The first question to resolve was how much technology could be delivered through local resources without losing quality. In 1979 a manual published by the World Health Organization proposed a simple, demystified set of technologies for the community and family levels, and a new type of service delivery system aimed at reaching as many as possible. It also suggested that the community members should manage the system.

After several years of trial and error, and after consulting project managers and field personnel working with CBR programmes, the latest version of the manual entitled "Training in the community for people with disabilities" (TCPD) appeared in 1989ⁱⁱⁱ. It proposed local dissemination of a significant proportion of technology traditionally reserved for professionals. This led to many misgivings from their side about the chances of success

resulting from such a radical change. It has, however, been rewarding to see how well local people have responded to the challenge. A number of external evaluations have shown that it is possible to achieve improvements fully comparable with those resulting from the "conventional" type of institution-based rehabilitation.

It must be emphasised that a system for service delivery that depends entirely on the community is unlikely to meet all the needs. From the very beginning, the authors of TCPD have pointed out the need for a referral system to provide high quality, and technically appropriate, solutions to problems that could not be solved by services at the community level. It is indeed unfortunate that there has been confusion between community-level and community-based rehabilitation.

Government involvement is necessary - and this is indeed one of the main arguments in this book. It is no longer politically acceptable to provide services to a large underprivileged group by relying wholly on charity and un-coordinated voluntary efforts. Governments must establish a network of public services aimed at organizational and technical supervision, providing the backbone of a countrywide organization. A public effort is needed to plan for and administer the programme. It is needed to assist in the training components and the dissemination of technology and to undertake research. This is not costly if a suitable plan for development is sought and as long as the communities can furnish most of the local resources.

Intermediate level resource and national centers should form part of an integrated system. Their work needs reorientation so they can provide higher quality services for referrals in a two-way process. Furthermore governments and institutions need to realise that the basic problems of disabled people cannot be solved through action from above, on the basis of central authority. It is not a question of "taking care of these people". The aim is to achieve their full social functioning and integration in the society where they live.

This cannot be done unless communities become involved and recognise their responsibility, open up their society to disabled people, and return to them the rights and opportunities of which they have been deprived. To this effort should be added a process of empowerment of disabled people and their families. Their influence should be encouraged and strengthened through networks of recognised organisations, which must be given a real influence in the society.

For a very long period in the future, efforts by development agencies and donors will still be needed. The change seen elsewhere, e.g. in the education system, from private missionary schools to public education for all, was brought about with the assistance of large external financing. This helped to create national teacher training colleges, develop curricula, improve educational technology, produce schoolbooks, etc. A similar contribution could help the national effort to build up services in the rehabilitation sector. But extended-contributions should not exceed the appropriate and maintainable level. Too much outside funds, especially for direct service delivery, will impede the sustainability of the CBR programme.

I am not proposing that the only model for bringing about this change is CBR; any rational and economically maintainable approach, with a clear strategy and well-tested systems for technology, service delivery and local management will do. After some twenty years of experience with the CBR system, we are still learning, and in each country local adaptations and adjustments have to be developed.

Until now, TCPD has been the main source of information for those who wanted to understand and practice the CBR system. As TCPD neither provides a detailed description of the ideas behind CBR, nor explains all the principles to be applied, this book is meant to complement it. The reader will find a detailed description of the CBR strategy on page 8.

The title of this book reflects the fact that many of the reasons behind the problems facing disabled people can be found in deep-rooted prejudices; an immense effort will be needed to change that situation.

If we could all act in a spirit of solidarity, recognising the principles of human equality, if we could bring services to all in need, if we could contribute to a better quality of life, reduce their dependency and transfer power to them, then we would restore to disabled people their right to a life in dignity.

References

¹ World Health Organization, Technical Report Series No. 419, Geneva, Switzerland, 1969.

² The general education system is also for disabled children. But the move from missionary schools to "education for all" has seldom been accompanied by a mainstreaming of special education facilities. The new global policy now is called "Inclusive Education", see T. Jonsson's book with this title, UNDP, 1996.

³ E. Helander, P. Mendis, G. Nelson and A. Goerd: Training in the Community for People with Disabilities, World Health Organization, Geneva, Switzerland, 1989.

WHAT IS COMMUNITY-BASED REHABILITATION ?

Definitions

Rehabilitation includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualisation.

Rehabilitation includes not only the training of disabled people but also interventions in the general systems of society, adaptations of the environment, protection of human rights and empowerment.

Protection of human rights is an obligation for the authorities of each country, for its communities and for every citizen. Disabled people shall have the same rights to a life in dignity as others, and there must be no exceptions. Special attention may be needed to ensure the following: access to health and social services; to education: ability training and income generation opportunities; to housing, transportation and to buildings; to information; to cultural and social life, including sports and recreational facilities; to representation and full political involvement in all matters of concern to them.

Community-based rehabilitation (CBR) is a common-sense strategy for enhancing the quality of life of people with disabilities by improving service delivery in order to reach all in need by, providing more equitable opportunities and by promoting and protecting their rights.

CBR builds on the full and co-ordinated involvement of people with disabilities and their families. It should be supported all levels of society: community, intermediate and national. It seeks the integration of the interventions of all relevant sectors - educational, health, legislative, social and vocational - and aims at the full representation and empowerment of disabled people, promotes interventions in the general systems of society, and adaptations of the physical and psychological environment that will facilitate the inclusion and the self-actualisation of disabled people. The **goal** of CBR is to bring about a change; to develop a system capable of reaching all disabled people in need and to educate and involve governments and the public. CBR should be **sustained** in each country by using a level of resources that is realistic and maintainable.

Suggestions for appropriate action at different levels: At the **community level**, CBR is seen as a component of an integrated community development programme. It should be based on decisions taken by its members. It will rely as much as possible on the mobilisation of local resources. The family of the disabled person is the most important resource. Adequate training and supervision should promote its skills and knowledge, using a technology closely related to local experience. The community should support the basic necessities of life and help the families who carry out rehabilitation at home. It should further open up all local opportunities for education, functional and ability training, jobs, etc. The community needs to protect its disabled members to ensure that they are not deprived of their human rights. Disabled community members and their families should be involved in all discussions and decisions regarding services and opportunities provided for them. The community will need to select one or more of its members to undergo training in order to implement the programme. A community structure (committee) should be set up to provide the local management.

At the **intermediate level**, the government should provide a network of support services. Its personnel should be involved in the training and technical guidance of community personnel, should provide services and managerial support, and should liaise with referral services.

Referral services are needed to receive those disabled people who need more specialised interventions than the community can provide. The CBR system should seek to draw on the resources available both in the governmental and non-governmental sectors.

At the **national level**, CBR seeks the involvement of the government in the leading managerial role. This concerns policy-making, planning, implementing, co-ordinating, and evaluating the CBR system. This should be done in co-operation with the communities, the intermediate level and the non-governmental sector, including organisations of disabled people.

Comment: CBR is not a blueprint or ready-made solution. It calls for flexibility, taking into consideration the social, cultural and economic situation, the daily realities as experienced by persons with disabilities, the country's existing services and personnel, and its phase of development, priorities and policies.
