PREJUDICE and DIGNITY

An Introduction to Community-Based Rehabilitation

By Einar Helander

United Nations Development Programme

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Interregional Programme for Disabled People
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AN INTRODUCTION
TO
COMMUNITY-BASED REHABILITATION

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"NOT UNTIL THE CREATION AND MAINTENANCE OF DECENT CONDITIONS OF LIFE FOR ALL MEN ARE RECOGNIZED AND ACCEPTED AS A COMMON OBLIGATION OF ALL MEN AND ALL COUNTRIES - NOT UNTIL THEN SHALL WE, WITH A CERTAIN DEGREE OF JUSTIFICATION, BE ABLE TO SPEAK OF MANKIND AS CIVILIZED."

ALBERT EINSTEIN, 1945.

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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.[2]

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 co-ordinated 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.

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

There are presently about 200 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 system should be managed by the community members.

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 1989[3]. 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 such a 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 technical supervision, providing the backbone of a countrywide organization. A national organization 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 most of the local resources can be furnished by the communities.

Intermediate-level institutions 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 school books, etc. A similar contribution could help the national effort to build up services in the rehabilitation sector.

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 more than ten 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 practise 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 7.

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.

COMMENTS AND REFERENCES

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

[2] Of course, the 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.

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

A DESCRIPTION OF COMMUNITY-BASED REHABILITATION

Community-based rehabilitation (CBR) is a strategy for enhancing the quality of life of disabled people by improving service delivery, by providing more equitable opportunities and by promoting and protecting their human rights.

It calls for the full and co-ordinated involvement of 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. It also aims at promoting such interventions in the general systems of society, as well as adaptations of the physical and psychological environment that will facilitate the social integration and the self-actualisation of disabled people. Its goal 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.

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. Its skills and knowledge should be promoted by adequate training and supervision, 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 vocational 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,** *a network of professional support services should be provided by the government. Its personnel should be involved in the training and technical supervision 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 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 a learning process, not a blueprint or a ready-made solution. It calls for flexibility, taking into consideration the social, cultural and economic situation, the circumstances of disabled people, the country's existing services and personnel and its phase of development, priorities and policies.

Projects or programmes that do not apply the basic principles of CBR, on the other hand, should use another term to describe their activities.

part one

background

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.[1] 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.[2]

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.[3] 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:

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 fulfil 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 labelled disabled.

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 labelled a "fool". Her great difficulty was that whenever she stepped outside, the village children would shout abuse at her and throw stones.

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[4] and 1.2. The first example, from Mali, illustrates the limits of what is considered "normal" appearance, and the second one, from Somalia, exemplifies the limits of "acceptable" behaviour.

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

Two more examples may serve to illustrate the various ways in which social and cultural factors affect the perceptions of disability (see Box 1.3).

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.

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 prothesis 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

Box 1.4

FUNCTIONAL LIMITATIONS

Functional limitations include difficulties that a person has, for instance, with

- moving (including dexterity: fingering, gripping, holding);
- seeing;
- 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).

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 are shown in Box 1.4[5].

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 are shown in Box 1.5.

Some comments are needed:

Box 1.5

ACTIVITY RESTRICTIONS

Activity restrictions include difficulties that a person has, for example, with

- 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 socialising;
- childcare.

- there are many degrees of functional limitation and activity restriction, from very slight to very severe. As we will discuss later on, most of those disabled 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 recognised 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 industrialised 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, disabled people will be officially recognised 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 a process leading to ever increasing demands at the workplace, where they are unable to compete. And finally there are those whose medical conditions may be fairly insignificant, but who have been squeezed out of the labour market in times of growing unemployment. (See Box 1.6[6].)

Phase 4. Concept related to self-recognised disability

After World War II, some affluent countries have been building rather 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-bound persons, entitling them to free or subsidised 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 subsidised housing, originally devised to pay for the extra space needed for a wheelchair-bound person. 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, etc. Each of these "self-recognised" 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 but a few. A recent study in USA showed that 15 per cent of all Americans aged 16 years or more, identified themselves as disabled. (See Comment 3.)

Some critics feel that this development has produced a sort of "disability culture" and that the system is being exploited. An example to illustrate this point is presented in Box 1.7.

Austerity programmes are now under way in many countries, as politicians are making efforts to cut spending. Benefits are being decreased, or hurdles are being put in the way of granting status as a "disabled person".[7]

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*[8]:

> *A disabled person is the one who in his or her society is regarded or officially recognised 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.

Box 1.6

EARLY RETIREMENT ON DISABILITY PENSION AS A POLITICAL TOOL

In a number of industrialised 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 industrialised countries will witness a contraction of their working-age populations, so the political tools for reducing the labour force will have to be seriously questioned.

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.[9]

The *scope of the term has changed,* a development that has been particularly noticeable in the industrialised countries over the last 25 years, and we may follow the phases suggested 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[10] "... 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".[11]

Box 1.7

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 have to 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 so costly that a thorough reform is planned. 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, had to be cut. In several countries in northern Europe, the average annual time on sick leave was about three weeks until recently - 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 presence 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. These individuals 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, who had difficulties crossing roads, entering transport facilities, orienting themselves in shops, receiving information via newspapers, etc. People with hearing or speech difficulties were at a disadvantage in such situations as road traffic, communicating in shops, in public offices and courts.

As these problems were realised, rehabilitation programmes in the industrialised countries started including a wide range of interventions aimed at changing or adapting the environment. New architectural norms for housing were issued. Apartments for disabled people were adapted at public expense. 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.

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[12] :

"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 started addressing the questions relating to general access to society as a whole, a good many years before the above term was coined. Many regulations or laws excluded disabled children from integrated schooling, while others barred adolescents and adults from access to vocational training and jobs.[13] There was a reluctance to socially integrate disabled people into public services, housing, transportation, leisure and 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 (WPA) adopted by the United Nations in 1982 makes equalisation of opportunities a major point.[14]

Phase 4. Concept focusing on human rights

The term equalisation of opportunities is cumbersome and is poorly understood by most 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 a number of 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;" in that context, many mottos were created, for instance, "new economic order," "health for all," "education for all."

During the next few decades, we should be able to go beyond these concepts and 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 has not been sufficiently promoted in the last few decades. But recently - 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 strategy of community-based rehabilitation.

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."[15]

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,
- promotion and protection of human rights.

In this book, the *following operational defin-*

ition of 'rehabilitation' is employed:

> *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 and protection of human rights.*
>
> *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 educational and work 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.*

3. *COMMUNITY*

As I will use the term "community" many times in this book, a short definition[16] 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 in every case 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.

COMMENTS AND REFERENCES

[1] 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 fulfilment 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.

[2] 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.

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

[4] 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).

[5] M. Chamie, ibid. The text in Boxes 1.4 and 1.5 is adapted from the Manual TCPD and from Chamie.

[6] For a review, see: B.A. Mirkin: Early retirement: an international review, Monthly Labour Review 110, p.19, March 1987.
The information in Box 1.6 has been supplied by the International Social Security Association, Geneva, Switzerland.

[7] 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) transvestism, 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."

[8] 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.

[9] 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.

[10] WHO Technical Report Series, No. 419, WHO Expert Committee on Medical Rehabilitation. WHO, Geneva, Switzerland, 1969.

[11] 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.

[12] DPI Manifesto, Singapore, 1981.

[13] 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, etc. in health.

[14] World Programme of Action Concerning Disabled Persons. United Nations, New York, USA, 1983.
This initiative has been followed by a number of UNCSDHA/UN meetings, resolutions and publications, all in support of the concept of equalisation of opportunities. Among these are:
Manual on the Equalisation of Opportunities for Disabled Persons, 1986.
Guidelines for Workers on the Equalisation of Opportunities for Disabled Persons, 1988.
Report of the International Expert Meeting on Legislation for Equalisation of Opportunities for People with Disabilities, 2-6 June 1986. Organised by Rehabilitation International in co-operation with the United Nations Centre for Social Development and Humanitarian Affairs, New York, USA, 1987.

[15] L. Despouy: Human Rights and Disability, UN Economic and Social Council, Doc. E/CCN.4/Sub.2/1991/31. UN, New York, USA, 1991.
A new effort to formulate "Standard Rules on the Equalisation of Opportunities for Disabled People" is under way at the UNCSDHA in Vienna.

[16] 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.

CHAPTER TWO: PREVALENCE, INCIDENCE AND CAUSES OF DISABILITY

The calculations in this chapter of the prevalence, incidence, and causes of disability have been limited to those disabling conditions for which there is a known effective technology. In Chapter Three, the statistics are translated into requirements for services, interventions, activities and opportunities concerning disabled people in the developing countries. The requirements thus quantified can be used for resource planning, e.g. of budgets and personnel.

In the past, many organisations have used the estimated numbers of disabled people in the developing countries for the purposes of raising awareness of a large-scale problem and as a justification for fund-raising. The numbers given here can also be used for such aims, with the understanding that, at each turn of the calculations, certain qualifications are added. This means they are to be used with a great deal of caution. As we have noted, disability is not a well-defined condition, and there are many terminological and conceptual difficulties. Moreover, the available statistics from the developing countries are not very reliable, and more "hard data" are required before more accurate conclusions can be drawn. Also, to the same extent as health conditions vary from country to country, disabled people's needs will differ from one country to the next.

1. PROJECTED GROWTH OF THE WORLD POPULATION

Disability is a global phenomenon of huge proportions. Before estimating its magnitude, an account will be given of the projected development of the world population (see Table 2.1[1]).

The world population is growing rapidly: by about 60 per cent from 1990 to 2025. The growth, however, is uneven. In the more developed regions, the increase is projected at only 12 per cent, whereas in the less developed regions it is forecast at 75 per cent. The increase is most pronounced in the older age groups. (See Table 2.2).

As disability is more common among the elderly, this rapid increase of the population aged 65 and above will have clear implications for the future prevalence of disability.

2. ESTIMATES OF THE PREVALENCE OF DISABILITY

Several global estimates of the prevalence of disability have been made in the past. The most often cited is the one made by the author in 1974, which was published by WHO in 1976.[2] This estimate - 10 per cent of the world population - was based on a number of calculations of disability rates resulting from diseases, trauma, malnutrition, genetic causes, etc., available at that time. These calculations included a high proportion of people with slight and with reversible disabilities, such as those caused by malnutrition.

Since then, a large number of surveys and studies have been made. The results of these surveys from 55 different countries vary dramatically, ranging from 0.2 per cent of the population to 21 per cent.

There are a number of problems related to these studies, many of which have been reviewed by M. Chamie working at the UN Statistical Office in New York[3]. The magnitude of the variance is more a result of the methods of the surveys than the actual number of disabled in the various countries. It illustrates the urgency of standardising disability definitions and survey technology.

In this context I have chosen to reproduce a few data taken from some interesting surveys, one African, one American, one Asian, and one European. The results are shown in Table 2.3.[4] The British study was carried out on a representative sample of the population in 1985. The Canadian one similarly builds on a representative sample and took place in 1986. The Chinese study is very large, with the sample close to 1.5 million people, and it was carried out in 1987. For comparison, I am also reproducing the results of a population census carried out in

Table 2.1: World population, as projected (medium-variant) by United Nations, 1990-2015

	POPULATION IN MILLIONS		
Year	**In more developed regions**	**In less developed regions**	**Total**
1990	1,207	4,086	5,293
1995	1,236	4,534	5,770
2000	1,264	4,997	6,261
2005	1,289	5,451	6,740
2010	1,310	5,895	7,205
2015	1,327	6,332	7,659
2020	1,342	6,750	8,092
2025	1,354	7,150	8,504

Table 2.2: Population in less developed regions. Projection by age groups.

AGE GROUP	**POPULATION IN MILLIONS**		**GROWTH**
	1990	**2025**	
0 - 4	0,544	0,620	+ 14%
5 - 14	0,909	1,225	+ 35%
15 - 29	1,178	1,782	+ 51%
30 - 64	1,273	2,955	+ 132%
65+	182	568	+ 212%
TOTAL	**4,086**	**7,150**	**+ 75%**

Mali in 1976.

As can be seen from Table 2.3, there appear to be large differences in the "all disability" prevalence rates between Canada and Great Britain on the one hand and China and Mali on the other. This is not surprising, as different survey methods were used and since there are large discrepancies regarding age composition and health situation.

For instance, the China data mainly include people with moderate and severe disability and underestimate some large groups of people with chronic non-communicable somatic disease - such as rheumatic back pain and joint conditions. In spite of this, the difference is not that great if we look at the prevalence rates by five-year groups. Half of the disability seen in Canada is mild or slight. If we compare the rate of the moderate and severe disability in Canada with the one observed in China, the differences in each five-year group are small.

The total disability prevalence in China is 4.8 per cent. This relatively low figure is partly due to the present age composition of the population. If we were to simulate a situation where the Chinese population had the same age distribution as the one we find in the industrialised countries, the average total prevalence in China would come to 7.7 per cent.

The British study is based on a questionnaire and types of examinations which are different from those applied in the Canada and China surveys. The prevalence is 11.6 per cent, out of which one quarter represents slight disability. Moderate and severe disability (severity categories 3-10) total 8.6 per cent. In this study, as in the others, the prevalence decreases from age group 10 to 14 to group 15 to 19. The researchers suggested that this might be attributed to a diminution in disability prevalence and increased mortality of disabled adolescents. In the age groups 30 to 69, the Chinese rates are the lowest of the three countries shown in the table. This suggests that the prevalence is diminished by mortality occurring before the age of 30. In the groups 70 and above, the differences are small.

Comparing the Mali census (1976) with the other, more carefully planned and executed studies, one notices some differences. The prevalence of disability in children is lower; this can be explained by the fact that disability is not a "diagnosis" made early in life in Mali. Parents believe their child to be sick and to recover sooner or later, which is why the label "disabled" is not used. Another likely reason for this low prevalence is an excessive mortality. In 1976, the under-five-mortality rate was estimated to be about 32 per cent, and it is likely that a large proportion of disabled children had died early. In the age group 15 to 64, the prevalence numbers do not differ much from those for moderate and severe disability in the other countries. After age 65, few disabled Malians survive, and disabling symptoms are seen as "normal in elderly people." Hence an elderly family member is not always perceived as disabled, even if afflicted with severe functional limitations and activity restrictions leading to total dependence on others.

In the last column of Table 2.3, I have proposed a "global operative prevalence rate of moderate and severe disability." (See diagram in Fig. 2.1.) The rate shown is based upon observations and attempts to identify a compromise between the individual prevalences for the four countries included in the Figure. This assumed rate will be used for all the calculations of prevalence of disability and needs of rehabilitation made in this book. For each country, this prevalence can be calculated individually, based on the age composition.

Using this assumed rate and the UN population statistics for 1990, we will arrive at a global estimate of the prevalence rate of moderate and severe disability of 5.2 per cent as shown in Fig. 2.1. This is an aggregate of prevalence of 7.7 per cent for the more developed regions and of 4.5 per cent for the less developed regions.

This brings us to the total estimate for 1990 that there are about 276 million moderately and severely disabled people in the world, of whom about 93 million (one third) live in the more developed regions and 183 million (two thirds) live in the less developed ones. The global average comes to 5.21 per cent (for age composition see Fig. 2.5). The prevalence for the developing countries in 1992 may be estimated at 200 million. The world total, at the end of that year was close to 300 million.

It would be reasonable to assume that most of the moderately and severely disabled people are dependent on others physically, psychologically, socially, or economically.

The figures above obviously do not include temporary or short-term disability caused by curable diseases or reversible conditions, or by terminal disability associated with severe disease (unless such disease is slow and degenerative). If such disability had been included, the prevalence of disabled people would increase considerably. In the developing countries, there are large numbers of people who have a long-lasting or a recurrent disability resulting, for instance, from bacterial or parasitic diseases, cancer and HIV infection. These people need care, but only a limited number of them could be expected to join a rehabilitation programme. It is for this reason that they have not been included in the above calculations. In most of the cases indicated in Table 2.4, the underlying condition is chronic, long-lasting or even lifelong. This does not mean that the dependency associated with the given disability must remain lifelong. For a large proportion of disabled people we are able, through rehabilitation, to eliminate or to reduce the dependency. It is clear that more accurate es-

Table 2.3 Disability prevalence rates by age groups, in Canada (1986), China (1987), Great Britain (1985) and Mali (1976), and a proposed global operative rate for calculating moderately and severely disabled people

PREVALENCE OF DISABILITY, PER CENT OF POPULATION							
AGE GROUPS	**CANADA**		**CHINA**	**GREAT BRITAIN**		**MALI**	**GLOBAL OPERATIVE RATE,** **MODERATE & SEVERE**
	Total	Moderate & severe	Moderate & severe	Total	Moderate & severe	Moderate & severe	
0 - 4	3.3	0.7	1.5	2.1	1.6	0.2	1.3
5 - 9	5.7	1.7	2.9	3.5	3.2	0.9	2.5
10 - 14	6.4	1.8	3.5	3.5	3.3	1.2	2.7
15 - 19	4.0	1.4	2.3	2.1	1.6	1.5	1.9
20 - 24	4.7	1.6	2.3	2.7	} 2.1	2.2	2.0
25 - 29	5.4	2.0	2.5	3.1		2.6	2.3
30 - 34	7.8	3.4	2.9	4.0	} 2.8	3.5	3.2
35 - 39	8.6	3.8	3.6	4.4		4.2	3.7
40 - 44	10.5	4.5	4.3	5.9	} 4.3	5.4	4.4
45 - 49	12.7	6.8	4.8	7.9		6.4	5.8
50 - 54	17.3	9.3	6.0	10.6	} 8.1	7.7	7.7
55 - 59	22.6	13.2	8.4	15.5		9.0	10.8
60 - 64	30.5	18.0	12.1	20.5	} 13.9	11.0	15.1
65 - 69	34.1	19.0	17.6	27.5		13.0	18.3
70 - 74	40.9	25.2	25.8	34.2	} 25.3	15.2	25.5
75 - 79	49.1	37.7	37.5	46.6		17.4	37.6
80 - 84	} 73.7	} 58.5	49.3	61.6	} 51.6	17.8	} 56.0
85+			58.6	77.9		20.5	
Average for the entire population	13.3	7.4	4.8	11.6	8.6	3.0	

Figure 2.1

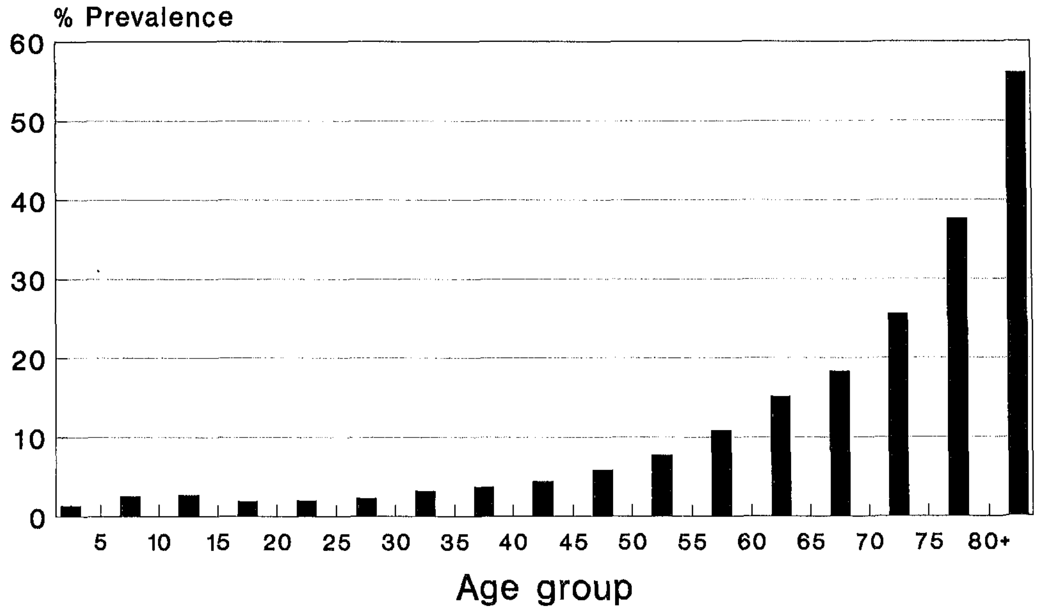


Table 2.4: Global estimate of prevalence of moderately and severely disabled people, based on the UN population projections for 1990, and on assumptions about disability made by the author

	MORE DEVELOPED REGIONS	LESS DEVELOPED REGIONS	TOTAL
Total population (millions)	1,207	4,086	5,293
Prevalence of moderate & severe disability	7.73%	4.47%	5.21%
Number of moderately & severely disabled people (millions)	93.3	182.2	276.1

timates would have been possible had there been access to more high quality surveys.

Before concluding this part of the estimations, it is important to add that people with slight disabilities too may need the help of a rehabilitation programme, particularly vocational training and jobs. In fact, most vocational rehabilitation is targeted at this group of disabled people. For the purposes of calculating such needs, I will assume that those with slight disability are equivalent to half of the group with moderate and severe disability.[5]

3. *INCIDENCE OF DISABILITY*

There are no studies or research regarding directly observed incidence of disability. This is easy to understand. In the group of children, for example, it might be difficult to identify a disability such as cerebral palsy, deafness, or mental retardation before the child is a few months old, at least. Many disabled infants and children die young, without having been recognised as disabled by the family, or by a medically competent person. And, even if some diagnosis has been made, it might not have been communicated to the family. In some developing countries, where the infant mortality rate has been very high, parents do not give the child a name until it is one year old. This makes inquiries into incidence and mortality among disabled inf-

Table 2.5: Estimated age-related annual incidence of moderate and severe disability in the less developed regions, based on data available from China

ANNUAL INCIDENCE			
AGE GROUP	INCIDENCE RATE (CHINA, 1987)	CORRESPONDING ANNUAL INCIDENCE (MILLIONS)	
YEARS		1990	2025
0 - 4	0.28	1.5	1.7
5 - 9	0.51	2.4	3.1
10 - 14	0.64	2.7	3.9
15 - 19	0.44	1.8	2.6
20 - 24	0.43	1.7	2.5
25 - 29	0.49	1.6	2.8
30 - 34	0.57	1.6	3.1
35 - 39	0.73	1.8	3.6
40 - 44	0.88	1.7	3.9
45 - 49	1.03	1.6	4.1
50 - 54	1.32	1.8	5.2
55 - 59	1.89	2.3	6.7
60 - 64	2.81	2.8	8.1
65 - 69	4.25	3.2	9.3
70 - 74	6.59	3.4	11.1
75 - 79	10.23	3.3	10.2
80+	21.00	4.5	16.8
TOTAL		40.5	99.5

ants and children even more difficult.

When it comes to old age, there is another problem. Most people suffering from a terminal disease have activity restrictions during a period before they die. For some people, this disability period lasts only a few days or weeks, for others it is longer. It is not easy to draw a line and to decide who will be counted as a "newly disabled" person and will consequently be included in the annual incidence. For other people, the experience is that disability sets in gradually and may be seen as "normal aging," "wear and tear," and the point at which a person enters the group of moderately and severely disabled people is not easy to decide.

This explains why the only existing estimates of annual incidence of disability are based on indirect methods. Relevant data have been derived only from prevalence rates and calculations of active (disability-free) life expectancy.[6] In Table 2.5, I have only reproduced data from China[7]. Projecting these data to all developing countries, we estimate that the number of people who became moderately or severely disabled during 1990 was about 40.5 million. This "annual incidence" is estimated to increase to about 99.5 million in 2025.

The total annual incidence estimates made below most likely under-represent the truth. Research is needed to establish more reliable data. However, the calculations made here serve the purpose of setting targets for provision of rehabilitation services in the developing countries. A certain proportion of the newly disabled will need such services. Most of the others will need care, help and support.

4. ESTIMATES OF CAUSES OF DISABILITY

My 1974 estimate that 10 per cent of the world population was disabled needs to be reviewed.

Three factors have led me to revise the calculations downward. The first one concerns malnutrition. The experts consulted in 1974/75 saw protein-caloric malnutrition as causing disability in about 100 million people, mostly children. Their views have changed now, and this condition is seen as a reversible impairment. It is not considered to cause chronic disability, except for some less frequent conditions such as xerophthalmia and cretinism, which affect some seven to ten million people. This change of view alone reduces the global prevalence rate calculated in 1974/75 from about 10 per cent to about 7.5 per cent.

The second factor is that, in 1974/75, the duration of life after the occurrence of a disability (for a person in a developing country) was overestimated, and this reduces the estimated prevalence further.

The third factor is that in the 10 per cent estimate were included a certain proportion of slightly disabled people. In view of the sometimes unclear borderline between ability/disability, and the fact that slight disabilities less often lead to needs for rehabilitation services, I am proposing that we confine ourselves to identifying the moderately and severely disabled.

Current estimates based on causes of moderate and severe disability can be seen in Figs 2.7 and 2.8. The figure draws on a series of inquiries made in 1987/88 in all relevant divisions and units of WHO. The author was provided with a large number of data and with estimates based on scientific publications, professional observations and field studies.

Fig. 2.7[8] is an attempt to account for the causes of disability on a worldwide basis. As is evident from the figure, there are four major contributors to disability: congenital or perinatal disturbances (15 per cent to 20 per cent), communicable diseases (about 20 per cent), non-communicable somatic and mental conditions (40 per cent to 45 per cent), and trauma/injury (about 15 per cent). Some trauma is related to violence, and this may result in later physical and mental disability (see Box 2.1[9]).

These numbers should be taken with a great deal of caution. Many derive from limited studies[10] on the prevalence of various chronic conditions, from extrapolations and from educated guesses.[11] They do, however, give an idea of the large number of factors that contribute to disability.

Table 2.6: Causes of disability and estimated prevalence of moderately and severely disabled people in the world, estimates for 1990

CAUSES OF DISABILITY	**GLOBAL SUGGESTED RANGES OF ESTIMATES OF THE PREVALENCE OF MODERATELY & SEVERELY DISABLED PEOPLE (WORLD POPULATION 5,300 MILLION)** **MILLIONS**
Congenital or perinatal disturbances	
Mental retardation	10 - 20
Somatic hereditary defects	10 - 25
Non-genetic disorders	15 - 20
Communicable diseases	
Poliomyelitis	5 - 10
Trachoma	8 - 10
Leprosy	3 - 4
Other communicable diseases	30 - 40
Non-communicable somatic disease	70 - 80
Functional psychiatric disturbances	15 - 20
Alcoholism and drug abuse	25 - 30
Trauma/Injury	
Traffic accidents	15 - 20
Occupational accidents	10 - 12
Home accidents	15 - 20
Other	2 - 3
Malnutrition	7 - 10
Other	2 - 3
ESTIMATED TOTAL	**250 - 300**

Box 2.1

VIOLENCE AS A CAUSE OF DISABILITY

Many developing countries have experienced long periods of independence wars, civil unrest, tribal/clan wars, etc. This has resulted in a number of casualties suffering from a physical disability, such as an estimated 30,000 amputated soldiers in Angola. But mental health complications resulting from violence are much more common. Severe psychiatric diseases or disturbance is seen among many who have either participated or lived through a war. Added to this, violence in the post-war years tends to remain elevated, often for as many as 30 or 40 years.

Also common in many countries is violence within the community: murder, attempted murder, as well as armed fights (guns, knives, other weapons) are frequent. Some of this is related to family conflicts combined with alcohol and drug abuse. In many countries, 20 per cent to 75 per cent of women report being regularly battered by their husbands.

Incest and rape are common causes of pregnancy among girls aged 12 to 16. In a maternity ward in a Latin American capital, 95 per cent of the girls admitted were pregnant for these reasons, a study from another capital on the same continent showed the proportion to be 90 per cent. Though underdiagnosed or hidden, child abuse is frequent. According to some reports, between ten percent and thirty per cent of all children are exposed to intense, continuous battering. Severe, but less frequent abuse affects another 50 per cent of children in a number of studies undertaken.

Added to the violence experienced in the family, is community violence, a frequent but underreported phenomenon.

A UNICEF study from Somalia undertaken in 1988 covered four district hospitals in a particular region. Each hospital served about 100,000 people. The author of the report states that "it was surprising to find that in the hospital records dating two years back, the only patients admitted for treatment in the hospital consisted of hundreds of cases listed as 'wounds' (dhawac). The hospital staff described these 'wounds' as resulting from domestic violence and other forms of community fighting. Other patients coming to the hospital for various health conditions had not been admitted as in-patients".

Violence often leads to severe injuries and/or loss of consciousness; the resultant physical and mental symptoms are often life-long and disabling.

No systematic studies have been made to assess fully the extent to which violence contributes to disability.

5. *DISABILITY PREVALENCE: PROSPECTS*

The prevalence of disability in the future will be affected by a multitude of factors. The *first factor to consider is disability prevention.*

With improved health care, interventions in the environment, etc., it is likely that the incidence of disability, especially among infants, children and adolescents, will be prevented or delayed. Such preventive efforts will take place at two levels. See Box 2.2.

Re-examining Table 2.6, one would expect a decrease in communicable diseases and malnutrition in the developing countries - similar to the experience in the industrialised world. A reduction of the incidence by 50 per cent over, let us say, the next 20 years, would bring down the present number of disabled people (resulting from these causes) from an estimated 64 (53-74) million to about 45 million, factoring in a 36 per cent increase in population in the developing countries. Thus, prevention at this level of success concerns about 10 million people in a decade. If the incidence in the next 35 years comes down by 75 per cent, we will by the year 2025 have "only" about 20 to 25 million people whose disability was caused by communicable diseases or malnutrition.

Primary or secondary prevention might not be expected to have any appreciable effect on the other causes of disability mentioned in Table 2.6. Disability as a result of congenital or hereditary

Box 2.2

DISABILITY PREVENTION

Primary prevention involves action taken to reduce the occurrence of conditions likely to cause disability, for example, provision of proper water and sanitation facilities; vaccination against communicable diseases; health education; proper child-rearing; improved nutrition, hygiene and physical fitness; limitation of the availability and use of alcohol, drugs and tobacco; legislation to reduce accidents and diminish occupational health hazards; better roads and vehicles; better training of drivers; effective control of drugs and toxic products that have disabling effects; education of the public aimed at diminishing trauma/injury caused by accidents; improved distribution and preparation of food; improved general level of education; measures to combat gross child neglect and abuse.

Secondary prevention takes place once a disabling disease or other condition is apparent, interventions can be either directed towards preventing the development of disability, e.g. early treatment of trachoma; use of effective drugs for communicable diseases such as leprosy, tuberculosis, onchocerciasis, meningitis, eye and ear infections, and for psychiatric disease and epilepsy; early ambulation after severe disease or surgery; elimination or reduction of risk factors or of continued exposure to hazardous agents. Or, if disabilities are already present, towards attempts at reversing these through curative treatment, e.g. surgical treatment of cataract, of contractures and deformities and so on.

The action listed above under primary prevention is more or less equivalent to an entire community health development programme supplemented by multi-sectoral interventions at all levels. Secondary prevention is one of the roles of the health sectors.

It is important not to confuse a disability prevention programme with a rehabilitation programme. The scope of the former is vast and does not lend itself to the single programme approach. Disability prevention should rather be seen as a concept - a concept that should be promoted so as to strengthen the necessary services and other activities in the various sectors.

Rehabilitation is sometimes said to be tertiary level prevention, its objective being to overcome the difficulties experienced by a disabled person. I will not use this term here.

conditions and non-communicable diseases as well as mental health conditions will most likely remain at that level. Disability caused by trauma/injury is on the rise.

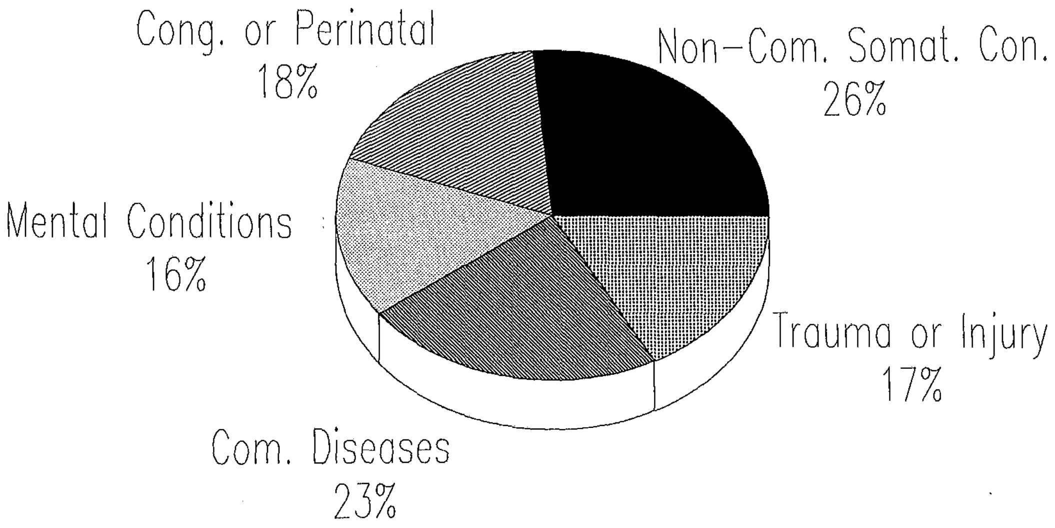
The conclusion is that disability prevention will slowly change the "disability panorama" in the developing countries. The results of effective prevention will not lead to a reduction in total prevalence rates, as other and more dominating causes (such as non-communicable disease and trauma) will cause an increase.

The *second factor* is related to the changes in the *age composition.*

It is likely that the expected survival rate will continue to increase quite considerably in the less developed regions. Fewer young people will die, and the proportion of elderly (+65 years) will more than triple between 1990 and 2025. Children and young disabled people, who now have an excessive mortality rate, will live much longer and so will the elderly disabled. This will eventually increase the prevalence of disability quite considerably, as illustrated in Fig. 2.9.

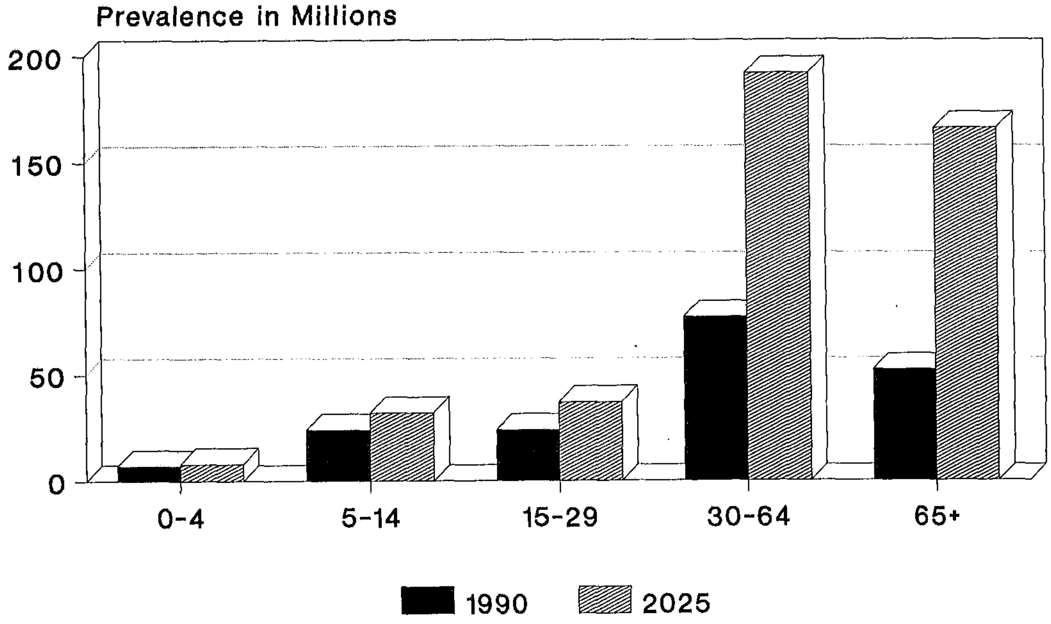
Table 2.7 shows that the group of moderately and severely disabled children (aged 0 to 14) increases by not more than roughly 30 per cent, that of young people (15 to 29) by 54 per cent, the adults (30 to 64) by 149 per cent, and the group aged 65 and over by more than 200 per cent. The average increase over 35 years is 137 per cent, i.e. from some 183 million to 435 million moderately and severely disabled people, or from 4.5 per cent to 6.1 per cent of the total population.

Figure 2.2



Causes of disability, global estimates in million people with moderate or severe disability

Figure 2.3



Expected increase in the prevalence of moderately and severely disabled people from 1990-2025

Similar changes are seen in the more developed regions. Projections for these countries (under the same assumptions) show that the prevalence in 2025 of "moderate and severe disability" will be 10.2 per cent.

The *third factor* concerns the influences of the *environment*.

The environment in the developing countries will undergo a variety of changes in the future. These will include increased urbanisation, more traffic, industrial development (causing pollution and injuries), increased use of hazardous chemical substances and of machinery in agriculture, deterioration of air, water and sanitation systems. All these are likely to contribute to an increased incidence of disability.

On the other hand, it is likely that some other changes may decrease the occurrence or severity of disability; these include e.g. better education and health, a lower pregnancy rate, improved child-rearing, less poverty, improved housing, shorter working hours and better communications.

Based on these three factors, we may now attempt to make a forecast for the next 35 years. In the less developed regions, where, in 1990, we had about 4.5 per cent moderately or severely disabled people, we will - some 35 years later - have over 6 per cent.

The positive effects of prevention will be more than offset by many other factors that will increase the incidence, and as people live longer the prevalence will tend to go up. If one combines the effects of prevention (for communicable diseases and malnutrition) with the effects of a changed age distribution, it is very likely that the number of disabled people in the age groups under 30 will remain largely unchanged. The increase of such people in the age groups above 30 will be considerable, and in the group above 65 it will be dramatic. By the year 2025, there will be at least 435 million moderately and severely disabled people in the developing countries, more than twice of what we have now.

6. *CONCLUSION*

The above text has shown that it is difficult to estimate the prevalence, the incidence and the causes of disability. The fact that there are few reliable studies and facts reflects the low priority given to disabled people in all sectors. Estimates like those made above are to a large extent based on guesses. In order to better plan for the future, a clear set of disability definitions is needed, the survey technology has to be standardised, and a number of more adequate scientific studies should be done.

When this has been achieved, the above predictions should be revised. In the meantime, it would be reasonable to assume that the prevalence of moderately and severely disabled people in the less developed regions is

in 1992 about 200 million, to increase by 2025 to about 435 million.

The corresponding global numbers are

in 1992 about 290 million, to increase by 2025 to about 573 million.

An average **eight and a half million severely or moderately disabled people are added each year to the total global figure - or 23,200 a day.** These figures point to the urgency of seeking solutions as to how best to provide the necessary services for disabled people, in a system that also gives them adequate representation and equal opportunities, and that promotes their human rights.

Table 2.7: Expected increase in the prevalence of moderately and severely disabled people, on the assumption of no change other than in age composition

AGE GROUP	LESS DEVELOPED REGIONS MILLION DISABLED PEOPLE		CHANGE %	MORE DEVELOPED REGIONS MILLION DISABLED PEOPLE		CHANGE %
	1990	**2025**		**1990**	**2025**	
0 - 4	7	8	+ 14	1.1	1.0	- 9
5 - 14	24	32	+ 33	4.4	4.2	- 5
15 - 29	24	37	+ 54	5.7	5.2	- 10
30 - 64	77	192	+ 149	35.2	44.0	+ 26
65+	51	166	+ 222	46.8	83.6	+ 79
TOTAL/avg	183	435	+ 137	93.2	138.0	+ 48
% of total population	4.5	6.1		7.7	10.2	

COMMENTS AND REFERENCES

[1] Source: Demographic Database from the United Nations Population Division, New York, USA, 1991. The terms "more developed regions" and "less developed regions" are taken from this and other UN publications. In this book, we mostly use the equivalent terms of "industrialised countries" and "developing countries".

[2] The original estimate was made in document A29/INF DOC/3, WHO, Geneva, Switzerland, 1976. Annex I of this document contains a very detailed review of the data existing at that time.

[3] A large number of these surveys and studies have been reviewed by M. Chamie, working at the UN Statistical Office, New York.

- M. Chamie: Aging, Disability and Gender. Quart.J.Int.Inst.Aging, Vol.1, No. 5, 1991;
  Development of Statistics of Disabled Persons: Case Studies (ST/ESA/STAT/SER.Y/2), United Nations, New York, USA, 1990;
- United Nations. Disability Statistics Compendium (ST/ESA/STAT/SER.Y/4); (esp. pp. 1/75), New York, USA, 1990; and
- M. Chamie: "Survey design statistics for the study of disability," World Health Statistics Quarterly, Vol. 42, No. 3, pp. 122-140, 1989.

[4] United Nations Statistical Office Disability Statistics Database, original data:
Canada - Health and Activity Limitations Survey, 1986.
China - National Sampling Survey of the Handicapped, 1987.
Great Britain - Office of Population Census and Surveys of Disability in Great Britain, 1985-86.
Mali - Population census, 1976.

[5] This estimate is based on several studies, such as those mentioned in Comment 3, as well as on several field observations using the identification technique described in TCPD, or similar methods, for instance in Mexico (Hindley-Smith); Somalia (Tiroler); Tchad (Directorate of Social Affairs); Bangladesh (University of Dhaka); Kerala, India (Menon and Hariharan); Karnataka, India (ActionAid); Pakistan (Finnstam, Grimby and Rashid); Philippines (Valdes).

For a review see also J.J. Arvelo: Epidemiology and rehabilitation, in (Eds. F.J. Kottke and E.A. Amate) Clinical Advances in Physical Medicine and Rehabilitation, Pan American Health Organization, Washington, D.C., USA, 1991.

[6] K.G. Manson, E. Stallard: J.Gerontology, Social Sciences, 46:170, 1991, Prevalence rates are divided by the number of expected years living disabled to give annual incidence rates for each age group.

[7] These data have been provided by Mr J.E. Dowd, Statistician, WHO, Geneva, Switzerland. His help is acknowledged with thanks.

[8] This figure builds on information received from, and on detailed discussions with, all relevant units and divisions in WHO during 1987/88. The author acknowledges this valuable help. The malnutrition-caused disability now includes only people with consequences of specific malnutrition, such as xerophthalmia and cretinism.

[9] L. Heise: Violence, Health and Development Project. Fact sheet from Women's Global Leadership, Rutgers University, New Brunswick, New Jersey, 1992.

B. Helander: Family Health Management in the Gansaxdheere District of the Bay Region, Somalia, UNICEF, Mogadishu, Somalia, 1988.

[10] For a detailed review of data on causes of disability as reported in national surveys and population censuses, see World Health Statistics Annual.

[11] In this chapter, I have omitted distinctions by gender. Most statistics show that the differences between male and female groups concerning age-related incidence are small. In some countries, disabled females have a higher excessive mortality rate than disabled males and, as a result, the prevalence of disability may be lower there for women than for men. For instance, the "Report on the Sample Survey of Disabled Persons in Nepal, June 1981", published by the Ministry of Health in Kathmandu, shows a sex distribution (12.28% male and 5.94% female) of "lower limb disability". Almost all of this disability is caused by polio, which affects both sexes equally. This leaves but one explanation of the sex distribution, i.e. a much higher mortality among young girls than among young boys with polio. At the time of the survey, Nepal had a very high under-five mortality rate. See also Box 3.3.

CHAPTER THREE: NEEDS OF DISABLED PEOPLE

1. A STUDY OF NEEDS

A thorough study of disabled people's needs should be the starting point of any plan for a rehabilitation programme. In the past, few such studies were made in the developing countries. Instead, experts straightaway proposed technical solutions, construction of facilities and training of personnel. Services were supplied in accordance with conventional ideas rather than in accordance with the realities.

People's needs are manifold, and each society sees its priorities differently. Many of the problems, like the lack of clean and safe water, proper nutrition, inadequate education, lack of jobs, poverty, difficulties in communication, access to health care, security concerns, or repression of human rights, are not unique to disabled people but are shared by other community members. Rehabilitation needs are specific to disabled people.

In the developing countries, rural communities are often very well organised, their members sharing the same values and traditions, with a close-knit network of social relations providing support and protection. This does not work to quite the same extent for marginal urban settlements, but even there one finds a local culture and a power structure, but far less social control.

For anyone intending to study the needs of disabled people, it is essential to have an understanding of the social structures, the cultural traditions, the organisation and the lines of authority prevailing in the communities where they live. This knowledge can only be acquired from people who have been living in the particular community for a long time, who share the culture, and who are familiar with local conditions.

Outsiders will need many years of experience, and to evaluate the specific needs of disabled people they must work with the local people. Where a rehabilitation programme is to be managed by the community, utilising its own resources, it is vital for it to be planned, structured and implemented in line with local customs and needs. This implies that any general rehabilitation programme should be described in such a way as to allow both adaptation to local conditions and preservation of local influence. It should build on existing technology, allow for a service delivery system opted for by the community and apply a management system that fits into traditional approaches. This will facilitate integration of programmes designed to meet the specific needs of disabled people.

2. TERMINOLOGY USED

The term "needs" may be used in various ways.[1] In this context, I will distinguish between three different types of needs.

- *"Felt needs"* are those verbalised directly or indirectly by the disabled person or his or her family or community, or needs observed over a long-term period, preferably by a community member.

- *"Expressed needs"* are those manifested by the disabled person and his or her family by the search for help in solving the particular problem. This help could come through traditional healers, religious or community leaders, or modern medicine or specialised facilities.

- *"Assessed needs"* are the rehabilitation needs assessed by a person with professional training in rehabilitation. To be able to give a qualified opinion as to the likely outcome of rehabilitative measures undertaken in the disabled person's setting, the person carrying out this assessment must have experience from developing countries.

These needs should be studied before starting to design a technology. In the past, the "felt" and "expressed" needs tended to be neglected. Also, most experts (expatriates and nationals alike) did not take the trouble to visit homes and communities of disabled people when assessing needs and evaluating the likelihood of success of proposed interventions. Mostly they based their views on studies of institutions for disabled people, of school populations, or of the working population, which are not very representative.

In the text below, some experience of studies, observations and conclusions on the subject of needs will be presented.

3. *FELT NEEDS*

The way people in the developing countries verbalise their needs is culture-dependent. Often they employ specific words or expressions to indicate symptoms, difficulties and problems, many of which relate to the interpretations or ascribed causes made locally. Hence, direct answers to a list of Western medical or social questions may not tell the whole story. What is striking, however, is the very high proportion of people with health complaints and the long-term duration of those complaints.

Studies[2] initiated by the author and carried out by a national scientific group in Indonesia yielded some interesting results. The list in Table 3.1 has been compiled on the basis of a representative household sample survey of impairments, disabilities, and handicaps.

The complaints listed in Table 3.1 are so common (55 per cent of the population surveyed) that they are almost accepted as normal. Among the people with such chronic symptoms, about one third (18 per cent) consider the symptoms as severe. As a rule, they are treated with local medicines such as herbs. These problems are rarely mentioned spontaneously. Those suffering from them are not normally seen as having "special difficulties". Such severe chronic symptoms do, of course, contribute to social and economic underdevelopment since they lower the economic, physical and psychological performance of those affected.

Even though they are "disabling", these chronic symptoms may, however, not be perceived as such.

There are a host of studies dealing with the prevalence of moderate and severe functional limitations. The information contained in Table 3.2 is mainly based on the results of screening procedures carried out in the context of CBR programmes. These numbers are a conservative estimate based on field experience and should be taken with caution.

It should also be noted that the conditions cited in Table 3.2 vary widely from country to country:

- moving difficulties are more common in countries which continue to have poliomyelitis and poor perinatal care (causing cerebral palsy); or in countries with a recent history of civil or liberation wars (causing amputations, etc.);
- seeing difficulties are more pronounced in countries with poor hygienic conditions (causing trachoma), a high incidence of cataract or avitaminosis A (causing xerophthalmia) and certain communicable diseases (such as measles or onchocerciasis);
- hearing/speech difficulties are more pronounced where meningitis, for example, is common, as well as in countries where ototoxic medicines are used indiscriminately;
- learning difficulties are more prevalent if there is a tradition of consanguineous marriages. Children suffering from combined infectious disease and malnutrition also experience learning difficulties, but this is a reversible condition, and therefore not counted as a disability;
- fits are very common among children and among adults with a high alcohol consumption. The low prevalence mentioned here reflects only people with long-term, high-frequency fits;
- strange behaviour is more often seen if there is a high consumption of some addictive drugs which cause psychoses. The low prevalence reflects mainly people with chronic mental disease of other than drug-related causes;
- feeling difficulties reflect the prevalence of leprosy, which worldwide is very unevenly spread.

When people in developing countries mention needs in connection with such difficulties, the most oft-cited concern is the burden to the family - physically, psychologically and economically. Dressing and feeding a disabled person, and attending to his or her personal hygiene, are time-consuming tasks. Mobility problems often remain unsolved, with the disabled person simply never leaving the house. Communicating with a deaf child takes time, even though most families invent

Table 3.1: List of the most common chronic complaints (more than three months) in Indonesia

TYPE OF COMPLAINT	PER CENT POPULATION WITH THIS COMPLAINT
Teeth problems	14.2
Chronic cough	9.2
Headache	7.7
Pain in arms and/or legs	6.9
Abdominal pain and/or diarrhoea	6.5
Backache	5.4
Breathlessness at rest or after effort	5.4
Skin symptoms	5.0
Chest pain	4.2
Malnutrition	3.8
Eye symptoms	3.5
Ear symptoms	2.2
Lame, weak, spastic muscles	1.6
Missing limbs and/or fractures	1.2

Table 3.2: Estimate of prevalence based on observed ranges of moderate and severe functional limitations among people in the developing countries

TYPE OF LIMITATION	PREVALENCE %
Moving difficulty	2.0 - 2.5
Seeing difficulty	0.5 - 0.8
Hearing/speech difficulty	0.5 - 0.8
Learning difficulty	0.2 - 0.4
Chronic fits	0.3 - 0.6
Strange behaviour	0.1 - 0.2
Feeling difficulty (in hands or feet)	0.1 - 0.2
Combinations of the above	0.2 - 0.3
TOTAL	4% - 5%

Table 3.3: Most common felt needs concerning disabled people in the developing countries

Functional problems in daily life activities
- self-care (eating, drinking, dressing, keeping clean by use of latrine or by "going to nature"
- mobility
- communicating, comprehension, ability to follow instructions
- behaviour.

Educational needs
- schooling
- vocational training

Needs for income-generating activities
- participation in household duties, jobs, self-employment

Lack of family and social integration

Concerns relating to participation and representation in community affairs

Security needs (protection of legal and human rights

a sign language of their own. For economic reasons, schooling of disabled children is seldom considered. As most disabled people are seen as unable to perform any work at home or outside (begging is, however, an alternative), they receive no vocational training.

Some families have tried to find an answer to the needs problem by applying "spontaneous" rehabilitation technology[3]. But the majority of the disabled people in the developing countries receive no such attention. The fact that there may be not much spontaneous rehabilitation is not contrary to the fact that families do provide all the care.

Examples of the felt needs of disabled people are given in Table 3.3 and Box 3.1[4]. Many of these are overlapping. It should be explained that the concept of "independent living" is a Western idea that has little to do with realities in the developing countries. There is no "push" to send disabled youths out to live on their own; they are welcome to stay. Families normally live a life characterised by interdependence. Of course, this does not imply that independence in ADL, mobility and communication is not seen as a great progress.

Community action and involvement should form the basis of the local rehabilitation programme, and therefore each community should carry out a study of the "felt" needs.

4. EXPRESSED NEEDS

"Expressed needs" are displayed in the action taken by the disabled person or his or her family to seek help. In this context, it might be useful to consider an example which illustrates how a child with an acquired disability is perceived, and what remedies may be sought[5].

In the developing countries, it is common to find children sick over long periods of time, in particular in the age group under five. Infectious diseases, malnutrition, asthma, diarrhoea and intestinal parasitosis, alone or in combination, have the effect of making the child weak and feverish for weeks or months. Such a child often lags behind in his or her development milestones such as ability to walk, to communicate and to self-care. This delay may be accentuated by the lack of physical and psychological stimulation and may be accompanied by behaviour problems.

Box 3.1

A DISABLED PERSON'S EXPECTATIONS OF REHABILITATION

"1. Like any other individual or citizen of a country, the disabled person expects and hopes to get good education, suitable vocational training leading to eventual socio-economic rehabilitation so that he[/she] can lead an independent satisfactory life.

"2. To be provided with regular medical care to improve the functioning as far as possible as well as prevent the disability from deteriorating any further.

"3. To be helped and guided in his orientation and readjustment in the family, community and society with full participation.

"4. To actively participate in his[/her] own rehabilitation, deciding for himself[/herself] the goals that he[/she] wishes to achieve, it is essential that he[/she] is trained in accordance with his[/her] potential and inclination.

"5. To be provided with suitable aids and appliances that help to bring his[/her] mental and physical potential to the maximum.

"6. To be provided easy access to physical environment including rehabilitation services through removal of structural barriers and communication problems.

"7. To be placed in a suitable job after training where facilities and safeguards are provided for the basic adjustment of his[/her] disability in order to enable him[/her] to function to his[/her] maximum capacity.

"8. To receive evaluation and follow-up services till such time that he[/she] is fully settled with success in his[/her] job. This evaluation and follow-up is a combined and cooperative process between the disabled employee, the placement officer and employer."

Thus it is not at all rare for a disabled child to be primarily perceived as sick and for the family to wait for its condition to improve. If there is no improvement in sight, the family will gather together to discuss what is to be done and will also consult any outsider believed to have some experience. In the end, a "diagnosis" may be established, and an appropriate remedy may be sought. The latter may consist in giving the child some herbs or in fetching some medicines from the local pharmacy. Should these fail to relieve the child, the family might consult a local healer or a religious leader. If this too gives no result, the family might next approach a more specialised healer or have resort to modern medicine, if available. The latter is normally costly and may require travelling to a far-away place, which explains why such action is often delayed.

It may be that the disabled child is none the better for all these interventions, upon which the family may conclude that a spell or a curse is the cause of the child's disability. To remove it, somebody with magic power has to be consulted, but such a person may not be easy to find, and the costs could be heavy. So, again, the consultation may be delayed for a long time.

Meeting such a family as an outsider, one often has the impression that what the family is looking for is a magic cure - some sort of intervention that will make the disability disappear.

At first contact, the family may therefore express its expectations of a cure for the disabled child, and it might be quite some time before they get back to the initial problems and a description of their initially "felt needs". What one may hear then is, for example: "the problem is that my child does not walk at all," "... does not eat or drink," "... needs help with everything, occupying an adult full time," "... cannot go to school," or "... has a behaviour problem".

Table 3.4

Review of rehabilitation needs among a group of 77 disabled people participating in a CBR project in Vietnam	
Need/Training for	**% with this need**
information about the disability	90
eating and/or drinking	51
washing/keeping clean	78
latrine use or similar	55
dressing/undressing	68
understanding simple instructions, etc.	53
expressing thoughts, needs, feelings, etc.	51
communicating with others	49
getting up from lying	39
moving hands and arms	42
moving legs	53
mobility around house	49
mobility around village	60
play activities	19
schooling (incl. adults)	84
participation in family activities	84
participation in household activities	77
participation in community activities	84
income/generating activities (adults only)	29

This example further illustrates the amount of energy, time and proportion of their meagre resources a family may have to spend in looking for a solution to the needs of a disabled member. Of course, there are also examples to the contrary, namely, not much interest in doing anything at all, and a tendency to leave the disabled person alone, which is a reflection of the perception that "nothing helps".

When a disabled child reaches school age, its parents may consider schooling, and the child may be successfully enroled in the local school, chances for special schooling being remote. If such a child manages to finish primary school, the parents may try sending him or her on to secondary school, with or without success. If enroled, the costs are normally high, which explains why so few of them are to be found in such establishments.

Helped by their families, some disabled adolescents may express their needs for vocational training and gainful employment. Efforts to gain access to such training and to the labour market outside the family's circle of influence are usually very frustrating, reducing the options to an occupation on the family farm or to employment in a small enterprise.

Disabled adolescents in desperate search for better opportunities may at that point decide to move to a nearby town or to the capital, hoping for better chances there. But they rarely find what they have been looking for, and some of them may resort to begging as an alternative.

Organisations of disabled people, where they exist in a city, may be trying collectively to negotiate better opportunities for their members with the local authorities, enterprises, etc. - a frustrating and mostly fruitless effort. The organisations or associations may then turn to other means. They may attempt to obtain donations or funds from abroad to finance projects which for the most part are designed to provide collective solutions: to create employment for their members. Many such projects have a touch of "magic cure for all". To what extent these projects are realistic needs to be evaluated in the light of the marketing situation, the likelihood of finding adequate resources and the group's possibility of acquiring a degree of mana-

Box 3.2

DISABLED WOMEN

There are a number of reasons to assume that disability causes more problems to women than to men. These are summarised in WPA as follows:

"The consequences of deficiencies and disablement are particularly serious for women. There are a great many countries where women are subjected to social, cultural and economic disadvantages which impede their access to, for example, health care, education, vocational training and employment. If, in addition, they are physically or mentally disabled their chances of overcoming their disablement are diminished, which makes it all the more difficult for them to take part in community life. In families, the responsibility for caring for a disabled parent often lies with women, which considerably limits their freedom and their possibilities of taking part in other activities."

Seventy-seven recommendations of actions to take on behalf of disabled women have been taken by the participants of a Seminar on Women and Disability, held at UNCSDHA, at Vienna, in 1990. A few of these are reproduced below; these concern ethics and human rights.

"Disabled women should be informed of their civil and human rights in order to be able to make their own decisions.

"Appropriate legislation that guarantees the full exercise of the rights of women to decide on sexuality, pregnancy, new reproductive technology, adoption, motherhood and any other relevant issue should be adopted and implemented.

"No medical decisions concerning a disabled woman should be made without her informed consent.

"Measures should be adopted to protect women with mental or learning disabilities and information should be provided in a manner that they can easily understand. When appropriate, an advocate should be provided to facilitate the decision-making of such women.

"Open and public discussions on topics such as sexuality, which are often considered too delicate to deal with, should be encouraged, with due respect to cultural norms, in order to increase the level of knowledge of disabled women, their families, professional staff and the general population.

"In countries where cultural and religious traditions make access to medical, vocational, rehabilitative and other services and to employment for disabled women difficult, measures should be taken to ensure that these obstacles are removed so that disabled girls and women can receive those benefits.

"Development and application of new reproductive technologies to prevent disabilities should be seen in terms of ethical and human rights."

Dr Fatima Shah, President of the International Federation of the Blind, and herself blind, lists the "special issues" concerning disabled women, as follows:

"a. Attitudes and prejudices of the public including family, community and even the Government, which are stereo-typed and negative towards disability.

"b. Lack of mobility, isolation, confinement to the house. Socio-cultural patterns, and traditions stronger and more effective than legislation itself, are conducive towards creating this situation more acutely for females than males.

"c. Lack of education and training. Generally the percentage of literacy amongst women is lower than [amongst] men in most of the countries in this region. In the case of women with disability it touches the lowest mark.

...cont'd

Box 3.2 cont'd

"d. Economic dependence on the male members of the family, lack of training and employment.
"e. Lack of environmental adjustment, rendering mobility for the physically disabled very difficult.
"f. Lack of equipment[,] necessary to cope with the disability, i.e. wheelchairs, prostheses, hearing aids, etc.
"g. Poor health due to malnutrition, lack of activity, poverty and ignorance.
"h. Marriage: This is a much greater problem for women with disability than it is for men, due to socio-cultural patterns and the concept of a woman's physical image of marriage. This deprives her of her traditional role and status as a wife and a mother, and combined with total economic dependence, she is relegated to the position of a non-person in the family and community.
"i. Motherhood: If she is married and has children she is not considered fit to look after them, which naturally deprives her of a role important for her emotional satisfaction and personal dignity.
"j. Severe frustration, inferiority complex: Lack of opportunities and access to education and training for self-improvement and independence destroys the self-confidence, self-image and self-esteem due to the concept of her physical body image dominating the socio-cultural pattern.
"k. Non-involvement in Self-help movements at all levels."

A UNDP publication about Safe Motherhood states:

"Death from maternal causes will claim the lives of one woman in 21 in Africa, one in 54 in Asia, and one in 73 in Latin America. By comparison this ... is the fate of only one in 10,000 in Northern Europe".

An even larger number of women become disabled following complications of pregnancy and childbirth. Among these, one finds: prolapsed uterus; damage to the leg nerves with paresis; urinary and faecal incontinence are often discovered. Women with these complications often become divorced; when rejected by their families, they may become outcasts, beggars or prostitutes.

Complications with incontinence and fistulation due to female circumcision are also known to cause disability. In Africa, 80 million women were estimated by WHO to have undergone this intervention.

gerial competence that will ensure its survival in an economically hostile climate.

So, when taking "expressed needs" into consideration, one has to understand how some of these have emerged through a sometimes lengthy process. There is a risk of such expressions having been distorted by traditional attitudes and by frustration. They have to be evaluated with caution. In fact it may prove advisable to analyse the initially "felt" needs instead and to start by designing individual rather than collective solutions.

On the other hand, the identification of "expressed needs" is a positive sign. It shows that the disabled people themselves, their families and their organisations are taking an active part in the search for a solution.

5. *ASSESSED NEEDS*

A well trained and experienced rehabilitation professional would be able to assess the needs of disabled individuals, to identify the priorities among felt needs, and to evaluate the likelihood of success of certain rehabilitative interventions carried out locally or following a referral. For an example of calculations of such needs, see Table 3.4. The data presented in this table derive from a study of Mendis[6]. The sample consisted of 77 disabled people, of whom 45 were under and 32 over the age of 15.

The prospects for achieving success depend, however, on the presence of a service delivery system and trained personnel. The key factor for a successful outcome is a competent community worker with knowledge of the local culture and social structures, who is able to correctly interpret "felt" and "expressed" needs and to provide an adequate training programme, as well as other interventions. He or she should also be part of a wider system which gives him/her access to other people who can help with problems that cannot be resolved locally. Thus, without such outside support, the person assessing needs may not have an easy time arriving at a conclusion as to the potential success of a given approach.

It is necessary to point out that disabled women are more disadvantaged than disabled men and that they have other types of needs. The reasons for this are described in Box 3.2, which also reviews some of the recommendations[7] for specific action for this group.

From these reflections upon the different types of needs it is clear that relevant studies are bound to be complex. In the past, when such studies were largely omitted, researchers used to come up with a series of supply-generated solutions which tended to distort the situation. Services "prescribed" by so-called "experts" often lead to poor results.

6. TRANSLATION OF NEEDS INTO REQUIREMENTS OF SERVICES, INTERVENTIONS, ACTIVITIES, OPPORTUNITIES FOR DISABLED PEOPLE

Needs studies should be carried out locally and ideally the rehabilitation should be designed to fit the "customer's needs". Later in this book, I will propose a system through which services are built from the grass-roots - a system better equipped to identify and address the individual needs. It is also important that disabled people and parents be given a formal role in the planning and implementation of services so as to enable them to inform the authorities of their needs and priorities.

It is the role of the government to design a broad national plan, to draw up a timetable for the provision of services, and to allocate resources for its part of the services and interventions. To do this governments need to have access to some data that will allow them to set quantitative targets: How many disabled people will need what, and for how long?

In Chapter Two, and in the preceding part of this chapter, some data have been given to estimate the size of the disabled population and its needs. I will now - with many reservations - attempt to translate the available information and experience into broad estimates of requirements for services, interventions, etc.

In most developing countries, it will take a long time to allocate the resources needed, to train personnel for services and administration. The quantitative targets given here, therefore, should be seen as long-term goals, reflecting what is required for providing the most essential services.

The following calculations represent a combination of what is required for all the developing countries together. Taking the global, operative rate of moderate and severe disability (see Table 2.3) as a basis, they can be recalculated and refined for each country, based on age composition, level of development, availability of health services, etc. The fact that the group of "moderately and severely disabled" is seen here as the main target group for rehabilitation does, of course, not exclude that rehabilitation is useful also for people with slight disabilities. This is particularly true when it comes to the needs of vocational rehabilitation in the developing countries. Certainly, functional training and schooling should also include slightly disabled people. But the size of the latter group is more difficult to calculate, and it is better to be on the conservative side estimating service needs.

The possible interventions that can be undertaken in favour of disabled people can be divided into roughly two categories: general (mainstream) and specific ones, as follows.

<u>general interventions</u>, including those aimed at:

- building awareness of disability, of the abilities of disabled people, and of the possibility to provide rehabilitation in the family and the community;
- providing more equitable opportunities, better access to the general systems of society, general interventions in the environment, and so on;
- increasing the representation of disabled people and their families on all formal and

informal bodies with authority to decide on plans, services, etc., for disabled people;
- promoting and protecting disabled people's human rights.

It is very difficult to estimate what this will require in terms of personnel and funding. But it is essential that personnel and other resources be set aside for sensitisation campaigns, drafting of new legislation, enforcement of both existing and new rules and regulations. Resources are needed centrally and also at the provincial and the district level.

specific interventions, including

- functional training in self-care, mobility, behaviour and communication, including provision of appliances and technical equipment to facilitate training and/or to alleviate the consequences of disability. Also included are environmental interventions in respect of individuals, such as removal of physical barriers for a disabled person, informing and sensitising the family and the community with a view of creating more positive attitudes and less discriminatory behaviour;
- special education calling for resources not available, or not properly used, in regular schools;
- vocational measures, including assessment, formal or informal vocational training, job placement, assistance in setting up small enterprises, etc.

Quantitative targets for these three specific areas will be proposed. These targets should be understood as guidelines for what has to be provided in order to meet the most essential needs of all disabled people. I am not proposing, at this point, any strategy how to provide the services necessary to meet these needs.[8]

- **functional training**

To calculate the requirements for services related to functional training[9], we need to know:
- the number of newly (moderately and severely) disabled people each year;
- how many of these people could benefit from training, and
- the length of time needed for training and follow-up.

The annual incidence in 1990 of moderately or severely disabled people in the developing countries was estimated at 40.5 million. By 2025, this number is expected to increase to 99.5 million.

Not all of these people will need, or want to have, functional training. For some of them, in particular children and elderly, the remaining lifetime will be short. Some will lack the motivation or the strength to participate in a programme requiring active, sustained efforts on their part. For those, it will be easier to content themselves with accepting a family member's services and care. Yet another group may be too severely disabled to participate in a programme, or be afflicted with medical complications (such as cardiovascular disease, or senility) that preclude their taking part in a rehabilitation programme. Others may have a rehabilitation potential that is extremely small or nil.

Based on this cautious estimate, the **initial target for service provision** should be set at about 30 per cent of the group of newly (moderately or severely) disabled people. This corresponded, in 1990, to 12.2 million people. Future plans should allow for an expansion of that number to about 30 million by the year 2025. The estimate suggested here corresponds to approximately 20 per cent of the total prevalence.

The people belonging to the target group will need attention for more than one year. The length of time for training and follow-up varies considerably from one individual to the next. Some will need but short periods of training, say, six to twelve months. Others, such as children with cerebral palsy, pareses, mental retardation, congenital deafness; adolescents and/or adults who have been victims of accidents causing brain damage, paraparesis, or who have arthritis, or a degenerative neurological or mental disease; elderly with stroke, amputations or Parkinson's disease, will need much longer training. Yet another group of newly disabled people will have mental health complications, such as depression, that delay the process of rehabilitation.

After completion of the training period, many disabled people need to be followed-up to make sure that the results gained are maintained. Or they have to be provided with regular technical service, such as repairs and maintenance for a leg prosthesis, and about every three years a new prosthesis is required).

Based on these considerations, I propose three years as the average time period required for functional training and follow-up.

These estimates allows us to conclude that the target set for 1990 would be service provision for 36.6 million (12.2 million multiplied by 3), while the service needs would increase to about 90 million (30 million multiplied by 3) by the year 2025. (See also Table 3.5.)

- **special education**

To set targets for provision of special education is difficult. From certain studies it appears that in some schools in the industrialised world more than 10 per cent of children are experiencing problems which need to be addressed by the school. At least 20 per cent of all children entering primary school in the developing countries will have difficulties passing their examinations. Of these, a large group is composed of children with psychological complications as a result of family problems. Other groups are made up of children with delayed development or of children belonging to underprivileged sections of the population and those with speech difficulties or social behaviour problems.

Estimating the needs for special education is further complicated by the fact that existing institutions provide a combination of functional training and schooling. For some children, the principal content of the education they receive is, in fact, functional training. The estimated needs for those services are already included above.

I have opted for using the prevalence rate for moderately and severely disabled children aged 5 to 14 as the basis for calculating the target. In 1990, the prevalence was 24 million children in the developing countries. Many of these have some very basic problems in school, related mainly to severe reduction of vision or hearing, or to mental retardation. In 2025, their number will be 32 million.

In addition, there is of course a proportion of children with development delay, with social and family problems, with learning and speech difficulties, etc. But it would be unrealistic to start advocating that all these needs should receive priority attention. A large proportion of the two to four million children with a history of poliomyelitis, as well as those who are slightly or moderately mentally retarded, are often able to attend regular schools. Efforts are, however, needed to ensure their enrolment in regular classes.

In trying to set a target for these needs of special education, I have assumed that, during the period when they are in the age group 5 to 14, the disabled children (in 1990 = 24 million) will receive schooling for a total average period of seven years. Using these estimates, the size of the target group, in 1990, was 16.8 million (24 million multiplied by 7/10); in 2025, it will be 22.4 million (32 million multiplied by 7/10). (See Table 3.5.)

The target group of children with needs for special education is currently forecast to increase by about 33 per cent between 1990 and 2025. This relatively modest increase is explained by the projected considerable decline in the natality rate over the same period. Moreover, it may be assumed that, over the same period, communicable diseases and malnutrition will diminish as causes of impairments and disabilities in this age group.

On the other hand, the scope of special education may be expected to widen with economic development, as more children with special needs (such as those mentioned above) are included. As a result, the increase might very well exceed the estimate of 33 per cent.[10]

It should be mentioned that there are also many adult disabled people who are illiterate and wish to have education. Given the virtually total absence of field studies on the number of such people and the scarcity of resources available for them today, I have refrained from estimating the size of this group.

The crude estimates given do not indicate the number of places required in segregated institutions and cannot be directly used to calculate the needs for trained teachers. Such calculations can only be made after a strategy decision has been taken.

- **vocational measures**

The tally of people needing vocational measures likewise reflects a cautious view of what may be achieved in realistic terms.

There is widespread unemployment in the developing countries, reaching in some cases 20 per cent or more of the existing potential labour force. Underemployment is another common phenomenon. The population grows by two to three per cent annually in many of these countries. The levels of investment and economic growth are not high enough to absorb the 80 to 120 million young men and women (in Africa, Asia, Central and South America) who try to enter the labour market every year. At the same time, employment opportunities for agricultural workers stagnate. The young rural population is moving to urban areas - a factor that tends to increase the competition for the jobs available in the service and industrial sectors.

The conclusion to be drawn from this situation is that, in the developing countries, with low, stagnant, or negative economic growth, only those disabled people who are able to compete on a basis of equal competence will succeed in entering the labour market.

In a few countries, the investments are higher and GDP growth reaches three per cent, or more. In these, the prospects for finding a job are better. The disabled people who will have the abilities to participate in ordinary work are mainly those with moderate and slight disabilities, and vocational rehabilitative measures should be targeted at this group.

To set a quantitative target for vocational rehabilitation, the following calculations have been made. In the developing countries, vocational measures are almost exclusively given to a group of adolescents and youths aged 15 to 29. After age 30, such measures are rarely successful and consist mainly in returning a newly disabled person to his or her old job. Thus the target group for the estimates is based on the age group 15 to 29.

I have not provided any estimate for the prevalence of moderate and slight disability in the previous chapter, but I will assume that prevalence approximates the one for moderate and severe disability. The prevalence of the last-mentioned is (see Table 2.6) 24 million, in 1990, and 37 million, in 2025.

Vocational measures will comprise: assessment of disabled people, informal and formal training, job placement, market assessment, assistance to self-employment and follow-up to ensure maintenance of rehabilitation gains.

Vocational measures are directed at many sectors, e.g. household activities, agriculture, small enterprises, manufacturing and services. It is proposed that the average time period needed for these measures and for follow-up be set at three years. These vocational services are foreseen to be given to all moderately and slightly disabled people in the age group 15 to 29 years.

Using these estimates, the size of the target group for vocational measures may be set at 4.8 million (24 million multiplied by 3/15 = three years of services and follow-up over a period of 15 years), for 1990, and at 7.4 million (37 million multiplied by 3/15), for 2025.

The total proposed targets appear in Table 3.5.

Based on these estimates shown in Table 3.5, we might calculate that services for rehabilitation were needed for close on 60 million disabled people in 1990 and that the need will increase to about 120 million in the year 2025. These global indicative figures should be taken with caution. They are based on modest assumptions and estimates, and on field experience. They correspond to permanent service provision targets for 1.4 per cent of the total population in 1990, and

Table 3.5: Indicative global targets regarding the number of disabled people for whom permanent rehabilitation services are required in the developing countries

Type of rehabilitation services	**Basis for calculation**	**Period over which services and follow-up are required**	**Services targets, million people needing rehabilitation**	
			1990	**2025**
Functional training	30% of incidence moderate and severe disability, all age groups	3 years	37	90
Special education	All children with moderate or severe disability aged 5-14	7 years	17	22
Vocational measures	All adolescents and youths with moderate or slight disability aged 15-29	3 years	5	7
		TOTAL	59	119

for 1.7 per cent of the total population in 2025. In these targets, I have not included other types of services for disabled people, such as home care and medical care.

It should be pointed out that the needs calculated here do not include the accumulative ones. It is clear that, in situations where services are virtually non-existent, or neglected, many people are "on the waiting list". For some of them - for example, those with contractures, or those beyond school age - it will, at some point, be too late to intervene. The others, particularly those with slight disability wanting a job, the chances of reaching results may still exist. It should also be noted that a large number of disabled people has yet to receive the technical appliances and aids they need, such as crutches, braces, spectacles and hearing aids.

It should be possible to recalculate the target estimates in each developing country and, based on this, to make some rough predictions regarding the requirements for personnel, budgets and facilities. These requirements will depend on the strategy for delivery of services used. Institution-based services will require other resources than community-based ones.

The targets proposed here should be seen as temporary. As countries develop, the demand will grow, services may become more time-consuming, and the target groups will widen.

I would like to reiterate that, in the absence of precise data, the estimates made above and the targets proposed are based on professional experience and on field work. They should be seen as indicators of the needs for services in the future and not as a final, exact calculation. Far more research is needed in order to provide accurate numbers.

In conclusion: specific services to cover the essential needs for functional training, special education, vocational measures were, in the developing countries, estimated to be needed

- *in 1990, for about 60 million disabled people*, and
- *in 2025, for about 120 million.*

An enormous gap exists today between what is provided and what is required. The requirements **grow by about 1.8 million a year, or by close to 5,000 a day**. The number 1.8 million is close to the estimate of the total service provisions today. The gap is widening rapidly.

COMMENTS AND REFERENCES

[1] P. Mittler in "Rights and Realities for People with Mental Handicap: can they be reconciled?", European Symposium on Bio-Technology, Ethics and Mental Handicap, June 4-8, 1989, Marburg, Germany, offers a thorough analysis of what is meant by "needs", who determines such needs, etc., and proposes participation of mentally handicapped people in the decisions regarding needs. Mittler also points out that "needs arising from impairments are not exclusively intrinsic to the individual. They depend in part on the opportunities for the satisfaction of these needs which can be provided by the environments in which the person is living and learning".

[2] This study was carried out in co-operation with the Research Department of the Ministry of Health in Jakarta, Indonesia, in 1976-78. The principal researcher was Dr Kartari, D.S.

[3] The word "spontaneous" is used to signify the actions a family takes instinctively on its own initiative, based on trial and error and without any professional advice.

[4] Quoted from F. Shah, Disability, Self Help and Social Change. ICIC Foundation, Karachi, Pakistan, 1990.

[5] B. Helander provides a detailed example of this process in "Disability as incurable illness: Health Management and Disabled in Southern Somalia" (to be published, 1992). The example concerns the Hubeer clan in Somalia.

[6] P. Mendis, Report from a CBR programme in Vietnam, courtesy The Swedish Save the Children Fund, Stockholm, Sweden. The order of needs follows TCPD, Guide for Local Supervisor, pp. 38-40.

[7] "World Programme of Action concerning Disabled Persons" (WPA), (A/37/351/Add.1 and Add.1/Corr.1, annex), para. 45.

"Disabled Women" in Women 2000, No. 1, 1991, UNCSDHA, Vienna, Austria.

Another review prepared by E. Boylan appears in "Women and Disability" (Women and World Development Series), Zed Books Ltd., London, UK, and New Jersey, USA, 1991.

F. Shah, ibid.

M. Law, D. Maine and M.T. Feuerstein: Safe Motherhood, Priorities and Next Steps. UNDP, 1991, New York, USA.

D. Maine: Safe Motherhood Programs, Columbia University, 1991, New York, USA.

R. Cook: Damage to physical health from pharaonic circumcision (infibulation) of females. Paper prepared for a WHO Seminar on Traditional Practices, 6-10 Febr. 1984, Dakar, Senegal.

World Health Statistics, WHO, Geneva, Switzerland, 1987.

[8] At present, many services are provided jointly, and in institutions or on an ambulatory basis. For instance, functional training is given either in medical facilities or as part of a special education programme, or in connection with vocational training. The calculations presented here cover all the needs of such training, regardless of where the service is given at present and without prejudging the future strategy.

[9] Functional training, mainly in the form of physiotherapy, is also part of acute medical care delivered in hospitals or to out-patients. In industrialised countries, such training is an integral part of the treatment administered to patients with fractures, arthritis, cardiac disease, stroke, neurological disorders, burns, etc. Some of the above conditions will become chronic and disabling, at which point the continued training becomes part of a rehabilitation programme.

The requirements for functional training during the acute phases of a disease, or after trauma, are not included in the estimates here.

[10] It is clear that, as economic development progresses, the perceived needs among and the resources provided for children with difficulties in school will grow considerably. In Australia, a recent report suggests that, in primary and secondary schools, there are respectively 14.7 per cent and 11.6 per cent of children "experiencing difficulties". Out of these, a large proportion "require assistance". The latter belong, in primary schools, to the following categories: vision 0.6 per cent (of all school children), hearing 0.5 per cent, co-ordination 1.5 per cent, health 0.6 per cent, speech and communication 1.8 per cent, general learning 4.9 per cent, specific learning 2.3 per cent, emotional or behavioural 3.1 per cent.

The conclusion is that to the degree that economic development allows it, there will be a growth of needs related to special education in the developing countries beyond the 33 per cent projected in Table 3.5.
Source: D. Pickering, C. Szaday and P. Duerdoth: One in Eleven. Faculty of Special Education, Victoria College, Victoria, Australia, 1988.

CHAPTER FOUR: THE CONVENTIONAL SYSTEM

In this chapter I will describe the conventional, still existing system for rehabilitation. The description is based on visits made to some 60 developing countries. It also draws on discussions with central and local authorities, professionals, representatives of organisations for and of disabled people, international development and donor organisations and local non-governmental organisations. I am further drawing on experience gathered during visits to several hundreds of centres, institutions, schools, training centres, hospitals and so on, as well as to hundreds of small rural communities and marginal urban settlements. The description is also based on the insights obtained from interviews conducted with disabled people and their families in their homes.

1. POLICY APPROACHES

The first subject for review concerns policies of interest to disabled people. Each country has a number of general policy statements, of which the constitution is the most important. Often the constitution was adopted after decolonisation, formulated in modern terms and revised in the light of more recent reforms. The constitution generally lays down the rights of all citizens: to education, to work, to public services, to freedom of association and expression, to legal protection, etc. It may sometimes include passages relating to disabled people, in which it is stressed that these share the same rights or that they should be given the special services they need.

The activities of each government sector are regulated by specific laws, decrees, rules or similar, based on the constitution. To give an example, the parliament, at the initiative of the Ministry of Education, may approve policies and legislation governing education, training of teachers, curricula and examination procedures. These instruments may include guidelines on how to educate disabled children and adults.

Some policy documents are specific and exclusively concern disabled people. For example, numerous countries provide assistance in the form of transport facilities or higher school allowance rates for disabled children. Many have also special labour regulations such as quota legislation or sheltered workshops, subvention schemes in respect of orthopaedic appliances, and so forth. Or the country's social security system may provide for workmen's compensation, rehabilitation services, etc.

Finally, there exists today a wide range of international resolutions, conventions, declarations which may or may not have been ratified and implemented by a particular country.

However, policies related to disabled people often fail to achieve their goals. This is because

(a) implementation of such policies is inadequate or non-existent. Most governments have not done enough to inform their citizens about their rights and their duties. In addition, there is a deficiency of administrative, political and service structures to ensure the implementation/-enforcement of the relevant policies;

(b) policies related to disabled people are seldom integrated and consistent because of the lack of clearly defined general political objectives in this area.

2. PLANNING APPROACHES

Few countries have any detailed medium- or long-term plan as to how disabled people's needs are to be met. The few plans I have seen failed to address the problems as a whole in a realistic way. Nor did they set precise targets in terms of population coverage.

External donor or development organisations which set up or contribute to services - sometimes in co-operation with the government or with a national non-governmental organisation - are not receiving enough guidance. The lack of government planning contributes to the haphazard and uncoordinated use of the resources set aside for disabled people. External initiatives clearly suffer from a lack of co-ordination at the national level. As a matter of fact, some countries have attracted over a hundred different small projects each, most of which are planned and executed in ways that leave much to be desired.

With a clear plan to follow, governments could redirect the use of external funds in such a way as to yield long-term benefits through the development of services and other facilities which are economically and professionally maintainable in the country, and which fit into the pattern of general socio-economic and human development.

3. TYPES AND STRUCTURES OF CONVENTIONAL SERVICES

I will now attempt to review the types and structures of existing services.

The conventional system of services exists in many different forms, for example:

- rehabilitation centres, mostly for disabled people with mobility problems;
- orthopaedic workshops, of which some also produce wheelchairs, crutches or small appliances for ADL;
- outpatient clinics for physiotherapy and occupational therapy;
- ordinary hospitals, which may have a physiotherapy department designed for acute patients (with fractures, stroke, post-operative treatment, etc.);
- rehabilitation hospitals, sometimes with their own department of orthopaedic surgery, an orthopaedic workshop and wards;
- special schools or integrated special classes and/or ADL training centres, e.g. for blind, deaf, physically disabled or mentally retarded children;
- vocational centres, almost none of which have facilities for assessment, so the main thrust is for training;
- sheltered workshops and co-operatives for disabled people;
- psychiatric hospitals, where one might find large groups of mentally retarded patients, autistic or epileptic children/adults, and a group of patients with chronic mental illness;
- leprosaria, for patients undergoing leprosy treatment with drugs. Some of them are sent home after the treatment, others remain for a life-time. Some of these institutions have an active rehabilitation programme;
- orphanages, where most children stay for only a short while (before being adopted). But disabled children often remain until they have reached maturity, because few people want to adopt them;
- beggars' homes or detention centres, where disabled beggars (after being rounded up and removed from the streets) may stay for very long periods of time;
- rehabilitation services, which may form part of some other activity, e.g. that of an ophthalmological assistant working in a district hospital, who may provide some training of blind people, or that of a bicycle manufacturer who also produces wheelchairs.

The services are provided either in boarding or in day centres and mostly to be found in the capital. Some of these have made attempts to set up an outreach programme.

4. ORIGIN AND FUNDING OF CONVENTIONAL SERVICES

The beginnings of some of the services I have seen go back to the 19th century. But most of them are the result of expansion since World War Two - a process that is still going on today.

Almost all early services for disabled people in developing countries were started by religious organisations. Missionaries and others observed the large number of disabled people everywhere and began looking for ways and means of helping them. They called for experts and professionals to design services and, in the early phase of development, these services tended to be copies of institutions in the industrialised countries. Such services multiplied and became the standard pattern.

In the years to follow, the trend was toward nationals being sent to certain well-established centres in the industrialised countries for training. Some of the returning professionals successfully convinced their governments to set up or, at least, to support a national centre in the capital. In a handful of countries, the government created decentralised services, e.g. on a regional basis.

Many non-governmental organisations followed suit, providing specific services for small groups of disabled people, the majority of them children. Support also came from multi- and bilateral donors. Today, the number of different service-providing projects financed by external funds can be estimated at 4,000 or more.

The funding of existing services is mixed. In the beginning, almost all facilities were built and equipped by funds provided by foreign donors, and the personnel consisted for the major part of expatriates. Most donors try to create, or get in contact with, a local organisation prepared to take over management and funding of the services. Expatriate staff is often phased out later on and replaced by nationals, which helps to reduce costs.

After a while, the national or local governments may start contributing funds, on an initially rather symbolic scale. Some services have been set up by social security funding, but in most developing countries these will cover but a small proportion of the population.

It is not easy to calculate the amount of funds currently used for providing services for disabled people in the developing countries. The total amount spent by external contributors (multilateral, bilateral and international NGOs) is at least US$ 300-400 million annually.[1] National governments, social security systems and NGOs spend probably no less than US$ 100 million for rehabilitation annually. This would bring the total to something in the order of US$ 500 million a year. But this is a conservative estimate. Using another approach, one could, for instance, calculate that about 2 million disabled people receive services (funded either by local or external donors or by their own government) at an annual cost conservatively estimated at US$ 500. Then the total comes to US$ 1,000 million per year.

5. *THE GAP BETWEEN NEEDS AND AVAILABLE SERVICES*

To judge from country visits and reports, the number of disabled people throughout the developing countries known to receive organised functional training, receiving special education or undergoing preparation for jobs was estimated to be roughly two million in 1985. In other words, not more than about 3 per cent of the requirements for rehabilitation calculated in Chapter Three have been met.[2] Others were given care by the family, a proportion of whom were receiving effective "spontaneous" training. Still others had been integrated in local schools or were earning an income. In the past few decades, the provision of rehabilitation has been lagging behind the population growth in many developing countries, where the combined effects of economic stagnation, high birth rates and structural problems tend to widen this gap.

The following three factors may help to explain what gave rise to this gap of some 97 per cent.

(i) *Costs*

Cost estimates undertaken in a number of conventional rehabilitation centres of reasonable quality in developing countries vary between US$500 and US$5,000 per disabled person per year. Based on this, the annual cost (including capital costs, administrative overheads, etc.) could reasonably be assumed to average roughly US$ 1,000.[3]

Thus, if we were to provide conventional services for all those moderately and severely disabled people, conservatively estimated at 60 million, who need a rehabilitation programme, the price tag would amount to some US$ 60 billion annually. This has made many decision-makers reluctant to embark on anything but small-scale services.

(ii) *Personnel*

In a large number of developing countries, there is a serious shortage of professional personnel. Many countries lack schools, while in others trained personnel "disappear" into the private sector or emigrate to countries which offer better salaries or career prospects. In most countries the professionals remain in the capital and prefer to work in institutions.

In addition, the "early expatriates" may have contributed to the problem. When their profession was introduced in the developing countries, they frequently insisted that there should be no change in personnel policies, in distribution of tasks between various categories of personnel (working as teams), in duration of training, and in curricula. This considerably increased the price for providing rehabilitation. It is hard to conceive of a better way of blocking the development of services for disabled people in the developing countries, or of a more effective instrument to make governments delay the setting up of services.

(iii) *Public perceptions*

The service gap is partially due to the perception that rehabilitation does not bring about any significant change in the life situation of a disabled person, that services are very costly and that they require a large number of qualified professionals.

At the origin of this perception is the fact that, for a small group of severely disabled individuals, the situation is too grave to allow for more than marginal improvement. Some conventional institutions which concentrate on functional training and segregated special education have also had a part in forming such perceptions. Many of them have not had appropriate programmes for the social and vocational integration of their clients; in such centres disabled people remain "for ever".

Another part of the explanation of the lack of services is prejudice. Disabled people are a low-status group with few "political resources", subjected mainly to charity-generated care, and this has prevented them from obtaining public services.

6. *ACHIEVEMENTS*

Without the international efforts to provide services for disabled people in the developing world, such services would in most likelihood not exist today. We must recognise the enormous importance of what has been done by all those dedicated workers who, in spite of all the negative reactions and the difficulties encountered, managed to get a service off the ground. We may sum up their achievements as follows:

- they demonstrated that disabled people are able to take care of themselves, to learn as well as others, to work and to earn an income;
- they created awareness of the fact that disability is a common problem and that next to nothing has been done about it;
- they encouraged nationals (governments and NGOs) to start services on their own, providing funds and personnel;
- they helped to develop a sense of international concern for an area that previously had a very low priority.

Therefore, the following comments should be read bearing in mind the substantial achievements of those dedicated pioneers.

7. *COMMENTS ON THE COST-EFFECTIVENESS AND QUALITY OF THE CONVENTIONAL SYSTEM*

I have chosen to comment on the conventional system by providing some examples of existing services (see Boxes 4.1 - 4.12).

The examples do not give the name of the country or the location. I feel this to be immaterial. The situation varies, of course, considerably from country to country. But when it comes to type of problems they do not differ much. Nor are the situations described in the following text unique to rehabilitation. Many other development projects (e.g. in agriculture, education, health and transport) have their share of similar problems.

Box 4.1 is an example of a well-funded project. It exemplifies several important problems with the conventional system:

- the relationship between the family and the disabled person is often broken, and those admitted to a centre have no way out;
- the costs are very high, and there are few chances for the system to be taken over by national authorities/NGOs without a major loss

in quality, so the donor has no way out.

Box 4.1

NO WAY OUT

The centre at X consists of a very large villa and a number of outbuildings, surrounded by a beautiful, well-kept garden. It receives about thirty boarders, all of them were initially mentally retarded children in the age groups 3 to 10 years. There are several small classrooms, which look more like play rooms than a school. It has eight professionals (of whom four are expatriates) and 15 additional staff for cooking, cleaning, gardening, etc. The rehabilitation programme consists of ADL training and special education and is of excellent quality. The personnel are well motivated and have activities in-and outdoors, games, etc., the whole day.

There are two children to a bedroom, and plenty of bathrooms. The buildings are luxurious, with marble floors, high-quality furniture, and carpets. The food is excellent, the whole place is tidy and orderly, the children look happy and love the staff.

Of course, the costs for the centre are very high and are totally donated by a foreign NGO. I visited it when it had just been inaugurated 16 years ago, and there were then some vague ideas of transferring it to a local NGO or to the government "later on". The principal felt that a few families might take home their children when their "education" was completed. Otherwise the centre might have to keep them and build a sheltered workshop for them.

Since then, almost no children have left the school, and the contacts with the parents are thinning out. Over half of the children have had no visit from a family member during the last year. There is no way out for them. The annual cost per child is now about US$ 9,000, and the donor organisation has desperately been looking for a national organisation to take it over. So far, nobody has shown any interest - so there is no way out for the funding NGO either.

Box 4.2 gives another example of a well-funded government project for mentally retarded children and adolescents.
My comments are:

- in spite of adequate facilities, salaries and training, the personnel neglect their duties, probably as a result of their negative attitudes and of the lack of supervision both by technical staff and by the family members (who only rarely come for a visit);[4]
- many disabled people lack the necessary resources to protect themselves against abuse in all its forms - a fact the personnel might be taking advantage of;
- in this country, schooling is compulsory and free. The centre has been set up mainly to "rid the normal school" of children who are "unwanted" by the teachers - and not out of concern for the welfare and education of these children.

Box 4.3 gives an example of sexual abuse of disabled young boys. Such abuse, of both girls and boys, unfortunately, is common, in particular when it comes to mentally retarded or deaf adolescents.[5]

Box 4.4 concerns a training programme for physiotherapy students, and Box 4.5 illustrates the practical outcome of a similar training course in another country.
My comments are:

- transferring a course for rehabilitation professionals from an industrialised to a developing country rarely yields the desired results;
- students attending such professional courses put their own interests first (such as emigration or starting private practice) and may not see themselves as serving the public;
- the educational objectives of many courses have not been formulated taking into account the realities of the particular country and do not always address the needs of the public;
- introduction of high-cost technology (such as electrotherapy) often leads to a neglect of the tasks to be done with low-cost technology (in this case, active exercises and ADL-training)
- or it fails completely (most swimming-pools in rehabilitation centres are dry).

Box 4.6 explains some of the problems encountered by orthopaedic workshops. Many people ask why this technology is so rarely functioning well, while highly sophisticated manufacture of computers, television sets, cars, ships, jewellery, watches and so on in some of the same countries is done with excellent quality. This may be accounted for by the following facts:

- training is inadequate, supervision and quality control (by professionals and by the disabled people who receive the appliances) are lacking; one of the main problems is the lack of understanding of biomechanics such as alignment[6] ;
- staff is not well paid and hence not well motivated for the job;
- presence of severe production problems, such

Box 4.2

TIE THE HANDS OF THE CHILDREN SO THE PERSONNEL CAN WATCH TV IN PEACE

In 1989 a UN expert visited a centre for mentally retarded in an Asian developing country and reported the following:

"... there is no consistent program of activities proposed to the children: besides eating and bathing, there are no activities where the children are actively involved; they are placed in a large room, without any stimulation of any kind, where they spend their time moving around, or sleeping on the floor, or indulging in self-stimulatory behaviour, until next feeding-time or bathing-time. Moreover, there is no furniture in the room besides a floor-rug. In order to prevent self-stimulatory behaviour, some of the children are either tied down all day long in their beds, or have their hands tied back. Occasionally, one of the care-takers interferes to take one or two children to the bathroom. Two or three times over a period of three months, the children were taken to the "club-room", another room on the same floor, over-equipped with decorative items and dolls. This room contains a video-set, but it was noticed that the video-system was never used; instead, regular television programs were put on for the pleasure of the care-takers.

"The relationship between the care-takers and the children is very distant: there is no corporal contact other than for punishment purposes, or for accompanying the child to the bathroom or to his bed.

"Feeding practices are as follows: two of the children are fed in a sleeping position on the floor or on a wooden bench; the others are seated in a row on a bench and the care-taker spoon-feeds them all using the same spoon and one single dish. This entire feeding procedure covering four to five children simultaneously does not last for more than ten minutes. There is no control as to whether the children washed their hands and mouths after the meals. During the time we spent there, only three children out of the entire group are allowed to eat independently at a table. No supervision is exerted upon their eating-habits. No training attempt was observed.

Other remarks in the same report are:

"... The services offered ... are merely at the level of boarding. No attempt has been made at implementing any systematic educational training program to clients. The staff directly involved with the children are not competent. There does not seem to be any control or follow-up of the staff performance" ...There is no clear-cut job-description to identify the proper responsibilities of each of the personnel, a factor which is greatly responsible for the general chaotic atmosphere.

"... the total lack of parental involvement in the training process of the clients: some of the children have been institutionalised for years [average time 8 years and 3 months] without any parental visit.

"... The structure of [the programs for another institution in the same country] were designed to fit the needs of the teachers for frames and forms rather than the actual priority needs of the children they are supposed to serve. In addition, there does not seem to be any planned program for the future of the clients served today."

Box 4.3

ABUSE IN AN INSTITUTION

A physically disabled expatriate went to an African country and through contacts in his home country managed obtain funds to open a "home" for disabled adolescents. He rented a large villa and had some simple boarding houses put up on the land. After a few years, he had collected a dozen disabled boys, who were lodged and fed in the "home". He employed some help to look after them, but there was no rehabilitation programme.

By court order, he had also been made custodian of four or five young male criminals, who were out of jail. These were not disabled.

One day, the expatriate suddenly had a fatal accident. The local church, which had given some economic support to the home, decided to take it over and employed a young couple to look after the boys. When they went through the belongings of the expatriate, they came across his diary. In it he had recounted his sexual experiences in great detail with all those who had been in his care. Interviews with the boys confirmed the story. They said that they had never dared to say anything or to complain, for the expatriate had threatened them with being thrown out in the street or sent back to jail. Besides they did not think that anybody would believe them - the expatriate had an excellent reputation and good connections with a number of high-ranking officials.

as lack of materials and spare parts,

- breakdown of machinery, power and water cuts, with the personnel eventually acquiring a resigned attitude to work; control of the means of production is to a large degree out of their hands;

- costs are high; very few people can afford to pay for their appliances, if only in part; the subvention system often breaks down or is inadequate;

- the authorities who should help to correct problems and provide/import materials and spare parts consider this activity as a low priority, so the delays are long - sometimes years.

Box 4.7 depicts an example of what happens when the conventional system is falling apart. Similar descriptions will be obtained in many countries when one is in a position to review the entirety of the institutions rather than the few showcases normally shown to visitors from abroad.

My comments are:

- we are here confronted with a decaying system. The reasons for this decay are multiple: withdrawal of resources by foreign donors, lack of interest and motivation among the staff, segregation, lack of contacts between the children and their parents, negative attitudes, and discriminatory behaviour toward disabled people;
- there seems to be no legal protection against this enormous abuse of disabled children, adolescents and adults.

Box 4.4

PHYSIOTHERAPY STUDENTS FAIL
- THE REASONS WHY -

In a UN organisation where I worked for several years, I inherited a project: a physiotherapy school in an Asian country. The school received each year about thirty female students, and the course was for three years. Its principal was an expatriate, and it had been a very costly project.

I wrote to the principal and asked for an evaluation. She sent me the course plan and the records of the examination results.

We then entered into a lengthy exchange of letters regarding the course contents. I wondered how this typical Western curriculum fitted into this very poor country. The course was quite adequate for learning about, say, cerebral palsy, multiple sclerosis and stroke, all these unusual diseases in this Asian country. On the other hand, the students did not receive sufficient training for polio patients. One third of the time was devoted to learning physics, the theory of electricity and the handling of various electrical appliances. The explanation for this was that advice about the course plan had been given by the professional international federation. Many of the students, so I was told, were taking the course in order to emigrate to an industrialised country and "needed" to follow what they perceive as the guidelines of the federation. It appeared that over a third of the students dropped out or failed their examinations, and that the theory and practice of electrotherapy was the big obstacle. I suggested cutting down on the "electricity" and to concentrate instead on active exercises. This was rejected immediately.

I then received a lengthy letter saying that it was after all not the "electricity" that accounted for the failures. The problem, wrote the expatriate principal, was that these students were all small and rather frail girls. They were not eating enough, and they were tired out by their job, so that they could not study as much as needed.

I should perhaps add that without the "electricity" component the students could not emigrate at the end of the course.

Box 4.5

REHABILITATION EQUALS ELECTRICITY

This is a large rehabilitation hospital in the capital of a Middle Eastern country. The medical doctor in charge has received training in the United States and takes pride in showing his signed photos of some physiatrists of worldwide renown.

A physiotherapist takes me to the therapy areas, consisting of the usual dry swimming-pool. It leaks, she says, and is awaiting repair. There are a few Hubbard tanks, a large gym hall (unused), as well as some twenty small booths for physiotherapy occupied by a number of patients with paralysis after polio, with hemiplegia or paraplegia. They are receiving one or the other of the following three types of electrotherapy: electrostimulation of muscles, diathermy, and ultrasound. I inquire about exercises such as training to walk, ADL, prevention of contractures - No, they do not have that. Physiotherapy is taught at a national school. It is a three-year course, and I am told that it is real tough and that the curriculum is approved by the international professional federation.

Box 4.8 relates a story of how well-wishing people sometimes set up facilities without ever giving a thought to what will happen in the future, thus causing serious frustration to those they wanted to help.

Boxes 4.9, 4.10 and 4.11 illustrate various approaches to vocational training. These represent classical examples of respectively government- and NGO-managed conventional centres. The comments are:

- a lot of vocational training has been set up without previous market studies, so it is common to see that the skills acquired are

of little use when it comes to earning an income;
- some centres are facing serious problems both concerning the quality of the training and the provision of funds;
- training costs as related to results in terms of probableincome-generation have not been the subject of sufficient concern;
- all vocational training should be preceded by vocational assessment or screening, and those capable of undergoing vocational training and of holding a job later on should be identified: In this way the costly and often unproductive trial-and-error training can be avoided;
- some vocational training programmes or workshops (e.g. for mentally retarded) have been set up to provide a place where parents can send their adolescents to be looked after during daytime - a legitimate need for recreational activities that can be met adequately at a much lower cost. Including these people in a vocational training programme evidently increases the expect-ations of both the disabled person and the family that there will be a job later on. When this does not materialise, frustration will grow.

Box 4.6

ON ORTHOPAEDIC WORKSHOPS

By now, I must have seen over one hundred orthopaedic workshops, in some sixty developing countries. Millions of dollars have gone into equipping them as well as into the training of thousands of technicians, who should be able to do a good job. No other technical area of rehabilitation has received so much external support. Yet the output of these workshops is lamentably low, very often not more than ten per cent of the potential output. Some of the products being of acceptable quality, others a far cry from it. And another big problem is alignment - a poorly understood subject.

The picture that presents itself is almost invariably that of a very run-down building, full of old, costly machinery, most of it in a state of disrepair; and with technicians who for many reasons are unable to master the technology.

There are some good examples, such as the highly effective and attractive workshop managed by expatriate staff that I saw in an African country. Another one, in Latin America, had an excellent staff and well-kept machinery in spite of a leaking roof. The building had not been repaired since they moved in 25 years ago, so the floor was covered by five centimetres of water, and we had to step on bricks placed here and there to move about. But this centre had no materials for the appliances because government "savings" measures and inflation had reduced the budget to well-nigh zero.

In another workshop I visited in Asia, they made no secret about the fact that they spent most of their time producing spare parts for private vehicles - a way of complementing their meagre salaries of a few US dollars a month. Here the machines were in very good order.

And yet another one comes to mind - a workshop run by the military for their soldiers. This one was highly efficient and low-cost, turning out excellent products, with a network of 20 annexes covering the whole of the country. It was all paid for through the army budget.

A leading physician in another Asian country had the idea of producing all the required modules for the entire country in a central industry, from where they were then sent out to annexes for fitting and local alignment. Although run by a retired general, the undertaking turned out to be a costly flop.

There are some examples of efforts to manufacture appliances using low-cost technology, e.g. by having them produced by local blacksmiths or by introducing production relying exclusively on simple tools/equipment that can be totally controlled, requiring no or few external inputs. These techniques are as a rule more productive than the "conventional" ones.

In the vocational area, there has been a tendency to create sheltered workshops and co-operatives. These have been set up because in many instances disabled people, even when qualified, tended to have difficulties finding a job. The underlying idea of the sheltered workshop was to provide a range of opportunities. Later on, it was thought of turning these institutions into co-operatives, i.e. units managed by the disabled people who worked there.

Unfortunately, the experience has not been very positive, as will be illustrated in Box 4.12.[7]

8. ANALYSIS OF THE CONVENTIONAL SYSTEM

In the following part of this chapter I will attempt to analyse some general factors that have given rise to the problems associated with the conventional system of rehabilitation.

In doing so I do not intend to criticise the pioneers of rehabilitation. The shortcomings of the system did not become evident until after several years, and many people believed that they would be able to overcome the problems with time and patience. Besides, there were no alternatives.

Box 4.7

WHEN CHARITY FAILS

The following text is quoted from a complete review of the existing services in an Asian country printed in a document made available to the author. There are no government institutions, all institutions are managed by NGOs. The study was carried out by a national university department of sociology.

A questionnaire was sent out to a total of 57 institutions, and then between two and four visits were made to all but one (which refused entry). The institutions cared for some 900 persons (in 24 centres) as boarders and for about 3,300 on an outpatient basis. Sixteen of the centres were for physically disabled, six for mentally retarded, and ten for both of these groups. Eight were for blind and four for deaf people. The rest was not specified.

Ninety-three per cent of the institutions said that they had problems of one sort or another; half of these said that they had financial problems; dealing with families of disabled people caused problems to 28 per cent, and 14 per cent reported problems in dealing with employees, etc.

The following observations were made: "Many of the institutions were initially unwilling to provide the information needed". "It was practically impossible for the team to reach the disabled for interview purposes...those responsible found this request rather threatening and expressed a distaste for the idea, to say the least...".

"Many of the institutions were located in isolated places...it continues to be unclear to the research team why the institutions...need to be located in 'out of sight' places...This raises the question of suitability of these locations for active community participation...and the ease of access for parents and families. Many of the institutions, especially those dealing with the mentally handicapped, suffered from inadequate physical conditions. Some...required major repair, others lacked proper sanitation, and others were found simply unsuitable for being inhabited at all. In one case, the mentally disabled ward was located completely underground. It was dark and humid, with a smell mixed with a stench of human excrement. In contrast another institution - for the blind - was characterized by a sunny building, well aerated, clean, well painted and generally full of life.

"...the large majority of the institutions that were visited lacked programmatic action. A special weakness was noted in the areas of social work, counselling and entertainment and learning through play...tended to concentrate around the areas of education and...physiotherapy... heavily dependent on mechanical manipulation of the patients...it seemed as if the organizers...saw these institutions as merely places to 'physically keep' the disabled...strong tendency...to think of technical solutions to disability problems in contrast to other forms of care needed...an excellent example...is the amazing proliferation of mechanical physiotherapy...to provide machine stimulation and relief...another example is the shamefully low level of counselling services...only [seen] in seven...The third is the lack of awareness...of social work...as a key element... Thus the machine substitutes for problem-solving, socially aware, behaviorally oriented programmes...

"Personnel either lacked adequate training or was not trained at all. Some seemed to function more like attendants than persons actively involved...staff were lacking in both knowledge and attitudes...some dealt with the disabled - notably the mentally disabled - in shamefully inhuman ways. In one institution...we saw a group of about 15 children all with heads completely shaven, almost all rather smelly and obviously not receiving even the minimal amount of physical sanitation and care. It took us about half an hour to come to the stunning realization that these children were in fact girls; nothing from their external appearance could have indicated this fact. Nothing, not even the most difficult financial conditions, could justify these unspeakable conditions.

"[Administration personnel] generally lacked training in administrative skills - for instance proper record keeping - as well as a good understanding of disability care...we noted a lack of problem-solving orientation ...a general lack of interest in making the conditions in the institutions better; many were simply apathetic. It was as if...their bad fortune...led them to 'land' their present employment.

"... We noted an unmistakable absence of participation of families and of the smaller and larger community in assisting, managing and overseeing the activities.

"The attitude of those caring for the disabled in some of these institutions leaves something to be desired... We noted a sense of lethargy, a lack of enthusiasm...many of those who worked in these institutions...did not have a real commitment to working with the disabled, but rather saw their role in terms of a job and livelihood ...so why 'rock the boat'...the old 'charitable' in contrast to the 'empowering' orientation ... was strongly felt...Some of the names of these institutions reflect this approach, for instance, 'The House of Light' for the blind, or 'The Four Homes of Mercy' and...'The Charity School'."

Box 4.8

SORRY, I HAVE TO LEAVE NOW.

Once in an African country I received a telephone call from a diplomat's wife. She told me that 18 months ago she had "managed" to open a "rehabilitation centre" for young adolescents who were physically disabled. By now, 14 boys had been admitted. The "centre" consisted of a large apartment she had rented, and she was supplying food, clothes and shelter for these boys. She had thought of starting some vocational training and finding jobs for them, but had not yet got around to organising these activities. She had obtained some funds from the embassy, but these had now run out. Her husband was going to be transferred, and she was leaving the country. As she said that she did not want to put the boys out in the street again, she wanted the UN organisation I represented to take over this activity. Of course there was no chance for this transfer - so the boys indeed went back in the street.

Box 4.9

WHAT A WASTE OF MONEY

This centre was built at the request of the national government and intended primarily to cover the rehabilitation needs among the heroes of the liberation war. The funds were provided by an external donor. It is situated at forty minutes' drive from an African capital, consists of about ten huge buildings and, so I hear, is a replica of the one in the donor's country capital. It is surrounded by agricultural fields and some forest, and not a house within sight, if one discounts the remainder of the farm that used to be in its place, with a handful of chickens and sheep suggesting that some farming still goes on.

This centre comprises an administration building with a big auditorium, a large number of offices, several gym halls and physiotherapy rooms to hold several hundred patients, a 25-metre-long swimming pool plus two Hubbard tanks, all empty. There are other areas for various types of therapy, a building with a big unit for surgery, pre- and post-operative emergency rooms, three theatres, several smaller units for sterilisation, and several large halls for vocational training. Six years after its construction, it stands mostly empty and unfurnished.

On our way to the vocational training unit - the purpose of our visit - we pass two very spacious rooms meant to hold twelve paraplegic patients each. I wonder about the difficulty under such conditions of preventing urinary tract infection with antibiotic-resistant bacteria from spreading among their occupants.

There are some 85 boys and ten girls receiving vocational group training in such trades as book-keeping, carpentry, typing and basket-weaving. Accorded a cursory examination of the trainees for the type and degree of their disabilities, I find almost all of them to be physically disabled, with sequelae after polio, a few amputated, and one or two having poor eyesight. Except for one young man in a wheelchair, all of them can walk (with some minor difficulties), and all of them are able to perform ADL.

The boarding trainees are put up in simply furnished rooms and taken good care of by a staff of some 100 persons.

At the end of this visit, I calculated that the annual cost for this affair came to roughly US$4,000 per person, not counting the amortisation and the interest on the buildings and other capital costs (which amounted to some US$ 15 million).

With perhaps one or two exceptions, all of the trainees could have participated in a vocational training programme for non-disabled - at a fraction of the current price.

I wondered what the centre, with a built-in capacity for several hundred more, would look like - and cost to operate - the day it was fully occupied, when the swimming pool would have its heated water, the surgeons would operate, and an army of personnel would be there.

Maybe there would be no room left for the chickens and the sheep.

I have chosen to comment on nine different factors - all of which are, of course, interrelated. These factors are:

(a) the charity factor;
(b) the attitudes and policies concerning financing;
(c) the transfer of technology and the type of professions;
(d) the vested commercial interests;
(e) the problems related to service delivery;
(f) the lack of parental and community involvement, including representation of disabled people;
(g) the lack of a credible evaluation system;
(h) the structuring of the conventional system,
(i) the lack of legal protection and human rights.

(a) the charity factor

The charity factor is an historical one, but continued reliance on charity may be doing more harm than good. Services for disabled people in the developing countries continue to be to a large extent concentrated in the private sector and to be funded by voluntary contributions collected by charity organisations.

The result is a system in which the role of the government is very small or nil. Consequently disabled people in the developing countries rarely see public services set up to meet their needs. This has created a dependency on charity organisations, either national or international. These in their turn use lotteries, telethons, mailing, etc. as approaches, often painting a picture of disabled people that many characterise as over-emotional. In some developing countries one can see the involvement of some rich people who in reality pay very low taxes or no taxes at all. Some of these will "tax themselves", for example by providing funds for a project concerned with disabled children.

The presence of charitable funding is one of several different explanations why so many governments in the developing countries fail to provide even the most essential services for disabled people. For other "vulnerable groups" the situation is similar. Governments might want to "benefit", well knowing that these groups are likely to attract external funds from concerned donors. Also, they might have the perception that rehabilitation is costly and not effective, and hence undeserving of public funds.

Box 4.10

SOME DO IT EXPENSIVELY, WITH NOT MUCH RESULT

This is a vocational training unit for about 25 mentally retarded adolescents in an Asian country. Some of them come from the neighbourhood and go home every day by a special bus. Others come from far away and are boarding.

The trainees are taught carpentry. They have four well trained instructors. The centre is equipped with several expensive pieces of woodworking machinery. But these are not used, for the trainees could not learn how to operate them, and besides, they were potentially dangerous. Thus the training consists of sawing and drilling by hand and of polishing various pieces of wood with emery paper. These are then painted and sold as part of a toy set used in nursery schools.

The vocational training project had been going on for three years. During this period, just one of the trainees had been placed in a job. However, in order for the boy to get the job, one of the teachers was sent along for four months to help him adjust to the job.

The annual cost of training was US$4,000 per trainee. These costs were covered by donations, mostly from external sources.

To be "charitable" is mostly seen as a positive trait. It demonstrates a feeling of kindness and willingness to help less fortunate people. But charitable action in favour of disabled people is mostly "charity at a distance" : providing funds while avoiding true personal commitment. It is often poorly organised, unreliable in the long run, and on a scale not large enough to achieve what is needed. Gross injustice can never be corrected by petty charity.

Some organisations are known to project images of disabled people that create feelings of guilt or pity, serve to reinforce the fear, distancing and stereotyping that should be avoided. (See Box 4.13).

This type of action has developed into a pattern, as well-meaning people all over the world in the advertising and the information field have learned exactly how to exploit economically the charitable emotions of the people in the industrialised countries.

People donate large amounts, responding to dramatic television images showing helicopters landing at sunrise, yellow bulldozers flattening out the landscape, tent cities with mountains of blankets and canned food, and energetic young doctors seriously administering blood transfusions, their white coats flapping in the wind. One month later most of this will be forgotten.

The implications for disabled people are serious. Rehabilitation services need to be permanent, nothing must be hasty or likely to be forgotten next month. When the enthusiasm of donors is short-lived, disabled people become "victims of charity."

There is no reason why disabled people should not have public services, financed with government funds - just like all other groups of people with "special needs".

Box 4.11

TRAINING FOR TRAINING'S SAKE?

In this African country, the government has set up several vocational training centres for disabled people. The one I was shown was housed in some extremely spacious buildings; one could easily have had 200 trainees here. As it was, the total came to not more than about forty.

"As usual", the disabled people were trained along conventional lines. The deaf boys and girls did carpentry. The blind youths were making baskets, and the physically disabled were learning how to sew.

As regards the carpentry, the products were of such poor quality that there was no way they could ever induce anybody to buy them. The tables or chairs had uneven legs, surfaces scratch marks, etc. The basket-weaving was done with acceptable quality, but selling these baskets would earn a hard-working disabled person not more than one US dollar a day. Those who did sewing turned out fine products. But with a sewing machine available in so many households nowadays, the prospects of earning an income from this activity are nil.

The government's austerity programme did not allow the vocational training centres in that country to operate for more than about eight months last year. The trainees were sent home to wait for the next budget year to come around. Though idle over all these months, the teachers' jobs were protected by law and they continued to draw their pay.

Closely connected with this dependency on charity is the difficulty of getting out of the

Box 4.12

CO-OPERATIVES

A review of economic co-operatives for disabled people carried out in 1985. It was estimated that there existed 400-500 such co-operatives, employing some 8,000 to 10,000 members, in the developing countries. Most of these were situated in Asia, predominantly in India. However, a large proportion of them was "dormant", and most of them experienced a quickly diminishing membership.

I have seen about 50 such co-operatives in some 30 countries. Some of these counted a few non-disabled persons among their members. Almost none of them had lived up to the expectation of providing their members with an income sufficient to support themselves or their families. A large proportion of them had for years been receiving subventions, or had subsisted on "charity income" from sales of goods 'manufactured by disabled people' organised on special occasions. The most common problems mentioned were: selling the products, low productivity of the members, products of insufficient quality, and high travel costs. Many of the co-operatives were conceived with the idea of providing "rehabilitation services", but more often than not the idea came to nothing. The review referred to above describes a number of co-operatives, but cites just one example of a successful enterprise, i.e. a co-operative in Ethiopia. I have seen five or six more where the members were able to earn an income comparable to that of an able-bodied person.

emotionalism when it comes to evaluate the conventional system. Attempts at a rational review of how funds are spent and with what results frequently meet with a considerable amount of resistance. In the long run, such attitudes to accountability will lead to a loss of credibility among people who in the past have been willing to contribute.

(b) the attitudes and policies concerning financing

Some of the problems are related to attitudes or policies concerning financing. For instance, in countries where the government is responsible for the institutions, it is not infrequent to observe a "contraction" in periods of economic restructuring, with curtailment of the funds allocated for social services, including rehabilitation centres. (See Box 4.11) As a consequence, the number of disabled "clients" admitted to such centres, whose funds may not allow them to stay open for more than a few months a year, is reduced. In some countries, the personnel belongs to the civil service and will be retained even if there is nothing to do.

When it comes to projects financed by external donors, one can observe that it has become customary for donors to start by insisting that they will themselves implement the project in question. After having paid considerable amounts over several years, the donor most often arranges for the project to be "taken over by the nationals". In most cases this has meant the future fund-raising is left to a national NGO. However, since most of them lack the necessary connections and the fund-raising capacity of the expatriates. Therefore, the situation following such transfers has tended to deteriorate quickly. Buildings are being left in a state of unrepair, electricity and water supply cut, professional staff forced to leave. In fact, the situation usually slowly approaches a point where there is barely enough to clothe or feed the "inmates" (Box 4.7).

Why have so many donor projects gone wrong? It seems that many international organisations prefer to support action where a lot of money can be dispensed in a hurry, with high visibility and no intention of sustaining long-term effects.

Fortunately enough, international donor agencies exist which have understood that one needs to stay on and continue to economically support what has been started until the services are financially maintainable using national resources.

The conclusion to be drawn is that one should try to re-orient the long-term role of donors. The charity approach should disappear, and contributions from the outside should be directed toward co-operating with the government in implementing their national rehabilitation plan. Frequently the development of rehabilitation should be an integrated part of a general community development programme. Community-based services, as opposed to institutions, will then have "grass-roots", and local people who have initiated their own projects are better able to sustain them in times of austerity.

(c) *the indiscriminate transfer of Western technology and types of profession*

To put it in a nutshell, this transfer has not been very successful, for a number of reasons:

- some technology does not fit well with the priorities and realities of the developing countries, while other parts are culturally not compatible;
- the effort to train personnel and to create rehabilitation teams after Western models has largely failed to give the expected results because of an inadequate understanding of how one can set up appropriate service delivery systems and rely on community self-management.

A thorough rethinking is called for. To start with, it is necessary to analyse the needs. Then, building on, and refining, existing local experience, the tasks to be accomplished should be described and shared out realistically as part of a decentralised delivery system. Dissemination of appropriate technology - built on already existing experience - is needed; not transfer of Western technology. Further, new strategies concerning the personnel at all levels in such a system have to be developed. The relevant educational objectives should be formulated and facilities set up for training such personnel, without attempting to copy Western models. Finally, the system should be evaluated and - whenever necessary - better adapted to local conditions.

Box 4.13

NO PITY, PLEASE.

Comments on the "Jerry Lewis Muscular Dystrophy Association Telethon" made by Evan J. Kemps, Jr., Executive Director of the Disability Rights Center, USA, who himself has a disability caused by a neuromuscular disease.

"The very human desire for cures for these diseases can never justify a television show that reinforces a stigma against disabled people...With its emphasis on "poster children" and "Jerry's kids," the telethon focuses primarily on children. The innocence of children makes them ideal for use in a pity appeal. By celebrating disabled children and ignoring disabled adults, it seems to proclaim that the only socially acceptable status for disabled people is their early childhood...The telethon emphasizes the desperate helplessness of the most severely disabled. In doing so, it reinforces the public's tendency to equate handicap with total hopelessness. When a telethon makes disabling conditions seem overwhelmingly destructive, it intensifies the awkward embarrassment that the able-bodied feel around disabled people. By arousing the public's fear of the handicap itself, the telethon makes viewers more afraid of handicapped people. Playing to pity may raise money, but it also raises walls of fear between the public and us... Barriers to employment, transportation, housing and recreation can be more devastating and wasteful of our lives than the diseases from which we suffer."

(d) *the vested commercial interests*

There are many organisations which, against a fee or against a certain percentage of the funds provided for the particular purpose, offer services to plan and/or execute projects, to construct and equip buildings and/or recruit personnel for rehabilitation programmes. Those responsible for such "consultancy services" are primarily interested in large-scale projects and do not question the concepts, the usefulness or the cost-effectiveness of the programmes in question. They have an interest in keeping the business going and will certainly not welcome a change.

One might also find that certain projects include training of personnel directed at the exclusive use of specific Western techniques which necessitate the import of components or supplies. This ensures continuous sales to a particular exporting company. Attempts to change such technology meet with resistance.

(e) *the problems related to service delivery*

The goal of rehabilitation is the social integration of disabled people. Unfortunately, many of the activities of the conventional system have been counterproductive and have promoted segregation. Disabled people are often kept in boarding institutions in far-away places for years, losing all contact with their families and their communities. Whenever education, vocational training or jobs are provided, a parallel system is often created. This is not done out of concern for the special needs of disabled children and adults. The main reason seems to be the wish to keep them separate, so they will not interfere with the training given to non-disabled pupils or trainees, or will not negatively influence the work performance of non-disabled employees.[8] Furthermore, services are fragmented, with components aimed at various groups of disabled people delivered separately. Services at home, at school, concerning vocational aspects, the elderly, for example, mostly have each their own separate system.

Services are maldistributed. Most of them located in the capital, with the remainder in other large cities. Rural services are rare, even in countries where between 70 and 80 per cent of the population lives in villages.

Services are costly, reflecting high building, equipment and personnel costs. In addition, many of these institutions and their personnel are under-utilised. In a centre that could easily receive hundreds, one might find not more than 25-50 people.

(f) the lack of parental and community involvement, including representation of disabled people

There are many examples of parents who leave their disabled child in an institution, never to return. (See Boxes 4.1, 4.2 and 4.7). Some such infants or children are secretly left on the doorstep of a centre or an orphanage in the early morning hours, leaving the centre no other choice but to take care of them. Rich parents may export their disabled child to another country and pay huge sums for "lifetime care".

These are examples of parental attitudes. Other examples of lack of co-operation between institutional staff and parents have been given elsewhere (see Box 4.2). Such attitudes are not easy to change. All rehabilitation systems must build on full family involvement. Parental education should therefore be a standard component of any system.

Disabled persons who have been institutionalised for a long period of time will find it difficult to return to their communities. This is particularly true of children. Social integration can come about only if the community accepts its disabled members, takes an active role in their rehabilitation and makes an effort to re-integrate those who have been away in an institution.

Disabled people who remain in their respective communities are today seldom consulted about their views of services provided for them. All communities should find ways and means of affording them adequate representation and influence and developing their political capacity. This is not an easy task, considering that many of them are unable to take care of themselves, to move about or to communicate, in addition to lacking schooling and employment.

There are two ways in which disabled people can be represented in matters that concern them. The first is through direct participation of disabled people in political bodies such as parliament/congress or similar, political parties, women's and youth organisations, labour unions and social security boards. The second is by forming their own organisations to act as pressure groups. Needless to say, all disabled people cannot be represented in such organisations. Children, for instance, should be represented by their parents.

Normally, organisations of this type will have very little say unless they form a national union or federation. Where this is the case, they may be officially recognised by the authorities as partners in the policy-making, planning and implementation processes concerning services for disabled people.

At present, groups of disabled people have limited direct or indirect representation in the developing countries. In some countries, the regulations in force require legal recognition of such organisations, limit their number, and place them under government tutorship. There are examples of governments dissolving some such associations by special decree, which is equivalent to denying disabled people freedom of association. In many instances it is the government that appoints the chairmen and executive officers from among the ranks of non-disabled professionals.

Organisations of disabled people are often split up into small groups, making them powerless. There are numerous problems related to their internal cohesion and administrative capacity.

Most organisations are only present in the capital or in the big cities. I have yet to come across an association formed in a rural setting. Unions or federations are very uncommon, a fact that has seriously weakened these organisations' potential role as advisors or partners of the government. And where they do exist, they are not very representative, with "normally" just a handful of young men, either physically disabled or blind. Among their members there are seldom any women or elderly persons, and other groups of disabled and parents of disabled people are often under-represented.

What characterises today's situation is that disabled people and their families are, generally speaking, powerless, lacking political influence in their own society and specifically with no say in matters of immediate concern to them.

(g) the lack of a credible evaluation system

The evaluation systems applied by most organisations involved in conventional rehabilitation are either non-existent or superficial. More on this problem in Chapter Fourteen.

(h) the structuring of the conventional system

The problems associated with the structuring of the system into its various levels: macro-level, intermediate level and micro-level, have already been mentioned in the Introduction.

The conventional system operates mainly on the intermediate level, with the macro-level (the government, the legislative and executive bodies) being mostly barely involved in providing symbolic policies, plans and services. At the micro-level communities and families have rarely been engaged in any activities.

The inputs from external resources - such as development/donor agencies - contribute for the most part to strengthening the intermediate sector, leaving the government believing that this is how the problems related to disabled people will finally be resolved. What is more, these inputs do not lead to community involvement, creating as they do the impression that families and communities have no part to play but merely to wait for the institutions to eventually acquire enough capacity to address the totality of the needs.

Structured that way, the system contributes to passivity on the macro- and the micro-level. What has been missing in the past is a willingness to challenge the system as such, to point out that the conventional approach will not and cannot succeed in meeting more than a tiny proportion of the needs. And to insist that it is conceptually wrong, unrealistic and has serious side-effects.

(i) the lack of legal protection and human rights

It is a matter of fact that most national constitutions accord all citizens a number of rights. These include the right to education, to employment, to services, to personal property and so forth. But there are many examples of disabled citizens being deprived of these rights. They are often refused entry to the local school; not accepted for vocational training; not given employment, even if fully qualified. They rarely receive legal assistance when their property or their land is stolen or when they suffer physical, psychological or sexual abuse in institutions.

What is needed is not so much more laws to protect disabled people but application of the existing ones. To provide such protection is a major challenge for any rehabilitation programme.

9. THE BEGINNING OF THE END OF THE CONVENTIONAL SERVICE DELIVERY SYSTEM

In the late 1960s and 1970s experts were beginning to express concern about the effectiveness of the conventional system.

One such clear expression of criticism of the way services for rehabilitation were developed was the report of a meeting of experts held in Killarney, Ireland, on 21-24 September 1969[9]; the report stated that:

> "...it is obvious that the pace at which personnel were being trained and other necessities for rehabilitation services were being developed was not adequate to meet the current problem and certainly incapable of coping with the predictable growth in the number of persons requiring professional help...
>
> "...it is possible that an objective analysis of methods of delivering rehabilitation services will suggest measures which can serve to provide at least the most essential assistance to large numbers of people with the resources available now or in the immediate future...
>
> "...experience in the less developed areas makes it clear that essential help may be given to disabled persons in ways which are often different from those methods established for use in industrialized and economically developed areas but are consistent with the available resources and the cultural, social, and educational patterns of the developing countries...
>
> "...it may be possible to identify forms and patterns of services which by requiring fewer trained personnel, less advanced levels of training, simple facilities, etc., may enable the delivery of essential services to be expedited and expanded."

Having reviewed the conventional system, the experts suggested in principle:

- a change of technology,
- a new service delivery system, and
- new types of personnel.

They did not, however, propose any practical solutions. To find these was left to others, and it is easy to see why. A solution was being sought to a problem that had the appearance of being intractable. The only existing system was the "conventional" one, and it certainly did not easily lend itself to the changes discussed by the experts.

In spite of all that was said in Killarney, experts and organisations still went on claiming that the only hope for services in the future lay in the extension of the existing pattern. Well knowing that there were insurmountable problems associated with the conventional system, they had in reality concluded that rehabilitation in the developing countries is not feasible in our times.

Seven years later, the following summary of the situation was given in a 1976 WHO document[10]:

> "...rehabilitation services are practically non-existent or grossly inadequate in developing countries;...
> "...there is an apparent lack of national planning and coordination of services (medical, educational, vocational, social, etc.) in most countries...
> "...medical rehabilitation services have usually concentrated on institutional care, with a low turnover of patients at a high unit cost;...
> "...when advanced rehabilitation services and technology have been introduced in developing countries, the result has often been discouraging or a complete failure."

In spite of some progress, these judgments are still valid 16 years later.

A recent UNESCO document states that: "The stark reality is that the great majority of children and young people with special education needs do not receive an appropriate education, if they are offered any education at all."[11]

In the last few decades, the ranks of disabled people in the developing countries needing rehabilitation have annually increased by close on two million people. The resources available have remained more or less static. Thus in reality the situation has rapidly deteriorated. We have on our hands a growing moral, social, health and economic problem of vast proportions, which we are incapable of dealing with by using the conventional system.

COMMENTS AND REFERENCES

[1] Spending on development programmes funded by the industrialised countries is at present estimated at a total of US$ 50 billion. Based on the estimate of US$ 300-400 million, the amount spent on programmes concerning disabled people is not more than 0.6% to 0.8% of the total. Only 0.3% of the UNDP budget for the period 1988-91 was used for projects concerning disabled people, and other UN agencies spent an even smaller percentage of their regular budgets for that group. Evidently, rehabilitation programmes do not rank high on the list of development priorities.

[2] A UNESCO document reports from a study carried out in 13 African countries in 1983. These countries had a total population of 107 million. The number of disabled children receiving special education was 13,067.
Source: Children with handicaps at school in Southern and Eastern African countries. UNESCO, Paris, France, 1983.
Another example appears in E. Klingberg: Specialundervisning för blinda barn i utvecklingsländerna från 1975 till år 2000. (SHIA, Stockholm, Sweden, 1987). She estimates that in sub-Saharan Africa, the proportion of blind children receiving special education has increased from about 1% (1970) to 1.6% (1985), a very marginal increase. During the same period, primary school attendance has gone up from about 30% to about 50%.

[3] Many centres with funding problems have tried to create sheltered workshops, hoping that this would help to pay for their running costs. It appears, however, that this effort almost invariably fails.

[4] This situation is similar to what is seen in many institutions in the industrialised countries. For instance, N. Beail reports in Int.J.Rehab.Research II(2), p. 172, 1988, from an English institution for mentally handicapped: "... only 16.3 per cent of their [the nursing personnel's] time was spent socializing and playing with the children. No training occurred. ... nearly 17 per cent of staff time was spent off the ward on various errands."

[5] Such abuse is relatively common in the industrialised countries as well, and every year newspapers in many countries carry reports of court proceedings related to this. Few people are ready to discuss this subject - and in the developing countries it is imperative that a system be set up for inspection of institutions so as to ensure no such abuse occurs.

[6] Alignment is the geometric relationship between the socket, shank and foot of a prosthesis. The purposes of static (standing) alignment are to check the fit and comfort of the socket, the length of the prosthesis, and the adequacy of the alignment relationships. Dynamic (walking) alignment adds the further consideration of normalcy of gait, energy consumption, and the adequacy of the suspension.

[7] J. Gudmundsson: Cooperatives of Disabled People. The Committee for the Promotion of Aid to Cooperatives (COPAC) and the Centre for Social Development and Humanitarian Affairs of the United Nations, Vienna, Austria, December 1985.

[8] These tendencies have been described by many others. T. Jönsson quotes several reflections in this vein, among them those of Chambers and Hartman, who write that disabled children "interfere with instruction" and "absorb the energies of the teacher and make so imperative a claim upon her attention that she cannot under these circumstances properly instruct the number commonly enrolled in a class". Chronbach remarks that intelligence tests have frequently been used as an instrument to drop children "by the wayside or to vegetate in an underdemanding slow classroom". Jönsson states that "the schools these children are de-selected from are characterised by a rigid examination-oriented system with the main task of identifying children with potential for a further academic career", and he ends with a UNESCO quote: "This elitism, that is still frequently advocated, seems to justify the educational institution in rejecting in some cases over one third or even half of the children entrusted to it. Such wastage would not be tolerated in any other sector of activity."
J. G. Chambers and W.T. Hartman: Special Education Policies. Their History, Implementation, and Finance. Temple University Press, Philadelphia, USA, 1983.
L.J. Cronbach: "How can instruction be adapted to individual differences? in R.M. Gagne (Ed.) Learning and individual differences. Columbus, Ohio, USA, 1965.
T. Jönsson: Special needs education, UNESCO, Paris, France, 1992.
UNESCO: Working document ED/C/27. Paris, France, 1991.

[9] This report was published by the International Society for Rehabilitation of the Disabled and entitled "The Development of Rehabilitation Services in Relation to Available Resources".

[10] Disability Prevention and Rehabilitation. WHO document A29/INF.DOC./I, p.26, Geneva, Switzerland, 1976.

[11] T. Jönsson, ibid.

CHAPTER FIVE: A HISTORICAL PERSPECTIVE

Having attempted a review of the global situation for disabled people, I will now look at the historical perspective.

There are three principal reasons for this:

- to better understand the situation described in the previous chapters;
- to see what lessons can be drawn from the past; to identify and apply positive experience while avoiding duplication of mistakes;
- to review the major concepts related to disabled people and to choose the most advanced and most humanitarian principles to guide the development of rehabilitation in the developing countries.

Over the centuries, the prejudiced beliefs, attitudes and behaviour of non-disabled people have largely determined the quality of life and the fate of disabled people, and they still do.

Alternative reactions to the presence of human beings with disabilities can be grouped under five main headings:

1. elimination - getting rid of them;
2. the poorhouse - removing them from the view of the non-disabled;
3. institutional care - providing care for them on a segregated basis;
4. integration - encouraging a process that would lead to the integration of disabled people in their families and communities, as well as in the general systems of society;
5. self-actualisation - supporting them in their efforts to develop their full potential.

Historically, the general trend in the development of concepts has been away from elimination and toward self-actualisation. But concepts are one thing and reality is another. To this day, all five of these reactions are still in evidence. So let us look at the elements of each of them.

1. ELIMINATION

As a reaction to disability, elimination is characterised mainly by the premature death of a disabled person - a fate shared by millions of them. For the purposes of this publication, the term "premature death" indicates that the death was *not* directly related to disability or to its causes (which would be true in the case of an infant dying from a severe, disabling malformation of the heart) but brought about by other human beings, either directly or indirectly.

The most infamous example of "premature death" is the systematic killing of mentally disabled people during World War II in Nazi Germany. At the Nuremberg Trial of war criminals, it was estimated that 300,000 people[1] with such disabilities had fallen victim to Hitler's euthanasia programme[2].

Even in our days, the survival of disabled people is jeopardised by widespread prejudice among able-bodied people. The behaviour borne out of such prejudice has led, and still leads, to premature death caused by negligence or by intent, as described in the following document on the situation in a developing country:

> *"Before the advent of hospitals, child welfare and maternity clinics, women gave birth in their ancestral homes. Before a newborn baby was officially announced, he was thoroughly examined for any visible defects of the body. A baby with any physical defect was promptly eliminated. The family was informed that the baby was stillborn. Congenital deformities were, therefore, not much of a social problem".*[3]

Misinterpretation of Darwinian theory - and in particular of the phrase "survival of the fittest" - has contributed to the belief that it is somehow in the best interests of societies to let the least viable go under.[4]

In our days, elimination is practised in many industrialised countries, where it is culturally and legally acceptable to diagnose the presence of a defective foetus by amniocentesis or similar techniques, and to grant permission for an abortion should the diagnosis be positive. In several countries, murder of an infant with a congenital defect will sometimes lead to nothing more than a suspended sentence, and the public at large is strongly in favour of such judgements. Recently, it was proposed (in a European country) to legalise infanticide committed during the first three days after the birth of a severely handicapped baby, a practice said to exist already clandestinely, on a limited scale[5].

On the other hand, arguing in favour of the view that "parents of severely disabled newborn infants should be able to decide, together with their physician, whether their infant should live or die," sometimes meets with strong opposition[6].

2. *THE POORHOUSE*

The "poorhouse approach" is an attempt to help the "impotent," "lame" or "feeble-minded,"[7] as well as unemployed and aged individuals, orphans and other groups of destitutes without any source of income.

The first poorhouses in Europe were set up by municipal action in the early 16th century, at a time when the medieval economic system was on the decline and the needs of the poor could not be met by religious charitable organisations.[8] The motive behind the creation of poorhouses does not appear to have been mainly charitable. Rather, it was the fear that vagrants might spread disaffection and that some might be recruited as mercenaries for rebel armies. To save costs, the local authorities in many communities gave the aged and those unable to work a licence to beg.

Not until very recently did the poorhouse disappear as a component of European and North American municipal structures, which raised "poverty taxes" to cover costs for the subsistence of the poor and the undesirable. These taxes supported many different groups, such as people with disabilities, with unusual behaviour or appearance, chronic alcoholics, criminals released from prison, the severely ill, members of certain ostracised ethnic groups, people thought to be carriers of communicable diseases (including epilepsy and some organic brain disorders), orphans, or others who simply happened to be jobless.

There are many interesting features to the poorhouse approach. The obligation "to put the poor to work" was instituted in England in 1601. This was thought to contribute to rehabilitation of the poor. Working conditions in the poorhouse were designed to act as deterrents to taking advantage of the system. Paupers had to wear special uniforms or garments. In some countries they were made to wear a large red or blue, plainly visible letter "P". They were denied the right to vote and subject to harsh discipline.

By the middle of the 19th century, the repressive "poorhouse" system started crumbling, helped by such factors as the development of democracy, humanitarianism, social security and more scientific approaches to dealing with poverty.[9]

But many of the attitudes associated with the poorhouse approach have persevered into our days, even among some highly educated people. Poverty is not infrequently thought to be a sign of God's disapproval. Many able-bodied people still prefer to make voluntary contributions or pay taxes in order to have poor disabled people removed from their sight and cared for by custodial staff.

Today, the poorhouse as an approach is rare in developing countries, high costs being one of the main reasons, so it seems. Communities generally accept to have a certain number of marginal people living amidst them - mentally-ill persons, beggars, jobless and destitute people, and others. Also, there often exists a limited welfare system: families, friends or neighbours taking care of their needs in terms of food, clothing and shelter.

Mental hospitals in these countries sometimes function as a type of poorhouse, in particular for the population affected by mental retardation or disease.

3. *INSTITUTIONAL CARE*

The first large-scale institution for disabled people in Europe seems to have been the "Hotel des Invalides".[10] Built in Paris between 1670-77 by King Louis XIV, it was designed specifically for disabled and aged soldiers. Eventually it housed 7,000 such veterans. This institution still exists today, though on a much smaller scale.

Institutions have also existed for centuries in several developing countries. In Sri Lanka, for example, King Buddhadasa built a very large institution as early as in the fourth century[11].

Later on, about 200 years ago, institutional care for "civilians" began to emerge as a "specialisation of the poorhouse." The "inmates" were divided into distinct groups and sent to separate boarding institutions, among them institutions for various groups of disabled people. Detention and charity were combined with rehabilitation, special education, therapy, vocational training and sometimes with a job in a segregated, "sheltered" surrounding.

New technology too began to emerge, such as characters in relief for blind people, a system used by l'abbé Valentin Haüy in 1784 which inspired the creation of the first specialised school for blind children in France. Louis Braille further developed the technology and, in 1824, invented the system that is now used by millions of blind people.

As countries became more affluent they tended, in some cases, to improve the image of such specialised poorhouses by ensuring a higher density of personnel, increased freedom to visit the neighbourhood, and less conspicuous signs of charity. Detention was enforced by creating psychological dependency rather than by locking doors.

In many places, the segregated institutions provided an increasingly improved technical rehabilitation programme. In "centres of excellence," disabled people were well "looked after." They developed many of their abilities and skills to become more mobile, more advanced in communication, better educated, more productive at work. More was done to assist them in finding their way back to their families or in trying to lead an independent life.

Yet, up to our own days, institutions have continued to be the subject of heavy and justified criticism. Recently the United States Supreme Court noted the undisputed facts about a large, well-known institution for mentally retarded people:

> *"Conditions ... are not only dangerous, with the residents often physically abused or drugged by staff members, but inadequate for the 'habilitation' of the retarded. Indeed the court found that the physical, intellectual and emotional skills of some residents have deteriorated."*[12]

Institutions are still the dominant type of facility for rehabilitation in the developing countries. The most common clientele are children receiving schooling and functional training. In addition, there are a number of facilities that provide orthopaedic appliances and gait training. Others aim at preparing people for employment or offer them sheltered work.

The establishment of day-care facilities for disabled people began mainly after World War II. Such facilities provide a better solution than residential, totally segregated institutions. Day-care can do much to support families which for several reasons are unable to take full care of their own disabled members. This step was followed by attempts at integration.

4. *INTEGRATION*

The conceptual evolution towards social integration and de-institutionalisation is the outcome of a gradual change in a number of factors, the most important of which are:

- new medical inventions,
- the lack of an adequate number of professionals or of effective remedies,
- economic necessity,
- the reactions of millions against authoritarianism, colonialism and paternalistic attitudes, and finally
- the growing influence of disabled people and parent groups.

At the end of World War Two, millions of disabled veterans returned home, stayed there and were integrated in normal community and family life. It is true, a number of veterans' hospitals and other facilities were set up to help with medical care and rehabilitation, but the idea of keeping all disabled veterans in institutional settings, i.e. creating a sort of large-scale 'Hôtel des Invalides', did not seem practical. Thus social integration became the solution, but out of economic necessity rather than choice. It did not cause any major problems, nor did it lead to lower-quality results.

The next decade, with the economic situation improving in a number of Western countries, marked the onset of a period of escalated construction of new institutions for disabled people. This development was paralleled by a tendency among a growing number of parents to prefer to keep their disabled children at home. Increasing prosperity, better housing conditions and higher levels of education made this possible. Many such families were later helped by day-care facilities and mobile specialists. The 1950s saw the beginning of a great revolution in psychiatry, precipitated, among others, by the invention of new psychotropic drugs which simplified the care of patients with chronic psychoses. In fact, they recovered to such an extent that, given a community psychiatric service as a supporting structure, they could be sent home or be admitted to half-way houses. In all industrialised countries, the majority of closed wards for the severely mentally ill were opened up. Several hundreds of thousands of patients were discharged to live outside the institution, either temporarily or permanently.

Economic constraints were a major contributor to this change. In the decades before 1960, tuberculosis accounted for the majority of deaths in institutions for disabled people and in hospitals for the chronically ill. With the invention of new drugs and the availability of BCG-vaccination, the death toll from tuberculosis declined considerably. With the disabled people living longer, specialised institutions and hospitals became overcrowded. The lack of funds did not permit the further expansion of existing facilities. So, in order to make room for new patients, the least disabled had to be discharged, sent home. Their needs for care had to be met by day-care centres rather than by closed wards.

The "space problem" was an interesting phenomenon. Initially, doctors were put on the defensive, apologising to patients and their families, and blaming the politicians for not raising taxes to pay for the institutions "needed". Later on, attitudes changed. The merits of social integration were discovered, and going home became part of an active and planned effort.

Another factor contributing to this change was the emergence of self-care programmes. These were set up either to cope with the shortage of professionals or because the therapy provided by the professionals failed to produce the desired results. Alcoholics Anonymous, which was started because most professional programmes had turned out a failure[13], is an excellent case in point. Alcoholics felt that they could do better on their own, and they started group therapy sessions on a regular basis. Today they have local organisations in almost every country.

Another movement that made its appearance in the period between the fifties and the seventies was the so-called "therapeutic community," encouraging mentally-ill patients to become more independent, or totally independent, of professional care-providers[14].

These two examples of rebellion are not indicative of the search for true social integration. Rather than breaking new ground, they continued to follow the old pattern of bringing together segregated groups of disabled people. However, their challenging of the authoritarianism exercised by professionals has been an important element in the development of the self-care concept.

De-institutionalisation was furthered by yet another factor. This was the rapid increase in the number of elderly disabled persons in industrialised countries, which strained all care facilities to the utmost. The professionals became over-extended and had to find solutions to cope with their daily workload. Physiotherapy departments started encouraging self-treatment of chronic conditions, using simple instruction pamphlets or training packages for in- and out-patients suffering from stroke, arthritis, back disorders and other complaints. Parents of children suffering from cerebral palsy were visited at home at about monthly intervals and given instructions and demonstrations on how to proceed with the training themselves. Many rehabilitation professionals changed their roles from that of therapy providers to teachers of self-therapy.

The authorities, recognising the benefits of the new trends, began to promote these efforts by providing economic and organisational support.

When scientists began reviewing the results of such "home rehabilitation/self-care," they found them to be equivalent or even superior, in some respects, to the results obtained by institution-based rehabilitation. It was then recognised that the frequency of emotional and behavioural disturbances not primarily caused by the particular disability was higher in disabled children treated in residential institutions than in those trained at home. These disturbances were interpreted as side-effects of the segregation typical of long-term institutional care. Many of the problems that disabled adults encountered in their contacts with non-disabled people, for example, in finding and retaining a job, could be attributed to their earlier segregation. Children receiving long-term care in boarding institutions often develop a special language (*argot*), which further impairs their ability to communicate with outsiders. Family integration and integration with a non-disabled peer group have been shown to diminish or eliminate such undesirable side-effects.

Integration and home self-treatment (or treatment by a family member) of disabled people, under the supervision of professionals, is now an accepted method and has proved to be an effective and preferred approach.

With family integration as the starting point, many countries have embarked on efforts to further social integration, including integrated housing, schooling, vocational training and jobs, sports and recreational facilities, and so forth. Large-scale programmes were introduced to eliminate physical barriers in the environment - such as providing accessible public buildings, transportation and housing for people with mobility problems. All-round social integration has yet to be achieved. And prejudice is the main obstacle on the road to this goal.

In the most developed countries, long-term institutionalisation of disabled people is now considered a second-choice solution, to be applied only to those for whom no other approach is possible. Social integration is, however, achieved only in part. The approach faces many an obstacle, including the predominantly negative attitude adopted now as before by non-disabled persons, and by a number of professionals.

Another sizeable hindrance to implementing integration is the fact that some governments have contented themselves with closing down institutions, especially those for mentally-ill persons, without providing the necessary resources for community level care. Given the general downward trend in social welfare allowances, this has given rise to an alarming phenomenon - the appearance of large groups of "homeless people". The majority of them belong to the groups of the mentally ill, drug addicts and alcoholics. There is no doubt that the change from institutional care to community care and integration cannot be brought about without real community involvement and an adequate network of local care providers. This staff must not only be easily available but must, moreover, make frequent home visits to provide all necessary follow-up action. Furthermore, the community should make adequate provision for all daily needs such as rent, food and clothing, and set up at least a simple programme of daily activities.

Finally, we should acknowledge the very active role played by the "consumers", in particular in the industrialised world. Organisations of disabled people and organisations of parents have firmly established themselves in the past twenty years. They are increasingly consulted by governments and local authorities in matters of policies and programmes targeted at them. Their effectiveness in lobbying for human rights and equal opportunities is growing, leading sometimes to successful "rebellion" against inadequate programmes, paternalism and prejudice.

In many developing countries, the social integration approach has been there from the very beginning. As specialised facilities are scarce, most disabled people stay with their families and in their communities. For most of them life is not easy, though some of them do receive "spontaneous" rehabilitation from the family. It would appear that more disabled people have received effective rehabilitation through their families than through institutions, and that they have remained socially integrated as a result.

5. *SELF-ACTUALISATION*

Self-actualisation implies that each disabled person should be able to fulfil his or her need for taking an active part in society and for living a life in dignity, independence and with self-esteem. This is the ultimate goal that rehabilitation aspires to - a goal not sufficiently acknowledged at the present time.

For a better understanding of the term "self-actualisation", it may be useful to review the basic concepts of human need, as described by Maslow[15]. In his "Theory of motivation" he describes five levels of human needs (material and non-material), as illustrated in Fig. 5.1.

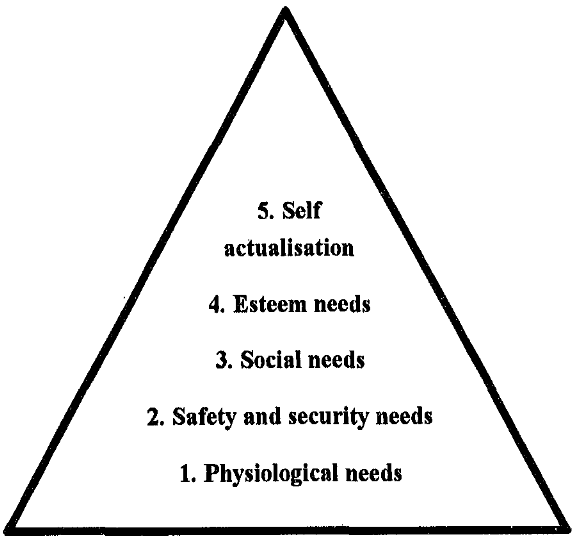


Fig. 5.1: Five levels of human needs, according to Maslow

In the figure the needs are presented in ascending order of their importance:

- Physiological needs are the essentials needed for survival, such as food, water, air, sleep.
- Safety/security needs are those of security and protection against danger.
- Social needs are those of belonging, affection and love.
- Esteem needs are those of self-esteem (self-respect) and esteem by others (recognition).
- Self-actualisation needs are those of self-fulfilment, to realise one's own full potential.

Most enquiries into disabled people's needs in the past have been very limited. The full scope of needs of people with disabilities has to a large extent been neglected.

It has been more or less presumed that once basic material needs are satisfied, conventional rehabilitation services and opportunities will be provided, and that, with this, the disabled person has "reached the highest possible level of ability" - all needs have been met. This view is too superficial to be acceptable. Esteem needs and self-actualisation too have to be satisfied, and a more dynamic, holistic approach is necessary.

Let us apply Maslow's theory to sum up the situation of disabled people.

The actual survival of disabled individuals was and still is threatened in many ways. The poorhouse and, later on, institutional care, were approaches designed to protect the survival of disabled people and to provide the physiological needs for water, food, shelter, clothing and safety. This is as far as we have reached today for most disabled people in the industrialised countries - not so in the developing ones.

The feeling of belonging, of receiving attention and love, comes more easily to disabled people who live in the midst of their families and friends. The integrated approach offers ways of better satisfying these needs. Nevertheless, most organisations working for disabled people in the developing countries have concentrated on the residential institutions.

Esteem and self-actualisation needs can only be fulfilled if disabled people live in the community, share the same rights and play a proper, meaningful role in their respective societies.

In the industrialised countries, the social integration approach is slowly replacing institutional care.

Nobody disputes the fact that for some disabled people no solution other than institutional care can be found. Disabled children or adults may be abandoned by all their relatives. Their disability may be so serious that round-the-clock care is needed. The care may prove too costly or involve technical equipment that is difficult to handle at home. Behavioural disturbances may become so severe that they are too much of a burden for a family to cope with. But, in reality, there are very few such disturbances provided there have been early intervention programmes. In several countries, it has been possible to reduce institutional care to a minimum.[16]

So the questions arise: Is there a way to avoid repeating the mistake of having the institutional system installed as the only model for services in the developing countries? Is there a way whereby priority can be given to a system building on social integration?

6. THE RIGHT TO PUBLIC SERVICES

The first actions in Europe to assist disabled people - during the medieval period - were set up by religious organisations. In the 16th and 17th centuries - when this system was breaking down - it was replaced by the poorhouses installed by local authorities.

Later on, a number of private initiatives emerged, for example the development of special education for blind and deaf children, "homes for the crippled" and so forth.

In this century, in the industrialised countries, numerous services were created in the private sector, financed by voluntary organisations - reflecting the growing influence of associations of parents or disabled people and the availability of donated money. This is the pattern most commonly copied in the developing countries.

But in the last few decades, this tendency has been the subject of severe criticism in the industrialised countries. The question is: Why should disabled people be dependent on charity? Why can they not have public services like everybody else? Why are not all schools for disabled children managed by the education department or by local authorities, just as "normal schools" are? Disabled people argue that they are treated as beggars and become dependent on charity.

So, in the more advanced societies, the services of private charitable organisations, along with economic contributions to disabled individuals, are in the process of being taken over by the public sector. Social security and other government systems increasingly take care of the economic side, including subventions and pensions.

In the developing countries, it is common to see disabled people begging. In many ways the culture and social stratification of many societies legitimise the dependency on begging and charitable action. But, in the long run this will diminish and disappear. Disabled people in the developing countries will - like their brothers and sisters in the industrialised world - demand that the authorities step in and replace charitable action by public services and social security.

7. LESSONS TO BE LEARNED FROM THE HISTORICAL PERSPECTIVE

The positive experiences of the past indicate that a rehabilitation programme in developing countries should incorporate a number of priorities:

- functional training approaches based on the modern technologies of self-care and home-care. To succeed, one must obviously try to demystify the technology, so as to make it easy to understand and to apply. Families and communities need to be mobilised to provide the care and rehabilitation needed;
- a system of schooling that is accessible to the

disabled children where they live, and emphasising integrated education;

- total social and vocational integration coupled with a programme of community preparation aimed at ensuring equal opportunities, better recognition, more positive attitudes and the disappearance of discriminatory behaviour towards disabled people;

- less paternalistic and authoritarian attitudes among professionals involved in the supervision and in referral care systems;

- interventions in the environment to reduce or to eliminate physical, psychological, cultural, social, and economic barriers;

- increased respect for the human rights of disabled people;

- efforts that promote self-actualisation, defining new roles for disabled people to look after their own interests and to influence society as a whole through their own organisations or interest groups. This would liberate them from the influence of power structures not of their own making and allowing them a life in dignity, on an equal basis with all other members of the common human society;

- far greater emphasis on adequate organisation of service delivery - leaving behind a system characterised by costly fragmentation, underperformance, and lack of co-ordination. A well-functioning organisation cannot be achieved without government involvement.

Concepts described in this chapter are poorly understood and even less applied, in real life. Few people who have heard of the principles of social integration and self-actualisation have tried to implement them. Innovative ideas call for innovative solutions; it is not adequate to go on with the conventional system, thinking that next time around perhaps it will not fail. In order to be innovative we need to experiment with new strategies. We need to find better solutions which integrate the most advanced and humanitarian principles into the design of the rehabilitation system.

COMMENTS AND REFERENCES

[1] Wolfersberger, Mental Retardation: 19:1, February 1981.

[2] At the Nuremberg Trial, a Nazi official made the following statement:
"Hitler's ultimate reason for the establishment of the euthanasia programme in Germany was to eliminate those people confined to insane asylums and similar institutions who could no longer be of any use to the Reich. They were considered as useless objects and Hitler felt that, by exterminating these so-called eaters, it would be possible to relieve more doctors, male and female, nurses and other personnel, hospital beds and other facilities, for the Armed Forces."

[3] J. Amoako in Expert Group Meeting on Social Services, United Nations, Geneva, Switzerland, 1976.

[4] H. Spencer, "The Man Versus the State", London, United Kingdom, 1884.

[5] Le Monde: 17 November, p.22, 1987.

[6] P. Singer: On Being Silenced in Germany, The New York Review of Books, Vol. 38, Nr. 14, August 15, 1991.

[7] These are terms used in the 17th century to characterise disabled people.

[8] An early description appears in Juan Luis Vives: De subventione pauperum sive de humanis necessitatus, 1526. A review of the history of the poorhouse appears in D.L. Disert: Entre la peur et la pitié. Int.J.Rehab.Research, 10(3), p. 253, 1987.

[9] A review appears in Encyclopaedia Britannica: "Poor Law", 1970.

[10] Source: Encyclopaedia Britannica, 1970.

[11] King Buddhadasa "built island refuges for the physically disabled and blind." His son Uptissa "erected great nursing shelters and alms-halls for cripples, women in travail, for the blind and the sick."
Source: T. Jönsson, Children with Special Needs in Sri Lanka, SIDA, Colombo, Sri Lanka, 1984.

[12] S.S. Herr, Columbia Human Rights Law Review, 12:1, 1980.

Another well-documented tragedy in the United States concerned a large institution for disabled children and adults in Willowbrook on Staten Island, N.Y. In 1972, a television crew entered a ward where there were "60 emaciated children, many naked, some in straitjackets, a place with feces smeared on the walls, and a single attendant. It was the impetus for a Federal Court suit... The federal judge would not settle for a better Willowbrook. He wanted the 5,400 residents moved out." New York Times, 18 December 1991. See also D. and S. Rothman: The Willowbrook wards. Harper & Row, New York, USA, 1984.

Similar living conditions still exist in a large number of institutions for disabled people all over the world. Recently, the conditions under which 40,000 disabled children used to live in state-run institutions in Romania were described in the press as one of the worst horror stories of modern times.

[13] A.A. was started in 1935. Its most significant growth occurred in the last twenty years. In 1982, the organisation reported an active membership of one million, forming 48,000 groups in 110 countries. (From "Alcoholics as a Resource for the Medical Profession," London, United Kingdom, 1982).

[14] Maxwell Jones, Social Psychiatry in Practice. The ideas of the therapeutic community, London, United Kingdom, 1968.

[15] A.H. Maslow, Motivation and Personality, Harper Brothers, New York, USA, 1970. Maslow's model has met with criticism, as it appears over-simplistic. The hierarchy of needs proposed by him does not apply to all. To give an example: some people are prepared to sacrifice their safety and their lives to gain the esteem of others, or for a specific cause.

[16] In Sweden there were in 1970 about 2,500 children placed in residential institutional care. Out of these, about 500 were under the age of seven. In 1990, 22 children under 7 remained in institutions, all of them severely disabled. This should be compared with the total number of "severely disabled children under 15," which was recently estimated at 1.3 per cent of the population, or about 100,000. K. Grunewald, Stockholm, Sweden, personal communication, 1991.
The state of Michigan, USA, diminished the number of places in institutions from 12,000 to 700 people in 20 years. In January 1991, New Hampshire closed its last institution (N.Y. Times, 18 December 1991).

CHAPTER SIX: PREJUDICE

1. INTRODUCTION

The word prejudice has two meanings[1], which slightly differ from each other:

(1) an "opinion, like or dislike, formed before one has adequate knowledge or experience",

(2) "legal injury to somebody's existing rights or claims that may arise from some action or judgement".

Opinions about disability and about disabled people form part of all cultures both in the industrialised and developing countries. Our knowledge of the former ones is fairly well substantiated through many anthropological studies. From the developing countries there is as yet no systematical collection of information. What we know has been based to a large degree on anecdotes, and "collecting and analysing fairy tales", but a new wealth of systematic data is emerging.

Most common opinions about disability, whether from industrialised or developing countries, are biased and lead to prejudice. There is a perception that there is no effective technology, that "nothing can be done to help". Such prejudice is reflected in existing policies or lack of policies, legislation and expressions by leaders or people in general and international bodies. Only to a small extent do even well-educated people perceive their own prejudice.

If we want to implement a programme that creates services for disabled people and protects their human rights we must understand the local beliefs, attitudes and explanatory models concerning disability. The success, or lack of success, is likely to be influenced by the extent to which these cognitive factors are negotiable.

We must also learn to understand the reactions to prejudice among disabled people - the second half of this chapter will try to explain the responses to their frustrations.

2. CULTURAL NOTIONS OF DISABILITY

We have certainly heard many tales about disabled people being disliked, neglected, abused, feared, ostracised, segregated, culturally invisible, etc. On the other hand we might also have been told about disabled children who are loved, well looked after and fully integrated in family life. Others may have been overprotected and, as a result, show non-acceptable behaviour.

So a great number of different situations exist in reality. What is preponderant might not be easy to recognise.[2]

For this analysis of cultural notions it may be useful to apply three levels of cognitive factors as proposed by Kleinman and modified by B. Helander.[3]

These are:

- "*a system of general cultural beliefs*, primarily concerned with the origin and consequences of disability. Beliefs operate at a fairly general level of culture. They connect disabilities to cosmological doctrines, religious dogmas, notions of sickness, disorder and abnormality."

- "*attitudes* are more or less explicit ideas held by single actors...built upon beliefs but are also shaped by experience of encounters with disabled persons. Attitudes also contain a strong emotional component."

- *explanatory models*, which "are tied to specific cases of disabled persons and represent the outcome of a process of recognition of disabling symptoms, a labeling of these and a judgement of the future career of a disabled person. The process is shaped by both general beliefs and the attitudes of the involved persons as well as by a number of other social and political factors." Such models may be "shared among a wider circle of people "who reach a community consensus" regarding a particular person.

In Boxes 6.1, 6.2 and 6.3 some examples are given.[4] [5]

Box 6.1

SOMALIA: CURSES AND JINNYS.

"The eye...is one of the primary possible causes to any unforeseen misfortune that people will consider in their search for an explanation". It is "not believed to strike randomly" and is "triggered by some neglected duty or obligation of the victim...such as failure to respond to greeting, insufficiently shown hospitality, arrogance, etc.". A "major cause of ... disability conditions are the curses,...which are intimately bound up with the authority of parental generations". "The strongest is that of the maternal uncle.". It is "incurred due to the transgression of rules or failure to fulfil obligations towards the elders". "Curses can wither your limbs".

"Sorcery emanates from the will of other humans". It causes disability and "strikes randomly and uncontrollably".

Spirits (jinnys) "are believed to inhabit the same world as humans, but to be invisible from them". "You have a jinny" is a synonym for "you're mad". Victims "seek to come to terms with the spirits by offering them the food and other items they are believed to require". "Often a sudden ache in the arms or legs is seen as a first sign of spiritual affliction". Cults are formed to offer relief by other members and specialists. "Many otherwise inexplicable chronic symptoms are often referred to the spirit cults".

Box 6.2

KENYA:
PLEASE DO NOT USE OUR POTS.

"The groups the society would look upon as disabled were the blind, physically handicapped, epileptics, lepers and mildly mentally retarded. The society would give shelter and food, but in a way which stigmatised the disabled persons. Often these people would be segregated in a way. Their huts were built at a distance from other huts, their utensils were not to be mixed with the rest of the family things. They were forgotten in most of the activities. This was mostly true for the epileptics, lepers and mentally retarded, who were thought to be contagious. The mentally retarded were also used for amusements, entertainments and so on".

3. DISCRIMINATORY BEHAVIOUR

Beliefs, attitudes and explanatory models do contribute not only to what people think about disabled people but also how they act towards them. Again there are no systematic studies about discriminatory behaviour towards disabled people, and obviously such behaviour varies a great deal.

The sight of a person who differs in appearance and behaviour mostly creates a feeling of discomfort and fear. There are many more levels of reaction to "discrepancy": pain, freezing, fright, avoidance, stigmatising, distancing, denigration and stereotyping. These reactions and the subsequent behaviour may be observed in adults, who avoid visual and physical contacts as well as communication with disabled people. Children normally do not (or have not yet been influenced to) perceive such differences, and several studies show that they do not spontaneously avoid contact with disabled children.

But discriminatory behaviour is widespread - although not much talked about. As explained in the previous chapter, it is common in several developing countries for newborn babies who have some slight, visible impairment to be put to death, and mothers who don't agree to conform may be threatened with severe sanctions.

Disabled children are sometimes hidden, particularly from foreigners. Many of them are neglected by their parents. This is the obvious situation in some countries where disability surveys have been published. Some surveys show a prevalence of paralysis caused by polio which is two to three times higher among boys than among girls[6]. Since the incidence must have been identical, this proves that there is a greater degree of neglect of disabled girls in countries where there is a bias towards boys, so more girls die. Similarly, there is an excessive mortality rate, for instance, among those born deaf (and certainly they do not die from deafness) and among mentally retarded[7]. In some countries it is difficult to find more than a few children who have survived to the age of 15 with cerebral palsy, yet the incidence should be much higher than in the industrialised countries.[8] It has been observed that children can have deformities which can only be explained as a result of severe trauma by an adult.

Box 6.3

A WEDDING IN SRI LANKA

"On my wedding day I wanted us to share some of the celebration and happiness with my friends at the home for disabled. But my mother strongly protested, because the married couple are expected to go to a place connected with prosperity and well-being. Many people still believe that just looking at a person with a disability or touching her on the wedding day, will surely cause the future baby to be disabled also. Apart from her own worries she also feared what the guests and relatives would think. But still my husband and I insisted to keep the programme, and we invited the guests to accompany us to the institution. Many were a little hesitant, but only a few refrained. It seemed, however, that they changed their minds on seeing how happy and normal those children were. We had another round of speeches, songs, distribution of sweets and laughter. I still continue my contacts with them, but certainly it has not caused me any kind of misfortune. Our baby, who is now two years old, is a healthy and harmonious little child."

It is true that we also observe family situations characterised by a very positive and caring behaviour towards the disabled children. This is to some degree caused by "selection": these are the survivors, and many of them are found in families with a better than average economic situation.

It should be pointed out that families living below the poverty line face a difficult situation. It might not be possible for all the children to survive in periods of economic distress and lack of food. The choice to let the strongest survive is forced upon such families by circumstances over which they have little control.

In balance, it is understandable that discriminatory behaviour with severe consequences, including excessive mortality, is dominant.

This is in conformity with the situation in some industrialised countries. Zigler[9] undertook a study of a group of mildly retarded children in the USA, and found histories of "extensive physical abuse or neglect" among 45 per cent of them. He may not have been aware of all such cases. And there are frequent stories in our Western newspapers of severe abuse of disabled children or adolescents who are at home or under the care or supervision of professional personnel in institutions.

4. THE EFFECT OF GENERAL SYSTEMS OF BELIEFS ON POLICIES

Most developing countries do not have a clear set of explicit policies related to disabled people. This most probably reflects the general systems of beliefs.

Politicians or legislators are no different from others and, if the general view is that disabled people are "useless" and will remain so, whatever is done, then naturally this belief will be reflected in policies.

Governments may avoid explicitly stating why they act as they do, and they may ignore the subconscious effects of traditional beliefs.

A great deal of effort is needed to give politicians adequate knowledge[10] and experience of rehabilitation, so as to convince them of the effectiveness of programmes for disabled people. The best way to achieve this is to actively involve governments in providing public services of rehabilitation.

5. HUMAN RIGHTS PREJUDICE

It is a fact that, as a result of general beliefs and negative attitudes, there is a neglect of the respect for human rights as applied to disabled people.

This neglect is visible in all areas: the rights to life, protection by the law, property, assembly, equal access to public service, work, standard of living, education and so forth. These rights are expressed in the Universal Declaration of Human Rights, proclaimed by the United Nations General Assembly on 10 December 1948.

Many experts believed that the remedy for this problem was for the United Nations to formulate some specific Declarations of Rights focusing on disabled people. In 1971, the United Nations General Assembly adopted the Declaration on the Rights of Mentally Retarded Persons (RMR). In 1975 followed the adoption of the Declaration on the Rights of Disabled Persons (RDP).

Alas, these Declarations too are influenced by the negative beliefs and attitudes toward disabled people held by official representatives and experts.

The texts of these declarations and the discussions held at the Economic and Social Commission before their adoption reflect in a very shocking way the prejudice against disabled people - reaching to the highest possible international levels. I do not think that these representatives and experts were aware of the degree of bias they harboured, which is clearly reflected in the texts of the Declarations.

In Annex I, the entire text is quoted with comments, and these speak for themselves. In short, these declarations begin by failing to give a clear definition of the "target groups." Most of the text includes references to rights already included in the Universal Declaration of Human Rights. But in RMR and RDP a number of restrictions are added almost everywhere, giving the impression that disabled people "do not qualify" for full rights. The most serious mistake is in Article 7 of RMR, and its text is repeated in Article 4 of RDP. It states:

> *"Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should <u>become necessary to restrict or deny some or all of these rights</u>[11], the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subjected to periodic review and to the right of appeal to higher authorities." (Paragraph 7 of RMR).*

It should be noted that the Universal Declaration of Human Rights lists, for example, the rights "to life," "to security of person," to not be subjected to "slavery or servitude," "torture," or "arbitrary arrest, detention or exile." *<u>The texts of RMR and RDP state that such rights may be eliminated</u>*.

So the United Nations have, without protest from anyone, approved a text - the only one of its kind - that *<u>foresees the possibility of denying a group of people **all** human rights</u>*. Furthermore, RMR and RDP propose that the procedure for implementation of this gross injustice should be based only on an evaluation by non-defined "qualified experts." In reality, this denies the disabled person the fair and public hearing required in the Universal Declaration of Human Rights. The prejudiced formulations in the two special Declarations have added insult to injury, but fortunately few people have bothered to read them. Maybe it would be a good idea to suppress or "undeclare" both texts?[12]

In this context, it might be interesting to read a statement by the United States Congress, namely the introduction to Public Law 101-336 adopted in 1990[13] (see Box 6.4). The statements here do apply equally to developing countries.

6. *THE REACTIONS OF DISABLED PEOPLE TO PREJUDICE: RESIGNATION, REFORM OR REBELLION*

It is easy to understand that disabled people today are discouraged and frustrated by the prejudice they constantly face. They are wondering if there is any way to bring some fundamental changes to a system that causes such widespread discontent and injustice. They want to move away from a set of values that classifies them as deviants and marginal human beings and accords the status of second-class citizens. There are several types of reactions to be found among those who face prejudice, both in the disabled and in the non-disabled population.

A model may be proposed to explain the social mechanisms causing frustration: the reaction of people to the injustices they encounter in their daily life.

Three basic social functions: performance, competence and aspiration are involved.

Performance signifies the level of function a person reaches, including performance at work, at home, during leisure time, and so forth;

Competence indicates the sum total of a person's abilities, education, experience, common sense and behaviour, or the maximum that this person could do if given the opportunity;

Aspirations reflect what a person would like to do, his or her dreams, ideas and wants.

These three functions have several levels and relate to each other.

- Ideally a person's *performance* should be equal to his or her competence. But many human beings will never be given the opportunity to function anywhere near their level of competence. At work, for example, there are far too many simple, repetitive and dull jobs requiring but a fraction of our competence. This is disturbing, and many of us seek compensation by way of leisure time activities such as hobbies, social contacts or membership in various interest organisations. An unemployed person will perceive that his or her work performance is zero. This is often the case for a disabled person. The opportunities for leisure time activities too may be reduced, causing frustration.

- *Competence* is more than the sum total of a person's innate physical and mental abilities. Education, both at school and as preparation for a job, will develop and refine these abilities. Later in life, experience will further enhance this competence: learning to develop skills out of knowledge, applying them using common sense, and developing an appropriate behaviour. Non-disabled people in developing countries are to a large extent deprived of the opportunities for education and experience. Those that are disabled are even worse off. They are often excluded as a group *a priori* without any proper examination of their individual competence. They rarely find employment even if qualified for the particular job. As a result, they become dependent on their families or turn to begging. A large gap between competence and performance gives rise to frustration.

- Our dreams, ideas and wants make up our *aspirations*. While young we may have unrealistic aspirations. With time and experience we learn to match them to what we may predict will happen to us in the future. It is not at all unusual to see people's aspirations surpassing both their performance and their competence. Some people are highly motivated, they strive for a better future, they want to achieve more.

Like everybody else, disabled people have their aspirations and ambitions, which will have to be adjusted to their respective level of competence while taking into consideration their abilities. But once these are matched, they find themselves up against a system of rejection that may pervade virtually every sphere of the society in which they live. Because of their functional limitation or on account of some other, visible minor problem they are often labelled "useless," irrespective of their competence. They also have the feeling that there is a widespread lack of respect for their human rights.

Box 6.4

PREJUDICE IN THE UNITED STATES

"The Congress finds that

(1) some 43,000,000 Americans have one or more physical or mental disabilities, and this number is increasing as the population as a whole is growing older;

(2) historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem;

(3) discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services;

(4) unlike individuals who have experienced discrimination on the basis of race, color, sex, national origin, religion, or age, individuals who have experienced discrimination on the basis of disability have often had no legal recourse to redress such discrimination;

(5) individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities;

(6) census data, national polls, and other studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally;

(7) individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society;

(8) the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals; and

(9) the continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity."

The level of aspiration will be affected by frustration caused, in turn, by the competence/performance gap. But the level of aspiration is not necessarily proportional to the degree of frustration. It depends to some extent on the personality structure. Some people react almost violently to minor injustices. Others may show very little feeling even when thoroughly abused. Some people may resist a lowering of their aspirations because they have an optimistic and strong personality. They exhibit an attitude that "somehow we will overcome the problem". Others refuse to lower their aspirations because they enjoy a supportive social environment. Others "overshoot" all realistic expectations and aggressively demand unreasonable favours. Others again show little resistance, and even small setbacks may cause their aspiration levels to plunge. Furthermore, the degree of frustration may not be constant, nor will a person's aspirations fall at all times by the same degree: we are more hopeful on some days and less so on others.

Box 6.5 shows three different levels of aspirations and the patterns of reaction caused by the degree of frustration associated with each of the three levels; comments are offered below.

- "*Resignation*" is a common reaction among disabled people, in particular in the developing countries. It affects those who have tried to conform to society's rules only to find its avenues closed everywhere. These are people who may lack the necessary inner strength or the necessary support from their social strata to try innovations or to rebel. Many of them have had no schooling and have always felt pushed aside or neglected. Among them are people who may have listened to those with power in their hands and who believed for as long as possible that one day they would make good on their political promises. Among them may be the disabled elderly or youths who are waiting for services that have as yet failed to materialise and perhaps never will.

Aspiration level	**Reaction to frustration**
Low	Resignation, the person feels defeated, depressed: "No use even to try".
Normal	Reform, the person has some hopes: "the system can be improved", "let us change the future".
High	Rebellion, the person rejects the entire value system and wants to replace it by a new one.

Box 6.5: Level of aspiration and patterns of reaction to frustration

Unfortunately, there are indications that resignation as a reaction to frustration may be gaining ground, as millions more will be resigned to the same fate. As mentioned earlier, every year, about two million join the list of disabled people in need of rehabilitation. If available resources continue to be mismanaged, misery and frustration will grow. And if the national authorities continue giving nothing but symbolic support, nothing will change for the better.

- "*Reform*" is what one should strive for, but few disabled people in the developing countries dare to hope. In this book, I will describe an innovative approach for reform which challenges the conventional system on almost every point. No doubt this is not the only alternative; there are others, and these should be presented and tested for their effectiveness.

Disabled people need to be encouraged to work for a reform of a system set against them. Only governments are in a position to exercise decisive, countrywide influence on the prevailing situation. Consequently, it is mandatory for governments to commit themselves and to accept responsibility for bringing about a change.

Organisations of disabled people should spearhead the call for reform. However, in the developing countries, they are severely hampered in such efforts, owing to their members' lack of functional training, education, of jobs, of status, of administrative experience, and of negotiating skills and of financial resources. They must shed a pattern of behaviour associated with beggars and appear as a group of citizens seeking rights assured to all under the constitution of their respective countries. To strengthen these organisations and to develop their potential for full partnership should become part and parcel of all rehabilitation programmes.

- "*Rebellion*". This term has been explained in a different context by Merton[14], and it might be interesting to quote his interpretation:

> *"When the institutional system is regarded as the barrier to the satisfaction of legitimized goals, the stage is set for rebellion as an adoptive response. To pass into organized political action, allegiance must not only be withdrawn from the prevailing social structure but must be transferred to new groups possessed of a new myth. The dual function of the myth is to locate the source of large-scale frustrations in the social structure and to portray an alternative structure which would not, presumably, give rise to frustration of the deserving. It is a charter for action. In this context, the functions of the counter-myth of the conservatives becomes further clarified: whatever the source of mass frustration the conservatives claim, it is not to be found in the basic structure of the society. The conservative myth may thus assert that the frustrations are in the nature of things and would occur in any social system...Or, if not the doctrine of inevitability, then the doctrine which deflects hostility from the*

> *social structure into the individual who is a "failure"...*
>
> *The myths of rebellion and of conservatism later work toward "a monopoly of imagination",... "seeking to define the situation in such terms as to move the frustrated towards or away from adaptation."*

Rebellion in the above context is a reaction against the prevailing value system. Our societies give supremacy to a limited set of values, for instance, wealth, power, beauty. Those at the lower end of the spectrum - the poor, the powerless and the unattractive are considered failures, and sometimes also blamed for it. Other values our societies certainly ought to recognise include: kindliness, honesty, empathy, affection, solidarity, willingness to help others, to make sacrifices. But these values do not seem to count for much.

The existing value system seems thoroughly integrated in most social and cultural environments, and most people would take exception to the idea that it can be changed. Most people argue: "This is the way all societies are ordered: some people are at the top, others at the bottom"; or "It is natural that those who fail want to blame those who are successful." It does not seem easy to propose a new value system that would serve to relieve the frustrations of the disabled people who have become marginalised.

Those representing "the cream of society" - the rich, the powerful and the beautiful - pull the strings and write the laws of the land. In the eyes of the disabled person, they may be seen as keepers of the prevailing value system. They set up rules that will force others out of focus. By defining disabled people as deviants, the leading forces of our society contribute to the very phenomenon that they see as the problem: underperformance, dependency and segregation.

So far, this system has not been seriously challenged. It seems to grow stronger as time goes on, adding to rather than relieving the burden for those considered "marginal" or "imperfect". Some societies are still finding innovative ways of circumscribing the human rights of disabled people, while others corrupt them by offering rewards for staying on the sidelines.

However, the situation is not hopeless. Gallaudet University in Washington D.C. provides a recent, successful example of rebellion. It is the most important academic institution for deaf people in the United States. A few years ago, its board met to choose a new president. They rejected a very competent candidate, who himself was deaf. They voted instead for an equally competent, hearing scholar. The students and the academic staff then started a series of demonstrations and strikes that went on for several weeks. The media offered daily coverage of this unusual event. Some members of the board gave interviews which clearly reflected a high degree of prejudice. Finally the chosen president found the atmosphere so hostile that she resigned, as did most of the board who had resisted the choice of the deaf candidate. The latter was then given the post.

This rebellion was successful, for several reasons:

- First, the group who rebelled was very homogeneous. It held a single undivided opinion, all members were in one place, which happened to be the nation's capital,

- Second, the group had excellent and undisputed leadership,

- Third, the group managed to catch people's imagination, so the media exposed the problem, including the high degree of bias among the board members, the lack of consultation with academic staff and students, and so forth.

Can such rebellions be expected to occur in the future? In the industrialised countries maybe. But there are many constraints. One is the fact that the group of "disabled people" is no longer a homogeneous one. It seems to "disappear in the haze" of identification problems. Social security legislation in many countries now labels as "disabled" very large groups of people who are socially marginal and rejected by the labour market for a variety of reasons. It might not seem easy to forge a coalition of partners out of

Box 6.6

THOSE WITHOUT VISION WILL ALWAYS PERISH

At the opening ceremony of DPI's III World Congress in Vancouver, Canada, in April 1992, Mr Joshua Malinga, DPI chairman, gave a statement. Excerpts are below:

"I remember a biblical saying that 'those without vision will always perish'. For over 2000 years, we have suffered all forms of degradation, humiliation, oppression, exploitation, discrimination and under-development.

"Disabled people all over the world are condemned to poverty and under-development, which manifests itself in abject poverty, pitiful lives, street begging, marginalization and complete rejection by almost every strata of society...the biggest crime against humanity.

"Our vision was to create a world where disabled people enjoyed the same rights with other people and where disabled people were afforded equal opportunities...

"DPI was born in order to spearhead the liberation of disabled people worldwide. That was an important, crucial decision and the world has never been the same for disabled people, for those who have maintained an oppressive regime in the name of rehabilitation and care.

"The vision of the future over and above the guiding philosophy is to be able to translate our thinking into concrete actions that will involve disabled people in all political, social, cultural and economic systems. Like any other struggle for social justice, disabled people have to realize that our struggle is long and protracted and it is against ingrained negative attitudes, and that it has to be fought at all levels and everywhere.

"We live in one world and we need each other and each other's support.

"Violation of human rights in one country should be seen as violation of human rights against all disabled people and should be met with violent force.

"My message to you all is that the struggle has only begun and, in the words of Winston Churchill, 'Never surrender, never, never!'"

this variety, or to get them all to agree on a common course of action under a unified leadership. But, on the other hand, we must realise that "disabled people know best who they are." Thus there is a likelihood that limited, homogeneous groups of disabled people will unite if need be. They can then choose examples of direct action which can be easily understood by the media. Organisations of disabled people could capitalise on the goodwill they have in the eyes of many ordinary citizens. Some inspiration can be drawn from the opening statement at last year's World Conference of Disabled People's International (DIP), which is reproduced in Box 6.6[15].

However, the situation in the developing countries still differs very much from that in the industrialised world. In developing countries, organisations of disabled people are very weak or circumscribed. Not much rebellion can yet be expected out of their own initiatives. Political systems in many such countries have little patience even for small-scale rebellions, and the media can rarely be counted on to give support. I have, however, seen several examples of successful demonstrations, both in African and Asian countries, which managed to draw the attention of the authorities. They even resulted in some important changes, such as the opening up of government posts to disabled people. Organisations of disabled people should not be the only ones to seek change of the current value system. Every decent citizen who reacts to injustice should mobilise his or her loyalty to stand up in defence of those now unfairly marginalised and therefore without a chance of ever living a life in dignity. This will call for summoning up the courage to challenge certain fundamental values of our present society.

7. LESSONS LEARNED FROM THE EXPERIENCE OF PREJUDICE

Prejudice directed against disabled people is common everywhere. It exists at all levels of culture, in the developing as well as in the industrialised countries. Beliefs, attitudes, explanatory models, and common discriminatory behaviour against disabled people are expressions of this prejudice.

Prejudice is built into a system that functions at the general level of all cultures. It makes its appearance even among the best educated people and shows very few signs of diminishing.

Given the many constraints, the main option left for relieving frustration among the disabled people in developing countries is to follow a programme aimed at reform. The programme should provide public services of good quality. It should be integrated into community efforts to meet all essential needs. And most important, it should provide better opportunities, greater influence and justice for disabled people.

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[3] B. Helander: Mercy or Rehabilitation? Culture and its Prospects for Disabled in Southern Somalia, Bruun-Ingstad, ibid.

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[5] R. Tiroler: Rapport Nr. 9, Social Förvaltningen Örebro, Sweden, 1991.

[6] Report on the sample survey in Nepal, see Comment 6, Chapter Two. Ministère des Affaires Sociales et de la Promotion Féminine: Rapport d'Enquête de Recensement des Personnes Handicappées. (Baboye Madbei et al.), N'Djamena, Tchad, 1989.

[7] A. Hasan and H. Aziz: Int.J.Mental Health UM 10, No. 1, p. 23, 1981.

[8] The lowest possible incidence of cerebral palsy would, in the opinion of the author, be 1 per 1,000, most likely it is 2-3 per 1,000 infants. Cf. also the Mali survey presented in Chapter Two.

[9] E. Zigler: Controlling child abuse in America. An effort doomed to failure? In Critical perspectives on child abuse, ed. R. Bourne and E.H. Newberger, pp. 171-213. Lexington Books, Lexington, Mass., USA, 1979.

[10] For instance, the UN International Year of Disabled People (1981) and the UN Decade of Disabled People (1983-92) have contributed to an increased awareness among politicians. Another important factor is to improve the image of disabled people. There are some excellent recommendations in "Improving Communications about People with Disabilities", Recommendations of a United Nations Seminar 8 - 10 June, 1982, Vienna, Austria.

[11] Underlining by author.

[12] As this is a proposition that is unheard of in the context of UN declarations, an effort is made to reword the text in a more positive manner. By 1993, UNCSDHA will be ready with a set of "Standard Rules on the Equalisation of Opportunities for Disabled Persons".

[13] Public Law 101-336, adopted on 26 July 1990 by the 101st United States Congress, "Americans with Disabilities Act of 1990".

[14] R.K. Merton: Social Theory and Social Structure, Collier-Macmillan, Ltd., London, UK, 1968.

[15] Vox Nostra, Vol. 5, No. 2, 1992, Winnipeg, Canada.

part two

an alternative solution

CHAPTER SEVEN: A REVIEW OF THE PROBLEMS

Disabled people in the developing countries face many problems, which call for solutions. The problems can be divided into four components:

- functional situation
- organisational problems
- environment
- political concerns.

1. FUNCTIONAL SITUATION

The functional situation of disabled people in general is characterised by:

- reduced level of performance of daily life activities (ADL) such as mobility, eating/-drinking, keeping clean, communicating, learning, doing household duties, etc., and/or behaviour discrepancies;

- lack of education, both schooling and vocational training;

- lack of job and income;

  These three factors result in: physical, psychological, social and/or economic dependency;

- increased rates of morbidity and mortality;

- generally low level of quality of life.

2. ORGANISATIONAL PROBLEMS

The organisational problems are evident:

- most developing countries have services that are merely symbolic. To organise and deliver sustainable services to cover all essential needs will require an administrative system at all levels;

- lack of a local infrastructure for service delivery. Few countries have organisational networks that reach into the communities. The best developed is the elementary education structure. Primary health care and local social services are in most countries very weak and as yet unable to serve the entire disabled population. Services provided by NGOs or external donors are fragmented;

- lack of professional and managerial personnel, and of community workers competent in CBR, as well as of training programmes/facilities for these groups. The existing rehabilitation personnel does not suffice for more than a small part of the essential services. Their training is oriented toward institutions. It needs to be re-oriented to the community level;

- problems related to referral services. In many countries, disabled people are often referred to the existing specialised centres whenever they seek help. These rarely are able to take care of more people than they already have, making the referrals meaningless. Most centres have low turnover and are under-utilised. With few exceptions, moreover, their quality leaves a good deal to be desired;

- co-ordination problems are frequent: between different ministries of the government, between the government and NGOs, and between NGOs;

- the financing of services is very vulnerable: governments often reduce the budgets for "social" programmes during periods of austerity. External donors often ask nationals prematurely to take over the funding of very costly programmes.

3. THE ENVIRONMENT

The psychological environment is characterised by:

- embarrassment: many disabled children and adults are hidden away, not even known to neighbours, and their presence may be seen as an indication of punishment by God for sins. Their presence can reduce the value of their relatives as potential marriage partners;

- neglect: although disabled family members are sometimes well cared for, the majority of them suffer from neglect. They are often last to be given food, clothing, health care, physical protection and so on. Neglect is the main contributor to an excessive mortality rate. Most people believe that it is unproductive to try to improve disabled people's performance; they are seen as "useless" and as "a burden to the family."

The physical environment is characterised by:

- lack of access, especially for physically disabled people, to public buildings, services, transport and so forth.

Another environmental problem is:

- the lack of opportunities, for example, for schooling, vocational training, jobs, access to health and other public services, information and leisure activities.

4. *POLITICAL CONCERNS*

There are number of political concerns:

- the perception of many governments - as of people in general - is that rehabilitation, education and job placement for disabled people is costly and non-productive. This explains - at least partly - why government services and financial participation are symbolic only. This sector has often been left to charitable organisations;

- disabled people and their families have very little influence over anything, including services set up for them. Their own organisations, if any, are weak, splintered into small fractions and often not very representative. With few exceptions, they also lack cohesion and financial resources. They may be dominated by non-disabled professionals or be under the close supervision of a ministry, indicating that disabled people are not considered as grown-ups. To sum up: disabled people and their families have no power;

- the human rights situation is in a shambles. Equal opportunities for schooling, education, vocational training, jobs and so on, exist on paper only; they are not a reality. The right to vote, to freedom of association, freedom of expression, does not always exist. Abuse in all its forms - verbal, physical, mental and sexual - is commonplace. This is a disgrace and makes us wonder how far we are from ensuring a life in dignity and decency for disabled people.

5. *SUMMARY*

The review above is brief and not complete. It should be emphasised that the situation globally is very diverse. There are some excellent services in many countries, trained and capable professionals and well-managed systems. Yet in spite of these positive factors, the problems described are considerable and concern very large groups of people. The disabled population grows rapidly, and a further deterioration of their quality of life can be expected if rapid and extensive measures are not taken by governments and other partners. The situation now is no better than it was 30-40 years ago.

The task in front of us is to try to outline an innovative set of solutions to these problems - the community-based rehabilitation strategy. In the following chapter, this strategy will be described, starting with the principles of CBR, a set of objectives and formulation of the general approaches to problem-solving.

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 rarely 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. 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 - disease, trauma, 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 form 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 has to be to make individualised care, training, schooling, vocational training and access to employment 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*.

Box 8.1

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 the disabled. 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, 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, a similar function is played by the extended family, the tribe, or the clan. 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. (See 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] (See 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 the human rights of disabled people;
- affording disabled people 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 economic and social means in a spirit of solidarity. And this can only be brought about by a change of prevalent attitudes and behaviour through sensitisation and education of the public at large, with the ultimate aim of gaining equality for disabled people. This will only happen if governments take over the responsibility for disabled people and provide public services.

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 CBR[4] 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 a developing country and to build on this experience. Not until the applied local technology builds on this general approach will the development be sustainable. This 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, agricultural improvements, 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 school teacher who has integrated 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. Similarly, parents or other family members who act as trainers of disabled individuals could develop their abilities through experience. Local school teachers 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 vocational training and help disabled people to find 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 set up service systems to cover entire populations, to build up management resources, and to locate the necessary funds to finance all this.

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.

Most governments seeking to improve the quality of life for their disabled citizens, and all development agencies involved, should bear in mind that sustained, active efforts are needed for a period of as many as 15 or 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.

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[1] The 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.

[2] A.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.

[3] Ethical issues have during the past 20 years or so become a major preoccupation 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 dearth 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 much debate.

[4] The 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-centred with a content that is life-centred 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.

CHAPTER NINE: CBR TECHNOLOGY

1. DEMYSTIFICATION OF REHABILITATION TECHNOLOGY

A large number of disabled people need a programme aimed at improving their functional capacities, at providing environmental interventions, schooling, vocational training and jobs. They also need legal protection. Most of these efforts should be carried out in the place where the disabled person lives. This necessitates large-scale dissemination of knowledge about disabilities and skills in rehabilitation to the people with disabilities, their families and the members of their communities.

The search for an innovative solution to this problem began in the 1970s with a critical study of conventional rehabilitation technology. Rehabilitation was, in many respects, a relatively new speciality. There had been little research on its effectiveness, it remained to a large extent dependent "on methods and techniques not fully researched or substantiated"[1] .

A number of technologies must be seen as part of a 19th or early 20th century heritage and not as rational approaches to a practical problem. In the medical sector, that inheritance included a number of common therapies related to the spa tradition: massage, treatment with water, electricity, or magnetic waves.[2] Other aspects were, for instance, breathing exercises originally set up with the rational purpose of reducing pneumonia and atelectasis appearing in the post-operative phase of abdominal surgery. However, most of these exercises became obsolete as early mobilisation of these patients became commonplace. Yet, in many general hospitals they continued constituting half of all physiotherapy given until as late as the 1970s. In addition, medical rehabilitation included a number of new, insufficiently understood and researched techniques, among them several highly complicated approaches to treatment of disability caused by degenerative neurological diseases.

In the educational sector, development of rehabilitation technology along conventional lines had been going on for about two hundred years. It involved special education on a segregated basis. Not until recently did a handful of industrialised countries start experimenting with integrated approaches. Research into the effectiveness of the various technical alternatives is still incomplete.

In the vocational sector, the situtation is very complex. Vocational training and sheltered employment had been part of the early 19th century efforts related to specialised institutions. A large number of industrialised countries started to adopt a more structured approach in the 1950s and 1960s. Disabled adolescents and adults first underwent a sometimes rather complex assessment, followed-up by formal training schemes. These were, as a rule, provided in segregated institutions. The results in terms of productive employment were mixed. As unemployment in the industrialised countries reached large-scale proportions, the difficulties associated with integrating disabled people in the open labour market became very nearly insurmountable. The resultant recourse to sheltered work and similar approaches may be seen as recognition of failure. New ways of dealing with this situation are being sought. They will have to take into consideration all the "new groups" of disabled people recognised by legislation or who perceive themselves as disabled, and the requirements of social security systems. More research is needed to fully understand the effects of vocational programmes in the industrialised countries. And then there is the open question of the basic concept: is work a right for all, regardless of productive capacity, or is it an opportunity for some who have this capacity?

Doubts about the adequacy and effectiveness of the existing rehabilitation system in the industrialised countries raise serious questions about advocating its transfer - in its current form - to the developing world. This questioning has led to the search for alternatives.

2. STUDIES OF APPROACHES TO REHABILITATION IN THE DEVELOPING COUNTRIES

The first part of this search was concerned with studies of the situation of disabled people in developing countries. Disabled people are mostly seen as totally unproductive, dependent on others for their daily functions and subsistence, neglected, and so forth. But one also comes across examples of disabled adults who have successfully trained themselves, or of disabled children who have been trained by family members. Most of these disabled people have had no access to rehabilitation professionals. They have had absolutely no knowledge of anatomy or physiology or diagnosis or assessment techniques or anything else that in the industrialised countries is thought to be indispensable in the handling of rehabilitation. They have had no commercially available equipment. They have had no special schools, nor any vocational training institutions tailored to all the specific needs of disabled persons. Quite often they have produced technical aids or appliances themselves or with the help of a local craftsman. Or they have managed to go to the local school and later found their way unassisted to a job or to self-employment.

Let us look at a few examples:

- *The setting is a Middle Eastern country. Following several years of drought, the government bought large amounts of grain to be used as seeds. The seeds had been dressed with alkyl mercury. Short of grain for bread-making, the farmers, though warned not to do so, used some of the seeds for that purpose. The aftermath was a widespread "epidemic" of alkyl mercury poisoning, adding many thousands to the list of people with disabilities. Among others, it caused blindness, tunnel vision, ataxia, and paralysis.*

Two years later, the need for rehabilitation was considered by the government, and I was asked to make a study of the situation. By that time, many of the disabled individuals had been rehabilitated by their family members. Blind people had been trained in mobility and now walked about in their neighbourhoods by themselves, using canes. Children who had suffered paralysis had been trained successively to sit up, to move arms and legs, to stand up, to walk, to dress, to feed themselves, and many other activities.

Mothers had played a key role in achieving results - results identical in quality to those one would have expected had professionals been involved. There was no need to send in any Western therapists to provide rehabilitation.

- *While visiting a family in a small village in a Central American country I was shown a 12-year-old boy who was severely hearing impaired. Herself barely literate, the grandmother explained to me that she had started taking care of the boy when he was little.*

Realising that he was deaf, she took him to a local health centre. The doctor told her there was no cure. The only advice he had to offer was to try sending him to a specialised school for deaf children. However, this school had a waiting list of several hundred children, and there was no way she could get the boy enrolled.

With this hope gone, the grandmother, with no access to professional advice, started training the boy at home to communicate by using simple sign language to start with. With the help of a mirror, she taught him with some success to speak a few words. Some time later, she began training him in lipreading, and when he mastered that, she took him to the local school, where he did well.

I also talked to the school teacher, who confirmed that the boy could follow the schooling well, and that he always passed his examinations. He explained to me that he had made it a point to talk and demonstrate from a place where the child could see his lips.

Having started school later than the others, the boy was two years their senior -a fact that had not caused any problems: there were other children of his age.

The teacher then took me to see three more children, all of them physically disabled, but attending classes in his school. Two of them were able to walk to school unassisted, while the third one was taken to school by some older boys, in a small, home-made carriage. That boy also needed help in using toilet facilities.

- *The next example is the story of a 30-year-old man in an Asian country. He had become blind at the age of three. When he recovered from the* *illness that caused the disability, his mother started training him to become mobile at home and in the village. Several years later, the mother for some reason moved to another place, while the young man remained behind. The mother then trained him to walk alone the seven kilometres through a dense forest that separated her new house from the village. He went to his mother's place once a week to fetch the food she had prepared for him.*

- *In a very poor African country, an organisation of disabled people had been set up. A most energetic local leader, who had himself a serious disability, had been chosen as president. With the help of local governors and village leaders, he managed to set up some dozen activities, providing schooling, jobs and an income for many of the organisations' members. All disabled children were sent to the local school, provided they could either walk there or be helped to get there. Training for jobs included: cloth-dyeing and sewing; shopkeeping; working in an agricultural co-operative; clerical jobs in the governor's and mayor's offices; community health worker, etc. All these disabled people received informal training/preparation, and the president used personal contacts to find them positions.*

- *Once I visited a new orthopaedic workshop set up in an African country by a Western charitable organisation. In one of the storage rooms, they had collected over 100 "old" appliances: wooden legs, braces, crutches, carriages, etc., which had been manufactured locally by a disabled person, by a local carpenter or a blacksmith. Most of these appliances had served well for several years, and all repairs had been carried out locally.*

Examples of this kind of spontaneous and successful efforts are numerous among disabled people in all developing countries.

Having discovered this effective type of "self-rehabilitation" in the community, the next step was to systematically describe the technologies observed and to identify features common to all.

This effort was complemented by several hundred interviews with disabled people and their family members. In these interviews, held at home in villages and marginal urban settlements, many aspects were covered. Parents were asked to tell us how the disability started and what they thought had caused it. They then related the problems they had experienced and what they had done to cope with them. It is very common to find their accounts of the causes of the disabilities influenced by common beliefs and local explanatory models. Mostly the parents had gone to a local healer for advice and afterwards, if available, to a nearby health service. Those consulted usually failed to propose anything useful. Most parents were looking for a "cure" - they thought some magic or medical procedure would make the disability disappear. But most of them were also willing to try some training at home to improve the functional situation of the disabled family member.

After every such family visit, I met with the community leaders to discuss the prospects of community involvement, of finding local employment, of ways to let disabled people participate in informal vocational training. And, to round off my visit, I would go and see the school, on which occasion I would discuss integrated education of disabled children with the headmaster or the teachers.

3. DEVELOPING STANDARD DESCRIPTIONS OF TECHNOLOGY: "TRAINING PACKAGES" AND "GUIDES"

Eventually a pattern of technologies was identified - a combination of "locally invented" and "interview-based" technologies. This information was then systematised[3] and described in great detail in the manual entitled "***Training in the community for people with disabilities***" (TCPD)[4]. The material consists of thirty training packages and a set of four guides intended for use at the community level.

Each training package is devoted to a particular subject. Some packages provide information about each disability directed at the family. Others deal with preventive measures (e.g.

Box 9.1

TRAINING PACKAGES

Training packages for family members of people who have difficulty seeing.

1. Information about the disability and what you can do about it
2. How to train the person to take care of himself or herself
3. How to train the person to move around

Training packages for family members of people who have difficulty speaking and hearing, or speaking and moving

4. Information about the disability and what you can do about it
5. For the child who has difficulty hearing and has not learned to speak, how to train the person to communicate
6. For the adult who has difficulty hearing but can speak - how to train the person to communicate
7. For the child who has difficulty speaking and moving but can hear, how to train the child to communicate

Training packages for family members of people who have difficulty moving

8. Information about the disability and what you can do about it
9. How to prevent deformities of the person's arms and legs
10. How to prevent sores caused by pressure on the skin
11. How to train the person to turn over and to sit
12. How to train the person to move from sitting to standing
13. How to train the person to move around
14. How to train the person to take care of himself or herself
15. How to train a person who has aches and pains in the back or the joints to do daily activities
16. Exercises for weak, stiff, or painful arms and legs

Training packages for family members of people who have no feeling in the hands or feet

17. Information about the disability and what you can do about it
18. How to prevent injuries and deformities of the hands and feet

Training packages for family members of adults who show strange behaviour

19. Information about the disability and what you can do about it
20. How to train the person to take care of himself or herself

Training package for family members of people who have fits

21. Information about the disability and what you can do about it

Training packages for family members of people who have difficulty learning

22. Information about the disability and what you can do about it
23. How to train a child who has difficulty learning to take care of himself or herself
24. How to train an adult who has difficulty learning to take care of himself or herself

General training packages

25. Breast-feeding a baby who has a disability
26. Play activities for a child who has a disability
27. Schooling
28. Social activities
29. Household activities
30. Job placement

how to prevent contractures, bedsores, leprosy complications). Others describe training procedures, including exercises, ADL training, communication, behaviour modification, etc. Still others treat general subjects such as breast-feeding, play activities for early stimulation, household and social activities, schooling and jobs. A complete list of all the packages appears in Box 9.1.[5]

Box 9.2

EXAMPLE OF AN EDUCATIONAL OBJECTIVE, AS DESCRIBED IN TRAINING PACKAGE OF TCPD

What is this package for?

The instructions in this package will help you to train the person who has difficulty seeing to move around more safely. The training includes how to move inside the home, around the yard, around the village, and on the roads, and how to travel by bus if necessary. You will also be able to train the person to use a guide or a stick.

At the beginning of each package, the educational objective is stated. (See Box 9.2). Then follows a simple description of what to do, illustrated by many line drawings. (See Box 9.3). Appended to each package are a Result Sheet to be filled in by the family and some advice on what to do in the absence of any progress. (See Box 9.4).

A comparison of these descriptions with the "conventional" Western procedures revealed that there was no discrepancy in principle. We had identified a sort of "core technology" for functional training, schooling, vocational rehabilitation, etc. Of course, being familiar with Western technology helped us to choose the most appropriate of the spontaneous examples we had seen and to fill out the gaps with descriptions of a similar nature.

The result is not much different from a demystified and simplified Western rehabilitation technology; the "innovation" consists in detecting and recognising the value of the spontaneous technology as a model. The technology builds on existing and successful local experience, avoiding this way the many pitfalls associated with the transfer and adaptation of Western technology.

Standardisation of technology, as proposed in TCPD, has been the subject of a lot of discussion.

I hold the view that, given their limited resources, development programmes should be based on a technology which is to the greatest possible degree standardised, if not for several countries, then at least within each country. On the other hand, the service delivery and management systems cannot be standardised.

There is nothing eccentric about this. All countries are known to train personnel using standard approaches. Teachers in schools and vocational training establishments have clearly defined curricula to follow in their work, and evaluation targets are set for them. The students use standardised school books. This does not mean that the teacher will not try to individualise each student's education as much as possible. Similarly, nobody wants, for instance, health care staff to transgress the very strict standardised rules for administering injections, performing a laboratory test, taking an x-ray or providing immunisation. Naturally, some health technologies, e.g. surgery for contractures, will be individualised, but always within a clear-cut set of recommendations.

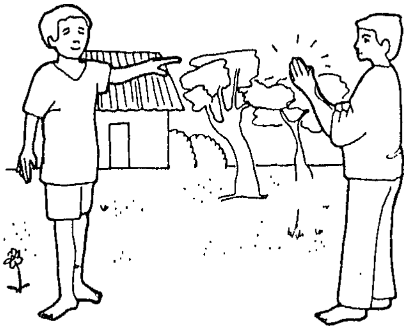
Unless technology is standardised there is no way larger groups of personnel can be trained or results can be evaluated. Of course, each disabled person is different, so the standardised technology should be applied and adapted individually.

Some people advocate a wider choice where technology is concerned, arguing that people should have two or three or four or five options to choose from. This possibility should be given some thought. Early on during the CBR testing period, we gave this idea a try to see how it would work. For example, we provided two descriptions of how to train children with learning

Box 9.3

EXAMPLE OF TRAINING PACKAGE

This page of training package No. 3 is taken out of a text about mobility training of people with seeing difficulties.

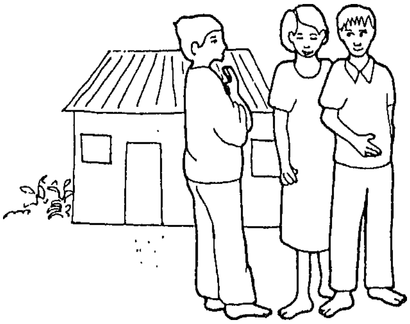


■ Teach the person to turn his or her head to listen to sounds. Help the person to learn the direction in which a sound is moving. Also teach the person to know where sounds are coming from and how far away they are.

You can teach this with an exercise: Go a few steps away from the person and then talk to him or her or clap your hands. Ask the person to point in your direction. Move to another place and repeat this until the person is sure of where you are. Then move further away and ask the person to guess how far away you are.

In this way the person learns where sounds are coming from and how far away they are.

■ Guide the person for walks around the village, describing things you meet on the way such as holes, big stones, or trees. Help the person to learn about these things by touching them with the hands and feet.



■ Describe the people who live in the houses nearby, especially the people of the same age as the person. Tell him or her the names and ages of all members of families nearby. If the person does not know these people, take him or her to meet them.

■ Encourage the person to talk with the people you meet in the village. Help the person to learn to know people by their voices.

■ Describe animals that the person meets, such as dogs, cats, cows, or chickens. Let him or her touch these animals, listen to the sounds they make, and get to know them.

■ Help the person to learn the sounds and smells of things, such as animals and rubbish, that should be avoided when walking.

Teach the person to recognize smells, for example, from cooking food, the market, and flowers. Teach the person to use these smells and the sound of voices to find his or her way around the village.

Box 9.4

EXAMPLE OF RESULT SHEET

This example of a result sheet is taken from same training package as the one reproduced for Boxes 9.2 and 9.3.

Results

After you have used this package for some time, answer the questions.

Begin by watching the person you are training. Then answer the questions by putting the date in one box after each question. Put the date in the box beside "Alone" if the person moves around without the help of another person. Put the date in the box beside "With help" if the person moves around with help from another person. Put the date in the box beside "Not at all" if the person does not walk or move around in the home or in the village.

Moves inside the home?	Alone	☐
	With help	☐
	Not at all	☐
Moves around the village?	Alone	☐
	With help	☐
	Not at all	☐

If both of your answers are "Alone," you and the person have done well. You can stop using this package.

If any answer is "With help" or "Not at all," it may be because of one of the reasons listed. Go through the list to find a possible reason for each of these answers and see what you can do about it.

REASON	WHAT TO DO ABOUT IT
1. You do not let the person do all that he or she can do.	Let the person try to do these activities with less help from you. Repeat the training until the person can do each activity. Then stop using this package.
2. You have not trained the person long enough.	Continue training the person. If you have no results in six months, ask your Local Supervisor for advice.
3. You have not followed the instructions correctly.	Read the package again. If you think that you have not understood the instructions, speak to your Local Supervisor. Then repeat the training until the person can do the activity. Then stop using this package.
4. The person cannot be trained to do this activity because of his or her disability.	The person will continue to need help for the activity. Discuss with your Local Supervisor whether you should stop using this package.

If you continue to use this package, train the person for some time. Then answer the questions again to see if the person can do more activities.

difficulties, to be applied by the family trainers and the local supervisors. The results were considerable confusion and mostly negative reactions. One should be aware of the fact that, in many local societies, people are not used to making a choice between two or more options because daily life has few or none to offer. And when a choice has to be made, it normally is a collective decision, rather than an individual one.

The conclusion drawn from this experiment together with the discussions held with community members convinced us that it was preferable to present only one standard technology. Should this fail, the professional in charge of technical supervision should be able to come up with and apply, some alternative technologies. The place where the appropriate set of technologies should be available is, of course, the referral services.

There is now another very important point to make. What is said above concerns the teaching procedures and the way advice and instructions are given to community workers and to families. But there are sometimes local initiatives to change technology, to experiment with alternatives. Some of these may be better solutions, more adapted to the local culture. It is important that such initiatives be supported and given freedom. People who are well-motivated and want to proceed following their own ideas should be encouraged and not put in a strait-jacket. Based on such local experiments, one may find reasons for modifying the standard technology.

In this context, a few words should be added as to which technology to select for standardisation. Personally I have no preference for one or the other technology, provided it is effective and culturally appropriate. There is certainly scope for variations between countries, for several reasons. There is also scope for developing more technology in particular areas, such as those related to mental disability. (See Box 9.5[6].)

Box 9.5

MENTAL HEALTH AND DISABILITY

In rehabilitation programmes, most of the attention is given to people with motor and sensory difficulties. When surveys are done in the developing countries, only a very small proportion of disabled people are in the groups of learning difficulties (mental retardation), or that of strange behaviour (psychosis and similar conditions). These groups are most likely underestimated because of cultural and social factors, and a large proportion of them are by tradition integrated in their families and communities. A very considerable proportion of children in the developing countries are delayed in their mental development. Diseases and malnutrition combine, with the result that normal "milestones" are not reached on time. In functional terms, the situation of these children does not differ from that of mentally retarded ones. Consequently, to catch up, these children need services. With development and increased recognition of mental health problems, these groups are likely to increase when surveys will be done in the future. It is easy to forget that every disability has its mental health aspects. A loss of "physical" or "sensorial" function or ability is a traumatic event, yet there might not be much counselling or enough social support mechanisms. Frustrations are common among disabled people (see Chapter Six) when they feel the pressure of negative attitudes, discriminatory behaviour and injustice.

Among disabled people who are victims of war or of social unrest, or refugees, the trauma of the experience of uncertainty, displacement, loss of relatives and social support structures adds considerably to their burdens. Violence is an important contribution both to physical and mental disabilities (see Box 2.1).

It is important that a mental health programme component is included in CBR and that the personnel trained is competent in handling the tasks described above. This is a particular complex area of technology, as it requires making allowance for local, cultural and social factors, the existence of indigenous resources (like traditional healers), and other aspects.

Nearly ten years of team-work involving a number of international experts and people in the field the world over have gone into the writing of the TCPD. But we all know that technology and terminology have one problem in common - everyone insists on having their own. Thus, notwithstanding the presence of TCPD and the availability of other descriptions of effective technology, a lot of time and money continue to be spent on writing or rewriting technology, on testing it, on finding out for whom it works. While this is being done, disabled people in all parts of the world are waiting for services to be set up.

Rather than re-inventing the wheel we should concentrate on providing the educational material needed for the personnel involved in service delivery and developing effective management systems. This would bring us a whole lot closer to meeting the urgent needs of the disabled population.

The Training Packages are complemented by a set of four Guides for community members carrying out special tasks for the CBR programme (see Box 9.6).

The *Guide for Local Supervisors* is meant to describe their work and can be used for their training. It is suggested that, on completion of their training, local supervisors undertake a house-to-house survey in their respective area (village/block) to identify all disabled people. These people should then be individually assessed. Based on this, the appropriate training package is chosen. Normally the disabled person and his or her family are given an informative package "about the disability and what can be done about it" to start with. Later, they will receive the specific packages for training in self-care, mobility, communication, behaviour, psycho-social stimulation, etc. The guide also contains guidelines on how to approach educational and vocational problems. Each local supervisor should carefully record the initial state of each disabled person and regularly describe the results of the rehabilitation. Forms for these evaluations are provided. Reports should be submitted to the community committee and to the technical supervisor.

Box 9.6

GUIDES

Four guides for community members carrying out special tasks for the CBR programme:

Guide for Local Supervisors -
for the community worker who implements the programme;

Guide for the
Community Rehabilitation Committee -
for the committee that manages the programme;

Guide for People with Disabilities -
describes what people with disabilities can do for themselves and for others in the community;

Guide for Schoolteachers -
will help teachers who integrate children with disabilities in the class.

The *Guide for the Community Rehabilitation Committee* explains the purpose of the Committee and suggests ways and means of carrying out the committee work.

The *Guide for People with Disabilities* is a brief outline of what disabled people can do to improve their quality of life and of how they can organise themselves at the community level.

The *Guide for Schoolteachers* is designed for use by local teachers in ordinary schools. It offers information on disabilities and gives examples of ways to cope with problems associated with the integrated teaching of disabled children.

4. FURTHER DEVELOPMENT OF THE TECHNOLOGY

It was realised at an early phase that technologies applied in the community would have to be further studied in order to find the answers to a number of pertinent questions, such as:

(1) *could they be used "globally"*, or would cultural and social factors require a whole

range of technologies, each built on a particular local experience?

(2) assuming we want to *disseminate the technologies* partly by way of printed training packages, how is this facilitated *in societies with low literacy*?

(3) would the *system work* effectively *without* the benefit of *medical diagnoses and prescriptions* regarding the interventions?

(4) in the absence of a medical diagnosis, how are *disabled people identified* in the community?

(5) how is *assessment carried out* within the CBR programme, and how can a *training programme be designed for a disabled individual*?

(6) how are training procedures to be applied when the person in question has *multiple disabilities*?

(7) how does one integrate *educational aspects* in CBR?

(8) how does one integrate *vocational training and finding jobs* in CBR?

(9) how are *environmental interventions* carried out as part of the CBR programme?

(10) what ways are there to *promote and protect human rights* at the community level?

(11) how could the *technology reach all disabled people*, and how could one be sure *that the system would be effective and remain in place*?

(12) how could *disabled people play a useful role* in their own societies?

The last two questions will be dealt with in the following chapters. As to the others, I would like to observe the following:

(1) The first question concerns the *global applicability of the technology*. Our studies have shown that the spontaneous technology observed varied little from one part of the world to another. This is to say, parents who had successfully trained a blind child to become mobile had been using the same method wherever such examples were found (including Botswana, India, Indonesia, Mexico and Nigeria). On completion of the first experimental draft Manual TCPD (1979), the standardised procedures described were tested in nine different countries of the developing world. The test results prompted us to make a number of modifications. Still, we concluded that it was possible to use a "global approach". The main parts of the technology could be applied everywhere, though we recommended that each country take a close look at the results, carefully evaluate every component of the technology, and then adapt it if necessary.

To facilitate the application of exercises, for instance, it would be useful to relate these to existing traditional practices, such as gymnastics or massage. Household activities vary widely, and this package needs to be adapted everywhere. The technology that goes into the manufacture of various appliances and technical equipment would include use of local materials and other resources at hand and would therefore necessitate local technical adaptations of the procedures in TCPD.[7] Technology should also be developed to reduce the constraints arising from physical barriers, including inaccessible public buildings and means of transport, stones, potholes, passages in the immediate environment, etc.[8]

Dealing with people who are mentally ill or who are suffering from leprosy, for instance, does require a variety of culture-related approaches. We decided not to cover such matters as sexual behaviour in TCPD. After initially trying to include them, we came to the conclusion that these subjects would be more appropriately dealt with in a special publication targeted at professionals.

(2) The second problem relates to the *dissemination of technology in societies with low literacy*. Among the countries where we tested the Manual were several areas with a very low level of literacy. We had first thought of asking the local supervisor (community worker) to lend the family

trainer the appropriate training package to guide in his or her training efforts, to explain the procedures to him or her, and then to supervise the work at home. Of course the written text served no purpose when all members of the family were illiterate. But in most of the cases there was at least one person in the family who was able to read. Also, illiterate people have trouble grasping the message of a drawing. When this happened to be the case, the local supervisor would have to repeatedly explain and show what had to done. We initially intended the training package to remain at home with the family for as long as it was needed, and still believe that this is the best approach. For practical reasons however, such as lack of local resources to produce a sufficient number of copies and logistics, most local supervisors tend to keep the full set of training packages and to show them to the families on the occasion of their visits. There is nothing to be said against this as long as it gives effective results.

In order to produce a TCPD text that would be easy to understand, we spared no effort to simplify the text, using several specially designed computer programmes. (See Box 9.7).

The Manual TCPD can seldom be used as it is. It needs to be translated into the local language. Thus far, its different versions have been translated into 40 languages. Translations should reproduce the simplified style of the original. The text and the drawings should be adapted to fit the particular country. WHO has published a special guide on how to translate and adapt the text and the drawings.[9]

In some countries, professionals may have reason to prefer other techniques than those described. Where this is the case, they could prepare and test their own training packages.

The text of the Guides (see Box 9.6) should be revised in each country to reflect the local service delivery system, community organisation, school system, labour market conditions, and so forth.

(3) We now come to the third problem - whether or not the system will work *without the benefit of having the disabling condition "properly diagnosed" and the interventions "prescribed"* by a specialist. In the conventional approach, one generally starts with an examination of the disabled person by a physician and the establishment of one or several diagnoses. Then follows an analysis of the impairments and their consequences in terms of disability and handicap. As a next step, the physician or another competent professional prescribes the interventions. This process would normally also precede any educational and vocational rehabilitation. We can call this a "medical model". The disabled person is most often perceived as a "patient" receiving "therapy."

In the conventional system, the interventions usually prescribed for disabled people in the developing countries are based on a Western model. They may be slightly modified to better fit into the local realities. And the facilities where these interventions are carried out are, as a rule, inspired by Western examples.

Quite naturally there are many examples of disabled people in the developing countries whose situation could be improved if they had access to a physician. This is particularly true when medical treatment is needed for epilepsy, psychosis, leprosy or eye infections. Or when surgical interventions could diminish or eliminate disability, for example in cases of cataract, contractures or leprosy complications. Medical visits are also needed to prescribe eyeglasses or hearing aids. In countries where this is possible, it is recommended that every disabled person make a visit to a local health centre. In other countries these possibilities are small or non-existent, so consultations have to be limited to those with priority needs.

Anyone who has grown up with the conventional medical model has a great deal of respect for it. It makes sense to find out the causes of a disability before one acts.[10] But in most developing countries, very few doctors are available, especially in rural areas. And even fewer doctors have experience in diagnosing disabilities and prescribing rehabilitation.

In order to overcome this difficulty, experiments started with a direct problem-solving sys-

Box 9.7

SIMPLIFYING THE TEXT AND DRAWINGS OF THE TCPD MANUAL

Parts of the efforts to simplify the text of the TCPD Manual consisted in using three specially designed computer programmes:

First, the text was entered into a word processor, and (using a mainframe computer) the words were then checked against a list of the 2,000 most common English words. All words (except for such indispensable ones as disability, rehabilitation, etc.) not listed among those 2,000 were changed into basic English.

Then, a list was produced of all the words used, in alphabetical order, indicating the frequency of each of them. Later on, words appearing only once, twice or thrice were replaced by synonyms wherever possible. In this way we had managed, as the final word count showed, to limit the number of different English words used to a total of about 1,800.

Finally, a programme was produced for analysing sentences and marking those which were longer than 25 words. These sentences (with few exceptions) were then split into several sentences, with a final average length per sentence of 11 words.

Besides the changes facilitated by the computer analysis, great efforts have been made to write all texts in a very simple and straightforward manner. Sentences are short, direct and have no double negatives. For clarity's sake, the text is somewhat repetitious. Each word carries only one meaning (e.g. the word "right" is used to signify exclusively the opposite of "left"; the opposite of "wrong" is "correct").

The technique for making drawings is based on a review of the current literature on the use of illustrations in manuals and other publications for developing countries. It appears that, apart from photos, line drawings alongside the text are the easiest to understand. The drawings have been field-tested and adapted accordingly. They have been made in such a way that local details such as dresses, hairstyles, houses, and so on, are easy to change to make them fit the actual environment.

tem. In practice this meant a training package was written for each problem related to mobility, to ADL, to communication, to child development, to schooling and to jobs. These contained a series of instructions aimed at directly solving the problem. It is easy to understand that the approach to training a blind person to move inside his or her home or in the village, for instance, would be the same whether the blindness was caused by trachoma, xerophthalmia, cataract or other diseases. A system for identifying a person with a disability was written and tested with the help of auxiliary personnel, and it proved to be effective.

In CBR, it is proposed to abandon the "medical model" for several reasons. First, in most developing countries, there is seldom access to competent medical personnel. Second, in a medical model, the tendency is to focus on the disabilities instead of on the person's abilities and potentialities. The diagnosing-prescribing system has proved to be of little consequence for the purpose of educational and vocational rehabilitation.

(4) As it is proposed not to follow a medical model for the *identification of disabled people*, how can we identify them at the community level? Here, a direct problem-solving system had to be adopted. In order to locate disabled people living in the community, local supervisors were trained to undertake a detailed survey of all households in the community for which they were responsible. The survey consisted of a series of questions, examinations and observations. The examinations consisted, among other things, of measurements of sight, hearing, mobility, communication abilities, skin sensitivity, behaviour, responses to simple instructions, signs of diseases leading to disability or trauma, etc. When it comes to identifying children with school prob-

Box 9.8

IDENTIFICATION OF SCHOOL CHILDREN WITH SPECIAL EDUCATIONAL NEEDS

UNESCO proposes that each school teacher will go through the following questionnaire and make a class list indicating the difficulties identified among the children. The overall difficulties of each child will then be rated as severe, moderate, or mild.

"THIS CHILD...
1. ... has problems in understanding what you are saying.
2. ... has difficulties in doing things by him/herself, like eating, dressing, bathing and grooming.
3. ... is a repeater.
4. ... has difficulty in seeing.
5. ... has difficulty in hearing.
6. ... has a speech that is difficult to understand.
7. ... has sometimes fits.
8. ... appears dull or slow compared with other children of his age.
9. ... often bumps into things.
10.... often rubs his eyes.
11.... can't move around without assistance.
12.... can't take fully part in sport.
13.... often turns his head in order to hear better.
14.... often scratches his ear and complains of pain and discharges.
15.... often asks the teacher to repeat what has been said.
16.... takes much more time than most of the others in learning anything new.
17.... can't carry out two simple directives in a row.
18.... has trouble paying attention.
19.... does not answer when called.
20.... is extremely bright.
21.... frequently gives the wrong answers to questions.
22.... is often sick.
23.... finds school work boring.
24.... avoids people, plays alone.
25.... is extremely shy.
26.... has short attention span - daydreams.
27.... places head close to book or desk when drawing, reading or writing.
28.... closes or covers one eye.
29.... is easily frustrated and has difficulties getting along with other children.
30.... has difficulty in understanding concepts like left, right, up, down, over, under, etc.
31.... has poor balance.
32.... has difficulties in learning to do things like other children of his age.
33. ADDITIONAL OBSERVATIONS."

lems, the questionnaire from UNESCO[11] reproduced in Box 9.8 has proven useful.

Finally, identification of disabled people with vocational problems contained interviews with the person and the family to find out his or her participation in household activities, in work outside the home, income level, vocational, including informal, training.

These techniques have proved very valid and reliable. There is no doubt that a well-trained local supervisor can correctly identify all disabled people in their community.

(5) How is *assessment carried out* within the CBR programme, and how can a *training programme be designed for a disabled individual*?

Each disabled person and his or her environment should be assessed before, during and at the

Box 9.9

ASSESSMENT IN A CBR PROGRAMME

The TCPD proposes that individual assessment be carried out with respect to 23 different factors, mostly in three steps, as seen in the following examples:

4.	Dresses and undresses?	Alone	☐
		With some help or sometimes	☐
		Not at all	☐
19.	Goes to school?	Yes, does normal school work	☐
		Yes, but does school work below his or her age	☐
		Yes, but does not do school work	☐
		No	☐
23.	Has a job or has an income?	Full-time job or income adequate for his or her needs	☐
		Part-time or seasonal job or some income	☐
		No job and no income	☐

The reason for having chosen the 23 factors proposed in TCPD is their high frequency of occurrence. A CBR programme may use fewer, or more, factors, and it can use several more steps. Adding more factors and/or steps may complicate the job of evaluation for the local supervisor.

Forecasting the outcome of rehabilitation is a more intricate procedure, as it requires to take into account factors like severity of the disability, motivation, presence/absence of family trainer, quality of family trainer, age of disabled person, duration of disability, environmental factors (including prejudice), and others.

It is essential to correctly judge the disabled person's abilities and how these can be used. The simplest way is by trial and error. For example, one could start with certain household duties, followed by simple productive tasks, e.g. in agriculture or handicraft. For children of school age, one could try in most cases to have them enrolled in pre-schools/kindergartens/child development schemes, where these exist. By observing them in these settings, one can judge when they will be ready for entering the ordinary school. Assessment of children not attending school is a major importance - among them one might identify a certain proportion of disabled children in need of services.

Regarding vocational rehabilitation at the community level, the TCPD proposes a set of steps consisting of:

Step 1. Prepare a list of suitable jobs for people with all kinds of disability
Step 2. Make a list of people needing jobs
Step 3. Find out about each person's ability to work
Step 4. Help the person to find a job
Step 5. Arrange job training for the person if necessary
Step 6. Help the person to start doing the job
Step 7. Help the person to deal with problems at the workplace
Step 8. Ensure the person's health and safety at the workplace.

Assessment forms part of Step 3 and, at that level, some simple screening measures can be applied.

Box 9.9 cont'd.

If an apprenticeship is proposed, the question of cost enters the picture. For this reason, the disabled person should preferably undergo a set of job-requirements-related tests. These could be quite straightforward. Where the necessary resources are available for a more thorough evaluation, they could include testing for intellectual capacity, educational level, manual skills, sight, hearing, ability to move or stand, need of help with various tasks, etc. Normally, this procedure will require referral - to the ILS, for example. More sophisticated screening procedures or tests may be available at the province or national levels and should, when appropriate, be given when formal training is proposed. Skills training should be preceded by assessment when a disabled persons wishes to become self-employed (in such trades as commerce, tailoring, carpentry, blacksmith, rattan repair) to make sure that the business aspects are clearly understood (e.g. accounting, estimating benefits, marketability, etc.). (See also 9.4 *Vocational training and finding jobs.*)

Sometimes, while placing a person in a job may prove impossible, a suitable productive activity can nevertheless be identified, in which case a simple assessment may be needed.

end of the training programme. Assessment aims at:

- determining the extent and degree of difficulties afflicting the disabled person;
- designing an individual programme for the disabled person, including the necessary adjustments of the environment;
- forecasting the probable outcome of rehabilitation. To do so requires a long period of experience;
- determining the abilities each disabled person has, and evaluating ways and means of how best to utilise these in the environment where the person lives;
- evaluate the results of the programme.

Box 9.9[12] provides some examples of assessment methods.

It is important that, based on the assessment, an individualised rehabilitation programme is designed for each disabled person. The personnel will, after a period of experience, normally be able to guide the family trainer so training programmes that fit each person are given. It is important that the intermediate level supervisor and professionals of the referral system give technical advice when needed.

(6) In the case of *multiple disabilities*, one would use the following approach. In the majority of cases, the disabled person is a child with cerebral palsy. These children are now rare in the developing countries, possibly because of their high mortality rate. But with increased survival, we should reckon with a prevalence rate of perhaps 2 per 1,000 in the future. Each child needs to have an individually designed programme.

The local supervisor will first discuss with the family the difficulties and find out which is the worst problem. This might be the one for which the disabled person needs most help from a family member, such as eating and drinking. If so, one would start with the specific training package that deals with this difficulty. On the other hand, if the family is not very well motivated, it might be useful to suggest starting training for a problem that can be solved in relatively little time. Seeing progress, the family might then be more disposed to work with the child.

It should be mentioned that multiply disabled children often receive virtually no stimulation of any kind. In such cases it is best to apply the training package with play activities. Also, to engage other children in the family in this part of the training might prove a good idea.

Training should always be tried, even where the child suffers from severe multiple disabilities due to cerebral palsy. From the studies undertaken it is evident that, if the family follows the instructions, almost all such children will show progress (Box 9.10).

(7) *Educational aspects* are integrated in CBR, applying the principle of creating an "inclusive

school".

In the conventional approach, a fragmented parallel school system was set up with segregated facilities for blind, deaf, mentally retarded and, sometimes, multiply disabled (mainly cerebral palsy affected) children. The purpose of these facilities often was to "rid the normal school" of pupils who were seen as unable to follow the education or as being likely to disturb it.

Box 9.10

APPROACH TO MULTIPLE DISABILITIES

I had the opportunity to meet twice a young girl with very severe athetoid cerebral palsy who participated in a CBR project in an Asian country.

Fifteen years old, the girl had never received any training. Her mother was a voluntary community health worker and had asked to take part in the course held to train local rehabilitation supervisors. Her principal motivation was to help her daughter.

Until the time the training programme started, the girl had been more or less hidden away in a room at the back of the house. She had been fed and dressed by the family, and given an occasional wash, and had used a potty placed in her room. She did not talk. In fact, communication between her and the rest of the family was very limited. She could not walk either, she never left the house and never played. She moved about in her room on her hands and knees.

At the time the training started, the family considered the priority to be for the girl to learn how to eat and drink. This was achieved within a few months. Then the mother began exercising the girl's arms and legs. This was followed by speech training, play activities and mobility training. After two years, the girl still had spastic movements and a speech disturbance, but she was out walking, playing with other children, talking and independent in self-care. Her behaviour was totally normal, and she was well-integrated in her village.

A fairly large proportion of all school children - perhaps as many as 20 per cent - have special education needs for longer or shorter periods in school. When such needs are not met, a high proportion of those children will repeat classes and/or drop out. For instance, a study in Benin of the results of the six-year primary school course revealed that, on average, each child who had managed to pass the final tests at the end of the sixth year had repeated two classes, and the drop-out rate was 83 per cent.[13]

A number of documents from UNESCO[14] promote CBR-related new approaches, for example: "... it is now realized that the education and training needs of the majority of children with special educational needs cannot be met by costly special schools and centres, which furthermore create a segregated life situation. Regular schools must play a bigger role by developing their objectives, teaching and curricula so as to cater for a greater diversity of pupils than is the case at present. Children with special educational needs should, as far as possible, receive their education in the regular classroom. Other types of programmes, like special schools and centres or special units within ordinary schools are sometimes needed for children with profound and complex difficulties, but may be considered only when classroom placement with shared team responsibility cannot meet the needs of the learner.

"In line with new trends, more and more special schools are functioning as resource centres and involved in outreach programmes, building on their extensive experience and knowledge, and linking with ordinary schools, families and community based activities.

"Integration has so far been seen mainly as a problem for individual pupils: they were different and therefore segregated, and integration meant reducing their differences so that they could attend a regular school. Progress can be achieved in this way, but it is ultimately limited since the regular school framework is left unchallenged. These children are currently excluded from the regular school system because it cannot cope with them: it is failing to meet their needs. For real progress to be made, this failure must be acknowledged and challenged. This is why integration has to be seen in terms of school reform, aimed at creating a common school offering differentiated provision for all according to need within a single coherent curriculum framework."

In the CBR approach, different models for an "inclusive school" are proposed. These models could follow one another, or they could be applied in parallel. The *approach of Model I* is to send as many disabled children as possible to the local school.[15] The experience is that, with sufficient preparation of the teachers and some simple arrangements, around 80 per cent of the children with "special educational needs" can benefit from schooling in an ordinary class. But for some of them, there will be problems, e.g.

(a) to *come to school and to move inside it*;
(b) to *do normal school work*;
(c) to *behave* normally;
(d) disabled children may be *badly treated by others*.

Some of these problems can be solved, others not. Here a few examples:

(a) some children with *moving difficulties* could be helped to come to school and to return home (trolley, carried, using an animal, etc.), and also helped inside the school, e.g. in using toilet facilities. Some children with mental retardation or with vision impairment could be accompanied to school by other children.

(b) it should be recognised that problems to *do normal school work* by disabled children will lead to either repeating of classes or to dropouts. This is common among non-disabled children as well. The school performance can be improved by better preparation of the teachers, by curriculum adaptation, and by assistance provided through special education.

(c) Some disabled children do have *behavioural problems*. Here increased efforts on the part of the family to correct the situation as soon as these problems become apparent may be useful. Integrating these children in pre-school activities often has beneficial effects on behaviour disturbances.

(d) In order to diminish *discriminatory behaviour by classmates*, the teacher needs to carefully prepare all the non-disabled children and their parents for the arrival of a disabled classmate, monitor the situation at all times, and take immediate corrective measures whenever there is a problem.

A detailed account of the positive aspects of Model I integrated schooling for disabled children appears in ***Guide for Schoolteachers*** in TCPD. These include:

- schooling and education will help these children to learn about the world around them and to become useful members of the community;

- even if these children cannot learn to read, write or count like other children, there are other reasons for schooling, for instance: it helps them to become independent adults; it prepares them for work; they learn to get along, how to behave and work with others; it develops their abilities; they learn to accept rules and responsibility; it helps to form friendships and creates the feeling of belonging to a group; it teaches them activities that will stand them in good stead in the future.

The Guide further contains advice for the local teacher about how to succeed with the integration of disabled children in the class. This is not complex or "specialised". Mittler and Serpell note[16] : *"There is too much mystification concerning the skills required to work with disabled children. Many of these skills - not all - can be learned comparatively quickly by families, volunteers, community workers and staff without formal qualifications. Skilled professionals are, however, needed to provide leadership, staff training and support."* (see also Box 9.11[17])

The *proposal for Model II* is to start training and employing a multi-disability resource teacher. The teacher should probably be someone who graduated from a teachers' college and who has some years of experience and a post-graduate course in special education. This course should allow him or her to acquire sufficient competence for primary school education for children with severe vision impairment, with severe hearing/-speech impairment, and with mental retardation.[18]

Box 9.11

A NEW APPROACH TO TRAINING TEACHERS TO WORK WITH CHILDREN WITH SPECIAL NEEDS

A UNESCO document states:

"The starting point must, however, be to improve ordinary teacher training and promote better schools for all by helping teachers to be more responsive to *all* the children in their classes.

"In practice the problem is a curriculum one. What we are witnessing is the inability of a teacher or group of teachers to provide class-room experiences that are meaningful and relevant given the interests, experiences and existing skills and knowledge of particular children.

"It is therefore important that issues related to children with special needs form a natural part of all types of basic teacher training programmes and various types of in-service training.

"A diversified, flexible training programme is needed for different categories of teachers. Existing 1-2 year special teacher training programmes have had a rather limited output of specially trained specialist teachers over the years. This type of training is not suitable, realistic or even needed for the assistance of the 80-90 per cent children who have minor difficulties.

"A new, promising approach has successfully been tested in some countries. A group of 30 already specially trained and committed teachers were given a short course leader training of about one month's duration. Thus three "Core Teams" were created and went out and carried out 3 week seminars on their own with 40 participants from primary schools. Basics in special needs education including a lot of practical exercises and the use of true learning methodology, where the participants are actively involved in gaining knowledge, were included. It was an eye opener to many participating teachers that a lot can be done with quite simple arrangements for mildly disabled children with special educational needs to make their stay in school meaningful. During two term breaks these three teams trained 240 teachers. With a few "specialists" it is thus possible to multiply their knowledge for the benefit of the many."

It is proposed to provide the mobile teacher with transportation, if needed, and to ask him or her to provide special education at local schools with a view to integrating the disabled children in a "normal" class at an appropriate time.

In *Model III,* a national system to provide resources for all special educational needs should be developed. This would include the establishment of courses, so that multiple-disability resource teachers can be provided everywhere. Special resource centres in the provinces/districts could follow. The training of single-disability resource teachers for children with severe or otherwise complex educational needs should continue. Most likely fewer such teachers will be needed than foreseen, as many of the tasks can be carried out by the multiple-disability teachers.

A referral system should be built up, the most useful idea being perhaps to create a system of mobile consultants.

For all these models, special technology should be provided. This has to fit into the requirements of the national school curriculum, as well as with the local CBR system. A number of functional training tasks often carried out in special education institutions should preferably be transferred back to the home or community. An individualised approach to the teaching of disabled children in an "inclusive school" is likely to give better results, and the family should be involved, supporting the school's efforts.[19]

(8) A few comments on *vocational training and finding jobs* as part of a CBR programme will now follow.

The conventional system included the setting up of special, segregated vocational training facilities for disabled people, located mostly in the capital. This is a solution that encounters many problems, such as:

- costs much higher than those for similar local training in the open sector;
- the difficulty of identifying vocational sectors marketable everywhere;

- the high dropout rate, in particular if training lasts longer than a year;
- the poor long-term results in terms of economic performance. An ILO document states: "... vocational rehabilitation centres have proven to be particularly ineffective when compared with the outcome criteria of employment."[20] Besides, most of those now attending a special institution could be integrated in ordinary vocational training, provided that some adaptive measures are added.

Similarly, the experience of setting up sheltered workshops or co-operatives consisting exclusively of disabled members, or similar efforts (such as employing only physically disabled in orthopaedic workshops), have not been very encouraging.[21] Such enterprises may work well in the beginning, but after a while the more productive members will often leave to set up their own business or enter the open market. The attendance rate often goes down. This is particularly true when the earned income does not even equal the cost of transport. The production rate may decline to the lowest common denominator. Moreover, many of these enterprises start losing money and need annual injections of donor capital to stay alive.

It is common to find that slightly and moderately disabled adolescents and adults have jobs in the open market or at home working in the fields. Most often this is the result of "spontaneous rehabilitation."[22] For those who are not working, attempts to find jobs for them should be made.

For disabled adolescents and youths in the CBR programme it is proposed to follow a set of steps already outlined in Box 9.9. It should be useful to find out the jobs available in the community that could be undertaken by disabled people. Then, a list could be drawn up of those who need a job, and their capacity for the available jobs could be assessed. Generally speaking, disabled adolescents and youths should try to enter the labour market in the same way as non-disabled people. In the developing countries, the largest sector is agriculture. Here jobs are normally learned with the parents or relatives. Such jobs are often repetitive; many disabled people are able to participate in some, though not in all, tasks.

Box 9.12

THEY DO NOT WASTE THEIR WORKING HOURS CHATTERING

It was on a beautiful sunny day in Africa when we were taken to a small bookshop selling religious literature. We met the vicar of a small parish, and he told us about his contacts with some deaf students. A few years ago, he had employed in his bookshop a deaf boy who had just finished school. The vicar was very satisfied with the job the student was doing. Some time later, with the help of a few business friends, he had set up a vocational training project for a group of (by now) 38 students. All of them had been included in ordinary apprenticeship training programmes in the informal sector.

In four or five places that we visited we saw deaf young boys and girls working as apprentices alongside boys and girls with normal hearing.

A big garage had five of them, a paint workshop four, several tailors each trained three or four of the youngsters, etc. Most of these apprentices paid the usual fee, but the congregation had helped the poorer ones to cover half of the cost. Out of this group of 38, only one had failed.

Asked how it worked, the owners of these enterprises told us that the first couple of weeks had been the most difficult part. But the deaf people were watching carefully what the others were doing and quickly caught on. Now, they all agreed, their deaf apprentices performed as well as the rest, with one big advantage: "they did not waste their working hours chattering".

The next largest sector is the service sector: commerce, artisans (tailor, shoemaker, carpenter, blacksmith, painter, repair of bikes, motorbikes and cars, radios), work in offices, hotels, etc. Non-disabled people who want to work in the service sector most often undergo a period of two to three years of apprenticeship. This is a useful and mostly successful way of entering the open labour market. This is equally true for disabled people. (See Box 9.12.) Those who want to start their own enterprises[23] may need a small initial capital, so it may be necessary to arrange for small bank loans or revolving funds to meet such needs. (See Box 9.13.).

Great attention should be paid to studying the local marketing situation. Answers are needed to such questions as: Is there a need for a tailor in this particular village, or is the market saturated? Will the income be enough? What services or products are imported from the outside, and could these be substituted by similar services or products provided by local disabled people? In each country, local marketing studies could be carried out. It is important to study the availability, locally, of materials and technology not dependent on scarce or unreliable resources such as electricity.

Another factor of importance may be the environmental constraints - factors which deny a competent disabled person the chance of vocational training and employment. Such factors should be analysed, and efforts should be made to overcome these by stressing the disabled person's abilities and potentialities. Here the community committee and community leaders can play a role to provide the opportunities required.

Box 9.13

STARTING NEW ENTERPRISES IN AN ASIAN VILLAGE

In a very poor Asian country, the Central Bank offered small loans for those who wanted to set up their own business. The CBR programme in the district managed to get loans for about a dozen disabled people. Examples:

- A severely physically disabled man and trained tailor obtained a loan for the purchase of a sewing machine, some tools and material. He started sewing trousers for men and school uniforms for children. Twelve months later he had earned enough to be able to pay back his loan, and after another two years he bought a second sewing machine and employed a disabled apprentice. Six months later, a large order came in from a nearby town. He rented two more sewing machines and employed two non-disabled people.
- Another physically disabled man, who walked on hands and knees, learned how to repair bicycles. In his village, people who went to town regularly rented a bicycle for the day. Locally, there was no such business, so to hire a bicycle people had to go to the neighbour village - a great inconvenience, for it meant a three-kilometre walk. With his bank loan he bought four bicycles and tools for repairing them, as well as a few spare tyres. His enterprise was an immediate success and soon earned him enough money to support his family. He managed to pay back his loan within two years.

As in the educational sector, one might distinguish between several models or phases of the vocational programme, depending on the level of development. However, irrespective of the particular circumstances, it is always desirable, in the first phase, to carry out an assessment or screening procedure of the disabled person to establish his or her interest, motivation[24], and particular abilities for work. Based on this, one should determine what kind of training is feasible and the chances that the disabled person can carry out a specific job as required. Such assessments should proceed from systematic observations and be based on tests designed to reflect local labour market requirements. The purpose of such an assessment is to guide each individual toward an economic activity that best fits his or her abilities. In addition, it will serve to avoid the kind of ad-hoc training that is common now and that all too often ends in frustration when the disabled person proves to be incapable of doing the job for which he or she was trained. Similarly, when a disabled person wants to start a small commerce, he or she should first undergo a proper assessment, for setting up shop takes investments and the consequences of a failure might be serious.

During a *second phase*, when more established vocational training programmes are available, one should seek to give disabled people more formal and recognised training, using "ordinary" systems for training.

This phase may be followed by a *third one*, during which more attention can be paid to transport conditions, modifications in the workplace in order to allow disabled people to be economically active, unhampered by problems of this kind.

One should, as a priority, increase disabled people's participation in mainstream development programmes. There are thousands of such programmes set up by national authorities, by communities themselves or by foreign donors. Many such programmes have components, in particular training-related ones, in which disabled people could be integrated. There should be a way of increasing the presently very meagre participation of disabled people in such training. Similar attempts of including a higher proportion of women, or of minority ethnic groups, have been successful.

Not every disabled will be able to earn a sufficient income through work. In developing countries, the percentage of unemployed and underemployed in the general population is often high. As a consequence, employers in many cases tend to hire non-disabled people by preference. In situations where no work is provided for disabled people it is imperative to find an answer to two major questions. These are:

(a) income substitution: will the disabled person be taken care of by the family? If not, will the community help?

(b) day activities: in cases where both parents of a non-working disabled adolescent go out to work and the disabled is left to himself or herself, some organised recreational activities during the day-time may be needed. Assistance may be sought from the community.

(9) How can *environmental interventions* be carried out as part of the CBR programme? For each disabled person identified, one should also analyse the specific environmental barriers that may contribute to an increase of the impact of disability. Physical barriers, such as bad pathways or roads, stones, and other impediments, are usually not too difficult to reduce or to eliminate. Others may be more cumbersome, for instance efforts to change inaccessible transportation or to gain access to public buildings. Such problems should be brought to the attention of the central authorities, and a programme for action should be adopted. It is our experience that centrally initiated changes, such as regulations in respect of architecture, building standards, specifications for buses and trains, are not adequately implemented.

As to psychological, cultural, economic and social barriers, large efforts have to be made locally to create better awareness of the abilities and responsibilities of disabled people, to create better opportunities for them to develop their abilities and to promote and protect their human rights. Usually, when the community becomes aware of the changes ensuing from the implementation of the CBR programme, attitudes tend to be much more positive. Prejudice and beliefs are hard to change, and an effort at community education is necessary.

(10) The *promotion and protection of human rights* of disabled people[25] is a very important subject. The conventional approach has been to adopt special laws giving "positive discrimination" for disabled people, such as requiring employers to hire a certain quota of disabled people. From a point of view of principle, this idea is in contradiction to the ideas of equality and social justice. Besides, the experience of quota laws is very discouraging. Concerning subventions for transportation and housing allowances. The goal should not be to create a group of passive recipients of general handouts but to activate disabled people, to give them jobs so that they can earn an income and preferably do without subventions. Their income should be supplemented by individual social assistance to those who need it.

The CBR approach envisages two actions:

- to protect the human rights of disabled people, and
- to suppress negative discrimination.

Regarding the protection of human rights, it may be useful to study the constitution of each country. Normally it provides for equal rights to public services, education, jobs, and protection against crime and abuse to all its citizens. But there are many examples of how disabled people are deprived of these rights (see Box 9.14) through negative discrimination.

Human rights cannot be protected unless a community action programme is set up. Disabled people - like most community members - will not be able to seek help from a distant capital or from legal authorities perceived as well-nigh unapproachable. It is for these reasons that the setting up of a local mediation procedure is advocated in the CBR system. This is easier to accomplish in societies where the enforcement of the law is in the hands of the local chief or the local authority.

Another problem relates to crimes against disabled people. In many societies, disabled people easily become victims, as they are unable to physically defend themselves or to seek legal recourse. An example of community action to defend these victims appears in Box 9.15. It is especially difficult to protect disabled people who are abused while in institutions. There are numerous examples of such abuse (see Box 4.3). The best way to deal with this problem seems to be to legislate norms for institutions and to inspect these establishments regularly, including holding regular interviews with their clients.

Box 9.14

NEGATIVE DISCRIMINATION

- In an African country, a disabled young man had managed to go through primary and secondary schooling and then to enrol in the only engineering school of the country. This school was known for its eminence and accepted not more than twelve new students a year for its four-year course. The disabled student graduated as the second best in his class. He then started looking for a job - he was only slightly disabled: one of his legs was partly paralysed after polio and somewhat shorter than the other, and he walked with the help of a stick.

  Two years after graduation, he was the only one who still hadn't found a job - on account of his disability.

- In a Latin American country, candidates for civil service employment were sent to a local doctor for a medical examination. This doctor followed to the letter the rules set up by the national medical association on its own authority and without consultation of the government. The relevant form contained a question to the effect: does the candidate have a disability. Anybody for whom the answer to this question was affirmative was automatically excluded as a candidate.

- In an Asian country there existed no rules governing the enrolment of disabled children in "normal" schools. Indeed, this country's constitution contained a paragraph saying that education was a right for all, that it was compulsory and free of charge.

  This notwithstanding, nearly all school teachers refused to accept children whom they considered disabled. They argued that since a separate college for special education had been set up, the government's intention obviously was to provide special education for them. Any argument that seven to eights out of ten disabled children refused could go to the local school without any pedagogic or organisational problems was rejected.

Disability is a common problem in all developing countries, and doctors advocate diagnosing and treatment of disabled people. Yet most medical schools lack courses or practical training in disability matters - a subject considered not necessary by the deans or professors of these establishments.

5. *TECHNOLOGY AT REFERRAL LEVEL*

Most of the above text has been devoted to the technology at the community level. Efforts should also be made to develop standard technologies at referral levels. The reasons for referral may be several. Some examples are given below:

- a diagnosis may be needed for unclear or unusual types of disability, followed by advice in the community on the type of training needed;
- medical treatment may be needed, e.g. for epilepsy, leprosy, psychosis, tuberculosis, eye or ear infections, or surgery for cataract, contractures, etc.; especially costly or complex procedures, such as treatment of paraplegia or brain da-

Box 9.15

ACTION TO PROTECT DISABLED PEOPLE AGAINST DISCRIMINATION AND CRIME

I met with members of an organisation of physically disabled people in a very large Asian city. Most of them were extremely poor and had great difficulty finding a job, although many of them had a good educational background.

They felt very frustrated because of the unjustified discrimination they encountered everywhere. They told me several stories about crimes against disabled people.

They had taken two initiatives. The first consisted in a large demonstration they had staged outside the government offices. Several hundred people had "occupied" the big square outside, some of them in wheelchairs, some walking on hands and knees or with the help of various walking aids. Their families and friends had rallied round them. They had carried banners with slogans, which they had shouted in front of the palace. At long last, the governor invited a group of them to come up and see him, but as they could not walk to him, he finally had to come down himself. They had a long discussion with him, at the end of which they handed him a petition, demanding among other things jobs in the civil service.

So far this action had resulted in jobs for eight of them, and a number of local businessmen too had offered jobs - the first positive development of this kind.

The second problem concerned acts of robbery committed against disabled people -robbing beggars of the money they had collected; theft of property from their homes; neighbours removing their fences and taking away their land; traffic accidents, with the driver who caused the accident simply leaving the scene on realising that the victim was a disabled person; a case of rape committed against a mentally retarded girl, etc.

With the help of an international donor agency, the organisation of physically disabled people had engaged the services of a lawyer. In one year alone, this lawyer had taken 26 cases to the police and the local court, out of which he won 25. As a consequence, disabled people had won a great deal of respect, and the number of crimes committed against them had diminished dramatically.

mage, are better carried out at higher referral levels;

- training at the community level may have failed. To solve this problem, the staff at higher levels need to be able first of all to carefully analyse what has gone wrong and, secondly, to rectify the local procedures. There are particular difficulties, especially in connection with behaviour problems. Professional personnel should receive adequate training to enable them to handle problems of this type;

- some techniques require a great deal of training and experience (manual treatment of clubfoot and contractures) or special equipment (of the type required for the manufacture and repair of orthopaedic appliances);

- teaching of Braille or of sign language, or other educational interventions of a complex nature;

- complex assessment of capacity for work, formal vocational training, etc.

For some of these techniques there might already exist nationally or internationally accepted procedures. These should be followed wherever appropriate in the social, cultural and economic environment of the particular country. Each technology should be described in detail, and should be standardised so that it can be used in training personnel and for evaluation purposes. In most developing countries, this job has yet to be done. Each referral task should be assigned to the level appropriate for the given country, and the personnel should be trained to full competence.

6. SUMMARY

Fig. 9.1 summarises some of the changes in approaches to technology.

What characterises the conventional system as introduced to the developing countries is its medicalised approach, where doctors are needed primarily to establish a diagnosis, following which they or other professionals will prescribe rehabilitation. By contrast, the CBR system adopts a problem-solving approach. All interventions can be carried out directly, without a diagnosis.

CBR further changes the approach from a profession-oriented to a people-oriented one. In the conventional system, the choice of a particular rehabilitation technology relies on the experience gathered by professionals in the industrialised countries with the use of that specific technology. In a people-oriented system, the technology used has its roots in existing "spontaneous" and successful technology, born in the hearts and minds of people.

The conventional system is dominated by formal, highly structured training systems, including team work by large numbers of different professionals. The system provides a combination of therapies and other interventions, special education in a parallel system of segregated schools for various categories of disabled children. It also relies on specialised and separate vocational training courses, the creation of segregated special jobs, and so forth. Facilities for various types of rehabilitation are often filled with complex equipment. They also operate with formalised procedures built around large groups of interacting professionals, all of them specialised in a particular aspect of disability.

In the CBR approach, emphasis is placed on informal systems integrated with those for non-disabled people. The primary aim is not to set up specific structures for disabled people but rather to ask how a specific activity is done for the able-bodied. For instance, much of vocational training in the developing countries is done informally, within the family or by way of an apprenticeship with the local artisan or shopkeeper. The same mechanism works just as well for disabled people.

In the conventional system, one sought to provide better opportunities for education and jobs. through positive discrimination such as quota laws. CBR prefers a system that protects the human rights of disabled people and, where successful, eliminates all negative discrimination.

APPROACHES TO TECHNOLOGY	
CONVENTIONAL	**COMMUNITY-BASED**
MEDICALISED	PROBLEM-SOLVING
PROFESSION-ORIENTED	PEOPLE-ORIENTED
IMPORTED PROCEDURES	USE OF SPONTANEOUS TECHNOLOGY BUILT ON RESOURCES AT HAND
DOMINANCE OF FORMAL HIGHLY STRUCTURED TRAINING SYSTEMS	EMPHASIS ON INFORMAL TRAINING SYSTEMS
INTRODUCTION OF LEGISLATION TO GIVE POSITIVE DISCRIMINATION	PROTECTION OF EXISTING HUMAN RIGHTS AT ALL LEVELS AND ELIMINATION OF NEGATIVE DISCRIMINATION

Fig. 9.1

COMMENTS AND REFERENCES

[1] Quote from R.E. Hardy "The Issue of Theory in Rehabilitation", in "Rehabilitation, 25 Years of Concepts, Principles, Perspectives" (Eds: S. Regnier and M. Petkovsek), National Easter Seal Society, Chicago, Ill., USA, 1985.

[2] For experts' opinions on these types of therapy see "Disability Prevention and Rehabilitation", Technical Report Series No. 668, WHO, Geneva, Switzerland, 1981.

[3] An early description of the work appears in: E. Helander, Proc.R.Soc.London, B209, pp. 139-140, 1980.

[4] E. Helander, P. Mendis, G. Nelson, A. Goerdt, WHO, Geneva, Switzerland, 1989.

[5] A more recent, supplementary WHO publication is entitled "Guidelines for the Prevention of Deformities in Polio", WHO/EPI/POLIO/RHB 91.1, WHO, Geneva, Switzerland, 1991.

[6] Reviews of several CBR mental health projects and of recommendations to increase community implementation of such projects can be found in: Social Reintegration of Persons Having Suffered Mental Illness. The First ILO Asia Regional Workshop held 21-26 March 1989 in Kuala Lumpur, Malaysia; ILO, Geneva, Switzerland, 1989. Specific studies exist, see, for instance, R. Agrawal and U.K. Kool: Mental health of persons with visual impairment in India. Internat.J.Rehabil.Res. 13, 83, 1990.

[7] For some discussions on this subject see, e.g., Rapport du seminaire sur les aides techniques pour les personnes handicapées, Conakry, Guinée. (Ed. Van Rolleghem-Marinček), Institut Universitaire de Réadaptation, Ljubljana, Slovenia, 1989.

[8] See: Designing with Care, CSDHA, United Nations, New York, USA, 1986.

[9] Guidelines for translation and adaptation of the Manual "Training in the Community for People with Disabilities", WHO/RHB/91.1, Rehabilitation, World Health Organization, Geneva, Switzerland, 1991.

[10] Quite often, however, there is a contradiction between the traditional, cultural notions of etiology of illness/disability in the developing countries on the one hand and those associated with diagnosing such conditions in the Western cultures. See, for example, N. Nichter: Anthropology and International Health. Kluwer, London, United Kingdom, 1990.

[11] T. Jönsson, ibid.

[12] See TCPD: Guide for Local Supervisors, pp. 38-40. A complete list of all the 23 factors is reproduced in Endnote 14, Chapter Fourteen.

[13] Ministry of Education, Cotonou, Benin, 1990.

[14] See e.g. UNESCO "Consultation on Special Education, 2-6 May 1988", Paris, France, 1988; "Examen de la situation actuelle dans le domaine de l'éducation spéciale", Paris, France, 1988;
S. Hegarty: The Education of Children and Young People with Disabilities: Principles and Practice, UNESCO, Paris, France, 1990; T. Jönsson, ibid.

[15] M. Miles has in "Children with disabilities in ordinary schools" (Mental Health Centre, Peshawar, 1985) studied a group of 43,416 pupils attending 103 ordinary urban primary and secondary schools in the North West Frontier Province in Pakistan. 1.9% of the pupils had a "perceptible disability", and these children were integrated in these schools without any provision of "special education". 32% had impaired speech, 31% physical disability, 22% visual impairment, 8% hearing loss and 7% other disabilities. 35% of the disabled children had difficulty in carrying out school work. 45% of the fellow non-disabled pupils had a positive attitude to their disabled schoolmates. Miles concludes that there are far more disabled children in normal schools than in special schools and notes "in the absence of any specialised training, the disabled children are thrown in with the rest and sink or swim largely by their own efforts. It was noticed that the majority of them seemed to swim rather than sink".

[16] P. Mittler and R. Serpell: in Clarke & Clarke, Mental Deficiency (J. Berg, Ed.), Methunen, London, United Kingdom, 1984.

[17] T. Jönsson, ibid.
The text in italics is quoted from M. Ainscow and Tweddle: Encouraging Classroom Success. (J. Berg, ed.), Methunen, London, UK, 1984.

[18] This approach is strongly supported by UNESCO, see e.g. UNESCO Consultation on Special Education, Paris 2-6 May 1988, Final Report, Paris): "Special teachers today need the skills to work as resource teachers ... non-categorical training programmes which prepare teachers to work with children with all types of disabilities ... should be encouraged".

[19] See also "Where there is no Special Needs Education" by T. Jönsson, ibid.

[20] Social Reintegration of Persons Having Suffered Mental Illness. The First ILO Asia Regional Workshop held 21-26 March 1989 in Kuala Lumpur, Malaysia; ILO, Geneva, Switzerland, 1989.

[21] W. Momm and A. König in "From Community-Based Rehabilitation to Community-Integration Programmes", ILO, Geneva, Switzerland, 1989, report from Indonesia that three types of vocational rehabilitation services were tried (none of these corresponds to the CBR system as described in this book): Mobile Rehabilitation Units (an outreach service to disabled people in remote villages), Community-Based Resource Centres (a focal point providing training in craft skills) and Community Co-operatives (self-managed and consisting of disabled people only). These efforts did increase the employment ratios and the average per-capita-income of the disabled clients, but the income levels reached were not more than slightly above half the Indonesian minimum wage.
See also Box 4.12.

[22] W. Momm and A. König, ibid., report that, in Indonesia, out of a sample of 207 disabled people, 150 were working "spontaneously".

[23] For more details about this experience refer to an ILO publication: M. Harper and W. Momm "Self-employment for disabled people. Experiences from Africa and Asia, ILO, Geneva, Switzerland, 1989.

[24] A study of patterns of vocational interests and work motivation among mentally retarded adults in Israel is presented in S. Reiter: Int.J. of Rehabil.Res. 13, 37, 1990.

[25] Documents regarding legislation have been published by UNCSDHA, Vienna, Austria, e.g.: "Report on national legislation for the equalization of opportunities for people with disabilities, examples from 22 countries and areas" was published in 1988, and the Report of the International Expert Meeting on Legislation for Equalization of Opportunities for People with Disabilities; in co-operation with Rehabilitation International in 1987.

CHAPTER TEN: A SERVICE DELIVERY SYSTEM FOR CBR

In this chapter we will examine the various alternatives for service delivery for CBR. The questions to answer are many: What is to be done to eventually reach as many as possible of those 60 million disabled people in need of a wide variety of rehabilitation services? Can we design a system that will require financial outlays of a level acceptable to governments and communities in the developing countries? How many personnel will be needed, and how will we train them? Also, we should not see service delivery as a passive system, with the disabled people at the receiving end. Any system must be participatory - disabled people need to be actively involved.

Before going on to suggest alternative ways of implementing, supervising and evaluating services, let us first look at the service delivery components of the conventional system (institutional care and outreach programmes).

1. THE CONVENTIONAL SYSTEM

In the conventional approach, services are basically supply-generated. The planning of such services is mostly done by experts with preconceived ideas about what to do. Once set up, these services tend to multiply as the experts often promote an increasing demand for what they provide. Little is done to analyse the actual needs and whether the priority given to certain types of services is justified.

Once a certain type of service is installed, few attempts are made to discuss innovations. More often than not, disabled people become passive recipients of such services. In many instances they are never consulted, for the "experts" know it all. The conventional system is mainly centralised. It builds on service delivery, either by closed institutions or through outreach (institution-based) programmes.

Closed institution-based service delivery

In a closed institution-based system (see Fig. 10.1), the disabled person comes to the institution and receives training from the professional personnel there. This may be on the basis of services given to boarders or as day-care.

This is the prevailing system of service delivery in developing countries today, in several thousands of institutions. A great number of them have been initiated by expatriates, who to this day may make up part of the staff. Most of these institutions are located in the capital city. In rural areas, they are few and far between.

This system should, in theory, produce rehabilitation services of excellent quality, even though for only a small group of disabled people. In practice, this is rarely so. This is usually because of the lack of contact with the family and the community, or due to environmental constraints such as problems with facilities, equipment, utilities or transportation. In some cases, insufficiently trained staff, including expatriates, is the explanation.

<u>CLOSED INSTITUTION-BASED</u>
<u>DELIVERY SYSTEM</u>

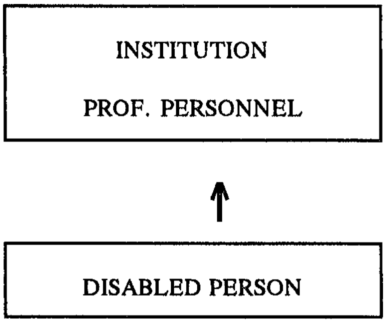


Fig. 10.1

Most important of all problems is the financial one. Services are often costly. In some institutions, total costs per place and year exceed US$ 5,000. Many are short of financing, and where they fail to find the necessary funds from external or internal contributors, the only option is to cut services and decrease quality.

The closed institution-based delivery system is inappropriate when it comes to solving large-scale problems. Most disabled people in the developing countries come from poor families with little schooling. They are unlikely to take the initiative, or to have the means, to come to an institution. These people have to be approached in their own homes.

The costs and requirements of professional personnel are further constraints that speak against expanding the alternative of closed institution-based rehabilitation.[1]

Institutionalising disabled people, in particular children, over long periods of time produces serious side-effects. The current trend in industrialised countries is to close down as many institutions as possible and to provide community care instead. There is little point in establishing in developing countries a system that is increasingly recognised as obsolete in the industrialised world .

This should not be read, however, as a proposal to close down any well-functioning institutions in the developing countries. Those that continue maintaining sufficient staff to ensure a quality programme could, in the future, serve as referral and resource centres for the community-based services. Moreover, their staff could contribute highly useful inputs to a CBR system by assisting in areas such as training, professional supervision and consultations. Such restructured institutions will probably have to be strengthened and increased in number. To this end, ways and means should be studied of how the relevant services could be made available in areas beyond the capital city and how their costs - if excessive - can be reigned in.

Outreach institution-based delivery system

In an outreach system, the professional goes out from the institution to the home of the disabled person and delivers the training (or other interventions) there. If necessary, he or she refers that person to an institution. This, in my experience, happens very often (Fig. 10.2).

There are many examples of this approach, and a large proportion of them today are erroneously labelled[2] CBR projects. Outreach programmes often start with the realisation that there are many rehabilitation problems, for example those related to ADL-training, integrated schooling, finding jobs and encouraging social activities, and that the solutions provided in an institution are inadequate. As a result - and this is basically an excellent idea - professionals start going to their clients' homes, meeting with the family and the community leaders to obtain a better idea of the nature of the problems and to find out what needs to be done in practical terms to solve them. The next step in an outreach programme is frequently the professional's attempt to try and treat or train the particular person at his or her home. This is likely to lead to better and more practical results than training in an institution.

OUTREACH INSTITUTION-BASED DELIVERY SYSTEM

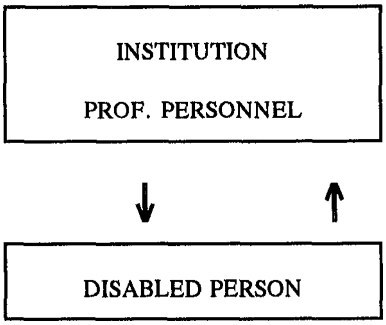


Fig. 10.2

However, a system of this kind is expensive. In a rural area, the professional may be able to treat one or two disabled people a day and a slightly bigger number in an urban area, while a professional in a centre may provide services for as many as eight or twelve disabled persons a day. Transport poses another problem, for most professionals insist on having a car at their disposal for making home visits. Simpler means of transport, such as a moped or a motorcycle are often considered inappropriate, especially if the professional in question is a woman.

Outreach programmes have been tried in several industrialised countries. But there as well, a serious decline in personnel efficiency is observed, and programme costs are in many cases perceived as insurmountable.

In some cases the outreach approach is conducted by a team. Several professionals will join together for each home visit, pushing costs to astronomical levels.

Realising the outreach system's lack of efficiency, some project personnel have begun reorienting their work towards community-based solutions. The first step in this direction may consist in co-operating with existing local health or social services and in training their community workers in identifying disabled people. Next, instead of having all these persons referred to the relevant institution, the professional will invite them to see him or her at the local health or social centre. Efforts to gradually convert the outreach approach into a community-based system meet, however, with major difficulties which are associated with the lack of community involvement. It is better to implement programmes which have their roots in the community, which are based on community decisions and are managed by the community.

2. *THE CONCEPTS OF THE CBR SERVICE DELIVERY SYSTEM*

The CBR service delivery approach may be described as needs-generated. Its starting point is in the community, with referral services being complementary. It builds on the experience from many countries, where people have become involved in rehabilitation and communities accept their responsibility for delivering the services locally. It is then possible to provide a substantial part of the services and opportunities needed, and to measure up in terms of quality with those offered by the professionals in the institutions. The CBR approach is based on the positive results of the "spontaneous technology" and many other development projects that build on "learning service delivery from the people." Unlike most of the technology, service delivery systems cannot be standardised. In each country a lot of thought must be given to the question of to how to establish a system that eventually can be used countrywide. One such proposal for an alternative system, which is the outcome of several years of experimentation, is illustrated in Fig. 10.3.

The figure shows an example of how a service delivery system could be constructed. In principle, the CBR system should be multi-level and multi-sectoral. Practical solutions for how to organise this have to be based on local conditions, existing and planned resources of public services, availability of personnel and experience from other development programmes.

The basic-level services are delivered by a "trainer", a family member. The trainer receives instructions and supervision from a community worker: the "local supervisor" (LS). The LS is also responsible for contacting the local teacher and for motivating him or her to educate disabled children, as well as for motivating the local authorities, or resource persons, for vocational training and employment of disabled persons.

The local supervisor is trained and supervised by a professional: the "intermediate level supervisor" (ILS), who should be supported, whenever feasible, by a mobile, multi-disability resource teacher. The training programme for the LS may follow the plan described in the Guide for Local Supervisors in TCPD.

In cases where training of a disabled person in the community does not give satisfactory results, that person should be referred to a competent person at a more central level of services. This could be at a health centre or hospital, in a resource centre for special education or in a vocational facility at the district or provincial levels. Further referrals to the national level should be available when these facilities are unable to meet the particular needs.

On the other hand, disabled people receiving services at the national or the provincial level should - as soon as the specialist is no longer needed - be referred back through the district-level ILS to the community-level LS, and the home. Such referrals should be carefully prepa-

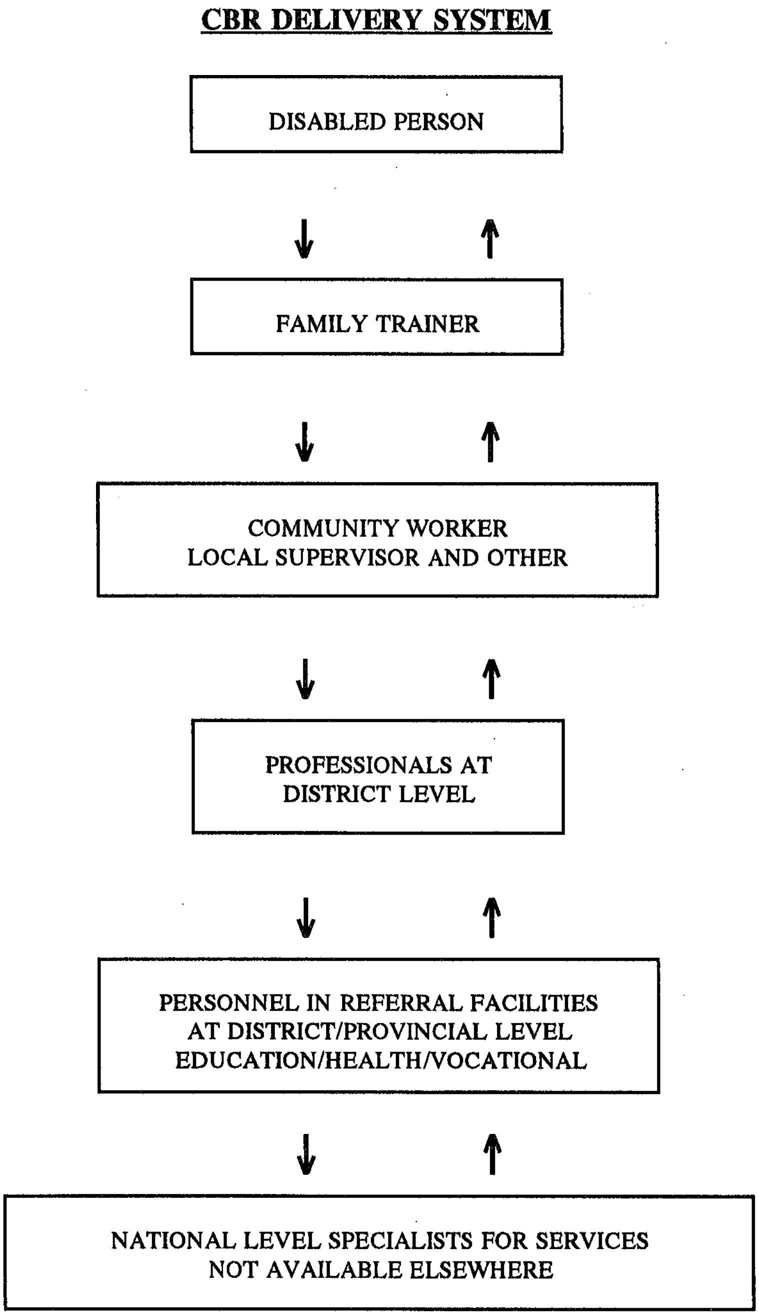


Fig. 10.3

red to ensure that the LS and the family receive detailed instructions as to the continued action to be taken, and that the referral centre has ways of monitoring the outcome of the process. Fig. 10.4 summarises the differences in approach between the "conventional" and the CBR system. The term needs-generated implies that one deals with the actual needs of the disabled person, starting with the priorities as perceived in the family setting. Problems that cannot be solved satisfactorily at the community level should be referred, and a multiple-level system is needed. Thus re-

APPROACHES TO SERVICE DELIVERY	
CONVENTIONAL	**COMMUNITY-BASED**
SUPPLY-GENERATED	NEEDS-GENERATED
DELIVERED BY OUTSIDERS	PARTICIPATORY
SINGLE LEVEL	MULTIPLE LEVEL
CENTRALISED SERVICES IN INSTITUTIONS OR AS OUTREACH PROGRAMMES	STARTING-POINT IN THE COMMUNITY, REFERRAL SERVICES SEEN AS COMPLEMENTARY
SINGLE SECTOR	MULTIPLE SECTOR
SEPARATE FROM OTHER COMMUNITY DEVELOPMENT PROGRAMMES	INTEGRATED IN OTHER COMMUNITY DEVELOPMENT PROGRAMMES

Fig. 10.4

ferrals result from established needs for more specialised interventions and are set up in response to what the community wants. They are not predetermined or supply-generated.

Institutions most often deliver services which are specialised to a single sector, such as giving elementary education to blind children. Their personnel is not always capable of dealing with other problems, such as vocational training.

Furthermore, CBR delivery should be integrated in a general community development programme. This is rarely the case with the services of the conventional system. Integration implies that communities will decide how to fit in this component with other, already existing programmes aimed at human, social and economic development, education, health, vocational training and creation of job opportunities.

When experiments started to set up a system along the lines depicted under the community-based approach, we met with considerable opposition. Many "experts" doubted that services similar to those delivered in Western countries by staff with many years of professional training and experience could be carried out by laymen with no loss of quality. Apparently these "experts" perceived our volunteers and community workers as ignorant, backward and primitive illiterates. Our experience is very different: we found most of them intelligent, enterprising, concerned, hard-working, and eager to learn. There is a possibility that some of those misgivings were voiced by "experts" who had never taken the trouble of familiarising themselves on the spot with the realities of community life in developing countries, and who had not been willing to learn from the people.

3. PERSONNEL FOR CBR

There are many different ways of providing a network of staff for dissemination of technology[3], and each country should decide how to integrate service delivery in other services and what are the best uses for existing groups of personnel. *Participation* in delivery at the community level is of utmost importance.

The intermediate level supervisor

For the purposes of providing services at the community level, it has been found useful to start by training a group of intermediate level supervisors (ILS).[4] The latter could be a nurse, a social worker, a therapist[5], a teacher, or - whenever appropriate - a suitable disabled person or a community worker who has proved capable and ready to move up a step in his or her career.

In the case of professionals, ILSs should receive three months of training, at least (see also Box 10.1). Where no professional group is avai-

Box 10.1

EXAMPLE OF COMPONENTS OF A TRAINING PROGRAMME FOR INTERMEDIATE LEVEL SUPERVISORS

(a) **for a group consisting of trained professionals**
1. Technology (as described e.g. in TCDP), with practice in the field.
2. Knowledge of the referral system, health, educational and vocational measures for disabled people.
3. Administration - planning, reporting systems, evaluation, budget calculations, etc.
4. Pedagogics: how to train local supervisors; how to prepare local teachers with a view of enabling them to better respond to special needs among school children; how to engage community leaders in the provision of equal opportunities for vocational training, jobs and social participation by disabled people.
5. Techniques for generating incomes among disabled people: market studies, assessment methods, informal and formal training, acquisition of funds for small enterprises, book-keeping, etc..
6. Normal child development and its application to disabled children.
7. Management: community social organisation; rural and urban development; community involvement; decentralisation and central support mechanisms, etc.
8. Social psychology: how to create awareness; how to sensitise the public to the problems of disabled people and to the solutions to these problems; networking; how to use the media and traditional techniques (such as plays or songs) to promote the programme.
9. Legislation: existing laws (including the national constitution) concerning human rights for all citizens and certain specific rights for disabled people; ways in which the community can mediate conflicts; legal procedures to give justice to disabled people.
10. Organisational techniques: how to set up legally recognised organisations of disabled people and parents; how to provide administrative training to their leaders, etc.

(b) **for a group of trainees with high-school background but no professional training**
1.-10. Same as above, but more detailed, notably practice in the field.
11. Disabilities, their causes and symptoms.
12. Primary health care.
13. The national education (schooling and vocational training) system and its principles.
14. The national economic situation, with particular reference to prospects for economic development, use of human resources, employment opportunities and so forth.
15. Extensive studies and review of the existing national rehabilitation services.
16. NGOs, both national and international, and their role in services for disabled people.
17. Basics of national planning.

lable to take on the ILS function, one might propose a new type of professional sometimes called a rehabilitation assistant or officer, district CBR agent or supervisor[6]. In most countries that follow this approach, the duration of basic training is twelve months at least. On completion of this training, the ILS can be sent out to be attached to a district health or social service.

The ILS sets out by inviting communities to decide whether they would be interested in organising services for their disabled members. More on this subject follows in the section on management below. Once the decision is taken, the communities will identify suitable community workers as "local supervisors".

The local supervisor - community worker

A local supervisor (LS) must be well motivated and literate. In some countries, this community worker - like others who support the CBR programme - is a volunteer. A review of the roles of volunteers is given in Boxes 10.2 and 10.3. The outcome of the programme depends to a large extent on the motivation of volunteers, especially that of the community worker.

In all CBR programmes one has to identify the appropriate motivating factor in that particular society, and a great deal of attention must be given to keeping everyone engaged and enthusiastic.

There are examples of local supervisors who stay for ten years, while others leave after a few weeks. I have seen examples both of community leaders who stayed on as driving forces for many years and of others who gave up early.

Box 10.2

WHO ARE THE VOLUNTEERS?

There are several different groups of volunteers, and each of these needs to be considered separately:

- family members of a disabled person. They provide basic training and other efforts at home;
- community workers. They are recruited by the community for the role of local supervision and co-ordination;
- school teachers. With some preparation, but without being specifically trained or compensated, integrate disabled children in regular classroom activities;
- other community members. They may be involved in informal vocational training or in providing opportunities for employment;
- members of the community rehabilitation committee. They use their free time to animate the members of their community, to mobilise local or external resources, to plan and manage the programmes, to protect the legal rights of disabled people and to make it possible for them to be represented;
- disabled people and parents. They make efforts to mobilise local resources for the "beneficiaries" of a programme and negotiate with the community on their behalf;
- significant people at all levels. They help to motivate the government, political leaders and local authorities, raise funds and manage part of the referral system.

Even where the rewards seem appropriate for the given society, it is not always easy to predict for what length of time a particular person would be willing to contribute voluntary work. We have found it difficult to retain the services of very young people, such as school leavers, for various reasons. They often seek a career elsewhere, they tend to be interested in alternating their working environment, they marry and have other responsibilities. Some join as volunteers for the wrong reasons. For example, there are those who harbour the thought of opening a "private practice" later on. Of these, most will leave after a short while, somewhat upset about the lack of financial progress. Enthusiasm and commitment come in different measures - for some both wear off quickly, for others it is a lifelong affair.

Women in their forties with grown-up children, on the other hand, often stay for a long time. Another group with good endurance prospects includes women who are themselves disabled or who have disabled members in their families. One has to recognise that such women may do a perfect job when it comes to tasks within their own experience, such as functional training and education, but may not be the appropriate persons to handle the vocational tasks.

The problems associated with a high turnover of volunteers are several: firstly, where volunteers work as local supervisors - or in any other regular long-term activity - somebody has to be trained to replace them. This is costly. Secondly, the person who takes over from them will need some time to gather the necessary experience. Hence, quality may suffer.

Some renewal of volunteers is, however, stimulating, for fresh eyes see problems and ways to solve them that may have been overlooked before.

In some parts of Asia, it is easy to recruit non-salaried volunteers for community work - I have come across good examples in India, Indonesia, Myanmar, Philippines, Sri Lanka, Thailand and Vietnam. In Africa, the tendency is to seek financial or other compensation. In some Latin American countries, as well as in some parts of Africa, governments eye voluntary work based on community initiatives with suspicion - the spark that may ignite subversion. In others, like Tchad and Ghana, to encourage voluntary development work is the government's declared policy.

Most likely the CBR system and all other development programmes would not exist if there was no willingness or solidarity among large groups of people to give a helping hand. In countries where there has been a lot of political repression, violence or hostility, voluntarism may have gone into hiding to reappear - it is to be hoped - when the situation has returned to normal. The availability of volunteers is influenced by many factors. Economic factors include the amount of time free from work and household duties, and competing possibilities for remuneratedoccupations. Diseases among family members such as HIV infection, hepatitis, tuberculosis, parasitic diseases, malaria, amoebiasis may prevent them from carrying out the training of disabled family members. There are also social and cultural factors which may influence motivation and attitudes. In societies where there is widespread HIV infection, it might be difficult to mobilise any adults to carry out development activities, including CBR.

Box 10.3

SOME EXPERIENCE OF VOLUNTEERS

The term volunteer should not be taken to indicate a person working without any reward. All volunteers need compensation or recognition for what they do, something that counts in their society. Locally recruited volunteers are usually better motivated, if they have a disabled family member or if they are themselves disabled and have benefited from the CBR programme. Such compensation or recognition could take the following form:

- appreciation or esteem by other people;
- official recognition of her/his work, e.g. in the local press, presentation of an award at an official ceremony, or a written recognition by an important person;
- a modest salary;
- a contribution in kind, such as some extra food, disposition of a piece of land to cultivate, a uniform, clothes, a horse, etc.;
- a signed diploma showing the competence required;
- a good training that is useful for the person;
- travel to a seminar or participation in a workshop;
- career prospects; unfortunately most such rewards consist in moving centrally - promotion and career need to be possible locally;
- in tightly controlled societies, working as a volunteer sometimes, for example, provides a woman with a legitimate reason for leaving the house and meeting other people;
- for family members the knowledge that their efforts will diminish the degree of dependency of a disabled family member is important; the disabled person will later on need less help and may contribute economically to the family.

Once recruited, the LSs should undergo training by the ILS (see Box 10.4, which presents a suggested programme for a 10-week course), after which they will commence working, supervised again by the ILS.

There are a number of other training approaches. One such approach is to condense formal training to the basics and to encourage self-studies of the TCPD Manual, followed by supervised hands-on training and a final evaluation of the trainees' competence. Other models include a three-week introductory course, followed by field practice, and a second course a year later. It should be noted, however, that reduced LS training periods will call for more direct supervision and interventions by the ILS, thus increasing the number of ILSs required.

Another approach, for use in densely populated areas, is to "specialise" the local supervisors: for example, one of them may work only with blind people, another only with people having mobility difficulties, and so on.

Ideally, an LS will work on a part-time basis in a catchment area of some 3,000 people. But where rural villages are smaller and unwilling to share a LS, one will have to train one LS for each of these villages. As a result, the training component of the programme will turn out more costly.

In keeping with the technical programme outlined in TCPD, the first task of the LS will be to carry out a house-to-house survey so as to identify all the disabled people in the community. Normally the first period of training will concentrate on ADL-func-

Box 10.4

EXAMPLE OF A TRAINING PROGRAMME FOR LOCAL SUPERVISORS

Local supervisors (CBR community-workers, CBR agents, CBR co-ordinators) are recruited by their own community, employed (and compensated) by it, and receive their managerial supervision from a local committee. The technical supervision is done by an ILS, who is at the same time the contact person for the mobile resource teacher and for other personnel at the district or at higher levels.

The Lss should be literate, have an interest in disabled people, and be well motivated for their job. They should bring a positive attitude to their task of assisting other people and be willing to learn their job well. They will normally work part-time.

There are many models for their training: it could be done all in one session, or a modular approach could be used. Below follows a proposal for a ten-week course, to be adjusted according to local conditions. Each student will need one copy of the TCPD, in addition to other educational material. The course can follow - with adaptations - the Guide for Local Supervisors contained in the TCPD.

EXAMPLE OF A TEN-WEEK COURSE FOR LOCAL SUPERVISORS

Week	Course Contents
1	Course evaluation and requirements to pass. Perceptions and definitions of disabled people. General interventions: functional training, education, vocational training, jobs, protection of human rights, organising disabled people, social integration. Role of community initiatives. Community organisations for development. Meeting disabled people, their families, and community leaders.
2	Local survey (theory and practice). Assessment of disabled people.
3	Seeing difficulties. Meet blind people, practise TPs, schooling, jobs. Referrals.
4	Hearing/speech difficulties. Meet deaf/mute people, practise TPs, schooling, jobs. Referrals.
5 and 6 and 7	Moving difficulties. Meet physically disabled people. Practise TPs (incl. prevention of deformities). Make walking aids and other technical appliances. Schooling, jobs, Referrals.
8	Feeling difficulties (leprosy); strange behaviour (mental disease); learning difficulties (mental retardation). Practise TPs, schooling, jobs. Referrals.
9	Child development; play activities; multi-handicapped; role of local healers.
10	Education of children with special needs; adult education; social activities; household activities; activities to identify opportunities for income-generation, including market situation, simple assessment, informal vocational training, employment and self-employment; protection of human rights; organisations of disabled people. Reporting; recording; file system; in-service training.

At weekly intervals, the trainees will, at the end of the course, have to pass a competence test (knowledge, skills and attitudes). LSs without the desired level of competence may be allowed a second try. If they fail this one as well, they should not be allowed to work.

tions. Based on an appropriate training package, the LS will design an individual rehabilitation programme and then instruct the family trainer. In most cases, this will be the mother, the grandmother, or an elder sister. The trainer will apply the relevant technology under the guidance and supervision of the LS. Some experience gathered by family trainers is given in Box 10.5.

Box 10.5

EXPERIENCE OF FAMILY TRAINERS

There is nothing new in the idea of asking family members to undertake services for their disabled children or adults. This is what they normally do. The difference is that the majority of them now provide passive care, such as feeding, dressing, washing, etc., but give very little active training.

It is normally very simple to explain to a family member that, if a disabled person could be trained to be less dependent, his/her need for care in the future would be accordingly less. Thus a limited period of training will pay off. In some cases, the disabled person may also be able to help with some household duties like looking after children, taking care of animals, growing vegetables and so on. Some disabled people may after training even be able to work and earn an income.

At the start of a CBR programme, about five per cent of families are seen to refuse to help with the training, for a number of reasons: they may think it will not be effective, that they have too much to do as it is, or they are waiting for a "magic cure" that will totally restore the disabled person, or they may be outright hostile. We have chosen never to "push" such people; it is not productive, and there is enough to do anyway. At some point they may come back by their own free will (e.g. after having seen a good result in a neighbour's family).

In our experience, it is sometimes more difficult to convince families in urban areas than those living in rural ones, particularly when their main income derives from commerce. Sitting at the market place takes the better part of the day; in such families a disabled member may be left alone for the entire day.

Family trainers who agree to take care of the tasks at home mostly carry it out consistently and effectively. Some, perhaps ten per cent of them, may drop out, however. The precipitating factors include: moving to another place, change of job, severe illness (of the trainer or the disabled person), lack of good results, or lack of supervision.

It is very useful to encourage the setting-up of a group of family trainers who will get together at regular intervals and share their experience, especially with newly recruited ones.

The local teacher

At an appropriate time, orientation courses should also be given to local teachers. These could last from one day to two weeks. During this time the teachers will be informed about the various disabilities, how to deal with disabled children in the classroom, and how to co-operate with a mobile resource teacher. An example of an orientation programme is provided in the Guide for Schoolteachers in TCPD.

The local personnel involved in activities aimed at generating incomes for disabled people

It is worthwhile trying to sensitise community leaders, local authorities and NGOs towards the idea of carrying out market studies, providing vocational assessment, local training and jobs for disabled people. Short meetings or seminars held, for instance, by the ILS could contribute to this end. As indicated in Box 10.4, the LS could be given training that takes account of the local market situation and the potential for providing local vocational training and employment for disabled persons.

4. THE ROLE OF THE REFERRAL SYSTEM IN CBR

The referral system should be established in co-operation with the existing centres or institutions. Once the referral needs at the community level are known, these should be specified and quantified. The ways and means of meeting those needs should be discussed at the national level. To start with, the following information needs to be collected. Which needs are the most important in quantitative terms? Where should the relevant services be delivered and by whom? In what ways will the peri-

Box 10.6

SOME IDEAS OF HOW TO USE EXISTING INSTITUTIONS FOR REFERRAL SERVICES

1. The first step in planning for referrals is to make an inventory of the existing referral services in the country. These should include both government- and NGO-operated services, as illustrated in the example below:

(a) health care facilities that can provide diagnostic and curative services, in particular orthopaedic surgery, ophthalmology, audiology, ear-nose and throat diseases, psychiatry. Services may include both specialists and generalists (e.g. district health personnel);

(b) health care facilities that offer a rehabilitation programme, such as national centres (set up mostly for physically disabled only), orthopaedic workshops, physiotherapy, occupational therapy and speech therapy services, mental health programmes; including training courses for health sector rehabilitation personnel;

(c) educational facilities providing special education, non-specialised schools able to receive disabled children and adolescents; including training courses for special educators;

(d) vocational facilities. Review the informal and the formal training sectors and their capacity to absorb disabled adolescents and youth; special vocational training centres; sheltered workshops; including training courses/facilities for specialised vocational training; if vocational assessment does not exist, such a service may be created within an existing facility, the objective being to determine whether or not disabled people can be referred to vocational training set up for the able-bodied and later on be placed in employment in the open labour market;

(e) legal structures and procedures for protecting human rights, including mediators (ombudsmen) at the central and local levels.

2. The next step consists in identifying and evaluating professionals and facilities capable of receiving referrals. Their number may turn out to be small and their capacities limited. Also, they will tend to be located mainly in the capital, making them inaccessible to a large proportion of the population. As a rule, the personnel need upgrading of their training to include CBR. In the medium-term perspective, this can be done at special seminars/courses. In the long-term, CBR should become an integral part of their professional training.

3. At this point, and in co-operation with the existing professionals/facilities, one could start negotiating a number of co-ordinated activities. The questions to be asked in this context are the following:

(a) can the referral services receive disabled people (and if so, how many), provide the desired services, and then send these persons back to the district and community with a follow-up programme?

(b) is there a possibility of decentralising the referral services, e.g. by creating smaller units at the provincial level?

(c) can the referral services become mobile, e.g. can visits to the province or district levels be undertaken, should this prove suitable and cost-effective (also taking into account the transport costs)?

4. After a period of 3-4 years of such co-operation, one could evaluate its outcome. At the same time one should estimate met as well as unmet community needs.

5. The referral services should then be reoriented to better provide for unmet community needs. Plans should be made to expand their responsibilities to larger parts of the country. These centres should help with teaching/training programmes and with continuous evaluation and research.

Box 10.7

TRANSPORTATION OF DISTRICT PERSONNEL TO THE FIELD

As professionals at the district level, the ILS and the resource teacher will work most of the time in the field, transportation is needed. No other single subject seems to attract as much attention during the planning phase.

I have received many interesting proposals, from horseriding to helicopters. Those requesting helicopters were arguing that their country was very mountainous, with very few roads!

Let us start by examining the question of who is going to pay for the transportation. It may be possible to find an external donor to pay for the means of transportation in the early phase of a development project. But time will come when these costs have to be taken over by a national or a local authority. Consequently, costs should be of a size maintainable in the country. In other words, they have to be as low as possible, without sacrificing the effectiveness of the programme. In some countries, the national government has been asked to pay because there is no decentralisation of such action. A better way would be to transfer the administrative action to the district level, where most of the intermediate-level CBR personnel is working. Districts that collect taxes or that are given a share in the taxes collected by the central government may be able to help with transport costs.

Another option is to ask for contributions from the community committees for rehabilitation. It is important that the matter of who pays how much for transportation is settled before commencing any CBR programme.

Let us now look at the options in terms of transport:

- on foot. This is practicable in densely populated areas such as marginal urban settlements, as well as in certain rural areas - no cost.
- by public means of transport. This can be done, provided there are buses going at reasonably frequent intervals to all the areas where the ILS and the resource teacher work - low cost. Yet, sometimes this may pose problems, as bus trips require authorisation and/or payments are not advanced. As a result, the entire programme may easily collapse owing to such administrative constraints.
- on mule or horseback. This is useful, in particular when the roads are in a poor state, when long distances have to be covered, and when this happens to be the traditional means of transport. It involves low cost. But arrangements will have to be made to feed the animal and make sure it will not be stolen.
- by bicycle. This is useful where there are at least some roads, and provided the distances are relatively short and not too hilly. This is also a low cost solution. Some external development NGOs have made a deal with the personnel in the sense that, if the personnel agrees to pay for the maintenance, the bicycle will become their property after a certain period of time, say two or three years, when a new bicycle will be supplied. Sometimes this approach is not practicable because of government regulations.
- by moped. Mopeds can be used if the roads are in a reasonable state. Distances to travel can be longer than those for bicycles - for costs see below. Maintenance may be a problem, as spare parts have to be available, as well as a competent person for repairs. The question of insurance against accidents and against theft has to be discussed.
- by motorbike (e.g. 125-200 cc cylinder capacity). These are very useful even for long distances, provided the roads are of reasonable quality. As with mopeds and bicycles, a number of cultural issues need to be considered. For instance, do women (pregnant or not) normally use these types of transport. As for the cost, see below. Again, maintenance and insurance are problems that have to be solved.
- by vehicle. This is what all district personnel want - a 4X4 vehicle of their own, complete with driver. This is practical only where main roads are in a reasonable condition and villages are accessible by car. The costs are very high. As a rule, there are no cultural obstacles, but maintenance and insurance costs cause serious problems. In most countries, this type of transport is reserved for the national programme manager, who travels over very large distances. In many cases, this type of transport can only be purchased, maintained and replaced if there are external funds to pay for it.
- by vehicles provided by other service units. It is often suggested that an existing vehicle, such as the one normally used by the health team for immunisations, should be shared with the CBR programme. I have never seen this function well - dependence on other people's vehicles has always affected efficiency, often reducing it to an unacceptably low level.

pheral service network co-operate? For the sake of maintaining the quality of the programme, it is vital to have access to referrals. Consequently, expansion of this level of services in the future is indispensable. Box 10.6 contains a few suggestions as to how existing institutions could be used for referrals.

It is important to realise that a CBR programme that includes family and community action with technical support at the district level can, in all countries, be set up at cost levels maintainable by national resources. It is when specialised referral services are provided that the costs may be more difficult to control; one has to ensure that such services are well managed, fully utilised (with some mobile components), and within reach of those living in rural areas and small-towns.

5. *FACILITIES, TRANSPORTATION AND EQUIPMENT FOR CBR*

The ILS and the mobile resource teacher should be attached to a network of public services at the district level (population about 50,000 - 100,000). It is most practical to provide an office integrated with other personnel belonging to the

Box 10.7 cont'd

Here some examples of cost calculations for the alternatives (e), (f) and (g), assuming that each moped/motorbike/vehicle will have to be renewed every three years.

Examples of annual cost calculations/of various transportation alternatives (US$)

TYPE	PURCHASE COST	ANNUAL COST				
		Capital Cost	**Gas/Diesel**	**Repair & Insurance**	**Driver**	**Total**
Moped	1,000	330	100	100	-	530
Motor-bike	2,000	660	200	300	-	1,160
Vehicle	20,000	6,600	1,100	3,300	1,500	12,500

We can now calculate the annual costs per inhabitant and per disabled person for the various types of transportation.

In this example, we assume that each ILS (and each resource teacher) has a catchment area inhabited by 50,000 people, that 1.4 per cent of these are involved in the CBR programme, and that there are either one (an ILS) or two (an ILS and a resource teacher) working in the district.

Example of an annual transport cost calculation per inhabitant/disabled person (US$)

Type	One ILS per 50,000 people		One ILS and one mobile resource teacher per 50,000 people	
	Annual cost per		Annual cost per	
	inhabitant	disabled person	inhabitant	disabled person
Moped	0.01	0.76	0.02	1.52
Motorbike	0.02	1.66	0.04	3.32
Vehicle	0.25	17.29	0.50	34.58

Given the fact that most governments spend rather small amounts per capita on health and social programmes, typically US$ 5-10 annually, it would seem that the vehicle alternative is too expensive. By contrast, the moped and motorcycle options seem feasible.

There is another side to the problem. The standard of transportation for district rehabilitation personnel should not contrast too much with that other personnel at the same level enjoys. CBR should not be seen as a high-cost enterprise, but rather as a low-cost but highly effective effort.

public sector. In this way the rehabilitation staff will quite naturally have contacts with colleagues as well as access to local and central authorities. Reports and statistics would be kept there.

However, the ILS and the resource teacher will work mostly in the field and should not have other duties in hospitals, centres or institutions. It is common experience that such an attachment will negatively influence their field work. Most professionals with a double set of duties will find excuses for remaining in the centre. The ILS will need transportation to the field. What exactly to provide in terms of transportation should be given a lot of thought. After salaries, the cost of transportation is the second largest component of the budget in most countries. For some ideas see Box 10.7.

It is important to develop pedagogic material for training of the ILS, the LS and the local teacher. Material providing advice is needed in matters related to market studies, vocational training and employment, both for local authorities and for NGOs. It should be adapted to the trainees' cultural, social and educational background. Tools and materials are needed for making various aids, e.g. for walking (see training package 13 in TCPD). Each LS needs a copy of TCPD (if possible an adapted national version in the local language), or a manual of comparable content describing all locally applied technology.

6. *OPTIONS AND CONSTRAINTS TO SERVICE DELIVERY*

All CBR delivery systems should be designed to eventually provide coverage of the entire population of each country. The system outlined above is only one alternative. Many others may be feasible. Let us now look at some of the options and constraints:

(a) It is easier to organise service delivery for densely populated areas than for underpopulated ones. If people live dispersed (e.g. 1-5/sq.km.) and the "villages" consist of extended families (30-60 people), it is indeed difficult to find a way of delivering services. In such areas there might also be no other public services, for instance, schools or health centres.

(b) There is very little experience of experiments with service delivery for nomadic populations, the majority of whom also lack education and health facilities. In some cases, however, nomadic populations may regularly stay in a specific area, where for a couple of months or so they could be reached. Nomadism is becoming less common, and may decrease substantially within the next few decades.

(c) Before starting a CBR programme, one should make an inventory of all existing systems with peripheral networks. These might include:

♦ *Religious leaders and priests.* This is in all cultures the earliest and most widely spread "system" that exists. Such leaders can be very valuable partners in sensitising populations and mobilising community resources.

♦ *Teachers and education services.* Although this network does not yet reach everyone in the countries concerned, it is impressive and constitutes the currently best developed public service system in the developing countries. We have tried to use teachers as ILSs or Lss, and there are some examples where this has been done successfully. Up until now, however, it has been difficult to conceive a system built on them as major service providers. Most teachers have large classes, or even double classes, to look after; their salaries are low, prompting them to seek a second income, e.g. through agriculture. But it is possible to count on their co-operation in integrating disabled children in school, as indicated above. This will be feasible if they receive supplementary training.

♦ *Health workers.* Some countries have developed or are planning to have a system of primary health care. There is a possibility of using community health workers for delivery of CBR, after a sufficient period of supplementary training. Alas, there are few countries with well-functioning primary health care systems. Most are still in their experimental phase. These programmes sometimes lack community involvement, and most of the work is oriented toward health education and prevention. We are usually told that health workers are overburdened with work and cannot deliver another component of services, such as rehabilitation. One should always seek their co-operation, for they represent diagnostic and therapeutic resources that can be of great importance for disabled people. In a few countries the government has agreed to have the CBR programme delivered by health workers and is using the referral network with success.

♦ *Staff in social services.* Such services are well developed in many countries, though usually not at the community level. There are cases where one finds a network of such services all over the country, with social workers at the district level. Some of these are involved in health and ordinary community development projects and can - after supplementary training - become ILSs. In such countries it is possible to build up a countrywide system linked to an existing public service network.

◆ *Staff in development programmes.* Where one is unable to find any existing networks of public services, one might look for integrated community development programmes. Supplementary training would enable them to carry out the CBR programme. Another factor that calls for close co-operation with the staff in developing countries is that these programmes can be used for "mainstreaming" disabled people. For instance, one could integrate disabled children in programmes aimed at stimulating and looking after the health and nutrition of under school-age children.

Other development projects concern e.g. the economy, creating jobs and income, providing education and health services, or improving the infrastructure and communications. Participation of disabled people should be sought in such projects.

◆ *Social security.* Some countries are slowly building up social security systems, and some of these do have rehabilitation components. These are mostly concentrated to institutions, such as hospitals, however. Social security services for rehabilitation should aim at multi-level and multi-sectoral programmes. It still remains to be seen whether this will be possible.

◆ *Organised disabled people.* Some organisations are large, with widespread networks of local chapters and could help to manage the CBR service delivery system.

◆ *Legal systems.* There are many areas in the world where local leaders are responsible for the enforcement of justice, law and order. These systems will not deliver CBR services, but their co-operation is valuable in such matters as promotion of human rights, provision of legal protection for disabled people and mediation of conflicts arising, for example, from lack of opportunities for education and jobs.

(d) When a decision has been taken on the delivery system, it will be necessary to take a second look at the technology to be used. Tasks may be revised or assigned to another level than the one proposed in TCPD.

It is a good idea to always start doing what is easy, such as delivering services in areas where transport is not a constraint, training the children of families who are interested to co-operate, schooling those who can benefit from education in regular classes, providing vocational training and jobs for those who are clearly competitive on the labour market and so on. We have to realise that meaningful rehabilitation services exist today for less than two per cent of those in need, discounting low-quality institutions. If we can improve the quality of life even for as few as 20 or 30 per cent of all those in need, it will be a great leap forward.

7. *ENTRY POINT OF CBR PROGRAMME*

The entry point for setting up a CBR programme varies from country to country.

In Mauritania, for instance, the programme was organised by a national handicap "umbrella" organisation, which, in co-operation with the Directorate of Social Affairs, recruited a handful of professionals who were then trained by an expatriate. The members of the organisation later assisted the programme in organising and delivering services. In Benin, Côte d'Ivoire, Ghana, and Malaysia, social assistants were trained by expatriates to set up services. In Vietnam, training was provided initially by an expatriate to PHC workers; later on, a course was also given to physiotherapists. In Myanmar, an expatriate first held a course for district physiotherapists, who then in their turn trained village volunteers. In the Philippines, PHC workers received training from the local project manager, who was assisted by a doctor and a few therapists. In Argentina, the project was initiated by a team consisting of two physicians, a psychologist, a technician and three occupational therapists;[7] in Zimbabwe, a two-year training course was given to rehabilitation assistants, who in their turn trained local supervisors who were mostly extension workers in other development projects. In St Lucia, an expatriate trained PHC workers.

COMMENTS AND REFERENCES

[1] In a recent project for vocational rehabilitation in a country where the estimated number of disabled people in need of this service is about 100,000, the evaluation team remarked: "During 4 years a total of 117 disabled people have received vocational training each for a period of 6 months. ...the cost for each person was US$ 3,500...and US$ 0 for the other 99,900 disabled people, and there was no policy for how this disequilibrium could be reduced."

[2] I have noticed in a large number of countries that institutions claim to have changed and that they tell visitors that they are delivering a CBR programme. In some cases, this may mean that they are now receiving part of their funding from local authorities. In other words, they have become community-financed, but that is the only change. In most other instances, there was no change whatever, but the institutions' managers had been asked by their donors to start describing their projects as "community-based" ones, as this would facilitate the fund-raising. And a few others had started outreach programmes on a small scale, without seeking any involvement with the community.

[3] Questions concerning personnel in rehabilitation are dealt with in many publications, see e.g. International Meeting on Human Resources in the Field of Disability, UNCSDHA, Vienna, Austria, 1989.

[4] A set of recommendations concerning ILSs was published recently by WHO: The Education of Mid-Level Rehabilitation Workers. WHO, Geneva, Switzerland, 1992.

[5] In 1978, it was proposed to develop a "multi-purpose therapist" for this task. See, e.g., E. Helander: "Das Ziel: Ein Universal-Rehabilitationstherapeut" in Zeitschrift Gesamte Hygiene 24(6); 478-81, Juni 1978.

[6] "Assistant" is not an appropriate term, for these professionals should be able to make their own judgments and to take their own technical decisions.

[7] A detailed description is available in: A.G. Loza, A. Garcia, E. Canavesio, C.T. de Sanchez, S. Fernandez, L. Canulli, A. Oliverea and Z. Micossi, Community Based Rehabilitation General Programme, La Rioja, Argentina; Pan American Health Organization, Washington, D.C., USA, 1991.

CHAPTER ELEVEN: MANAGEMENT OF CBR

Management consists of all the efforts to ensure smooth functioning of the operation of a programme. This includes policy-making, planning, training of personnel, implementation at all levels, provision of resources, monitoring and evaluation.

In the conventional system, the limited management that exists is centralised and often applied from the top downward. If the government is involved, it will make plans, get involved in the training of personnel, and introduce development projects at the district and the community level. The governments usually see communities as grateful and rather passive recipients of what they in their benevolence have organised. As a result, there might not be much local involvement. If NGOs are the main providers of services, they normally limit themselves to managing their own centre.

Box 11.1

DECENTRALISATION: TRANSFERRING POWER TO THE PEOPLE

The main constraint to development in many countries is not the lack of resources. It is the inertia of governments in planning for, implementing and undertaking the day-to-day decision-making and management of centrally operated programmes. They are ineffective because of the sheer complexity of trying to do everything at the national level. If the resources at the community level were better used, the constraints would be much smaller. Thus governments would do well to adopt a policy aimed at preparing, encouraging and actively engaging local leaders and people in decentralisation and accepting that, in fact, this implies a transfer of power to the people.

As long as the rehabilitation services consist of a handful of institutions, the system can easily be managed centrally. But when one tries to involve communities in service delivery, much larger resources are needed, both centrally and in the periphery. Central direction is no longer adequate, as it induces a certain degree of passivity in the population. People often take the view that they just have to wait for the government to come and provide a service for them. This becomes frustrating, for governments in most developing countries will have large initial difficulties managing even the most essential services.

One of the key features of the CBR programme is decentralisation. But this is not enough. There is no guarantee that this process by itself will lead to community development. Decentralisation must be accompanied by a change of attitudes. The government and its civil servants should see themselves not as the leaders and decision-makers but as partners in development, supporting the population, and they should listen to what the community wants to do and facilitate its implementation.

1. DECENTRALISATION

Decentralisation implies that the responsibility for the functions of an organisation, along with the authority for carrying out these functions, is delegated to those at the periphery of the organisation. (See Box 11.1.)

There are several steps in achieving decentralisation: functions can be assigned successively to provinces, to districts, and to communities. These steps may be seen as a continuous process, aiming at reaching the highest possible degree of authority, autonomy and responsibility at the most peripheral point in an organisation.

Decentralisation in regard to government is generally supposed to be an admirable goal. It evokes the image of benign local leaders or service providers, easily accessible to the people, capable of taking the right decisions, of delivering the action needed, or of providing services quickly, without being slowed down by a central bureaucracy. This is of course only partly true. The quality of decentralisation is closely related to the quality of those who are responsible at the local level.

Decentralisation can never be complete. Central governments need to keep key functions under control in one way or another, for instance, by controlling their own inputs (financing), processes (applying consistent administrative processes (applying consistent administrative rules), and outputs (results). And some matters (such as foreign affairs, defence or external trade) are necessarily centralised.

To decentralise too much power could create a problem. In various parts of the world, notably in rural communities, some local leaders already exercise a high degree of social control. To avoid a monopoly of power, one must make sure that it is being *shared through community participation.*

Decentralisation requires *competence* on the part of those who are going to carry out the functions locally. Training programmes leading to the desired competence must be set up before decentralising. Adequate supervision is another condition. Where there is a shortage of competent staff, decentralisation should proceed cautiously and gradually.

In the following, four aspects of decentralisation will be discussed one by one:

- services
- administration
- provision of resources (financing), and
- policy-making.

Decentralisation of services

In a centralised system, all services are carried out in one place, as a rule in the capital city. This system makes services inaccessible to and expensive for, most of the users, who have to travel to receive them. As with institution-based rehabilitation, service coverage will be limited to a low percentage of the population.

The logical first move away from centralisation would be to decentralise the services requiring only a minimum of competence. However, exactly which services require the least competence, might prove difficult to say. Why? Because of the tendency to unnecessarily complicate services delivered by professionals, especially when these have successfully acquired expensive equipment.

Consequently, demystifying apparently complex technology so that lay people understand how to use it may be an early step toward delivery at the community level.

Next, one should try to decentralise the most routine, high-frequency services. It is more economical to deliver such services locally, as it means less travel for the disabled people receiving them. In this context it should further be noted that many components of rehabilitation are best carried out locally. These include training in mobility, ADL, communication and behaviour. Opportunities for schooling, informal vocational training and jobs should preferably be found locally. Human rights conflicts should be mediated in the community. Social integration of disabled people will come true only in a decentralised system building on local initiatives. It is important to maintain continuous technical supervision of services delivered by non-professionals.

Once it has been decided what to do at the family and the community level, one must establish the referral levels for the remaining tasks. Some services should be given at the district level, while others might require facilities at the provincial and national levels. Low-frequency services, in particular those that are very costly and not very urgent, should be assigned to the central level.

Decentralisation of services is greatly facilitated by standardisation. Standard procedures are more reliable and easier to remember. Standardisation simplifies the training of community workers and the supervisor's tasks of checking and reporting on the service delivered. One should not interfere, however, with local initiatives to "invent" new procedures or to modify existing ones. Community workers and families should be encouraged in their efforts to individualise and experiment with the technology.

Decentralisation of administration

In a centralised system, all administration is carried out at the head office, situated as a rule in the capital. Such a system is time-consuming and expensive. In a fully decentralised system of administration, all decisions and actions would be taken in the community.

Advocates of a centralised system point to uniformity of approach as the reason behind their preference. Civil servants can carry out a high volume of standardised administrative procedures. They are easier to supervise, and any inconsistencies in their work are easier to correct when the system is totally centralised. Where the same tasks are carried out by a multitude of civil servants in many separate places, rather than at the head office under the supervision of one single manager, the results are likely to differ.

Those who propose a decentralised system claim that it is more effective and gives better justice to the ordinary citizen than centralisation. The central system has very little feedback from the public. Hence there is a great risk that faulty procedures and injustices may go uncorrected owing to a lack of awareness at the central office.

Further constraints that hold back citizens from approaching the civil servants are the impressive size of the system, the difficulty of finding out who is responsible for what, and the social gap between ordinary rural people and civil servants living in the capital. In a decentralised system, all these constraints can be reduced.

There is no ideal solution to this dilemma. A compromise will therefore have to be found, the final goal being to attain the highest possible degree of administrative decentralisation through a gradual, step-by-step approach.

The first functions to decentralise should be those of high frequency, with no or few economic implications, such as a large number of decisions on servicing of staff. Provincial and district managers, who mainly utilise locally provided resources, should gradually be given authority to handle all routine decisions.

The extent to which functions can be decentralised will depend on the competence of the local staff, on the quality of supervision, and on the source of the budget. All managers should receive appropriate training.

As regards the source of the budget of the CBR programme, it is suggested that local communities pledge resources for the local services. It would be normal to expect community leaders to take all local decisions concerning locally funded programme components.

The existence of a decentralised administration may mean, however, that the central government will have its fingers everywhere and interfere with every minor, local decision. This tendency should be counterbalanced by increasing local political influence.

In a truly decentralised system, administration of a rehabilitation programme by the central government could be limited to a few central functions. These could be: the planning of the national programme development; the training and employment of intermediate-level professional personnel; responsibility for the referral services at the national level, co-ordination, monitoring, and evaluation.

Decentralisation of the provision of resources

Resources for a rehabilitation programme may be provided by a community, a district, a province, or a central government, in any of the following forms: funds, personnel, equipment, transportation, buildings, statistical services, research, information, other contributions in cash or kind. In some countries, the central government collects taxes and returns a proportion thereof to provinces, districts or communities to pay for locally-run programmes.

A community may have various other methods of financing locally established services or programmes. In addition, there might be contributions in kind. For instance, a community might be able to mobilise voluntary community labour for various development purposes, such as making roads, building schools or irrigation dams or wells. In addition, such existing resources and procedures could contribute to the rehabilitation sector. Communities may have the legal authority to finance decentralised programmes by taxes collected and spent locally. Where this is the case, one might speak of "decentralised provision of resources".

Decentralisation of policy-making

The previous section on responsibility for providing resources has brought us very close to the concept of political responsibility. More often than not, central governments decide and impose all sorts of development programmes on communities. (See Box 11.2[1].) Rarely consulted, communities may show a growing resistance to some of these programmes. But with the central government, non-governmental organisations or foreign donors financing such programmes, communities have had very little reason to refuse them. This has given rise to problems: development projects without grassroots are not sustainable. (See Box 11.3[2].).

Rather than taking all decisions on policies centrally, as in the situation described above, development should be stimulated by delegating political responsibility for community programmes to the communities proper. It should be for them to decide what is a priority for their own people. Thus, should a particular local service be needed, the community members would decide on its implementation and raise contributions from their members to pay for all or part of it. The central government might contribute financially to local programmes or ask donor agencies to do so. In this way, the external provider of funds might, for instance, share the costs by paying for building material for a school and by supplying technical know-how, while the community will provide the necessary labour. Or, in the case of CBR, these organisations might support the costs of training programmes and the phasing in of the services. However, the future maintenance cost should not be financed by donors. The community will retain the "ownership" of the programme, its members initiating, organising and managing their own programme.

Box 11.2

BREAKING OUT OF OLD PATTERNS AND GENERATING NOVEL WAYS OF DOING THINGS

While dealing with environmental issues, "The Manila Declaration on People's Participation and Sustainable Development" contains a number of remarks that parallel those made in favour of CBR:

"Current development practice is based on a model that demeans the human spirit, diverts people of their sense of community and control over their own lives, exacerbates social and economic inequity...

"We are concerned that foreign assistance ... too often contributes more to the problem than to its solution. It places the initiative and responsibility in the hands of the foreigners rather than in the hands of the people ...

"There is a current need for a fundamentally different development model based on an alternative development. Authentic development enhances the sustainability of the community ...

"A people-centered development seeks to return control over resources to the people and their communities to be used in meeting their own needs ...

"A people-centered development seeks to broaden political participation, building from a base of strong people's organisations and participatory local government ...

"It seeks to build within people a sense of their own humanity ... Those who would assist the people with their development must recognize that it is they who are participating in support of the people's agenda, not the reverse ...

"The future of all people depends on a basic transformation in thought and action, leading people to discover their essential humanity and to re-create their relationships with one another. It is pragmatism more than idealism that makes the change possible."

A necessary precondition for decentralised policy-making is for the government to improve public education and information to enable people to understand the import of the decisions taken by them.

The government may assist in setting up the appropriate local organisation, where this is missing or insufficient in scope. Community leaders and administrators could be trained to upgrade their competence in such areas as policy decisions, handling of financing, and local administration. The outcome of decentralisation depends largely on the quality of the trained local leadership. Ideally, the reduced role of the central government would be to provide on request technical and managerial supervision, as well as to coordinate the local activities. However, they would have to avoid pushing their "pet" projects, something that usually only serves to create powerless local "puppets".

Partnership

With this we may eventually reach a system building on partnership between the communities and the government. The latter will see it as their main function to respond to and to facilitate, local initiatives. The role of the government and of its local administrative network is no longer to direct but to co-operate and to become partners in development. Action in the community and government support become complementary and linked to each other.

Macro- versus micro-level

There are a number of development agencies, such as the World Bank, that have been involved in some very large-scale projects carried out at the "macro-level". In Box 11.3, some reflections from the World Bank as to the futility of this single-level approach are quoted, and full involvement of the "micro-level" in all development programmes is recommended. The author stresses that the prerequisite for sustainability of a development project is the autonomy and competence achieved at the grass-roots level during the development period. This experience has been applied for many years by a large number of small development agencies.[3]

2. *MANAGEMENT OF CBR AT THE COMMUNITY LEVEL*

The basic approach of CBR is to "learn from the people". In no other area is this more essential than in that of management. There is now some experience of how a CBR programme can be set up step by step. The information gathered so far is, of course, very diverse and culture-dependent. The steps suggested below may be useful for planning purposes, but there are many other ways of going about it.[4]

Step 1 Awareness-building (sensitisation)

People in the communities of the developing countries need to be informed that:

- disability is common (although to some extent hidden);
- there are simple methods of training and educating disabled people that can be applied where they live and that will lead to more independence and better social integration;
- they need not wait for external initiatives or for special institutions to be set up, for they can achieve a good deal through a community action programme of their own (how to do this, too, should be explained, including the

Box 11.3

FROM THE WORLD BANK:
DETECTING THE GRASS-ROOTS

"Institution-building [in Africa is often advocated by development agencies] in a one-sided, macro-biased manner. Undue attention is channelled to the strengthening of national-level agencies and central macro-organisations, while institution-building at the grass-roots is chronically neglected.

"Many development programs have failed to achieve post-program sustainability precisely because they neglected to build up local organizational capacity. Only if local populations assume an increasing responsibility for program-assisted activities, during implementation and especially following completion, can development programs be sustained. Such responsibility can be fostered by increased degrees of autonomy and reliance on grass-roots beneficiaries' organizations."

obligation to provide resources from the community).

The important principle is that community members should discover the fact that it is possible for them to transform the conditions in which most disabled people live; and that they could and should acquire the skills and take the action needed.

Here a few words of explanation should be added as to **when** and **how** to build awareness/sensitise. Many mistakes have been made as to the **when**.

Examples of national-level techniques are radio and television programmes and articles in newspapers. Radio programmes will reach large numbers of people. Their content should be carefully structured. Some countries' radio stations feature regular weekly or monthly programmes on the topic of disability. In some of these, people are advised as to the causes of disability and how to prevent them. Others present interviews of disabled people who tell of their frustrations and successes. Once a CBR programme is on its way, radio and newspapers can be used to inform people about it.

Box 11.4

AWARENESS-BUILDING WITHOUT SERVICES CREATES FRUSTRATION

In one African country, an intensive effort was made to identify, assess and register all disabled children under 15 years of age. Considerable funds were spent in a two-phase study. In the first phase, a team of health/education/vocational experts went to the field to screen entire population groups, and in the second, specialists carried out thorough examinations. The end result of this exercise was to register close on 10,000 "severely" disabled children. Ten years later, no action had been taken to set up any programme to provide training and education for these children. Parents had filed endless requests and had eventually given up in frustration. In the meantime, interminable internal debates had been going on about which ministry should do what, what sort of co-ordination should be set up, what technology to use, etc.

In an Asian country, a large-scale survey was started, in the course of which several thousand disabled people were identified, diagnosed and turned into statistics. The survey staff promised these people on identification that services would be provided but, five years later, next to no such services had been created.

In yet another Asian country, no fewer than three surveys had been conducted - one by an NGO, one by the Ministry of Health, and the third by the Ministry of Education. When the Education Ministry went out to do their survey, they met with widespread refusal among the population - people had seen enough surveys and did not care for yet another. What they wanted was practical help - not registration.

Awareness-building should be undertaken only if services can be set up immediately. In Box 11.4 examples are given to show how registration of disabled people and surveys raise expectations, and how they lead to frustration and loss of credibility when there is no action in sight.

How to create awareness depends on the local culture. In each country, there is normally plenty of experience to build on, both in terms of successes and failures. This experience could be disseminated and applied both nationally and locally.

In several CBR programmes, it is the ILS who builds awareness through information/sensitisation meetings or local visits. One example of such an approach is to send a message via the local radio station, inviting people to come for an information day on the subject of disability/rehabilitation. Another example is to invite a number of local leaders to a discussion. During such meetings, relevant information can be given and discussed. One can also use the opportunity for presenting a few disabled persons who have been successfully trained at home along with a few others for whom nothing has been done. Other programmes have used, for example, audio-visual material, slides and video films, etc. for disseminating information.

Another way of spreading information is to visit the communities which indicated their interest; this allows larger groups of local people to attend, including disabled persons and their families.

Box 11.5

A LESSON IN THE SCHOOL

In this small town of a South American country, I encountered a severely disabled local businessman. He told me the story of his life, the problems he had been up against initially, and how he went into business, first lost some money, but then learnt his lesson. Though confined to his wheelchair, he travelled a lot by car.

Once a year he went to the local school, where he gave a lesson to all fourth graders. On that occasion he invited the children to ask him questions, which they did, after some hesitation. In the course of the ensuing dialogue, he explained to them the problems he had to cope with when he was small, and he pointed out to them that there were many disabled persons who were faced with other people's negative attitudes toward them. At the same time, he conveyed the message that a disability in no way must interfere with one's success in life. And this the children had no trouble to understand, for after all, he was the richest person around.

For six years now he had regularly given this lesson, and the teachers told me that it had helped considerably in bringing about a change of attitude among the people of the community.

Local techniques for awareness-building are of great importance. Here, community leaders, teachers, local committees and disabled people (see Box 11.5) and their families can help. Some countries have tried with good results theatre, songs, poetry (see Box 11.6[5]), story-telling, puppet theatre, and other ways and means. Religious leaders, politicians and others too can give a helping hand.

Step 2 Animation

I take "animation" to indicate the process through which a community decides to initiate a development programme. This decision should not be the result of outside pressure. Programmes that are the result of political pushing or interference are unlikely to be successful. "Interference" can also take the form of financial incentives that create too much temptation, especially in the absence of community participation in resource provision. Another example of interference is when the results of rehabilitation are described in over-optimistic or unrealistic terms.

Box 11.6

POEM

Little friends

Around my garden and around my home
you are fighting, and then
you become friends again.
Pushing my wheelchair,
you bring happiness to my world.

Though I cannot enter your world,
mine is filled
with buds of wishes.
They will bloom
in your lovely world.

Do not take me to my dark world!
It is surrounded
by four walls.
Take me far,
far away little friends.

Though my foot lacks the strength
to kiss mother earth,
my weary life gets happiness
from your smiles flowering.
They fill my lonely world.

Before deciding on setting up a local CBR programme, the community needs to know what it has to do. This includes the provision of local management and some of its own resources. They also need to understand what the expected outcome is likely to be and how the authorities will provide central support, such as training and technical supervision, administrative support and referrals.

The mechanism through which animation takes place depends on local tradition and culture. In some societies, the local leaders, whether elected or appointed, have a great deal of influence, while in others there will be extensive consultations with community members. Decision-making could be influenced by disabled members of the community or their families and by personalities outside the leadership structure. Animation should be allowed to take its time; a CBR programme is no quick fix and will require a long time to implement. Communities may feel reluctant to do the programme until they have seen others do it - or they might say no.

The reasons for rejection may be many, among them: other, more pressing priorities, negative attitudes, beliefs and superstition, or else an inappropriate way of building awareness. One has to realise that action to improve the quality of life for disadvantaged groups is never a community's first development priority. Most of them will find it necessary to start local efforts with the digging of a well, with increasing food production, setting up some small-scale industry to earn more money, providing primary health care and schooling. When all this is well on its way, and only then may the time have come for taking care of the disabled people in the community.

Realising that a CBR programme is not a first priority, one might choose to encourage animation and to concentrate local awareness-building efforts in those communities that already have had experience and have seen success of other development programmes. This will facilitate implementation since one can draw on the existing managerial structure in such communities. Ideally a local rehabilitation committee will be integrated in a general development committee.

Once a community is decided to start a programme, a certain number of formalities may have to be observed. The district administration must be advised and, in some cases, formal permission must be obtained.

Step 3 Community mobilisation

The fact that, following a period of animation, a community decides to set up a CBR programme may not necessarily mean that there will be a programme. To start with, one will have to define the resources that need to be mobilised.

These include, for example:

- a community worker who, after training, is willing to do the job of a CBR local supervisor. After training, the volunteer will work eight to ten hours a week to serve a population of 1,000 people living in a limited area. In rural areas, most hands are needed during certain months of the year, for planting and harvesting. If the local supervisor takes part in this, the CBR work has to be somewhat delayed, which normally does not pose much problems. In some parts of the world, the local supervisors will work as volunteers without being remunerated; in others, some compensation, but not necessarily a salary, will be needed. The community should mobilise this compensation.

- provision of funds to cover training costs. If the training takes place outside the community, the community worker may need a daily subsistence allowance to cover the costs of food and lodging. There are examples of how such costs are sometimes paid by the government or by external donors. Where this is not the case, they have to be met by community funds.

- Communities may decide to extend their contributions to assist disabled members,for instance to pay for schooling costs (e.g. uniforms, books) and/or to contribute to the cost of vocational training by subsidising informal local apprenticeships, or providing help for braces, eyeglasses, or transport to referral centres.

Each community has to decide what it wants to do and how it will raise the necessary funds. There are a number of ways in which resources can be mobilised. Some communities do receive governmental contributions, perhaps channelled through a district or a province administration. These funds rarely suffice to finance everything a community wants to develop, requiring it to have recourse to its own means, supplemented in some cases by financing from external donors.

Local resources can be raised by taxes or contributions; there are many ways of doing this: per-capita contributions, taxes on income, on land, on crops or commodities produced; on marriages; or through local health insurance or essential drugs schemes; contributions to local services like water supply and garbage disposal. Other sources include funds collected at feasts, on religious occasions, in fund-raising drives, at auctions; or donations; and fees for services delivered. Besides there might be contributions in kind, such as voluntary labour. In one community, the leader explained to me that there were 19 different ways his community obtained income.

The mobilisation of community resources may be slow and stepwise. No programme can get off the ground as long as there is no local supervisor, but the extended resources mentioned above can perhaps wait for a while. It is important that the community understands that once a CBR programme is started, it has to be maintained. CBR is there to stay.

Step 4 Community organisation

Each community has to set up a management structure to plan for the programme, supervise the programme's quality, mobilise resources, establish links with authorities and technical expertise at the district, and evaluate the programme.

In many communities certain development structures - committees or similar - are already in place. If so, it is preferable to use these structures. Other communities may need more guidance in how to set up an appropriate managerial structure. In addition, appropriate training should be provided for those whose job it will be to manage the programme. Local government ministries and NGOs may have many years of valuable experience in how to set up and train local managerial groups. There are examples of countries where a large number of national NGOs have formed a union in order to provide joint managerial courses.

The community organisation should include disabled people and their families, many of whom have ample experience as to what is needed in terms of training and what its outcome should be, and could therefore provide valuable social support. These people may have formed their own local organisation. If so, this organisation should be regularly consulted. Providing administrative training for these representatives of the disabled population should not be overlooked whenever an opportunity for managerial training offers itself in the community.

Step 5 Implementation

Once the community management structure has been established, the local supervisor should be chosen, trained and put to work.

After the initial survey, the LS should start working with a small group of disabled people. There is a tendency to try to do everything at once, but having 10 to 15 disabled children and adults to take care of is tough for a beginner. As the LS becomes more experienced he or she may expand the group. Most functional training of disabled people can be completed within nine months. Schooling, vocational training and jobs require less intensive but regular guidance. To build a system for legal protection is a big job in the beginning, but once established, the work-load may diminish. A very long - perhaps life-long - monitoring of the CBR participants is needed in order to maintain achievements and prevent deterioration.

It is important that the ILS and, where available, the mobile resource teacher provide regular visits to the communities for technical guidance. Many programmes that do not have an ILS suffer in quality, and motivation may become hollow after a while. All referrals should be discussed with the ILS. There is often a tendency to send virtually everybody for a referral at once. Experience has shown that about 70 to 80 per cent of all disabled people participating in the CBR programme manage quite well without such referrals.

The ILS should not intervene in the local management of the programme and should not give orders to the community. The role of the ILS is to inspire and encourage the communities and the Lss to find their own solutions and to build up their own experience; he or she should guide when there are problems and praise them for work well done. The ILS will motivate the Lss to keep proper records, and will check them regularly.

Finally, the ILS should meet regularly with the local committee and provide advice and trouble-shooting on request. Again there should be no pushing on his or her part. Rather, he or she should motivate and inspire everybody to continue and provide the information necessary to this end.

Step 6 Building-up referrals

The ILS and the LS should visit and discuss referrals with potential providers of resources at the district level. These resources include the district hospital (for diagnosis and treatment), the school authorities (for placement of disabled children in secondary and higher education), the social authorities (to help with social and economic as well as private problems disabled people are having), labour or employment officials (for placement in integrated formal vocational training and jobs), and the legal authorities (to find help in setting up mediation processes for settling human rights conflicts).

In addition, the ILS may approach those provincial and national authorities likely to be able to provide help not available at the district or local levels. These contacts may include resource centres for children with special educational needs, professionals who can provide complex vocational assessment and training, medical specialists and orthopaedic workshops. These authorities also need to be advised of the fact that the community is able to receive the disabled person after a period of referral and to continue the programme at home.

Step 7 Evaluation at the community level

It is important that communities do not just plan and implement CBR programmes, but that they thoroughly evaluate (see also Box 9.9) the outcome of the programme in terms of:

- *relevance*: do our disabled people and their families feel that the programme is meeting their needs?
- *effectiveness*: did the project achieve its objectives for our disabled people in terms of improvements in functional ability, schooling, income and social integration; are their rights better protected through mediation?
- *efficiency*: have the resources provided by our community, and supplemented by the government, been used in the most efficient way?
- *sustainability*: are we as a community able to continue this programme using our own local resources, assuming that the government will go on providing technical supervision and access to referral services?
- *impact*: have the attitudes of our non-disabled people changed for the better as a result of this programme? Are disabled people participating now more than before in social activities? Are they better represented and listened to? Are the disabled people and their families comfortable with the technology? Has the physical environment become more accessible to people with moving difficulties?

The community itself should take an active part in this evaluation, but for technical advice it may wish to engage the services of an outside consultant.[6]

3. *MANAGEMENT OF CBR AT THE CENTRAL LEVEL*

Principles

As explained earlier, a CBR programme is a multi-level system. The levels above the community need to manage:

- the personnel at the intermediate level, such as the ILS and the mobile resource teacher;
- public or NGO-operated services, such as referral centres, health facilities, educational, social and vocational structures or law-enforcement bodies - all of which will be involved to some degree in the CBR system;
- various educational institutions involved in the training of rehabilitation personnel or in the orientation, information and sensitisation of related personnel in various sectors;
- rehabilitation components integrated in national, province, and district administrations. These plan for, contribute resources to, and deliver decentralised services, and provide support to community projects.

I am advocating three principles to be applied:

Firstly, that the government takes the leading role in the management of these components of the rehabilitation system.

So far, many governments have played an insignificant or a symbolic role in providing management of services, etc. for their disabled citizens. This has created the impression that governments consider the work not worthwhile and to be left to charities. This reinforces people's beliefs in the same direction. Efforts must be made to change governments' and people's perceptions. There is no justification for any government to keep aloof from efforts to provide services for disabled people.

Secondly, that the government, at least in the early phase of development, tries to designate one ministry or authority as responsible for setting up a mechanism for co-ordination and consultation that will satisfy all partners involved.

In the early phases of development, it will greatly facilitate the work if governments assign programme management to one specific ministry. Once development is well under way, the various other ministries, for example, education, health, justice, labour, social affairs, development and local government can do their part. The experience of too many divergent ideas and a variety of ways of implementing, or of reasons for delaying, services is extremely negative.

The ministry in charge of management needs to set up a satisfactory inter-ministerial mechanism for co-ordination, and in this, all ministries and authorities and NGOs concerned should be involved. Partnership should also be established with representatives of all organisations of and for disabled people. To this end, it is useful for them to form a union or a federation.

Thirdly, that NGOs reorient their work to become partners of the planned system, implementing projects or services at the request of the government, services that are within the framework of acknowledged policies and guidelines.

In the past, many NGOs have set up their operations in an ad-hoc way, without much planning and without much guidance from the government. Some NGOs are technically specialised for certain types of work. Their contribution should be designed for it to fit into the government's plans. It would be desirable for international NGOs not to go to a country with a preconceived idea of what they want to do. Instead, they should ask the government how they can be most useful.

Developing central management

A step-by-step approach may be followed.

Step 1 Surveying interest

At an early phase, the government should assign an appropriate person or a team to contact communities with a view of finding out their ideas about disabled people and the extent to which they may be willing to undertake local action. One might develop some printed material to be sent to a sample of communities, and then visit them for discussions. Once there appears to be enough interest and willingness to commit local resources, one might proceed to set up a CBR programme.

Step 2 Reviewing existing rehabilitation, and possible networks of public services to implement a programme

The government will identify the public service network (health, education, social services or similar) to be used in the future. Any such network may be incomplete, so information on its eventual extension will have to be sought. Agreements have to be signed so as to ensure that the personnel concerned will have both the time and the necessary resources to carry out their roles for CBR at the district level. The necessary human and technical resources to provide managerial support in the future should be available at the provincial and national levels. Existing personnel in centres and institutions should be contacted, and their role within the network should be outlined. If needed, agreements regarding their eventual reorientation and co-operation should be formalised.

Step 3 Calculating costs

At this point, some cost calculations may be useful with a view to estimating the budget requirements for the government.

Step 4 Setting up an administrative structure

Normally all programmes need a national manager. This could be a person who works part-time and has other functions besides. A better solution is to employ someone full-time for this specific purpose, given the considerable workload involved in initiating and maintaining a community-based programme. The national manager will need support from a structured system at the provincial and district levels. As many functions as possible should be delegated to these levels. Hence their staff need to be informed and trained. The national manager and those who carry out decentralised administrative functions need transport, as well as other resources, which should be identified and supplied.

Step 5 Training of personnel at the intermediate level

Next follows the training of intermediate-level personnel. This training and the subsequent placement of the trainees at the district level are, in our experience, the best entry points for a CBR programme. The national manager will participate in the first training course for ILSs. This course may be taught by an expatriate with experience of CBR. Subsequent courses could be conducted by the national manager or by a suitable national. An in-service training programme should be set up and maintained.

Step 6 Implementation

Once the students of the training course for intermediate-level personnel have passed their examinations, they may start work at the community level while based at the district level.

The national manager should carefully guide the early implementation phase. It is necessary to ensure that the development of the programme is based on community involvement, and that it does not become a conventional delivery system with the ILS providing the entirety of the services. At the end of a given evaluation period, certain adaptations that take account of the experience gathered during that period will be necessary. This done, one might proceed with the second training course and so forth. At this stage, the provincial managers could be brought into the picture.

Given the costs of "post-graduate" courses for professionals, one will soon arrive at a point where it is time to consider changing the curriculum for the professionals who represent the district level network. Once CBR has been made part of their undergraduate course curriculum, supplementary courses will no longer be necessary.

Step 7 Monitoring and evaluation

The ILS and all the managers involved need to check that a reporting system is set up and maintained. One such system is proposed in TCPD. With this system in place, it will be possible to monitor the development of the programme. Evaluation should be carried out regularly, and should involve all partners. On this basis one might reorient the programme with a view to increasing its relevance, its effectiveness, its efficiency, its sustainability and its impact.

Step 8 Formulating a national plan

After an initial period of trial and error, it should be possible to formulate a national plan[7]. It should be pointed out that no national plan can be made without a thorough study of what the communities see as their needs and what they are willing to provide. All national plans have to be revised periodically. Such a plan should not be seen as a strait-jacket for the future, but as a direction of how to proceed with the work.

Step 9 Maintaining motivation

Probably the most important role for a manager is to maintain motivation among all those involved, not only at the "grass-roots", but at all levels. The manager needs to develop a support network of politicians, important persons, local leaders, NGOs, external agencies and so on, in order to maintain the resource base. Many activities are needed to keep these groups motivated. These include media information, seminars, personal meetings, invitations to follow the field programme, and other initiatives.

4. *CO-ORDINATION AND CO-OPERATION AT THE NATIONAL LEVEL*

Development of services for disabled people is an area that brings together a wide spectrum of partners, for instance:

- **Governmental ministries/authorities**

  Education
  Health
  Labour
  Social Affairs, and sometimes:
  Civil Affairs
  Defence (Veterans)
  Justice
  Local Government
  Planning and Development

- **National non-governmental organisations**

  Organisations of and for disabled people (often divided into groups separately representing various disabilities)
  Religious organisations
  Professional groups
  Development NGOs

- **International development organisations**

  UN agencies, such as ILO, UNCSDHA, UNDESD, UNDP, UNESCO, UNHCR, UNICEF and WHO

  Bilateral (government to government) development organisations
  Intergovernmental organisations for development.

Finding the appropriate way of co-ordinating the work of all partners in a more cost-effective and better-planned fashion than today is a delicate task. A national co-ordinating body is needed. There is no blueprint for how to co-ordinate, and each country has to find its own ways of addressing this significant problem.

A number of useful proposals are available in some recent UNCSDHA documents[8], and I will here make a few comments:

- The first decision to take is whether the *co-ordinating body* is to be an *advisory or an executive organ*. With strictly advisory bodies, the available experience is rather mixed. If executive, it will need its own budget and a managerial structure for implementation.

- There should be *approved and clear policies and a detailed and budgeted national plan* that describes what the country wants to do. Very few countries have formulated their policies and plans. It may thus be appropriate to provide an initial project for training the national personnel in planning techniques. This is presumably better than the alternative of sending for an expatriate expert. At present, many countries ask for assistance in formulating a proposal for a plan from an international expert. Such outsiders have made the sad discovery that most of these plans are later shelved and never see the day of implementation.

- *A mechanism for establishing full co-ordination* between all the partners. This must have its starting-point within the government itself. It would be useful to choose a particular ministry as the one responsible for all questions relating to policy-making, planning and implementation. Other ministries would contribute the resources under their respective supervision. It will be necessary to set up a permanent procedure for maintaining a dialogue among all partners.

When this has been done, the government should discuss the policy options with national organisations of disabled people and professional groups. Subsequently, these options should be reviewed with the members of the inter-ministerial co-ordinating groups, the NGOs, and the donors implementing programmes for disabled people. Their future specific roles should be decided in accordance with the national plan, the aim being to optimise the resources all organisations have at their disposal.

- *A follow-up mechanism* should be set up. The government will need to evaluate the work done and to see to it that its intentions are being followed. Should an existing NGO service require restructuring, the government could provide what is needed in terms of managerial assistance, if necessary.

- *External development agencies should, through the national co-ordinating body, receive proper guidance to ensure that their resources are used for the purposes described in the national plan, as well as to encourage long-term commitment.* The government may wish to avoid a situation where all of a sudden they have to "take over" a service for disabled people that was neither planned by them nor conforms to existing policies and plans. There are cases where governments learn for the first time of an NGO activity when the donor advises them that the responsible expatriate manager is about to leave, or that the NGO in question has run out of external funds.

International NGOs who wish to provide resources for a specific component should, first of all, discuss the activity with the government. Basing themselves on existing policies and plans, they should then present to the government, or to the national co-ordinating body, a clear project document outlining their future obligations, resources to be provided, a timetable for their work, and how they expect their services to be eventually continued with the use of national resources. When reviewing such documents, the government should aim at making NGOs cost-conscious and personnel-conscious. If services are costly and require a large number of professional personnel, the government should make sure that the funding agency is prepared to stay for as long as is needed. Also, the government should say "no" to NGOs who want to enter the country and start an activity that does not fit with government policies.

- *Co-ordination at district and provincial levels* is also needed and is normally much easier to achieve, as staff working at these levels are much closer to each other and to the problems in hand.

- *Co-ordination should aim at economising resources at all levels.* All organisations involved need to co-operate with each other in order to avoid duplication of services; to distribute them more evenly over the country, especially to rural areas; and to share use of cost-intensive services, professional personnel, equipment, means of transport and communication.

- Another area for co-operation could be the *joint training of expatriate and national personnel.* This training should be streamlined and standardised. Criteria to evaluate the competence of national personnel and expatriates alike should be set up. Ways must be identified of how all those presently working in private institutions can be integrated in the system that is eventually to be operated by the government.

5. SUMMARY

The managerial capacity to undertake rehabilitation programmes varies widely around the world. And so do the ways management is carried out. Thus we should not take what has been said above as rules or as a rigid system. Nevertheless, the experience of carrying out general development programmes following the series of steps proposed above, or a similar approach, is extensive and mainly positive. By contrast, experience with the use of these approaches in CBR programmes is as yet limited, and time will be needed to adapt and refine the managerial processes. Even when proven effective in one country, managerial processes cannot easily be copied in another.

Moreover, one should realise that some communities will fail in motivating their members to provide the resources needed or to maintain the programme. Just as we must allow communities to say no to the programme, we should allow them to fail and shut down an effort for which they were inadequately prepared or for which they did not receive the central support necessary. This is no different from what happened e.g. in a European country, where the statistics showed that fifty per cent of all newly registered commercial enterprises had failed within the first three years. We are still happy for the fifty per cent that succeeded.

Similarly, some governments will not be able to provide the motivation or the resources needed, or they may fail after a while. They may have other priorities, such as economic development, and may want to approach projects concerning human development at a later phase. Or they are obliged to restructure the economic system by application of an austerity programme. A failure should not be seen as the end of the efforts to provide services for disabled people. Failures should be analysed and, as a result, ways of avoiding them may be better known. Also, at some later opportunity, the same country or community may have arrived at a phase that lends itself better for a CBR programme.

COMMENTS AND REFERENCES

[1] Source: Declaration adopted at the Inter-Regional Consultation on People's Participation in Environmentally Sustainable Development, Makati, Metro-Manila, Philippines, 6 - 10 June 1989.

[2] M.M. Cerner in "IDA Monographs on Development Anthropology", Westview Press, Boulder, Colorado, USA, 1986.

[3] The development of appropriate technology at the micro level is often constrained by incompatible macro-level policies and programmes. In F. Stewart, H. Thomas and T. de Wilde (Eds): The Other Policy, Appropriate Technology International, London 1990. The conclusion is that "macropolicies affect micro-level decisions, by manipulating economic incentives and constraints, such as the money supply, interest rates, currency exchange rates and the availability of credits for different sectors and even sub-sectors. Direct public investments in infrastructure and human resource development and the tying of foreign aid frequently favour the selection of inappropriate technologies. Proposed reforms ... would remove the hostility toward appropriate technology prevalent in many countries and the bias in favour of large-scale capital-intensive industry."
G. Benello, R. Swann and S. Turnbull: Building sustainable communities, The Bootstrap Press, New York, 1989.

[4] See also: Training in Community Participation, Report of an African Regional Workshop for Programme Staff. Prowess Africa, Abidjan, Côte d'Ivoire, 1989.
P. Oakley: Community involvement in health development. WHO, Geneva, Switzerland, 1989.

[5] The author is Wimal Bandara from Sri Lanka, a wheelchair-bound man about 35 years old with severe muscular dystrophy. Many of his poems, including the one above, have been published in newspapers and read or recited on radio. The translation has been provided by R. Tiroler.

[6] Cf. Chapter Fourteen.

[7] A guide on national planning of rehabilitation is being prepared by UNDP/IRPDP, Geneva, Switzerland.

[8] Guidelines for the Establishment and Development of National Co-ordinating Committees on Disability or Similar Bodies, published by UNCSDHA, Vienna, Austria, 1991; and
Directory of National Committees on Disability or Similar Bodies, UNCSDHA, Vienna, Austria, 1991.
A recent resolution of the UN General Assembly "Calls upon Member States to establish national coordinating committees or similar bodies on a permanent basis and to provide them with the necessary staff and resources during and after the Decade, bearing in mind that their structure and methodology of work should be in conformity with the circumstances of the countries in which they are situated."

CHAPTER TWELVE: GOVERNMENTS AND CBR

Services and other interventions in favour of disabled people must be permanent, and they should aim at eventually covering the needs in every part of the specific country. This will not be possible without competent personnel and a proper organisational structure. Only governments can provide such organisation, and it is necessary that they become interested in this role and assume their responsibilities for policy-making, planning and execution of the CBR programme.

1. HOW TO CONVINCE GOVERNMENTS

When we present ideas to governments and try to convince them to change policies, it is not enough to argue that disabled people are a neglected group and deserve their attention. A more substantive and structured argument is needed. In this chapter I will discuss how we might influence governments to make the priority decisions necessary for the CBR programme. Three methods will be described: the cost-benefit and the cost-effectiveness approaches, and the analytical system for deciding human services priorities.

Cost-benefit method

After the Second World War, this method started to be used to promote rehabilitation, primarily in the USA. There were arguments, such as: "a disabled person who works will pay back the costs of rehabilitation several-fold. Just the taxes he or she pays will suffice to generate US$3 for US$1 invested."[1]

More scientific methods to calculate cost-benefits were developed in the 1950s and 1960s, and became fashionable at that time. By putting an economic price tag on everything, one would in theory be able to find out where the highest benefits at the lowest costs could be expected, and so allocate government funds in an optimal way. The cost-benefit method started to be widely applied, but the implication for human services projects was that someone had to decide the price of the non-monetary benefits. Some of those were not market but political prices. How, for instance, do we compare the benefits of having 500 more teachers with having 500 more policemen? How do we compare the benefits of having a football stadium with those of having a district hospital, or of having a place of worship?

This method seemed especially controversial when applied to the human services field such as rehabilitation programmes.[2] The mathematical techniques to calculate production benefits, for example, are highly questionable in countries with high unemployment. Would the addition of work performed by disabled people substitute for that of the able-bodied, who would become unemployed? Or would it, and this was doubtful, contribute to an increase in national production? Promoting services for disabled people to governments by using a profit motive of this nature was theoretically and practically dishonest and morally questionable, since it deprived the rehabilitation concept of its primary humanitarian content. However, it is clear that, when successful rehabilitation leads to a decreased dependency on others, family members will be free to undertake other, in many cases income-generating, activities. This indirect benefit is of great importance.

Cost-effectiveness method

When the cost-benefit argument failed, it was followed by the cost-effectiveness method.[3] If a certain rehabilitation result is sought, can it be achieved at a lower cost, by employing an alternative technology and/or service delivery system?

A question we have to face in the developing countries is whether or not we believe that a certain type of rehabilitation results can be achieved at a lower cost while maintaining the same quality. A study of low-cost approaches, which forms part of the evaluation of the CBR technology, will be helpful in convincing governments that this is possible.

Using generally accepted criteria to set priorities in the human services sector

The governments facing a variety of choices for priority action must establish a reasonable methodology to guide their political decisions. This applies to the human services sector, where it has become accepted that what is done has not only economic and political implications but also humanitarian ones.

The following approach has been applied and accepted in many developing countries as part of the country health programming exercises.

As a first step, those who want to convince a government should gather all the information relevant to a specific problem, in this case concerning disability. The second step is to review the situation in the light of predetermined criteria. A set of such criteria[4] is seen in Fig. 1. These can be used as the basis for a presentation to be submitted to a government.

CRITERIA USED FOR DECIDING PRIORITIES IN THE HUMAN SERVICES SECTOR

CRITERIA

1. MAGNITUDE OF PROBLEM

- Incidence/prevalence
- Severity
- Duration
- Degree of distress caused to those afflicted and among family members

2. TECHNOLOGICAL ASPECTS

- Availability of technical solution
- Effectiveness of technical solution
- Possibility of quickly training technical and management personnel

3. GENERAL CONCERN

- Public concern
- Likelihood of achieving community involvement
- Requirements of personnel
- Requirements of budget

Figure 1 Criteria used for deciding priorities in the human services sector

I will start with the **first group of criteria** related to the **magnitude of the problem**. For example, concerning disabilities, it should be useful to point out to the government that the incidence of disability is high and that the prevalence of moderate and severe disability in the developing countries is generally about five per cent. This is a very high proportion. Very few serious health conditions, if any, will arrive at this prevalence. Consequently one would expect about every fourth family to have a disabled member. Most of these are dependent on help from others for self-care or economically, at an age when they should be self-supporting. For many of these people, the difficulties start at an early age and are life-long. The degree of distress in those afflicted is high. Many of them have complications, such as deformities caused by severe contractures, pressure sores, pain or problems with communication: they do not participate in normal family or social life, and are excluded from opportunities such as education and jobs. One should also explain that there is a high price for doing nothing. The burden on the family is large, as they have to give daily care to their disabled members, and there are many psychological and economic consequences causing distress.

This can be illustrated by statistics resulting from a small-scale national study of the prevalence, the rates of dependency, the age at the start of the disabling condition, the degree of complications, and the time required by relatives for daily care. No governments, after such a presentation, should be able to claim that disability is a problem of no importance or to be ignored; it is large-scale, severe, long-term, causes a lot of distress, and the price for a policy of non-intervention is high.

Let us now look at the **second group of criteria**: those related to the **technological aspects**. Governments are often under the impression that services can only be provided by professionals in institutions. It should be pointed out that there exists an alternative CBR technology. Simple examples from the TCPD Manual could now be shown. It should be pointed out that a large number of interventions can be carried out at home by a family member, with the same (or better) effectiveness as that achieved by personnel working in institutions (see Chapter Fourteen).

Regarding **technical and managerial personnel**, it should be explained that there are alternative ways in which it will be possible to train and supervise community workers, provide in-service training or supplementary courses for already existing personnel and volunteers. The system for providing rehabilitation at home and in the community by alternative personnel should be described. The conclusion should be that there are certainly effective solutions which can easily be applied, and that competent personnel can be trained in a reasonable time.

Let us now look into the **third group of criteria**. Governments are more likely to take action if it is apparent that disability is a problem of **general concern** to the public. All governments are also concerned about the requirements for personnel. Finally, they want to know whether the costs for a programme are maintainable within their present frame of resources.

It should be pointed out that, since about every fourth family has a disabled member, there will indeed be enough public concern. Since most people perceive disability as intractable and because there is a lot of prejudice, this public concern may not be adequately expressed. Once the facts are better known and people have become aware of the progress that is possible, this concern will grow. As it will take some time to build up services, it would be a positive move to start a programme ahead of an expected increasing public demand. Each government will have its own experience from integrated community development projects and should see the CBR programme in this light. Success is related to the quality of community leadership and the degree of community participation. It is necessary to foster local management and self-financing systems. Such systems should be similar to those applied to other community-initiated development projects.

The requirements for personnel salaried by the government are small. The total costs to the government are small, compared to those associated with the alternative of closed institutional and outreach programmes. It is assumed in our model that there is financing on three levels: the communities will compensate their own local worker and contribute to the costs for helping those of their members who need contributions to meet their costs for education, apprenticeships, and so on. The second level is the government, which will provide the salaries for the intermediate level supervision and maintain referral services. The third level is represented by donors and development agencies, which could contribute to the training and start-up costs.

The conclusion is that this programme should be able to attract community participation, that the requirements of personnel are small and that the programme budget can be tailored to a cost level that is maintainable by national resources. Furthermore it might be useful for a government to see this effort for disabled people as part of a human development programme, as advocated by UNDP and increasingly accepted as an integral component of the socio-economic development sought by all.

A government will now of course - using the above or similar criteria for decision-making - compare the case for a CBR programme with other projects presented to them. It is to be hoped that a detailed presentation along these lines, supported by available information and data, will be convincing and that the government will decide to become involved in the management and provision of community-based rehabilitation services.

2. *POLICY-MAKING*

The next item on the agenda, once a government has decided to become involved, concerns the formulation of appropriate and detailed policies. It is most common to find that ministries and governments do not have any, or very rarely formulate any, policy documents.[5] Where documents exist, they are mainly for a single sector. For instance, the Ministry of Education would have a policy on special education. Only in isolated cases does there exist a multi-sectoral po-

Box 12.1

EXAMPLE OF A DETAILED POLICY STATEMENT

STEPS	SUMMARY OF THE TEXT
1 Who makes the policy statement (degree of authority)	The Congress has issued a statement explaining the policies adopted with respect to services for disabled people.
2 Describe the problem and why a change is needed	Five per cent of the population of our country is estimated to have a moderate or severe disability. Disabled people are not fully integrated in our society; they are socially and economically disadvantaged. The quality of life of disabled people is lower than that of the average population. Current government policies on human rights, equality, security, and dignity for disadvantaged groups have not been sufficiently applied. Rehabilitation services fail to reach 97 per cent of the disabled people who need them.
3 State the objectives (what is to be achieved)	In order to achieve full social integration of disabled people, rehabilitation services, and opportunities for education and jobs should be provided for all and changes in the environment should be made to ease the daily life of disabled people.
4 Describe the strategy (how to achieve the objective)	In order to achieve this change, a community-based rehabilitation strategy will be applied, employing effective rehabilitation methods and technology. The services will be integrated into the health and social service systems. A procedure for referrals and supervision will be established. Already existing institutions for disabled people will be adapted to meet specialised referral needs. Other public services now used mainly by the non-disabled will be more effectively opened up to disabled people. As rehabilitation methods relate to several sectors - education, health, labour, social services, etc. - a multi-sectoral, coordinated approach will be used. At the community level, an approach including local decision-making, cost-sharing and management will be employed.
5 Indicate the time perspective (when)	Implementation will begin (date) and full coverage will be reached in (date).
6 Commit the resources needed (personnel, materials, money)	All personnel needed for this new programme will be trained; basic facilities for referral services will be set up; supervision and equipment will be provided through budgetary allocations made by the government. Community resources will be mobilised to meet the local costs. The government has included an amount (...) in the next five-year-plan in order to meet its part of the costs. The necessary funding will also be provided for the subsequent planning periods.

Box 12.1 cont'd

STEPS	SUMMARY OF THE TEXT
7 Who is responsible?	The Ministry of Health and Social Welfare will co-ordinate all action taken to implement the programme. For this, a new post of Director of Services for Disabled People will be created. Co-operation will be provided by the Ministries of Education, Justice, and Labour, by all provincial and district administrations, and by communities which have decided to adopt the programme. For this purpose there will be co-ordination committees at the national, province and district levels. Disabled people and their organisations will be asked to become active members of these committees, and a special procedure will be established in order to seek their continuous advice.
8 Monitoring	The Congress will review the results of the programme at its session in (year), based on the reports received from the Ministry of Health and Social Welfare.

licy formulation that is issued by the government as the outcome of inter-ministerial consultations and decisions. This is one of the reasons why national co-ordination often is poorly developed.

Policy review

All governments have some general policies which are applicable to disabled people. Such policies are laid down in instruments such as the Constitution or the Bill of Rights of a country, or in the U.N. Declaration on Human Rights (which all Member States of the United Nations have adopted), among others.

Besides, there may exist specific policies formulated as decrees, legislation, administrative rules and regulations, statements in a five-year country plan and so forth.

All existing policies should be reviewed and evaluated with two questions in mind:

(1) have these policies been fully implemented or not? If not, how can one promote their application?

(2) are these policies adequate or not? If not, what amendments are needed?

Promoting existing policies

Many of the existing policies concern human rights or are of a general nature and were not formulated specifically with disabled people in mind. Examples of these are: the rights to public services, to education and to work.

In the developing countries, systems concerned with these sectors are only partly in place. So, any deficiencies in sectors such as health services, schooling, employment opportunities and others will affect disabled people and able-bodied people alike. When it comes to using what is there, however, disabled people are often up against an added difficulty - discrimination. And this should be done away with.

Too little is being done to implement specific policies concerning disabled people. Legislation, decrees, etc. related to positive discrimination are not enforced. But these may not be required if a sufficient effort is made to enforce existing legislation and policies in favour of **all** citizens.

Box 12.2

EXAMPLE OF THE CONTENTS OF A GOVERNMENT PLAN

1 Introduction	1. Background: Who took this initiative for planning? Were there any guidelines given, if so, quote? Who participated in the planning; which ministry(ies), representatives of political bodies, professions, representatives of organisations (e.g. of disabled people or their parents)? Did the planners undertake any particular studies: surveys, questionnaires, studies of development projects, study tours to other countries, seminars and so on?
2 Situation Analysis	2. (a) estimate the prevalence of disabled people, the causes of disability, the expected future development (See Chapter Two.) (b) review existing policies, decrees, legislation and specific measures to assist disabled people. Evaluate the impact of these policies. (c) describe existing specific services for disabled people (government, NGO, etc.): their programmes, number of disabled people admitted or served in one year, annual intake, costs, quality and long-term results (if known). Finally, estimate the proportion of needs met through existing services; (See Chapters Three and Four.) (d) estimate the extent to which disabled people are using ordinary public services: health, education, vocational training, transportation, etc., as well as the number of disabled people finding employment in the open market; (e) estimate the social and the economic situation of disabled people (economy, existing prejudice, degree of social integration); (f) assess the importance of various environmental factors that influence the quality of life of disabled people;
3 Problem Definition	3. A short account of the problems disabled people are facing, especially their low quality of life. Almost all of them have no access to services. They have next to no opportunities for schooling, vocational training or employment. They face a number of environmental constraints. Their human rights are not well protected. They lack organisations representing their interests, as well as adequate political representation. (See Chapter Seven.)
4 Strategies	Discuss various options of resolving the problems listed above, such as an expansion of the present system, and the alternative of community-based rehabilitation. Analyse the potential achievements of each alternative. Then calculate the relevant inputs needed for the implementation of each in terms of personnel, equipment, budget and so forth, and discuss the constraints that are liable to delay the implementation of individual programme components. Finally, propose a strategy that has the potential to solve the problems defined above at a minimum of constraints and within a reasonable time limit.

Box 12.2 cont'd

5	Objectives and Targets	Formulate the objective: a general description of what the programme seeks to achieve. Then specify the objectives of each programme component, including services providing functional training, special education, vocational training and employment, environmental interventions, legal protection and representation. Mainstream programmes should be given priority; special services should be proposed only when necessary. As a next step, formulate the targets: specific quantitative results to be achieved within a period of 5 to 10 years. Formulate such targets separately for each programme component and revise them on completion of the entire planning document so as to make sure they are realistic. (See Chapter Eight.)
6	Programme Description	Describe the activities that should be carried out concerning services and management at the various levels. Start with the community: what will be the community's role in the planning/implementation/evaluation processes of the programme? Who will do what (the community committee, the community worker, the teacher, etc.)? How will the various activities be financed at the community level? Then describe the activities at the intermediate level: which are the tasks to be done by the intermediate level supervisor, and how many of these will be needed? Will there be a mobile resource teacher? How will he/she work? How many are needed? How will disabled young people undergo vocational assessment, followed by vocational training? How will jobs be sought for them? Discuss means of transport to reach the communities. Then review the present network of referral services in the various sectors, and outline how these can be used in an integrated system. Finally, outline the government's role in management, development of personnel, financing and evaluation. (See Chapters Nine, Ten, Eleven.)
7	Personnel	Describe how the training of community workers will be carried out: by whom, duration, where, learning material, costs. Then discuss the various options for choosing an existing group of intermediate level supervisors or - if need be - how to train a new profession for this purpose. Decide on the best alternative. Define the educational objectives of the training, outline the detailed contents of the various courses, and propose a timetable for the courses, including for those related to maintenance and upgrading of knowledge and skills. Describe all inputs needed: teachers of all the personnel; how are they going to be trained; school facilities, pedagogic material, equipment, transport, teachers' and students' accommodation, etc. (See Chapter Ten.)
8	Time Plan	Make a time plan, listing all action to be taken, dates for start and for completion, and who is responsible. The time plan for the short-term period (1-2 years) needs to be detailed; for the following years an outline is normally sufficient.

Box 12.2 cont'd

9 Budget and Financing	Calculate the budget for a medium-term period of five years. This budget should cover the cost of the specific programme components at the intermediate and the higher levels. It is assumed that the costs at the community level will be covered by the local committee. These costs need to be calculated so as to inform the communities. The use of mainstream programmes will only include extra costs, e.g. for adaptation of premises and for transport. For the purposes of the financing of the budget, divide it into two components: one for programme development and one for programme functioning. The first component could include all costs for training of personnel including buildings, means of transport, equipment, pedagogic material, study tours and fellowships. The second component includes salaries for government personnel, their offices, communication costs and, after an initial period, their transportation. Funds for the development components should be sought from development agencies, whereas the second component is proposed to be financed by the government. There needs to be a discussion of the extent to which the government will participate in the funding of the existing, externally financed institutions or referral centres. It is preferable to integrate these, if considered viable, into the CBR system and to ask the donors to contribute to their reorientation and future functioning. In most countries such centres are slowly being absorbed by the government, starting with small annual contributions that increase with time. (See Chapter Twelve.)
10 Evaluation	Describe what is going to be evaluated (the targets), how (choice of indicators), when, and by whom. Propose action to be taken concerning reprogramming or adaptations in light of the evaluation. Who will have the authority to undertake such action? (See Chapter Fourteen.)
11 Management and Co-ordination	Describe how the management of the national programme will be done. Which ministry will be responsible? How are the others going to be involved? How is co-ordination to be achieved - by a steering committee or by a national co-ordinating body? Make a post description for the post of national manager, and describe the responsibilities of the provincial and district managers. Plan for delegation of responsibility for local decisions. Outline how consultations of local, district, province and national organisations of disabled people and parents will be done, as well as consultations of community leaders/committees. Formulate the respective roles of the legislative and executive branches of the government. (See Chapters Ten, Eleven, Twelve and Thirteen.)

Formulating new policies

If a government decides to implement a CBR programme, one of the first steps could be to formulate a detailed policy statement, outlining how the programme will be carried out. Such a statement could read something like the text presented in Box 12.1. It is an example of a policy declaration that covers all aspects. It should be noted that the body which formulated the statement (in our example, the Congress) ensured that the document included reference to the following:

- **what** is going to be achieved
- **how** to implement a change
- **who** is going to be responsible for the change
- **when** can such a change be made, and
- a **commitment to provide the resources** needed for the change.

In this way, no false hopes were raised. Apparently, the government in our example had been briefed about the situation and given an analysis of alternative strategies, objectives, programmes and requirements of resources before this statement was issued.

3. PREPARING A GOVERNMENT PLAN

As stated above[6], very few countries have formal government plans for how to deliver services, etc. to their disabled people. Existing plans are almost always made for a single ministry, as are policies. Also, they do not apply a multi-sectoral approach. Nor do they provide for sufficient national co-ordination. It is certainly desirable to have a well-coordinated plan which outlines who is responsible for what and describes the mechanisms for consultations and co-operation.

It is the governments' role to decide if, when and how they would like to produce a plan. Of course, allowance will have to be made for the particular pattern of a country's planning process, particularly the established procedures for inter-ministerial plans.

There are many ways to prepare a formal government plan for rehabilitation. Some of these are fairly sophisticated, with their techniques targeted at high-level management courses or described in complex planning manuals. There are few opportunities for learning the specific planning of a community-based rehabilitation programme. A national plan for a developing country need not be very complex. (See Box 12.2. The Chapter numbers quoted refer to this book.)

It is useful to set up an Advisory Committee to assist in the formulation of the plan and in reaching a consensus among those representing disabled people and their families, professionals, administrators and representatives of communities.

All plans should be flexible and should be revised from time to time in the light of the realities.

4. ISSUING GOVERNMENT GUIDELINES

Such guidelines should be issued formally by the government and will be built on the details of the national plan. They should concern:

- International NGOs: advising them of the government strategies, policies and plans, and requesting them to work along those lines. Or, if such organisations are already present, help them to reorient their services accordingly, so they can become Self-reliance Promoting Organisations.

Their co-operation is welcome and could help to advance the activities planned by the government, or the NGOs could supplement the latter with inputs that may serve to broaden the skills and knowledge of national staff, such as fellowships abroad, training courses, research grants, etc.

- National NGOs: since these have been involved in the policy-making and planning efforts, the government plans should be known to them. They should receive guidance on how to advance the activities in the government's plan.

- Other donors, such as bilateral or multilateral development agencies: these organisations will deal directly with the authorities and will therefore have advance knowledge of the government's policies and plans in the field of rehabilitation.

5. COSTING OF A CBR SYSTEM

CBR is not a low-cost system per se

There are many misunderstandings about CBR and some relate to its costs. The alternative of CBR has **not** been proposed to provide a "low-cost solution using second-rate technology" for poor countries which cannot afford "real rehabilitation".

CBR is an alternative for giving quality rehabilitation. It is built on modern principles no different from those existing in the industrialised countries. It aims at achieving the goal of full social integration and self-realisation.

Social integration cannot be brought about by keeping disabled people in institutions. The community needs to be mobilised, to rid itself of the ever present prejudice, to break the patterns of injustice and to open itself up to full acceptance of its disabled members. Co-operation with the families gives the best results, both in the industrialised and in the developing countries.

To give families a chance of becoming partners in rehabilitation they have to acquire knowledge of disabilities. They must also learn skills to apply a technology built on their experience and adapted to their background. This means - just as it does in the industrialised countries, where families also are involved - that the technology has to be simplified and demystified. This does not in any way make it less effective or a second-rate technology.

CBR is proposed as an alternative to a mostly ineffective and costly system that has contributed to segregation, to a concentration on the few instead of trying to do something for all. The conventional system has tried in vain to operate on a single service level. It remains inaccessible for most people, requiring resources out of proportion to its results. Usually it operates in isolation from the surrounding community.

CBR is not necessarily low-cost, as will be demonstrated below. Its cost level can be tailored to any level desired - but the end product should always be a system that is economically viable while relying exclusively on government and community resources, without outside funding.

Cost alternatives for the functioning of the programme

Below are some examples of cost calculations for a CBR programme. These will facilitate the understanding of the problems related to budgeting and give an idea of national and local costs alike. The numbers given are indicative and build on the experience of field studies.

Before entering into details, we will assume, in these examples, that in country X there will be one LS per each village or city block, and that the average population is 1,000. Among them we expect to find 50 people (five per cent) moderately or severely disabled. For some of these there will be a need to provide rehabilitation. The indicative numbers should be about 2.4 to three per cent for people needing functional training; 0.5 to 0.7 per cent for people needing attention to their special educational needs, and 1.0 to 1.4 per cent for people needing vocational measures. Most young disabled people need to receive consecutively all three types of service. These numbers represent the accumulated needs at the time a CBR programme is started. Later on, they will gradually decrease as needs are being met. Permanent services will subsequently have to be established for about 1.4 per cent of the population.

We assume that the LS will start providing services gradually, and that about 1-2 working days per week will be sufficient.

At the district level, which in these examples is assumed to have a population of 100,000, there will be one or several ILSs (Intermediate-Level Supervisors) and MRTs (Mobile Resource Teachers. These will have no other duties than those directly related to the field work.

Some disabled people will be referred for services that cannot be provided by the local personnel. Some referrals will be to the general health care system for diagnoses and treatment, and I have chosen to exclude the costs for this in our calculations. The health care system is set up for all, and its costs are borne elsewhere in the system of public services. Similarly, the costs for general education, vocational training, etc. are not included in the budget presented here. In each community, some funds are needed for support, especially for disabled members of poor families.

One might distinguish between two types of referrals, simple ones for short-term assessment or rehabilitation, perhaps requiring only a visit for a day or so; and more complex ones, which might require a stay in a referral institution for an average time of, say, one month. These are called referrals I and II respectively.

I have excluded the costs related to the work carried out by the family trainer. This is a difficult and controversial subject. On the one hand there is the fact that many family members are underemployed - how do we estimate the cost of their free time? On the other hand, families who train their disabled members to a higher degree of independence will in the long run perhaps gain more time than they used to spend on training them, thus reducing future costs.

Below are given some examples of costs; these are all estimates for a district of 100,000 people, assuming that 1,400 disabled people will have access to permanent services. Cost for transportation of the district-level personnel (ILS and MRT) is included in the support costs. Support costs at the community level include, for instance, assistance to produce walking devices and other aids, subventions for appliances produced in orthopaedic workshops, school uniforms, books, assistance for apprentices and trainees, seminars/ workshops for leading members of organisations of disabled people, funds to provide legal protection, and travel costs. For each example, the per capita cost and the cost per disabled person have been calculated. The cost given below may be typical of certain countries, but not of others. For each country the appropriate figures have to be introduced. These costs do not cover external contributions from donor and development agencies.

Once included in a CBR programme, disabled people often remain under observation for several years. The most intensive training will be done in the beginning, but later on the skills and abilities acquired will need to be maintained, and after functional training other components, such as schooling, vocational assessment, training, and a job may follow. Newly disabled people will also be identified.

EXAMPLE 1

This example assumes that the LS does not receive any salary or compensation. There is very little personnel (just one ILS) at the district level, and support costs and referrals are kept low.

This example only applies to the early beginnings of a CBR programme; it is, in fact, an example of a minimum-cost level.

	US$ annually for 100,000 population
COMMUNITY LEVEL	
LS, unpaid volunteer (1 per 1,000 pop. = 100 Lss in the district)	-
Support costs (100 x US$150)	15,000.00
INTERMEDIATE LEVEL	
One ILS (US$1,800 x 1), no MRT	1,800.00
Support costs	1,800.00
REFERRALS (annually)	
Type I 10% of 1,400 disabled people at US$25	2,500.00
Type II 2% of 1,400 disabled people at US$100	2,800.00
TOTAL	23,900.00
Per capita cost/year in US$	0.24
Cost per disabled person/year in US$	17.07
Cost for referrals in % of total	22%

EXAMPLE 2

This example assumes that the LS receives a small salary, and that there are two supervisors at the district level and increased support costs and referrals.

	US$ annually for 100,000 population
COMMUNITY LEVEL	
LS, paid in cash/kind (US$100 x 100 Lss)	10,000.00
Support costs	15,000.00
INTERMEDIATE LEVEL	
One ILS, one MRT (US$2,000 x 2)	4,000.00
Support costs	4,000.00
REFERRALS (annually)	
Type I 15% of 1,400 disabled people at US$35	7,350.00
Type II 5% of 1,400 disabled people at US$150	10,500.00
TOTAL	50,850.00
Per capita cost/year in US$	0.51
Cost per disabled person/year in US$	36.32
Cost for referrals in % of total	35%

EXAMPLE 3

In this example, salary levels are increased, and there is more personnel at the district level. Referrals are increased to a higher level and account for close to half the cost.

	US$ annually for 100,000 population
COMMUNITY LEVEL	
LS, paid in cash/kind (US$150 x 100 Lss)	15,000.00
Support costs	15,000.00
INTERMEDIATE LEVEL	
Two ILS and 2 MRT (US$2,400 x 4)	9,600.00
Support costs	9,600.00
REFERRALS (annually)	
Type I 20% of 1,400 disabled people at US$50	14,000.00
Type II 10% of 1,400 disabled people at US$200	28,000.00
TOTAL	91,200.00
Per capita cost/year in US$	0.91
Cost per disabled person/year in US$	65.14
Cost for referrals in % of total	46%

EXAMPLE 4

This example shows a variation of the previous one, with far greater emphasis on decentralisation. Salaries are not changed, but support costs at the community level are doubled, there is more personnel at the district level (upgrading from below), but referrals have been curtailed (15 per cent of total costs).

	US$ annually for 100,000 population
COMMUNITY LEVEL	
LS, paid in cash/kind (US$150 x 100 Lss)	15,000.00
Support costs	30,000.00
INTERMEDIATE LEVEL	
Three ILS and 3 MRT (US$2,400 x 6)	14,400.00
Support costs	14,400.00
REFERRALS (annually)	
Type I 10% of 1,400 disabled people at US$50	7,000.00
Type II 2% of 1,400 disabled people at US$200	5,600.00
TOTAL	86,400.00
Per capita cost/year in US$	0.86
Cost per disabled person/year in US$	61.71
Cost for referrals in % of total	15%

These examples can be varied. It is seen that a large part of the cost concerns the referral level, cost for the basic and in-service training of the personnel, as well as administrative costs have to be added.

Each country should undertake an estimation of the alternatives of the cost of services at. Then it can choose a level of service provision and of costs that is maintainable using national resources. An example of cost calculations from Argentina is shown in Box 12.3[7]. It is clear from the examples that it may "pay" to provide more competence and more funds at the peripheral level of the system.

Box 12.3

EXAMPLE OF COST ESTIMATE FROM LA RIOJA, ARGENTINA

The report from La Rioja, Argentina, contains some interesting comparisons of very different approaches to providing rehabilitation and of the relevant costs. As far as the CBR alternative is concerned, the estimate includes salaries, transport of personnel, office and telephone costs, expenses for secretarial assistance, equipment and printed material.

COSTS/MONTH/DISABLED PERSON	US$
Community (CBR) programme	2.53
Institutional programme	
Ambulatory care	50.00
Hospital care (government hospital)	810.00
Hospital care (social security hospital)	3,690.00

Costs related to the training of personnel

Costs for training of personnel are not included above. These relate to courses for personnel at all levels. The relevant estimates can be made by using examples from other areas of training in government-financed schools and courses.

The costs for training are usually considerably lower than those related to the functioning (see above) of the programme. However, if the particular training system provides for a large number of community workers to be trained, or if there is a high personnel turnover, costs may rise appreciably.

Total cost estimates and financing

These have been divided up to reflect the costs proposed to be borne by the government, by the community, and by external donors.

- ***by the government***

CBR is a programme proposed to be phased in over a period of at least ten years. This should facilitate the financing from government funds, as well as allowing for some evaluation and adaptation during that same period.

Assuming that the government will fund the intermediate and referral levels, the following calculations can then be made based on the examples above. (See Fig. 2.)

To these costs should be added approximately 30 per cent for training and administrative expenses (or any other proportion that has been estimated as realistic). In the long-term plan, adjustments for local currency inflation should be made.

In many countries part of the system may already exist, reducing the requirements of financing. Also, NGOs may agree to finance some of the referral system, and this further brings down the costs.

- ***by the community***

In the examples above, the costs for the community vary from US$ 0.15 to US$ 0.45 per capita. These can be phased in over a period of several years. The requirements for cash are lower if the LS is compensated in kind. As indicated above, communities are unlikely to commit themselves to a CBR programme unless their own funds are spent locally under the control of their own people.

- ***by external donors and development agencies***

Basically external donors and development -

GOVERNMENT FUNDING: EXAMPLES.
COST CALCULATION IN US$ FOR A POPULATION OF 1,000,000

Example	Total cost at full implementation	Annual budget increment if programme developed over a period of		
		10 years	15 years	20 years
1	89,000	8,900	5,900	4,450
2	25,850	25,850	17,200	12,960
3	61,200	61,200	40,800	30,600
4	41,000	41,000	27,330	20,500

Figure 2 Example of cost calculation, government costs for CBR in US dollars

agencies may contribute in two different ways:

- by *funding the developmental costs*, such as training of personnel during an initial period, pedagogic material and equipment, by providing transportation, equipment and facilities during the early period of the programme, by fellowships, seminars, giving assistance to evaluation and research, etc. Funding of personnel, e.g. salaries of intermediate-level supervisors, may be required, but should be financed externally only if the government agrees to take over the salary commitments at a predetermined date.

- by *funding of referral services*. NGOs are already involved in a number of institutions which could form part of a referral system. It is preferable to have long-term commitments, possibly for 10-20 years, so the government can avoid costly surprises.

The size of contributions by external donor and development agencies varies according to the size and density of population, the needs of the country, the size of the programme, its expansion rate, etc. In the example of Ghana (see Box 15.2), with a population of about 15 million, the annual amount contributed totalled approximately US$ 125,000.

It is appropriate to add a few words of criticism of the way technical co-operation has been carried out in the past.[8] The present system as a whole is under fire, for several reasons. These are related to poor co-ordination[9] and "hasty and poor design of technical assistance projects"[10]. Other problems concern insufficient quality in expatriate technical personnel, who are not equipped for the task. "[who are] mixing policy, institution-building, and technical and operating responsibilities ... [are showing] lack of knowledge ... and insensitivity to local cultures."[11] The efforts have not led to sufficient build-up of indigenous capacity, and national institutions have seldom become self-reliant.

The time has come to review the purpose of external support to programmes for disabled people both within the UN system and within bilateral agencies and NGOs.

Redistribution of costs in countries with transitional economies

In some countries, the process of industrialisation has started and the economy may grow rapidly, say between six and ten per cent annually. In such countries, the government revenues increase quickly, and there may then be more funds available to pay for programmes concerning disabled people. It is then common to see that the government starts paying costs previously met through community resources. For instance, the government may start to pay the salaries for local supervisors, take over the support costs at the community level and so forth.

This "assistance" from a central government poses the risk of community involvement being curtailed. The CBR committees may consider themselves unnecessary and resign themselves to the government delivering all the services.

Most governments have not taken a long-term view of the consequences of such action. Community initiatives and local responsibility must be encouraged. The community spirit must survive because no government will ever have the resources needed to maintain a system of cradle-to-grave care for their disabled citizens.

Instead of starting to take over existing and locally funded services, the government may seek to become a Self-reliance Promoting Organisation and to develop a partnership with its communities. This might mean that the government could subsidise certain costs and might, for example, make a contract with a community organisation about the maintenance of services. In this way the local-management will be kept in place and will continue to play an important role; contrary to what has happened in Western countries, the community spirit will not be lost.

6. *CONCLUSION*

The calculations made earlier are meant to give a rough idea of the costs of a CBR programme. They illustrate that there are many cost alternatives for such a programme. Each country should seek to tailor its programme to its needs and possibilities. There are several options: the programme may be a low-cost or a moderate-cost or a high-cost system. Whenever the government has more funds available for the provision of services for disabled people, it should not seek to take over the management of the programme from the community. It is important to promote and maintain the local initiatives and involvement.

COMMENTS AND REFERENCES

[1] Built on not more than anecdotal evidence, this statement was yet quoted in the United States Congress and in a large number of publications.

[2] For a review see e.g. B. Jönsson: Cost-benefit analysis in public health and medical care. Economic Studies No. 112, University of Lund, Sweden, 1976.

[3] For a detailed review see E. Helander: "Enquête économique à propos de la réadaptation", in Réadaptation, No. 264, C.I.P.E.S., Paris, France, 1979.

[4] This set of criteria has been provided by Dr S. Moday, MPN, Headquarters, World Health Organization, Geneva, Switzerland. It has been slightly abridged. These criteria have been formulated on the basis of discussions with authorities in over 40 developing countries and have then been widely used in workshops related to national health programming.

M. Thorburn (see Thorburn, Marfo, ibid.) proposes a similar set of elements that are required in order to go "to scale" with the CBR programme.

1. Availability of a technology
2. An imaginative marketing plan
3. The pressure of political will
4. The development of an appropriate strategy
5. The development of a clear organisational plan
6. Measures for sustaining momentum.

[5] See Chapter Four.

[6] See Chapter Four.

[7] A. Guzman Loza et al., ibid.

[8] E.J. Berg: Rethinking Technical Cooperation, UNDP, New York, USA, 1993.

[9] UNDP and World Bank, "Somalia: Report of a Joint Technical Cooperation Assessment Mission." New York and Washington, USA, 1985.

[10] B. Buyck: "The Bank's Use of Technical Assistance for Institutional Development." Working Paper Series No. 578, The World Bank, Washington, USA, 1991.

[11] Technical Cooperation in African Development. An Assessment of its Effectiveness in Support of the UN Programme of Action for African Economic Recovery and Development 1986-90, UNPAAERD, UNDP, 1989.

CHAPTER THIRTEEN: CBR AND THE ROLE OF DISABLED PEOPLE AND THEIR ORGANISATIONS

Disabled people, their families and their organisations can play an extremely important role within a CBR system.[1]

1. CARE PROVISION

It has already been explained that 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 adults to read and write or contribute to vocational training.

There is evidence that recruiting disabled people as local supervisors for CBR gives excellent results. I am not advocating that all local supervisors 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.

A particularly useful role can be played by successful disabled adults: in the local schools, for instance. (See Box 11.5.) This might be one way of overcoming some of the negative attitudes 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 vocational training and jobs.

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 their human rights are violated, they should approach those in the community responsible for legal protection and ask them to take action.

3. 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 parents' 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 social[2] 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.[3]

At a later stage, local groups may join provincial or regional ones and eventually form a national organisation. Again, 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 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.

Box 13.1

A DECLARATION FROM DISABLED PEOPLE'S 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."

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. The goal should be to obtain formal recognition of the union or federation as a government partner, and to formulate and apply formal procedures for consultation.

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. There is little coincidence of interests between such diverse groups as parents concerned about the future of their disabled children, elderly people worrying about their dependency in daily life activities, wheelchair users confronted with the problem of access to transport and public buildings, blind people without adequate supply of information or of deaf people seeking to develop their own culture, and so on. With interests being so diverse and social, cultural and economic conditions varying widely, each group may want to stay independent. This notwithstanding, disabled people can play an important role in international development - as expressed by Tambo Camara in his introduction to a recently published book[4] : "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." An example of a political expression from an international organisation of disabled people is reproduced in Box 13.1[5]

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. ASSISTANCE TO ORGANISATIONS OF DISABLED PEOPLE AND OF PARENTS

In order to carry out their political and organisational roles, many organisations in the developing countries need economic assistance.

This is often provided by sister organisations in the industrialised countries, or through donor/-development agencies. One of the most often-cited needs 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 types of NGOs such as women's organisations, environmental groups, scouts and community development groups.

Transport is another major area where assistance is required. There are frequent requests for cars, buses and tickets for transport by air. No doubt it is costly to set up regional- or district-level organisations and to arrange meetings of their respective representatives. Few of the existing organisations can meet such costs.

More co-operation is called for in efforts to strengthen the role of these organisations.

COMMENTS AND REFERENCES

[1] 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.

[2] There are many studies which 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.

[3] 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 describes how an organisation can be set up.

[4] Disabled People in International Development (Ed. D. Driedger), Coalition of Provincial Organisations of the Handicapped, Winnipeg, Canada, 1991.

[5] The Vancouver Declaration. Vox Nostra, Vol. 5, No. 2, 1992, Winnipeg, Canada.

CHAPTER FOURTEEN: EVALUATION AND EXPERIENCE OF CBR

In this chapter the subject of evaluation as applied to CBR programmes will be reviewed. The first part will deal with the principles of evaluation, the second with a review of some representative case studies which report the outcome of CBR. Finally, I will also present and discuss some of the different opinions of CBR.

1. PRINCIPLES OF EVALUATION

In the conventional system, many NGOs presented evaluations consisting of subjective descriptions and anecdotal evidence. Their accounts were mostly made to show expenditure.

Larger organisations have often followed an administrative approach, with adherence to objectives (in terms of trained personnel or number of disabled people provided with services), spending and timetable as items of evaluation.

In these types of evaluation, the direct benefits for disabled people, the impact (physical and psychological) on the environment, the sustainability of the programme, and the degree of community involvement are not in every case part of the exercise.

Thus it will be necessary to develop a set of more detailed guidelines for evaluation which will enable us to correctly estimate the five factors[1] described in Box 14.1.

Other important questions concern:

- **for whom** is the evaluation carried out, for instance,
  - for the community in which it is meant to benefit disabled people?
  - for the government?
  - for the donor or development agencies that have contributed to the programme?

They should all wish to monitor the outcome of the programme and to take concerted managerial action to address problems identified in the process of evaluation.

- **who** will carry out the evaluation:
  - internal, or
  - external evaluators?

Evaluations by governments, donor or development agencies should preferably be carried out by external evaluators.

- **when** will the evaluation be carried out?

It is useful to have quarterly reports as a way of monitoring the programme, and to hold annual meetings of all those concerned.

2. REVIEW OF PUBLICATIONS, DOCUMENTS, AND OTHER MATERIAL RELATING TO EVALUATION OF CBR PROGRAMMES

This part of the chapter does not intend to review the entire literature on CBR. For a bibliography and a database, I refer the reader to other sources[2]. Below follows a summary of studies from various parts of the world: Argentina, Guyana, Jamaica, Kenya, Nepal, the Philippines, Vietnam, Zimbabwe. The relevant texts contain many details, as these are case studies that report not only on achievements but describe, moreover, the difficulties a particular CBR programme is meeting. I should perhaps add that, apart from an occasional visit to three of them, I have had no part in any of these programmes, and that I am relying on reports produced by each author.

When reviewing case studies and descriptions of the results of CBR programmes, is should be useful to keep to the distinction between evaluation of

- technology,
- service delivery, and
- management system.

Ideally, an **evaluation of the technology** would consist of measuring the progress made by disabled individuals following a CBR programme.

Any such attempt would presuppose a careful baseline study, followed by an equally careful evaluation of the achievements by the end of the training period. One way of doing this is to emp-

Box 14.1

FACTORS TO CONSIDER IN THE EVALUATION OF CBR

Factor	*What to look for*	*Comment*
Relevance	Does the programme meet the needs of the disabled people, their families and communities, and does its purpose remain valid and pertinent?	As long as we have disabled people in our societies, a rehabilitation programme will be needed and should remain relevant, provided the needs have been properly identified and met in an individualised way.
Effectiveness	Did the programme achieve its objectives both in terms of benefits for disabled people and population coverage?	The programme objective should be formulated beforehand. It should specify the diminution of the degree of disability (quality) and the population coverage (quantity) to be achieved. Targets should be realistic, taking into account both the available resources and the constraints.
Efficiency	Were the resources made available used in the most efficient way?	This relates to the management of personnel, training programmes, means of transport, budget provisions, and so forth.
Sustainability	Will the programme continue once external assistance is withdrawn?	Where a CBR programme has grass-roots, where the community feels that it owns the programme and that it is responsible for it, where the government continues providing its part of the support, the CBR programme should be sustainable. External donors should take care to not introduce components that cannot be maintained by national means.
Impact	What effects has the programme had on its institutional, technical, economic and social settings?	A CBR programme may have an impact on the attitudes and behaviour among the non-disabled. For example, disabled people may be better accepted and given more equitable opportunities and representation. It may bring about removal or reduction of physical barriers.

loy the assessments proposed in the TCPD, and this has indeed been done in some of the publications on this subject (see e.g. Lagerkvist). More complex evaluation systems have sometimes been used (see e.g. O'Toole). It should be relatively easy to design a standardised system of quantifiable indicators.

Preferably such assessments should be performed by outside evaluators.

It is important to evaluate the efficiency of the CBR **service delivery** system. One example of such a system is described in Chapter Ten, i.e. the immediate training at home done by a family member under the supervision of a community worker, who in his/her turn has an ILS as well as access to a referral network, but there may also be others. A review should cover all the sectors (functional training, services to meet special educational needs, vocational measures and so forth). This requirement is met by some studies. (See e.g. O'Toole, Thorburn.) But in many of the projects, there has been a long-term presence of expatriates, which most likely has had a bearing on the results. Results achieved by nationals having only access to short-term inputs from outside experts are more revealing (see e.g. Mendis; Saunders and Zinkin).

It would be ideal to follow the progress of the programme, in particular the coverage achieved; to evaluate whether or not the training of personnel has been adequate in providing sufficient competence; and further, if this competence is being applied in the proper way. On this subject there are fewer studies - and this is common in all development projects: most outsiders are technology-oriented but not especially concerned with the question of how the technology can reach all the target groups.

Regarding the evaluation of the **management system**, there are some specific questions of relevance. These concern, firstly, the commitment of the government and the resources provided by it. Has the government shown clear indications of its willingness to build up a functioning management system able to eventually cover all those in need? Secondly, are the communities being involved, and if so, to what extent? What is the degree of self-reliance, sustainability and responsibility assumed by the communities? As far as these factors are concerned, it is not easy to provide a quantified evaluation system. To begin with, until a way of quantifying the indicators has been found, one may have to make do with descriptions of the action taken. Few studies exist on this aspect of CBR. (See e.g. Arnold).

Field studies

The earliest study on the effect of CBR was published by Mendis and Nelson[3] (1982) and was based on observations of a total of 417 disabled people who had participated in a CBR programme. The authors had visited and followed-up the results in five countries - Botswana, India[4], Mexico, Pakistan and Sri Lanka. Improvements were seen in 78% of the disabled people participating in CBR. This was an early indication of the effectiveness of the technology; it was followed by a number of more elaborate reports focusing on the delivery and management systems.

O'Toole (1988) has presented an evaluation of a CBR project initiated by him in Guyana. Its purpose was to scientifically evaluate a "small scale experiment genuinely questioning the validity and potential of the approach."

The experiment started by inviting volunteers to participate in the execution of the project, and out of those who applied, 26 were accepted (nurses, teachers, clerks, technicians and housewives). O'Toole also engaged a group of nursery school teachers to undertake the experiment in another rural area.

Both groups of "local supervisors" underwent a CBR training programme. Three co-ordinators were recruited to supervise and guide the execution of the programme: the investigator, an educational psychologist, and a senior physiotherapist.

In the areas of intervention "53 children were identified to work with: 3 cerebral palsy, 22 epilepsy and mental retardation, 5 Down's syndrome, 7 deaf, 7 speech problems, 6 physically handicapped and 3 undiagnosed." The children underwent a home training programme; in each household, a person was trained to help the child. Activities suggested by the local supervisor (LS) were shown to the trainer, then the latter would try the activity and finally discuss it. The LS kept a "detailed diary" of what was happening with the programme.

O'Toole used a multiple-baseline design and evaluated the outcome of the project using several different techniques applied "pre, post and 6 months after the end of the programme". The results were as follows:

a) Portage assessments: "The success rate was 77% based on the children who completed the programme;"

b) Griffith's assessments: the results were positive and "significant at the 0.01 level;"

c) assessments by independent evaluators: these were based on "interviews with mothers, observations of the children and field-journal entries". In this part of the study, 30 children are reported to have undergone a complete training programme (out of the initial 53 identified children, 7 were trained without involvement of the LS, 9 others did not participate, and 8 had moved). Out of these 30 remaining children, 11 had "markedly improved", 6 were "moderately improved", 6 "showed a little improvement" and 7 "no improvement". The results for the volunteers were consistently better "than those of the nursery school teachers;"

d) assessments made by mothers: 85% of the mothers of the children trained by the volunteers "found the programme 'very helpful'". All these mothers "saw noticeable change in their children as a result of the programme"; several of them "noted their children being happier, more independent, better behaved, more mobile and more motivated". The corresponding results regarding the mothers of the children trained by the nursery school teachers were less positive (72% found it helpful and 6% saw noticeable change).

The degree of progress did not seem to be dependent on the educational level or the financial resources of the parents nor did it seem to be related to the degree of impairment. A more significant factor appeared to be parent involvement in the programme.

O'Toole summarises the study as follows: "The response of the mothers, the rehabilitation therapists and the administrators revealed that the concept of simplified rehabilitation was acceptable. The work with the volunteers suggested that it is feasible to train persons from the community to work with disabled children. Throughout the programme however the volunteers were significantly more involved than the teachers, thereby questioning the infrastructure through which the project can be introduced and maintained. ... parental involvement is a realistic proposition... The majority of parents accepted the role. ... The attitudes of the mothers improved as a result of the programme. One of the most satisfying features of the project was the real involvement of the community. ... The project truly became a community-based model of rehabilitation."

Arnold (1988)[5] describes a successful project carried out in Nepal, and concludes: "All CBR programmes need to be set in a broader context of community development to be truly effective in integrating the disabled into the community.

"The great strength of such programmes is that they do not require huge additional inputs from governments already hard pressed but rather a creative redirection of existing resources in order to develop and expand rehabilitation services. As such they can be appropriate and replicable in many parts of the developing world.

"However, this great strength is dependent on political will. To be successful in more than a few pilot projects this approach requires a commitment to make rehabilitation professionals available to supervise, encourage and advise the community rehabilitation and health extension workers, the teachers and the families. Without such support community rehabilitation schemes will fare no better than primary health care schemes in similar circumstances.

"Family support programmes are proving themselves to be a viable alternative. Indeed they are an extremely effective way to achieve our goals giving the child a chance to develop his potential and find a useful place in his own community.

"We are in a position to do a great deal to prevent most disabilities and to effectively assist those already disabled. What we need is the will to deliver."

In 1987, Mendis[6] was recruited to start a CBR project in Vietnam. Initially four villages were selected, and three more were added later on. During the initial assignment, Mendis visited the relevant authorities and existing services, and the objectives of the project were formulated, a plan was made in co-operation with the authorities, management structures were set up and a one-month training course for selected staff at the intermediate level was held. In this Chapter, a very detailed account is given of the Vietnam programme - in a case study showing how the CBR strategy is adapted in a flexible way to the realities of a specific country. The early efforts described here developed later on - thanks to the dedication of the government and to the involvement of the communities - into a large-scale programme. By the end of 1992, the CBR programme in Vietnam covered a population of more than three million.

The following objectives were formulated for the project:

(i) to gain experience in integrating CBR with the PHC system;
(ii) to assess the delivery system and personnel needs of CBR;
(iii) to assess the effectiveness of CBR technology as described in TCPD and to determine the adaptations necessary for Vietnam;
(iv) to evaluate the impact of CBR on the lives of disabled people, their families and the communities;
(v) to assess and develop a system for recording, reporting, monitoring and evaluating rehabilitation;
(vi) to develop a provincial/regional teaching and demonstration area for rehabilitation.

The project was visited one year later to carry out the evaluation in co-operation with a national team, and the most important results are summed up here.

At the beginning, managerial (steering) committees had been set up at all levels, and these functioned well. The team "noted the attention to detail ... and careful delegation of managerial responsibility at each level". "A striking feature was the synthesis between group responsibility and decision making, and the personal dedication of individuals in carrying out functions assigned to them." A total of 116 PHC workers (37 male, 79 female, average age 23 years) had been trained for periods ranging from 20 to 24 days, using the TCPD. One year later, 63% of these worked in the project. The training costs amounted to US$ 275. At the end of the course, the performance was evaluated as excellent in 21%, as good in 63% and as average in 16%.

A number of detailed results are reported by Mendis, and I will only mention some which are particularly interesting. "In most instances trainers were family members - mothers as well as fathers, grandparents, brothers, as well as sisters. In instances where family members were not available (e.g. elderly people living alone) the public health workers (PHW) have taken the role of trainer. In such cases PHWs were often relatives or very close neighbours. In the future, however, PHWs will delegate this role to others". - "99 Vietnamese manuals were used in 46 hamlets. Some of them were kept by the PHWs for reference and others were taken apart for distribution." - "Following discussions between family health workers, people with handicaps and their families, home based training was started. This was generally started with the easiest needs to meet and then progressed." - "In all instances where technical aids were necessary for people with mobility handicaps, the family had made them, using the training material given them from the Vietnamese manual; support was obtained when necessary from the primary health care workers, and then if necessary from the assistant doctors or the physiotherapist." - "Assistant doctors spend 3-4 days a month for home visits with primary health workers to give necessary support for all PHC activities, including CBR. A physiotherapist from the district visits the communes once a week to give necessary technical support." - "Children and adults with schooling needs and need for economic productivity were discussed at steering committee level. Home visits were made by the community leadership and members of mass organisations etc. to discuss possible solutions, most of which was successful." - "Overall, very few referrals had been made to higher levels. Vertical programmes for mental illness, leprosy control and trachoma control reach down to the commune health stations. So there was no need for higher referrals for these areas."

Regarding coverage, Mendis reports: "Personal interviews were held to determine the following:

(i) The level of rehabilitation needs coverage of the project
(ii) Whether all the rehabilitation needs of people with handicaps had been included in the 23 questions on Form No.2

"Measurements in this area were hardly necessary because all those interviewed (individuals with handicaps and their family members, primary health workers and the community leadership) expressed their satisfaction with the needs coverage related to both aspects above, and could offer no suggestions for improvement.

"Disability arising from a wide variety of disease was noticed - cerebral palsy, poliomyelitis, psychiatric illness, epilepsy, Down's syndrome etc. etc.."

On effectiveness of functional training, Mendis says: "The effectiveness of technology was assessed by sampling during household visits. Records kept at the Health Station and in the home were used as the base for providing information regarding rehabilitation needs and the status of the need. Three levels were used - total dependence, assisted, supervised or occasional and independence. Individuals were assessed to determine measurement in terms of achievement of steps of progress.

"Four areas of rehabilitation were used for this measurement: Self care activities, mobility, communication and socialization. Schooling and income generation have already been assessed on targets.

Findings are listed below:

	"ACTIVITY	ACHIEVEMENT RATIO
(I)	Independence in self care	85%
(II)	Independence in mobility	90%
(III)	Communication	40%
(IV)	Socialization within family and community	81%

Analysis of rehabilitation needs of people with [disabilities] reveals that prevalence of the need is highest in the area of self care followed by mobility and socialization, and the proportion of communication needs is relatively lower.

The high success levels recorded in areas of greatest needs indicate a high level of effectiveness.

Communication training and re-training is acknowledged to be an area of lower achievement even with skilled specialization. Moreover many of the children with this need are children who have Down's syndrome [and] who improve little in this activity. On the other hand, in spite of the lower effectiveness of communication training the fact that children with this need have now been at school for 2 terms and that both children and adults with this need have had success in socialization is significant. The achievement level of 40% should therefore be considered satisfactory for a project of 8-9 months duration. There is however a very strong need for improvement of technology for community level training in this area."

On schooling, Mendis goes on to report: "The integration of 34 children of varying ages between 06 - 15 in the existing school system in so short a time is a remarkable achievement. Of the 11 other children of school age who have not yet started schooling, nine have very severe disability and it seems unlikely that they will be able to attend the primary school. Therefore in real terms achievement in relation to need may be 90% and ratio to target 300%.

In some communes school teachers were included in their training courses for primary health workers which increased their motivation and involvement. Members of mass organizations, in particular of women's organizations, participated in counselling and motivating hesitant families regarding the importance of educating their children who have handicaps. The People's Committee members responsible for education or the Director of Schools are members of the Steering Committee for Rehabilitation. Teachers have the "Guide for Teachers" from the Vietnamese Manual and find it useful."

On economic productivity: "The interpretation of this term was often discussed with the conclusion that it was necessary to use this in the cultural context - where economic productivity is a collective effort of family members together, contributing to the productivity of Brigades (groups of families) or contributing to the productivity of cooperatives (groups of brigades).

"Many people with handicaps who were not previously doing so are now contributing to the collective effort of economic productivity of their families be it in the cultivation of rice, fruits and vegetables, in fishing or animal farming, in the making of handicrafts and utensils or in the marketing of all these.

"Progress in this component was evaluated only in respect of people who were visited at home and represents a very small sample which does not reflect the level of achievement. However there is no doubt that there is room for improvement in this area of rehabilitation."

Regarding the use of TCPD: "Assistant doctors, physiotherapists and primary health workers expressed the view that TCPD is invaluable for performing their role in rehabilitation. Relevant training material was well selected for distribution to individuals, and although kept carefully between sheets of old newspaper and magazines appeared to have seen frequent use. It was always produced at the commencement of each household visit. When relevant, advice and instructions had been carefully followed and at other times, adapted with remarkable innovation to suit the individuals' varying needs and environments. Users commented on the unique suitability of the Vietnamese Manual's text and drawings to their socio-cultural ethos. Moreover it was considered useful to [both] technical people and lay people alike."

"Assessment of the knowledge, skills and attitudes of both the intermediate level manpower and of the primary health workers and the effectiveness of their performance indicated an adequate basic training and preparation for their role in CBR.

"The 3 year training course of assistant doctors and their previous experience in the health sector no doubt enabled them to undertake the teaching function successfully even though it was their first experience of doing so.

"In general, primary health workers have had several years of secondary schooling which enabled them to use the knowledge and skills learnt in 3 weeks and develop them further."

Mendis reports that, after one year, 61% of the 141 trained primary health workers were still active in the programme, but that 32% had dropped out and 6% were working irregularly. She explains that too many had been trained and that the drop-outs had been mainly due to the fact that these trainers tended to work in small hamlets with no or only few disabled people. The training targets had then been adjusted accordingly.

Regarding intermediate level support, Mendis observes: "The project [in one province] has demonstrated with clarity the ability of the assistant doctors to manage, organize and administer the project in their commune. The ability to utilize and develop the technical knowledge and skills of rehabilitation learned during a one month course ...demonstrates their ability to continue to give some degree of technical support to primary health workers and families.

"That the technical support given by assistant doctors alone is insufficient to raise project output and quality to a significant level has also been clearly demonstrated. This has clarified the need for involvement of physiotherapists to provide the specialised rehabilitation technical support.

"[In this province] assistant doctors and physiotherapists have cooperated and collaborated closely and successfully to produce good project output and quality. [In another province] this cooperation and collaboration was unfortunately lacking. This, together with the non-involvement of assistant doctors and of primary health workers, and insufficient delegation of responsibility to the community leadership, has resulted in the district project continuing to be more of an "outreach" project rather than a community-based one. Steps were taken to correct this problem."

On project management: "Much of the success of the project must also be attributed to the high level of managerial inputs to the project.

"Management at district and provincial level has included overall direction and monitoring both through a reporting system and through monthly field visits from officers delegated by the district and province health bureau.

"A satisfactory reporting system has been developed from hamlet through the commune and district to the province and National Steering Committee.

"Management at Commune Level has included home visits to primary health workers for problem solving with families and a bi-monthly group meeting with primary health workers at which the project is discussed.

"Management at these three levels has given the project direction and guidance necessary for success."

Mendis concludes: "(i) The greatest success of the project lies in its impact on the lives of people it served; - those with handicaps, their families and their community membership at large. This impact appears to be immeasurable. Changes it has brought about in this short time are often dramatic and have served to stimulate an awareness, interest and satisfaction in the membership that the rehabilitation needs of members with handicaps can be met through their own community efforts.

"The low number of people who needed rehabilitation in the project area may lead one to doubt the depth of the impact of this project. In this regard, the evaluation team noted particularly the pattern of disability seen generally (moderate to severe, many adults for example being completely bedridden for several years, children being totally dependant) and the consequent deep impact that success achieved with each individual had on their own life, their family and community.

"(ii) Education is of very high priority in Vietnamese Society. There is much satisfaction therefore that children who previously appeared to have no future are now going to school alongside non-disabled children. There is understanding that these children will not achieve much academically, but the social benefits have begun to show, and with it generated sufficient determination to make integrated special education a success.

"(iii) Mothers express their relief at the lifting of the burden of constant care, leaving them more time for other tasks. Fathers show satisfaction that their children who appeared to have no future can participate in family and community life. Relatives and neighbours have rallied round to contribute what they can, be it as trainers or be it in making the technical aids that have been another proven area of total community self reliance. Elderly people with handicaps describe their happiness at their renewed independence and removal from isolation and loneliness, and the interest that is once again being shown in them.

"(iv) The usual beliefs exist also in Vietnamese Society that people who have disability are a punishment to the family, are useless and a burden, brought ill-fortune, etc. etc.

"Personal interviews both with community leaders and with neighbours show a positive change which they account for by the increased understanding about disability and by the success demonstrated in the lives of individuals being rehabilitated, which increased hope and confidence. This has brought about increased community participation in the project and has strengthened relationships both within families and between families."

"(v) These social benefits appear to have a strong impact on the community (political) leadership. Although there was political support for the project from its beginning in 1986, the community leadership said that they had been concerned about the technical nature of the project. Any elements of doubt which persisted at the beginning they said were dispelled with early results, and they now consider this very much as a social development project.

"(vi) Leaders appear to have good contact with people who have handicaps and their families, visiting them often. They say their satisfaction increased with visible results. Seeing for themselves the impact on individuals and families, they responded to increasing demands with increased support for the project.

"(vii) The leadership feels that the project has increased community confidence in the leadership, has brought the community membership closer and has strengthened the community spirit. This has in turn increased community motivation and involvement in other community activities. For example, families that have benefited by the project show an increased motivation for economic and cultural productivity."

Regarding costs, Mendis reports: "All costs related to the training course for primary health workers (midday meal, tea, stationery) was met with funds mobilised by hamlets and cooperatives in the 6 communes. Certain supplementary payments made to primary health workers were included in the budget.

"Costs incurred by the District Health Office and Provincial Health Office were for monthly monitoring, monitoring in October and evaluation in March and included expenses related to stationery, printing, petrol and transport. "The costs incurred by the District Health Office and Provincial Health Office were met by budgetary inputs from the District People's Committee and Provincial People's Committee respectively."

"The financial self reliance of this project must be noted."

For a period of four years, financial contributions made by the Swedish Save The Children Fund amounted to US$ 78,000 to cover costs for consultants, training courses, paedagogic material and similar. The remainder was paid for by local and government contributions - and these costs were very small.

An outside evaluation of a CBR programme carried out in Kenya has been reported by Saunders and Zinkin (1990).[7]

The programme in question was set up in 1983 in order "to identify and develop simple rehabilitation plans for children under the age of 15 affected by all types of disability". The programme employs national personnel and had, at the time of the evaluation, worked with about 300 families and their children.

"The following activities are part of the programme: home visits by community rehabilitation workers undertaking identification, home training and follow-up; play-groups for children and parents; production of aids, appliances and equipment; a child-to-child programme ....in primary schools; support to the integration of disabled children in ordinary schools; training workshops for parents and community leaders; and referrals to specialist ...centres; efforts had started to extend the activities into promotion of associations of disabled people and into vocational training and employment schemes."

The evaluation was carried out on a representative sample. The report contains no statistical data but a large number of observations. It arrived at the following conclusions:

"... there are effective community solutions to a significant proportion of the problems ... for many children it is possible to provide medical rehabilitation and ensure full educational and social integration. Parents have demonstrated a readiness to be involved in home-based programmes, local teachers encourage integration in the ordinary primary schools, and community awareness of disability issues is increasing.

"For a small number of children ... with multiple disabilities, especially those with severe mental handicap combined with epilepsy and cerebral palsy, or those with mental handicap and severe behaviour disorders, solutions are not easy to come by. ...CBR workers do manage to support such families. This form of intervention may have minimal long term effect on the child's disability but can significantly improve the family's mental health. ... a substitute for [regular visits by CBR workers can be] found in the form of formal or informal parent groups. CBR workers have developed an exceptionally good home visit practice which is having real impact"

"Coverage is still partial ...[but] the team is confident that they can ... cope with more. In addition the process of establishing a community support network through CHWs, play-groups, and the Parents and Friends Associations relieves the CBR worker of certain responsibilities for individual families. We know that Community Based Rehabilitation is the best form for rehabilitation for the disabled person and the family. We must also assume that, given increasing awareness within the community, the barriers currently faced by disabled people can be lessened. Community support and community knowledge are essential ingredients of this process. The interrelationship between primary health care and CBR, and the experience of training traditional birth attendants and community health workers are also reviewed."

"Parents and Friends Groups" have been set up in four different locations. These groups were independent, acted mostly as pressure groups and raised funds locally to support their activities. The report includes a reference to the fact that in one such association "the parents also thought they would like residential facilities ...the school where children from a distance would stay. They were not clear how this would function, and it would be ..... for the CBR team to discuss this with the parents' group, advising them of the possible dangers of this developing into a residential institution, with all the associated problems for the children and the community programme.

"Playgroups provide every opportunity for parents to see the value of play and stimulation activities for their children ... they form an essential feature ... and it is important that ...

coverage ... is extended. The "child-to-child" component of the programme "was not impressive."

Contacts with the government showed that the programme was done "in consistence with the policies of the Ministry of Education and Health, and received the full support of the local authorities."

A. Guzman Loza et al. describe their experience from the La Rioja province in Argentina, where CBR was attached as a module to PHC. In the first phase, a survey was carried out, revealing a disability prevalence rate of five per cent. Training using the TCPD was given to 32 sanitary agents, and the training was then expanded until, in 1988, the CBR programme was included in all the zones covered by PHC. The project was led by a physician specialising in rehabilitation and an occupational therapist.

Guzman et al. state that "from the beginning we have affirmed that to work in the community is not easy. ... the community attitudes in La Rioja are not different from the rest of the country. The characteristic is that people are always awaiting all the possible help from their leaders ... our communities need a continuous motivation for achieving common actions and solidarity. ... With many difficulties ... a local group was found, the members of which mainly were non-disabled. The group seeks to mobilize funds to support the purchase of aids and equipment and the medicines for psychiatric patients. A community drugstore, selling at low costs, has been set up.

The TCPD had been adapted for use in Latin America and only a few modifications were needed related to early stimulation and production of aids using local material."

Regarding the local supervisors, Guzman et al. state that "from the beginning they worked with sanitary agents, who were engaged in PHC. CBR was added as a component and the results were positive. But there were some managerial difficulties. PHC workers were part of the health services and received their instructions from a different manager. So our CBR programme depends on the willingness of the person in charge of the PHC program." Later on Guzman et al. also trained volunteers from the community.

The person in charge of the sanitary agents acted as intermediate-level supervisor. These agents were assisted by rehabilitation professionals, mainly occupational therapists. These were given a 50-hour basic course as part of their professional studies at the university. The course consisted of five modules using the TCPD and appropriate parts of the WHO Management Guide, and covered the various aspects of technology, community participation and management. The teaching staff consisted exclusively of nationals. Following this experience, Guzman et al. note that "we consider that the most difficult to obtain in our professionals is a change of attitude referred to the framework, due to the differences between the community and institutional approaches. Specially it is difficult to change the "attitude of authority". ...[Through] theoretical content and good practical training [such attitudes] would be modified [and would make the professionals] feel comfortable outside of the institutions."

Regarding "community participation, it is important to take into account the folk or culture of each country, because in some countries [as in Argentine] there is not much [experience of such] participation."

Guzman et al. give no numbers to describe the outcome of the training of disabled individuals but confine themselves to stating that "the results are positive. Community participation is the most important aspect of the programme. There is not a unique method, it depends on the characteristics of communities. The attitude of rural communities is quite different from that of the city districts. To achieve integration is also more easy in rural areas. Although we can inform that in both areas [urban and rural] we have achieved good results."

Based on many years of experience in the Caribbean, Thorburn[8] offers the following advice concerning community workers:

"Selection.

"Anyone can be selected from any background, but serious intent about work, motivation to assist others in need, an empathetic and respectful (rather than a pitying) attitude towards disadvantaged persons, good health, stable family background, and literacy (if the programme is in a largely literate population) are essential qualities.

"Where existing staff are to be trained for a special project, selection needs to be based on positive attitudinal characteristics of empathy towards children and disadvantaged persons, good observational skills, and evidence of being able to establish good relationships with all levels of staff. Interest in learning new skills, accepting supervision, and interpersonal communication skills are also important.

"In situations where new people are being recruited, especially if the programme is advertised, persons with too high academic qualifications will tend to drop out because of increased social mobility and work options. Orientation workshops and volunteer working sessions provide opportunities to observe the characteristics outlined above and have proved to be effective methods of selection in our programme.

"If continuity of employment is an indicator of good selection, 8 of the original 16 trained in 1975, and five of the first 8 trained in 1985, are still (1990) working in the same jobs. Of those who have left, most have emigrated or gone on to higher education.

"Course content for New Workers.

"The total length of training and the exact content will depend on the tasks required of the CW and their previous training and exposure. ... In some of the training courses trainees have differing levels of education and training. This can be overcome by preparing a training matrix in which the different topics are targeted at each ... according to need. Lower levels of staff usually need more time to learn the new techniques and the more senior staff can be used to help them learn and practice.

"Hands on Practice.

"This is essential for community-level persons, especially for technical skills. It is easy to arrange if there is an ongoing service from which clients can be brought in for demonstration and practice. If training is being conducted for the first time in a new area, the basic course can be split and after the first week the trainees can do a survey or go out and find the clients to practice the identification procedure. Cases so identified can then be brought in and used for the other tests. In our projects, many of the staff are drawn from the parents of disabled persons, so they bring their own children. When the new staff need more practice, they go out with more experienced workers and practice on their clients. In teaching developmental screening, health clinics and day care centres are used to obtain normal children for practice.

"The Trainers.

"Ideally, local professionals should do the training, if possible. However, although well qualified professionals are often available and willing, they have little or no experience in working or teaching this level of person and tend to make their presentations too academic. The second option is to utilise persons from other developing countries, but such people must be completely familiarised with the needs of the programme and must be prepared to be flexible and adaptable. As stated earlier, they should be involved in a task analysis of the roles of the personnel involved and plan jointly with local programme directors. If the three basic prerequisites for training described above are adhered to, external consultants should be involved at least 2 to 3 years into the programme for morale support, continuity, and quality control.

"Programme Philosophy.

"This needs to be fully discussed in the planning stage and during the training itself. Currently, in the Caribbean, there is a general acceptance of the principles of normalisation and integration at a superficial level. In practice, however, funding and other practical constraints may push people into solutions which are expedient but not in keeping with such a philosophical approach. People at the community level may not have given much explicit thought to this topic, but talks and films showing the situations and group exercises can test the trainees' reactions in different settings. This often brings out strong positive feelings.

"Part-Time, Full-Time, or Volunteer.

"This is not so much an issue of training but of the utilisation of personnel in different settings and programmes. All are possible but each has its own constraints. The projects described here have utilised all these alternatives. There is also the question of whether a person can do specialised rehabilitation work along with working in a generic programme, such as health care or day care.

"In the Jamaican projects, the CWs have all been full-time disability workers and are paid. We have taken the route of developing a new cadre of worker, which, we think, could be absorbed, in its specialised role, into a generic programme. I have had no experience with volunteers in Jamaica, and many people do not think it is feasible or satisfactory where economic constraints force people to find work. The type of volunteer widely available in developed countries is not able or willing to do the demanding job of a CW where transportation is hazardous and unreliable.

"In Trinidad, the project started out with a large group of enthusiastic volunteers but during the training, the numbers dwindled to about half. After training was completed, with a worsening economic situation, most of the volunteers dropped out. Approximately six returned when remuneration was offered. In Belize, an initial project started in 1985 by a Peace Corps volunteer with Red Cross volunteers lasted about three years.

"Regarding the issue of generic workers doing disability work, this was the case in Barbados (in day care) and Grenada (day care and primary health care). The former was evaluated one year after training was completed and there were a number of logistical problems which could have been solved with reorganisation. More recently, Rock (personal communication) felt that the workers in the day care programme who were caring for disabled children should be full time on this responsibility. In Grenada, the programme has not yet been well enough established to draw any conclusions. In St. Lucia and in Jamaica, trials of the WHO CBR approach were conducted in 1981 and 1982 respectively. Previously also, an attempt had been made to train community health aides (CHAs) in Jamaica in 1980. Both Jamaican projects were abandoned after only a few months as no policy for the introduction of CBR into the primary health care system had been established. Although the CHAs were receptive and willing, pressures of other work and lack of support resulted in very little work being done.

"In St. Lucia however, an official policy was established and the programme still continues. At present, there is an attempt to improve the early intervention aspects (Jolie, personal communication) by in-service training of staff with the instruments described above.

"Professional Supervision.

"Professional supervision is essential for programme quality and support. Three of the above settings have experienced setbacks due to inadequate support, monitoring, and programme direction.

"In Jamaica, our project experienced a 20-month period in which a rehabilitation coordinator could not be found. The programme suffered in loss of morale, poor record keeping, inadequate follow up of clients, loss of quality in home programmes, and, of course, lack of acquisition of new and maintenance of existing skills by Cws. Lack of supervision also played a role in the failure of the Jamaican primary health care projects.

"Conclusion.

"From the above experience it can be concluded that the potential for using and training community-level personnel for childhood disability services is very great providing precautions are taken to maintain training, quality control, supervision, and motivation. Our experience in using parents of disabled children as workers has been very rewarding, though we have not as yet compared their quality of work with nonparents.

"Out of this experience and the use of different techniques of varying levels of sophistication, a conceptual framework is the need for opportunities for professional advancement for those Cws who have the ability, initiative, and education to advance up the ladder. In the past 5 years, three of our Cws have gone on to professional training in special education and three have taken courses at the Extra-Mural Department of the University."

Lagerkvist (1992)[9] has undertaken a scientific outsider evaluation of two CBR programmes: one in the Philippines and one in Zimbabwe.

The programme in the Philippines started in 1981[10] and has been "managed and supervised from a rehabilitation centre. It was based on local supervisors (LS) who were community workers. They had been recruited from the village, where each one was expected to work for 1-2 days a week with 4-8 disabled persons. They had a short training for some weeks based on TCPD, and from the beginning they were employed on a voluntary basis.[11] After one year they were upgraded. The LS identified disabled persons in house-to-house surveys and assessed them or referred them to the centre for assessment, and started training using training packages from TCPD and a trainer in the family. The LS supervised the training closely in the family, being guided by staff at the rehabilitation centre. In 1988 this CBR programme comprised a total of 573 disabled people under active training in 53 barangays (villages) and cared for by 107 Lss.

"In Zimbabwe the CBR programme[12] had been run by the Zimbabwe Red Cross in two districts since 1985. Two rehabilitation assistants with 1-2 years medical education were responsible for assessment of clients, analysing a rehabilitation plan for each client, keeping records and referring clients when necessary, and training local coordinators and volunteers. The local coordinator was a community worker with some months of medical training. She was responsible for 300-400 disabled people in her area, identifying them in a house-to-house survey, arranging for assessments by the rehabilitation assistant, identifying a trainee in the family and a volunteer to assist the family, and following up the training. In the programme 1755 clients have been visited and trained. The rehabilitation assistants and local coordinators have continued the work for several years.

"A sample matched for sex, age, living area, and type of disability was drawn from the disabled clients in the two CBR programmes, yielding 106 people in the Philippines and 100 in Zimbabwe. Criteria for selection included that subjects should be 4 years of age when the programme started or be entered into the programme more than 6 months before evaluation - significant improvements would then be expected to result from the training; be functionally disabled when the training began, according to the evaluation instrument used; be from different families; and be given a diagnosis falling into the groups used for the WHO CBR programme.

"Subjects were visited at home (85%), at school (9%), or in special workshops for disabled people (4%). Present at the home visits were the family and people from the CBR team responsible for that individual. The visit included history taking, testing the ability of the individual, investigation, and discussion of the findings. The individual's record was always available.

"The history was taken from the CBR team, and checked with the subject and also against the CBR record. Occasionally, discrepancies were identified, and a consensus was arrived at by discussion between the individual, the CBR team, and family members. The history was focused on the cause of disability, the social situation, the ability of the subject when taken into the CBR programme, and achievements made up to the time of evaluation. A structured form was used for registration, consisting of Form 2 from TCPD with added scoring.

"Current ability was tested in activities such as eating, dressing, talking, sign language, lip-reading, walking, and moving around. Appraisals were based on observed performance and on verbal descriptions of the activities, and served to confirm the already reported abilities of the subject. Ability was scored and compared against what could be expected of a non-disabled person of the same age and sex. Ability before the start of the CBR programme was judged from the verbal history and records.[13]

"Increase in ability score reflected the individual's benefit from the CBR programme. An increase of two points on one variable indicated an achievement from none to top function during training, whereas an increase of one point reflected achievement from none to intermediate or from intermediate to top level of function. No increase in the score indicated top function was present at the outset, or that there had been no achievement. Variables 17 and 21 could not be included in the scoring and so have been presented separately.

"Disabilities were assigned to six types recommended in TCPD, and the variables relevant to each are presented. Variables where no functional limitation could be expected for disabilities of a particular type were not included. For instance, moving difficulties are not relevant to individuals with hearing difficulties and assessment of speech is not relevant to the blind. The severity of disabilities was classified as mild, moderate, or severe based on activities of daily living (ADL) relevant to the type of disability; the last covered moving (including sitting and walking), learning, strange behaviour, and seeing. The severity of hearing and speech difficulties was based on communication abilities, and of the severity of fits on the frequency of convulsions. An index of social integration was designed in a similar manner, based on variables 16 for those aged 4-16 years or 19 for those above 16 years, and variables 18 and 20."

There were 53% males and 47% females in both samples, the age was between 5 and 83 years.

The main results of Lagerkvist's study are contained in Tables 1 - 4, showing the mean scores before the start and at the end of the CBR training period. Table 1 shows the rating of severity of disability among CBR participants before and after training. There is quite a considerable reduction in severity. Table 2 confirms that social integration is much improved after the CBR programme. Table 3 shows that, in the Philippines, 26% of the enroled children started attending school as a result of CBR; the corresponding figure for Zimbabwe was 69%. Table 4 finally shows that, in the Philippines, 61% of adults aged 16 to 60 years worked at least part-time, against 50% in Zimbabwe. None of these people had held a job before the programme started.

Lagerkvist also states: "The similarity of the results in the two countries is interesting. In spite of different cultures, management, education, and socioeconomic status in the Philippines and Zimbabwe, the greatest achievements were gained in the same areas - ADL, social integration, schooling, and getting jobs - and around 80-90% of individuals in the samples showed improvement. The similarities may have arisen from the very low status of rehabilitation services in the localities evaluated before the CBR programme was introduced, but much credit must be given to these programmes in that encouraging results were obtained in different parts of the world. This suggests that CBR is an effective tool for governments and non-governmental organizations in developing countries that decide to undertake the challenge of improving the situation of people with disabilities, while having the merit of allowing disabled people to be trained at home."

The author concludes that the "CBR programme is highly effective for disabled people in the community being trained at home, for both children and adults, and yields similar results in different types of society; it can be accomplished at very low cost by recruiting volunteers and mobilizing human resources in the community while promoting self-esteem."

3. THE INTERNATIONAL DEBATE OVER CBR

Several hundred articles, reports and documents have been written about CBR[14]. Some of these concern country projects. In others, the authors debate the concept of CBR and some of its details. A review will follow.

Definition/description of CBR

What is meant by the strategy of CBR? Can there be more than one description?[15] Is everyone entitled to his or her own version? Or, as someone formulated it : "Nobody can claim to have a monopoly to describe what is meant with CBR, I have my own ideas."

The description proposed in the Introduction to this book has been presented to a large number of experts, to the UN agencies concerned and to many NGOs. There has been a number of suggestions from them and, as a result, the description has been amended and clarified. There is no doubt that, after some years, when we will have gathered more experience, the definition may be revised, and that the time will come for new concepts.

When reading reports on rehabilitation projects labelled CBR, it is often difficult to discern how some of these have been designed and managed.

In the developing countries there seem to exist relatively few programmes for disabled people that follow the description of CBR as presented in this book. Virtually hundreds of projects use the CBR label and yet lack genuine community involvement. Nor are they managed by the local people. Most so-called CBR projects are outreach programmes still, or they amount to window-dressing of closed institutions to facilitate fund-raising. While the CBR strategy ought to be seen as highly flexible, there is a certain limit that must not be passed.

It might be useful to consider the fate of the definition of PHC (Primary Health Care). From the outset, the definition was too vague and too much the victim of compromises - a proper "committee product". PHC programmes consequently suffered conceptual and design problems. What emerged was a policy of "anything goes, as long as it is labelled PHC."

Such a calamity can be avoided if those who have different ideas and design other types of programme for disabled people use other terms to describe them. For example, Miles[16] has proposed a different system named "information-based rehabilitation", while Momm and König speak of "community-oriented rehabilitation"[17].

Critical articles should be read bearing in mind that some of the criticism voiced therein refers to so-called CBR projects that turned out unsuccessful because they failed to apply the basic ideas of community involvement, or to properly train the CBR personnel, or to provide the family and the community with the relevant technology (for example, in the form of training packages). Or they failed because no family members or community workers were trained and asked to carry out the rehabilitation processes described in the TCPD or in similar manuals, or because no follow-up was made and no referral system was available (See Box 14.1.)

Percentage of clients in the Philippines and in Zimbabwe by severity of the disability before CBR training and at the time of the evaluation

TABLE 1

Grade of Severity	Philippines (n=106)		Zimbabwe (n=100)	
	Before CBR training (%)	At the evaluation (%)	Before CBR training (%)	At the evaluation (%)
Mild	23	72	23	81
Moderate	39	21	43	8
Severe	38	7	34	11

Source: Lagerkvist, ibid.

Percentage of clients in the Philippines and in Zimbabwe by degree of social integration before CBR training and at the time of the evaluation

TABLE 2

Grade of Social Integration (Score built on variables 16/19/18,20)	Philippines (n=106)		Zimbabwe (n=100)	
	Before CBR training (%)	At the evaluation (%)	Before CBR training (%)	At the evaluation (%)
Good (score 4-6)	43	84	21	72
Intermediate (score 1-3)	47	16	47	24
Insufficient (score 0)	10	0	32	4

Source: Lagerkvist, ibid.

TABLE 3

Percentage of clients 7-20 years in the Philippines and in Zimbabwe by type of schooling before CBR at the time of the evaluation

Type of Schooling	Philippines[a] (n=50) (%)	Zimbabwe[b] (n=36) (%)
Doing normal school work	16	14
Special education or schoolwork below-age-	22	50
Going to school/not doing schoolwork	4	11
Not going to school at all	58	25

[a] 26% started school as a result of CBR.
[b] 69% started school as a result of CBR.

Source: Lagerkvist, ibid.

TABLE 4 **Percentage of male disabled clients aged 16 to 60 years by type of employment or occupation**

Type of Occupation	Philippines (n=23) (%)	Zimbabwe^b (n=26) (%)
Full or part-time jobs	61	50
No occupation	39	50

Source: Lagerkvist, ibid.

Some critical articles have been written based on misinformation or misunderstandings, assuming that the CBR concept meant something it was never intended to mean, or something that was never written by its originators.

However, there are other articles that do debate the CBR concept, its technology and the feasibility of its service delivery and management systems. A review of the questions posed in these contexts will follow.

Technology

When the CBR technology was introduced in TCPD, some experts had trouble accepting it. Many were obviously surprised by the simplicity of the text and the drawings - the 'demystification' of technology. They did not believe it would work. Others had reservations concerning some details of the early versions of this technology. After a period of field work with extensive feedback from the disabled people themselves, from family trainers and local supervisors, parts of the text and drawings were corrected or rewritten. Before the publication of the official version (1989), a large group of international experts was consulted. They made surprisingly few changes.

The field studies reviewed above indicate that the technology described in TCPD is effective. It is not, and cannot be, effective for 100 per cent of all disabled people. Nor is any other technology effective to that extent. Studies of similar technologies developed by other authors likewise reveal a high degree of effectiveness. What matters is not to choose what is presented in TCPD. The important point is to have one single, standardised technique for each situation. Such techniques should build on the existing experience of the local people, using, wherever feasible, appropriate traditional methods, such as massage and exercises, to supplement it. It is preferable to describe only one technique, for there is evidence that people are mostly confused when given choices. If a certain technique fails, one should avoid suggesting right away a second, a third, and so on, as many Westerners do. Rather, one should analyse why it failed. It may not have been applied correctly, or the disabled person has not been given a chance to actively participate, or the results may have been slow to come owing to the severity of the difficulties. And one should give those who want to modify the technology at the community level support to develop their own ideas. If the technology still fails, advice from a higher level of service should be sought regarding the choice of an alternative technology.

There is a large number of guides and manuals available which describe technologies for rehabilitation. Some of these are used in community programmes. Most such manuals or guides are, however, confined to a single disability, for example, those related to ADL-training of blind people, or training programmes for mentally retarded children. It is rare to find texts designed for use direct use by the disabled person or by the family trainer. Most material is best used at referral centres. Some existing books, the contents of which are destined to community workers, include whole medical systems for case reporting, diagnosis of a large number of diseases and therapies. Such books are more useful at the referral levels.

Another question on which opinions in the debate diverge is the level to which community workers should be trained. Some authors clearly want to upgrade these workers to a point where they are fully conversant with all the complexities of the medical system. To introduce such details in community worker training is time-consuming and costly, however, in addition to being seldom directly applicable, as our experience has shown[18]. Also, it does not lead to improved rehabilitation results.

It will never be possible to reach a consensus on rehabilitation technology. But, no doubt, with time other descriptions, built on scientific studies, will become available. Our communication techniques, too, will improve and, as a result, wider use will be made of the media and of audio-visual aids such as slide sets and video-films. Finally, the technology will be better adapted to the local culture.

Service delivery

Many questions have been raised regarding the delivery system described and tested for CBR in numerous countries. One such question is: Does it work?

Box 14.2

WHY SOME PROGRAMMES HAVE FAILED

Below follow several examples of programmes that were launched under "the CBR label" and failed:

1 A programme in an Asian country was set up in the following way: the community was sensitised and formed a rehabilitation committee; all this was inspired by a university department of physical medicine and rehabilitation (located some 50 kms away). The professor and all the team members then went out to that community and gave lectures on how rehabilitation was carried out at their hospital. A few disabled people were referred for treatment. No community worker was trained, no manual or other descriptions of technology were made available to the local people. Everybody was rather excited by the project, but after two years and no change, the population began complaining, and by the end of another year the project was closed.

2 Another programme in an Asian country benefited from the presence of a full-time expatriate professional. She spent three years holding meetings and writing her own technology manual (in English, a language virtually nobody was familiar with). Then another expatriate was employed and set about to train some 20 young girls freshly out of school. They occupied themselves identifying disabled people, who were then referred. However, in the almost total absence of referral centres, nothing much happened. By the end of a few years, almost all of the young girls had left, and the project was closed. At the time I went to visit the programme I came across 2,000 unused copies of the rewritten manual sitting in the attic of the organisation that had paid for its preparation.

3 In an African country, the intermediate-level supervisors had been properly trained and had acquired an appropriate competence. They were then sent out to all the districts of the country. The areas to be covered were large and the population was scattered. No transportation was put at their disposal, as they were supposed to go out together with the health team, sharing their vehicles. But mostly this was not feasible. As a result, the ILSs stayed in their offices, and very few disabled people were included in the CBR programme.

4 There are numerous examples of the government (central or local) deciding to shift the trained personnel (mainly ILSs) from their jobs to other duties, in this way depriving a project area of the only competent person available. In one particular country, this happened not once, but several times. The same expatriate teacher had trained no fewer than 40 ILSs in three different periods. The programme was closed when the ILSs had "disappeared".

5 In an Asian country, a hospital-based specialist group initiated the programme and trained successfully a group of ILSs. No attempt was made, however, to inspire any community participation, so there was no way of sustaining the programme. With time, the ILSs, who were part of the health care system and had many other tasks to do, were so overburdened with other responsibilities that all rehabilitation activities ceased.

Several authors have pointed to the similarities between CBR and Primary Health Care (PHC)[19]. As mentioned above, PHC has been a disappointing experience in many countries. They suggest that CBR will suffer the same fate. There are certainly many lessons to be learnt from the mistakes of PHC. First of all, the tasks for which PHC workers (PHCW) were trained were too many. The choice of trainees was not always adequate. For example, one has trouble seeing how illiterate, or semi-literate, people could be taught to master this complex programme. Often, the training of PHCW was too superficial and theoretical; too many lectures and too little skills practice. There were seldom adequate books to describe the technology. Added to this, the cost level of a PHC programme is much higher than that for a CBR programme, drugs and vaccines being particularly expensive. Referrals (and urgent ones) are required for a large number of patients whose diagnoses and treatment presupposes the availability of a facility complete with laboratory and x-ray equipment. Such a facility is expensive to supply, to operate and to maintain.

Finally, in many cases the community involvement was too superficial. In many countries community health committees were set up and asked to provide resources. There are many examples of locally collected funds having been sent out of the community to pay for a far-away hospital. And many health committees resisted providing resources, as they lacked control over the use of their funds.

In the light of this experience, it is imperative to ensure that those who are trained for community work with disabled people are fully literate, are trained to full competence, receive hands-on training, adequate technical supervision, and have books or manuals at their disposal that describe in detail the technology to be applied. Also, they should be assigned a limited number of tasks. In this way, mistakes can be avoided.

Furthermore, one must ensure that the decision-making power rests with the community, and that locally mobilised resources are, in fact, used locally.[20]

PHC is a much more complex programme to implement than CBR. One might argue that the results of PHC should not be taken as an unquestioned reference for predicting the outcome of CBR.

It would make for more justice to compare CBR with other community development programmes, for instance, programmes for local supply of water, sanitation, food production and protection, women, education and vocational training. It is well known that thousands of such programmes built on volunteers and local forces function well in many countries.

As regards CBR, it is our experience that parents or other family members do participate to a large degree in the training[21]. Schools, once teachers are sensitised, normally accept disabled children into regular classes. Apprenticeships and jobs are often opened up to disabled people after sensitisation.

There are many problems related to the recruitment of community members, and their compensation is a frequent subject of discussion. A high degree of flexibility has to be shown in adapting to the realities of local life. Community workers should, on principle, be compensated by their own communities. Employing them on government salaries would contribute to the development of a totally top-down system; giving them salaries paid for by external donors will create dependency and diminish the programme's sustainability.

In some parts of the world, such as Eastern Asia, it is common to see community members taking on voluntary development jobs in favour of their community. In other areas, for instance in Africa, people generally ask for a compensation. This has not always been so. The change has come largely in the wake of the availability of Western aid. In many places, expatriates arrived with their pockets full of money and eager to see their project with an imposed deadline get under way as quickly as possible. One could cite numerous examples of nationals who quit their ordinary jobs because they were offered salaries out of all proportion (say, thrice that of the country's president), or of community trainees who were given per diems that would easily cover their costs of staying in a luxury hotel. Unspecified amounts of funds tended to be spent in mysterious ways and, if not accounted for, they were simply replenished with few questions asked. Programme workers were often provided with four-wheel drive vehicles, complete with drivers, and allocated a generous budget for gasoline and repairs in order to add to their efficiency and help the donor to meet his targets in time.

This way, elements displacing the existing system were introduced and, once in place, the nationals tended to take this for the style of externally funded projects. Of course, these projects were not "owned" by the community; they were not sustainable, and most of them disappeared when "Santa Claus" went back home.

Many critics claim that it is too idealistic to believe that a CBR programme can be carried out using community resources. It is true, in some countries the behaviour of external donors has ruined the chances for future efforts of contributing to a sustainable system. It is vital that the overspending of charitable organisations be curtailed; that those wanting to become involved in CBR programmes learn from the successes of other programmes built on genuine community involvement and auto-financing.

Regarding the training courses, there is ample evidence now of the effectiveness of the training programmes proposed for the local supervisors.

The training programmes for intermediate-level supervisors have been rather diverse. Their role differs from country to country, and they are recruited from a variety of groups, depending on which ministry is in charge of rehabilitation in the respective country. Each country should describe in clear terms the tasks to be accomplished and the technology to be used. Some literature suitable for this group of personnel is available.

The existing rehabilitation services and other relevant services have not yet been organised in a way to provide a proper referral system. It would be useful to undertake in-depth research with a view to evaluating the needs for referrals and predict the likely outcome of these. There is now in many country programmes a tendency to refer too many CBR participants. This is mostly a sign of pressure from existing professional groups and does not necessarily improve the results.

Mostly CBR programmes have operated by providing services at home or in the community. No building is required. Some critics argue that establishing a small resource centre in the community may help to make service delivery more efficient. This is certainly a point to consider in areas with a high population density, in particular in urban areas. No doubt, it would be possible to bring together several family trainers and disabled people for joint information sessions, for demonstrating the techniques to be used, for conducting play activities (involving non-disabled brothers and sisters), and for discussions among the parents or the disabled people themselves.

In addition, there is undoubtedly a need for day care, in particular if all care-providers are working and away from home during day-time, leaving nobody to look after the disabled person at home. To meet this need, communities could take the initiatives to provide care on a collective basis and eventually decide to have a local resource centre.

Let me add, however, that it is not uncommon to see that such "modest institutions" being turned into dumping grounds for children or adolescents of parents who do not care much for their disabled members, or who are not engaged in any training and would gladly see their child go to a boarding institution to remain there for the rest of its life, allowing them to forget about it. There are also cases of such modest institutions moving later on from low-cost to high-cost approaches, using more and more professional personnel, and providing boarding. These risks are avoidable, provided the community is aware of them. One possible way is to use temporary facilities, such as a school or a community centre, during the time it is not occupied by others.

Another fundamental point is whether professional expatriates should be involved on a long-term basis in CBR programmes. Expatriates are often seen exercising a great deal of influence over the development of services, deciding on their content and expansion, and patterns of dependency tend to develop among those nationals who are seen as "users" but not as masters of such services. In CBR, an approach aiming at transferring power to the people is important: communities and disabled people are encouraged to take their own decisions in line with their priorities, to make their own plans, to evaluate the programme and to make their own changes (and mistakes). Expatriate personnel should only stay for short periods. They could carry out the initial training courses for intermediate-level personnel, and then return for short follow-up and evaluation missions. Their skills and knowledge must be transferred within the shortest possible time to make the national staff to the highest possible degree self-sufficient.

There can be no question that a great deal more work will have to be invested to further develop effective service delivery systems. The debate on the feasibility of the system proposed for CBR has been challenging. Several decades of work will be needed to identify the appropriate ways of arriving at a system capable to deliver essential services to all those in need.

Management

A number of local rehabilitation committees do exist. Their success rate varies considerably. The ones that work best have taken over the responsibility for the local CBR project. They decide on its priorities and programmes, identify and remunerate local supervisors, and collect funds to support disabled individuals. But their numbers are yet few. Others are aspiring to such a role.

It is clear that many difficulties are associated with the implementation of decentralised management, with the sensitisation process needed to achieve community involvement, resource provision and so forth. First of all, this type of democratic movement may not be very welcome by the authorities. Secondly, by tradition, some countries have not had much experience of active involvement in development in the past; a passive attitude, waiting for the government, expatriates, foreign donors, or magic, have become a habit. Thirdly, before a community will start moving, it has to realise that it has quite a number of disabled people in its midst, and that it can cope with most of the problems on its own. Community members also need to become aware of the fact that, when trained, a local worker can deliver effective rehabilitation using the existing resources.

It may take a long time to inspire, inform and sensitise community members to the needs of disabled people, as well as to the fact that they have the resources needed to succeed in doing the job themselves. This process is culture-dependent, and highly flexible approaches should be used. Also, one has to realise that, currently, many communities are wasting their resources, their time and their opportunities by waiting for outsiders to do the job. Such outsiders may include the government (which may have promised to "take care of all disabled people"), or donor agencies, or expatriates who are in the "rehabilitation business." Expatriates who stay over extended periods have to consider whether their work leads to sustainable services or whether it merely contributes to increasing the communities' dependency on outsiders.

Far greater efforts are called for to mobilise actions in the right direction. One should try to learn from other successful community development programmes. When starting the CBR programme, co-operation with cultural anthropologists is valuable. Advice is needed in order to understand community management processes, social structures, patterns of influence and so forth. When carrying out evaluations, the programme's cultural compatibility should be reviewed, in particular with a view to ensuring the programme's sustainability.

Management at the national level is another problem. So far, co-operation between all the partners involved - ministries, NGOs, centres and projects - has not been very successful, in spite of the calls for more co-ordination. There is no standard solution to this. Perhaps, efforts at formulating joint national plans could help.

Moreover, there is the question of whether governments can be mobilised at all to participate in creating the infrastructure for service delivery. In the past, few governments have shown more than a superficial interest. It is not clear how the present situation can be improved. But pressure is certain to come from many sources: inside - from national organisations of disabled people and parents, political groups and professionals, and outside - from UN agencies and donor or development organisations. The inclusion in the UNDP Human Development Report[22] of an index reflecting the quality of life of disabled people will unquestionably reveal the lack of commitment of many governments when it comes to establishing relevant policies, plans and programmes for this group. The development strategy increasingly turns to the support for human and social programmes, a fact that, in the long run, should benefit disabled people.

Finally, in order to develop CBR in the future, more research is needed. Donor and development agencies should preferrably support national research institutes and universities to undertake critical reviews and studies which can serve to develop the CBR strategy.

COMMENTS AND REFERENCES

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[8] M.J. Thorburn: Training community workers for early detection, assessment and intervention, (Eds M.J. Thorburn and K. Marfo), ibid.

[9] B. Lagerkvist: Community-based rehabilitation - outcome for the disabled in the Philippines and Zimbabwe, Disability and Rehabilitation, Vol. 14, No. 1, pp. 44-50, 1992.

[10] This has been described in greater detail by A. Periquet in Community-based rehabilitation services - the experience of Bacolod, Philippines and the Asia/Pacific region. Monograph 26, World Rehabilitation Fund, New York, USA, 1984.

[11] The community workers receive no salaries; their main incentive is the recognition they get from the community.

[12] Other reports from Zimbabwe are also available, e.g. M. McAlister: Community-based Rehabilitation in Zimbabwe, Physiotherapy, 75:7, July 1989, and H.J.M. Finkenflügel: Identifying people in need of rehabilitation in Rural Zimbabwe, Central African Journal of Medicine, 37:105, 1991.

[13] Lagerkvist used the variables suggested in the Guide for Local Supervisors, Form 3. These concern: 1 feeding, 2 dressing and undressing, 3 keeping clean, 4 using latrine, 5 understanding simple instructions, 6 expressing needs, 7 understanding movements and signs for communication, 8 using movements and signs for communication which others understand, 9 lip-reading, 10 speaking, 11 sitting, 12 standing, 13 walking, 14 moving around house, 15 moving around village, 16 pains or aches in joints or back, 17 breast-feeding disabled baby, 18 child playing as children of same age, 19 going to school, 20 joining in family activities, 21 joining in community activities, 22 participating in household activities, 23 doing a job or having an income.

[14] See comment No. 2 above for bibliography.
M. Miles has produced over 100 articles during the last twelve years, many of which concern CBR. Among these are

M. Miles: Where there is no Rehabilitation Plan, Peshawar, Pakistan, 1984.
M. Miles: Misplanning in Asia, Peshawar, Pakistan, 1985.
M. Miles: The "Community Base" in Rehabilitation Planning: Key or Gimmick? In (Eds M.J. Thorburn and K. Marko) Practical Approaches to Childhood Disability in Developing Countries, ibid..

[15] The editor of CBR News in No. 13, 1993, invited the readers to comment on the description of CBR (see p. 8) "on whether you agree or disagree with it." AHRTAG, London, UK, 1993.

[16] Miles has outlined how he proposes to develop the "information-based rehabilitation services" in the developing countries using computers and satellites to transfer information on technology. Rehabilitation workers while working in villages or in marginal urban settlements will carry with them "a lap-top, buffalo-proof, battery-operated, solar-rechargeable, limitedly interactive, rehabilitation library comprising, say, 5,000 illustrated pages, with assisted steering to access and screen-display required data.

"This gives the potential to identify and assess a wide variety of disabilities and levels of severity in pre-electric villages, and to watch on screen, with relevant audience, commentated sequences of hands-on therapy with that type of disability. Call-in facility by satellite link will make available rapid reference to central advice. Rehabilitation technicians of the future will know first of all how to handle information equipment. For hands-on rehabilitation knowledge, they could train themselves on the job using their own 'three-dimensional' information resources".

Operating the system described above by Miles will meet with large practical difficulties. The computers and the large outdoor parabolic antennas for satellites have to be carefully maintained, under the weather conditions of developing countries. The antennas need minute directing to ensure exact targeting of the signal toward the satellite in outer space. If the equipment is to be mobile, maintenance and transportation will cause problems, given the road conditions (or lack of roads), not to speak of the careful redirecting required each time the antenna is moved. Another concern is language. Few community workers have English, so communication will have to be in the local language, using keyboards with locally used characters - Arabic, Chinese, Cyrillic, Korean, Sanskrit, Thai, etc. Calling-in for "central advice" would presuppose translation of the relayed messages. Moreover, satellite time is costly and, because of the different time zones, a 24-hour service would be needed. Thus this system will be very expensive.

M. Miles: Information Based Rehabilitation for Third World Disability. Social Science and Medicine, 28(3), p. 207, 1989.
M. Miles: Rehabilitation Development in South-West Asia: Conflicts and Potentials. In L. Barton (Ed.): Disability and Dependency. Falcon Press, London, UK, 1989.

[17] Momm and König say that vocational rehabilitation should not follow a "medical model...vocational rehabilitation is not part of the nursing or therapeutical function...As Ministries of Health as a rule neither have the mandate, nor the professional competence to deal effectively with vocational rehabilitation, an insistence on covering vocational rehabilitation within a medically oriented CBR programme carries the risk that vocational rehabilitation is either largely neglected or is unprofessionally conceived...In order to prevent misunderstandings and confusion it would therefore have been advisable to abandon the term CBR and to distinguish instead clearly between community-based medical rehabilitation (CBMR) and community-based vocational rehabilitation (CBVR) and to create similar denominations for other disciplines."

There is no disagreement as far as the medical model is concerned. But Momm's and König's publication has led to the perception that the authors prefer the conventional idea of having a fragmentation from the top to the community of the delivery system. This will not be possible, for economic reasons. For CBR, it is proposed that the local rehabilitation committee should manage all components at the community level. The place of vocational rehabilitation specialists is at referral levels.

The authors hold the view that "any CBR programme falls short of an essential element ... equalisation of opportunities ... consequently a term is called for ... which addresses the objective of integration. This is of particular importance for programmes which deal with disabled youth and adults and which are concerned with vocational training and employment aspects...

"A distinct feature of such [a] programme is the availability of various specialists who are not necessarily rehabilitation specialists but any other community development personnel such as skill training and small business advisers. Their function is to ensure that rehabilitation specialists or volunteers receive the required technical back-up..."

These practical aspects are all valid in the CBR programme, so I fail to see the difference between what is proposed by Momm and König and what is practised in CBR programmes.

W. Momm and A. König: From Community-Based to Community-Integration Programmes, ILO, Geneva, Switzerland, 1989.

[18] D. Werner has in Disabled Village Children produced a very detailed reference book, which has been widely used, particularly by expatriates. His strategy differs from the one described in this book.

Werner uses a medical model. A large part of his book concerns medical examinations, diagnoses and prescriptions. This is at variance with the CBR system, where application of a medical model at the community level is considered unnecessary, since it will not contribute to the quality of the outcome of rehabilitation, and since we do not see the disabled person as a patient. The review below seeks to explain how elaborate Werner's system is.

According to Werner, the village worker (who has an "average of 3 years of primary school education") will undertake a number of procedures for history-taking and examination as detailed as those of a specialist physician and/or a therapist in a Western country. Five pages record the outcome, based on some 200 questions, of this examination. Also included are the testing of over 20 muscle groups, rating each of them on a scale of six degrees of strength. Rather than indicating the angles of impaired joint movement by means of a simple device, body-size so-called flexikins have to be assembled from 37 separate pieces made of thick paper, cardboard, or old x-ray film. Kins are held together by pins, threads or rivets. In spite of its elaborateness, this technique does not allow for determining all types of joint movement, and the measurement results are not easy to reproduce.

Werner mentions about 80 different diagnoses, and the VW will learn to master them (e.g. cerebral palsy, polio, arthrogryposis, brain tumour, Erb's palsy, chlamydia, Legg-Perthes disease, lathyrism, athetosis, Guillain-Barré's paralysis, rickets, brittle bone disease, 10 different forms of arthritis, 9 types of epileptic fits, 3 forms of leprosy, etc.). The degree of development delays has to be assessed in respect of 13 different components of development.

Other parts of Werner's book deal with medical treatment. For instance, regarding epilepsy, he provides six pages of advice on how to choose between nine different drugs and, in case of "long-lasting fits", on how to inject medicaments intravenously ("if someone knows how").

Werner also describes bladder catheterisation for people with spinal cord injury. He states that "children as young as age 5 learn to catheterize themselves." This procedure presumes the availability in the village of proper, sterilised catheters and syringes, alcohol, or surgical soap, a lubricant dissolvable in water but not in oil, sterile cotton and so forth. It further presumes that the person with spinal cord injury will not - while manipulating the catheter in an unhygienic environment - introduce bacteria into the bladder. A urinary tract infection may be self-diagnosed, and the recommended treatment for such an infection, according to Werner, is antibiotics, to be changed over once or twice if unsuccessful to broad-spectrum antibiotics after two days.

For wheelchairs, 43 different features are listed. On the other hand, the description of how to make artificial legs is devoid of any mention of the all-important alignment procedure.

Werner's book also explains a large number of technologies, such as those related to exercises, ADL activities and communication.

His model is concerned, almost to exclusion, with one level only: the village worker. It offers virtually no material that can be used directly by the disabled people themselves, or by their families, and although referral to higher levels of services is mentioned here and there, such reference is usually accompanied by a number of warnings as to the incompetence of the personnel of these services. In CBR, by contrast, a multi-level system is seen as essential.

Werner has given but a very vague idea of how to set up a delivery system to allow the programme to go to scale. He says that the entry-point is "often...a person with some background in rehabilitation and in community work, to stay for a while in a village." This agent should provide "information and choices." How a general service delivery system can develop from this is unclear.

Werner's approach is costly, because it requires very long periods of training local personnel - personnel that once the training is completed are left without supervision. It foresees decentralisation to the community level of almost all technology that could be handled at lower cost and with greater effectiveness at referral levels. Rather than following the problem-solving approach in CBR, it uses a complex medical model. The basis for services is charity and not the obligation of governments to provide adequate services for all their citizens.

Werner has contributed to demystifying rehabilitation technology. He has pointed out that, helped by the families of disabled people, community workers can indeed carry out certain parts of the overall rehabilitative process. His book is a useful resource work, mainly for professionals within the referral system.

D. Werner: A guide for community health workers, rehabilitation workers and families, The Hesperian Foundation, Palo Alto, Calif., USA, 1987.

[19] O'Toole raises the question whether or not the "PHC system is a viable infrastructure for introducing CBR ...PHC requires a political commitment to an equitable society, a decentralisation of the decision-making process, and a preferential allocation of resources to the poorest section of society. Sickness, disease and malnutrition are symptoms of a deeper malaise stemming from social inequality, economic exploitation, and political oppression. PHC, therefore, challenges unjust political structures. It is not surprising therefore that most governments prefer to take their course of PHC in small doses."

The experience of attaching a CBR component to PHC - in spite of the similarity in basic ideas - has rarely been described. Very few CBR programmes have been set up in the context of PHC - the reason being an unwillingness on the part of the health authorities to even discuss the matter - a problem described by Thorburn as follows: " ... it does imply a widely developed health infrastructure onto which rehabilitation can be grafted. In many developing countries this infrastructure may not exist and in others, where it does, it may not be flexible enough to accommodate the additional responsibility. However, this does not preclude the development of CBR services in the community. It means more careful planning may be required with full utilisation of resources both formal and informal, governmental and nongovernmental."

B. O'Toole: Guide to Community-Based Rehabilitation Services. Guides for Special Education No. 8, UNESCO, Paris, France, 1991.
B. O'Toole: Community-Based Rehabilitation: The Guyana Evaluation Project, in Practical Approaches to Childhood Disability in Developing Countries(Eds M.J. Thorburn and K. Marko) , ibid.
M.J. Thorburn: Practical Aspects of Programme Development, in Practical Approaches to Childhood Disability in Developing Countries (Eds M.J. Thorburn and K. Marko, ibid.)

[20] O'Toole states that "there has long been a tendency for rural programmes to be planned and implemented by urban bureaucrats without the consultation and involvement of the intended consumers ... if the subjects of development do not participate ... change will be impossible ... participation is essential ... how can one guide individuals who, for so long, have traditionally been led by others, to take charge of their own affairs?"

B. O'Toole: ibid.

[21] O'Toole discusses whether parents are willing to become involved. Obviously some parents will refuse to do so because of "overwork, poverty, severe social tensions ... exhaustion ... practical and emotional burdens, etc."

Many other people share at least part of these misgivings, but where the CBR programme has been tried out, only a small proportion of families refused to help with the training. Most of them realise that the training process is an investment, for the disabled person will be less dependent and consequently require less help later on. O'Toole himself reports rather satisfactory levels of parental co-operation (see above).

[22] Human Development Report. Published annually by the United Nations Development Programme (UNDP) and Oxford University Press.

CHAPTER FIFTEEN: PARTNERSHIP AND INTERNATIONAL CO-ORDINATION

1. THE PARTNERS

A great many partners are involved in international programmes for disabled people, such as:

- ***International governmental or inter-governmental organisations***:
  - United Nations (ILO, UNCSDHA, UNDESD, UNDP, UNESCO, UNHCR, WHO);
  - other multinational organisations (such as the World Bank, EEC, OAU, OAS, Arab League);
  - bilateral development/co-operation organisations.
- ***International non-governmental organisations***
  - ○ ***representing disabled people***, e.g.:

    Disabled People's International
    International League of Societies for Persons with Mental Handicap
    Rehabilitation International
    World Blind Union
    World Federation of the Deaf

  - ○ ***development organisations*** :

    general development organisations, and organisations giving support to programmes for disabled people

  - ○ ***organisations representing various groups of rehabilitation professionals***

    occupational therapists
    physicians
    physiotherapists
    social workers
    special educators
    vocational specialists.

The above list is incomplete, for in all there are several hundred organisations involved, but it may suffice to reveal the complexity of the subject "partnership and international co-ordination". As explained elsewhere, it has been estimated that over US$ 300 million is dispensed by donors in industrialised countries for over 4,000 projects in the developing countries. These projects are often undertaken in co-operation with the governments and/or with non-governmental organisations in the recipient countries.

2. CO-ORDINATION - TODAY

As mentioned in a previous chapter, national co-ordination is very difficult to organise. Even more intricate is the subject of international co-ordination, in particular as regards policies, planning, approaches and activities concerning disabled people in the developing countries.

A number of international organisations concerned with disability and with disabled people have been meeting more or less annually for about 40 years. These include mainly the UN organisations and a few umbrella organisations representing NGOs. Until now, this type of co-ordination meeting has always been held in New York, Geneva, Paris or Vienna - never in a developing country.

Other limited efforts are made to co-ordinate certain sectors, e.g. among organisations involved in programmes for blind people.

It is extremely difficult to find common ground during these meetings as to how best to co-ordinate field activities in the developing countries. Some of the constraints relate to:

- the limited choice of representatives to attend;
- the subjects discussed;
- the expected outcome of co-ordination meetings;
- the policy-making mechanisms of the organisations concerned.

The **representatives** include for example:

- administrators, usually well-trained in management or sociology or economy, but mostly without technical knowledge of disability and rehabilitation, and rarely with experience from developing countries;

- disabled people, who represent the views of some (but not all) consumer groups; most have very limited managerial and field experience;

- professionals with a background of field work in developing countries: very few have experience of macro-systems (such as setting up countrywide programmes with governments), most have experience from the intermediate level (mainly small centres and institutions), and again very few know about micro-systems (communities);

- professionals from industrialised countries - with no or with limited managerial and field experience in developing countries.

The two groups whose involvement in discussions on international co-ordination would be most appropriate - national rehabilitation managers working in developing countries and representatives of donor/ development agencies - seldom participate.

Box 15.1

GUARDING ONE'S TERRITORY

A recent ILO document observes:

"In the past ... each [UN] agency followed its own objectives and strategies within their field of competence, in particular in the framework of technical co-operative projects. There was a clear delineation of mandates within the UN system and much care was taken to seeing that no organisation encroached upon the other's field of competence. Another feature was that these organisations competed frequently for funding for their projects from the same funding source. In this environment there was little need to co-ordinate activities at the operational level and consequently co-ordination and co-operation were rarely more than the obligatory information about each other's activities - a function that greatly determined the agenda of the various inter-agency groups."

The **subjects discussed** at these meetings include a variety of issues, and many of these relate to the situation in industrialised countries. The purpose seems to be not to move ahead in a concerted way but mainly to exchange information. (See Box 15.1[1].) Since most of the important donors are absent, whatever is said or agreed - however vague - does not have much impact.

The **expected outcome of these meetings** was that each participating organisation would prepare a report to its central administration or its governing body. On the basis of the discussions, the appropriate committee of the United Nations each year will consider the subject of disabled people and adopt a resolution that looks like the twin of the one adopted the year before. I sometimes ask myself how many people actually read these and what is the cost of this rather futile exercise?

The annual repetition of this ritual is nothing to be particularly proud of. The blame is not to be laid at the doorsteps of the Secretariats of the UN agencies, which on request deliver the background material and draft proposals. They only do what they are asked to do by member states. So the idea suggests itself that the member states reconsider the way they make the Secretariats work.[2] Millions of US dollars are spent every year to produce beautifully worded documents[3], but anyone visiting a small village or an urban marginal settlement in a developing country will discover in no time that the disabled people living there have never heard of the United Nations and, what is more, that 40 years of high-level declarations and repeated recommendations certainly have not brought forth much in terms of services[4].

The next subject concerns **policy-making mechanisms**. All international organisations concerned with disabled people have their own governing bodies, executive boards or members, which decide their policies and activities. They have often spent a considerable amount of time discussing their orientation and terms of reference, and most of them are in no hurry to become agents of change, or innovators. If new ideas do come up, there is reluctance to accept them. Most major donors almost never meet with others to discuss policies or approaches, nor do they invite outsiders for such discussions. Many have set up projects and facilities in the developing countries that do not lend themselves to change - most of their funds have already been earmarked far into the future. This is understandably an obstacle, and it is for this very prosaic reason that donor organisations sometimes are not free to consider any real policy changes.

The conclusions that I draw from these reflections convince me that a thorough review is needed of the entire effort of international co-ordination. The present forum for international co-ordination is not effective as an instrument for change.

3. *FALSE CONTRADICTIONS AS CONSTRAINTS TO CO-ORDINATION*

The next point to be considered is the perceived deep and fundamental contradictions regarding strategies that seem to be major obstacles to international co-ordination. To my mind, these are for a major part due to misunderstandings, reflecting the fact that the relevant experience of representatives of international organisations is rarely broad enough to cover the entire field. As a result, approaches which appear to be competing but are in fact complementary. There are four groups of apparently contradictory approaches:

- developing macro-systems/intermediate level systems/micro-systems
- professional therapy/home-based training and interventions
- small-scale/large-scale programmes
- dependency on donors/self-reliance.

• *developing macro-systems/intermediate-level systems/micro-systems*

Some experts working for very large donor/development organisations, and those engaged by national governments, are mainly preoccupied with the development of macro-systems. They often propose programmes aimed at strengthening the ministerial/central capacity- for setting up and managing development programmes.

Many of the "macro-experts" often are not sufficiently knowledgeable in matters of decentralised micro-systems. For example, they may not be familiar with how communities function or understand whether what they propose is compatible with the existing social structures. Nor would they be expected to know whether a particular technology fits into the cultural environment. Some experts have never even visited a village or an urban marginal settlement. To them, these are exotic places about which cultural anthropologists will tell interesting anecdotes. Furthermore, to them, villages and urban marginal settlements are sort of empty spaces, to be filled up with wonderful transplants of systems conceived in the industrialised world. These even include systems that have not worked well even in those countries.

Most field experts in rehabilitation have worked with intermediate-level systems, such as institutions with special programmes for groups of disabled people. Examples are: vocational training centres, special education in segregated schools, orthopaedic workshops, physiotherapy schools. Normally none of these form part of a planned macro-system, nor do they have much contact with the community.

The experts who deal with micro-systems come both from large international organisations and from small NGOs. However, few experts in the area of disability and rehabilitation work with communities.

Many international NGOs are negative toward any proposal to co-ordinate their work with the government. Their knowledge of the macro-system is sometimes as anecdotal as the macro-experts' knowledge of communities. They will tell you stories about the failures of the government. Their views seem to be quickly accepted by the nationals with whom they work. I have noticed that many NGOs - whether working with centres or in communities - believe that any attempt at national co-ordination is a waste of time.

In reality, the three systems mentioned above are complementary. It is necessary that governments become involved and organise public services for disabled people. Given the limit to what can be achieved through centrally-managed services, these need to be complemented both at the community and at the intermediate level. Only when micro-, intermediate-level and macro-systems merge into one single co-ordinated system will we be able to provide "rehabilitation for all".

- ***professional services versus home- and community-based training and interventions***

The conventional pattern of service delivery has, in theory at least, been built on professional, specialised rehabilitation personnel. In practice, few centres or outreach programmes use such staff exclusively.

There is a misconception that the use of family and community members for tasks "traditionally reserved" for certain professions constitutes a threat to the latter.

In the early times of CBR, this misconception had been at the bottom of much of the resistance shown to the approach as a whole by most rehabilitation professionals and their organisations. They saw problems where there were none. First of all, in most developing countries there is an enormous shortage of rehabilitation professionals. Those who do exist in the health sector are often absorbed by the hospitals for care of acute patients or by other institutions. There is no risk that they will be put out of work. Those who work in the social sector are occupied with a number of activities related to e.g. counselling, alcohol and substance abuse and delinquency. This sector is headed for a major build-up, and so is the education sector. Once interventions are carried out at the community level, many more disabled people will be referred to the provincial and national levels. There will be a call for more professionals - not less.

Self-training by disabled people or training assisted by a lay person is a very common complement to therapy by professionals in the industrialised countries. It has been found to be effective and less costly. Normally therapists will give hand-outs or training packages to people with chronic conditions. Alternatively, they may visit them at home and instruct a family member of a disabled child, for example, what to do. Many formal and informal training programmes for parents and other family members are conducted by professionals. Similarly, it is well known that a very large proportion of disabled adolescents and youths find opportunities for vocational training and jobs through informal contacts taken by the family, for example.

These two approaches are and should remain complementary. Currently the lack of professional staff in many developing countries seriously restricts the much-needed referral services, and this gap will eventually be closed. The families' capacities to provide rehabilitation inputs must be strengthened - in that respect the people in developing countries should seek to follow an approach that has been practised with success in the industrialised countries.

- ***small-scale versus large-scale programmes***

As indicated above, most current projects for disabled people are small-scale and rarely concern more than about 20 or 30 people. The organisations which start such programmes want to keep them small, for that makes them easier to manage. Where expatriates are used in small centres, the services certainly become very costly and not very efficient. Nobody wants to see large-scale centres with hundreds or thousands of places. These are inhuman and often not very effective. There is full agreement that small-scale projects should remain the base in the future.

By contrast, single, small-scale projects do not make such sense. Given the fact that our ultimate aim is to reach very large groups of people, we need to multiply the number of small projects. The large-scale CBR programmes that I propose might include hundreds or thousands of small community projects, held together by a network decentralised to the district and the provincial level and involving the government in the organisation, administration, technical supervision and monitoring of the totality of services. In this way the large-scale approach is complementary and goes several steps further than the single small-scale projects on which it is built.

- *dependency on donors versus self-reliance*

There are many examples of donor-dependent services for disabled people. No doubt donors are needed, and those who have provided funds in the past should continue to do so. The concept of community-based rehabilitation is not in conflict with the mobilisation and use of external funds for development. But we should analyse how such funds can be employed in the most meaningful way to achieve eventual self-reliance and independence in the recipient country. In the past, developmental funds often served to build and equip facilities, to engage costly professional personnel and to pay for daily transport or boarding for disabled children or adults. It is difficult to withdraw external funding from such services in countries that lack the means to continue. In most poor countries, those who started this type of effort may need to stay for as many as 25 to 50 years.

The other alternative for donors is to provide external resources for the time it takes to build up a community-based programme. This would imply funding of training of the first groups of personnel, providing them with means of transport to the field, and supplying limited funds until an auto-financing system has been created. In many countries, these start-up costs cannot be met by financing available in the national budget. One prerequisite should be that the government agrees to provide at a predetermined time the funding for the personnel at the intermediate level, whose training costs will be covered by the donor.

4. CO-ORDINATION - TOMORROW

Better economic use of resources would be facilitated by improved international co-ordination clearly focused on achieving better cost-effectiveness of field activities. There are already examples of similar efforts in other sectors. One such example is the co-operation between donors which provide funds for the treatment of leprosy - the International Federation of Anti-Leprosy Associations (ILEP). This association was founded in 1966. It co-ordinates the activities of 22 donor associations in 98 countries (all in all, there are over 1,000 projects; the combined budget totals more than US$ 60 million). All grant-giving is co-ordinated according to an agreed policy, and the secretariat of ILEP plans and undertakes evaluation missions and other central operational functions.

The efforts to write vague policy documents and resolutions and to launch small uncoordinated projects have had their time. International organisations should now consider how they should work in the future. Instead of spending funds on costly international meetings or repetitive paperwork, these organisations should identify the most sensible way of translating what is on paper into action in the developing countries. The outcome of such action should be evaluated in a very clear way. How many disabled people benefit? What happens to them in terms of improving daily life activities, opportunities for schooling, training and jobs? Do they have an income? Do they have access to the general systems of their respective society? Have they achieved social integration and political power?

To make headway it is necessary to rethink the mechanisms for international co-ordination. I can foresee several steps in a fresh attempt:

1/ creating a new co-ordination mechanism along the lines of the one referred to above for leprosy programmes. To this end, it is proposed that all potential partners should be invited - UN agencies, governmental international development organisations, and NGOs. Should it prove not possible to set up one facility, regional ones could perhaps be created instead. Moreover, looking at the experience of other similar organisations, it would appear preferable for such a co-ordinating agency for rehabilitation to be non-governmental;

2/ commissioning a group of experienced

Box 15.2

EXAMPLE OF A CO-ORDINATED, MULTI-SECTORAL PROGRAMME FOR A DEVELOPING COUNTRY - GHANA

Following a request from the Ministry of Employment and Social Welfare in 1992, an exploratory mission was undertaken by representatives of ILO, UNESCO, UNOV, UNDP and WHO. Also participating in the mission were the Norwegian Association of the Disabled and the Swedish Organisation of the Handicapped International Aid Foundation. The latter two are NGOs which receive government support in their home countries.

The mission lasted four weeks. During this period discussions were held with the central and local authorities in the social, health, education and labour sectors. A number of services were visited, both general ones and services specifically set up for disabled people. Associations of disabled people were contacted, and field trips to rural areas were carried out.

The conclusions drawn from this visit were that it would be feasible to start a joint programme in Ghana; the authorities were interested, and the existing infrastructure and personnel of the social services (in all of the over 100 districts of the country) could accommodate a programme for community-based services for disabled people.

The two Scandinavian NGOs launched and financed the programme in 1992 while negotiations were under way with UNDP about its funding.

Then a planning committee was set up, and another visit to Ghana followed by the end of 1992. The Project Document calls for a total UNDP expenditure of US$ 500,000 during a four-year period in support of a government-operated CBR programme. The purpose of the programme is "to improve the quality of life of children, youth and adults with disabilities, through the mobilisation of community resources, the provision of services, and the creation of educational, vocational and social opportunities."

The project "is designed to strengthen the CBRP through technical guidance, through training of personnel and through establishment of a training capacity within the CBRP. It also strengthens the technical and training capacity of collaborating NGOs, essential for the effectiveness of the CBRP."

As indicated, the CBR programme will be a component of the social welfare services, in co-operation with education and health sectors.

During the initial period, social workers from ten districts were trained, using the TCPD Manual. Separate courses were held for mobile resource teachers from the same districts. These professionals were given a motorbike each and a budget to cover their travel costs. The first phase consisted in contacting the villages/urban blocks in the district and finding out whether these communities were interested in a programme for their disabled citizens. If so, a management committee was set up by the local leadership and asked to identify and "employ" a local supervisor. Groups of local supervisors were then trained by the social workers. Continuous technical supervision is given by the district social workers (they work full-time for the CBR programme).

On completion of their training, the mobile resource teachers visited the villages and identified the disabled children locally. Efforts were made to advise the school teachers on mainstreaming of the disabled children. Special efforts to support individual children will follow.

The chief technical advisor to the programme comes from one of the participating NGOs; the two NGOs share in the costs for the programme components they are most interested in.

The participating organisations consult each other on all questions concerning the programme. Experience has shown this to be time-consuming but worthwhile, as it allows full co-ordination of the various sectors' activities. The participating NGOs welcome this experience which could be applied in other programmes funded by them.

national programme managers and field experts to propose a new set of policies for the co-ordinating agency and to guide its implementation effort;

3/ formulating detailed guidelines regarding the approaches to be applied, with each developing country formulating its own guidelines and setting up a co-ordinating agency to advise external donor/development organisations;

4/ reaching an agreement between donor/development agencies on how the work can be divided up so as to avoid the present concentration on a few countries;

5/ joint planning by all those who work in a specific country under the leadership of the government - with an obligation to pool their resources and to use them in the most economical way;

6/ creating a joint mechanism for follow-up and evaluation.

I have positive impressions from several planning missions to developing countries, undertaken jointly with other organisations and working with all national partners concerned. When one faces the realities together and listens to the voice of both the government and the people, it is easy to agree on what needs to be done. This type of joint planning should be multiplied, and followed by joint execution. A reform along these lines is urgently needed. An example of such a joint programme, involving all relevant UN agencies as well as two NGOs, is related in Box 15.2.

The present co-ordination system needs to be reviewed. It was inspired by goodwill and dedication. Unfortunately it developed in an ad-hoc, unplanned manner. There is ample experience available today to evaluate the past and, on this basis, to start up new efforts. These should be based on rational and realistic approaches, on a logical analysis of the strategy options, on joint planning and pooling of resources, and on an agreed procedure for evaluation.

COMMENTS AND REFERENCES

[1] ILO contribution to long-term strategy. Document dated 9.3.92 from the Vocational Rehabilitation Branch, ILO, Geneva, Switzerland, 1992.

[2] A former senior UN official has published a "history" of the system, characterising it as follows:

"An immense task of establishment [of the UN system] was achieved in this first year by an organization which was still searching for a home, recruiting its staff, and establishing its methods of work. No less than twelve permanent international commissions and subcommissions as well as the Economic and Social Council, the International Court of Justice, UNICEF, and the International Refugee Organization were constituted and started their work during the remainder of 1946. The result of this tremendous burst of international procreation was a proliferating and overlapping web of activities and bureaucracies. Certainly an unprecedented range of human activity was covered, but the possibility that governments might not follow up, on the national level, these high-minded international activities was not considered. Nor did we suspect that our efforts to build a brave new world would, in some cases, soon degenerate into fixed and parochial bureaucracies repeating, year by year, in excruciatingly tedious intergovernmental meetings, ideas which had become almost meaningless clichés. The gap between international incantations and harsh national realities was still not apparent.

"There is nothing intrinsically wrong with bureaucracy - quite the contrary; without bureaucracy, modern society would not run. But when bureaucracy becomes involved with more or less abstract ideas, a terrible elephantiasis often sets in, and this happened in the United Nations system. Cockeyed ideas from member states or other sources begot studies which produced reports which set up staffs which produced more reports which were considered by meetings which asked for further reports and sometimes set up additional bureaucratic appendages which reported to future meetings. The process was self-perpetuating. Few senior officials were able to resist the siren call of empire-building in their departments, and governments were insatiable in their thirst for jobs."

Source: B. Urquhart: A Life in Peace and War, Weidenfeld and Nicolson, London, UK, 1987.

[3] The latest resolution was adopted by the United Nations General Assembly on 16 December 1992. See Chapter 17, Comment No. 7.

[4] During the UN General Assembly debate at the closure of the UN Decade of Disabled Persons, the French Minister for the Disabled Mr Gillibert made the following statement: "The proclamation in 1982 of the United Nations Decade of Disabled Persons and the adoption of a World Programme of Action concerning Disabled Persons were a starting-point for States Members of the Organization in their resolve of access to equal rights and opportunities in accordance with their fundamental human rights, to which our countries are so committed.

"The Decade comes to an end today. Let us be quite candid: the sum total of all the good intentions, of all the recommendations adopted since 1982, falls far short of the anticipated results, and I know that many of those now present share my view. It would be hypocritical not to acknowledge this fact.

"Let us not engage in any self-congratulation. These large gatherings are indispensable, but they should not be used merely to draw up a catalogue of our texts, each more eloquent than the other. We must also admit our failures and acknowledge the indifference that remains a fact of life - indifference to the injustice and the pain of disability. Let us not come with our statements already prepared. Let us throw out these papers a priori. Let us build the future. Let us have the courage to depart from this same old routine of producing texts. Those with disabilities cannot afford to wait any longer.

"But let us also be candid about the difficulty of this undertaking: how can we find an approach that is coherent, effective and applicable to more than 180 countries with specific conditions that are as various as they are complex, and with contexts that differ widely one from the other?

"Are we to conclude that there is no solution? Personally, I refuse to do so."

Source: Official records of the UN General Assembly 13 October, 1992.

part three

future challenges

CHAPTER SIXTEEN: THE NEED FOR A CARING SOCIETY

1. The CBR strategy builds on commitment to a "caring society"

Establishing a CBR service system presupposes, first, a clear political commitment of the government to provide the backbone of such a system. Second, the communities must be ready to accept responsibility for their disabled members by providing some of their own resources; creating in this way a "caring society".

Given governments' past records in this respect, persuading them to carry out their role will not be easy. Nor will it be easy to achieve community involvement in every case. Some organisations that have given the CBR strategy a try have come to realise that such a programme is difficult to implement. Having arrived at that conclusion, some of them gave it up and returned to the conventional system. In the wider context, this would mean bidding farewell to prospects of improving the situation of disabled people in developing countries. The availability of services using the conventional approach continues to be limited to a small group of disabled persons, which means that the service gap will widen.

Those who, in spite of the difficulties, believe in the need to act should first of all analyse what is required in terms of political action in order to create a "caring society". No doubt, political leaders have to be convinced of the necessity of re-educating the general public, of creating a far higher degree of awareness, of inspiring and mobilising solidarity. Political action from the top is called for, as are education programmes in schools, awareness-building and information campaigns in the media, along with measures to sensitise the grass-roots population. It is time to abandon the "wait-and-see" attitude built on expectations that governments will eventually take care of everyone. People must be awakened to the fact that the resources needed to create a "caring society" are right at their doorsteps - untapped today, and hence wasted. Breaking the old patterns of inaction, selfishness and ignorance in order to create a society built on solidarity is a formidable challenge.

2. CARE NEEDS AMONG DISABLED PEOPLE

This book has concentrated on a strategy for rehabilitation to meet the needs for functional training, education, income-generating activities and so forth, of disabled people in the developing countries. Little has been said about care needs and about the industrialised countries.

The prevalence of moderately and severely disabled people in the developing countries is estimated to increase from 183 million in 1990 to 435 million in 2025. In the industrialised countries, the numbers will rise from 93 million in 1990 to 138 million in 2025.

Rehabilitation services will benefit a large population of all moderately and severely disabled people, but it will not restore all of them to full independence and social integration. Thus many disabled people will, to varying extent, be dependent on others in their daily life: they need care, help and support. These needs include medical care of acute and chronic diseases (e.g. in hospitals, others institutions, or through primary health care), professional services at home, environmental adjustments (e.g. making bathroom and kitchen facilities accessible), and home help. As the proportion of disabled people increases, so do the requirements for these types of care.

In the developing countries, medical services are mostly restricted and seldom deal with more than a small proportion of disabled people. With economic growth, the demand is likely to grow. The requirements are difficult to predict, so no attempt will be made here to calculate these. Home help is normally given by the family and not through public services.

The most pronounced problems related to care provision concern the industrialised countries, in particular the increasing group of disabled elderly. I will make a few reflections related to their situation - there is an important lesson to learn concerning the need to preserve and strengthen what now remains of a "caring society".

3. *THE PROSPECTS FOR DISABLED PEOPLE IN THE INDUSTRIALISED COUNTRIES*

Using the global operative rate of moderate and severe disability (see Chapter Two) for the age groups 60 and above, the number of people with such disabilities in the industrialised countries may be calculated (Table 16.1).

Table 16.1: Number of moderate and severe disability among people aged 60 and above, in the industrialised countries

AGE GROUP	PREVALENCE OF MODERATELY AND SEVERELY DISABLED PEOPLE %	PEOPLE WITH MODERATE AND SEVERE DISABILITIES, MILLIONS 1990	2025
60-64	15.1	9.1	13.2
65-69	18.3	9.1	14.7
70-74	25.5	8.7	17.3
75-79	37.6	11.3	19.1
80+	56.0	17.7	32.5
	TOTAL	**55.9**	**96.8**

The number of moderately and severely disabled people in these countries is estimated to be about 56 million, or 60 per cent of all disabled people, corresponding to 4.6 per cent of the total population, in 1990. It is projected to grow to about 97 million, or 70 per cent of all disabled people, corresponding to 7.2 per cent of the total population, in 2025. This growth rate implies that the number of moderately and severely disabled people will grow by 70 per cent in 35 years.

The situation of these people differs a great deal from that of the group of elderly disabled in the developing countries. Services are, to a large extent, available, and we know that some 70 per cent of all medical care in the industrialised countries is consumed by people aged 65 and above, the costs amounting to about four to seven per cent of total GDP. Costs for medical care have until now progressed at a faster rate than GDP growth; and the expected annual 1.6 per cent increase in the number of elderly disabled persons will contribute to a health demand never experienced before.

A large proportion of this increase will most likely go to meet the costs for professional care at home by physicians, nurses, physiotherapists and technicians, since elderly people tend to prefer receiving such care at home. Administering care this way will probably not result in any total cost savings, because more personnel will be needed (as they will spend a high proportion of their time on travel). Most likely the increase in medical care costs will amount to an additional three to seven per cent of GDP during the period 1990-2025.

Estimates concerning home help for moderately and severely disabled elderly people in the industrialised countries will now be made. Home help includes assistance with daily functions that disabled people are unable of carrying out alone: dressing and undressing, eating, washing and keeping clean, moving, buying and preparing food, house-cleaning, transportation, communicating such as telephoning, writing, reading letters and newspapers, paying bills, bookkeeping, reporting on health status (to medical-care provid-

Table 16.2: Examples of a calculation of needs for home help (HH) among moderately and severely disabled people aged 60 and above, in the industrialised countries; estimates for 1990 and 2025.

1990					
Age group	**HH hours/day**		**Number of people needing HH, in millions**	**Daily needs of HH, million hours**	**Annual needs of HH, million hours**
60-69	3		18.2	54.6	19,929
70-79	4		20.0	80.0	29,200
80+	6		17.7	106.2	38,763
		TOTAL	**55.9**	**240.8**	**87,892**

2025					
Age group	**HH hours/day**		**Number of people needing HH, in millions**	**Daily needs of HH, million hours**	**Annual needs of HH, million hours**
60-69	3		27.9	83.7	30,551
70-79	4		36.4	145.6	53,144
80+	6		32.5	195.0	71,175
		TOTAL	**96.8**	**424.3**	**154,870**

ders), security, etc. Apart from these, home help may comprise looking after medication, measuring blood pressure, pulse and temperature, coping with incontinence problems, administering enemas or injections, and exercising the elderly disabled person.

These needs are today very large, partly unmet and, to some extent, hidden or unrecognised. In Table 16.2, I have given an example of how home help needs could be calculated. The figures refer to industrialised countries and constitute total estimates for all of them.

In the calculations presented in Table 16.2 it is assumed that the average need for home help for these disabled people amounts to 3 hours/day for those aged 60-69, to 4 hours/day for those aged 70-79, and to 6 hours/day for disabled persons aged 80 years and above. The three age groups are of more or less the same size -one third each - and some experts may prefer to abandon the division into age groups in favour of a division into three groups of severity. The end-result will be the same. Assuming the daily requirements for home care referred to above, the need for home help will go up from 88,000 million hours annually in 1990 to about 155,000 million hours in 2025. This number will be correspondingly lower if a proportion of these people are cared for in hospitals or care institutions.

The numbers above may be recalculated to show the number of home helpers required. If we assume that the effective number of working hours per year and per full-time worker amounts to 1,800, we arrive at the estimation given in Table 16.3: 49 million were needed in 1990, and 86 will be needed in 2025.

Thus the home help needs for elderly disabled people in the industrialised countries are already very high, and they can be expected to increase quickly. The number of elderly is growing rapidly, in particular in the age group above 75 years, where the prevalence of moderate and severe disability is high. There is evidence to show that we can expect a higher proportion of severe disability during the next few decades[1], mainly because of increased survival. This will partly be offset by the resulting general decrease

Table 16.3: Example of the numbers of full-time home helpers required to meet needs among moderately and severely disabled elderly people in the industrialised countries

1990	48.9 million (= 4.05% of the total population
2025	86.1 million (= 6.36% of the total population

in the disability rate owing to improved health in the ageing population.

The number of moderately and severely disabled people in the industrialised countries is expected to grow by 41 million between 1990 and 2025. At the same time, the population aged 20 to 59 years - the main group of economically active people - is expected to grow by not more than 31 million. It may be worth mentioning that the number of elderly people aged 75 years and over with senile dementia is estimated to increase in the more developed regions from nine million in 1990 to 18 million in 2025.[2] A similar pattern will emerge, with some delay, in the less developed regions.

It is already now very difficult to make available the care personnel needed for home help. And this situation is bound to worsen in the future. But, assuming that theoretically it would be possible to provide the needed personnel, what would it cost the government/-authority/social security system to pay for this army of home helpers?[3] An attempt at calculating these costs is presented in Box 16.1.

Box 16.1

EXAMPLE OF COST CALCULATIONS FOR PROVISION OF HOME HELPERS

The following example assumes that a full-time home helper receives a salary equivalent to the GNP per capita.

We will now calculate the costs - in per cent of total GNP - for employing the number of home helpers required according to the estimate in Fig. 16.4.

In the calculations, we assume that these are extra costs for work carried out at night or during weekends, as well as overhead costs for social security and other benefits, amounting to 60 per cent of the annual salary costs. Further, that transportation and administration costs for organising home help amount to 30 per cent, over and above the salary (including social costs).

The calculations only include costs for home help as described above (excluding costs for medical care at home given by health professionals - physicians, nurses, physiotherapists - or costs for professionals-related equipment, supplies or transportation).

Under these conditions, the costs for home help are:

in 1990 GNP/capita x 1.60 x 1.30 x 4.05% = 8.42% of GNP;
in 2025 GNP/capita x 1.60 x 1.30 x 6.36% = 13.23% of GNP.

Based on this example, recalculations can be made in each country.

In Box 16.1, we arrive at the conclusion that the costs for home help to a government/authority/social security system willing to pay for everyone would expand from currently 8.4 per cent of GNP to 13.2 per cent by 2025.

These numbers are an example. Some experts will propose to reduce the number of beneficiaries, to cut the number of hours of home help provided, to lower the total estimate to, say, somewhere in the neighbourhood of five to eight per cent of GNP.

The gap between home help needs and home help provision in the industrialised countries is very large today. Public services cover a small proportion of what the 56 million disabled elderly need today. The remaining needs are, to some extent, covered by voluntary help from families, neighbours and friends. Many people argue that this stop-gap will not suffice in the future. Women, who in the past have been providing most of the home help, are increasingly working outside the home. They are also having their children later, and may not be free to look after an elderly parent. Occupational mobility is on the increase, so children may no longer live close by their parent's home. Other volunteers may be less available, lacking either motivation or time - hence the prospect for most disabled elderly will be to be abandoned. As a result, an army of millions of helpless at home will be added to the army of millions left homeless in our streets.

4. OPTIONS FOR THE FUTURE

Our options for the future to deal with this dilemma are basically three:

(1) do nothing;
(2) governments, authorities, social security systems, and so on, will step up service provision to cover the needs;
(3) we create a caring society.

At present, **option number one** is dominating.

Public services to cope with this development, along with other efforts to meet future needs, are - in the eyes of most experts - poorly planned and not convincing. Nothing much is being done to organise a "caring society". Politicians are sometimes seen as running away from rather than facing up to unwelcome realities. Many of them - influenced by the illusions that emerged during the years of dynamic economic growth - have promised to "take care" of just about everyone: the sick, the poor, the unemployed, the addicts, the weak, the homeless and the disabled. In many countries, governments had started to build up a system of safety nets, but later, under economic pressure, these human service systems have been curtailed.

Curtailing of benefits has caused great harm to many people and - in some countries - loss of credibility of the system, into the bargain. Cuts in housing and food allowances have caused new groups of beggars, homeless and abandoned elderly to emerge, now counted in their millions.

The general public is deeply aware of the limitations inherent in the strategy related to broken promises - there will be millions more of uncared-for human beings. Most people know - even if they prefer not to think about it - that this problem concerns us all. On the average, we will spend ten per cent of our lives disabled -a period equivalent to six to eight years, in the industrialised countries.[4] With option number one, many will not be able to live a life in dignity.

Let us now consider **option number two**: providing public services to cover all needs. This is the option that would be preferred by politicians favouring a welfare state. As mentioned above, health care costs are likely to expand by at least three to seven per cent of the GDP in the next few decades. As shown above, using public services for home help, as well, would imply that government spending would have to increase by another conservatively calculated five to eight per cent of GDP during the period 1990-2025.

Most politicians and leading economists would be reluctant to campaign in favour of this option. In many countries, the future of our children is already heavily mortgaged through loans taken to cover past budget deficits, which means that the costs for increased human services cannot be covered by more borrowing. Added to this, there is public pressure to lower rather than step up taxation.

The next problem is the availability of personnel. In some countries attempts have been made recently to increase home care for elderly disabled persons. In Sweden, for example, the average care hours per year and care receiving person went up from 185, in 1982, to 282, in 1987. In 1987, in Sweden, out of a total population of about eight million, 76,700 people were employed as home-helpers. Keeping present standards, which cover about a quarter of the needs, that number will have to increase to 100,000 by the year 2000.[5] The turnover of such personnel is very high. It was calculated that, assuming no change in the present turnover rate, an additional 500,000 care providers will have to be recruited and trained between 1988 and 2000 - a very high proportion indeed of the available labour force in Sweden. And yet, this would not suffice to cover more than a quarter of all home help needs. A similar situation is developing in other industrialised countries as disabled and elderly people strongly express their preference for staying in their own homes rather than being sent to a care institution. Under such circumstances, the demand for personnel is going to multiply.

There are, however, a number of options open to governments to use untapped personnel resources. Among these are all the millions of unemployed people who could be required to do community service in exchange for unemployment benefits; young people, including young girls, who could choose to do civilian instead of military service, and students who receive certain benefits but are free during the summer.

The problem with the mobilisation of these resources is that the personnel will need training and supervision, and there will most likely be a high turnover. Only some of this personnel may be truly interested in serving the elderly. Too little has been done to gather experience on how a system of extended community service based on such resources would function.

In view of the problems cited above, one may conclude that option number two is difficult to implement; the labour market schizophrenia seems difficult to cure.

Let us now look at **option number three**: creating a caring society. I take the term "a caring society" to indicate a community of people which understands that providing care is not a service that relies solely on the government or the local authorities but that it is the responsibility of all citizens. The term indicates that all of us - in the spirit of solidarity - would care about the well-being of our fellow human-beings, whether relatives, neighbours, friends or unknown members of our community. It would imply being prepared to spare some of our time and other resources for taking care of those who, to survive or to live a life in dignity, depend on others for help. It would **require that we rediscover our essential humanism.**

There is no dearth of examples of the presence and the value of generous voluntary efforts to help. In most industrialised countries, family members provide a great part of the daily help to disabled people, including the elderly. There are examples of community and non-governmental groups, or of individuals such as friends and neighbours providing home help. One also sees healthy elderly taking care of disabled peers and groups of unemployed people doing community service. These efforts need to be built up in an organised way. (For an example, see Box 16.2.)

If voluntary efforts could cover a large part of the needs (mainly for home rehabilitation and care), governments could concentrate on medical and referral services which voluntary forces are not equipped to operate, including short-term, costly interventions requiring high technology not available outside institutions; training of personnel, including volunteers, and technical supervision.

The general idea of building a home-service programme largely on solidarity and voluntarism strikes many people as naive, absurd and impossible. The way we live our lives is more and more self-centred and egoistical. The idea of providing a service for a needy person free-of-charge[6] is rejected outright by most people. Social contacts within families are on the decline, and many of us do not even know our immediate neighbours. Whatever free time we have is spent increasingly on leisure-time activities. And we are not much in the habit of committing ourselves to any solidarity schemes or to voluntary community work.

The community spirit our forefathers experienced has all but disappeared in the wake of urbanisation, professionalisation of local services and politics, replacement of grass-roots initiatives by top-down politics, moving from a "caring society" to a welfare state with excess bureaucratisation and regulation.[7] All these, and many other factors, stifle fresh initiatives.

Can all this change? And does anyone appreciate the urgency of the need to set about addressing the problems associated with a non-caring society? Unlike the future, which approaches without any effort of our own, development does not. It is late already. Time is running short.

Box 16.2

A CARING SOCIETY IN PORTUGAL

I have had the opportunity to follow the development of a caring society in a small town in Portugal.

During my first visit, I was taken to see the local hospital and talk with its staff. It had 30 beds, all occupied by elderly people, most of whom had been staying there for a long time. The waiting-list was long, and the hospital could no longer take care of even the most urgent cases on the list. Rehabilitation programmes were given by a few therapists. These had no helpers and were overloaded with work. Sometimes, when a patient had been successfully rehabilitated, other obstacles, such as lack of help in buying and preparing food, or an inaccessible toilet, prevented the person's discharge.

In addition to the hospital, I visited about a dozen elderly disabled people at home; the town had no resources for home care, causing the situation to become more and more desperate.

A meeting of the local health and social committee had been convened, and the options for action were discussed. Most avenues seemed closed for financial reasons, such as the possibility of expanding the hospital's capacity, or of providing a modicum of home help. So it was proposed to try to recruit a group of volunteers and to set up a CBR programme to see if this could be the way to solve an urgent, growing problem.

Five years later, I returned to have a second look. As on the previous occasion, the doctor showed me round, and I noticed that now only 15 of the beds were occupied and that there was no waiting list. Some of the unoccupied rooms were used for day care financed from savings made on the hospital's current expenses. Some of the staff whose services were no longer needed at the hospital now worked in home care for the most severely disabled.

I then met with the leaders of the group of volunteers. The group had been set up through the efforts of the local church. It now counted some 50 home assistants, most of them women aged between 40 and 70 years and working on a regular basis.

Whenever the hospital staff identified a person with problems in the home, they contacted the volunteers' group, which then mobilised a suitable caretaker person. A professional designed an individualised home-care programme, instructed the volunteer, and supervised the activities.

Finally, I again went to see a sample of elderly, disabled people at home: the situation had changed completely. Some of these people had been discharged after up to four years spent in the hospital. In each home I visited, there was a volunteer carrying out a simple rehabilitation programme and helping with daily household chores if needed. The results were obvious: elderly people previously confined to bed or to a chair were up and walking, taking care of themselves and doing household work. A volunteer artisan had helped with adjustments at home, such as putting up a rail, fixing shelves in the kitchen, modifying the bathroom, and so on. Obstacles in the pathways and roads in the neighbourhood had been removed.

Interviews with the elderly people clearly indicated that they were very content with the improvement of their situation, but being at home was what they were most happy about.

5. *PREREQUISITES FOR A CARING SOCIETY*

First of all, a caring society cannot be brought about unless people change their attitudes and behaviour. Only through a major political effort will it be possible to raise awareness and to create a sense of solidarity and commitment - an effort that may not have much initial popular appeal. A long-term period of re-education of the public is needed to motivate people to participate in the caring society, and each country will have to draw up a plan to that effect. It might be easiest to mobilise people who have recently retired themselves, as well as some of those who are on unemployment benefits, and groups engaged in non-governmental organisations. A new ethic - a feeling of individual and common responsibility - must be created. The authorities, knowing that all other options carry a high political price, already have all the incentive they need to motivate them for their involvement in a caring society.

Secondly, a caring society needs organisation. People in need have to know where to look for help. Ad-hoc measures will not do - they will leave many disabled vulnerable and insecure.

Thirdly, those engaged in providing care should receive adequate training, and to this governments could give support. Also, the work of care providers should be technically supervised.

I will now return to the reason for including this chapter in a book dealing with developing countries. The lesson for these countries is unequivocal: political leaders, government officials, community groups, private organisations, along with all other forces in a country, must be mobilised to preserve the spirit of solidarity and to strengthen the caring society wherever it exists. Resources should be set aside to sustain this spirit and, in particular, to educate and convince the younger generations.

To achieve a "caring society" is difficult, complex and time-consuming. Once the politicians and other leaders in the industrialised countries are ready to tackle this task, they should turn to the developing countries to learn certain things. Maybe that will be the moment for them to see in a clearer light that the concentration on crude economic development, accompanied by an almost total neglect of the social and human aspects, has had serious side-effects. Among these is the displacement of the meaning of the word solidarity: it has moved a few centimetres from the heart to the pocketbook. Our efforts now should focus on moving it back to its original setting.

COMMENTS AND REFERENCES

[1] There is a large number of scientific studies to support this finding as well as other views given in this chapter. See e.g.

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K. Steel, A. Rosenfeld, A. Bissonnette, M. Pajk, E. O'Brien: Home Care Cost and Utilisation, in press, 1992.

[2] This estimate is based on international data reproduced in Ansvaret för Äldreomsorgen, Socialdepartementet, Ds 27; Stockholm, Sweden, 1989.

[3] In Sweden, for instance, already in 1986, costs for home care alone totalled SEK 1,000/capita (US$ 170). Added to this, 70% of all hospital beds for short-term care and 100% of those for long-term care were occupied by people over 65 years of age. The total costs for medical care, hospitals included, in Sweden amounted to about 10% of GDP; in the OECD countries, 9% of GDP was spent on health care, in 1991. See Socialdepartementet, ibid.

[4] Data regarding per cent of total life expectancy spent free of disability have been published by Reves in its Statistical Yearbook 1991. The disability-free life expectancy at birth (in per cent) is for Canada (1986) 82.6%; United States (1985) 73.5%; Spain (1986) 80.8%; for United Kingdom (1985), for categories (see Chapter Two) 1-10 87.3%, and for categories 4-10 92.5%; Indonesia (1977) 92.5%.

It might be reasonable to conclude that we are disabled during an average of 10% of our lives.

[5] Personalförsörjningen inom hemtjänsten, Socialdepartementet, No. 7; Stockholm, Sweden, 1988.

[6] There is an interesting experiment in New York City aimed at mobilising voluntary forces. An elderly person who undertakes voluntary work in the community (helping disabled elderly at home) reports his/her working hours to a "bank". The bank gives "credit" for these hours and, in exchange, the volunteer receives an equal amount of home help when he or she needs it later on.

[7] The process of moving from a welfare state built on unrealistic political assumptions towards a caring welfare society requires a new strategy. Wiman argues that it is important to move away from the present type of "social-worker-does-it-all" approach to a process aiming at "enablement". This approach has already been officially adopted in Finland, and Wiman has, built on his experience, some advice for developing countries:

"The enablement approach [used in the social welfare sector] is slowly replacing the old caretaking approach. We believe that this new approach is more suitable to the affluent societies of today. In the poorer societies it is not advisable to copy the centrally planned, institution centered, formalized, and bureaucratic care taking approach of the rich Welfare States. The Welfare State is a rich man's invention. It is expensive and it has a tendency to destroy the traditional community based ways to produce security and support. Involving the people at all levels as co-producers is a cheaper and a more effective way of producing social security and support. The Welfare States have much to learn from countries which have not built an impersonal institutionalized social welfare system.

"But functioning and functional social welfare systems do not grow out of the ground. To build a society that makes it possible to increase the well-being of all members calls for active planning. We maintain that the enablement approach interpreted in the right way is a more functional and easily applicable approach for poorer countries as well. On the other hand the Welfare State has to make a 90 degree turn from the road which was leading to caretaking from the cradle to the grave." R. Wiman: Towards an Integrated Theory of Help, The National Board of Social Welfare in Finland, Helsinki, Finland, 1990.

CHAPTER SEVENTEEN: A PLAN OF ACTION FOR THE FUTURE

In this chapter, a review will be made of the programme formulated for the U.N. Decade of Disabled Persons (1983-92), followed by proposals concerning strategies and priorities for the coming decades.

1. THE UN DECADE 1983-92

The approved strategies, approaches and guidelines for the Decade appear in the "World Programme of Action Concerning Disabled Persons" (WPA)[1], which was adopted by the United Nations General Assembly in 1982.

The WPA is a fairly long and detailed document consisting of 201 operative paragraphs. It covers all possible aspects in all countries, emphasising three areas. These are prevention of disability, rehabilitation, and equalisation of opportunities.

A statement regarding priorities was needed, and this was presented by the UN Secretary-General to the General Assembly held in October 1984.[2] The Secretary-General states that he had reviewed the WPA "with the aim of identifying priority areas for activities at the national, regional and interregional levels during the Decade". The entire text, including nine priorities, is reproduced in Box 17.1.

Box 17.1

PRIORITIES OF THE UN DECADE 1983-1992
ACCORDING TO THE UN SECRETARY-GENERAL

"(a) One of the most important institutional arrangements at the national level consists of the national disability committees that were created during the International Year of Disabled Persons in most Member States. These committees should continue and, if necessary, be strengthened so as to be able to carry out the work during the Decade of Disabled Persons on a more permanent basis. They should include representation of organizations of disabled persons;

(b) Member states should be encouraged to review their national legislation, especially legislation related to human rights and to social assistance and security, with the aim of eradicating all discriminatory and segregating elements. When reviewing the legislation consideration should be given to the realization of the objective of full participation of disabled persons and their organizations in the decision-making processes in various sectors of society;

(c) Countries should give high priority to further improvements in collection of basic data on disabled persons on a regular basis and to close collaboration between users and producers of these data in the analysis of data requirements and use of the resulting data. National and international technical co-operation and donor agencies and other interested international organizations, including non-governmental organizations, should provide every possible assistance to interested countries in this field, in the context of developing national statistical capabilities and uses of disability data;

(d) Rules and regulations ensuring accessibility to buildings and facilities should be established. In the view of the Secretary-General consideration should be given by the National Disability Committees as a priority to ensuring that no new buildings or institutions are built without due consideration to the accessibility problem for various categories of disabled persons;

(e) Special attention should also be given to an adequate provision of technical aids;

(f) Prevention of disability, both in the medical and in the social field, should be given high priority. Since prevention covers a vast area, detailed guidelines for priorities should be worked out for the Decade of Disabled Persons;

(g) Equalization of opportunities within the educational system should be another main issue during the Decade;

(h) Public information and evaluation elements should be built into all programmes;

(i) At the international level the management of the Trust Fund, the establishment of effective services for exchange of information, and the monitoring and evaluation of the implementation of the World Programme of Action are closely linked activities to support activities during the Decade at all levels. It would be useful to establish guidelines on how best to undertake activities for the Decade; such guidelines would not only assist Member States to formulate and implement long-term national plans and programmes, but would also assist in co-ordinating the activities of the United Nations system and those of the non-governmental organizations."

The outcome of these recommendations will now be reviewed:

(a) a large number of countries kept their *International Year of Disabled Persons committees*, but the activities of many of these have been far less visible than one had hoped for. They included for the most part representation of organisations of and for disabled people;

(b) a number of developing countries have reviewed their *legislation*, eliminating some negative discrimination and adding some positive one, mainly quota laws. However, this has been of limited help to disabled people seeking full participation, and it has only marginally strengthened their organisations' decision-making role. Work is under way in UNCSDHA to formulate a set of "Standard Rules on the Equalisation of

Opportunities for Disabled Persons";

(c) *disability statistics* have been collected from a large number of countries; training has been given by the U.N. Statistical Office, New York, USA, to more than 200 professionals in over 60 countries in order to develop their statistical capabilities; publications are now available to show the outcome of this effort;

(d) a small number of developing countries have issued new rules and regulations to ensure improved *accessibility* to public buildings and facilities, and a useful guide has been published by UNCSDHA;[3]

(e) several seminars and workshops on the subject of *technical aids* have been held at regional and national levels;

(f) programmes aiming at the *prevention of disability* are carried out by all governments, sponsored and technically supported by UNICEF, UNDP and WHO and assisted by a large number of international donor/development organisations. Such activities comprise, among others, the expanded programme of immunisation, efforts to combat communicable diseases and malnutrition, the special programmes for blindness and deafness prevention, extension of health education, improvements of water supply and sanitation, and promotion of better maternal and child health care;

(g) equalisation of opportunities within the *educational* system is a subject that has received increased publicity. However, a major change in national policy and practice is required to produce more tangible results.

(h) as to *public information*, a few journals and newsletters have made their appearance. In a large number of countries radio and television have carried programmes dealing with disability, and articles about disability issues have been printed in the press. However, this information seems to reach not more than a selected group in each country, a group consisting mainly of professionals.

In terms of evaluation, few governments or organisations have progressed beyond the mere reporting of the amounts of funds spent and the number of disabled people served, with no account of the effects.

(i) the *Trust Fund* has had its value as a provider of seed money. Its proceeds have not been significant and they have been spread thinly, in amounts too small to have any real impact. A service for *exchange of information* was established at the end of the Decade. The *monitoring and evaluation* of the implementation of the WPA was carried out by CSDHA: a mid-term review held in Stockholm in 1987 revealed that "the outlook was rather pessimistic", and the experts urged all partners "to translate into action" the priorities for global activities contained in the WPA. In reality, very few long-term national plans and programmes have been formulated, while co-ordination of "the activities of the United Nations system and those of the non-governmental organizations" has barely started and is meeting enormous problems because of vested interests and reluctance to co-operate.[4]

The reader will perhaps feel somewhat surprised at the choice of priorities for the Decade 1983-92. For instance, no mention is made of the needs for better access to all types of public services and mainstream programmes, for functional training, for vocational assessment and training, for income-generating activities, for economic assistance to needy disabled people, and so on. Nor is there any reference to the need to strengthen the role of the family and the community so as to enable them to better support their disabled members, or to the need for governments to build decentralised networks with competent personnel as the basis for a credible service delivery system.

2. *STRATEGIES FOR THE DECADES AHEAD*

It would seem appropriate to propose more relevant priorities for the coming decades.[5] No consensus can be expected on this subject. The list below includes some of those mentioned by the Secretary-General of 1984. But many people with field experience would like to put the emphasis elsewhere.

Below, six priorities are proposed for the developing countries that should receive attention during the the next few decades. (See Box 17.2.)

Box 17.2

PROPOSED PRIORITIES FOR PROGRAMMES CONCERNING DISABLED PEOPLE IN THE DEVELOPING COUNTRIES FOR THE NEXT DECADES

(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, by the year 2000, 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.*

These priorities are explained in detail below[6].

(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***

This is the most urgent need to be addressed by governments.[7] As shown above, in most developing countries services are lacking to meet 97-98 per cent of the needs. The greater part of services and opportunities is provided through private and charitable organisations. Services are largely un-coordinated, sometimes of questionable quality, as well as costly and inaccessible to the majority of the population.

These services and opportunities should encompass: (i) improved *access to general development and mainstream programmes*, especially those with a training component, and to all public services, for instance, in the sectors of health, transport, information and administration; (ii) all types of *specific community-based rehabilitation measures*: functional training, education, vocational assessment and training, and income-generating activities; and (iii) continuing *interventions in the environment* to remove barriers (physical, psychological and cultural).

This priority presupposes national action to be taken at all levels: by governments at the central and the intermediate level, and by the communities at the local level. Preferably delivery of services and creation of better opportunities for disabled people should form part of all integrated community development programmes.

All action should, in principle, be preceded by the formulation of clear-cut policies, long-term objectives, and by a description of the strategies and plans to be followed. Other prerequisites are: programmes for development of competent personnel, formulation of guidelines for NGOs, description of detailed activities, timeplans and budget provisions.

Governments should seek to develop a co-ordinated organisational structure, including a network of staff at central, provincial and district levels responsible for providing administrative and technical support to a service system aimed at eventually meeting the needs of all their disabled citizens. Multi-sectoral programmes for disabled people will be easier to co-ordinate if based on interministerial policy documents and jointly formulated plans.

Governments should stimulate, promote and sustain efforts by local communities to act independently in all matters related to community development, including CBR.

Governments should realise that their role is not to provide - in some distant future - all the services to all their citizens for their entire life. Rather, they should inspire responsibility and encourage their citizens to develop their own independent resources for common causes and to provide, in the spirit of solidarity, among other things, human services for disabled people.

Communities should use existing, or set up, local permanent structures for the purposes of disability-awareness building, dissemination of rehabilitation-related knowledge and skills. Such structures should plan the functional training programme, promote social integration in such areas as schooling, vocational training and income-generating activities and protect the human rights of disabled persons while fostering an atmosphere of solidarity, equality and social justice.

Existing centres, institutions and programmes operated by private and charitable organisations should seek their integration in a comprehensive service delivery system, where their skills and specialised knowledge can be fully utilised.

(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, by the year 2000, 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

It should be possible to provide the services and more equitable opportunities for disabled people, if

- sufficient development funds are available, and
- governments and communities in the developing countries commit themselves to carry out this programme.

Resources, such as funds, personnel, facilities, equipment and organisational structures, are already available, mainly from NGOs and some international development agencies. However, it is very difficult to support a government's implementation of a community-based programme for disabled people without an increase in the funds available. It is proposed that, *by the year 2000, all bilateral, relevant multilateral development agencies and NGOs make available for this programme one per cent of their budgets.* At present only one development agency, SIDA, in Sweden, reports that its support to programmes for disabled people has reached the 1%-level. By comparison, the spending by the UN agencies is particularly low. UNDP, for instance, in 1991, used 0.3 per cent of its budget for this purpose.

The use of the available external resources (mainly from private and charitable organisations) does not follow a consistent set of policies or guidelines. The activities are fragmented, and there is little co-operation among those implementing the programmes, both at the national and the international level. It is necessary to put these resources to a more effective use.

Ideally, each recipient government would advise donor/development agencies on its policies and plans, and subsequently seek to channel the funds offered to its specific priority areas. In this way, any external (or national) voluntary contributions could serve to speed up service delivery, to improve quality, etc., cutting down on the time needed to implement a programme that aims at full coverage.

In addition, it would seem ideal to have a mechanism through which international resources could be pooled and distributed by preference to the countries most in need, whenever these are ready for action concerning rehabilitation.

Each fund-raising organisation has its specific profile, specific areas of professional interest and competence. It may also have specific target groups or countries and, in many cases, a different set of overriding priorities, such as giving preference to certain religious groups, or providing assistance to certain organisations. For these reasons, some organisations may not be ready yet for co-ordination. For the time being, co-ordination can only be established between those willing to seek a more collective role.

It should be possible to start co-operation in the field, involving the relevant UN agencies, bilateral development and non-governmental organisations. For those ready for co-ordination, it is proposed to set up either a global or a few regional operative non-governmental organisations.

(c) strengthening all efforts aimed at sensitising the public and making it more aware of the abilities of disabled people

Efforts are already under way, with some partial success. The general public knows more about disabilities, disabled people and rehabilitation now than it used to in the 1970s. National leaders have become more sensitive, and media exposure of the subject has improved since 1981 (IYDP) and during the UN Decade.

Nevertheless, the messages have not reached the ordinary citizen to the extent necessary. There are better ways to reach the grass-roots. Experience has shown the school system to be a useful medium; CBR programmes to be capable of sensitising community members to the potentialities and abilities of disabled people; local interest groups to be able to contribute to increasing awareness with the help of culturally appropriate means of information; and community leaders to have a decisive role to play in inspiring people to abandon their wait-and-see attitudes and passivity.

(d) developing an active local and national role for disabled people and their families

Involvement of disabled people and their families should receive special attention, in particular as far as management of CBR programmes at the community level is concerned.

At the national level, co-operation should be promoted among the various organisations of disabled people, parents, and others. They should be encouraged to join in a federation or a union and seek official recognition from the authorities, including their right to participation in the national co-ordinating body. Further, formal procedures should be established for consultations with such a federation/union about government objectives, plans, programmes and evaluations.

(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

As far as human rights are concerned, disabled people are experiencing great difficulties. This concerns equal opportunities in respect of schooling, vocational training, employment, public services, transport, recreation, access to buildings, etc. To remedy the situation, each country should draw up a long-term plan of relevant measures.

Moreover, disabled people are often targets of abuse and crime in all its forms - both within their communities and in institutions. Legal protection of their rights as citizens should be provided. This necessitates a pertinent community mechanism, for instance a local committee responsible for monitoring the human rights situation and for taking corrective action. As not all problems can be solved locally, a system should be set up that would allow disabled people recourse to higher levels of legal authority (e.g. mediators, ombudsmen). Regular inspections and quality controls of institutions are needed.

(f) *improving collection and dissemination of information*

One single international agency should act as a clearing-house. Requests to the clearing-house should be transmitted to the organisation where the data-base is located, or to the organisation that has collected the information requested.

Information should cover the following:

- rehabilitation activities in each country, including interventions in the environment;
- organisations of and for disabled people;
- donor/development agencies supporting programmes that include, or could include, people with disabilities; and their expenditure;
- methods/technology;
- disability statistics; harmonisation of concepts and definitions to facilitate information gathering and data collection; development of policies and programmes based on statistical predictions of needs; evaluation systems;
- research concerning rehabilitation in the developing countries.

On the basis of this information, an index reflecting the quality of life of disabled people will be developed and included in the UNDP Human Development Report.

3. *TOWARDS A SOCIETY FOR ALL*

There is probably no other group of people as neglected, abused, powerless and poor as disabled people. No one doubts the urgency of remedying this situation.

All the declarations, resolutions and recommendations needed for progress have already been written and adopted. Enough documents and publications to support them are available by now. We know what to do.

We need to proceed consistently and tirelessly with practical work in the developing countries, to make it a society for all. The process to meet the essential needs of all disabled people will be a long one, maybe 15 - 25 years, and it may be neither glorious nor eye-catching. What matters most is to apply common sense and realism.

Progress will be easier when all outside forces come together. There is a role for everyone. In the future we should preferably play together, as a team and not as lone actors.

This book might serve to inspire the future partners in that team. Let us hope that governments will take seriously the challenge ahead - to provide public resources sufficient to help fill a service gap of large proportions. Individuals too must show the spirit of solidarity required to improve the quality of life of a group living in their midst whose resources and abilities have never been recognised, and whose needs and rights have always been neglected.

To conclude, let me recall the statement made recently by the UN Secretary-General Dr Boutros Boutros-Ghali to mark the end of the UN Decade of Disabled Persons[8]:

> *"In the modern world, requirements of productivity, profitability and economic maximization are too often at the forefront. Too often these imperatives take precedence over the search for harmonious development of societies, for balanced development in which there is a concern for each human being. To plead the cause of the disabled is to plead also the cause of a more humane world, a world intent on seeing that everyone finds his place because each person's place is useful to all. It is in this spirit that one must understand the United Nations programme for the disabled.*
>
> *"... In this area, as in many others, the United Nations cannot do everything by itself. It provides support and encouragement. That's why it is important that Governments themselves make the question of the disabled one of their priorities. Since this is an issue that addresses the handicapped, those who suffer and those who are alone, it will undoubtedly lead the leaders of each country to take the most noble part of collective action."*

COMMENTS AND REFERENCES

[1] U.N. General Assembly Resolution No. 37/52 of 3 December 1982.

[2] Report of the Secretary-General to the U.N. General Assembly (A/39/191) dated 12 October 1984.

[3] Designing with Care, A Guide to Adaptation of the Built Environment for Disabled Persons, U.N. CSDHA, Vienna, Austria, 1983.

[4] The achievements, shortcomings and challenges of the UN Decade 1983-92 have been reviewed in Disabled Persons Bulletin No. 2, 1992, UNCSDHA, Vienna, Austria, and in a UN document: H. Sokalski: Statement before the Third Committee of the forty-seventh session of the General Assembly.

[5] Under the motto "Towards a Society for All - from Awareness to Action", UNCSDHA is presently seeking to reach a consensus on "a long-term strategy to further the implementation of the World Programme of Action Concerning Disabled Persons to the Year 2000 and beyond". Source: Documents relating to a meeting held in Vancouver, 25th to 29th April 1992.

[6] See Chapter Fifteen, where I describe ILEP, an international federation of donor organisations concerned with anti-leprosy programmes, as an example of successful pooling of resources, agreed common policies and so forth.

[7] The UN General Assembly, on 16 December 1992, adopted Resolution No. 47/88. Among other things, the Resolution "urges governments to show their commitment to improving the situation of persons with disabilities, inter alia, by:

(a) Establishing an appropriate governmental mechanism to be responsible for policy relating to persons with disabilities and overall coordination;

(b) Addressing disability issues within integrated social development policies linked to other socio-economic issues and providing preventive and rehabilitative measures and an equalization of opportunities, with the ultimate objective of facilitating the full integration of persons with disabilities into society;

(c) Where appropriate, creating new or strengthening existing high-level national coordinating committees or other similar bodies in accordance with the Beijing Guidelines for the Establishment and Development of National Coordinating committees on Disability or Similar bodies;

(d) Supporting the development of organizations of persons with disabilities and using the body of knowledge accumulated by persons with disabilities or their representatives in decision-making processes;

(e) Integrating, where possible, disability components into technical assistance and technical cooperation programmes;"

[8] Boutros Boutros-Ghali, United Nations, Official Records of the General Assembly, 12 October 1992.

ANNEX I

REVIEW OF HUMAN RIGHTS DECLARATIONS

Declaration on the Rights of Mentally Retarded Persons

Below is the Declaration on the Rights of Mentally Retarded Persons (RMR), Resolution 2856 (XXVI), adopted by the UN General Assembly on 20 December 1971.

After having quoted the preambular paragraphs, I have divided each page into a left side (quoting the text of the Declaration) and a right side (offering comments on the text).

TEXT	COMMENTS
"1. The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.	1. No definition is offered of "mentally retarded person." The formulation of this paragraph leaves a negative impression. It suggests that the mentally retarded person might not have the same rights as other human beings. The meaning of "feasibility" is not explained.
2. The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.	2. The right to proper medical care, etc. is, unfortunately, made conditional on the probability that this care "will enable him to develop his ability and maximum potential." This can be read as justification to withhold this right from individuals who cannot "develop their ability," yet who need normal medical care to maintain their health, just as other citizens do. The wording chosen may restrict disabled people's opportunities in education and employment in cases where "experts" express doubts that such measures are worthwhile.
3. The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his capabilities.	3. The first sentence is a shortened version of UDHR Article 25. The second sentence should be compared with UDHR Article 23. Here again one must regret the added restriction of this right in the words "to the fullest possible extent of his capabilities."
4. Whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.	4. This paragraph needs to be reformulated to better convey the message that it is best to let a mentally retarded person stay with his or her family. The wording "whenever possible," "with foster parents," "the family with which he lives," "care in an institution," may make some readers feel that it is better not to let a mentally retarded person stay with his or her own family. The text fails to say that no efforts should be spared to make sure that all mentally retarded people stay with their families and that these families receive all necessary support. There is no definition of what constitutes the factors making it "necessary" to provide "care in

	an "institution." The words "surroundings and other circumstances" are vague. Do they mean the furniture or do they include parental love?
5. The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interests.	5. The mentioning of a "guardian" could be interpreted to imply that the parents are considered unqualified and have to give up their rights to decide about their own mentally retarded children. This paragraph will serve to strengthen the position of the principals of institutions, who often take over legal authority from the parents. What is meant by "protect his personal well-being and interests?" Does this include the right of the guardian to keep a mentally retarded person away from his or her family? Does it include the right to decide to castrate or sterilize a mentally retarded person?
6. The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If prosecuted for any offence, he shall have a right to due process of law with full recognition being given to his degree of mental responsibility.	6. The first sentence is a short reformulation of UDHR Articles 4 and 5. The second includes some formulations from UDHR Articles 6 and 7, with the added clarification that mentally retarded people may be excused if they commit a crime. It should be noted, however, that mentally retarded people break the law much less than other citizens.
7. Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.	7. This paragraph describes the procedure "should it become necessary to restrict or deny some or all of the rights of mentally retarded persons." A very negative statement. Are there really ever any reasons to deny the mentally retarded or anyone else "all of the rights?" UDHR lists, for example, the rights to "life," to "security of person," to not be subjected to "slavery or servitude," "torture," "arbitrary arrest, detention or exile," "arbitrary interference with his privacy, family, home or correspondence." Is it conceivable that such rights might ever be denied? Furthermore, the "equal safeguard against every form of abuse" does not offer much of a protection. The clause states that the procedure should include "an evaluation of the social capability...by qualified experts." This is a much watered-down version of UDHR Article 29, which states that rights may only be restricted "for the purpose of securing the due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society." UDHR Article 10 makes it clear that in the determination of anyone's rights there must be a "fair and public hearing of an independent and impartial tribunal." Why is this denied to a mentally retarded person?

Declaration on the Rights of Disabled Persons

Below is the Declaration on the Rights of Disabled Persons (RDP), Resolution 3447 (XXX), adopted by the UN General Assembly on 9 December 1975.

The same pattern of text and comment as for the previous document will be followed here: after having quoted the preambular paragraphs, the text of RDP will be reproduced to the left and the comments to the right.

TEXT	COMMENTS
"1. The term "disabled person" means any person unable to ensure himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of a deficiency, either congenital or not, in his or her physical or mental capabilities.	1. The definition of the term "disabled person" is very loose. It seems to be over-inclusive. There are several unclear statements: what are "the necessities of a normal life?" What is meant by "individual" and "social" life? Is anybody able to ensure by himself or herself wholly the necessities of social life? What is a deficiency in the physical or mental capabilities? Certainly this definition could be made to include almost everyone, a fact important to consider when we read the limitations of rights for disabled persons proposed in Paragraph 4.
2. Disabled persons shall enjoy all the rights set forth in this Declaration. These rights shall be granted to all disabled persons without distinction or discrimination on the basis of race, colour, sex, language, religion, political or other opinions, national or social origin, state of wealth, birth or any other situation applying either to the disabled person himself or herself or his or her family.	2. A reformulation of UDHR Article 2. A positive and clarifying statement.
3. Disabled persons have the inherent right to respect for their human dignity. Disabled persons whatever their origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.	3. A reformulation of UDHR Articles 22 and 25. This is a well-formulated and positive statement. It contains the essence of the Declaration. The last six words should have been left out, as they unnecessarily restrict what is said before.
4. Disabled persons have the same civil and political rights as other human beings; paragraph 7 of the Declaration on the Rights of Mentally Retarded Persons applies to any possible limitation or suppression of those rights for mentally disabled persons.	4. This paragraph enlarges the group for whom civil and political rights can be limited or suppressed. In RMR, only the mentally retarded were mentioned. Now all "mentally disabled persons" may see some or all of their rights restricted or denied. UDHR lists, for example, the rights to "life," to "security of person," to not be subjected to "slavery or servitude," "torture," "arbitrary arrest, detention or exile," "arbitrary interference with privacy, family, home or correspondence" - obviously the authors of RDP have foreseen situations where <u>all</u> these rights could be "suppressed.

	Considering that the definition of a "disabled person" is unclear, overly inclusive and loose, this paragraph implies a serious threat to the human rights of many people.
5. Disabled persons are entitled to the measures designed to enable them to become as self-reliant as possible.	5. Are not these measures mentioned the same as those mentioned in the next paragraph?
6. Disabled persons have the right to medical, psychological and functional treatment, including prosthetic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the process of their social integration or reintegration.	6. This paragraph contains a specific list of various rehabilitation measures. But it qualifies these services by stating that they will be provided if they "enable them to develop their capabilities and skills to the maximum and will hasten the process of their social integration or reintegration." Thus, if there are doubts among the experts about such an outcome, those services may be denied. The list covers only measures directed at the disabled person. It fails to mention the need to reduce obstacles in the physical environment such as public buildings, houses, roads, and transportation facilities. It fails to address the subject of what can be done to change attitudes and discriminatory behaviour in the community. It fails to specify that one must also remove legal barriers to education and employment. It fails to mention all other actions needed to open up the general systems of the society in order to better equalise opportunities.
7. Disabled persons have the right to economic and social security and to a decent level of living. They have the right, according to their capabilities, to secure and retain employment or to engage in a useful, productive and remunerative occupation and to join trade unions.	7. The first sentence is a reformulation of UDHR Article 25. The second contains some words from UDHR Article 23. But the text limits the right to employment by inserting the phrase "according to their capabilities." This seems to imply that disabled people have a status different from that of non-disabled persons.
8. Disabled persons are entitled to have their special needs taken into consideration at all stages of economic and social planning.	8. These "special needs" are already mentioned in Paragraphs 6 and 7.
9. Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No disabled person shall be subjected, as far as his or her residence is concerned, to differential treatment other than that required by his or her condition or improvement which he or she may derive therefrom. If the stay of a disabled person in a specialized establishment is indispensable, the environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age.	9. The positive formulation in the first sentence is seriously challenged by the following ones. The second sentence, which is confused, may be interpreted as meaning that some disabled people may be subject to treatment "in specialized establishments" against their will and against the will of their families. It is left rather open who can make such a decision and what procedures are available to the disabled person who wants to appeal.

10. Disabled persons shall be able to avail themselves of qualified legal aid when such aid proves indispensable for the protection of their persons and property. If judicial proceedings are instituted against them, the legal procedure applied shall take their physical and mental condition fully into account.	10. The UDHR Articles 11, 12, and 17 have a similar text mentioning protection against "arbitrary interference with his privacy," "the right to own property," and stating that, if a person is charged with a penal offence, there are "guarantees necessary for his defence." The only innovation here is that the legal procedure "shall take their physical and mental condition into account."
11. Organizations of disabled persons may be usefully consulted in all matters regarding the rights of disabled persons.	11. Why not "should" be consulted?
12. Disabled persons, their families and communities shall be fully informed, by all appropriate means, of the rights contained in this Declaration."	12. No comment.

ANNEX II

ANNEX III

BOXES

TABLES

ANNEX IV

abbreviations

AA	*Alcoholics Anonymous*
ADL	*Activities of Daily Living*
AHRTAG	*Appropriate Health Resources and Technologies Action Group*
CBR	*Community-based rehabilitation*
CHA	*Community Health Aide*
CW	*Community Worker*
DPI	*Disabled People's International*
EEC	*European Economic Community*
GDP	*Gross domestic product*
IDA	*International Development Agency*
ILEP	*International Federation of Anti-Leprosy Associations*
ILO	*International Labour Organisation*
ILS	*Intermediate level supervisor*
IYDP	*International Year of Disabled People*
LS	*Local supervisor*
MRT	*Mobile Resource Teacher*
NGO	*Non-governmental organisation*
OAS	*Organisation of American States*
OAU	*Organisation of African Unity*
PHC	*Primary Health Care*
PHW	*Public Health Worker*
RDP	*Declaration on the Rights of Disabled Persons*
RI	*Rehabilitation International*
RMR	*Declaration on the Rights of Mentally Retarded Persons*
TCPD	*"Training in the Community for People with Disabilities" (a Manual published by WHO, 1989)*
TP	*Training Package*
UDHR	*Universal Declaration of Human Rights*
UK	*United Kingdom*
UN	*United Nations*
UNCSDHA	*United Nations Centre for Social Development and Humanitarian Affairs*
UNDESD	*United Nations Department of Economic and Social Development*
UNDP	*United Nations Development Programme*
UNESCO	*United Nations Educational, Scientific and Cultural Organization*
UNHCR	*United Nations High Commissioner for Refugees*
UNICEF	*United Nations Children's Fund*
UNOV	*United Nations Office at Vienna*
USA	*United States of America*
US$	*United States of America, dollars*
WHO	*World Health Organization*
WPA	*World Programme of Action Concerning Disabled Persons*

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 a 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 7.7 per cent in the industrialised countries and at 4.5 per cent in the developing ones; the global rate comes to 5.2 per cent. In 1993, these rates corresponded to a prevalence of about 95 million severely and moderately disabled persons in the industrialised world, and of about 200 million in the developing countries, bringing the world total close to 300 million.

The present annual incidence of severe and moderate disability is estimated at about 40 million in the developing countries.

Large increases are seen in the future, mainly due to a general population increase and to ageing of the population. Thus, by 2025, the prevalence of moderate and severe disability is estimated at a world total of about 575 million. The annual incidence of such disability may increase to reach about 100 million in the developing countries by the year 2025.

The causes of disability, the approaches to prevention, and the possible outcome of effective disability prevention are reviewed. A reduction of the prevalence by about ten million people should be achievable in one decade.

Based on these estimations, we may calculate that 8.5 million severely and moderately disabled people - almost all of them depending on others for help - will be added to the prevalence each year, or over 23,000 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, in 1990, permanent services to provide rehabilitation and follow-up were needed for close on 60 million disabled people. Within 35 years, these requirements will double, bringing the number of those in need to about 120 million, an increase by 1.8 million a year. With the ageing of the population, the requirements of services, which currently correspond to about 1.4 per cent of the population, will increase to 1.7 per cent, in 2025.

Rehabilitation services now reach two million people at the most - the gap between needs and supply is enormous.

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 near 100 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 all-round vocational 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.

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 people in daily life activities, and mobility; making orthopaedic appliances; integrated schooling; informal vocational training, 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, as well as approaches to the multiply disabled child, mental health aspects, the integration in CBR of educational and vocational 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 built on experience and comprising 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) is described, with the intermediate-level supervisor providing 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.

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.

This is followed by a few notes 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, 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.

Chapter Thirteen focuses on the role of disabled people 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, using their own experience. Disabled people and parents of disabled children can contribute to sensitisation, animation and management at the community level by forming local interest groups, for example. At the national level, such groups should be set up and 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.

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, with-out 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, divided into two parts. The first part describes the experience of field programmes. There is now ample literature describing effective and culturally relevant technology. But 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 system for service delivery and management. The second part reviews part of the international debate over the CBR strategy.

Chapter Fifteen deals with the subject of international co-ordination. The present coordination has only marginally contributed to more effective use of the available funds for disabled people in the developing countries. There is urgent need for an effort to better involve donor/development agencies active in this area. A concrete proposal for future coordination is made.

PART THREE deals with some future challenges.

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 refound 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, 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, by the year 2000, 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.

WHO IS THIS BOOK FOR?

This book has been prepared primarily for all those who are interested in efforts to improve the quality of life of disabled people in the developing countries:

- *governments and authorities responsible for national programmes concerning disabled people;*
- *disabled people living in those countries, their families and communities;*
- *development and donor organisations (multilateral, bilateral and non-governmental), which today provide a major proportion of funds and services;*
- *professionals working in rehabilitation programmes (including expatriates).*
- *the general public.*

WHAT IS THIS BOOK ABOUT?

This book introduces readers to the concept and experience of community-based rehabilitation (CBR), an alternative strategy proposed for programmes concerned with disabled people in the developing countries. There are now close to 200 million severely or moderately disabled people in these countries, and only about one per cent of them receive effective rehabilitation.

The author argues that a fundamental change of the conventional rehabilitation system is required in order to use future resources in a more effective and less costly way. Large efforts are needed in order to improve access to services and to provide more equitable opportunities, as well as to promote and to protect the human rights of disabled people. It is necessary to design new approaches which make such a programme sustainable using national resources. For this reason, delivery of local services should be based on demystified appropriate technology and should be managed by the community. Governments need to take the organisational and technical responsibility for providing the backbone of a CBR system whose ultimate objective is to meet the essential needs of disabled people in their own countries.

THE AUTHOR

Dr Einar Helander graduated as MD from the University of Gothenburg, Sweden, in 1953, and took a doctorate in biochemistry in 1957.

He had a long background in medical and vocational rehabilitation before being recruited by the World Health Organization in 1974 to take charge of its rehabilitation programme. While at WHO's Geneva headquarters, he started developing the concept and strategy of community-based rehabilitation (CBR) as well as the first experimental manual entitled "Training in the community for people with disabilities," which appeared in 1979 (final version in 1989 with Mendis-Nelson-Goerdt).

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