

## ***CHAPTER NINE: CBR TECHNOLOGY***

### ***1. DEMYSTIFICATION OF REHABILITATION TECHNOLOGY***

Many disabled people need a programme aimed at improving their functional capacities, at providing environmental interventions, schooling, training for and income-generation. 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 transfer of knowledge about disabilities and skills in rehabilitation to persons 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"<sup>1</sup>.

A number of technologies are part of a 19th or early 20th century heritage and may not be rational approaches to practical problems. 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<sup>2</sup>. Another example is: breathing exercises originally set up to reduce pneumonia and atelectasis appearing in the post-operative phase of abdominal surgery. Most of these exercises became obsolete as early mobilisation of the patients became common-place. Yet, in many 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 some complicated approaches to treatment of degenerative neurological diseases.

In the educational sector, conventional special education on a segregated basis had been going on for about two hundred years. Not until recently did a handful of industrialised countries start experimenting with inclusive approaches. Research into the effectiveness of the various technical alternatives is still incomplete. In the vocational sector, the situation is very complex. Vocational training and sheltered employment had been part of the poor houses and then of the 19<sup>th</sup> and early 20<sup>th</sup> century efforts related to specialised institutions for disabled persons. 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 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 to share for those 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, many are neglected. But one also comes across examples of disabled adults who have successfully trained themselves, or of disabled children whom family members have trained. 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 procedures in 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 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 government considered the need for rehabilitation, and I was asked to study of the situation. By that time, their family members had rehabilitated many of the disabled individuals. 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 at an early age..*

*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 lip-reading, and when he mastered that, she took him to the local school, where he did well.*

*I also talked to the schoolteacher, who confirmed that the boy followed the schooling well. He always passed his examinations. The teacher 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 and attending classes in his school. Two of them were able to walk to school unassisted, while some older boys took the third one to school, in a small, homemade 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 his food.*

- *In a very poor African country, an organisation of disabled people had been set up. A most energetic local leader with 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 jobs.

- A new orthopaedic workshop had been set up in an African country by a Western charitable organisation. Over 100 "old" appliances were collected in a storage rooms:: 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 these 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, held at home in villages and marginal urban settlements, many aspects were covered. Parents told me how the disability started and what they thought had caused it. They related the problems they had experienced and what they had done to cope. It is very common to find their accounts of the causes of the disabilities influenced by common beliefs. Most parents had gone to a local healer for advice and afterwards, if available, to the health service. Those consulted usually failed to propose anything useful. Most parents were looking for a "cure" - some magic or medical procedure that would make the disability disappear. But most of them were willing to try some training at home to improve the functional situation of the disabled family member.

At each place, 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 job training. And, to round off my visit, I would go and see the school, on which occasion I would discuss inclusive 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<sup>3</sup> and described in great detail in the manual entitled "*Training in the community for people with disabilities*" (TCPD)<sup>4</sup>. The material consists of thirty training packages and a set of four guides intended for use at the community level. It was first used in 1979.

Each training package is devoted to a particular subject. Some packages provide information about each disability directed at the family. Others deal with prevention e.g., 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 child stimulation, household and social activities, schooling and jobs. A complete list of the packages appears in Box 9.1.<sup>5</sup>

#### **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,**

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

**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

At the beginning of each package, the educational objective is stated. (Box 9.2). Then follows a simple description of the training procedures, illustrated by line drawings. (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 progress. (Box 9.4)

**BOX 9.2. EXAMPLE OF AN EDUCATIONAL OBJECTIVE, AS DESCRIBED IN A TRAINING PACKAGE OF TCDP**

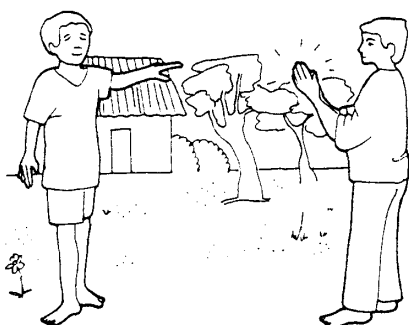
**What is this package for?**

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.

BOX 9.3 EXAMPLE OF TRAINING PACKAGE

EXAMPLE OF TRAINING PACKAGE

This page of training package N° 3 is taken out of a text about mobility training for persons with seeing problems

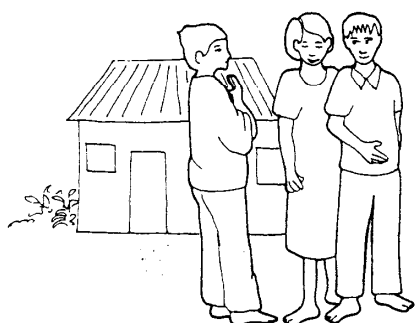


■ Teach the person to turn his or her head to listen to sounds. Help the person to learn the direction in which a sound is moving. Also teach the person to know where sounds are coming from and how far away they are.

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 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.

<p>Moves inside the home? Including walking, crawling, etc. using trolley, wheelchair etc. Help means with the help of a person or using walking aids.</p>	<p>Alone and without aids With little help With some help or sometimes With a lot of help Not at all</p>	
<p>Moves around the village? Including walking, crawling, etc. using trolley, wheelchair, etc. Help means with the help of a person or using walking aids</p>	<p>Alone and without aids With little help With some help or sometimes With a lot of help Not at all</p>	

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
<p>1. You do not let the person do all that he or she can do.</p>	<p>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.</p>
<p>2. You have not trained the person long enough.</p>	<p>Continue training the person. If you have no results in six months, ask your Local Supervisor for advice.</p>
<p>3. You have not followed the instructions correctly.</p>	<p>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.</p>
<p>4. The person cannot be trained to do this activity because of his or her disability.</p>	<p>The person will continue to need help for the activity. Discuss with your Local Supervisor whether you should stop using this package.</p>

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.

A comparison of these descriptions with the “conventional” Western procedures revealed no discrepancy in principle. A "core technology" for functional training, schooling, ability training and methods for income-generation, etc had been identified. Of course, being familiar with Western technology helped us to choose the most appropriate of the spontaneous examples seen and to fill the gaps with descriptions of a similar nature.

The result amounts to a demystified and simplified 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 debate. 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. Standard approaches to train personnel are used in all countries. Teachers follow set curricula and evaluation targets. Students use standardised schoolbooks. Their teachers try to individualise students' education as much as possible. Health care staff does not transgress the strict standardised rules for administering injections and immunisations, performing a laboratory test, or taking an x-ray.

Unless technology is standardised larger groups of personnel cannot be trained or results 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. 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 difficulties, to be applied by the family trainers and the local supervisors. The results were considerable confusion and mostly negative reactions among family trainers and local supervisors. 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 another 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, better adapted to the local culture. Such initiatives should 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 scope for variations between countries. There is also scope for developing more technology in particular areas, such as for mental disability. (Box 9.5.<sup>6</sup>)

Ten years of teamwork involving a number of international experts and people in the field the world over have gone into the writing of the TCPD. But all that technology and terminology have one problem in common - many “experts” insist on having their own. In spite of 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 the services they need.

Rather than re-inventing the wheel we should concentrate on 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.

#### **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. Very considerable proportions 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 become more "visible" 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.

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

#### **BOX 9.6 GUIDES**

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

##### **Guide for Local Facilitators -**

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;

The *Guide for Local Facilitators (Supervisors)*<sup>7</sup> describes the activities of the "community worker" (see p.122). It can be used for their training. It is suggested that, on completion of their training, local facilitators 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 first given an information package "about the disability and what can be done about it". Later, they receive the specific packages for training in self-care, mobility, communication, behaviour, play activities, etc. It contains guidelines on how to approach educational and vocational problems. Each local facilitator should carefully record the initial state of each disabled person and regularly assess the results of the rehabilitation. Forms for these evaluations are provided. Reports should be submitted to the community committee and to the technical supervisor at the intermediate level.

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 local teachers in regular 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 different set (e.g. for each country) of technology descriptions, 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) *how are disabled people identified in the community without a medical diagnosis?*
- (5) *how is assessment carried out within the CBR programme, and how can a training programme be individually designed?*
- (6) *how to apply training procedures, when the person has multiple disabilities?*
- (7) *how does one integrate educational aspects in CBR?*
- (8) *how does one integrate ability training and income generation in CBR?*
- (9) *how are environmental interventions carried out in the CBR programme?*
- (10) *what efforts will be needed to promote and protect human rights?*
- (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 can disabled people be empowered and play a 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 showed that the spontaneous technology observed varied little from one part of the world to another. 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 traditional practices, such as martial arts, gymnastics or massage. Eating and household activities vary widely, and this package needs to be adapted everywhere. The technology for the manufacture of various appliances and technical equipment could include use of local materials and other resources at hand. This would necessitate local technical adaptations of the procedures in TCPD<sup>8</sup>. Technology should also be developed to reduce the constraints arising from physical barriers, including inaccessible public buildings and transport, stones, potholes, passages in the immediate environment, etc<sup>9</sup>.

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 facilitator (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. In most households 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 facilitator would repeatedly explain and show what had to be 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 better approach. For practical reasons however, such as lack of local resources to produce a sufficient number of copies and logistics, most local facilitators tend to keep the full set of training packages and show them to the families at 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. (Box 9.7).

#### **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.

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 over 50 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<sup>10</sup>.

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

The text of the Guides (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.

Many disabled people in developing countries whose situation could be improved if they had access to a competent physician. Examples are: medical treatment for epilepsy, psychosis, leprosy or eye infections. Others are: surgical interventions to 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 visit the local health centre. Where these possibilities are small or non-existent, consultations will be limited.

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. 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 system. 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 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 schooling, and income generation.<sup>11</sup>

(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? In order to locate disabled people living in the community, local facilitators 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 problems, the questionnaire from UNESCO reproduced in Box 9.8 has proven useful.

The identification of disabled people needing an income 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, formal or

informal, training.

These techniques have proved very valid and reliable. There is no doubt that a well-trained local facilitator can correctly identify all disabled people in their community.

**BOX 9.8. IDENTIFICATION OF SCHOOL CHILDREN WITH SPECIAL EDUCATIONAL NEEDS**

UNESCO proposes that each schoolteacher 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."

(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, for instance at 3 months interval and at the 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<sup>12</sup> provides some examples of assessment methods (see also Chapter 15).

#### **BOX.9.9. ASSESSMENT IN A CBR PROGRAMME**

A complete list of the 27 factors proposed for use in a CBR programme appears in Chapter 15. The reason for choosing these is their high frequency. 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 facilitator.

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 measures to provide income generation opportunities 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. If an apprenticeship is proposed, the question of cost enters the picture. For this reason, the disabled person could preferably undergo a set of job-requirements-related tests. These could be quite straightforward. A more thorough evaluation, using tests for e.g. intellectual capacity, educational level, manual skills is rarely needed. More sophisticated screening procedures or tests may 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.).

Sometimes, while placing a person in a job proves impossible, a suitable productive activity at home can be identified, in which case a simple trial and error method can be used.

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 ILS and professionals of the referral system give technical advice when needed.

(6) In the case of *multiple disabilities*, one would use the following approach. Most such children have a cerebral palsy. These children are now rare in the developing countries, possibly because of their high mortality rate. But with increased survival, we should in the future count on an incidence rate of some 2 per 1,000 new born. Each child needs to have an individually designed programme. The local facilitator 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.

Multiply disabled children are often isolated at home and may not receive any stimulation. 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 when the child has severe multiple disabilities due to cerebral palsy. From our studies it is evident that, if the family follows the instructions, almost all such children will show progress (Box 9.10).

#### **BOX 9.10. APPROACH TO MULTIPLE DISABILITIES**

I meet twice a young girl with very severe 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, she was well integrated in her village.

(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 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 being likely to disturb it.

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<sup>13</sup>.

A number of documents from UNESCO<sup>14</sup> 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<sup>15</sup> 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. 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. Other children could accompany some children with mental retardation or with vision impairment to school.

(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. The school performance can be improved by better preparation of the teachers, by curriculum adaptation, and by assistance provided through mobile resource teachers.

(c) Some disabled children do have *behavioural problems*. Increased efforts on the part of the family are needed to correct the situation as soon as these problems become apparent. 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 should 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 corrective measures whenever there is a problem.

An account of the positive aspects of Model I inclusive schooling for disabled children appears in *Guide for Schoolteachers* in TCPD:

- 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<sup>16</sup>: "*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 Box 9.11<sup>17</sup>)

The *proposal for Model II* is to start training and employing a multi-disability resource teacher. The teacher should preferably be someone who graduated from teachers' college and have some years of

experience and a post-graduate course in inclusive 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<sup>18</sup>. The mobile teacher may need transportation. (Chapter 13) Whith this stage the disabled children are integrated in a "regular" class<sup>19</sup>.

**BOX 9.11. A NEW APPROACH TO TRAINING TEACHERS TO WORK WITH CHILDREN WITH SPECIAL EDUCATION NEEDS.**

A UNESCO document states:

"The starting point must...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 teams trained 240 teachers. With a few "specialists" it is thus possible to multiply their knowledge for the benefit of the many.

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 the multiple-disability teachers can carry out many of the tasks.

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<sup>20</sup>.

(8) A few comments on *ability training and income generation* 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."<sup>20</sup> Most of those now attending special institutions could, with some adaptive measures, be integrated in mainstream vocational training.

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 (see Chapter 4)<sup>21</sup>. 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, at home or working in the fields. Most often this is the result of "spontaneous rehabilitation."<sup>22</sup> For those not working, attempts to find jobs should be made.

For disabled adolescents and youths in the CBR programme a set of steps are outlined in Box 9.9. It should be useful to find out the jobs 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 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 or some other "family trade". 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.

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 often undergo a period of two to three years of apprenticeship. This is a useful way of entering the open labour market. This is equally true for disabled people. (Box 9.12.)

#### **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 boys and girls 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 often undergo a period of two to three years of apprenticeship. This is a useful way of entering the open labour market. This is equally true for disabled people. (Box 9.12.) Those who want to start their own enterprises<sup>23</sup> may need a small initial capital, so it may be necessary to arrange for small bank loans or revolving funds to meet such needs. (Box 9.13.) Great attention should be paid to studying the local marketing situation. Answers are needed to such

questions as: Is a tailor needed 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 by local disabled people? In each place, 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<sup>24</sup>.

### **BOX 9.13 STARTING NEW ENTERPRISES IN AN ASIAN VILLAGE**

In a very poor Asian country, local offices of the Central Bank offered small loans 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 rent and 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 paid back his loan within two years.

Another factor of importance may be the environmental constraints - factors which deny a competent disabled person the chance of training and employment. Such factors should be analysed, and efforts should be made to overcome these by stressing the disabled person's abilities and potential<sup>25</sup>. The community committee can play a role to provide the opportunities required.

One might distinguish between several phases of the income generation programme, depending on the level of development. It is useful, in the *first phase*, to carry out an assessment or screening procedure of the disabled person to establish his or her interest, motivation<sup>26</sup>, and particular abilities for work. Based on this, one should determine what kind of training is feasible and the chances that the disabled person will meet the job requirements. Such assessments should proceed from systematic observations simple tests and counselling. The purpose 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. This too often ends in frustration if the disabled person proves incapable of doing the job for which he or she was trained. When a disabled person wants to start a small commerce, he/she should first undergo a proper assessment and training; setting up shop takes investments. Consequences of economic failure might be serious.

During a *second phase*, when more established training programmes are available, one should seek to give disabled people formal and recognised training, using mainstream systems for training.

This phase may be followed by a *third one*. 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 which disabled people can easily be integrated. The meagre participation of disabled people in such training should be increased. Similar attempts of including a higher proportion of women, or of minority ethnic groups, have been successful.

Not every disabled person 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 adult go out to work and the disabled person is left to himself or herself, some organised recreational activities during the day-time may be needed. Assistance may be sought from the community.
- (c) is this person secure at home. Are there risks for abuse, violence or crime for him/her? Is the protection adequate?

(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 easy to reduce or to eliminate. Others are 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 authorities, and a programme for action should be adopted. At present centrally initiated changes, such as regulations in respect of architecture, building standards, specifications for buses and trains, are not adequately implemented.

There are many psychological, cultural, economic and social barriers. Large efforts are needed 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. When the community becomes aware of the changes ensuing from the implementation of the CBR programme, attitudes tend to be more positive. Prejudice and beliefs are hard to change, and community education is necessary.

(10) *Legislation, promotion and protection of rights* of disabled people<sup>27</sup> are important subjects. With the term "rights" we should include human, civil, social, economical, political, developmental and rights and others.

The conventional approach to legislation has been to adopt special laws with "positive discrimination" for disabled people. These require employers to hire a certain quota of disabled people. In principle, this idea is in contradiction to the ideas of equality and social justice. The experience of quota laws is very discouraging. Other legislation may concern 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 gives preference to action that will:

- protect the human rights and security of disabled people, and
- suppress negative discrimination.

The rights for the citizens are often published in the constitution of each country. Normally it provides for equal rights irrespective of gender, ethnical group, religion etc., but there are many examples of how disabled people are deprived of these rights (Box 9.14) through negative discrimination.

#### **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 were 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 eight 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 and practical training in disability matters - a subject considered not necessary by the deans or professors of these establishments.

A community action programme is needed to protect the rights. Disabled people - like other poor community members - will not be able to seek help from a distant capital or from legal authorities perceived as unapproachable. A local mediation procedure is better. This may be easier in societies where the enforcement of the law rests with 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 (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 9.15. 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 action the jobs reserved for them 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. For example, -robbing beggars of the money they had collected; theft of property from their homes; neighbours removing their fences and taking away their land. I was also told of 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.

## **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 to the community e.g. on interventions;
- 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 damage, 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 analyse what has gone wrong and, secondly, to rectify the local procedures. There are particular difficulties, e.g. in connection with behaviour problems. The ILS could 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, which can be followed. Each technology should be described in detail, and standardised so that it can be used in training personnel and for evaluation purposes. 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.

**FIG. 9.1 APPROACHES TO TECHNOLOGY**

<b>CONVENTIONAL</b>	<b>COMMUNITY-BASED</b>
MEDICALISED, PROFESSION-ORIENTED IMPORTED PROCEDURES	PROBLEM-SOLVING PEOPLE-ORIENTED USE OF SPONTANEOUS TECHNOLOGY BUILT ON RESOURCES AT HAND
DOMINANCE OF FORMAL, HIGHLY STRUCTURED TRAINING SYSTEMS APARTHEID SYSTEM WITH SEGREGATION	EMPHASIS ON INCLUSIVE EDUCATION AND INTEGRATED INFORMAL TRAINING SYSTEMS
INTRODUCTION OF LEGISLATION, TO GIVE POSITIVE DISCRIMINATION	PROTECTION OF EXISTING HUMAN RIGHTS AT ALL LEVELS AND ELIMINATION OF NEGATIVE DISCRIMINATION

The conventional system as introduced to the developing countries is characterised by medicalised approach. Doctors are needed to establish a diagnosis, following which they or other professionals will prescribe rehabilitation. By contrast, the CBR system adopts a problem-solving approach. Almost all interventions can be carried out directly, without a diagnosis.

CBR changes the approach from a profession-oriented to a people-oriented one. In the conventional system, the choice of a rehabilitation technology relies on the experience gathered by professionals in the industrialised countries. In a people-oriented system, the technology used has its roots in existing local "spontaneous" and successful technology, born in the hearts and minds of people.

The conventional system is dominated by formal, highly structured 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 segregated special jobs, sheltered workshops and so on.

Facilities for 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 ability 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.

#### COMMENTS AND REFERENCES

<sup>1</sup>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.

<sup>2</sup>For experts' opinions on these types of therapy see "Disability Prevention and Rehabilitation", Technical Report Series No. 668, WHO, Geneva, Switzerland, 1981.

<sup>3</sup>An early description of the work appears in: E. Helander, Proc.R.Soc.London, B209, pp. 139-140, 1980.

<sup>4</sup>E. Helander, P. Mendis, G. Nelson, A. Goerd, WHO, Geneva, Switzerland, 1989.

<sup>5</sup>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.

<sup>6</sup>Reviews of several CBR mental health projects can be found in: Social Reintegration of Persons Having Suffered Mental Illness. The First ILO Asia Regional Workshop, 21-26 March 1989 in Kuala Lumpur, Malaysia; ILO, Geneva, Switzerland, 1989. Specific studies exist: R. Agrawal and U.K. Kool: Mental health of persons with visual impairment in India. Internat.J.Rehabil.Res. 13, 83, 1990.

<sup>7</sup>In the 4<sup>th</sup> edition of TCPD, the term "Local Supervisor" is still used. There is a general agreement that the term "Local Facilitator" better reflects the duties of this community worker.

<sup>8</sup>For some discussions on this subject see, e.g., Rapport du seminaire sur les aides techniques pour les personnes handicapées, Conakry, Guinée. (Ed. Van Rollegem-Marin\_ek), Institut Universitaire de Réadaptation, Ljubljana, Slovenia, 1989.

<sup>9</sup>See: Designing with Care, CSDHA, United Nations, New York, USA, 1986.

<sup>10</sup>Guidelines for translation and adaptation of the Manual "Training in the Community for People with Disabilities", WHO, 1991.

<sup>11</sup>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.

<sup>12</sup>See TCPD: Guide for Local Supervisors, pp. 38-40. A complete list of all the 27 factors appears in Chapter 15.

<sup>13</sup>Ministry of Education, Cotonou, Benin, 1990.

<sup>14</sup> 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.

<sup>15</sup> 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 schoolwork. 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".

<sup>16</sup> P. Mittler and R. Serpell: in Clarke & Clarke, *Mental Deficiency* (J. Berg, Ed.), Methuen, London, United Kingdom, 1984.

<sup>17</sup> T. Jönsson, *ibid.* The text in italics is quoted from M. Ainscow and Tweddle: *Encouraging Classroom Success*. (J. Berg, ed.), Methuen, London, UK, 1984.

<sup>18</sup> 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".

<sup>19</sup> In Gujarat, India, the blind children in a part of the State are the first prepared at home by learning Braille by specialised teachers. Each teacher prepares 8 children, these children are then given support for their books and stationary, uniform and transport allowances and special equipment. The scheme is highly successful. In the earlier system, based on segregated boarding schools there were 94% boys and 6% girls. With the inclusive system there are now 58% boys and 42% girls.

<sup>20</sup> 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.

<sup>21</sup> W. Momm and A. König in "From Community-Based Rehabilitation to Community-Integration Programmes", ILO, Geneva, Switzerland, 1989. The authors 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.

<sup>22</sup> W. Momm and A. König, *ibid.*, report that, in Indonesia, out of a sample of 207 disabled people, 150 were working "spontaneously".

<sup>23</sup> 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.

<sup>24</sup> Studies carried out show that many jobs held by poor people in developing countries give very low and irregular income. So many stay below the poverty level in spite of having a job. As regards small enterprises, most of these do not have a profit. The income may be just enough for survival. For this reason there is not much investment or risk-taking.

<sup>25</sup> In South Asia the caste system is another constraint, as it implies a reduction of choice of income generating activity.

<sup>26</sup> The patterns of vocational interests and work motivation of mentally retarded adults in Israel is presented in S. Reiter: *Int.J. of Rehabil. Res.* 13, 37, 1990.

<sup>27</sup> Documents about legislation appears in e.g.: "Report on national legislation for the equalization of opportunities for people with disabilities, examples from 22 countries and areas" was published by U.N. 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.







change technology, to experiment with alternatives.

Some of these may be better solutions, better adapted to the local culture. Such initiatives should 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 scope for variations between countries. There is also scope for developing more technology in particular areas, such as for mental disability. (Box 9.5.<sup>6</sup>)

Ten years of teamwork involving a number of international experts and people in the field the world over have gone into the writing of the TCPD. But all that technology and terminology have one problem in common - many "experts" insist on having their own. In spite of 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 the services they need.

Rather than re-inventing the wheel we should concentrate on 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 CBR Training Packages are complemented by a set of four Guides (Box 9.6) for community members carrying out special tasks for the CBR programme

The *Guide for Local Facilitators (Supervisors)*<sup>7</sup> describes the activities of the "community worker" (see p.122). It can be used for their training. It is suggested that, on completion of their training, local facilitators undertake a house-to-house survey in their 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. Very considerable proportions 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 become more "visible" 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.

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 first given an information package "about the disability and what can be done about it".

Later, they receive the specific packages for training in self-care,  
Box 9.6

### GUIDES

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

**Guide for Local Facilitators -**

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 include children with disabilities in the class.

mobility, communication, behaviour, play activities, etc. It contains guidelines on how to approach educational and vocational problems. Each local facilitator should carefully record the initial state of each disabled person and regularly assess the results of the rehabilitation. Forms for these evaluations are provided. Reports should be submitted to the community committee and to the technical supervisor at the intermediate level.

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 local teachers in regular 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:

- (2) *could they be used "globally", or would cultural and social factors require a whole different set (e.g. for each country) of technology descriptions, 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) *how are disabled people identified in the community without a medical diagnosis?*

- (5) how is *assessment carried out* within the CBR programme, and how can a *training programme be individually designed*?
- (6) how to apply training procedures, when the person has *multiple disabilities*?
- (7) how does one integrate *educational aspects* in CBR?
- (8) how does one integrate *ability training and income generation* in CBR?
- (9) how are *environmental interventions* carried out in the CBR programme?
- (10) what efforts will be needed to *promote and protect human rights*?
- (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 can *disabled people be empowered and play a 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 showed that the spontaneous technology observed varied little from one part of the world to another. 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 traditional practices, such as martial arts, gymnastics or massage. Eating and household activities vary widely, and this package needs to be adapted everywhere. The technology for the manufacture of various appliances and technical equipment could include use of local materials and other resources at hand. This would necessitate local technical adaptations of the procedures in TCPD<sup>8</sup>. Technology should also be developed to reduce the constraints arising from physical barriers, including inaccessible public buildings and transport, stones, potholes, passages in the immediate environment, etc<sup>9</sup>.

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 facilitator (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. In most households 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 facilitator would repeatedly explain and show what had to be 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 better approach. For practical reasons however, such as lack of local resources to produce a sufficient number of copies and logistics, most local facilitators tend to keep the full set of training packages and show them to the families at 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. (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 over 50 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<sup>10</sup>.

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

The text of the Guides (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.

Many disabled people in developing countries whose situation could be improved if they had access to a competent physician. Examples are: medical treatment for epilepsy, psychosis, leprosy or eye infections. Others are: surgical interventions to 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 visit the local health centre. Where these possibilities are small or non-existent, so consultations will be limited 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. 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 system. 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 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 schooling, and income generation.<sup>11</sup>

(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? In order to locate disabled people living in the community, local facilitators 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 problems, the questionnaire from UNESCO reproduced in Box 9.8 has proven useful.

The identification of disabled people needing an income 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, formal or informal, training.

These techniques have proved very valid and reliable. There is no doubt that a well-trained local facilitator 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?* 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, for instance at 3 months interval and at the 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<sup>12</sup> provides some examples of assessment methods (see also Chapter 15).

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 ILS and professionals of the referral system give technical advice when needed.

(6) In the case of *multiple disabilities*, one would use the following approach. Most such children have a cerebral palsy. These children are now rare in the developing countries, possibly because of their high

mortality rate. But with increased survival, we should in the future count on an incidence rate of some 2 per 1,000 new born. Each child needs to have an individually designed programme.

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.

**Box 9.8 IDENTIFICATION OF SCHOOL CHILDREN WITH SPECIAL EDUCATIONAL NEEDS**

UNESCO proposes that each schoolteacher 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."

The local facilitator 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

Box.9.9.

### ASSESSMENT IN A CBR PROGRAMME

A complete list of the 27 factors proposed for use in a CBR programme appears in Chapter 15. The reason for choosing these is their high frequency. 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 facilitator.

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 measures to provide income generation opportunities 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. If an apprenticeship is proposed, the question of cost enters the picture. For this reason, the disabled person could preferably undergo a set of job-requirements-related tests. These could be quite straightforward. A more thorough evaluation, using tests for e.g. intellectual capacity, educational level, manual skills is rarely needed. More sophisticated screening procedures or tests may be given when formal training is proposed. Skills training should be preceded by assessment when a disabled person 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.).

Sometimes, while placing a person in a job proves impossible, a suitable productive activity at home can be identified, in which case a simple trial and error method can be used.

Box 9.10

### APPROACH TO MULTIPLE DISABILITIES

I meet twice a young girl with very severe 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, she was well integrated in her village.

that can be solved in relatively little time. Seeing progress, the family might then be more disposed to work with the child.

Multiply disabled children are often isolated at home and may not receive any stimulation. 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 when the child has severe multiple disabilities due to cerebral palsy. From our studies 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 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 being likely to disturb it.

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<sup>13</sup>.

A number of documents from UNESCO<sup>14</sup> 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<sup>15</sup> 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. 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. Other children could accompany some children with mental retardation or with vision impairment to school.

(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. The school performance can be improved by better preparation of the teachers, by curriculum adaptation, and by assistance provided through mobile resource teachers.

(c) Some disabled children do have *behavioural problems*. Increased efforts on the part of the family are needed to correct the situation as soon as these problems become apparent. 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 should 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 corrective measures whenever there is a problem.

An account of the positive aspects of Model I inclusive schooling for disabled children appears in ***Guide for Schoolteachers*** in TCPD:

- 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<sup>16</sup>: "*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 Box 9.11<sup>17</sup>)

The *proposal for Model II* is to start training and employing a multi-disability resource teacher. The teacher should preferably be someone who graduated from teachers' college and have some years of experience and a post-graduate course in inclusive 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<sup>18</sup>. The mobile teacher may need transportation. (Chapter 13) Whith this stage the disabled children are integrated in a "regular" class<sup>19</sup>.

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 the multiple-disability teachers can carry out many of the tasks.

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<sup>20</sup>.

#### Box 9.11

##### **A NEW APPROACH TO TRAINING TEACHERS TO WORK WITH CHILDREN WITH SPECIAL EDUCATION NEEDS.**

A UNESCO document states:

"The starting point must...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 teams trained 240 teachers. With a few "specialists" it is thus possible to multiply their knowledge for the benefit of the many.

(9) A few comments on *ability training and income generation* 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."<sup>20</sup> Most of those now attending special institutions could, with some adaptive measures, be integrated in mainstream vocational training.

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<sup>21</sup>. 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, at home or working in the fields. Most often this is the result of "spontaneous rehabilitation."<sup>22</sup> For those not working, attempts to find jobs should be made.

For disabled adolescents and youths in the CBR programme a set of steps are outlined in Box 9.9. It should be useful to find out the jobs 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 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 or some other "family trade". 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 boys and girls 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".

sector is agriculture or some other “family trade”. 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.

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 often undergo a period of two to three years of apprenticeship. This is a useful and way of entering the open labour market. This is equally true for disabled people. (Box 9.12.) Those who want to start their own enterprises<sup>23</sup> may need a

small initial capital, so it may be necessary to arrange for small bank loans or revolving funds to meet such needs. (Box 9.13.).

Great attention should be paid to studying the local marketing situation. Answers are needed to such questions as: Is a tailor needed 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 by local disabled people? In each place, 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<sup>24</sup>.

Box 9.13

#### **STARTING NEW ENTERPRISES IN AN ASIAN VILLAGE**

In a very poor Asian country, local offices of the Central Bank offered small loans 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 rent and 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 paid back his loan within two years.

Another factor of importance may be the environmental constraints - factors which deny a competent disabled person the chance of training and employment. Such factors should be analysed, and efforts should be made to overcome these by

stresssing the disabled person's abilities and potential<sup>25</sup>. The community committee can play a role to provide the opportunities required.

One might distinguish between several phases of the income generation programme, depending on the level of development. It is useful, in the *first phase*, to carry out an assessment or screening procedure of the disabled person to establish his or her interest, motivation<sup>26</sup>, and particular abilities for work. Based on

this, one should determine what kind of training is feasible and the chances that the disabled person will meet the job requirements. Such assessments should proceed from systematic observations simple tests and counselling. The purpose 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. This too often ends in frustration if the disabled person proves incapable of doing the job for which he or she was trained. When a disabled person wants to start a small commerce, he/she should first undergo a proper assessment and training; setting up shop takes investments. Consequences of economic failure might be serious.

During a *second phase*, when more established training programmes are available, one should seek to give disabled people formal and recognised training, using mainstream systems for training.

This phase may be followed by a *third one*. 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 which disabled people can easily be integrated. The meagre participation of disabled people in such training should be increased. Similar attempts of including a higher proportion of women, or of minority ethnic groups, have been successful.

Not every disabled person 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 adult go out to work and the disabled person is left to himself or herself, some organised recreational activities during the day-time may be needed. Assistance may be sought from the community.
- (d) is this person secure at home. Are there risks for abuse, violence or crime for him/her? Is the protection adequate?

(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 easy to reduce or to eliminate. Others are 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 authorities, and a programme for action should be adopted. At present centrally initiated changes, such as regulations in respect of architecture, building standards, specifications for buses and trains, are not adequately implemented.

There are many psychological, cultural, economic and social barriers. Large efforts are needed 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. When the community becomes aware of the

changes ensuing from the implementation of the CBR programme, attitudes tend to be more positive

Prejudice and beliefs are hard to change, and community education is necessary.

(11) *Legislation, promotion and protection of rights* of disabled people<sup>27</sup> are a very important subjects. With the term “rights” we should include human, civil, social, economical, political, developmental and rights and others.

The conventional approach to legislation has been to adopt special laws with "positive discrimination" for disabled people. These require employers to hire a certain quota of disabled people. In principle, this idea is in contradiction to the ideas of equality and social justice. The experience of quota laws is very discouraging. Other legislation may concern 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 gives preference to action that will:

- protect the human rights and security of disabled people, and
- suppress negative discrimination.

The rights for the citizens are often published in the constitution of each country. Normally it provides for equal rights irrespective of gender, ethnical group, religion etc., but there are many examples of how disabled people are deprived of these rights (Box 9.14) through negative discrimination.

A community action programme is needed to protect the rights. Disabled people - like other poor community members - will not be

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 were 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 eight 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 and practical training in disability matters - a subject considered not necessary by the deans or professors of these establishments.

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 action the jobs reserved for them 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. For example, -robbing beggars of the money they had collected; theft of property from their homes; neighbours removing their fences and taking away their land. I was also told of 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.

able to seek help from a distant capital or from legal authorities perceived as unapproachable. A local mediation procedure is better. This may be easier in societies where the enforcement of the law rests with 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 (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.

## 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 to the community e.g. on interventions;
- 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 damage, 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 analyse what has gone wrong and, secondly, to rectify the local procedures. There are particular difficulties, e.g. in connection with behaviour problems. The ILS could 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, which can be followed. Each technology should be described in detail, and standardised so that it can be used in training personnel and for evaluation purposes. 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.

The conventional system as introduced to the developing countries is characterised by medicalised approach. Doctors are needed to establish a diagnosis, following which they or other professionals will prescribe rehabilitation. By contrast, the CBR system adopts a problem-solving approach. Almost all interventions can be carried out directly, without a diagnosis.

CBR changes the approach from a profession-oriented to a people-oriented one. In the conventional system, the choice of a rehabilitation technology relies on the experience gathered by professionals in the industrialised countries. In a people-oriented system, the technology used has its roots in existing local "spontaneous" and successful technology, born in the hearts and minds of people.

The conventional system is dominated by formal, highly structured 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 segregated special jobs, sheltered workshops and so on.

Facilities for 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 ability 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.

Fig. 9.1 **APPROACHES TO TECHNOLOGY**

CONVENTIONAL	COMMUNITY-BASED
MEDICALISED PROFESSION-ORIENTED IMPORTED PROCEDURES	PROBLEM-SOLVING PEOPLE-ORIENTED USE OF SPONTANEOUS TECHNOLOGY BUILT ON RESOURCES AT HAND
DOMINANCE OF FORMAL HIGHLY STRUCTURED TRAINING SYSTEMS APARTHEID SYSTEM WITH SEGREGATION	EMPHASIS ON INCLUSIVE EDUCATION AND INTEGRATED INFORMAL TRAINING SYSTEMS
INTRODUCTION OF LEGISLATION TO GIVE POSITIVE DISCRIMINATION	PROTECTION OF EXISTING HUMAN RIGHTS AT ALL LEVELS AND ELIMINATION OF NEGATIVE DISCRIMINATION

**COMMENTS AND REFERENCES**

<sup>1</sup> 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.

<sup>2</sup> For experts' opinions on these types of therapy see "Disability Prevention and Rehabilitation", Technical Report Series No. 668, WHO, Geneva, Switzerland, 1981.

<sup>3</sup> An early description of the work appears in: E. Helander, Proc.R.Soc.London, B209, pp. 139-140, 1980.

<sup>4</sup> E. Helander, P. Mendis, G. Nelson, A. Goerd, WHO, Geneva, Switzerland, 1989.

<sup>5</sup> 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.

<sup>6</sup> Reviews of several CBR mental health projects can be found in: Social Reintegration of Persons Having Suffered Mental Illness. The First ILO Asia Regional Workshop, 21-26 March 1989 in Kuala Lumpur, Malaysia; ILO, Geneva, Switzerland, 1989. Specific studies exist: R. Agrawal and U.K. Kool: Mental health of persons with visual impairment in India. Internat.J.Rehabil.Res. 13, 83, 1990.

<sup>7</sup> In the 4<sup>th</sup> edition of TCPD, the term "Local Supervisor" is still used. There is a general agreement that the term "Local Facilitator" better reflects the duties of this community worker.

<sup>8</sup> For some discussions on this subject see, e.g., Rapport du seminaire sur les aides techniques pour les personnes handicapées, Conakry, Guinée. (Ed. Van Rollegem-Marin\_ek), Institut Universitaire de Réadaptation, Ljubljana, Slovenia, 1989.

<sup>9</sup> See: Designing with Care, CSDHA, United Nations, New York, USA, 1986.

<sup>10</sup> Guidelines for translation and adaptation of the Manual "Training in the Community for People with Disabilities", WHO, 1991.

<sup>11</sup> 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.

<sup>12</sup> See TCPD: Guide for Local Supervisors, pp. 38-40. A complete list of all the 27 factors appears in Chapter 15.

<sup>13</sup> Ministry of Education, Cotonou, Benin, 1990.

<sup>14</sup> 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.

<sup>15</sup> 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 schoolwork. 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".

<sup>16</sup> P. Mittler and R. Serpell: in Clarke & Clarke, Mental Deficiency (J. Berg, Ed.), Methuen, London, United Kingdom, 1984.

<sup>17</sup> T. Jönsson, *ibid.* The text in italics is quoted from M. Ainscow and Tweddle: Encouraging Classroom Success. (J. Berg, ed.), Methuen, London, UK, 1984.

<sup>18</sup> 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".

<sup>19</sup> In Gujarat, India, the blind children in a part of the State are the first prepared at home by learning Braille by specialised teachers. Each teacher prepares 8 children, these children are then given support for their books and stationary, uniform and transport allowances and special equipment. The scheme is highly successful. In the earlier system, based on segregated boarding schools there were 94% boys and 6% girls. With the inclusive system there are now 58% boys and 42% girls.

<sup>20</sup> 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.

<sup>21</sup> W. Momm and A. König in "From Community-Based Rehabilitation to Community-Integration Programmes", ILO, Geneva, Switzerland, 1989. The authors 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.

<sup>22</sup> W. Momm and A. König, *ibid.*, report that, in Indonesia, out of a sample of 207 disabled people, 150 were working "spontaneously".

<sup>23</sup> 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.

<sup>24</sup> Studies carried out show that many jobs held by poor people in developing countries give very low and irregular income. So many stay below the poverty level in spite of having a job. As regards small enterprises, most of these do not have a profit. The income may be just enough for survival. For this reason there is not much investment or risk-taking.

<sup>25</sup> In South Asia the caste system is another constraint, as it implies a reduction of choice of income generating activity.

<sup>26</sup> The patterns of vocational interests and work motivation of mentally retarded adults in Israel is presented in S. Reiter: *Int.J. of Rehabil. Res.* 13, 37, 1990.

<sup>27</sup> Documents about legislation appears in e.g.: "Report on national legislation for the equalization of opportunities for people with disabilities, examples from 22 countries and areas" was published by U.N. 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.