

CHAPTER TEN: A SERVICE DELIVERY SYSTEM FOR CBR

In this chapter we will examine the various alternatives for service delivery for CBR. The questions to answer are many: What is to be done to eventually reach as many as possible of those 70 million disabled people in some 140 countries in need of a wide variety of rehabilitation services? Can we design a general system that will require financial outlay of a level acceptable to governments and communities in the developing countries a system that can be adapted to each country? How many personnel will be needed, and how will we train them? Also, service delivery is not a passive system, with the disabled people at the receiving end. It must be participatory - with disabled people actively involved.

Before suggesting alternative ways of implementing services, let us first look at the approaches of the conventional system over institutional care and outreach programmes.

1. THE CONVENTIONAL SYSTEM

In the conventional approach, services are basically supply-generated. Experts mostly do the planning of such services based on preconceived ideas. Once set up, these services tend to multiply as the experts promote an increasing demand for what they provide. Little is done to analyse the actual needs and whether the priority given to certain types of services is justified.

Once a certain type of service is installed, few attempts are made to discuss alternatives or innovations. More often than not, disabled people become passive recipients of such services. In many instances they are never consulted, for the "experts" know it all. The conventional system is mainly centralised. It builds on service delivery, either by closed institutions or through outreach (institution-based) programmes.

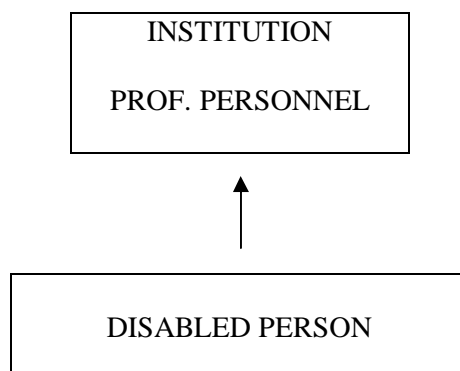
Closed institution-based service delivery

In a closed institution-based system (see Fig. 0.1), the disabled person comes to the institution and receives training from the professional personnel there. This may be on the basis of services given to boarders or as day-care.

This is the prevailing system of service delivery in developing countries today, in thousands of institutions. Expatriates have initiated many of them. Most of these institutions are located in the capital city. In rural areas, they are few and far between.

This system should, in theory, produce rehabilitation services of excellent quality, even though for only a small group of disabled people. In practice, this is rarely so. There is an apparent lack of contact with the family and the community, There are environmental constraints: problems with facilities, equipment, utilities or transportation. In some cases, insufficiently trained staff, including expatriates, is the explanation.

Fig. 10.1 CLOSED INSTITUTION-BASED DELIVERY SYSTEM



Most important of all problems is the financial one. Services are often costly. In some institutions, total costs per place and year exceed US\$ 5,000. Many are short of financing, and where they fail to find the necessary funds from external or internal contributors, the only option is to cut services and decrease quality.

The closed institution-based delivery system is inappropriate when it comes to solving large-scale problems. Most disabled people in the developing countries come from poor families. They are unlikely to take the initiative, or to have the means, to come to an institution. These people have to be approached in their own homes.

The costs and requirements of professional personnel are further constraints that speak against expanding the alternative of closed institution-based rehabilitation.¹

Institutionalising disabled people, in particular children, over long periods of time produces serious side effects. The current trend in industrialised countries is to close down as many institutions as possible and to provide community care instead. There is little point in establishing in developing countries a system that is increasingly recognised as obsolete in the industrialised world.

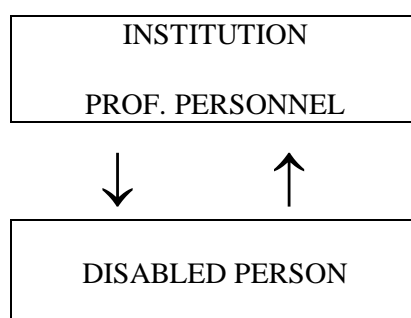
This should not be read, however, as a proposal to close down well-functioning institutions in the developing countries. Those that continue maintaining sufficient staff to ensure a quality programme could, in the future, serve as referral and resource centres for the community-based services. Moreover, their staff could contribute highly useful inputs to a CBR system by assisting in areas such as training, professional supervision and consultations. Such restructured institutions will probably have to be strengthened and increased in number. To this end, ways and means should be studied of how the relevant services could be made available in areas beyond the capital city and how their costs - if excessive - can be reigned in.

Outreach institution-based delivery system

In an outreach system, the professional goes out from the institution to the home of the disabled person and delivers the training (or other interventions) there. If necessary, he or she refers that person to an institution. This, in my experience, happens very often (Fig. 10.2).

There are many examples of this approach, and large proportion of them today is erroneously labelled² CBR projects. In an outreach programme the responsibility lies into the external organisation, it is a community-level programme, but not community-based. Most outreach programmes have sustainability problems.

Fig 10.2 OUTREACH INSTITUTION-BASED DELIVERY SYSTEM



Outreach programmes often start with the realisation that there are many rehabilitation problems, for example those related to ADL-training, integrated schooling, finding jobs and encouraging social activities, and that the solutions provided in an institution are inadequate. As a result - and this is basically an excellent idea - professionals start going to their clients' homes. There they meet with the family and the community leaders to obtain a better idea of the nature of the problems and to find out what needs to be

done in practical terms to solve them. The next step in an outreach programme is frequently the professional's attempt to try and treat or train the particular person at his or her home. This is likely to lead to better and more practical results than training in an institution.

However, a system of this kind is expensive. In a rural area, the professional may be able to treat one or two disabled people a day and a slightly bigger number in an urban area, while a professional in a centre may provide services for as many as eight or twelve disabled persons a day.

Transport poses another problem, for most professionals insist on having a car at their disposal for making home visits. Simpler means of transport, such as mopeds or motorcycles are some times considered inappropriate, especially if the professional in question is a woman.

Outreach programmes have been tried in several industrialised countries. But there as well, a serious decline in personnel efficiency is observed, and programme costs are in many cases perceived as insurmountable. In some cases a team conducts the outreach projects. Several professionals will join for each home visit, or will visit the disabled person consecutively pushing costs to astronomical levels.

Realising the outreach system's lack of efficiency, some project personnel have begun reorienting their work towards community-based solutions. The first step may consist in co-operating with existing local health or social services and in training their community workers in identifying disabled people. Next, instead of having all these persons referred to the relevant institution, the professional will invite them to be seen at the local health or social centre. Efforts to gradually convert the outreach approach into a community-based system meet, however, with major difficulties, which are associated with the initial lack of community involvement. It is better to implement programmes that have their roots in the community from the start are based on community decisions and management.

2. *THE CONCEPT OF A CBR SERVICE DELIVERY SYSTEM*

The CBR service delivery approach may be described as needs-generated. Its starting point is in the community, with referral services being complementary. It builds on the experience from many countries, where people have become involved in rehabilitation and communities accept their responsibility for delivering the services locally. It is possible to provide a substantial part of the services and opportunities locally, and to measure up in quality with those offered by the professionals in the institutions. The CBR approach is based on the positive results of the "spontaneous technology" and many other development projects that build on "learning service delivery from the people." Unlike most of the technology, service delivery systems cannot be standardised. In each country a lot of thought must be given to the question of how to establish a system that eventually can be used countrywide. One such proposal for a general alternative system, which is the outcome of several years of experimentation, appears in Fig. 10.3.

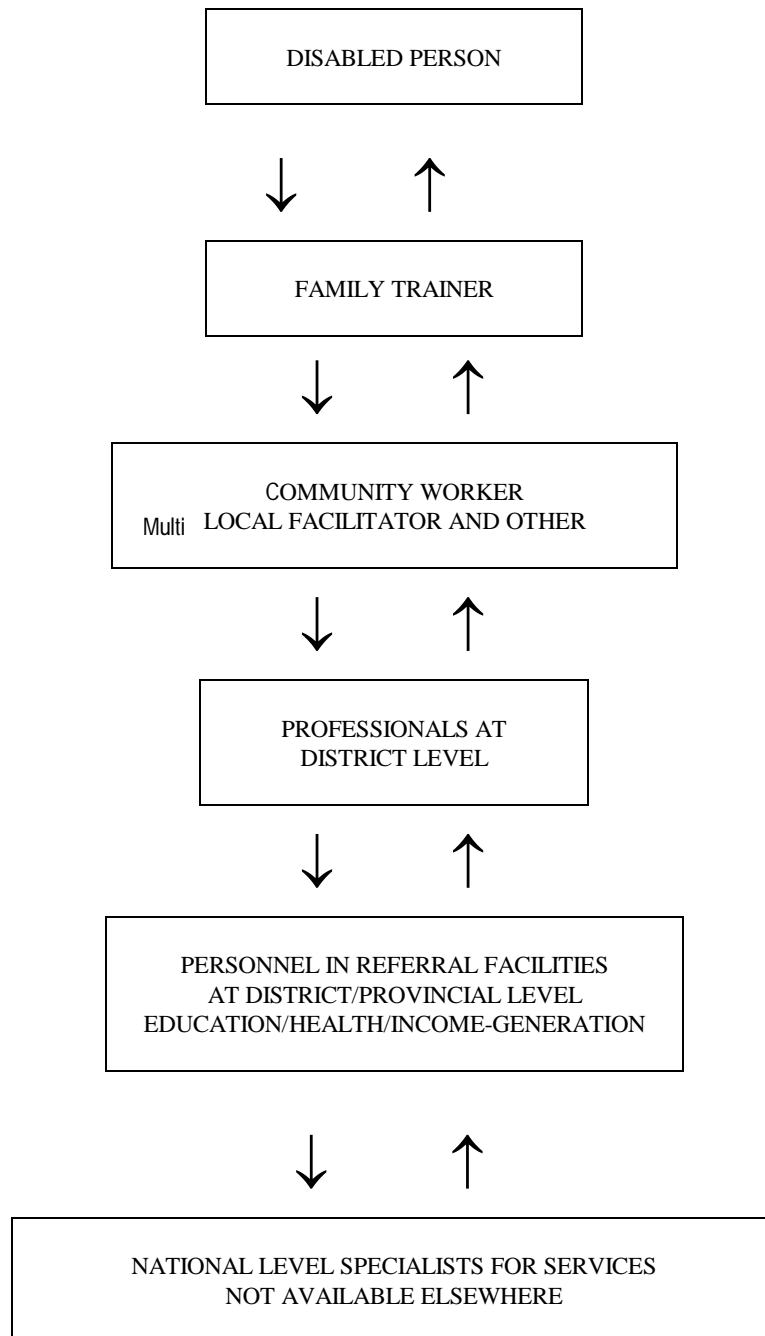
The figure shows an example of a multi-level and multi-sectoral CBR system. How to organise this practically will be based on local conditions, existing and planned public services, availability of personnel, presence of NGOs, and experience from other development programmes.

The "trainer", a family member delivers the basic-level services The trainer receives instructions and supervision from a community worker: the "local facilitator" (LF). The LF is also responsible for contacting the local teacher and for motivating him or her to educate disabled children, as well as for motivating the local authorities, or resource persons, for ability training and employment of disabled persons.

The local facilitator is trained and supervised by a professional: the "intermediate level supervisor" (ILS), who should be supported, whenever feasible, by a mobile, multi-disability resource teacher (MRT). The training programme for the LF may follow the plan described in the Guide for Local Supervisors in TCPD. In cases where training of a disabled person in the community does not give satisfactory results, that person should be referred to a competent person at a more central level of services. This could be at a

health centre or hospital, in a resource centre for special education or in a vocational facility at the district or provincial levels. Further referrals to the national level should be available when these facilities are unable to meet the particular needs.

Fig. 10.3 CBR DELIVERY SYSTEM



On the other hand, disabled people receiving services at the national or the provincial level should - as soon as the specialist is no longer needed - be referred back through the district-level ILS to the community-level LF, and the home. Such referrals should be carefully prepared to ensure that the LF and the family receive detailed instructions as to the continued action to be taken, and that the referral centre has ways of monitoring the outcome of the process. Fig. 10.4 summarises the differences in approach between the "conventional" and the CBR system. The term needs-generated implies that one deals with the actual needs

of the disabled person, starting with the priorities as perceived in the family setting. Problems that cannot be solved satisfactorily at the community level should be referred, and a multiple-level system is needed. - Referrals should result from established needs for more specialised interventions and be set up in response to what the community wants. They are not predetermined or supply-generated.

FIG. 10.4. APPROACHES TO SERVICE DELIVERY	
CONVENTIONAL	COMMUNITY-BASED
SUPPLY-GENERATED	NEEDS-GENERATED
DELIVERED BY OUTSIDERS	PARTICIPATORY
SINGLE LEVEL	MULTIPLE LEVEL
CENTRALISED SERVICES IN INSTITUTIONS OR AS OUTREACH PROGRAMMES	STARTING-POINT IN THE COMMUNITY, REFERRAL SERVICES SEEN AS COMPLEMENTARY
SINGLE SECTOR	MULTIPLE SECTOR
SEPARATE FROM OTHER COMMUNITY DEVELOPMENT PROGRAMMES	INTEGRATED IN OTHER COMMUNITY DEVELOPMENT PROGRAMMES

Institutions most often deliver single sector services, such as elementary education to blind children. Their personnel are not always capable of dealing with other problems, such as finding a suitable local job.

Furthermore, CBR delivery should be integrated in a general community development programme³. This is rarely the case with the services of the conventional system. Integration implies that communities will decide how to fit in this component with other, already existing programmes aimed at human, social and economic development, education, health, ability/vocational training and creation of job opportunities.

When experiments started to set up a system along the lines depicted under the community-based approach, they were met with considerable opposition. Many "experts" doubted that services similar to those delivered in Western countries by staff with many years of professional training and experience could be carried out by laymen with no loss of quality. Apparently these "experts" perceived our volunteers and community workers as ignorant, backward and primitive illiterates. Our experience is very different: we found most of them intelligent, enterprising, concerned, hard-working, and eager to learn. Some of those misgivings may have originated from the "experts" who had never taken the trouble of familiarising themselves on the spot with the realities of community life in developing countries, and who had not been willing to learn from the people.

3. PERSONNEL FOR CBR

There are many different ways of providing a network of staff for dissemination of technology⁴, and each country should decide how to integrate service delivery in other services and what are the best uses for existing groups of personnel. *Participation* in delivery at the community level is of utmost importance.

The intermediate level supervisor

The entrypoint for the start of services at the community level, is proposed to be the training a group of intermediate level supervisors (ILS).⁵ In some countries high school graduates are recruited for this training, but one might also use a suitable disabled person or a community worker who has proved capable and ready to move up a step in his or her career.

An outline of the course content for the ILSs appears in Box 10.1, and an example of a time plan in Box

10.2⁶. The ILS, is sometimes called a rehabilitation assistant or officer, or district CBR agent.⁷ In some countries that follow this approach, the duration of basic training is 12 months or more. On completion of the training, the ILS can be attached to a district administration for e.g. 100.000 population (Chapter 12)

The ILS sets out by inviting communities to decide whether they would be interested in organising services for their disabled members. More on this subject follows in the section on management below. Once the decision is taken, the communities will identify suitable community workers as "local facilitators".

The local facilitator - community worker

A local facilitator (LF) must be well motivated and literate. In some countries, this community worker - like others who support the CBR programme - is a volunteer. A review of the roles of volunteers is given in Boxes 10.3 and 10.4. The outcome of the programme depends to a large extent on the motivation of volunteers.

Box 10.1 EXAMPLE OF COMPONENTS OF A TRAINING PROGRAMME FOR INTERMEDIATE LEVEL SUPERVISORS

1. Disabilities, their causes and symptoms. Examinations and assessments.
2. Technology (as described e.g. in TCPD), with practice in the field.
3. Knowledge of the referral system, health, educational and vocational measures for disabled people.
4. Administration - planning, reporting systems, evaluation, budget calculations, etc.
5. Pedagogics: how to train local facilitators; how to prepare local teachers enabling them to better respond to special needs among school children; how to engage community leaders in the provision of equal opportunities for ability/ vocational training, jobs and social participation by disabled people.
6. Techniques for generating incomes among disabled people: market studies, assessment methods, informal and formal training, acquisition of funds for small enterprises, book-keeping, etc.
7. Normal child development and its application to disabled children.
8. Management: community social organisation; rural and urban development; community involvement; decentralisation and central support mechanisms, etc.
9. Social psychology: how to create awareness; how to sensitise the public to the problems of disabled people and to the solutions to these problems; networking; how to use the media and traditional techniques (such as plays or songs) to promote the programme; counselling.
10. The health care system.
11. The national education (schooling and vocational training) system and its principles.
12. The national economic situation, with particular reference to prospects for economic development use of human resources, employment opportunities and so forth.
13. Review of the existing national rehabilitation services
14. NGOs, both national and international and their role in services for disabled people.
15. Basics of national planning.
16. Legislation: existing laws (including the national constitution) concerning human rights for all citizens and certain specific rights for disabled people; ways in which the community can mediate conflicts; legal procedures to give justice to disabled people.
17. Organisational techniques: how to set up legally recognised organisations of disabled people and parents; how to provide administrative training to their leaders, etc.

Box 10.2 EXAMPLE OF DISTRIBUTION OF HOURS FOR AN ILS COURSE

Below follows subject groups and time requirements for an ILS course. Training time of three terms, equivalent to 66 weeks with 40 hours per week; the total time is 2640 hours. Total time for subjects groups listed below: 2430 hours. Reserve time and holidays 230 hours.

- **Subject Group 1:** CBR, Introduction - 120 hours
- **Subject Group 2:** CBR for persons with moving difficulties - 400 hours
- **Subject Group 3:** CBR for persons with seeing difficulties - 40 hours
- **Subject Group 4:** CBR for persons with hearing/speech difficulties - 80 hours

- **Subject Group 5:** CBR for persons with learning difficulties - 100 hours
- **Subject Group 6:** CBR for persons with other difficulties - 80 hours
- **Subject Group 7:** Income-generation, and participation in community development - 40 hours
- **Subject Group 8:** Public organisation and services - 90 hours
- **Subject Group 9:** Pedagogy and communication - 90 hours
- **Subject Group 10:** CBR Management - 150 hours
- **Subject Group 11:** Group work and individual projects with presentations - 60 hours
- **Subject Group 12:** Field practice - 1000 hours
- **Subject Group 13:** Examinations - 180 hours

BOX 10.3. WHO ARE THE VOLUNTEERS?

There are several different groups of volunteers, and each of these needs to be considered separately:

- family members of a disabled person. They provide basic training and other efforts at home;
- community workers. The community for the role of local supervision and co-ordination recruits them;
- school teachers. With some preparation, but without being specifically trained or compensated, integrate disabled children in regular classroom activities;
- other community members. They may be involved in informal ability/vocational training or in providing opportunities for employment;
- members of the community rehabilitation committee. They use their free time to animate the members of their community, to mobilise local or external resources, to plan and manage the programmes, to protect the legal rights of disabled people and to make it possible for them to be represented;
- disabled people and parents. They make efforts to mobilise local resources for the "beneficiaries" of a programme and negotiate with the community on their behalf;
- significant people at all levels. They help to motivate the government, political leaders and local authorities, raise funds and manage part of the referral system.

BOX 10.4 SOME EXPERIENCE OF VOLUNTEERS

The term volunteer should not be taken to indicate a person working without any reward. All volunteers need compensation or recognition for what they do, something that counts in their society. Locally recruited volunteers are usually better motivated, if they have a disabled family member or if they are themselves disabled and have benefited from the CBR programme. Such compensation or recognition could take the following form:

- appreciation or esteem by other people;
- official recognition of her/his work, e.g. in the local press, presentation of an award at an official ceremony, or a written recognition by an important person;
- a modest salary;
- a contribution in kind, such as some extra food, disposition of a piece of land to cultivate, a uniform, clothes, a horse, etc.;
- a signed diploma showing the competence required;
- a good training that is useful for the person;
- travel to a seminar or participation in a workshop;
- career prospects; unfortunately most such rewards consist in moving centrally - promotion and career need to be possible locally;
- in tightly controlled societies, working as a volunteer sometimes, for example, provides a woman with a legitimate reason for leaving the house and meeting other people;

- for family members the knowledge that their efforts will diminish the degree of dependency of a disabled family member is important; the disabled person will later on need less help and may contribute economically to the family.

One has to identify the appropriate motivating factor in that particular society, and give a great deal of attention to keeping everyone engaged and enthusiastic.

There are examples of local facilitators who stay for ten years, while others leave after a few weeks. I have seen examples both of community leaders who stayed on as driving forces for many years and of others who gave up early.

Even where the rewards seem appropriate for the given society, it is not always easy to predict for what length of time a particular person would be willing to contribute voluntary work. We have found it difficult to retain the services of very young people, such as school leavers, for various reasons. They often seek a career elsewhere, they tend to be interested in alternating their working environment, they marry and have other responsibilities. Some join as volunteers for the wrong reasons. For example, there are those who harbour the thought of opening a "private practice" later on. Of these, most will leave after a short while, somewhat upset about the lack of financial progress. Enthusiasm and commitment come in different measures - for some both wear off quickly, for others it is a lifelong affair.

Women in their forties with grown-up children, on the other hand, often stay for a long time⁸. Another group with good endurance prospects includes women who are themselves disabled or who have disabled members in their families. One has to recognise that such women may do a perfect job when it comes to tasks within their own experience, such as functional training and preparation for education, but may not be the appropriate persons to handle the tasks related to income generation.

The problems associated with a high turnover of volunteers are several: firstly, somebody has to be trained to replace them. This is costly. Secondly, the person who takes over from them will need some time to gather the necessary experience. Hence, quality may suffer. Some renewal of volunteers is, however, stimulating, for fresh eyes see problems and ways to solve them that may have been overlooked before.

In some parts of Asia, it is easy to recruit non-salaried volunteers for community work - I have come across good examples in India, Indonesia, Myanmar, Philippines, Sri Lanka, Thailand and Vietnam. In Africa, the tendency is to seek financial or other compensation. In some countries, governments see voluntary work based on community initiatives with suspicion - the spark that may ignite subversion. In others, like Tchad and Ghana, to encourage voluntary development work is the government's declared policy.

Most likely the CBR system and all other development programmes would not exist if there were no willingness or solidarity among large groups of people to give a helping hand. In countries where there has been a lot of political repression, violence or hostility, voluntarism may have gone into hiding to reappear - it is to be hoped - when the situation has returned to normal. The availability of volunteers is influenced by many factors. Economic factors include the amount of time free from work and household duties, and competing possibilities for remunerated occupations. Diseases among family members such as HIV infection, hepatitis, tuberculosis, parasitic diseases, malaria, amoebiasis may prevent them from carrying out the training of is widespread HIV infection, it might be difficult to mobilise any adults to carry out development activities, including CBR.

In many countries, it will not be possible to maintain a CBR programme with unpaid, voluntary personnel. These persons have to receive compensation.

Once recruited, the LFs should undergo training by the ILS (see Box 10.5, which presents a suggested programme for a 10-week course), after which they will commence working, supervised again by the ILS.(F) There are a number of other training approaches. One such approach is to condense formal training to the basics and to encourage self-studies of the TCPD Manual, followed by supervised hands-on training and a final evaluation of the trainees' competence. Other models include a three-week introductory course, followed by field practice and a second course later on. It should be noted, however, that reduced

LF training periods will call for more direct supervision and interventions by the ILS, thus increasing the number of ILSs required, and the costs (See Chapter 12).

Another approach, for use in densely populated areas, is to "specialise" the local facilitators: for example, one of them may work only with blind people, another only with people having mobility difficulties, and so on.

As a model, a LF will work full time in a catchment area of some 5,000 people⁹. But where rural villages are smaller and unwilling to share a LF, one will have to train one LF for each of these villages. As a result, the training component of the programme will turn out more costly.

In keeping with the technical programme outlined in TCPD, the first task of the LF will be to carry out a house-to-house survey so as to identify all the disabled people in the community. Normally the first period of training will concentrate on ADL-functions. Based on an appropriate training package, the LF will design an individual rehabilitation programme and then instruct the family trainer. In most cases, this will be the mother, the grandmother, or an elder sister. The trainer will apply the relevant technology under the guidance and supervision of the LF. Some experience gathered by family trainers is given in Box 10.6.

The local teacher

At an appropriate time, orientation courses should also be given to local teachers. These could last from one day to two weeks. During this time the teachers will be informed about the various disabilities, how to deal with disabled children in the classroom, and how to co-operate with a mobile resource teacher. An example of an orientation programme is provided in the Guide for Schoolteachers in TCPD.

The local personnel involved in activities aimed at generating incomes for disabled people

It is worthwhile trying to sensitise community leaders, local authorities and NGOs towards the idea of carrying out market studies, providing vocational assessment, local training and jobs for disabled people. Short meetings or seminars held, for instance, by the ILS could contribute to this end. As indicated in Box 10.5, the LS could be given training that takes account, the assessment of the local market situation and the potential for providing local ability training and employment for disabled persons.

Box 10.5. EXAMPLE OF A TRAINING PROGRAMME FOR LOCAL FACILITATORS

Local facilitators (CBR workers, CBR agents, CBR co-ordinators) are recruited by their own community, employed (and compensated) by it, and receive their managerial supervision from a local committee. The technical supervision is done by an ILS, who is at the same time the contact person for the mobile resource teacher and for other personnel at the district or at higher levels.

The LFs should be literate, have an interest in disabled people, and be well motivated for their job. They should bring a positive attitude to their task of assisting other people and be willing to learn their job well. They will normally work full-time.

There are many models for their training: Below follows a proposal for a ten-week course, to be adjusted according to local conditions. Each student will need one copy of the TCPD, in addition to other educational material. The course can follow - with adaptations - the Guide for Local Supervisors contained in the TCPD.

EXAMPLE OF A TEN-WEEK COURSE FOR LOCAL SUPERVISORS

Week	Course Contents
1.	Course evaluation and requirements to pass .Perceptions and definitions of disabled people. General interventions: functional training, education, vocational training, jobs, protection of human rights, organising disabled people, empowerment, social integration. Role of community initiatives. Community organisations for development. Meeting disabled people, their families, and community leaders.

2. Local survey (theory and practice). Assessment of disabled people.
3. Seeing difficulties. Meet blind people, practise TPs, schooling, jobs. Referrals.
4. Hearing/speech difficulties. Meet deaf/mute people, practise TPs, schooling, jobs.
5. Moving difficulties. Meet physically disabled people. Practise TPs (incl. prevention of and deformities).
6. Make walking aids and other technical appliances and Schooling, jobs, counselling.
7. Referrals.
8. Feeling difficulties (leprosy); strange behaviour (mental disease); learning difficulties (mental retardation). Practise TPs, schooling, jobs. Referrals.
9. Child development; play activities; multi-handicapped; role of local healers.
10. Education of children with special needs; adult education; social activities; household activities; activities to identify opportunities for income-generation, including market situation, simple assessment, informal vocational training, employment and self-employment; protection of human rights; organisations of disabled people. Reporting; recording; file system; in-service training.

At weekly intervals, the trainees will, at the end of the course, have to pass a competence test (knowledge, skills and attitudes). LFs without the desired level of competence may be allowed a second try. If they fail this one as well, they should not be allowed to work.

The experience of family trainers aware reviewed in Box 10. 6 .

Box 10.6 EXPERIENCE OF FAMILY TRAINERS

There is nothing new in the idea of asking family members to undertake services for their disabled children or adults. This is what they normally do. The difference is that the majority of them now provide passive care, such as feeding, dressing, washing, etc., but give very little active training.

It is normally very simple to explain to a family member that, if a disabled person could be trained to be less dependent, his/her need for care in the future would be accordingly less. Thus a limited period of training will pay off. In some cases, the disabled person may also be able to help with some household duties like looking after children, taking care of animals, growing vegetables and so on. Some disabled people may after training even be able to work and earn an income.

At the start of a CBR programme, about five per cent of families are seen to refuse to help with the training. The reasons are several: they may think it will not be effective, that they have too much to do as it is, or they are waiting for a "magic cure" that will totally restore the disabled person, or they may be outright hostile. We have chosen never to "push" such people; it is not productive, and there is enough to do anyway. At some point they may come back by their own free will (e.g. after having seen a good result in a neighbour's family).

In our experience, it is sometimes more difficult to convince families in urban areas than those living in rural ones, particularly when their main income derives from commerce. Sitting at the market place takes the better part of the day; in such families a disabled member may be left alone at daytime.

Family trainers who agree to take care of the tasks at home mostly carry them out consistently and effectively. Some, perhaps ten per cent of them, may drop out, however. The precipitating factors include: moving to another place, change of job, severe illness (of the trainer or the disabled person), lack of good results, or lack of supervision.

It is very useful to encourage the setting-up of a group of family trainers who will get together at regular intervals and share their experience, especially with newly recruited ones.

4. THE REFERRAL SYSTEM IN CBR

The referral system should be established in co-operation with the existing centres or institutions. Once the referral needs at the community level are known, these should be specified and quantified. The ways and means of meeting those needs should be discussed at the national level. To start with, the following information needs to be collected. Which needs are the most important in quantitative terms? Where should the relevant services be delivered and by whom? In what ways will the peripheral service network co-operate? For the sake of maintaining the quality of the programme, it is important to have access to referrals. Consequently, expansion of this level of services in the future is indispensable. Box 10.7

contains a few suggestions as to how existing institutions could be used for referrals. of services in the future is indispensable. Box 10.7 contains a few suggestions as to how existing institutions could be used for referrals.

BOX 10.7. SOME IDEAS OF HOW TO USE EXISTING INSTITUTIONS FOR REFERRAL SERVICES

1. The first step in planning for referrals is to make an inventory of the existing referral services in the country. These should include both government- and NGO-operated services, as illustrated in the example below:

- (a) health care facilities that can provide diagnostic and curative services, in particular orthopaedic surgery, ophthalmology, audiology, ear-nose and throat diseases, psychiatry. Services may include both specialists and generalists (e.g. district health personnel);
- (b) health care facilities that offer a rehabilitation programme, such as national centres (set up mostly for physically disabled only), orthopaedic workshops, physiotherapy, occupational therapy and speech therapy services, mental health programmes; including training courses for health sector rehabilitation personnel;
- (c) educational facilities providing special needs education, non-specialised schools able to receive disabled children and adolescents for inclusive education; training courses for MRTs;
- (d) income generation opportunities. Review the informal and the formal training sectors and their capacity to absorb disabled adolescents and youth; mainstream ability/vocational training courses; facilities set up for the able-bodied for placement in employment or self-employment in the open labour market;
- (e) legal structures and procedures for protecting human rights and all other rights, including mediators (ombudsmen) at the central and local levels.

2. The next step consists in identifying and evaluating professionals and facilities capable of receiving referrals. Their number may turn out to be small and their capacities limited. Also, they will tend to be located mainly in the capital or big cities, making them inaccessible to a large proportion of the population. As a rule, the personnel need upgrading of their training to include CBR. In the medium-term perspective, this can be done at special seminars/courses. In the long-term, CBR should become an integral part of their professional training.

3. At this point, and in co-operation with the existing professionals/facilities, one could start negotiating a number of co-ordinated activities. The questions to be asked in this context are the following:

- (a) can the referral services receive disabled people (and if so, how many), provide the desired services, and then send these persons back to the district and community with a follow-up programme?
- (b) is there a possibility of decentralising the referral services, e.g. by creating smaller units at the provincial level?
- (c) can the referral services become mobile, e.g. can visits to the province or district levels be undertaken, should this prove suitable and cost-effective (also taking into account the transport costs)?

4. After a period of 3-4 years of such co-operation, one could evaluate its outcome. At the same time one should estimate met as well as unmet community needs.

5. The referral services should then be reoriented to better provide for unmet community needs. Plans should be made to expand their responsibilities to larger parts of the country. These centres should help with teaching/training programmes and with continuous evaluation and research. It is highly recommended not to start a referral system, until the CBR has been place for 1 to 3 years, so one really knows what and how much referrals are needed.

It is important to realise that a CBR programme that includes family and community action with technical support at the district level can, in all countries, be set up at cost levels maintainable by national resources. It is when specialised referral services are provided that the costs may be more difficult to control; one has to ensure that such services are well managed, fully utilised (with some mobile components), and within reach of those living in rural areas and small-towns.

5. FACILITIES, TRANSPORTATION AND EQUIPMENT FOR CBR

The ILS and the MRT should be attached to a network of public services at the district level (population about 50,000 - 100,000). It is most practical to provide an office integrated with other personnel belonging to the public sector. In this way the rehabilitation staff will quite naturally have contacts with colleagues as

well as access to local and central authorities. Reports and statistics could be kept there.

However, the ILS and the MRT will work mostly in the field and should not have other duties in hospitals, centres or institutions. It is common experience that such an attachment will negatively influence their fieldwork. Most professionals with a double set of duties will find reasons for remaining in the centre. The ILS will need transportation to the field. What exactly to provide in terms of transportation should be given a lot of thought. After salaries, the cost of transportation is the second largest component of the budget in most countries. For some ideas see Box 10.8. and Table 10.1.

Box 10.8 TRANSPORTATION OF DISTRICT PERSONNEL TO THE FIELD

As professionals at the district level, the ILS and the MRT will work most of the time in the field, transportation is needed. No other single subject seems to attract as much attention during the planning phase.

I have received many interesting proposals, from riding donkeys to helicopters. Those requesting helicopters were arguing that their country was very mountainous, with very few roads!

Let us start by examining the question of who is going to pay for the transportation. It may be possible to find an external donor to pay for the means of transportation in the early phase of a development project. But later on these costs have to be taken over by a national or a local authority. Consequently, costs should be of a size maintainable in the country. In other words, they have to be as low as possible, without sacrificing the effectiveness of the programme. In some countries, the national government has been asked to pay because there is no decentralisation of such action. A better way would be to transfer the administrative action to the district level, where most of the intermediate-level CBR personnel is working. Districts that collect taxes or that are given a share in the taxes collected by the central government may be able to help with transport costs.

Another option is to ask for contributions from the community committees for rehabilitation. It is important that the matter of who pays how much for transportation is settled before commencing any CBR programme.

Let us now look at the options in terms of transport:

- on foot. This is practicable in densely populated areas such as marginal urban settlements, as well as in certain rural areas - no cost.
- by public means of transport. This can be done, provided there are buses going at reasonably frequent intervals to all the areas where the ILS and the MRT work - low cost. Yet, sometimes this may pose problems, as bus trips require authorisation and/or payments are not advanced. As a result, the entire programme may easily collapse owing to such administrative constraints.
- on mule or horseback. This is useful, in particular when the roads are in a poor state, when long distances have to be covered, and when this happens to be the traditional means of transport. It involves low cost. But arrangements will have to be made to feed the animal and make sure it will not be stolen.
- by bicycle. This is useful where there are at least some roads, and provided the distances are relatively short and not too hilly. This is also a low cost solution. Some external development NGOs have made a deal with the personnel in the sense that, if the personnel agrees to pay for the maintenance, the bicycle will become their property after a certain period of time, say two or three years, when a new bicycle will be supplied. Sometimes this approach is not practicable because of government regulations.
- by moped. Mopeds can be used if the roads are in a reasonable state. Distances to travel can be longer than bicycles can - for costs see below. Maintenance may be a problem, as spare parts have to be available, as well as a competent person for repairs. The question of insurance against accidents and against theft has to be discussed.
- by motorbike (e.g. 125-200 cc cylinder capacity). These are very useful even for long distances, provided the roads are of reasonable quality. As with mopeds and bicycles, a number of cultural issues need to be considered. For instance, do women (pregnant or not) normally use these types of transport? As for the cost, see below. Again, maintenance and insurance are problems that have to be solved.
- by vehicle. This is what all district personnel want - a 4X4 vehicle of their own, complete with driver. This is practical only where main roads are in a reasonable condition and villages are accessible by car. The costs are very high. As a rule, there are no cultural obstacles, but maintenance and insurance costs cause serious problems. In most countries, this type of transport is reserved for the national programme manager, who travels over very large distances. In many cases, this type of transport can only be purchased, maintained and replaced if there are external funds to pay for it.
- by vehicles provided by other service units. It is often suggested that an existing vehicle, such as the one normally used by the health team for immunisations, should be shared with the CBR programme. I have never seen this function well - dependence on other people's vehicles has always affected efficiency, often reducing it to an

unacceptably low level.

TABLE 10.1. EXAMPLES OF COST CALCULATIONS FOR THE ALTERNATIVES (E), (F) AND (G), ASSUMING THAT EACH MOPED/MOTORBIKE/VEHICLE WILL HAVE TO BE RENEWED EVERY THREE YEARS.

Examples of annual cost calculations/of various transportation alternatives (US\$)

TYPE	PURCHASE COST	ANNUAL COST				
		Capital Cost	Gas/Diesel	Repair & Insurance	Driver	Total
Moped	1,000	330	100	100	-	530
Motor-bike	2,000	660	200	300	-	1,160
Vehicle	30,000	10,000	1,100	3,300	1,500	15,900

We can now calculate the annual costs per inhabitant and per disabled person for the various types of transportation. In this example, we assume that each ILS (and each resource teacher) has a catchment area inhabited by 50,000 people. 1.5 per cent of these are involved in the CBR programme. There are either one (an ILS) or two (an ILS and a resource teacher) working in the district.

Example of an annual transport cost calculation per inhabitant/disabled person (US\$)

Type	One ILS per 50,000 people		One ILS and one mobile resource teacher per 50,000 people	
	Annual cost per		Annual cost per	
	inhabitant	disabled person	inhabitant	disabled person
Moped	0.01	0.7	0.02	1.41
Motorbike	0.02	1.55	0.04	3.09
Vehicle	0.32	21.20	0.64	42.40

Given the fact that most governments spend rather small amounts per capita on health and social programmes, typically US\$ 5-10 annually, it would seem that the vehicle alternative is too expensive. By contrast, the moped and motorcycle options seem feasible. There is another side to the problem. The standard of transportation for district rehabilitation personnel should not contrast too much with what other personnel at the same level enjoys. CBR should not be seen as a high-cost enterprise, but rather as a low-cost but highly effective effort.

It is important to develop pedagogic material for training of the ILS, the MRT, the LF and the local teacher. Material providing advice is needed for market studies, ability training and employment, both for local authorities and for NGOs. It should be adapted to the trainees' cultural, social and educational background. Tools and materials are needed for making various aids, e.g. for walking (see training package 13 in TCPD). Each LF needs a copy of TCPD (if possible an adapted national version in the local language), or a manual of comparable content describing all locally applied technology.

6. CONSTRAINTS AND OPTIONS TO SERVICE DELIVERY

Constraints

All CBR delivery systems should be designed to eventually provide coverage of the entire population of each country. The system outlined above is only one alternative. Many others may be feasible. Let us

now look at some of the constraints:

(a) It is easier to organise service delivery for densely populated than in under-populated areas.

If people live dispersed (e.g. 1-5/sq.km.) or the "villages" consist of only small extended families (30-60 people), it is indeed difficult to find a way of delivering services. In such areas there might also be no other public services, for instance, schools or health centres.

(b) There is very little experience of service delivery to nomadic populations, the majority of whom also lack education and health facilities. In some cases, however, nomadic populations may regularly stay in a specific area, where for a couple of months or so they could be reached. Nomads are becoming less common, and may decrease substantially within the next few decades.

(c) A constraint found everywhere is that it will take time to develop a functioning service delivery system. During this time a (at the start a considerable) part of the population will not be reached.

Options

To overcome the above mentioned constraints other options for service delivery may be tried. Examples of such options are:

- delivery using other peripheral networks
- distance education

Before starting a CBR programme, one should make an inventory of all existing systems with peripheral networks. These might include:

◆ *Religious leaders and priests.* This is in all cultures the earliest and most widely spread "system" that exists. Such leaders can be very valuable partners in sensitising populations and mobilising community resources.

◆ *Teachers and education services.* Although this network does not yet reach everyone in the countries concerned, it is impressive and constitutes the currently best-developed public service system in the developing countries. We have tried to use teachers as ILSs or LFs, and there are some examples where this is successful. Up until now, however, it has been difficult to conceive a system built on them as major service providers. Most teachers have large classes, or even double classes, to look after; their salaries are low, prompting them to seek a second income, e.g. through agriculture. But it is possible to count on their co-operation in integrating disabled children in school, as indicated above. This will be feasible if they receive supplementary training.

◆ *Health workers.* Some countries have developed or are planning to have a system of primary health care. There is a possibility of using community health workers for delivery of CBR, after a sufficient period of supplementary training. There are few countries with well-functioning primary health care systems giving full coverage. These programmes sometimes lack community involvement, and most of the work is oriented toward health education and prevention. We are usually told that health workers are overburdened with work and cannot deliver another component of services, such as rehabilitation. One should always seek their co-operation, for they represent diagnostic and therapeutic resources that can be of great importance for disabled people. In a few countries the government has agreed to have the CBR programme delivered by health workers and is using the referral network.

◆ *Staff in social services.* Such services are well developed in some countries, though usually not at the community level. There are examples where one finds a network of such services all over the country, with social workers at the district level. Some of these are involved in health and ordinary community development projects and can - after supplementary training - become ILSs. In such countries it is possible to build up a countrywide system linked to an existing public service network.

◆ *Staff in development programmes.* Where one is unable to find any existing networks of public services, one might look for integrated community development programmes. Supplementary training

would enable them to carry out the CBR programme. Another factor that calls for close co-operation with the staff in developing countries is that these programmes can be used for "mainstreaming" disabled people. For instance, one could integrate disabled children in programmes aimed at stimulating and looking after the health and nutrition of under school-age children.

Other development projects concern e.g. the economy, creating jobs and income, providing education and health services, or improving the infrastructure and communications. Participation of disabled people should be sought in such projects.

Social security. Some countries are slowly building up social security systems, and some of these have rehabilitation components. These are mostly based in institutions, such as hospitals. Social security services for rehabilitation should aim at multi-level and multi-sectoral programmes and have CBR components. It still remains to be seen whether this will be possible.

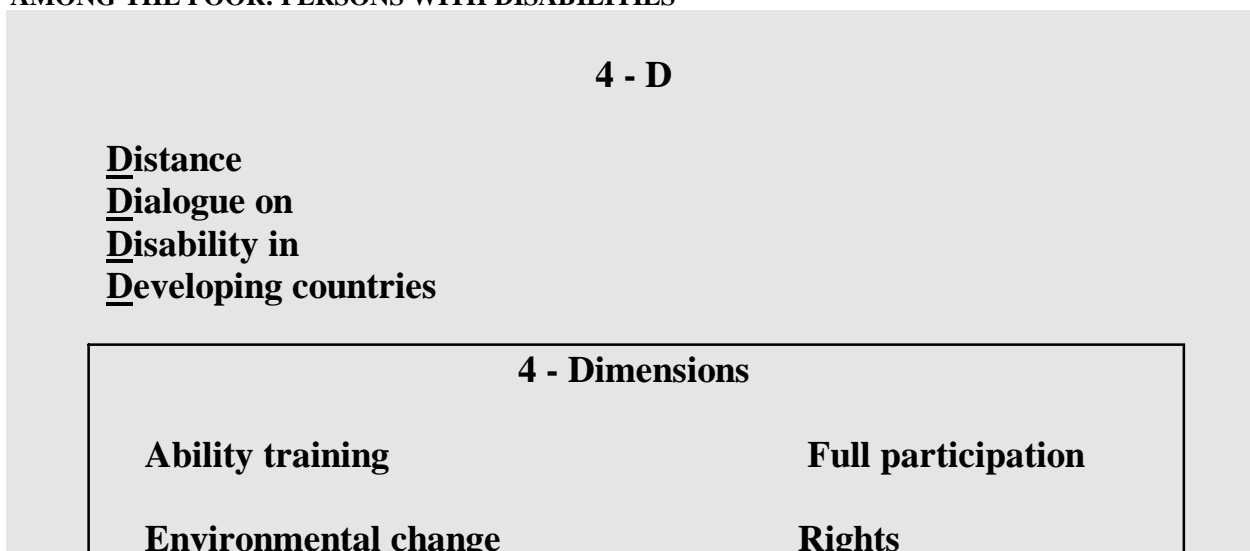
◆ *Organised disabled people.* Some organisations are large, with widespread networks of local chapters and could help to manage the CBR service delivery system.

◆ *Legal systems.* There are many areas in the world where local leaders are responsible for the enforcement of justice, law and order. These systems will not deliver CBR services, but their co-operation is valuable in such matters as promotion of human rights, provision of legal protection for disabled people and mediation of conflicts arising, for example, from lack of opportunities for education and jobs.

If a decision is taken on an alternative delivery system, it will be necessary to take a second look at the technology to be used. Tasks may be revised or assigned to another level than the one proposed in TCPD. It is a good idea to always start doing what is easy. Examples are: services in areas where transport is not a constraint, training the children of families who are interested to co-operate, schooling those who can benefit from education in regular classes, providing ability training and jobs for those who are clearly competitive on the labour market and so on. We have to realise that meaningful rehabilitation services exist today for only a few per cent of those in need. If we can improve the quality of life even for as few as 20 or 30 per cent of all those in need, it will be a great leap forward.

The second option is to set up a distance education programme - or as I prefer to call it a distance dialogue programme. Many countries use such programmes and are quite successful. For examples see Box 10.9 and Box 10.10.

BOX 10.9 ACTION PROGRAMME TO IMPROVE THE QUALITY OF LIFE FOR THE POOREST AMONG THE POOR: PERSONS WITH DISABILITIES



Box 10.10. DISTANCE DIALOGUE PROGRAMME IN INDIA

“Most persons with disabilities are poor, dependent, abused, neglected, excluded from education, training and jobs, die early and have no power while alive.”

The rural radio in Bangalore, India has made plans to start carrying a regular programme on disability. The programme has been planned for two years and is supported by a grant from the Karnataka State Government. It will be set in the local language: Kannada.

These programmes will be carried out in several phases:

1. **General introduction:** what is disability, how many are affected and which are the consequences? At present persons with disabilities account for about one in six of the 1,400 million poor people in the developing countries, or some 350 million (in India there are some 45 million moderately or severely disabled persons). Interviews of persons with disabilities, to discuss their social and economic situation and expose the unresolved problem that they face. Dialogues with disabled persons, who have been successful, reached full independence and integration.

2. **Message:** it is possible to change to lives of disabled persons, if they are given ability training (mobility, communication, daily life activities, preparation for jobs), fully participate in development programmes (education, health services including prevention of disability, income-generation), if changes in the physical (such as obstacles to access to public buildings and transport), and psychological environment (attitudes an behaviour among non-disabled people) and full protection of their rights (empowerment of their organisations, protection against physical, economic, psychological and sexual abuse). Disabled people are today virtually excluded from their societies. In India 98 per cent of them are neglected. It is important that family and community members discover the fact that is possible for them to transform the conditions in which most disabled people live, and that they can acquire the skills and knowledge to take the action needed.

3. Through the radio programmes and with the assistance of other media, persons with disabilities, their families and communities are encouraged to write postcards or letters to the radio station (the postage for such cards is very cheap).

4. When the questions arrive, these will answered in the radio station. When there is enough mail, special programmes about e.g. mentally handicapped children, spastic children, blindness, problems related to polio and leprosy will be sent.

5. Local newspapers will be asked to take part. The same type of messages can be printed. Secondly, the newspapers could carry excerpts of the training packages from of the WHO Manual “Training in the Community of People with Disabilities”.

6. The local cable TV network will be used on occasions to relay videotaped portions of how training of persons with disabilities is carried out.

COMMENTS AND REFERENCES

¹ In a recent project for vocational rehabilitation in a country where the estimated number of disabled people in needed of this service is about 100,000, the evaluation team remarked:” During 4 years a total of 117 disabled people have received vocational training each for a period of 6 months. ... the cost for each person was US\$ 3,500... and US\$ 0 for the other 99,900 disabled people, and there was no policy for how this disequilibrium could be reduced.”

² I have noticed in a large number of countries that institutions claims to have changed and that they tell visitors that they are delivering a CBR programme. In some cases, this may mean that they are now receiving part of their funding from local authorities. In other words, they have become community-financed, but that is the only change. In most other instances, there was no change whatever, but the institutions’ managers had been asked by their donors to start describing their projects as “community-based ones, as this would facilitate the fund-raising. And a few others had started outreach programmes on a small scale, without seeking any involvement with the community.

³ For a more detailed outline on how this can be done, see E..Helander, Sharing Opportunities, UNDP, Geneva, 1996.

⁴ Questions concerning personnel in rehabilitation are dealt with in many publications, see e.g. International Meeting on Human Resources in the Field of Disability, UNCSDDHA, Vienna, Austria, 1989.

⁵ A set of recommendations concerning ILS was published recently by WHO: The Education of Mid-Level Rehabilitation Workers. WHO, Geneva, Switzerland, 1992. There are now several country examples of ILS. Training periods usually vary between 12 and 24 months, Students are - if not already trained in another job - often recruited from high school students.

In 1978, it was proposed to develop a “multi-purpose therapist” for this task. See, e.g. E. Helander: “Das Ziel”: Ein Universal-Rehabilitationstherapeut” in Zeitschrift Gesamte Hygiene 24(6); 478-81, Juni 1978. Some countries are now - for economical and political reasons - considering a new system - “a joint” physio- and occupational therapist.

⁶See E. Helander: "Personnel for CBR; in preparation".

⁷"Assistant" is not an appropriate term, for these professionals should be able to make their own judgements and to take their own technical decisions.

⁸A study of a large group of LF, was recently carried out in Sri Lanka confirming this experience.

⁹This is for the situation where the population density is 30/sq.km or more. See E. Helander: A Guide on the Analysis of Costs, Effectiveness and Efficiency of Rehabilitation Programmes, 1996

¹⁰A detailed description is available in A.G. Loza, A. Garcia, E. Canavesio, C.T. de Sanchez, S. Fernandez, L. Canulli, A. Oliverea and Z. Micissi, Community Based Rehabilitation General Programme, La Rioja, Argentina; Pan American Health Organization, Washington, D.C., U.S.A., 1991