

## **CHAPTER THREE: NEEDS OF PEOPLE WITH DISABILITIES**

### **1. A STUDY OF NEEDS**

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

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

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

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

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

### **2. TERMINOLOGY USED**

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

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

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

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

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

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

### 3. FELT NEEDS

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

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

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

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

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

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

experience and should be taken with caution. It should also be noted that the conditions cited in Table 3.2 vary widely from country to country:

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

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

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

When people in developing countries mention needs in connection with such difficulties, the most oft-cited concern is the burden to the family - physically, psychologically and economically. Dressing and feeding a disabled person, and attending to his or her personal hygiene, are time-consuming tasks. Mobility problems often remain unsolved, with the disabled person simply never leaving the house. Communicating with a deaf child takes time, even though most families invent a sign language of their own. For economic reasons, schooling of disabled children is seldom considered. As most disabled people are seen as unable to perform any work at home or outside (begging is, however, an alternative), they receive no ability/vocational training.

Some families have tried to find solve the disability problem by applying "spontaneous" rehabilitation technology<sup>3</sup>. But the majority of the disabled people in the developing countries receive no such attention. The fact that there may not be much spontaneous rehabilitation is not contrary to the fact that families may provide all the care.

Examples of the felt needs of disabled people are given in Table 3.3 and Box 3.1<sup>4</sup>.

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

<p><b>Functional problems in daily life activities</b></p> <ul style="list-style-type: none"> <li>• self-care (eating, drinking, dressing, keeping clean)</li> <li>• mobility</li> <li>• communication, comprehension, ability to follow instructions</li> <li>• behaviour.</li> </ul> <p><b>Educational needs</b></p> <ul style="list-style-type: none"> <li>• schooling</li> <li>• ability training</li> </ul> <p><b>Needs for income-generating activities</b></p> <ul style="list-style-type: none"> <li>• participation in household duties, jobs, self-employment</li> </ul> <p><b>Lack of family and social integration</b></p> <p><b>Concerns relating to participation and representation in community affairs</b></p> <p><b>Security needs (protection against abuse, promotion of human and legal rights)</b></p>
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Many of these are overlapping. It should be explained that the concept of "independent living" is still very much a Western idea that has not yet much of a following (see Chapter 13) in the developing countries. There is no "push" to send disabled youths out to live on their own; they are welcome to stay. Families normally live a life characterised by interdependence. Still a programme that will lead to independence in ADL, mobility and communication is seen as great progress.

**Box 3.1 A DISABLED PERSON'S EXPECTATIONS OF REHABILITATION**

- "1. Like any other individual or citizen of a country, the disabled person expects and hopes to get good education, suitable vocational training leading to eventual socio-economic rehabilitation so that he[/she] can lead an independent satisfactory life.
- "2. To be provided with regular medical care to improve the functioning as far as possible as well as prevent the disability from deteriorating any further.
- "3. To be helped and guided in his orientation and readjustment in the family, community and society with full participation.
- "4. To actively participate in his[/her] own rehabilitation, deciding for himself[/herself] the goals that he[/she] wishes to achieve, it is essential that he[/she] is trained in accordance with his[/her] potential and inclination.
- "5. To be provided with suitable aids and appliances that help to bring his[/her] mental and physical potential to the maximum.
- "6. To be provided easy access to physical environment including rehabilitation services through removal of structural barriers and communication problems.
- "7. To be placed in a suitable job after training where facilities and safeguards are provided for the basic adjustment of his[/her] disability in order to enable him[/her] to function to his[/her] maximum capacity.
- "8. To receive evaluation and follow-up services till such time that he[/she] is fully settled with success in his[/her] job. This evaluation and follow-up is a combined and co-operative process between the disabled employee, the placement officer and employer."

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

#### 4. EXPRESSED NEEDS

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

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

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

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

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

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

This example further illustrates the amount of energy, time and proportion of their meagre resources a family may have to spend in looking for a solution to the needs of a disabled member.

Of course, there are also examples to the contrary, namely, not much interest in doing anything at all, and a tendency to leave the disabled person alone, which is a reflection of the perception that "nothing helps".

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

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

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

**Table 3.4 Review of rehabilitation needs among a group of 77 disabled people participating in a CBR project in Vietnam**

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

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

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

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

### **Box 3.2. DISABLED WOMEN**

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

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

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

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

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

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

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

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

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

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

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

- "a. Attitudes and prejudices of the public including family, community and even the Government, which are stereo-typed and negative towards disability.
- "b. Lack of mobility, isolation, confinement to the house. Socio-cultural patterns, and traditions stronger and more effective than legislation itself, are conducive towards creating this situation more acutely for females than males.
- "c. Lack of education and training. Generally the percentage of literacy amongst women is lower than [amongst] men in most of the countries in this region. In the case of women with disability it touches the lowest mark.
- "d. Economic dependence on the male members of the family, lack of training and employment.
- "e. Lack of environmental adjustment, rendering mobility for the physically disabled very difficult.
- "f. Lack of equipment [,] necessary to cope with the disability, i.e. wheelchairs, prostheses, hearing aids, etc.
- "g. Poor health due to malnutrition, lack of activity, poverty and ignorance.
- "h. Marriage: This is a much greater problem for women with disability than it is for men, due to socio-cultural patterns and the concept of a woman's physical image of marriage. This deprives her of her traditional role and status as a wife and a mother, and combined with total economic dependence, she is relegated to the position of a non-person in the family and community.
- "i. Motherhood: If she is married and has children she is not considered fit to look after them, which naturally deprives her of a role important for her emotional satisfaction and personal dignity.
- "j. Severe frustration, inferiority complex: Lack of opportunities and access to education and training for self-improvement and independence destroys the self-confidence, self-image and self-esteem due to the concept of her physical body image dominating the socio-cultural pattern.
- "k. Non-involvement in Self-help movements at all levels."

A UNDP publication about Safe Motherhood states:

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

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

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

## 5. ASSESSED NEEDS

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

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

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

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

Services "prescribed" by so-called "experts" often lead to poor results.

## 6. GENERAL CONDITIONS OF LIFE AND POVERTY AMONG PERSONS WITH DISABILITIES.

Before going into the final part of this discussion, a review of the general conditions of disabled people will be made. I have in Chapter 2 mentioned that the health condition of disabled persons in the developing countries is worrying. It appears that both mortality and morbidity are excessive. Some of this is related to the health conditions that caused the disability, but most is not. There is no doubt that disabled children often, and in some countries especially girls, do not receive the health care available to other children. This includes both preventive and curative care. The same can be seen among adults with a disability.

The economic situation is characterised by poverty. Poverty, no doubt causes disability, but any visit to a rural village will reveal that disabled people are less well dressed than others, that their food requirements are less well, and that their housing of lower quality than the average. Disabled people are seen as the poorest among the poor by villages themselves, as illustrated in Table 3.5.

The World Bank defines a poor person, as one who is able to spend less than US \$ 1 a day. The Bank's estimate at present is that there are some 1,400 million poor people in the developing countries. The UN and its agencies have recently stated a decade for the eradication of poverty, and are advertising the expectation of eliminating poverty "in our life-time". Disabled people are at least 235 million now. They are most likely to be found among the poor. Thus about **one out of six poor in the developing countries is a disabled person.**

In view of this situation, one would expect that development programmes for disabled people, would rank high in the budgets of the UN and its agencies. One would also expect that poor countries would give a high priority to programmes for rehabilitation as part of their national budgets set aside for community development. But there are few signs of such a change. When later on in this Chapter, we will calculate needs for disabled people, we should keep in mind that what is proposed should be seen as part of the general community development programme, and preferably not as a commitment "earmarked" for

disabled persons.

**TABLE 3.5. THE POOREST AMONG THE POOR.**

A short illustrative list of some criteria used by local people in “ill-being” grouping and ranking: a selection of sources in Asia and sub-Saharan Africa. Those on the top of the list are seen as worst off.

- Disabled (e.g. blind, crippled, mentally impaired, chronically sick)
- Widowed
- Lacking land, livestock, farm equipment, grinding mill...
- Cannot send children to school
- Having more mouths-to-feed, fewer hands to help
- Lacking able-bodied members, who can fend for their families in the event of crisis
- With bad housing
- Having vices (e.g. alcoholism)
- Being “poor in people”, lacking social supports
- Having to put children in employment
- Single parents
- Having to accept demeaning or low status work
- Having food security for only a few months each year
- Being dependent on common property resources.

Source: R Chambers <sup>8</sup>.

## 6. *TRANSLATION OF NEEDS INTO REQUIREMENTS OF SERVICES, INTERVENTIONS, OPPORTUNITIES AND ACTION FOR DISABLED PEOPLE*

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

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

How many disabled people will need what, and for how long?

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

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

The following calculations represent a combination of what is required for all the developing countries together. Taking the global, operative rate of moderate and severe disability (see Table 2.3) as a basis, a recalculation, based on experience and survey studies, is needed for each country. One should include data about age composition, level of development, availability of health services, education, labour market conditions, etc. The fact that the group of "moderately and severely disabled" is seen here as the main target group for rehabilitation does, of course, not exclude that rehabilitation is useful also for people with slight disabilities. This is particularly true when it comes to the needs of ability/vocational rehabilitation in the developing countries. Certainly, functional training and schooling should also include slightly disabled

people. But the size of the latter group is more difficult to calculate, and it is better to be on the conservative side estimating service needs.

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

General interventions, including those aimed at:

- building awareness of disability, of the abilities of disabled people, and of the possibility to provide rehabilitation in the family and the community, sensitising the community to create more positive attitudes and less discriminatory behaviour;
- providing more equitable opportunities, better access to the general systems of society, mainstream interventions such as health care, education and training, community development, poverty alleviation and environment programmes, and so on;
- increasing the representation of disabled people and their families on all formal and informal bodies with authority to decide on plans, services, etc., for disabled people;
- promoting and protecting disabled people's rights.

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

Specific interventions, including

- functional training;
- special needs education calling for resources not available, or not properly used, in regular schools;
- ability training and other vocational measures for income generation.

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

The annual incidence in 2000 of moderately or severely disabled people in the developing countries was estimated at 49.7 million. By 2035, this number is expected to increase to 126.5 million.

- **functional training**

Functional training includes all the efforts to improve the abilities for self-care, mobility, behaviour and communication, including provision of appliances and technical equipment to facilitate training and/or to alleviate the consequences of disability. Also included are environmental interventions in respect of individuals, such as removal of physical barriers for a disabled person.

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

To calculate the requirements for services concerning functional training<sup>8</sup>, we need to know:

- the number of newly (moderately and severely) disabled people each year;
- how many of these people could benefit from training, and
- the length of time needed for training and follow-up.

Based on a cautious estimate, the **initial target for provision** of such training could be set at about 30 per cent of the group of newly (moderately or severely) disabled people. This corresponds, in 2000, to about 16 million people. Future plans should allow for an expansion of that number to about 40 million by the year 2035. The estimate suggested here corresponds to approximately 20 per cent of the total prevalence.

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

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

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

These estimates allows us to conclude that the target set for 2000 would be service provision for about 45 million (15 million multiplied by 3), while the service needs would increase to about 120 million (40 million multiplied by 3) by the year 2035. (Table 3.6.)

- **special needs education of children with disabilities**

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

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

I have opted for using the prevalence rate for moderately and severely disabled children aged 5 to 14 as the basis for calculating the target. In 2000, the prevalence is 28 million children in the developing countries. In 2035, their number will be 32 million. Some of these have some very basic problems in school, related to severe reduction of vision or hearing, or to mental retardation.

In addition, there is a proportion of children with development delay or, with social and family problems and or on behaviour problems, etc.

In trying to set a target for these needs of education, I have assumed that, during the period when they are in the age group 5 to 14, the disabled children (in 2000 = 28 million) will receive schooling for a total average period of seven years. Using these estimates, the size of the target group, in 2000, will be 19.6 million (28 million multiplied by 7/10); in 2035, it will be 22.4 million (32 million multiplied by 7/10). (See

Table 3.6.)

The target group of disabled children with needs for special education is currently forecast to increase by about 10 per cent between 2000 and 2035. This relatively modest increase is explained by the projected considerable decline in the natality rate over the same period.

On the other hand, the scope of special needs education may be expected to widen with economic development, as more children with special needs (such as those mentioned above) are included. As a result, the increase might very well exceed the estimate of 10 per cent.<sup>9</sup>

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

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

- **income-generation**

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

The tally of people needing interventions for income-generation likewise reflects a cautious view of what may be achieved in realistic terms.

There is widespread unemployment in the developing countries, reaching in some cases 20 per cent or more of the existing potential labour force. Underemployment is another common phenomenon. The population grows by two to three per cent annually in many of these countries. The levels of investment and economic growth are not high enough to absorb the 95 to 120 million young men and women (in the developing countries) who try to enter the labour market every year<sup>11</sup>. At the same time, employment opportunities for agricultural workers stagnate. The young rural population is moving to urban areas - a factor that tends to increase the competition for the jobs available in the service and industrial sectors.

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

In some countries, where the investments are higher and GDP growth reaches three per cent, or more, the prospects for finding a job are better.

The disabled people who will have the abilities to participate in ordinary work are mainly those with moderate and slight disabilities, and vocational measures should be targeted at this group.

To set a quantitative target for income-generation for persons with disabilities rehabilitation, the following calculations have been made. In the developing countries, such measures are almost exclusively given to a group of adolescents and youths aged 15 to 29. Later on, such measures are rare and consist mainly in returning a newly disabled person to his or her old job. Thus the target group for the estimates in this book is based on the age group 15 to 29.

I have not provided any estimate for the prevalence or incidence of moderate and slight disability in the previous chapter, but I will assume these rates approximate those for moderate and severe disability. The prevalence of the last-mentioned is (see Table 2.6) 27 million, in 2000, and 37 million, in 2035.

Income-generation measures are directed at many sectors, e.g. household activities, agriculture, small

enterprises, manufacturing and services. It is proposed that the average time period needed for these measures and for follow-up be set at three years. These services for all moderately and slightly disabled people in the age group 15 to 29 years. It would be reasonable to calculate for a period of services and follow-up of 3 years.

Using these estimates, the size of the target group for vocational measures may be set at 5 million (27 million multiplied by  $3/15 =$  three years of services and follow-up), for 2000, and at 7.4 million (37 million multiplied by  $3/15$ ), for 2035.

The total proposed targets appear in Table 3.6.

**TABLE 3.6: INDICATIVE GLOBAL TARGETS REGARDING THE NUMBER OF DISABLED PEOPLE FOR WHOM PERMANENT REHABILITATION SERVICES ARE REQUIRED IN THE DEVELOPING COUNTRIES**

Type of rehabilitation services	Basis for calculation	Period over which services and follow-up are required	Services targets, million people needing rehabilitation	
			2000	2035
<b>Functional training</b>	30% of incidence moderate and severe disability, all age groups	3 years	45	120
<b>Special needs education</b>	All children with moderate or severe disability aged 5-14	7 years	20	22
<b>Ability training and other vocational measures</b>	All adolescents and youths with moderate or slight disability aged 15-29	3 years	5	7
		<b>TOTAL</b>	70	149

The dominating need is for functional training, those for special needs education and income-generation are much smaller.

Based on these estimates shown in Table 3.6, we might calculate that services for rehabilitation are needed for close on 70 million disabled people in 2000 and that the need will increase to about 149 million in the year 2035. These global indicative figures should be taken with caution. They are based on modest assumptions and estimates, and on field experience. They correspond to permanent service provision targets of 1.5 per cent of the total population in 2000. In 2035 the provision should be for 1.9 per cent of the total population. In these targets, I have not included other types of services for disabled people, such as home care or their participation in general, mainstream development programmes. The rehabilitation process is seen as a preparation for disabled people's participation in services and opportunities offered to all citizens - with or without a disability.

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

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

- *in 2000, for about 70 million disabled people, and*
- *in 2035, for about 149 million*

An enormous gap exists today between what is provided and what is required. The requirements **grow by about 2.3 million a year, or by over 6,000 a day**. 2.3 million is a number probably close to the estimate of all existing provision of active rehabilitation in the developing countries now. The gap is widening rapidly.

### **Translation into service planning**

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

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

Based these calculations and on experience, it should be **realistic to plan for a system that will at the present time be capable of providing services for about 1.5 per cent of the population**. About one third of these represent newly disabled persons and about two thirds follow-ups.

Before these requirements can be translated to budget estimates and requirements of personnel, an effective technology and an efficient and sustainable service delivery and management system have to be designed.

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

### **COMMENTS AND REFERENCES**

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

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

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

<sup>4</sup> Quoted from F. Shah, *Disability, Self Help and Social Change*. ICIC Foundation, Karachi, Pakistan, 1990.

<sup>5</sup> B. Helander provides a detailed example of this process in "Disability as incurable illness: Health Management and Disabled in Southern Somalia", 1993. The example concerns the Hubeer clan in Somalia.

<sup>6</sup> P. Mendis: Report from a CBR programme in Vietnam; courtesy The Swedish Save the Children Fund, Stockholm, Sweden. The order of needs follows TCPD, *Guide for Local Supervisor*, pp. 38-40.

<sup>7</sup> "World Programme of Action concerning Disabled Persons", UN, Vienna 1982  
"Disabled Women" in *Women 2000*, No. 1, 1991, UN, Vienna, Austria. Another review by E. Boylan appears in "Women and Disability" (*Women and World Development Series*), Zed Books Ltd., London, UK, and New Jersey, USA, 1991.  
F. Shah, *ibid*.

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

<sup>8</sup> Compilation by R. Chambers: *Poverty and Livelihoods. Whose Reality Counts? A Policy Paper* commissioned by UNDP for the World Summit for Social Development, Copenhagen, March 1995. Sources include Sarch 1992, Redd Barna 1993, A. Rajaratnam and J. Rajaratnam, 1993.

<sup>9</sup> Functional training, mainly in the form of physiotherapy, is also part of acute medical care delivered in hospitals or to out-patients. In industrialised countries, such training is an integral part of the treatment administered to patients with fractures, arthritis, cardiac disease, stroke, neurological disorders, burns, etc. The requirements for functional training during the acute phases of a disease, or after trauma, are not included in the estimates here.

<sup>10</sup> It is clear that, as economic development progresses, the perceived needs among and the resources provided for children with difficulties in school will grow considerably. In Australia, a recent report suggests that, in primary and secondary schools, there are respectively 14.7 per cent and 11.6 per cent of children "experiencing difficulties". Out of these, a large proportion "require assistance". The latter belong, in primary schools, to the following categories: vision 0.6 per cent (of all school children), hearing 0.5 per cent, co-ordination 1.5 per cent, health 0.6 per cent, speech and communication 1.8 per cent, general learning 4.9 per cent, specific learning 2.3 per cent, emotional or behavioural 3.1 per cent. The conclusion is that to the degree that economic development allows it, there will be a growth of special needs education in the developing countries beyond the 10 per cent projected in Table 3.6. Source: D. Pickering, C. Szaday and P. Duerdoth: *One in Eleven. Special Education*, Victoria College, Victoria, Australia, 1988.

<sup>11</sup> In 2000, 95 million persons in the developing countries, reach working age of 16 years, in 2035, 121 million.