

TRAINING THE DISABLED IN THE COMMUNITY

**AN EXPERIMENTAL MANUAL ON REHABILITATION AND
DISABILITY PREVENTION FOR DEVELOPING COUNTRIES**

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FOREWORD

Improving the fate of the disabled who live in developing countries today is a difficult and challenging task.

Many factors militate against such improvement: Governments are not inclined to believe that disability in the community is a problem, and rehabilitation is generally viewed as a luxury because it is almost exclusively left to the care of charitable institutions with apparently high expenditure. Nor is there anything very dramatic or eye-catching about government action aimed at improving the situation for the estimated 10 percent of any population who suffer from disablement. The poor, the dependent, the vulnerable disabled speak either with a humble voice or with none at all. They have no influence and carry no political weight. Today we estimate that 98 percent of them are totally neglected in developing countries - a percentage that is even higher now than it was 25 years ago.

Yet their situation can be improved. There is no valid reason for directing all available resources in the health sector towards problems related to acute disease and mortality, while neglecting persons with chronic impairments and permanent disabilities. Handicaps loom large in people's lives; disablement makes life very difficult, creates dependency on other members of the family or community, and prevents the disabled from making their full contribution to society.

This Manual describes a set of new approaches. The process of rehabilitation has been demystified by breaking it up into component parts, each of which is described in such a way that rehabilitation can safely and effectively be carried out by lay persons, such as a family member or a friend of the disabled, or by the disabled persons themselves. Components with evaluation sheets form training packages, and these packages have been arranged in six different booklets for the six major disablements dealt with here, i.e., moving, seeing, hearing and speaking, learning, fits, and strange behaviour.

The Manual not only provides these sets of booklets; it also includes guides and other information dealing with the entire system for implementing rehabilitation. In addition, it deals with many aspects of disability prevention in the community. Preventive action is most important as it may reduce the incidence of disability by at least 50 per cent, or postpone it for many years. Any effective application of disability prevention also requires action at the national level; however, any attempt to cover all aspects would call for a separate publication. The presence of all this material has already made it rather voluminous, but any cuts would have deprived the reader of material necessary to understand these totally new concepts and how they can be implemented.

This Manual is an experimental edition. It is being tested in several developing countries in all parts of the world. In each area it has to be translated into the local language, and adapted to the social and cultural setting. What has been provided here is a kind of Master Manual, containing material which may in turn suggest new concepts. The authors welcome any criticisms or suggestions for changes; they hope that a final version will be printed in 1982.

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Geneva, 12 September 1980



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THE PROBLEM

There are some 400 million disabled in the world, or about 10 percent of the world's population.

It may be estimated that on any one day 60 million people in the world could be helped to a better life through the provision of rehabilitation; that is, through the improvement of their functional capacity, and provision of educational and vocational measures. Also, through a better understanding of the problems and better acceptance of the disabled in the community. All this aims at better integration of the disabled into the main stream of our societies.

Some 40 million of these disabled who need rehabilitation today live in developing countries. Very few of them receive any services at all. This Manual describes effective yet inexpensive means to provide rehabilitation at the community level.

The family is given the responsibility of rehabilitating and assisting the disabled with self-training. Local supervision and guidance will be provided. The disabled and their families cannot wait any longer for the services they need now -- this Manual describes how they can provide the essential rehabilitation for themselves.

THE OBJECTIVES OF THIS MANUAL ARE:

1. TO PRESENT NEW POLICIES AND APPROACHES TO REHABILITATION OF THE DISABLED IN DEVELOPING COUNTRIES TO POLICYMAKERS AND PLANNERS AND TO LOCAL COMMUNITY LEADERS.
2. TO PROVIDE GUIDELINES REGARDING SUPERVISION OF REHABILITATION AT THE COMMUNITY LEVEL AND EVALUATION OF ITS EFFECTIVENESS TO LOCAL SUPERVISORS, AND REGARDING EDUCATIONAL ASPECTS TO LOCAL TEACHERS.
3. TO PROVIDE DETAILED TRAINING PACKAGES FOR THE TRAINING OF THE DISABLED AT THE COMMUNITY LEVEL TO BE USED BY THEIR FAMILY MEMBERS OR BY THEMSELVES.
4. TO PROVIDE EVALUATION OF THE USEFULNESS AND EFFECTIVENESS OF THIS MANUAL AS BACKGROUND MATERIAL FOR THE FORMULATION OF NATIONAL MANUALS ADAPTED TO LOCAL NEEDS.

This is not the final text of the manual. It is an experimental edition completed in September 1980 by Einar Helander, Padmani Mendis, and Gunnel Nelson, Programme of Disability Prevention and Rehabilitation, Division of Strengthening of Health Services, with the cooperation of other programmes at WHO Headquarters, Geneva, Switzerland. Illustrations are by Gunnel Nelson.

It contains material for field-testing. Various methods have been used to present it so that it is not consistent in order to better allow evaluation.

The final aim is to inspire the preparation and distribution of national manuals and training packages adapted to local conditions, in order to improve the present conditions of the disabled in developing countries in an effective way at a cost that can be afforded.

CONTENTS OF THE MANUAL

This Manual contains the following:

1. Training material for family members of the disabled or for the disabled themselves, called TRAINING PACKAGES.

2. Several training packages together form a BOOKLET.

There are six booklets, one each for the training of persons who have:

- fits
- hearing and/or speech difficulties
- learning difficulties
- moving difficulties
- seeing difficulties
- strange behaviour

3. In order to provide the proper introduction of services for the disabled -- i.e., supervision, guidance, referrals and cooperation by teachers -- there are four GUIDES:

- for policymakers and planners
- for local supervisors
- for community leaders
- for teachers

SUMMARY

The Manual "Training the Disabled in the Community" comprises about 1100 pages. A summary is provided below.

The Foreword (page i) and The Problem (page v) describe the background. Attempts to improve the fate of the disabled in developing countries face many obstacles. At present there are some 250 - 300 million disabled in these countries and 40 million of them need rehabilitation on any one day. Yet the services that are available are only for very few. In addition, they are too expensive and ineffective. Institutions and similar services provide rehabilitation for about 2% of those in need, and the 98% are left without attention. This Manual introduces an entirely new set of approaches, describing the community delivery of the essential rehabilitation training. The process of rehabilitation has been demystified by breaking it up into simple component parts. Each of these "training packages" is described in such a way that a "lay" person or the disabled themselves can undertake the training. The Manual not only provides 49 training packages, collected into 6 booklets for various disabilities, but also describes the entire system for its implementation in various Guides.

The objectives of the Manual appear on page vi and a short description of its contents on page vii. This Summary, an alphabetical subject Index (page xv) and References (page xxx) follow.

The Manual continues with four Guides: "Guide for Policymakers and Planners" (P), "Guide for Local Supervisors" (LS), "Guide for Community Leaders" (C) and "Guide for Teachers" (T).

The "Guide for Policymakers and Planners" provides information and general material aimed at providing the necessary background information for the formulation of policies and detailed plans. It describes how one can start, evaluate, maintain, further develop and upgrade the programme.

The first section (P-3) provides the WHO definitions of the terms "impairment", "disability" and "handicap" in order to facilitate a consistent use of terminology.

The second section (P-7) reviews available global estimates of the size and nature of the disability problem world-wide. It has been determined that 7 to 10% of the world's population is disabled, or some 400 million people. On any one day, 1 out of 6 disabled persons, or about 1.5% of the world's population, is in need of and could benefit from the type of community rehabilitation training described in the Manual. It is likely that the proportion of disabled will remain unchanged in the future. However, if effective prevention were instituted, one might expect a lower proportion of disabled children.

The third section (P-13) gives three possible ways of undertaking an assessment of the disability rate in a developing country: a simple house-to-house survey, a scientific sample survey and utilization of local health statistics to estimate the problems. The first survey is simple and low-cost; the second is complicated and expensive but will yield the best possible assessments that planners may require. The estimation technique is also quite simple and will suffice in most countries in order to plan appropriately. To utilize census questions for the purpose of identifying the disabled is discouraged.

The next section (P-20) deals with prevention of disability. First level, second level and third level prevention are defined. The most important measures to provide such prevention are reviewed. It is estimated that the incidence of disability/handicap can be reduced by at least 50% if appropriate and effective first and second level disability prevention were to be implemented in developing countries.

Section 5 (P-25) reviews methods aimed at assessing costs, efficiency and effectiveness of rehabilitation services. A detailed, simplified way of determining costs of institutional and community services is presented, resulting in estimates of daily costs per disabled. Examples of efficiency measures, the quantitative outcome of the expenditure, are then given. These include utilization rate, turnover rate, annual admission capacity, manpower density and population coverage. Finally, various ways to assess effectiveness, the qualitative outcome of the expenditure, are reviewed. Comparisons are made between the probable results of institutional care and community-based rehabilitation. These two forms of rehabilitation are unlikely to achieve the same results in terms of effectiveness. The community-based programme should achieve better results, especially regarding long-term outcome related to physical, vocational and social factors. The institutional treatment is likely to lead to better short-term physical results and long-term educational ones. It is a mistake to believe that the introduction of community-based rehabilitation will lead to a substitution of quality for quantity. The final rehabilitation results should be measured in terms of effective social integration, something that cannot be achieved by institutions.

The next section (P-42) deals with the identification of the gap between needs and available services, and how it can be closed. It gives a realistic example from a developing country in which the gap between needs and available resources was found to be 98.9% (i.e., of all persons in need at a particular time, only 1.1% receive rehabilitation). If in such a country one would attempt to cover the rehabilitation needs by institutions, one might calculate that the budget requirements would be US \$34 per capita per year. To spend such an amount on services for the disabled only appears totally unrealistic in most developing countries. Also, to train the necessary manpower and to provide the facilities is beyond the means of these countries. On the other hand, providing full coverage by community-based rehabilitation would in our example require an annual cost increase of only US \$1.78 per capita. Further, an attempt to calculate the time it would take to provide full coverage is made under the assumption that the expenditure for rehabilitation could be allowed to increase by 10% per year. It would then take 124 years to implement full coverage by extension of institutional rehabilitation, but only 11 years to reach full coverage by community-based care.

Section 7 (P-44) describes the process of formulation of a national policy aimed at promoting the development of community-based rehabilitation. It ends with a text that could be used as a guideline.

Section 8 (P-46) describes the role of organizations of and for the disabled. Organizations for the disabled can be found in many developing countries, but organizations of disabled are still relatively rare. The roles of present organizations in regard to fund-raising, project implementation, their role as pressure and promotion groups, and as providers of information are reviewed. It is pointed out that the organizations would benefit from increased representation of the consumers, i.e., the disabled themselves. It is also suggested that competing organizations be merged, or an umbrella organization formed. The organizations under such

an umbrella should seek a more active role in policymaking and planning, and their partnership should be sought by the government and local authorities.

Section 9 (P-49) describes the system for intermediate-level supervision and referrals. It is necessary to provide intermediate-level supervision by a professional with a broad experience in rehabilitation. It is also suggested that the present institutions be integrated into the system based on community rehabilitation by involving their specialists as mobile consultants. The institutions could then form part of a two-way referral system. Examples of referral services are provided. The involvement of the institutions would lead to their re-orientation and a longer perspective to their upgrading, and to new roles for their professionals.

Section 10 (P-53) provides a summary description of how a plan and programme for community rehabilitation can be formulated. Various steps are described, utilizing background material and guidelines from all the preceding sections. This is more or less aimed at the "professional planner". In this section detailed plans regarding the implementation and development of an organizational structure are provided.

Section 11 (P-62) gives a more simple description of how to set up, develop and upgrade a community-based rehabilitation programme. The final steps suggested describe an ideal situation, where the community-based services form the backbone of all other rehabilitation, with appropriate supervision, training of family members and referrals being fully implemented.

Annex I (P-67) provides the references and/or text of a number of useful international documents, such as the UN Universal Declaration of Human Rights and the UN Declaration on the Rights of Disabled Persons.

Annex II (P-73) provides a suggested curriculum for local supervisors.

The "Guide for Local Supervisors" is a self-training manual, to be used by persons selected for this job in a village. The material in the Guide can also be used in connexion with a formal course, as suggested in the curriculum in Annex II of the previous Guide (P-73). The "Guide for Local Supervisors" first describes the aims of training (LS-1): to help the disabled lead more normal lives, to train them to move around and to look after themselves and to arrange for children to go to school and adults to work. It also points out that the disabled should participate in family and community activities. The role to be played by the local supervisor includes locating the disabled and identifying those who need training, assessing the disabled and selecting the appropriate Booklets and training packages for each of them, finding and teaching a trainer for each disabled, guiding, supervising and motivating the trainer, involving the community in the training programmes, keeping records and referring persons who need other services (LS-2).

Then follows a detailed description (LS-3) of how to recognize the various disabilities with which the Manual deals. This helps the supervisor in the "diagnosis of disability", and also helps him/her to understand in simple terms the underlying condition. It also describes changes in behaviour that may be seen in disabled persons (LS-14). Page LS-15 provides a simple list of tasks that a disabled person may not be able to do and page LS-16 tells what can be done in general terms to improve the life of the disabled.

The next part of the Guide (LS-17) gives detailed instructions on how to use the Manual. Various steps are given on how to use the Booklets and

the training packages. There is also a description regarding the three other Guides.

It is desirable that the local supervisor be able to undertake a simple house-to-house survey in order to identify the disabled (LS-20). This includes mapping the village, making a list of household members and meeting each of them and asking questions in order to find out whether there is any disability.

Once the disabled have been located, the local supervisor will identify those in need of training. Instructions on how to proceed to the correct Booklet and training packages are given (LS-24). A trainer for each disabled should be identified and properly instructed (LS-27). A record should be kept (LS-30) regarding each disabled in order to facilitate the follow-up. The respective roles of the community (LS-31) and teachers (LS-32) are then described. Any system for community care will need referral services (LS-33). Reasons for referral are provided.

Finally, there is a general review of how a programme for the disabled can be run in the community (LS-36) and how rehabilitation can help the disabled (LS-37). Advice is then provided regarding the field testing of the Manual (LS-38) and an evaluation sheet ends the Guide (LS-39).

The annexes of this Guide provide a review of what should be kept as records (LS-41), material regarding the house-to-house survey and records regarding the work of the local supervisor (LS-43).

The "Guide for Community Leaders" starts with information on the definition of a disabled person and describes the aims of the community rehabilitation training (C-1). The community-based rehabilitation programme is explained, including the roles of various persons in the community involved in the programme such as the local supervisor and the school teachers (C-2).

Then follows a review of the most important community services of a general nature which should be provided to everyone, including the disabled, such as health care (C-3), safe water supply (C-4), safe disposal of excreta and wastes (C-5), improved nutrition (C-6) and hygiene (C-7). The need for schooling is stressed and some advice given when there is no school (C-8). The importance of disabled children attending school is stressed (C-9). The role of the community to provide jobs is then reviewed (C-11), as well as various occupations in which disabled persons can be employed, such as in food production, utility cottage industries, handicrafts and community services. It is also stressed that the community may take responsibility to provide loans for disabled who need some money to start a job (C-14). Safety measures at the job are then described (C-15).

It is pointed out that disabled persons should participate in social activities in the same way as persons without disabilities (C-17). Community leaders should see that the disabled are always included in community meetings, voluntary organizations, religious activities, traditional meals, etc. If qualified, they should be allowed to be elected to various positions in the community. It is pointed out that disabled and elderly should not be separated from their families by sending them to or building institutions (C-18). The importance of communication as a responsibility for everyone in the community is pointed out and useful examples of sign and picture language are given (C-21).

The "Guide for Teachers" is aimed at the local primary school teachers. It describes how schooling can be given to disabled children within the

ordinary community school. It starts with information to define disabled children, and the aims of the training programme in the community (T-1). There is a review of the reasons why disabled children should attend school, such as learning how to get along with others, developing normal relations and forming friendships with other children in the community and learning how to belong to a group (T-3). Even if the academic results prove less satisfactory with some of the children, they should for social reasons get the same opportunity as other children. The Guide also recommends that there be schooling for adults and that disabled adults should participate (T-4).

The Guide then provides advice on how disabled children can get to school and back (T-4) and gives some general advice regarding activities for school children in which disabled children can also participate (T-5).

Then follows detailed advice regarding the schooling for each of the various groups of disabled covered in the Manual (T-11). It is suggested there could be voluntary helpers from the community who could assist, for example, the blind children by reading books at home, helping those with mobility problems to get to and from the school, and taking over some of the children for special classes whenever disabled children cannot participate in a school activity. The Guide ends with useful examples of sign and picture language (T-24).

Six Booklets follow the four Guides. They are "Booklet for Persons Who Have Fits" (F), "Booklet for Persons Who Have Difficulty With Hearing and/or Speech" (HS), "Booklet for Persons Who Have Difficulty With Learning" (L), "Booklet for Persons Who Have Difficulty With Moving" (M), "Booklet for Persons Who Have Difficulty With Seeing" (SE) and "Booklet for Persons Who Show Strange Behaviour" (SB). All six Booklets are arranged in the same way. The first five contain material for both children and adults, the last one for adults only.

Each Booklet begins with a set of instructions for the local supervisor on how to use the training packages in the Booklets (F-1, HS-1, L-1, M-1, SE-1, SB-1).

There are a total of 49 training packages in the Booklets. Each of them provides a description on how to proceed with the training. This description is for whoever will undertake the training - family members, a friend of the family or the disabled themselves. Very simple language and simple drawings have been used. Each training package is broken down into small components, none of which require professional knowledge or skills unless under very special circumstances (then the referral services should be used). There is provision for evaluation of each disabled by a set of simple questions regarding the state of the disabled at the beginning, during and end of the training. Finally, as this Manual is an experimental edition aimed at field testing in developing countries, there are questions related to the evaluation of the various Booklets and training packages.

Some of the training packages are common to several of the Booklets. These will be described first. Then follows a review of the training packages which are different in the different Booklets.

The first five Booklets have a training package related to breastfeeding (F-13, HS-31, L-3, M-5, SE-11). This is to encourage the use of breastfeeding for disabled infants and children who may otherwise be neglected. It is explained why the baby should be breastfed, how often and also how to hold and feed the baby. Advice regarding cleanliness is included.

In the first five Booklets there are also training packages related to play activities (F-21, HS-39, L-33, M-13, SE-19). First in each of them comes a simple review of how children develop. This serves to identify the stage to which the child has developed (regardless of whether the development is normal or retarded). Play activities are used for children as a means of developing their abilities. There is a description of how to choose the appropriate activity in order to start the training of the disabled child at the appropriate stage.

Next follows in the first five Booklets a training package related to schooling of children with various disabilities (F-65, HS-103, L-77, M-217, SE-83). It includes advice for the family members regarding the usefulness of schooling all disabled children within the framework of normal primary schools. Other advice, aimed at the local teachers, is provided in the "Guide for Teachers".

In all six Booklets there are training packages regarding social activities (F-71, HS-109, L-85, M-223, SE-91, SB-19). It is explained that the disabled should as much as possible take part in family and community activities. Every disabled should play his/her normal role as an active member of the family and community and not be excluded. The disabled can often perform a majority of all such normal duties, and will be better accepted if this is encouraged. Also, the other family and community members will benefit from the contributions of the disabled. Disabled may also take responsibility in such activities as village councils, religious committees and school boards. They could, along with interested community members, form an advisory group to deal with the problems related to the disabled in the community.

The next training package common to all six Booklets relates to the daily tasks of rural women (F-77, HS-115, L-91, M-229, SE-99, SB-25). Many disabled women can perform most of these tasks. Parts of this training package deal with cleanliness, cooking, fetching water and firewood, growing vegetables, pounding, grinding and sieving grain, taking care of children, sewing, washing clothes, cleaning and repairing the home. As much as possible, disabled women should be trained to do every task they would normally do.

Another training package common to all Booklets is related to job placement (F-91, HS-129, L-105, M-243, SE-113, SB-39). Most disabled today are idle because it is generally believed that they are unable to work. However, many disabled can be trained to do useful jobs and can thus contribute to the family and community in the same way as everybody else. The package gives reasons why a disabled should work and gives advice regarding the choice of jobs (including food production, utility cottage industries, handicraft industries and community services). How to select an appropriate job for a disabled person and then train him/her is described. Sometimes it may be desirable to help the disabled person with a community loan in order to start a job. Safety measures for the various disabilities are described.

In each of the Booklets there are specific training packages relating to each disability. The Booklet for training of persons who have fits contains a training package on how to deal with a fit and train the disabled to look after himself/herself (F-3). There are simple suggestions regarding the use of medicines for some persons with fits, how to identify a fit and what to do when a person has a fit. There is also specific advice regarding a number of safety measures aimed at protecting the person with fits from accidents.

The Booklet for the training of persons who have difficulties with hearing and/or speech contains two specific training packages regarding communication. The first describes the training that can be given a child who is born without hearing and/or speech (HS-3). There is a general description of language development. Then follows the suggested steps related to the development of alternative means of communication, such as lip reading, drawing, writing and reading, picture language and sign language. The second package dealing with communication concerns a person who has lost the ability to hear or speak (HS-83). It contains the same elements but is more geared to the needs of older children and adults. In both of these packages, it is encouraged that not only should the person with difficulties with hearing and/or speech try to find the best possible ways of overcoming the disability or compensate for it by using every possible other means of communication but also that other persons in the village learn how to communicate with them. Further explanations regarding the specific roles of the community leaders and teachers in this context are given in the Guides.

The Booklet for the training of persons who have difficulty with learning contains one special package, dealing with training in looking after himself/herself (L-11). After some explanations of the development of children who have learning disabilities, there are detailed descriptions of how a child can be taught an activity, e.g., drinking, eating, washing, dressing, using the latrine. The activity must be divided into very small steps, each of which will be taught separately until the child knows how to do it.

The Booklet for the training of persons who have difficulty with moving contains ten specific training packages. They deal with the various mobility problems in different parts of the body, how to strengthen weak muscles (M-57, M-103), how to overcome pain in joints (M-205), and what to do with persons who have no feeling in hands or feet as the result of leprosy (M-175, M-193). The packages also describe training in daily life activities (M-69, M-85, M-95) and give various steps in mobility training (M-123, M-137). The packages describe a number of aids, e.g., for walking, that can be locally produced in the village.

The Booklet for the training of persons who have difficulty with seeing contains three specific packages. The first one deals with mobility training of children under age 4 (SE-3), the second with similar training for children above age 4 and for adults (SE-63). The third package describes specific activities that can be used to train in looking after themselves (SE-75). How to use the blind stick is described.

The Booklet for the training of persons who show strange behaviour contains one special package on how to train the family to deal with this type of disabled person and how to train the disabled to look after himself/herself (SB-3). Family members are encouraged to understand that strange behaviour is part of an illness. If appropriate, the disabled should take medicines to reduce the symptoms of the disease. Specific advice is given regarding what the family members can do to cope with the various symptoms. The trainer is also encouraged to activate the disabled to perform all common daily activities, including eating, drinking, washing and keeping clean, using the latrine and simple household activities.

Some of the Booklets also contain stories (F-109, M-259, M-265, SE-129). These tell a typical story about what happened to a particular disabled. They are meant to be told to both children and adults to help change their attitude toward disabled persons and to increase their understanding that something can be done for most disabled to improve their lives. Teachers, parents or a local storyteller can use the stories.

SUBJECT INDEX

This index is for users of the Manual to help them find a subject they are looking for but it is not intended for family members involved in the training of the disabled.

Thus the index contains words such as 'arthritis' which are not actually mentioned in the Manual, but the page number refers to the place where, for instance, training of persons with joint pain and stiffness is dealt with. The final version of the Manual might not include an index at all, unless reviewers express the opinion that it is valuable. Instead, there might be a need for a glossary explaining some of the most important terms of the Manual. It is not clear at this time if such a glossary is needed or whether the simple definitions given in Part A are sufficient.

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SEE ALSO Job placement

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