



REPORT OF THE CONSULTATION ON DISABILITY PREVENTION
 AND REHABILITATION IN LEPROSY

Geneva, 9-11 March 1987

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1. INTRODUCTION

Leprosy is considered with fear by the general public and with concern by the public health authorities, largely because of the deformities and disabilities (which can be crippling at times), that are observed in a proportion of leprosy patients. Leprosy control programmes all over the world are an expression of this concern. Those who contract leprosy may be handicapped because of disabilities and also because of the stigma attached to leprosy. Disability, "dehabilitation" and destitution of the badly crippled and rejected patients perpetuate the prejudice against leprosy and thus there is a great need to prevent disabilities and to rehabilitate disabled leprosy patients both from a humanitarian aspect as well as to demonstrate the successful leprosy control programmes.

Primary prevention of disabilities by diagnosing the disease at an early enough stage and treating it adequately and properly is still the best strategy. However, leprosy patients need additional help as antileprosy treatment to prevent deformities and disabilities resulting from damage to eyes and nerves and to prevent ulceration, wounds, cracks and joint stiffness in those who have damaged nerves. Enough knowledge is already available which, if applied, can prevent disabilities in a substantial proportion of leprosy patients. Permanent or long-term institutionalization of leprosy patients is not the solution to this problem and is in fact counterproductive in the long run as it perpetuates the hideous image of leprosy. Such a solution, if implemented, should be reserved for the severely incapacitated patients only.

Expensive and difficult methods to correct deformities, alleviate disabilities and rehabilitate patients can be avoided to a large extent by the community based rehabilitation approach; nerve damage, eye damage, and damage to insensitive extremities can be prevented by low-cost strategies. Similarly, by this approach effective rehabilitation of the affected patients can be achieved locally, through mobilization of support from the patients' families and local community.

At present, few leprosy control programmes are structured to carry out the tasks involved in disability prevention and rehabilitation. Incorporation of these necessary tasks in the programme will require new inputs at administrative and organizational levels and in the working pattern at the peripheral level.

In view of the above, the leprosy unit of WHO organized a consultation meeting during 9-11 March 1987 to develop optimal approaches for the prevention of disabilities and rehabilitation of leprosy patients within the community. The meeting was opened by Dr S.K. Noordeen, Chief of the Leprosy Unit, who outlined the background to the consultation and its objectives. The objectives of this meeting were:

1. To review the state-of-the-art on disabilities in leprosy and their prevention.
2. To identify practical and cost-effective methods for disability prevention as part of leprosy control.
3. To develop strategies for implementing cost-effective disability prevention and rehabilitation methods in leprosy through the community-based rehabilitation approach.
4. To develop training approaches so that disability prevention and rehabilitation components could be incorporated into leprosy control programmes.
5. To identify areas for research directed towards improving available technologies for disability prevention and implementing appropriate strategies for rehabilitation within the community.

3. BACKGROUND INFORMATION AND THE STATE-OF-THE-ART

Papers providing the necessary background information were presented by the participants. A summary of these presentations is given below.

In reviewing the global situation, Dr. Noordeen pointed out that reliable information on the number of disabled leprosy patients in different geographical situations was very limited and often incomplete. There were approximately 2 million leprosy patients with disabilities of Grades 2 and 3 and while there was some information on physical disability, there was little general information on the social handicaps of leprosy patients. He pointed out that disability rates depended on the criteria for classifying disabilities and on the denominator used. He suggested that total population, not patient populations, be used as denominators for calculating disability rates, since active cases in leprosy registers were likely to be relatively early cases and with multidrug therapy programme patients would be taken out of the register after completion of treatment. Absolute numbers, instead of rates and proportions of leprosy disabled, would also be needed. Lastly, Dr Noordeen pointed out that the intense prejudice against leprosy as well as its capacity to handicap patients, varied in different cultures and societies. The challenge was to develop methods by which the disability/rehabilitation component could be integrated into leprosy control programmes in the most widely applicable and cost-effective ways.

Dr H. Srinivasan reviewed Nerve Involvement in Leprosy and its consequences as events occurring at tissue level, patients' body level and at societal level. Of the five stages of nerve involvement at tissue level the later three stages of clinical involvement, reversible damage and permanent destruction of nerve trunks were significant to the patient and the clinician. Neural deficit in leprosy occurred insidiously and progressed gradually, and that was more common than its episodic occurrence and saltatory progression associated with attacks of acute/sub-acute neuritis. Destruction of dermal nerve twigs and cutaneous nerves resulted in autonomic and sensory paralysis in relevant areas. In addition, muscle paralysis with characteristic deformities and disabilities also occurred when nerve trunks were damaged. The patterns of nerve trunk involvement, damage and recovery were different. From a broader perspective, the consequences of nerve involvement were secondary impairments and consequent disabilities, from unprotected use of anaesthetic extremities, and motor paralytic disabilities relating to manual dexterity and locomotion. These led to a variety of handicaps affecting occupation, mobility, economic independence and social integration of the patients. In course of time, a proportion of patients became "dehabilitated". Some of them became completely alienated from society and ended up as destitutes. The different kinds of interventions that would be needed at the various stages to arrest the downhill course of the patients' situation were mentioned. Lastly, Dr Srinivasan pointed out that rehabilitation proper, especially in leprosy, was difficult, expensive and not always successful, and earlier interventions aimed at, (i) prevention of secondary impairments by proper instructions, practices and use of aids, (ii) prevention of disabilities by preventing destruction of nerve trunks, and (iii) prevention of handicaps and "dehabilitation" by "re-ablement" procedures were feasible and would provide maximum benefit to the greatest number of patients.

Dr Srinivasan, in his presentation on Physical Rehabilitation in Leprosy, defined physical rehabilitation as those interventions aimed at preventing handicaps of disabled patients, interventions which were also often needed as the first step to rehabilitate handicapped and "dehabilitated" patients. As the expertise needed was the same, the scope of physical rehabilitation extended beyond such "re-ablement" measures and included earlier interventions to prevent secondary impairments and those to prevent disabilities as well. Secondary impairments were anaesthetic deformities, like ulceration and contractures, that resulted from unprotected use of insensitive extremities. The patients at risk had to know how these deformities developed and learn to avoid them. Such patients needed to be identified, trained in self-care practices and supported with a supply of protective aids, of which protective footwear was the most important. Disabilities could be avoided by preventing permanent destruction of nerve trunks, although that posed difficulties as patients at risk could be identified only after some nerve damage had become evident.

However, if such patients were recognized early and treated adequately with steroids (supplemented by surgery and other supportive therapy) nerve trunks would recover and disabilities could be prevented in many cases. Recent studies suggested that sensibility of the sole could be restored by early surgical decompression of the posterior tibial nerve. "Re-ablement" measures included (i) surgical procedures to correct deformities and motor disabilities, (ii) sensory re-education of the hand, a technique that remained unexploited in leprosy, and (iii) healing and prevention of plantar ulcers. Dr Srinivasan concluded that it was technically feasible to help most leprosy patients by timely physical rehabilitation measures, but that would require new skills and facilities as well as restructuring leprosy control programmes which were mass programmes to provide individualized attention that disability prevention and rehabilitation demanded.

Dr Margaret Brand, in her presentation on Eye Complications in Leprosy, made the point that visual impairment was quite common in multibacillary cases and that patients with insensitive extremities became hopelessly crippled when they developed loss of vision. Exposure and inflammation were the two major factors contributing to ocular pathology and loss of vision. Exposure of cornea and related problems were to be found in patients with weakness or paralysis of eyelid muscles and insensitivity of cornea. Inflammatory problems of the eye were associated with ENL phenomenon which could occur as a low grade process and remain painless, though causing progressive impairment of sight. While corrective medical and surgical treatment could improve vision in a proportion of these patients even after significant impairment, that would require the services of ophthalmologists with experience or interest in leprosy. Dr Brand stressed the importance of identifying ocular involvement early and treating it at that stage itself, and discussed the methods of treatment. Lastly, she pointed out that early treatment was extremely effective and such treatment could pre-empt the need for later, expensive and difficult treatment by ophthalmologists.

Miss Jean Watson, in her presentation on Disability Prevention Methods Within Leprosy Control Programmes, stressed that while the disability prevention methods were well-known they were not being implemented. This was due to insufficient attention being paid to recognizing patients at the time of onset of decrease in nerve function and organizing steroid treatment, lack of planned attempts to provide protective footwear to all patients with plantar insensitivity, and inefficient teaching and lack of planned training of patients to take proper care of their anaesthetic extremities to avoid wounds, cracks and stiffness and to get their wounds healed promptly. For more effective prevention of disabilities, the following were suggested: (1) Improved management; (2) setting specific, measurable disability control objectives; (3) improved team work; (4) adoption of a disability-oriented recording system; (5) paying greater attention to preventing endangered nerve function; (6) improvement in the provision of footwear and other aids, and (7) improvement in the standard of training of patients in life-long self-care to avoid wounds and cracks and their complications and joint stiffness. Miss Watson then briefly discussed the measures that could be taken to achieve the above.

Dr Thylefors gave a brief resumé of the WHO Programme for Prevention of Blindness which was established in 1978 to take action against the growing problem of preventable and curable blindness in many developing countries. More than 90% of the blind lived in developing countries mainly in poor and remote areas. Blindness due to leprosy has not yet been listed among the major causes of visual loss which included trachoma, cataract, xerophthalmia, onchocerciasis, trauma and glaucoma. In recent years the concept of "Primary eye care" implying a range of simple activities by trained personnel at the community level, taking into account local needs and priorities and based on available resources, has been developed. These activities included recognition and treatment of certain simple disorders like trachoma and conjunctivitis, referral of some others, (e.g. superficial trauma) after recognition and initial treatment and referral of the rest without further action. Leprosy could also be included in primary eye care scheme if simple criteria and guidelines were worked out. Training aids and educational material addressing the various levels of health personnel involved in leprosy control would be needed and could be developed relatively easily. Dr Thylefors concluded by saying that national programmes for prevention of blindness were being implemented in some 50 countries and that opportunities for collaboration and co-ordination of activities should be sought between those programmes and leprosy control programmes.

Dr S.D. Gokhale gave an overview of Disability and Leprosy with special reference to social and vocational rehabilitation. He pointed out that leprosy patients had problems of the disabled worsened by the stigma of leprosy. He stressed the need to expose the community to well-planned information campaigns to dispel the ignorance surrounding leprosy and the disabled. That had to be coupled with successful physical rehabilitation measures, to get the deformities corrected and to make the patients able again, as well as effective use of social work techniques like case-work and counselling. Counselling should be non-judgemental and non-directive and aimed at helping the patient to accept the reality and to realize his or her inner strength needed for rehabilitation. Counselling was also aimed at the community to recognize the needs of the patient and assist the patient. Planned vocational rehabilitation would also be needed in some instances. Dr Gokhale then described the work of the Gandhi Memorial Leprosy Foundation in the area of changing public attitude and community behaviour.

Dr Maria Leide Oliviera, in her presentation on Priority for Rehabilitation with a Leprosy Control Programme, pointed out that rehabilitation was neglected in many leprosy control programmes. The rehabilitation process needed an integrated information feed-back system enabling patients to be attended to at the local level, and, as and when necessary, to be referred to regional or central levels of medical care/services. Rehabilitation also needed various actions at these three levels. Teaching and training patients with anaesthetic extremities and paralytic deformities in self-care, treatment of simpler plantar ulcers, and provision of protective footwear, and protection of eyes and nose could be done at local level. More complex means of prevention of disability such as corrective surgery, physiotherapy and provision of more sophisticated footwear could be undertaken at regional and central levels. The most complex means of rehabilitation, i.e. vocational rehabilitation, would have to be undertaken at regional and central levels. Lastly, Dr Leide de Oliviera stressed the need to find strategies for carrying out such a programme and the need for proper communication and meaningful dialogue between leprosy control programmes and the other departments and organizations engaged in social welfare programmes.

Dr Helander, in his presentation on Community-based Rehabilitation, mentioned that 7% to 10% of the world's population consisted of people who had disabilities and suffered adverse consequences in their daily life. Disabled children had the lowest survival rate of any group of children and the surviving children had almost no access to schooling. Disabled adults found it very difficult to earn a living and had practically no influence on the services set up for them. A substantial amount of money (about US\$200 million) was being spent on services for the disabled. However, 98% of the disabled still had no access to those expensive services which were concentrated in institutions making use of highly trained professionals. In order to better meet the needs of the disabled, WHO has launched the community-based rehabilitation programme built on community and family resources, using simplified yet effective technologies on the same principles as the primary health care programme training packages carrying simple instructions showing family members and others like teachers how to train a disabled person have been designed and they were being distributed by primary health care workers and volunteers. The programme has been introduced in about 50 countries and many non-governmental organizations were becoming increasingly involved in it. Dr Helander concluded by saying that in 1985 only 2 to 3 million disabled persons were given rehabilitation services and that a large effort would be needed to better organize and expand community-based programmes so that the needs of most of the 150 million disabled persons expected by the year 2000 could be met at least by the year 2010.

Mrs J. Santos Valdez, in her presentation, described the Community-based Rehabilitation System (CBRS) programme at Negro, Occidental, Philippines. This programme started in a small way in the poorest part of Bacolod City and now covered four towns and cities comprising 34 villages with a population of 154 000. Initially the local supervisors, who were trained volunteers, were mostly mothers from large low-income families. Later, primary health care workers were involved as local supervisors, particularly in the rural areas. Disabilities of mobility, seeing, hearing, speaking, learning, fits, loss of feeling in hands and feet and strange behaviour were covered by the project. Community preparation, training of family members and local production and development of appropriate aids were some of the features of the project. The programme focussing on developing local

initiative and resources, self-help and self-reliance found acceptance and encouragement from the government as well. Mrs Santoz Valdez concluded by saying that in this project CBRS had proved to be a simple, low-cost, yet effective means of bringing basic and essential services to the disabled in poor and rural areas.

Dr W. Felton Ross discussed Training of Health Workers and Community in Rehabilitation. The purpose of training was to create a cadre of competent and motivated persons to perform specified rehabilitation tasks in a given context. He outlined the managerial process involved in developing a rehabilitation manpower system and warned against overloading the community health worker with unrealistic, unmanageable and irrelevant tasks. There was also the need to train the community rehabilitation workers to some degree, at least in the many different aspects of the rehabilitation process. He emphasized the importance of a supervisory system which was often neglected in practice, as well as the need for good pre- and post-training assessments in order to improve the learning process and to ascertain that the trainees had attained competency to carry out the tasks for which they had been trained. Dr Felton Ross concluded by pointing out that what mattered most was the relevance of training to the needs of the people with disabilities and the success of the workers in helping the disabled persons in their community achieve the maximum quality of life.

Dr Patricia Rosenfield, in her presentation on Social Science Research in Relation to Rehabilitation, stressed the need for understanding the social, psychological, cultural and economic conditions influencing the ability of patients, including the rehabilitated ones, to function effectively in their communities for the development of appropriate rehabilitation programmes. The reality surrounding the restoration of a leprosy patient to his or her "proper condition" and "normal life" was complex and required detailed understanding for developing viable rehabilitation programmes. There was a need for social and economic research focused on the patients' environment, existing services and the level of motivation of the users and the providers of the services, as well as on social and economic costs including the time demands on family members, associated with the use of services. The WHO meeting at Kuala Lumpur in 1981 on Social and Economic Aspects of Leprosy had identified certain areas (social environment, cultural environment, patient environment, health worker and economic environment) as of general importance for studying leprosy in a given community. These areas were equally relevant for studying problems of rehabilitation within leprosy control. Dr Rosenfield concluded by saying that the strategy would be: (1) to encourage communities to identify and undertake priority tasks which were within the community's abilities and were likely to succeed; (2) Not asking communities to undertake tasks which could not be completed or maintained financially; and (3) the rehabilitation programme to be built upon social structures already existing in the community.

The participants then formed two groups; Group I to suggest strategies for preventing and limiting disabilities, and Group II to suggest strategies for rehabilitation. The group reports were fully discussed in detail by the participants and finalized. These reports are given below.

3. PREVENTING AND LIMITING DISABILITIES

The goal of of the disability prevention programme in leprosy patients may be defined as: NO DISABILITY TO OCCUR IN THE LEPROSY PATIENT APART FROM THAT FOUND IRREVERSIBLE AT THE TIME OF DIAGNOSIS. Preventing and limiting disability has two objectives: (1) to prevent the occurrence of new disabilities; and (2) to prevent worsening of existing disabilities. Appropriate preventive actions may be taken at home by the patient and the patient's family members, with suitable help and guidance from the health/leprosy worker, and that by itself may often be sufficient to prevent the onset and worsening of disabilities. However, there will also be situations where such simple home attention may not be sufficient or adequate and in many of these cases the peripheral clinic may be able to provide the necessary support and treatment to prevent and arrest disabilities. For more serious or more complicated conditions, referral for specialist or higher level medical care will be required. The remarks presented below are confined to what was needed

to be done at the home level and at the clinic level for preventing the onset and worsening of disabilities. It must be emphasized that for such a programme to be fully successful, the peripheral clinic should be backed up by referral centres or facilities for higher level medical care.

In practical terms, the objectives of a disability prevention programme are:

- (1) To save nerve function and prevent permanent nerve damage;
- (2) To prevent deformities occurring in anaesthetic and weak extremities by unprotected use and neglected wounds; and
- (3) To save the patient's sight and prevent blindness.

The actions needed for achieving these objectives are different and therefore they were discussed separately. However, the following are common for achieving any of the above objectives:

- (a) Identification of patients at risk before the deformities/disabilities have occurred/worsened;
- (b) Keeping baseline records of disability status for future comparison;
- (c) Appropriate training of patients and their supporters in the family in self-care and disability preventive behaviour; and
- (d) Frequent monitoring of the patients at risk to assess the effect of advice/treatment and for taking decisions regarding further action.

High risk patients

Patients at high risk of developing permanent nerve damage are:

- those with partial/incomplete neural deficit;
- those with recent, complete neural deficit (recent = up to 12 to 24 weeks);
- those with acute/subacute neuritis with very tender nerve trunk;
- those with multiple nerve trunk involvement;
- those with borderline leprosy;
- during the first 12-18 months after initiation of treatment;
- women patients during pregnancy and after delivery.

Patients with sensory loss - especially inability to appreciate pressure, pain or heat - in the palm or the sole of the foot are in danger of developing ulceration and deformities. Patients with very dry skin are in danger of developing cracks, ulceration and stiffness of joints. Patients with muscle weakness in the hand and ulceration are also in danger of developing stiff joints.

Patients with history of eye problems, those who are unable to close their eyes properly and those with corneal or pupillary abnormalities are in danger of developing serious problems in their eyes which may lead to loss of vision.

Assessments

The risk status of the patients must be assessed at the beginning of the disability prevention programme and those found to be at risk must be identified as such in their charts and registers. Specific actions such as teaching the patient in preventive measures, treating treatable conditions, providing protective aids (e.g. footwear, eye shields etc.) and referring for higher level advice and treatment must be undertaken after assessment.

The risk status of every new patient must also be assessed and baseline records on sensory status, visual acuity and strength of muscles of eyelids, fingers and feet, must be made for future comparison. Baseline records must also include information on duration of nerve function loss, ulcers etc. (A sample baseline record is given in Annex A).

Reassessments

Reassessment regarding risk status and disability status should be done at every clinical assessment during the period of treatment and surveillance. Patients at risk must be instructed at the beginning of treatment about danger signals and self-care and to continue to look for danger signals and practice self-care even after completion of surveillance and removal of their names from the register.

Patients completing surveillance and have been removed from the register must be instructed about where to seek help when they notice danger signals.

Ready recognition of those needing attention (high risk patients) can be made possible by using a system of codes (e.g. a red tab with indication of endangered sites attached to their charts and against their names in the registers).

Actions Needed

In order to prevent the onset and worsening of disabilities specific actions will have to be taken (i) by the patient in his home, and (ii) by the health worker/clinic staff at the peripheral health centre/leprosy clinic. The objectives of actions at home are:

1. To recognize and report onset of nerve damage without undue delay;
2. To recognize and report and treat eye pathology at onset, without undue delay and save sight;
3. To prevent wounds, cracks and stiffness of joints; and
4. To get wounds healed early.

The objectives of actions at the clinic by the health worker area

1. To recognize patients at risk of developing nerve damage, eye damage and worsening of disabilities;
2. To train them in life-long self-care activities;
3. To treat treatable conditions;
4. To refer those who need to be referred; and
5. To monitor the patients that they are practising self-care activities properly.

The kind of tasks that need to be carried out at home and at the clinic for the above purposes are listed in Annex B.

Note on Disability Grading

The current system of classification and grading of disabilities in leprosy patients, in use since 1976, was considered unsatisfactory from many points of view and Group I was asked to examine this issue also and suggest improvements. This was done and the subject was further discussed in the final plenary session. A summary of the points discussed and agreed upon is given below.

1. The type of classification and grading of disabilities/deformities depended upon why such a classification or grading was required and how the information obtained was proposed to be used. No one system of classification will meet the needs of the epidemiologist, the clinician and the research worker.
2. Deformities and disabilities are the most important consequences of leprosy that contribute to the morbidity of the disease. The Health Authorities should, therefore, have general information on the disability status of the leprosy patients in a given area, region or country at a given time, for comparing the morbidity of the disease in different areas as well as for longitudinally assessing the impact of leprosy programmes on the morbidity in a given area.
3. Prevention and management of disability will require full information on the disability status of the patient, early recognition of any change in that status, ready remedial action and monitoring the results. That level of information will not be needed for assessing the morbidity of leprosy in an area. It will also be difficult to collect information in such detail and process it. The purpose of the health administrators will be served by having a simple system of classification giving only essential information.
4. A simple classification having three grades (0,1 and 2) is suggested for classifying the disability status. The basis of such grading is as follows; Grade 0 indicates no involvement, the part is essentially normal in structure and function; Grade 1 indicates that there is some involvement of the part, probably some disability and that the risk of severe disability/deformity or damage has increased very much; Grade 2 indicates that significant deformity/disability or damage has already occurred.
5. Based on the above the following classification and grading of deformities/disabilities involving hands/feet is suggested.

- Grade 0: Normal, no anaesthesia, no visible deformity or damage;
- Grade 1: Not normal, anaesthesia present, but no visible deformity or damage;
- Grade 2: Visible deformity or damage present.

Each hand and foot to be assessed and classified separately.

"Damage" includes ulceration, shortening, disorganization, stiffness, loss of part or whole of hand or foot.

It may be noted that the proposed grades 0 and 1 are the same as the existing grades respectively. However, the proposed grade 2 will include existing grades 2 and 3.

6. Eyes: A provisional three grade classification (Grades 0-2) was suggested along the following lines:-

- Grade 0: Normal, no eye problems, no evidence of visual loss
- Grade 1: Corneal anaesthesia or lagophthalmos or both, but vision apparently not affected
- Grade 2: Severe visual disability. Vision $< 6/60$, i.e. inability to count fingers at 6 metres.

7. In view of the fact that it is now the practice to discharge the patients after completing the limited duration of treatment with MDT and remove their names from the case register, the situation will soon arise when patients with disabilities will be excluded from leprosy statistics after completing treatment. This will give a false picture of the load to the community arising from the leprosy disabled. It is therefore suggested that the load of the leprosy disabled should be expressed in terms of the community, using the total population (not the population of leprosy patients in the registers) in the denominator.

4. REHABILITATION

Rehabilitation is an active process aimed at reducing the societal impact of disabilities and handicaps due to leprosy and at enabling the affected individuals to achieve economic independence, social integration and personal dignity.

About 20% of leprosy patients may suffer from physical disabilities and psychosocial handicaps and may be in need of some type of rehabilitation help and continuing medical care. Leprosy is unusual among disabling diseases in that the disabilities are often insidious on onset and progressive in nature. Unless active steps are taken to prevent deterioration, patients with relatively "minor" problems can progress to severe disablement. In addition, fear of and prejudice against leprosy is still widespread and as a consequence patients often suffer social rejection and handicaps.

The process of development of disability and handicap in leprosy has three major components:-

1. The disease itself with its direct and indirect physical effects;
2. The psychosocial reaction of the patient to the disease and the nature of the role adopted by the patient as a "sick" or "affected" person with effects on his or her personality, behaviour, social contacts and economic status; and
3. The attitudes and behaviour of the patient's family and society at large which also affect the patient's self concept, social concept, social contacts and earning power.

All these three components must be taken into account if efforts to rehabilitate the patient are to succeed.

There are two successive steps in rehabilitation of leprosy patients:-

1. Prevention of further deterioration in the patient's situation; and
2. Increase in the patient's level of economic independence and social integration until it reaches the normal level for his or her social group.

In principle, every leprosy patient who needs rehabilitation should receive whatever help that may be necessary to achieve Step 1 in its entirety. In practice, priority will have to be given to those most likely to deteriorate rapidly without help.

With respect to Step 2, priority should be given to those whose rehabilitation is most likely to be successful. This is particularly important at the beginning of a rehabilitation programme when it is essential to convince patients and public alike that leprosy patients can be rehabilitated.

Migrant patients who wander from community to community, often in organized groups, and cases already institutionalized present special problems and are not considered here. Only patients more or less permanently resident in a community have been considered.

Three interrelated basic strategies are recommended for rehabilitation of leprosy patients:-

1. Access into the medical system for continuing care through out-patient clinics;
2. Home care; and
3. Community based rehabilitation (CBR)

It is recognized that home care could be mediated through the medical system or through CBR. But it seems to us to be important enough to warrant separate consideration.

Contribution of the health services through the clinic

Most leprosy patients in need of rehabilitation are already in contact with the health services through registration at one or several clinics. Five objectives were identified for clinic action:

1. Cases in need of rehabilitation identified and categorized;
2. Action instituted to arrest patient's situation;
3. Links developed with local resources;
4. Clinic support of action by the family and community instituted; and
5. Patients likely to benefit from more complex rehabilitation measures referred to the appropriate service.

Contribution of the patient's home

The majority of even severely disabled leprosy patients still continue to be part of a basic family unit. As far as possible this relationship should be maintained. Many families undoubtedly find the presence of a disabled handicapped patient a significant economic and social burden, and programmes should give greater priority to family unit support than has been done so far.

Besides actions to meet basic human needs, three objectives were identified for the home:

1. Disabled person fully accepted as a member of the family;
2. Disabled person encouraged and assisted, if necessary, to practise daily self-care, and
3. Disabled person encouraged to function within the community in the most normal way possible.

Contribution of the community

Wherever CBR services or a fully developed community health care programme exists, most of the rehabilitation needs of the majority of disabled/handicapped leprosy patients can be met through community services provided the providers of the services have had appropriate training. Where the CBR services do not exist, or the community health care system is not developed, the leprosy clinic staff should be encouraged to take the initiative in stimulating the development of appropriate community based services. Special provision will also have to be made for providing protective footwear for leprosy patients with anaesthetic feet either through the medical or the rehabilitation system.

Four objectives were identified for community action:

1. Disabled persons fully accepted as members of the community;
2. Local community resources identified and made accessible to disabled persons;
3. Responsibility accepted for the development of additional resources for disabled persons; and
4. Disabled persons encouraged to participate in decision-making activities of the community.

The objectives, the action to be taken and the resources needed for community based rehabilitation of leprosy patients are given in Annex C.

5. RESEARCH

It was recognized that very little research was being carried out in the areas of nerve damage, rehabilitation and rehabilitation. The following topics were identified as suitable for research:-

- . Basic research on nerve and eye damage
- . Methods of recognizing, preventing and treating silent neuritis
- . Risk factors in nerve and eye damage
- . Cost effectiveness of different methods of wound treatment, including traditional methods, and other preventive measures like footwear
- . Process of stigmatization
- . Coping mechanisms of leprosy patients
- . Operational research on implementation of disability prevention and limitation
- . Measurement of social distance
- . Traditional methods developed by societies to cope with the problem of the disabled
- . Methods of estimating social costs of leprosy/disability/rehabilitation
- . Problems in integration of leprosy services into CBR/rehabilitation

6. RECOMMENDATIONS

This consultation meeting recommends that:

1. Leprosy control programmes adopt a systematic approach to prevent and limit disabilities as an integral component of the programme, with emphasis on prevention of wounds, preservation of sight and prevention of irreversible damage to nerves.
2. Community based rehabilitation to be adopted as the basic approach to rehabilitation in leprosy.
3. A manual on prevention and limitation of disability be developed for use in leprosy control programmes; and that
4. Research should be promoted in the following areas:
 - (i) Basic mechanisms involved in nerve and eye damage in leprosy patients;
 - (ii) Study of risk factors for nerve and eye damage and methods for their prevention, and
 - (iii) Social and economic factors that hinder rehabilitation of leprosy patients.

ANNEX A

THE BASELINE DISABILITY RECORD

SENSATION
Sensation tested by light skin denting at dot sites
√ = Feels within 3 cm
X = Does not feel

C = Clawed
☹ = Wound or open crack
— = Shortening level

RT Palms LT RT Soles LT

STRENGTH AND BLINK

	RIGHT		LEFT			
	Yes	No	Yes	No		
Blink problems?			Yes	No		
Light closure lid gap	mm		mm			
Little finger in	S	W	P	S	W	P
Thumb across and up	S	W	P	S	W	P
Foot up	S	W	P	S	W	P

SWP = Strong/Weak/Paralysed

NEURITIS CHECK

Sensation or strength change within past 6/12? Yes No

Nerve pain or tenderness? Yes No

If answering "yes", detail below.

ASSESSOR: JMW

COMMENTS: 4.4.85. Left foot: Sole sensory loss and leg weakness started 2 months ago, according to patient. Can pull foot up fully, but cannot resist at all.

- Where leprosy control planners wish to refer to a **deformity index**, a question suited to their purpose can be added to the form. Example: "Has the patient any visible deformity or open wounds? Yes/No."

PREVENTION OF DISABILITIES

I. LIST OF SPECIFIC TASKS

TASKS AT HOME LEVEL

To be carried out by the patient and helped and encouraged by family members and the health worker.

Objective 1: Recognize and report onset of nerve damage without delay: (Instructions for all patients).

Action: Report to health worker - change in sensibility;
- change in strength of muscles of eyelids, fingers and feet;
- occurrence or worsening of nerve pain.

Resources: Knowledge

Objective 2: Recognize and treat eye pathology at onset, without delay, and save sight: (Instructions are for "eye risk" patients).

Action

1. Check visual acuity of each eye separately, daily - by looking at a standard object from some standard distance, at the same time, every day.
2. Inspect eyes daily - in a mirror or by a relative - looking for redness, weak eyelids or other changes.
3. Report any problem like red eye, pain or dimness of vision to the field worker.
4. For those who already have weak eyelid muscles and so cannot close their eyes fully:
 - Strengthen lid muscles - opening and closing the eyes tightly 20 times at a time, three times a day.
 - Use tear substitutes (like methyl cellulose, polyvinyl alcohol, castor-oil, liquid paraffin or any other locally available emollient) in suitable containers that can be used even by those with deformed hands.
 - During waking hours - cultivate "think blink" habit, blinking as often as possible as a conscious act;
 - Not to rub the eyes even when they seem to itch;
 - Use tan coloured dark glasses to protect eyes against wind, dust impact, evaporation, etc;
 - Keep eyes clean and keep flies away from the eyes;
 - During sleep: keep eyes covered.
5. Comply with eye treatment advice without fail - family member to help patient.

Resources Tear substitute drops/ointments;
Eye shields;
Dark (tan coloured) glasses;
Information sheet regarding eye care.

Objective 3: Prevent deformities/problems in insensitive/weak hands and feet:
(Instructions to those with anaesthetic areas in palms/soles)

Sub-objective 3.1: Prevent wounds, cracks and stiff joints

- Action:
1. Inspect daily insensitive skin areas for dry or hard skin, and for cracks and injuries.
 2. Practice skin care daily: soak the part in water, rub off hard skin and apply oil.
 3. Practice exercises daily.
 4. Work out probable cause of past wounds and make practical plans to avoid repetition of similar injury.
 5. Use protective footwear and other necessary protective aids and appliances.
 6. Keep footwear in good condition and replace them promptly when they are worn out.

Sub-objective 3.2: Get wounds to heal early

- Action:
1. Recognize wounds and cracks early through daily inspection.
 2. Treat the wound/crack properly:
 - keep it clean,
 - cover it, and
 - rest the part - use walking stick if needed.
 3. Inspect daily to check that the wound/crack is healing. Report to health worker if it has not healed in a few days or if it worsens (as indicated by increasing redness, swelling or pus).

Resources:

- Protective footwear
- Protective gloves
- Tool adaptations if and as indicated
- Oil for skin care
- Soap, salt for skin
- Clean cloth dressing or adhesive plaster strips for wound care
- Walking stick (if indicated)
- Information sheets for care of insensitive hands and feet.

TASKS AT CLINIC LEVEL

To be carried out by health worker, to recognize, instruct, support and monitor patients at risk.

Objective 1: Save nerve function (in face, hands and feet)

- Action:
1. Identify high risk patients.
Make a special note in the record.
 2. Make a baseline record of location and extent of sensory loss, site and degree of strength loss and their duration.

3. Teach high-risk patients to look for and report any change in sensation or strength, and any nerve pain.
4. Refer (if necessary) those with recent (6 months or less) sensory or strength loss for proper medical advice and arrange treatment (usually steroid treatment will be required).
5. Assess high risk patients periodically for change in sensory or motor status.
6. When patient reports sensory or strength loss re-assess to confirm change.
7. When decrease in nerve function is noted carry out (or refer for) appropriate treatment (usually steroid therapy will be required, and other supportive treatment like splinting may also be needed).

Resources: Manual
Supplies
Equipment

Objective 2: Prevent deformities secondary to nerve damage

- Action:
- A. For those with anaesthetic extremities to prevent wounds and complications
 1. Identify those at high risk (those with anaesthesia of palm and sole, and those with history of repeated wounds and ulcers).
 2. Provide practical training and encouragement to the patient in his or her home care tasks.
 3. Ensure patient can demonstrate self-care tasks.
 4. Inspect periodically the anaesthetic palms and soles and the footwear of the high risk patient and assess patient's compliance with self-care instructions.
 5. Take appropriate actions to correct problems at early stage (problems like callous, wounds and dry skin) and teach patients how to recognize and take care of them.
 6. When patients report an unhealed wound, in spite of proper care, approve patient's action and provide appropriate advice/treatment.
 7. Provide crutches where necessary.
 8. Provide protective footwear and other appliances like drop-foot strap and other protective devices (e.g. gloves) as may be necessary.
 9. Instruct the patient regarding maintenance and repair of footwear appliance and aids.
 10. Have organizational arrangements for repair and replacement of the appliances/aids.

B. For those with muscle weakness to prevent stiffness of joints

1. Instruct simple exercises
2. Ensure patient has learnt them properly.
3. Periodically verify patient's compliance and that no stiffness is developing.

Resources: Supplies
Equipment
Drugs
Manual

Objective 3: Save patients' sight

Action 1: 1. Identify patients at high risk of loss of sight.

They are: - those with damaged cornea
- those with incompletely closing eyelids
- those with infrequent blink, and
- those with dangerous inflammation in the eye (signs: blurred vision with or without pain, redness around cornea, small pupil).

Patients with corneal breakdown and those with inflammation in the eye are in great danger of losing sight and need immediate treatment.

2. Instruct patient and family member about home care of eyes and ensure that they have understood instructions.
3. Verify that instructions are followed correctly.
4. When patient reports with eye problem examine the eye for corneal ulceration (actual and imminent) and eyelid function. If cornea is abnormal and eyelids do not close completely, (i) apply suitable antibiotic eye ointment, (ii) support lower lid with strips of adhesive plaster, (iii) protect eye with cone shaped shield and (iv) refer patient to persons trained in eye care for further evaluation and care.
5. When patient reports with painful red eye with small pupil refer patient immediately for treatment by trained personnel. If delay in treatment is envisaged, dilate pupil with a few drops of phenylephrine (2% or 3%), and protect eyes with shield.
6. When patient reports diminished visual acuity examine eyes for abnormalities of eyelids, cornea and pupil. If cornea and pupil are not abnormal apply wetting drops (tear substitutes). If there is no improvement after such applications, refer patient to trained persons for further evaluation, advice and treatment.

II. STRATEGY FOR PREVENTING AND LIMITING DISABILITY AND MANAGEMENT TASKS AT CENTRAL, REGIONAL AND LOCAL LEVELS

Reliable information on the size of the problem is not available for most administrative authorities. It is estimated that in the average control programmes, about 20% of leprosy patients are likely to have significant disability. It is therefore important that prevention and limitation of disability is incorporated as a matter of policy in the existing leprosy control programmes. The following points may be made in this context:-

1. Many patients suffer decrease in nerve function shortly before diagnosis or while receiving antileprosy treatment. Such decrease can often be arrested and reversed if recognized at an early stage and treated with steroids. This requires alert staff and informed patients.
2. Once the nerve is irreversibly damaged, the patient has a permanent disability of loss of sensibility with or without muscle paralysis and is in life-long danger of developing wounds and wound complications, skin cracks and joint stiffness. Such patients need to be trained in life-long self-care, and life-long use of protective devices including protective footwear.
3. The staff need to understand the reasons why patients fail to follow the advice given. For this they must be trained to listen to, observe, train and encourage the patients.
4. Much can be done at the peripheral level itself and much can be achieved by way of disability prevention and limitation at very little financial cost per patient using commonly available things like soap, oil, adhesive plaster etc. Of these, protective footwear is the most expensive item, but it is a relatively durable commodity. Here, it is important to make the best possible use of locally available resources and guide the patient to do likewise.
5. Effective prevention and limitation of disability requires the following:
 - Preservation of nerve function
 - Preservation of sight
 - Preservation of hands which are insensitive
 - Preservation of feet which are insensitive
 - Prevention of skin cracks
 - Prevention of stiffness of joints of fingers and toes
 - Early healing of wounds and cracks
6. In a busy leprosy control programme it may not be practical to attempt and implement action to achieve all the above simultaneously, all at one time. Priorities may need to be determined at national, regional and local levels to meet the problem step-by-step in a phased manner. In order to identify negative factors that hinder or slow down the disability prevention programme, feed-back information and incorporation of evaluation procedures are also necessary in this as in any other public health programme.

A broad outline of the strategy and management tasks involved in implementing a disability prevention programme within the leprosy control programme is given below.

TASKS AT CENTRAL LEVEL

1. Adopt disability prevention in leprosy patients as a policy.
2. Plan national implementation of the policy of disability prevention.
 - Identify agencies to carry out implementation
 - Establish priorities, determine timing, phasing and extent of coverage
 - Budget allocation and fund mobilization
 - Incorporate disability parameters in the information system (records, returns, etc.)
 - Plan appropriate task-oriented, competency based training programmes
 - Provide for interdepartmental collaboration where necessary.

TASKS AT REGIONAL LEVEL

1. Plan regional implementation of national policy and programme.
2. Specify responsibilities and tasks for all staff involved.
3. Arrange appropriate task-oriented staff training.
4. Ensure provision of supplies and equipment - budget, purchase, inventory, distribution.
5. Provide for production, distribution and utilization of adequate quantities of protective footwear - budget, design, production, distribution, prescription, utilization, repair.
6. Ensure access of patients to referral facilities.
7. Ensure that patients who already have peripheral nerve damage and have been discharged after adequate chemotherapy will have support facilities for obtaining footwear and for any other problem related to their disabilities.
8. Plan and implement appropriate supervision, evaluation and encouragement procedures.

TASKS AT LOCAL/CLINIC LEVEL

Ensure that the clinic staff are competent to carry out the following tasks:-

- 1.1 Plan clinic implementation of regional disability control policy.
- 1.2 Complete nationally agreed disability records and returns to an acceptable and agreed standard of performance.
- 1.3 Ensure provision of materials necessary for disability control - Indent, purchase, inventory.
- 1.4 Identify disability preventive actions needed for individual patients and ensure that these actions are taken.
- 1.5 Allocate specific responsibilities and tasks to all the clinic staff and train staff in these tasks.
- 1.6 Ensure that individual patients are given practical training in appropriate self-care procedures until they can correctly demonstrate them and actively encourage the patients to continue to practice these procedures thereafter.
- 1.7 Identify local sources and special needs of protective footwear (including repair of footwear).
- 1.8 Identify local sources of other protective devices.
- 1.9 Implement appropriate supervision and evaluation procedures.
- 1.10 Ensure that even after completion of surveillance, patients having peripheral nerve damage are familiar with support facilities for obtaining footwear and for any other problem relating to their disability.

COMMUNITY BASED REHABILITATION OF LEPROSY PATIENTS

AT CLINIC

- General objectives:
1. To arrest the process of debilitation
 2. To rehabilitate individuals already debilitated.

Sub-objectives:

Objective 1: Cases in need of help identified and categorized.

- Action 1:
1. Review all registered cases by interview and clinical examination and collect the following data:
 - (a) Disease type
 - (b) Clinical activity and disease status
 - (c) Physical disability
 - (d) Age
 - (e) Nature of existing problems
 - social relationships
 - changes in economic status
 - (g) Education and marketable skills
 2. All cases found to be in need of rehabilitation identified, categorized and given appropriate priority rating.

Resources:

- Clinical records
- Psychological/social/economic status assessment form
- Trained staff familiar with local milieu
- Time for staff to perform duties
- Rehabilitation need categorization and priority scale.

Objective 2: Action instituted to arrest the process of debilitation.

- Action:
1. Teach self-care to the patient and monitor his or her self-care activities
 2. Help patient to obtain suitable aids for self-care (including protective footwear) and daily living
 3. Counsel "family" group regarding giving appropriate support to the patient.

Resources:

1. Manual for self-care
2. Manual for patient and family counselling
3. Staff training
4. Time
5. Protective footwear (unless it is available through local resources).

Objective 3: Links developed with local resources.

- Action:
1. Identify, list and review all local resource groups, e.g., health education, sports, training, medical, non-governmental agencies, employers, religious and social groups, professional groups, shoemakers, CBR programme
 2. Establish contact with local resource groups
 3. Link patient in need of help with specific local resources
 4. Develop on-going information exchange with local resource groups

- Resources:
1. Training in community relations
 2. Local credibility of health worker
 3. Time

Objective 4: Clinic support of action instituted by the family

- Action:
1. Make a list of families to be visited and supported on a regular basis
 2. Regularly visit - to encourage family's efforts, to find out any problems and to work out solutions
 3. Record kind of support needed and actions taken

- Resources:
1. Manual on family counselling
 2. Knowledge and aptitude
 3. Time

Objective 5: Patients likely to benefit from rehabilitation services referred

- Action:
1. Select cases for referral (only after community resources are exhausted)
 2. Write referral letters
 3. Arrange referrals
 4. Follow up referrals

- Resources:
1. Trained staff with:
 - (a) knowledge of referral services (manual and local list of services)
 - (b) ability to use criteria for referral and make appropriate referral decisions.

AT HOME

Objective 1: Disabled person fully accepted as a member of the family.

Family action: Provide opportunity for the disabled person to perform activities and accept responsibilities normal for his or her age and position.

Disabled person's action: Accepts and carries out responsibilities and fully utilizes the opportunities provided by the family.

Resources: Counselling from health/rehabilitation worker
Support from the community
A handbook to reinforce the teaching given

Objective 2: Disabled person encouraged and assisted, if necessary, to practise daily self-care.

Family action: Work with the disabled person as he or she practise a self-care activities.

Disabled person's action: Practices self-care activities.

Resources: Knowledge of required self-care activities.
Manual of self-care
Knowledge of disease, symptoms and treatment
May need financial assistance for protective footwear, aids.

Objective 3: Disabled person encouraged to function within the community in the most normal way possible.

- Family action:
1. Encourage disabled person to undertake social activities normal for age and sex, e.g. play with other children, go to school, attend social functions.
 2. Interact with members of the community to provide opportunities for disabled person to participate in normal activities.
 3. Work with community leaders and health professionals to change negative attitudes of community members.

Resources: Knowledge of disease
Positive attitude
Support from health/rehabilitation worker
Credibility and standing of health/rehabilitation worker

BY COMMUNITY

Objective 1: Disabled person fully accepted as member of the community

Community Action:

1. Community leaders impart relevant information about:
 - What disabled persons can do and their problems (environmental and social barriers to normal life activities);
 - The causes and effects of specific types of disabilities commonly found in the community; and
 - The care and help that can be given at home and by the community.
2. Community leaders act as advocates for disabled person's interests through legislature, pressure groups and mass media.
3. Draw attention to what disabled persons can do to help themselves, e.g., "show" cases, sports.
4. Community leaders set personal examples of acceptance of the disabled person.

Resources: Technical information from clinic and health system
Mass media
Special skills/talents of community members
Funds raised within the community

Objective 2: Local community resources identified and made accessible to disabled persons.

Action by community leaders and "pressure groups":

1. Assist clinic staff to identify local resources
2. Assist clinic to build referral network through tapping key people in community having time, connections and money; and
3. Assist disabled person to recognize and take advantage of opportunities

Resources: Information from clinic
Manual
Interested people in the community
Outside "catalysts"

Objective 3: Responsibility accepted for the development of additional resources for disabled persons.

Action: By community leaders and support groups.

1. Explore possible ways to assist the disabled, e.g. local employment, cheaper locally made protective aids (including protective footwear), adult education, income generating activities.
2. Raise funds from within the community
3. Scout for outside funding to develop resources in the community
4. Develop CBR

Resources: Time, money, ingenuity
Information from national and regional levels
Local organization
Manual

Objective 4: Disabled persons encouraged to participate in decision-making activities of the community.

Action by community leaders and support groups:

1. Identify disabled persons already established in community
2. Invite disabled person to participate in community committees, e.g. in health developmental, social, administrative activities.
3. Encourage development of local associations to work for disabled persons.
4. Make available to the local association new and relevant information.
5. Strengthen the confidence of disabled persons and their families by encouraging their efforts.

Resources: Manual
Local people with interest and drive
Outside leadership

CONSULTATION ON DISABILITY PREVENTION
IN LEPROSY CONTROL PROGRAMMES

Geneva, 9-11 March 1987

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