

National Leprosy Eradication Program

Disability Prevention and Rehabilitation

1. Introduction

Health is defined as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

The disease control is defined as "reduction of the incidence and prevalence of the disease and of morbidity and mortality from the disease to a locally acceptance level as a result of deliberate efforts. Continued intervention is required to maintain the reduction".

The strategy to achieve disability prevention in leprosy comprises of three major elements:

- Early case deduction and adequate treatment (MDT)
- Prevention of leprosy related disabilities (POD), and
- Rehabilitation

However, disabilities still occur among treated patients in distressing frequency therefore, the immediate priority is the establishment of adequate services for POD. POD may be defined as 'a concept comprising all activities at individual community and program level aimed at preventing impairments, activity limitations and participation restrictions'. POD comprises the identification & management of reactions / nerve damage, the training of patient in self-care, counseling & ulcer care, provision of footwear & other aids and reconstructive surgery.

Early case detection and adequate treatment with MDT have been accepted universally as an important tool for prevention of disability.

In addition to these two fundamental components of the leprosy control strategy, rehabilitation of people with leprosy related disability is important. 'Disability' is defined as an umbrella term for impairments, activity limitation and participation restriction as a result of the interaction between an individual (with a health condition and the individual's contextual factors (environmental factors)). Impairments in leprosy are mainly concerned of loss of function of eyes, hands and /or feet. In its most serious form this may lead to blindness, chronic ulceration and other permanent deformities of hands and feet. Patients who are affected in this way are often stigmatized and even treated as outcasts by their communities and sometimes even by their family.

Common examples of activity limitations are difficulties in grasping objects due to hand impairments or difficulties in walking due to a foot drop / ulcer. Participation restrictions include problem experienced in relationship such as marriage or friendship, problems with employment or education and other forms of social exclusion.

2. Prevention of Disabilities:

During the course of disease, even during the Multi Drug Therapy (MDT), Leprosy cases may develop complications like lepra reactions, Ulcers on anesthetic parts, new nerve damage leading to paralytic deformities and absorption of fingers / toes. These complications are treatable and thus disabilities can be prevented. In integrated set up, services for Prevention of Disabilities (POD) are provided at 3 levels. First, at primary level (PHC, CHC, Dispensaries) reactions and simple ulcers are managed. Difficult cases, grade II disabilities and eye complications are referred to secondary level i.e. district hospital or temporary hospitalization wards. Those cases, which require investigations & surgery and cases which can not be managed at secondary level, are referred to tertiary care centers. To increase the accessibility of services, proper 'referral system' need to be strengthen. Improving performance of GHC staff, counseling of cases, supervision & monitoring of these services are integral parts of POD.

All Leprosy Affected Persons having physical disabilities need to learn & adopt self - care. Developing 'Self Care Groups' (SCG) to sustain the self - care practices is one of the priority. Attention is paid to develop SCG / SHG in leprosy colonies / Ashrams along with promoting 'Home Based Self Care'.

3. Rehabilitation:

The objective of rehabilitation is to facilitate equal opportunities for the people concerned to fulfill a role in the home and in the society to enable them to optimize their quality of life. The UN defines rehabilitation as "all measures and at reducing the impact of disability for an individual, enabling him / her to achieve independence, social integration, a better quality of life and self-actualization".

3.1 Comprehensive rehabilitation:

Over the last years more and more attention has been paid to physical rehabilitation of leprosy affected person (LAP). However, to the affected person, limitation in daily activities and restriction in (social) participation are much important than impairments as such. How useful is reconstructive surgery if a person does not have a job or other meaningful work to go back to? Why provide protective footwear if a person has to earn a living with begging and can do so more effectively with visible foot-ulcers? If constructive surgery is done for cosmetic, stigma reducing reason, the underlying reason is often to improve social acceptance and integration. To enable a person to live a life with dignity and respect, a comprehensive approach to rehabilitation is needed. Successful POD and rehabilitation activities increase the credibility of services. This in turn promotes early self-reporting of new cases and better treatment compliance and thus contributes to the reduction of leprosy as a public health problem. Socio-economic rehabilitation, particularly vocational training and incoming generation, may be essential for POD (e.g. a change in agriculture method to protect damaged hands & feet). Appropriate and timely

rehabilitation will prevent people with leprosy related disabilities ending up on the streets and perpetuating the negative image of leprosy as a crippling disease leading to destitution.

3.2 Integrated Rehabilitation

The National Leprosy Eradication Program (NLEP) subscribes to the principal of integrating the rehabilitation of people with leprosy & related disabilities into general rehabilitation program. This does not mean that they will receive preferential treatment or better quality services, than people with other disabilities in the same areas. As leprosy control activities have now become the responsibility of multiple health workers in the general health services, in the same way rehabilitation of people with leprosy related disability should be integrated into general rehabilitation services. An integrated approach will help to break down stigma and enhance sustainability of rehabilitation services.

The interactions between the local community and the secondary & tertiary centers are mutually beneficial. The secondary & tertiary care centers get a feel for the ground realities, and the community gets the benefit of the knowledge & expertise of these centers. Together they can then evolve solutions that are relevant and appropriate for the community. In addition, linking with other community development programs, government & non government organizations will further enrich the rehabilitation programs and facilitate long term sustainability.

3.3 Institutional Based Rehabilitation (IBR):

Many people need temporary assistance by special services that are often institution based. Among this group are people requiring corrective surgery, physical and occupational therapy, orthoses or prostheses. Therefore, for successful implementation of rehabilitation services, a close co-operation between these specialized services and CBR programs should be promoted..

Government of India set up Rehabilitation Council in 1986 as registered society. There after this was converted to a statutory body under the Rehabilitation council of India Act w.e.f.31 July, 1993. This is under the administrative control of Ministry of Social Justice & Empowerment. There are 31 PMR (Physical & Medical Rehabilitation) institutes, 9 of them are being upgraded. 11 District Rehabilitation Centers are functioning in 10 major states. 4 Regional Rehabilitation Centers (RRC) are also functioning. The National Handicapped Finance and Development Corporation (NHFDC) has been incorporated by Ministry of Welfare, Government of India as a company not for profit. It extends loan to the persons with disability.

3.3.1 Physical Medicine & Rehabilitation Institutes:

Central council of health & family welfare (5th-6th) recommended setting up of department of Physical Medicine & Rehabilitation in all medical colleges. At present only 31 colleges have PMR department. 9 of them are being

upgraded to perform surgery also. Specific objectives in 11th five year plan are to upgrade and develop 2 apex PMR depts., to set up PMR in 30 medical colleges- one in each state. These PMR institutes will conduct training program for medical students in UG & PG level for medical rehabilitation, train 200 district level specialists on disability assessment, prevention of disability, CBR and to provide medical rehabilitation services at all levels of health care delivery system. Planning commission has taken a positive view on the proposed scheme under the “centrally sponsored main scheme new initiative, 2007-08” in 11th 5 year plan.

3.4 Community Based Rehabilitation (CBR):

Institutional rehabilitation provides excellent services to address the problems of individual disabled person and is often available only for a small number at a very high cost. Moreover, the endeavors in an institution are often out of context to the felt needs of the disabled person, and thus falls short of their expectations. In an institutional rehabilitation program, the community is not linked with the process. Hence, when the disabled person returns home, it may become difficult for them to integrate into their community.

Disability often requires life-long management, therefore, activities aimed at enabling people with disability should be community based as much as possible. Community Based Rehabilitation (CBR) is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. However, although most basic rehabilitation activities can be carried out in the person's own community. A multi -sectoral / multi-disciplinary concept of CBR is to be adopted. This concept emphasizes working with and through the community to create positive attitude towards people with disabilities, to provide assistance to people with disabilities and to make the necessary changes to the environment and service delivery systems. In response to this conceptual change, CBR is now defined as a community development program that has seven different components –

- I. Creation of a positive attitude towards people with disabilities
- II. Provision of rehabilitation services
- III. Provision of education and training opportunities
- IV. Creation of micro and macro income – generation opportunities
- V. Provision of long term care facilities
- VI. Prevention of causes of disabilities
- VII. Monitoring & Evaluation.

The resources, skills and initiative to start and sustain CBR program require the cooperation and collaboration of people with disabilities & their families, communities, governments, NGOs, medical professionals and private sector. CBR program must be flexible so that they can operate at the local level and within the context of local conditions

3.5 Networking in Rehabilitation

Comprehensive rehabilitation requires a wide range of services, from surgery and assisting devices to vocational training and micro-finance. No organization in the country can provide these services themselves. That's why networking plays a key role in rehabilitation. An effective network should include governmental, non-governmental, private and community based organizations. Organizations of people with disability and others who can be involved in political lobbying should also be a part of rehabilitation network.

Networking will also be of importance with other organizations involved in supporting rehabilitation. NLEP has long partnership with many ILEP agencies involved in similar work. The department of social justice and empowerment, Government of India has taken up several initiatives for rehabilitation of people living with disability. Recognizing the importance of networking, Central Leprosy Division (CLD) will make these key components of its rehabilitation policy.

3.6 Activities to be undertaken

Comprehensive rehabilitation would include services for prevention of impairments, promotion of self-care, provision of assisting and protective devices (e.g. wheel chairs and prostheses), physiotherapy & occupational therapy, counseling, formation of self-help groups, corrective surgery, vocational training, inclusive education, literacy, micro-credit schemes and other developmental activities. Besides, CLD will support operational research aimed at developing models for program planning, implementation, monitoring and evaluation. Development of suitable indicators to monitor and intervention to evaluate will be given priority. Care has to be taken that most of the activities listed above require specialist expertise and skills to be provided in a professional way. This will require capacity building and service improvements.

3.7 Components of Disability Prevention & Rehabilitation

3.7.1 Re assessment of disabilities (grade I & grade II) –

All the cases, under treatment and completed treatment are to be mobilized by peripheral health workers and brought to medical officer, PHC for clinical assessment, need assessment and service provisions. AWW & ASHA may also contribute in mobilizing process. Basic data on disability assessment need to be recorded to judge the progress after interventions.

3.7.2 Prevention of new disabilities –

Regular monitoring of nerve functions in all cases at risk and treatment of neuritis / reactions is done at primary level. Difficult cases are referred to district hospital

LAP with anesthesia sole are taught to protect the part from acute & chronic injuries and are given protective footwear. Counseling for self care and supervision of self care practices will be regularised

3.7.3 Control / reducing existing disabilities –

Ulcer care and physiotherapy in deformed cases to prevent worsening is to be strengthened. Developing 'self-care-groups' / 'self-help-groups' in leprosy colonies and home based self care in other cases will be promoted. Provision of dressing material, splints and other assistive devices will assist self care.

3.7.4 Reconstructive Surgery –

Correction of deformities like foot drop, claw hand and lagophthalmos will improve the functions of that part. All back log cases requiring such surgery will be simultaneously cleared by government and non government hospitals together. CLTRI, JALMA, SLTRI Karigiri, RLTRI, 9 PMR institutes, 5 medical colleges and 33 ILEP hospitals will contribute in surgical treatment. Pre & post operative care is integral part of it.

3.7.5 Capacity building of General Health Care (GHC) staff-

-Infrastructure development – Vacant post will be filled up, specially that of district Nucleus.

-Formal training courses – A plan of training activities will be implemented at state, district and PHC level and trainers will be supported to supervise the performance & evaluate the trainings done.

-On the job training – Regular hand on trainings during supervision will be strengthened to improve the clinical skills mainly at primary & secondary level.

3.7.6 Reducing stigma & discrimination –

Advocacy meetings during village health day and with 'Rogi Kalyan Samiti' participatory rural appraisal and demonstration of non discriminatory behavior will reduce the perceived fear of infection & misconceptions related to leprosy.

3.7.7 Socio-economic rehabilitation –

Increased accessibility to SE rehabilitation services for LAP also will be tried through developing links with social welfare departments. Meeting with MOSJE at national level and with social welfare dept. at district level will facilitate these provisions. Local NGOs & CBOs will be supported for this purpose.

3.7.8 Legislative measures –

Repealing of some acts that are not relevant now, will further boost the process of rehabilitation and in regaining self-esteem by LAP.

3.7.9 Monitoring & Evaluation –

Progress of disability prevention & rehabilitation will be monitored by some process indicators & outcome indicators such as early case detection, cure rates by cohort, no of new disabilities, and changes in EHF score. Proportion of cases operated, rehabilitated and treated for neuritis will guide on further interventions required.