

## Report of Activities

1 FEB' 2001 to 31 Juli' 2003 (von der verantwortlichen indischen Behörde)

### BOMBAY LEPROSY PROJECT

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## INTRODUCTION

It is well known that leprosy is a progressive disease and in spite of treatment there is a risk of developing loss of function and even incapacitating deformities in a small proportion of leprosy patients. Bombay Leprosy Project (BLP) has developed a special strategy to practise Prevention of Disability [POD] activities, particularly in remote rural areas by involving Community Volunteers (CVs) to assist the trained para-medical workers of BLP. The techniques used for offering necessary POD services were extensively field tested by BLP and demonstrated for mass application by the leprosy workers as well as CVs. BLP has already gained some experience by instituting simple field techniques to treat the disabilities in leprosy that are delivered at the patients' doorstep in urban areas. However the disabled leprosy patients living in far remote rural areas in Thane and Raigad districts adjoining Bombay are not provided with such services. The Government of Maharashtra manages these areas for basic leprosy control activities. These disabled leprosy patients are referred to established treatment centers in Bombay for POD and further preventing worsening of disabilities. As a result these patients neglect the care required for their disabilities and are struggling to cope up with the consequences of leprosy. Since the priority is mainly focused on disease control, it is necessary that the activities related to POD should also be practised without compromising the quality of work aimed at achieving leprosy elimination. To achieve this, BLP has implemented a special project with the aim of providing POD services to disabled leprosy patients living in the slums of Bombay as well as in adjoining villages of Thane and Raigad districts. This special project supported by German Dentist's Sponsorship (Hilfswerk der Deutschen Zahnärzte, HDZ), Germany has helped us to offer POD services needed to prevent and treat disabilities at the field level. This report summarizes the activities that were carried out during the period from February to July 2003.

## NEED TO OFFER POD SERVICES

In leprosy, considerable number of cases manifests with variable grades of physical deformities, which results in severe handicap, if they do not get proper treatment at the appropriate time. Despite the rapidly falling prevalence of leprosy, the disability and handicap resulting from loss of nerve functions, due to irreversible nerve damage, will remain a huge burden in terms of medical and social problem for many more years to come. Patients treated and cured by multidrug therapy may nevertheless present handicaps, such as deformities resulting from the disease, which have personal and social consequences. Cost-effective programmes for the prevention of disabilities in leprosy also require active involvement of the patients and their families as well as an integrated team approach. This therefore, necessitates review of the current strategy and calls for a feasible plan required to be practised within the existing infrastructure.

Considering the large number of leprosy patients with deformity and within the limited resources available, it is important that POD services are targeted towards those who are most in need. This is required more so with the objective of preventing the worsening of existing deformities. This programme has facilitated us to deliver doorstep POD services and has created tremendous impact in the disability status of the deformed leprosy patients. This project has also immensely helped us to offer disability care services and enable to improve the quality of life of the leprosy patients living in rural areas.

**TASK-ORIENTED TRAINING OF PARA-MEDICAL STAFF & COMMUNITY VOLUNTEERS:** Community Volunteers who were recruited from the local area have been given task-oriented training on various aspects of POD & disability services by the senior staff of BLP. The training include demonstration of simple methods of identifying and managing risk prone cases for nerve function impairment and practical demonstration of all the service modalities for disability care. These CVs under the Supervision of BLP staff visited the patient's house and provided disability care services.

## PROJECT SITE

The project activities were mainly focused on the disabled leprosy patients living in the slums of Mumbai and rural areas of Thane & Raigad Districts. A few areas in these districts were adopted for POD programme, which are about 60 to 80 kms away from Mumbai and are easily accessible by public transport facilities.

## PROJECT BENEFICIARIES

In 2001, the Government of Maharashtra reported that there are about 2200 and 860 persons with various kinds of disabilities due to present and past leprosy in Thane and Raigad districts respectively. However this does not include those patients who were cured with DDS monotherapy and also those who developed new disability after being declared cured and deleted from the active treatment register. Hence we undertook a disability survey mainly to identify and reassess all the disabled leprosy patients living in these areas. It is estimated that there may be about 5000 disabled leprosy patients living in these two districts. Since beginning, we have identified 1530 disabled leprosy patients from these areas. All these deformed leprosy patients have been offered disability care services at their doorsteps / villages using "Mobile Service Unit". The following are the details of the disabled leprosy patients who were treated by the leprosy staff and CVs during this reporting period.

	Grade-wise disability		Total
Grade – 1	Grade – 2	Grade – 3	
40	169	34	<b>243</b>

243 disabled leprosy patients with various types of deformities were offered POD services by the leprosy staff, which included 139 deformed leprosy patients who were offered services previously. The services were monitored by the Supervisory staff from BLP who made field visits to the villages along with the local CVs to assess the compliance as well as the progress in disability. The following are the details of services provided during this reporting period.

POD services	Number	POD services	Number
Self care measures	170	Dressing kits	295
Pre-fabricated splints	86	MCR footwear	77

\* No. of services will not tally with the number of patients as some patients have been given multiple services for their multiple deformities.

#### OUTCOME MEASURES

This project has helped to improve the technical skills and knowledge of leprosy staff and community volunteers to practise POD services to leprosy patients.

Improvement in the disability status after interventions has enhanced the functional capability; thereby improving their quality of life.

The methodology adopted in this project has facilitated to develop an operationally feasible plan for implementing a field based POD programme along with the basic leprosy control programme.

#### NEED TO SUSTAIN THE POD SERVICES

It is a known fact that leprosy leads to physical deformities, which eventually becomes a serious handicap thereby limiting the functional capabilities of afflicted persons. This emphasizes the great need for sustaining the services and intensive follow-up of all the disabled leprosy patients till they learn to adjust with the situation that will help to limit their disability and prevent worsening. The effect of self-care learning by leprosy patients in prevention of disabilities were found to be effective in containing occurrence of new deformities among high risk patients and healing of trophic ulcers in hands and feet. Strategy for service delivery to the disabled leprosy patients along with the routine leprosy control programme by concerned field personnel without prejudice to their routine work is feasible. In view of the integration of leprosy services with the Primary Health Care (PHC) system, this strategy in the long run will help to ease out the problems. Training of local health workers and volunteers will enhance their skills to offer POD services to leprosy patients. We propose to adopt few more areas in these districts and offer the POD services to the disabled leprosy patients [New] as well as to sustain the follow-up services to the previously treated disabled leprosy patients [Old] during the next phase of this project.

