

SAPEL

A Special Project for Special Circumstances

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ABBREVIATIONS

ANM	Auxiliary Nurse Midwife
BEE	Block Extension Educator
BHS	Block Health Supervisor
BMO	Block Medical Officer
CHG	Community Health Guide
DANIDA	Danish International Development Assistance
DANLEP	Danish Assistance to National Leprosy Eradication Programme
DDL	Deputy Director, Leprosy
DLO	District Leprosy Officer
HE	Health Educator
HI	Health Inspector
HSC	Health Sub-Centre
ICDS	Integrated Child Development Scheme
IEC	Information, Education, Communication
LEU	Leprosy Eradication Unit
MB	Multi-Bacillary
MDT	Multi-Drug Therapy
MO	Medical Officer
MPW	Multi-Purpose Worker
NGO	Non-Government Organisation
NLEP	National Leprosy Eradication Programme
NMA	Non-Medical Assistant
NMS	Non-Medical Supervisor
PB	Pauci-Bacillary
PHC	Primary Health Centre
POD	Prevention of Disability
PR	Prevalence Rate
RFT	Release From Treatment
SAPEL	Special Action Project for the Elimination of Leprosy
SHG	Self Help Group
SSL	Single Skin Lesion
TLM	The Leprosy Mission
VAO	Village Administrative Officer
VHN	Village Health Nurse
VVW	Village Voluntary Worker
WHO	World Health Organisation
ZC	Zonal Coordinator

EXECUTIVE SUMMARY

INTRODUCTION

India aims to eliminate leprosy by the year 2005. Elimination is defined as a prevalence rate (PR) of less than one case per 10,000 population. In the mid-1990s the World Health Organisation (WHO) put forward the concept of Special Action Projects for the Elimination of Leprosy (SAPELs), for coverage of difficult, inaccessible areas and neglected population groups. SAPEL is an intense time-bound project, concentrating resources within a limited area.

This document deals with the first round of SAPELs (1997-2000) in the states of Madhya Pradesh, Chhattisgarh, Orissa and Tamil Nadu where the Danish Assistance to the National Leprosy Eradication Programme (DANLEP) actively supports the state governments in leprosy elimination. These SAPELs were initiated and largely implemented while Chhattisgarh was still a part of Madhya Pradesh. By the time the field work for this documentation was undertaken in November-December 2000, Chhattisgarh had become a separate state. Information compiled during the first round of SAPELs include the projects in Chhattisgarh under Madhya Pradesh.

AIMS OF SAPEL

- Take leprosy detection and treatment to remote, inaccessible areas and unreached populations.
- Make people in the project areas aware of the causes, symptoms and treatment of leprosy and that it is fully curable.
- Remove misconceptions and the stigma attached to leprosy.
- Promote community participation through voluntary detection and Information, Education Communication (IEC) campaigns by local groups.

- Promote knowledge about leprosy among service providers in the general health system.

AREA SELECTION

Criteria for selection of SAPEL areas are poor access, poor communication, inadequate or no health services. Leprosy endemic areas with high PR, areas with low PR not reflecting the true picture due to poor detection, nomadic populations and urban slums also qualify. Proposals are examined by a screening committee in each state. 47 projects in MP, six in Orissa and five in Tamil Nadu were approved in the first round.

PLANNING AND IMPLEMENTATION

Planning was the responsibility of the district health/leprosy officers. Plans in each project area covered deployment of health personnel at various levels, transport and other communication facilities, selection and training of field staff, IEC methods and materials, tools for case detection, extent of coverage, arrangements for confirmation of suspected cases, treatment and follow-up and cost estimates and budget planning for all these components.

The management team consisted of the District Leprosy Officer (DLO), Block Medical Officer (BMO) and Non-Medical Supervisor (NMS), advised and supported by DANLEP coordinators at zonal or state level. Field staff selected and trained for the detection survey included general health workers and volunteers from the community.

TRAINING

Selected field workers were trained in:

- conducting the detection survey;
- questions to be asked;
- conducting the physical examination;
- use of body chart;
- recording of suspected cases;
- providing information to potential patients and families;

- persuading them to be examined for leprosy symptoms;
- discussing beliefs and attitudes about leprosy;
- ways of helping to remove the stigma attached to it.

SPREADING THE MESSAGE

The SAPEL concept emphasises community awareness and participation. IEC activity before the detection survey included putting up posters, writing wall slogans, broadcasting messages from vehicles using loudspeakers, large and small group meetings, rallies, street and folk theatre and music.

THE DETECTION SURVEY

The house-to-house survey to detect suspected cases of leprosy was conducted intensively over a few days. Volunteers usually worked in pairs of one male and one female covering a specific population. In most project areas, it was not found practical to conduct a physical examination of every person surveyed. Volunteers described the signs and examined those who came forward, those in whom they noticed likely signs, and family members of diagnosed/suspected patients.

Motivation of the search teams was high and coverage was more than 90% of the population in most areas. The survey was most successful where it followed immediately after training of field workers. Seasonal factors like flooding of rivers during and after monsoon and migration in search of work affected coverage.

CONFIRMATION AND TREATMENT

Suspected cases were checked for confirmation by the NMS/ NMA (non-medical assistant), sometimes by the DLO or Medical Officer (MO). In most areas, additional transport facilities available for the survey were used to complete the confirmation in the same period. In some, suspected cases were told to come to the primary health centre (PHC) or health sub-centre (HSC) on a specified day. In a few areas confirmation took place several weeks or months after the survey.

In every SAPEL area, multi-drug therapy (MDT) was initiated immediately upon confirmation. Patients were given the first dose on the spot and the month's blister pack to take home. The first

dose for each subsequent month was to be similarly supervised, but this depended on the circumstances. In some, multi-purpose workers (MPWs) were able to meet the patients every month. Where this was not possible during the monsoon, patients were given three or four months' supply at one time. In very few areas was there a consistent method of ensuring that the full medication was consumed.

CASE STUDIES

Project Bastanar in Bastar district of Chhattisgarh covered 43 scattered villages and hamlets in hilly, forested terrain. The population is mainly tribal and largely illiterate. Pre-survey IEC was effective in ensuring cooperation during the search. All the villages were visited. Confirmation and initiation of treatment was immediate. Of 30 suspected cases, 25 were confirmed. Volunteers could not be selected from the target community because of low literacy levels. Survey was conducted by MPWs and anganwadi workers. The MPWs' high motivation, commitment to and familiarity with the people they serve contributed to thoroughness in detection, treatment and follow-up. SAPEL has spread awareness that leprosy is curable and there is familiarity with patches as signs. Understanding of the causes and nature of the disease is not high.



Project Gurur in Durg district of Chhattisgarh covered an area where the care of leprosy patients had been left to a missionary organisation, The Leprosy Mission (TLM). TLM is known for quality of treatment, but has no infrastructure for detection. The government health system has no trained leprosy workers. Combining the health system's network with TLM's expertise, SAPEL was a learning experience for both. All 122 villages of Gurur block were covered by the survey. There were 144 suspected cases, of which 17 were confirmed. The level of voluntary reporting and early detection in the post-SAPEL period shows increased awareness in the populace.

Project Lanji covered the most difficult to access area of the hilly, forested Lanji block in Balaghat district of

Madhya Pradesh. There is a large tribal population. Communication facilities are poor. SAPEL in Lanji is an example of total community involvement. Volunteers were selected from local residents, particularly youth groups. They were involved in IEC on a continuing basis, forming their own troupes and using local traditions of song and dance. The body chart was used effectively, with most of the target population being physically examined. Volunteers helped field health workers keep track of patients and ensure regular medication. Of 91 suspected cases 68 were confirmed. The youth groups continue to work for leprosy elimination through IEC, and by holding skin and prevention of disability (POD) camps. Involvement of all health staff, from BMO and DLO to MPWs, the active interest of the district Collector and the dedication of the DANLEP zonal coordinator helped enthuse the community.

Project Gulaimal covered 17 villages in Khalwa block of Khandwa district, Madhya Pradesh. This is an isolated, tribal area with rough, forested terrain and bad roads. The reach of the general health system and the leprosy elimination staff is poor. A low literacy rate, low standard of living, and seasonal migration in search of work are additional problems. Because of the physical difficulties, including post-monsoon flooding of rivers, SAPEL was implemented in two phases, covering six villages in the first and the remaining eleven after three months. Of 115 suspected cases, 11 were confirmed and placed under treatment. Searchers were mainly village voluntary workers (VWVs) and some anganwadi workers. There has been no voluntary reporting of cases after SAPEL and it is assumed that given the nature of the terrain, the migratory population and coverage of just over two-thirds of the population during SAPEL, hidden cases still exist.

Project Krushnaprasad in Puri district of Orissa was conducted in 109 villages and 46 hamlets, spread over 22 scattered islands in Chilika Lake, peopled mostly by fisherfolk. Access is difficult, especially in the monsoon. Searchers included leprosy staff and MPWs, anganwadi workers and other volunteers. All the villages and hamlets were visited and nearly 84% of the total population was contacted. Of 368 suspected cases, 179 were confirmed. IEC has raised the general level of awareness considerably, and health staff are confident that voluntary reporting will be the norm



in future and there will be no more hidden cases. Volunteers for the search, selected largely on the basis of the MPWs' recommendations, proved good, demonstrating the MPWs' familiarity with the people they serve.

Project Kollu Hills was located in Namakkal district of Tamil Nadu in a geographically distinct hill area, with rough terrain, poor roads and villages and hamlets scattered far and wide. Nearly 95% of the population is tribal. Intensive IEC activity was followed by a one-day training programme for health staff, Integrated Child Development Scheme (ICDS) staff, noon meal organisers, teachers, panchayat members and *madhar sangam* members. But the detection drive was conducted only by field health workers. While extra transport was made available, many remote hamlets could be accessed only on foot. 99 cases were detected. The outstanding feature of this project was the

dedication of the VHNs and HIs who worked with ungrudging enthusiasm during SAPEL and maintained their familiarity with each patient's case months after the course of medication had been completed. A neglected resource was the non-use of other personnel, like *anganwadi* workers, who had been trained but not given any part to play. Community participation was poor.

CONCLUSIONS AND LEARNINGS

These are based not just on the six case studies, but also on reports and discussions relating to all the first-round SAPEL projects in the three states.

- In every project area, the access problem has been overcome, the majority of people surveyed, most if not all cases detected and treated.
- With one exception, community participation has been limited to passive cooperation in the search process. Women's groups and teachers, who could set an example in participation, have not been motivated to do so.
- Stigma has been reduced to the extent that there is no isolation or neglect of patients. But the disease is not willingly

identified as leprosy and health personnel who insist on doing so are faced with hostility and withdrawal.

- General health workers have attained greater knowledge and awareness of leprosy but this needs to be sustained through refresher courses and by including leprosy in periodic reviews at PHCs.
- In most project areas, dependable means of ensuring that the patient takes the medication regularly have not been established.
- Post-SAPEL sustainability of elimination needs to be addressed.

The SAPELs have succeeded in most of their aims but much remains to be done to make people in the project areas aware of the causes of leprosy and to eliminate the social stigma that is still attached to it.