



## Background

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 Organization (WHO) put forward the concept of Special Action Project for the Elimination of Leprosy (SAPEL) for coverage of difficult, inaccessible areas and neglected population groups, including, among others, many tribal communities. SAPEL is an intensive time-bound project, concentrating resources within a limited area.

The first round of SAPELs were organised in the states of undivided Madhya Pradesh, Orissa and Tamil Nadu between 1997 and 2000. Consequently, information compiled during the first round of SAPELs includes the projects in the present state of Chhattisgarh under Madhya Pradesh.

## Aims of SAPEL

- Take leprosy detection and treatment to remote, inaccessible areas and un-reached populations.
- Make people in the project areas aware of the causes, symptoms and treatment of leprosy, emphasising the fact that it is fully curable.
- Remove misconceptions and the stigma attached to leprosy.
- Promote community participation through voluntary detection and information, education and communication (IEC) campaigns by local groups.
- Promote knowledge about leprosy among service providers in the general health system.

<sup>1</sup> Gita Narayanan is a DANLEP consultant and author of SAPEL- A Special Project for Special Circumstances. DANLEP, 2002: New Delhi

## Area selection

Criteria for selection of SAPEL areas are poor access, poor communication and 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. SAPEL proposals are generally made in writing by the competent health authority, such as the district leprosy officer (DLO), and examined by a screening committee in each state. Forty-seven projects in Madhya Pradesh, six in Orissa and five in Tamil Nadu were approved in the first round between 1997 and 2000.

## 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-levels. Field staff selected and trained for the detection survey included general health workers and volunteers from the community.

**Table 1: Human resources for SAPEL Projects 1997-2000**

Health workers variously referred to in the different states	Multi-Purpose workers (MPWs), Auxiliary Nurse Mid-wives (ANMs), Health Inspectors (HIs), Village Health Nurses (VHNs)
Community volunteers	Anganwadi workers (AWWs), teachers, panchayat members, NGO workers, <i>mahila mandals</i> members, educated youth, and any person who have participated in other health programmes.

## Training

Selected field workers were trained in:

- conducting the detection survey;
- type of questions to be asked;
- doing the physical examination;
- using the body chart;<sup>2</sup>
- recording suspected cases;
- providing relevant information to potential patients and families;
- persuading people to be examined for leprosy symptoms;
- discussing beliefs and attitudes about leprosy;
- ways of addressing the stigma attached to leprosy.

## Spreading the message

The SAPEL concept emphasises community awareness and participation. IEC activities 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 and 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

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<sup>2</sup> The body chart is a technique of physical examination during a house-to-house survey by non-medical personnel. The body chart represents a figure of the human body divided into eight segments. The surveyor is required to tick off the segments that he or she has actually examined for each of the persons surveyed. Since using the body chart requires additional training inputs, and it is a time-consuming process to implement on a large scale, body charts were only used in Madhya Pradesh during the first round of SAPELs.

flooding of rivers during and after monsoon and patterns of migration in search of work affected coverage.

## Confirmation and treatment

Suspected cases were checked for confirmation by the NMS or NMA, 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 areas, 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 a month's blister pack to take home. The first dose for each subsequent month was to be similarly supervised, but this depended on the local circumstances. In some cases, multi-purpose workers (MPWs) were able to meet the patients every month. Where this was not possible during the monsoon, patients

**Table 2: Overview of SAPEL Projects 1997-2000**

State	No. of SAPELS	No. of Districts	Population covered	Cases detected
Madhya Pradesh	47	21	1,360,000	822
Tamil Nadu	6	6	360,000	838
Orissa	5	5	70,000	353

were given three or four months' supply at one time (accompanied MDT). In very few areas was there a consistent method of ensuring that the full treatment course was completed.

Reasons for low coverage included:

- Too short a time period for survey, given the distances between the hamlets in the difficult terrain.
- Too large population to be covered by each volunteer.
- Wrong time of the year for survey (when major rivers were in spate, or when workers had migrated to other areas for seasonal employment).
- Inadequate number of volunteers, especially female volunteers.

## 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. The survey was conducted by MPWs and *anganwadi* workers. The MPWs' high motivation, commitment to and familiarity with the people they served contributed to thoroughness in case detection, treatment and follow-up. The SAPEL spread awareness that leprosy is curable, as well as familiarity with patches as signs of the disease. However, the understanding of the causes and course of the disease was 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 was known for quality of treatment, but had no infrastructure for case detection. The government health system had no trained leprosy workers in Gurur block. 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 showed increased awareness among the people.

Project Lanji covered the most difficult to access area of the hilly, forested Lanji block in Balaghat district of Madhya Pradesh. The block has a large tribal population. Communication facilities were poor. The SAPEL in Lanji was an example of a high level of 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, an isolated, tribal area with rough, forested terrain and bad roads. The reach of the general health system and the leprosy elimination staff was poor. A low literacy rate, low standards of living and seasonal migration in search of work were additional problems. Because of the physical difficulties, including post-monsoon flooding of rivers, a SAPEL was implemented in two phases, covering six villages in the first phase and the remaining eleven after three months. Of 115 suspected cases, 11 were confirmed and put on treatment. Surveyors were mainly village voluntary workers (VVs) and some *anganwadi* workers. There was no voluntary reporting of cases after the SAPEL, and it was believed that given the nature of the terrain, the migratory population and a coverage of just over two-thirds of the population during the SAPEL, undetected cases still existed.

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 was difficult, especially in the monsoon. Surveyors included leprosy staff and MPWs, *anganwadi* workers and other volunteers. All the villages and hamlets were visited and nearly 84% of the total population were contacted. Of 368 suspected cases, 179 were confirmed. IEC had raised the general level of awareness considerably, and the health staff was confident that voluntary reporting would be the norm in future, and that there would 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 served.

Project Kolli Hills took place in Namakkal district of Tamil Nadu in a geographically distinct hilly area, with rough terrain, poor roads and villages and hamlets scattered far and wide. Nearly 95% of the population was tribal. Intensive IEC activity was followed by a one-day training programme for health staff, Integrated Child Development Services (ICDS) staff, noon meal organisers, teachers, *panchayat* members and *madhar sangam* members. However, 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. Ninety-nine 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 other personnel, like *anganwadi* workers, who had been trained but not given any part to play. Community participation was poor.

## Conclusions and learnings

Based not just on the six case studies mentioned above, but also on reports and discussions relating to all the first-round SAPEL projects in the three states, the following were the main issues and lessons learnt:

1. In every project area, the access problem was overcome, the majority of people surveyed, and most if not all cases were detected and treated.
2. With one exception, community participation was limited to passive cooperation in the search process. Women's groups and teachers, who could set an example in participation, had not been motivated to do so.
3. Stigma was reduced to the extent that there was no obvious isolation or neglect of patients. But the disease was not willingly identified as leprosy, and health personnel who insisted on doing so were faced with hostility and withdrawal.
4. General health workers attained greater knowledge and awareness of leprosy but this needed to be sustained through refresher courses and by including leprosy in periodic reviews at PHCs.
5. In most project areas, dependable means of ensuring that the patient takes the medication regularly had not been established.

Given the poor community participation in top-down approaches such as SAPEL, there was a need to identify more sustainable and cost-effective strategies for leprosy elimination in tribal (and other hard-to-reach) areas.

