

SAPEL

A Special Project for Special Circumstances

Gita Narayanan

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For further information :

DANLEP

A1/148 Safdarjung Enclave, New Delhi - 110029

Phone : (91-11) 6181909/7339/7340

Fax : (91-11) 6181099

E-mail : danlep@danlep.com

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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 (VVs) 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.

INTRODUCTION

India is a signatory to the global alliance on leprosy elimination. It is envisaged that through the implementation of the WHO recommended elimination strategy, leprosy will cease to be a public health problem in India by the end of 2005. Elimination is defined as less than one case of leprosy per ten thousand population.

LEPROSY ELIMINATION IN INDIA

In 1955, the Government of India launched a nationwide leprosy control programme as a centrally sponsored programme; this programme was substantially revised in 1982 with the advent of multi-drug therapy (MDT). Health departments of the different states targeted leprosy by setting up a separate, vertical structure of specially trained personnel — from State Leprosy Officer to field level workers — who have carried through various programmes and campaigns. These have significantly brought down the PR in most areas. With reduced prevalence, leprosy staff are being integrated into the general health system and personnel in the general system are being trained so that they can play their part in leprosy elimination as they do in other health programmes. So far, integration has been fully implemented in Tamil Nadu and partially in several other states.

The key elements of all leprosy elimination programmes have been:

- Spreading awareness of the facts about leprosy among the target population, through IEC.
- Early detection and treatment.
- Counselling of patients and their families to ensure that medication is taken fully, and to rid them of misconceptions and fears which contribute to social stigma and ostracism.
- Encouraging voluntary disclosure of patches and other symptoms.

THE SAPEL CONCEPT

Though the PR has been reduced in many areas, there are

several isolated, inaccessible pockets and disadvantaged populations not reached by health services. The SAPEL concept was developed by WHO in the mid-1990s. It was specifically designed to fill the gaps in existing leprosy elimination programmes in developing countries by ensuring coverage of difficult and inaccessible areas and neglected population groups, to promote equity in health care.

A SAPEL project is an intense, time-bound effort to detect, treat and cure cases of leprosy. The emphasis is on reaching the otherwise un-reached areas to achieve high rates of detection and cure, raising community awareness and participation, removing misconceptions and fears about leprosy. A higher level of expenditure than for most other health-related projects covering a comparable area is therefore incurred.

Innovation, flexibility and a locale-specific approach are the essential features of SAPEL. Those who plan and execute each project are expected to structure it to suit the ground realities and needs of their area. However, there are some features which have been found essential everywhere and which provide a common overall framework. These include initial IEC activity, selection and training of search team members including volunteers, a house-to-house detection survey to list suspected cases followed by examination of these cases for confirmation, treatment and follow-up of confirmed cases.

DANIDA, the Danish International Development Assistance, which has been supporting various development and health projects/programmes of Central and State Governments in India, also assists leprosy elimination through DANLEP. DANLEP supports (since 1986) the high endemic states of Madhya Pradesh, Chhattisgarh, Orissa and Tamil Nadu, directly in leprosy elimination programmes including SAPELs. This support is financial as well as consultative and participatory with regard to planning, implementation, monitoring and evaluation.

AN OVERVIEW

SAPEL IN MADHYA PRADESH, CHHATTISGARH, ORISSA AND TAMIL NADU

AIMS OF SAPEL

- To take leprosy detection and treatment to remote, inaccessible areas and make the service available to hitherto unreached populations.
- To make people in the project areas aware of the causes, signs / symptoms and treatment of leprosy. Above all to make them aware that it is fully curable through MDT and to teach them methods of preventing and minimising disabilities arising from leprosy.
- To remove misconceptions and inaccurate beliefs about leprosy and so remove the stigma attached to it.
- To promote community participation in all areas of leprosy elimination by encouraging voluntary detection and IEC/ awareness campaigns by local groups.
- To promote knowledge and awareness about leprosy among service providers in the general health system and so ensure their participation in leprosy detection and treatment.

SELECTION OF SAPEL AREAS

SAPEL is a high-cost, need-based intervention to be carried out within a limited time period. While flexibility on the ground is seen as essential, very specific criteria have been laid down for selection of areas in which SAPEL is to be implemented.

CRITERIA

Factors contributing to poor access and inadequate health services, are the criteria to select an area for SAPEL. These include:

- Difficult terrain as in hilly, forested regions.
- Distance from service providing agencies, where villages/ hamlets are remote and isolated.

- Poor communication facilities including bad or non-existent roads made worse during the monsoon, with flooded rivers and streams further cutting off settlements.
- Inadequate or no health services, both general and leprosy related.
- Leprosy endemic areas with high PR not yet subjected to any concentrated elimination campaign because of any or all of the above factors.
- Areas with low PR which, however, may not reflect the true picture due to lack of or poor detection campaigns. Such areas are consequently expected to have many hidden cases.
- Nomadic populations not subject to detection/treatment procedures for long periods.
- Urban slums with poor health services.

PROPOSALS

Once the decision was made to implement SAPELs with DANLEP participation in the states of Madhya Pradesh, Orissa and Tamil Nadu, health personnel at the district level (more specifically those in charge of leprosy programmes) were briefed on the concept and asked to present proposals for specific project areas. The proposals were to include:

- Geographical description of the proposed project area.
- Demographic details including literacy levels, livelihood and living patterns, existing beliefs, practices relating to leprosy.
- Description of existing health services, their accessibility and effectiveness.
- Communication facilities or their lack in the project area.
- Reasons for considering the area eligible for SAPEL.
- Plan of implementation of SAPEL.
- Budget estimate.

APPROVAL

A State Screening Committee was set up in each of the three states to study the project proposals. The committee consisted of representatives from the state health system (generally the

Joint Director in charge of leprosy) and representatives of DANLEP in the state.

Following scrutiny by the committee, some proposals were returned to the concerned district officers with requests for more information.

AT A GLANCE

The first round of DANLEP-supported SAPELs in the states under study took place between 1997 and 2000. The number of SAPELs carried out, population covered and cases registered in this round are as follows (figures for Madhya Pradesh include Chhattisgarh):

State	Number of SAPELs	Number of districts	Population covered, in lakhs	Cases detected
Madhya Pradesh	47	21	13.6	822
Orissa	6	6	3.6	838
Tamil Nadu	5	5	0.7	353

MADHYA PRADESH

Not surprisingly Madhya Pradesh (including Chhattisgarh), a large, high endemic state with hilly terrain and extensive forest cover, produced the highest number of proposals for areas which met the criteria of inaccessibility and poor health services. In the first round of SAPELs, 47 proposals were approved and implemented in the state. The 47 SAPELs were spread over 21 districts and covered a population of 13.6 lakhs. A total of 822 cases were detected in this first round of SAPEL in Madhya Pradesh.

Most of the project areas are inhabited by tribals who constitute 23% of the state's population and are among the most poorly served groups when it comes to health needs. These hilly and forested project areas, with poor roads, are difficult to access at all times; they are totally isolated in the monsoon when rivers and streams are in spate and cut off villages and hamlets from each other as well as from the nearest PHC or HSC. Some of the more isolated hamlets are not visited by health workers for long periods — sometimes two or three years.

In many of the thickly forested areas, stories are told of wild animals, including sighting of tigers. In some, especially near the borders of Maharashtra and Andhra Pradesh, Naxalites are said to be in control of some areas. But one is assured, in the same breath, that the Naxalites never interfere with health providers. Some examples of such difficult to access areas in which SAPEL was undertaken lie in the districts of Bilaspur and Bastar in what is now Chhattisgarh, in Balaghat south of Jabalpur and in Khandwa and Khargaoan south of Indore. Among the exceptions is Gurur in Durg district of Chhattisgarh where the problem is not one of accessibility. It was selected because it had no government leprosy service structure but was in the care of a leprosy mission which provided excellent treatment but poor coverage for detection.

ORISSA

Also a high endemic state having many hilly, forested stretches with isolated tribal populations, Orissa came up with only six SAPELs, one in each of six districts. Covering a population of 3.6 lakhs, these six projects resulted in detection of 838 cases, a total higher than that of Madhya Pradesh with its 47 SAPELs! This is indicative of a high rate of incidence combined with a low rate of detection in the state. An intensive programme like SAPEL demonstrates its utility in such a case.

The six SAPEL areas were Palahara in Angul district, Kotagad in Phulbani district, Naktideul in Sambalpur district, Bonai in Sundergarh district, Mahakalpara & Rajnagar in Kendrapara district, and Krushnaprasad in Puri district. Four of these are in hilly, forested terrain, inhabited mainly by tribals in scattered villages and hamlets, which are remote and difficult of access. Of the two project areas located in coastal districts the one in Kendrapara, in the Mahanadi delta, has more river ways than roads, making many parts inaccessible except by boat. Krushnaprasad project area in Puri district is also a largely tribal area. It covers 22 islands spread across the southern part of Chilika lake, a huge lagoon separated from the Bay of Bengal by a long sandbar.



According to the Orissa state screening committee, only six proposals were received in the first round, though more would have been welcome. Apparently the SAPEL concept, when first mooted, was unknown territory and many DLOs were hesitant to commit themselves to such an intensive project given the poor infrastructure at their disposal and the existing workload of the more conventional leprosy elimination campaigns. As far as the former factor (poor infrastructure) is concerned, it would seem that what should have been the reason for SAPEL was actually a cause for hesitation in the beginning.

TAMIL NADU

A low endemic state with fewer isolated areas, Tamil Nadu planned for five projects, one in each of five districts, in the first round. These covered a total population of just around 70,000. The number of cases detected was 353.

Four of the areas selected, though relatively small in extent, are isolated, hilly areas, inhabited by tribals living in scattered and inaccessible hamlets, with poor communication facilities and not well served by the health system. These areas are seen as hardship postings by medical personnel and health workers; few have any thought of staying in these hills for long. The fifth SAPEL was conducted in the plains, over an area which had not hitherto been covered by a leprosy detection survey and elimination programme.

PLANNING AND IMPLEMENTATION

Planning of the project was again the responsibility of the district health/leprosy officers who had the knowledge of local conditions to take advantage of the flexibility that was part of the SAPEL concept. Major components in all project areas were 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, of course, cost estimates and budget planning for all these components.



MANAGEMENT TEAM

The management team in each project area consisted of the DLO/DDL, BMO and NMS, advised and supported by DANLEP coordinators at zonal or state level. The BMO as facilitator and the DLO as project manager were to conduct training of the field staff and supervise the work of the NMS and NMA. The

BMO was responsible for the provision and utilisation of funds and material for the project. The DLO was expected to be involved in the project on a day-to-day basis, guiding the field staff and ensuring continuous appraisal of the project's progress. In project areas where non-government organisations (NGOs), such as a leprosy mission, were involved in SAPEL, they provided some of the management team members. In Gurur in Chhattisgarh, both the NMS and NMA were mission staff. In Badwaha in Indore zone of Madhya Pradesh, the mission managed and implemented the project completely.

The NMS and NMA formed a link between the field staff and the management team. The former was to plan and coordinate training activities, IEC and survey work, maintain the smooth flow of IEC material and drugs, organise skin camps, maintain daily accounts and deal with news media. The NMA was in charge of assigning the detection work to the survey teams, examining suspected cases for confirmation, registering new cases and initiating treatment, counselling patients and their families and ensuring continuous supply of drugs to patients.

FIELD STAFF SELECTION

Field staff for SAPEL were:

- i. Health workers variously designated as MPWs, Health Inspectors (HIs), Auxiliary Nurse Midwives (ANMs), Village Health Nurses (VHNs) in the different states.
- ii. Volunteers from the community could include:
 - *Anganwadi* workers
 - Teachers

- Panchayat members
- NGO members
- *Mahila mandal* members
- Educated youth
- Persons who had worked in other health projects.

Field health workers were necessary as they would subsequently be in charge of ensuring continuing medication for patients in their area.

Since community participation was seen as an essential part of SAPEL, volunteers from the local community were to be recruited and trained, to be used particularly in the detection survey and also, perhaps, in other activities like IEC and raising awareness.

Criteria for volunteer selection included local residency status, literacy (education up to 8th class level), and ability to devote time and energy to the project. It was also recognised that an equal number of male and female volunteers would enable them to work in pairs since, during the detection survey, a subject would be more amenable to questioning and physical examination by a person of his/her own sex.

Certain categories of government and quasi-government employees were seen as logical choices in almost all project areas. These included teachers, Village Administrative Officers (VAOs), elected panchayat members, *anganwadi* workers of the ICDS, and noon meal (midday meal) workers. Members of women's groups, traditional midwives and members of NGO groups were also among the volunteers selected in many areas. Educated youth who had not yet obtained employment and were interested in serving their community provided some volunteers.

Methods of volunteer selection varied. In some areas, the project management team worked through the local panchayat members who provided the names of likely volunteers who were then interviewed by the BMO and/or DLO. Where community participation was high, it often began with the panchayat calling a meeting of the people at which the project was explained to them and they were invited to participate. In other project areas, specific groups (*anganwadi* workers, teachers, the local NGO, *mahila mandal*) were identified as volunteer sources. In some cases,

the choice of volunteers was based entirely on the recommendation of the local health worker. This was the case in the Krushnaprasad project in Orissa, where the female MPW in each PHC/HSC identified possible volunteers. Her choice was based on her personal knowledge of people in her area. Many of those selected in this manner had previously volunteered for other health-related projects and campaigns. In many project areas there was little or no differentiation made between MPWs and other volunteers. In some, only MPWs were selected for the volunteers' work, so that the two terms were used interchangeably. In one project area in Madhya Pradesh, when the DLO visited the villages with a list of possible volunteers, he found that none of them was willing to undertake the work. The rapport of the leprosy and general health staff with the people was so poor that no volunteers were forthcoming. However, when SAPEL was handed over to a leprosy mission long established in the area, they were able to recruit volunteers from the same villages and complete the project with their cooperation.

TRAINING

Training of selected health workers and volunteers was conducted by the BMO, DLO and the DANLEP state or zonal coordinator. Much of the organisation for training was carried out by the NMS. There were some projects where the NMS also undertook the actual training because the BMO and/or DLO had little interest in the project or had too heavy a workload.

Training was generally for two days, imparting facts about the causes and symptoms of leprosy and its treatment. The trainees were taught to conduct the detection survey, the questions to be asked, conduct of the physical examination and recording of suspected cases. They were trained to provide information to potential patients and families and talk to them in ways to win their trust and persuade them to be examined for leprosy symptoms. They also learnt to discuss beliefs and attitudes about leprosy and ways of helping to remove the stigma attached to it. In project areas where the body chart was used, they were trained in its use. The extent of training in IEC varied. (In some projects volunteers have taken part in IEC activity. There have also been several projects in which IEC activity was carried on not only

before, but also during and after the survey.)

In most project areas, training was conducted for one or, at the most, two batches of trainees and took place at the PHC in block headquarters. In some areas this was a problem as transport from remote villages was irregular and trainees needed two to three hours to travel to the PHC in the morning and could not stay late into the evening. This cut down the time available for training. The quality of training and the extent of understanding and retention among trainees varied. Understanding and retention was highest among MPWs and *anganwadi* workers. It was generally low among teachers, panchayat and *mahila mandal* members, apparently due to lack of interest and non-participation in other aspects of the project. Lanji in Balaghat district of Madhya Pradesh was the exception, with almost the entire community participating in the project and showing a high level of understanding and commitment.

SPREADING THE MESSAGE

Leprosy elimination in general, and the SAPEL concept in particular, places heavy emphasis on community awareness and participation leading, hopefully, to benefits like voluntary detection and destigmatisation. IEC is, therefore, a significant component of the project. In many project areas, a well-publicised inaugural meeting and rally, with the district collector and other important persons participating, was the first step. The most intense IEC activity took place before the detection survey. These included putting up of posters, writing of wall slogans, verbal broadcasting of messages from vehicles using loudspeakers, large and small group meetings, rallies, street and folk theatre and music.



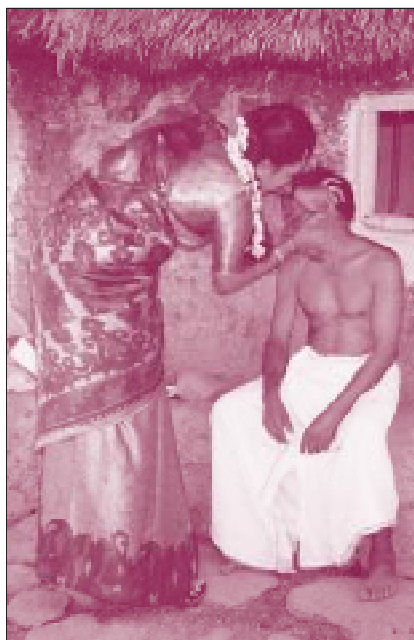
The pre-survey use of IEC was seen as a means of making people aware of the coming survey — to inform them that house-to-house visits would be made on certain dates for search and detection — so that they would expect it and cooperate with the survey team. In this, it was

largely successful everywhere. Subsequent IEC was mainly through personal contact, with health workers and volunteers talking to patients, their families and neighbours, individually or in small groups. In this, the emphasis was on promoting voluntary detection and making people aware that the disease was curable. The question of stigma was quite often underplayed or bypassed. Where POD camps were part of the follow-up activities, there was further IEC activity aimed at community awareness and participation.

Lanji in Madhya Pradesh was again the exception. Volunteers here took up a variety of IEC activities on a continuing basis and have sustained them even after completion of the project. They have used all possible methods: wall slogans and posters, rallies, group meetings, personal contact and folk music. The last has been very popular and effective because a group of volunteers have formed their own band of performers, composing the songs themselves.

DETECTION SURVEY : COVERAGE AND METHODS

The house-to-house survey to detect suspected cases of leprosy was conducted intensively over a limited period of time, usually five days. Volunteers were to work in pairs of one male and one female covering a specific population (ranging from 500 to 1000). In all project areas the survey had to be conducted early in the morning when most of the people would be available before they left for work. Some mop-up work was done later in the day or in the evening.



In almost all project areas, it was not found practical to conduct a physical examination of every person surveyed though in a few, like Lanji, volunteers tried to do so. In most, volunteers described the symptoms and asked if anyone in a family had them; they then examined those who came forward. They also examined those in whom they themselves noticed possible signs, as well

as family members of previously diagnosed and suspected patients.

The extra inputs provided for SAPEL were most evident during the survey period when more manpower was mobilised and more transport made available for the task. Motivation of the search teams was generally high and coverage, on the whole, was commensurate with the extra inputs and the enthusiasm generated by the project. In most areas, substantially more than 90% of the population was covered by the survey. Only those who had left home for several days, or went to work far too early for even the most persistent searcher, remained uncovered.

Where coverage was low the reasons given were:

- The time period for survey was too short, given the distances between hamlets in difficult terrain.
- The numbers to be covered by each volunteer was too high.
- The survey was initiated at the wrong time of the year when rivers and streams were in spate or when migratory workers had left for seasonal jobs in other places.
- Not enough volunteers were available either because some of the original trainees had dropped out or because training had not been conducted for all batches of trainees. In some areas of Madhya Pradesh, there was difficulty in getting enough female volunteers.

The scheduling of the detection survey was a major factor in its success or failure. Where the survey followed immediately upon training and IEC activity, it was comprehensive and highly effective — provided, of course, that the quality of training was good. Examples of this are the SAPELs in Lanji in Madhya Pradesh and Kolli Hills in Tamil Nadu. In both areas, the search teams faced difficulties of terrain and distances between hamlets. But in both, the searchers (volunteers in Lanji and MPWs in Kolli Hills) were fresh from training and highly motivated. They saw the job as an exciting challenge. In such circumstances, the short period over which the intense search was conducted was an advantage as enthusiasm was sustained and concentrated.

On the other hand, in Alirajpur of Jhabua district in Madhya Pradesh, there was a gap of several weeks between training and survey. When the survey was initiated, in October 1999, it

was found that large numbers of the population had migrated out of the area for seasonal work elsewhere. In the first round only nine of 24 selected villages were surveyed. The percentage of the population covered was very low and the body charts, forming the records of the survey, were found to be unsatisfactory. The survey in the villages covered had been inadequate because:

- Volunteers (mostly MPWs and *anganwadi* workers) misunderstood their instructions about how body charts should be marked.
- They also thought that children below the age of 15 need not be surveyed.
- Volunteers complained of poor support from the National Leprosy Eradication Programme (NLEP) and general health staff.
- They felt that it was too much to expect one volunteer to survey 1000 persons in five days.
- They were resentful that enough body charts had not been distributed when they were briefed and they had to travel to the PHC again, at their own expense, to collect them.

Because the survey results as they stood were unsatisfactory, volunteers were trained again and a re-survey of the initial nine villages was undertaken along with the survey of those not previously covered. But by December 1999, only 16 of the 24 villages had been covered.

Similarly, in project Sondhwa in Madhya Pradesh, inadequate training resulted in the survey being repeated after re-training of volunteers. Among the misconceptions that rendered the first survey unacceptable was the volunteers' belief that the body charts had to be used only for suspected cases. In this project area, a check by the DLO, following the survey, turned up 13 actual cases in a group of villages which had been recorded by volunteers as having zero suspected cases.

Also in Madhya Pradesh, in project Gulaimal in Khandwa district, there was early recognition of the difficulty in covering the whole project area at the same time. So the project, including training of volunteers, was carried out in two phases, the first covering six villages and the second, the remaining 11. This was

a practical solution to a problem recognised in time. But even here, the first phase was implemented in September, soon after the monsoon, and rivers and streams still in spate made the survey very difficult.

Other problems related to the detection survey that arose in some of the project areas were:

- Volunteers were not given a list of cases already under treatment or released from treatment (RFT) and this led to their being listed among the suspected cases.
- In many areas, the search yielded large numbers of suspected cases which proved to be not leprosy at all. Training appears to have been inadequate with reference to discriminating between signs of leprosy and of other skin ailments like leukoderma. In some areas, the DLOs felt that the high numbers yielded by the search were due to excess of zeal and a belief among the volunteers that they were proving themselves by producing more suspected cases.
- On the whole, fewer cases of children than expected have been registered in SAPEL. This raises a question about the extent to which children were examined.
- The volunteers were paid Rs.25/- each for each day of the survey. This was an honorarium meant to help with their expenses, not a salary. In some project areas volunteers were dissatisfied with the amount. In one area, there were complaints that payment was subject to their performance as judged by the NMA.

All those trained were not used in the detection survey. This was particularly true of the Tamil Nadu projects. In Kolli Hills, for example, 411 persons were trained of whom only 40 were health staff (NMS, MMA, VHN, HI, etc). The others consisted of ICDS (anganwadi) workers, noon meal organisers, teachers, VAOs, panchayat members, traditional midwives and *madhar sangham* members. For the survey, however, only the health staff were used and the others remained an untapped pool of trained volunteers. It has been pointed out that in all the Tamil Nadu SAPEL programmes, health staff tended to ignore local groups, adopting the attitude that only they had the expertise to detect leprosy cases. The *anganwadi* workers, whose knowledge and retention

level was high, said that they had not been called upon to participate in the programme after training.

THE BODY CHART: INNOVATION FOR BETTER DETECTION

SAPEL in Madhya Pradesh provides an example of the practical application of innovative thinking — the body chart. Designed by DANLEP, Madhya Pradesh, it shows the front and back outlines of the human form, divided into sections numbered from one to seven. Space is provided below for the name, address, age, etc, of the person examined. Instructions on filling the chart are also printed alongside. The volunteer has to tick those numbered sections of the body which have been physically examined and mark with small circles areas where signs of leprosy have been detected. All those who are marked as having any signs, are re-examined by the confirming authority who notes his/her findings and signs the chart. Like all innovations, the use and efficacy of the body chart has been variable. A majority of the volunteers who were given these charts found them useful in recording the findings of their search.

The chart was used in all project areas of Madhya Pradesh (except Chhattisgarh) with varying levels of thoroughness and efficacy. Lanji provides an example of an area where it was put to optimum use, thoroughly and accurately. The chart had been revised by the DLO, Balaghat, to incorporate further subdivisions in the human form and with more headings under which written information could be incorporated. The survey in the project area covered most of the population and the body chart was used in almost every case. The volunteers understood the use of the chart and marked it with care and honesty.

On the other hand, there were areas where volunteers apparently saw the body chart as a chore, to be got through as fast as possible, with scant regard for reflecting the true picture. There were, of course, many project areas which took the middle way: here volunteers used the body chart only for those persons who, after questioning, warranted a physical examination in their judgement.

An examination of a set of body charts used by one pair of volunteers (male and female) in a village in one of the MP project areas raises some pertinent questions. A total population of 818

in 282 households was surveyed over two time periods of five days each in April 1999. It was recorded that 615 persons were examined. There were 15 suspected cases, of which four were found to be old cases. Of the rest, five (all males) were subsequently confirmed. (It should be noted that confirmation was carried out only in January of the following year.)

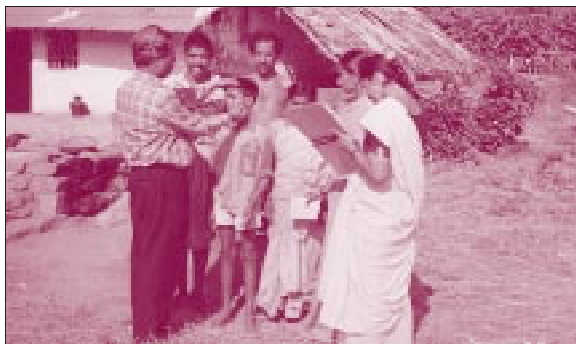
525 body charts were made available to the documenter in December 2000. The others were missing and these included one confirmed case and two of the old cases. Of the 525 charts, 279 were of males and 246 of females. 76 of the males and 32 of the females were children of 15 and below. Of the 279 males, 70 were recorded as having been examined fully. None of the females was so recorded. For a majority of the others, both front and back of the groin area numbered 6, had not been examined; for a few males (14) only the front had not been examined.

Two points give rise to the suspicion that the marking was automatic and did not follow actual attempts at physical examination: firstly, number 6 was unmarked even for children as young as three and four years old; secondly, the chest area (number 3, front) was marked as examined for all, including females.

One other question raised by these body charts is their use in the confirmation procedure. While the charts for the four confirmed cases and two RFT cases that were available were so certified and signed by the NMS/NMA (though several months after the survey), others which were apparently suspected cases had patches marked on them but bore no remarks or initials of the confirming authority.

Body charts were not used in Chhattisgarh, or in the states of Orissa and Tamil Nadu. All concerned in the management of projects in Chhattisgarh had exercised the option not to use the charts as they questioned its usefulness. In all these areas volunteers were provided with illustrated booklets and other printed material indicating what to look for, and with forms in which to record signs of suspected cases. Both in Chhattisgarh and in Orissa it was felt that the charts took up too much time, were undependable because the extra work, largely unsupervised, would result in volunteers fudging the records.

CASE CONFIRMATION



Once volunteers had completed the detection survey and listed the suspected cases with their signs / symptoms, these cases were checked for confirmation by the NMS/NMA, sometimes by the DLO or MO. The logistics of the confirmation process varied. In most areas, the additional transport facilities made available for the survey period was used to

complete the confirmation within the same period. In Bastanar, an NMS or NMA accompanied each of the 15 search teams and the confirmation procedure took place as soon as a suspected case was turned up. In Krushnaprasad, the NMS/NMA came after the search team, on the same day or the next, to carry out the confirmation procedure. In some project areas, the search team instructed suspected cases to be present either at the PHC/HSC or some other designated place on a specified day and they were examined there. There were a few areas where confirmation took place several weeks or even months after the survey.

TREATMENT AND FOLLOW-UP

In every SAPEL area, MDT was initiated immediately upon confirmation. The single skin lesion (SSL) cases were given their single dose at once. The pauci-bacillary (PB) and multi-bacillary (MB) cases were given the first dose on the spot and the month's blister pack to take home, having had the medication course explained to them. Administration of subsequent doses depended on the circumstances in each project area. In most, the MPWs had the responsibility of seeing that the course of medication was completed. Some were able to meet the patients every month, either at the PHC/HSC or at the patients' homes, supervise the first monthly dose and give the rest to the patients. Many found that monthly delivery was not possible during the monsoon and, for this period only, gave the patients three or four months' supply at one time. In some areas volunteers residing in the same village followed-up on the patients, checking that they had taken their medicine regularly. In others, MPWs and NMAs/NMSs talked to the patients' family members about ensuring that the medicine was taken.

In all the project areas, patients have been noted as released from treatment six months after treatment was initiated for PB cases and twelve months after for MB cases. What was the process of confirming that each patient had actually consumed the full course of medication? In some areas the DLO/BMO or NMS/NMA said they made regular monthly visits to check on the patients. In others, MPWs said that, as general health workers, they were so constantly in touch with the people they served that they were able to follow up on the leprosy patients and could confidently confirm that the medicine had been taken. Some admitted that they had only the word of the patient, backed up by his/her family, that the medicine had been consumed. In one case, while a patient was assuring the MPW that he had taken the medicine, his little girl ran out of the house with a tin full of unused blister packs.

In a village in Khandwa district of MP an old woman told visitors, more than a year after the detection-confirmation-initiation of treatment process, that she had taken the medicine for three months and then stopped because she felt better. In Kolli Hills, a schoolboy had suffered a bad reaction to the drugs and his parents had stopped giving him the medicine. It was several months later that this was discovered and steps were taken to advise his family about visiting the PHC and renewing the course with other medicine to control the reaction. In the same project area, on the other hand, an old woman who had taken the full course, been checked and pronounced cured, insisted that she needed more medicine because her 'claw' fingers had not straightened out fully. She did not believe that the processes of care that she had been taught at a POD camp would work as well as more tablets.

In an exceptional project area like Lanji, the volunteers have the interest and persistence to help MPWs check that each patient has consumed the full course of medication. Besides which, the DLO, BMO, NMS, NMA and the DANLEP Zonal Coordinator (ZC) have kept in touch with the community, visiting regularly and checking on needs and problems.

Other follow-up activities have included skin and POD camps and counselling. The extent and effectiveness of such activity varies from project to project. A report on SAPEL in Tamil Nadu has commented that the enthusiasm shown in case detection has not been sustained for treatment and follow-up.

FAMILIARITY AND ACCEPTANCE EQUALS PERFORMANCE

Acceptance by the local community, whether of health staff, NGOs or volunteers, proved a crucial factor in the conduct of SAPEL. In Lanji, for example, something close to the ideal situation was achieved, with the DLO, BMO, DANLEP ZC and field health staff gaining as much acceptance in the community as their own volunteers drawn from local youth groups and other village institutions. Other programmes too demonstrate the importance of familiarity with and acceptance by the community.

In Bilaspur district, four SAPELs were conducted in areas which were isolated by fast flowing rivers and nullahs for seven months in the year. Most health staff were non-resident, lacking the familiarity that comes from living in their duty stations. The volunteers who were picked from among the residents of each village became crucial to the conduct of the project. After the survey, detection of cases and start of treatment, the volunteer in each village was assigned specific days in each month for checking on the patients and giving them the month's medication. Despite difficulties of terrain and weather, health officers like NMS, MO and DLO conducted periodic checks in the SAPEL area. The volunteer, being a local person, usually gained the patients' trust and so played a central role in suspecting leprosy and ensuring full treatment.

Badwaha block in Khargoan district is not so heavily forested. The more open bush is interspersed with chequered fields laid out among undulating, rounded hills, making the landscape look deceptively orderly and organised. But the hamlets are small, few and far between. The roads are poor (which is not unusual in Madhya Pradesh) and travel from hamlet to hamlet takes almost as long as it does in the forested hills elsewhere. For these reasons, the block was proposed and approved for SAPEL. However, when the district health officers visited the area, they discovered the extent to which they were out of touch with the local people. They could not get any volunteers to work on the project. SAPEL was therefore entrusted to the missionaries of the St Joseph's Leprosy Centre in Sanawad. Because they were known and accepted by the local population, they were able to recruit volunteers who covered 11 villages in the detection survey, produced six suspected cases, of whom one was confirmed. This also illustrates that the effectiveness of SAPEL is not to be judged only by the number of detected cases but as well by the fact that a population hitherto not surveyed for leprosy incidence has now been fully covered.

SIX CASE STUDIES**PROJECT BASTANAR**

The district of Bastar in Chhattisgarh is hilly and forested. Streams and rivers compound problems of access, especially during the monsoon. Tribals form a large proportion of the population and the languages they speak are very different from that spoken by non-tribals in the state. The literacy level is low, as is the standard of living.

SAPEL was initiated in January 1999, in block Bastanar, sectors Badekilepal and Kodanar. MPWs of the general health system were fully involved and were an essential part of the survey teams. Selection of other volunteers — *anganwadi* workers, VVWs and *sarpanches* — was finalised by the district collector, who took an active interest in the project. All volunteers underwent two days' intensive training in the signs and symptoms of leprosy, methods of detection and recording of symptoms, how to approach the people to be surveyed, explain facts about leprosy to them and persuade them to undergo examination.

Pre-survey IEC involved recorded messages broadcast from a moving jeep and performances of a play about leprosy. The house-to-house detection survey was conducted over five days, 9th to 13th of January, 1999. Fifteen search teams of one male and one female volunteer each were each accompanied by an NMS or NMA for immediate confirmation. MDT was initiated at once. The full course of drugs for each patient was entrusted to the volunteer for that area, usually the MPW, with periodic checks by the NMS/NMA or MO. The DLO visited the area twice a month during the period of treatment. Except for one who left the area before completion of treatment, all patients received their full course and were checked at the appropriate time for RFT.

The project area covered 43 scattered villages and hamlets containing a population of 39,747. All the villages were visited and 28,467 persons were contacted during the survey. Of 30 suspected cases, 25 were confirmed. These consisted of eight SSL type, 12 PB type and five MB type cases, with one patient in grade 1 of disability. Six of the 25 cases were detected in May 1999, in a mop-up survey.

OBSERVATIONS

In the opinion of the DLO and others involved in the project, pre-survey IEC was effective in raising awareness and familiarising the target population with the health system. After SAPEL, people have been going to their MPWs/volunteers about all their health problems, not just leprosy. It is doubtful if IEC appreciably increased the general level of knowledge about leprosy. The disease is known variously in the tribal languages as *maddi bhimari*, *daagi* and *rog*. Patients and their families agree that it is curable and that if anyone else in the family had it, they would report it themselves. Patches are the well-known symptoms. There is little familiarity with any of the other symptoms. MPWs say there is no stigma or ostracism prevalent among the tribals. Nor is there any problem about conducting full body examination of women.

Among MPWs and other volunteers, much of the knowledge gained during training has been retained by those who have actually participated in the detection of one or more cases and in the treatment of patients. Volunteers in areas where there have been no cases remember less. Knowledge of patches is common; other symptoms are remembered on prompting, or not at all. Several volunteers said they would like some re-training, including demonstration with an actual case. "It has been two years since the training and we have to deal with so many other health problems also," said an MPW who had found no leprosy cases in her area.

The motivation level of MPWs, especially the women, is high. The population an MPW has to cover is scattered over a large area with difficult terrain, requiring much walking from hamlet to isolated hamlet. During SAPEL, female MPWs and *anganwadi* workers showed a high level of commitment, covering many miles on foot to keep in touch with their patients, sometimes making repeated visits when a patient was away from home. Because of low literacy rates identifying volunteers among the tribal population was rare. Non-tribal volunteers needed some knowledge of the local dialect to communicate effectively. MPWs maintain a high level of familiarity with the people they serve, picking up words and phrases of their language and establishing a workable base of communication. Some MPWs do not see their own

families for a week or more at a stretch. One who chose to live in the village where her HSC was situated, visiting her family only on weekends, commented that she could do little to improve the health of “her people” if she lived in town and operated the HSC like a 9-to-5 office. As in so many other SAPEL areas, the female MPW has contributed substantially to the success of the project.

LIMITED KNOWLEDGE, LIMITED EXPECTATIONS

In one family, where the MB patient was a 10-year old girl, the parents were happy that the MPW had given medicine to cure her because the patches had made the girl reluctant to step out of the house and may have spoiled her marriage prospects later. They had little interest in naming the disease or learning anything more about it. The girl’s older brother showed knowledge of many symptoms, knew what could be the result of neglect and had made sure his sister took the medication. He was happy to be complimented on his knowledge but not interested in using it to look out for symptoms among friends or neighbours or to participate as a volunteer in a future project.

SALIENT FEATURES

- Hilly, forested area with scattered tribal population, low literacy and poverty.
- IEC effective in raising awareness of health system, making known that leprosy is curable and promoting voluntary reporting. No general interest in anything further.
- Cooperation during detection but no community participation.
- Thorough survey and follow-up. Specific procedure for RFT.
- Commitment of female MPWs a major factor in success of project.

PROJECT GURUR

Gurur block in Durg district of Chhattisgarh lies in the plains, has reasonable communication facilities and no access problems. It was selected for SAPEL for other reasons: There has been no leprosy elimination unit or trained leprosy workers within the government health system. Patients were cared for by The Leprosy Mission (TLM), known for the excellence of its treatment. TLM

treats reported cases; it does not have the infrastructure for large-scale detection. The mission has only one NMS for the whole population of Gurur (over 130,000). It was suspected that there may be a large number of hidden cases in Gurur and that the PR, based on registered cases, did not reflect the reality. SAPEL was to correct this imbalance by:

- Covering the entire population of the block, revealing almost all hidden cases;
- Training general health workers in detection and treatment of leprosy, preparing them for integration;
- Increasing people's awareness and participation in leprosy elimination;
- Establishing a close working relationship between the mission and the general health system.

SAPEL was initiated in Gurur in early 1999. Trainees included 48 MPWs (29 female and 19 male). For volunteers, persons suggested by *gram panchayats* were interviewed by the MO, Block Extension Educator (BEE) and NMS. Criteria were literacy, interest and availability (having the time). The preference was for *anganwadi* workers, students and young married women — daughters-in-law of local families who would not leave as daughters do, had the time (not in paid employment) and influence among women (being educated).



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The one-day training of volunteers — demonstration of detection procedures and slide shows — was conducted by the MO and NMS. IEC included posters, film shows, music and announcements from a mobile van. The detection survey was by 29 teams covering the 29 HSC areas took a week. Each team had a female MPW, a male MPW (where possible), an *anganwadi* worker and a lay volunteer. The teams were in the field from 6 am to 10 am daily. A mission booklet, with illustrations similar to the body chart, was provided for marking symptoms.

All 122 villages of Gurur block were covered. In a population of 131,259, 119,976 persons were con-

tacted; 97,422 were physically examined. Of 144 suspected cases, 17 were confirmed. Three were MB cases and 14 were PB. There were 12 female and five male patients. The first Tuesday of every month was fixed for patients to collect their medicine and take the first dose in the MPW's presence. When patients did not turn up, the MPW took the medicine to their homes. Smear tests and clinical examinations were conducted by the mission staff after completion of treatment, concluding with RFT.

OBSERVATIONS

A major outcome was the close cooperation established between the government health system and the mission. The former provided the manpower and the latter the expertise. Health staff received much-needed training in leprosy work. Going by the recollection and understanding of MPWs nearly two years after the survey, training was very effective. The understanding of other volunteers was naturally less, said the mission's NMA: "It will hopefully improve as we plan to continue their involvement in leprosy elimination. With the MPWs also, we work to refresh their memories and add to their knowledge. Mission staff attend the weekly sector meetings and monthly PHC meetings to discuss the situation regarding leprosy with government health staff."

The large number of suspected cases (144) compared to the number actually confirmed (17) may indicate volunteers' inability to distinguish between leprosy and other skin problems. It could also be the result of excessive zeal.

Over 90% of the population of the block was covered. The survey confirmed that the pre-SAPEL PR figure was deceptive. In the mid-80s, Gurur had a very high PR of over 30. This had come down yearly, and in 1998 the PR was 2.1. The survey brought the figure for 1999 to 4.4, confirming the existence of hidden cases. Since then, public awareness has resulted in more voluntary reporting. The PR for 2000 was 4.9. It is expected that early detection and treatment will again bring the PR down, now reflecting the true situation. There was no ostracism or isolation of cases even prior to the project. There was some fear stemming from traditional misconceptions. IEC has dispelled much of this fear. Volunteers generally had no problems in conducting full body examination, especially if privacy was ensured. Some re-

luctance existed among upper class women and Muslims in *purdah*. With just 17 cases in an area of easy access, it was possible to ensure that each took the full quota of medicine. Intermediate checks during the treatment period by the MO and NMS and a standard system for RFT are positive features.

SALIENT FEATURES

- No access problems. Health staff not familiar with leprosy work. No previous detection drives.
- Expertise provided by mission. Cooperation between health system and mission.s
- People's participation in detection survey.
- Major role of female MPWs.
- Large number of hidden cases revealed; increased voluntary reporting.
- Standard RFT procedures.

PROJECT LANJI

Lanji block in Balaghat district of Madhya Pradesh is a hilly, forested area with poor roads and a significant tribal population of nearly 50%. Villages and hamlets are scattered in remote, difficult to access areas. In the more remote areas there is Naxalite activity. Lanji is a high endemic area with a pre-SAPEL PR of over 9.6. SAPEL covered the most difficult to access area in the block, containing 28 villages and several outlying hamlets and settlements. The PR in this area was 41.63, with 16 cases under treatment before SAPEL.

Training of volunteers and detection survey were conducted in early 1999. For selection of volunteers, community meetings were held in each village with the help of *panchayat* members. Many volunteers were VVWs or community health guides (CHGs) and/or belonged to NGOs like the Mahatma Gandhi Nav Yuvak Sangh, the Jan Swasth Rakshak, the Gayatri Parivar and several more. A total of 56 volunteers (one female and one male from each village) was trained.

IEC, initiated before the survey, consisted of rallies, folk music and drama, drumbeat announcements, slogan writing on walls,

distribution of literature about leprosy and SAPEL, meetings with the target population in groups and individually. All the volunteers took an active and major part in IEC. Such activity was not confined to the pre-survey period but was continued in a sustained manner for more than a year.

The body chart had been revised by the DLO, Balaghat, to incorporate further subdivisions in the human form and with more headings under which written information could be included. The survey covered most of the population and the body chart was used in almost every case. A total of 15,058 persons (7,656 males and 7,402 females) were examined by the volunteers and 91 suspected cases were recorded. 68 of these (38 male and 30 female) were confirmed as having leprosy (two SSL, 28 PB and 38 MB). Twenty of the MB cases were in grade 1 of disability and one case in grade 2. Six of the 68 patients were children.

USING THE BODY CHART

There has been maximum use of the body chart in Lanji. A group of 14 volunteers said that they had, together, surveyed 5,686 persons, in a total population of 5,908 in the area assigned to them. They had used the body chart in every case. In 592 cases (a little over 10%), they were unable to conduct a full examination because “there was a problem with number six”. (The groin area is numbered 6 in the body chart.) They had been able to persuade everyone else to agree to a full examination. One of the young female volunteers, explaining how she convinced reticent women to accept a full examination, said: “I have known them all my life. I call them elder sister, aunt, or grandmother. I tell them, ‘when you have a baby do you worry about the midwife or anyone else who is helping you? This is also a matter of your health.’”

MDT was initiated immediately after confirmation. While the MPW was in charge of distributing subsequent doses, the volunteers bore the responsibility of ensuring that every patient collected and regularly took the medicine, sometimes carrying it to the patient themselves. Volunteers also participated in organising and conducting skin and POD camps. Through all these, IEC activity continued in the project area. Community participation

was high, with *panchayat* members and other elders helping to organise each activity and women's groups and schoolchildren being present in large numbers.

The ZC, DANLEP, Jabalpur, the DLO, Balaghat and the BMO, Lanji were actively and involved in planning and organising SAPEL and developed a personal equation with several of the volunteers and patients. The CHMO, Balaghat and the Collector also extended their active cooperation.

OBSERVATIONS

Responsibilities were clearly defined from the proposal stage and everyone in the management team was deeply involved in the project. Much responsibility was also delegated to the community, particularly to the volunteers. Most of the village voluntary workers in this block are members of a *Nav Yuvak Sangh* (youth group). Their enthusiasm, commitment and determination have converted SAPEL into a total community activity.

At every stage, from preparing IEC material to ensuring that each patient takes medicine regularly, volunteers have understood what they are doing, why they are doing it. They have had the support and appreciation of their families and their community. Knowledge and understanding about leprosy among volunteers is very high. Community awareness is also at a high level. There is genuine and continuing progress towards elimination of the disease, and of the myths and misconceptions, fears and stigma that surround it.

The young people of Lanji have structured SAPEL's IEC activity to suit their community. They have a group of musicians who have written songs about leprosy elimination. They have organized rallies, information campaigns and POD camps. While SAPEL is an exercise limited in time, it has generated such momentum in Lanji that the community seems to have dedicated itself to continuing what SAPEL initiated and ensuring that their area is leprosy free.

ALL IN IT TOGETHER

At a 3-day POD camp visited by the documenter, members of the local mahila sangam were present in strength. They organised the cooking and serving of community meals. Volunteers and health workers together showed patients how to treat ulcers and other disabilities. The sarpanch and village elders took an active part. On the last day there was a rally of school children. The general level of understanding of the causes, symptoms, prevention and cure of leprosy was high. At the end, a volunteer led the gathering in taking an oath that the community would eliminate leprosy and would aid and comfort those among them who had contracted the disease. This was already being practised! There was no fear of contagion or ostracism of any patient. Among those who cooked the meal were some who had been cured during the SAPEL project or were under treatment. In sitting down to the meal there was no moving away from even the badly disabled or deformed.

SALIENT FEATURES

- Difficult to access, high endemic area.
- Almost total coverage and excellent use of body chart.
- Full community participation, particularly of youth, with innovative IEC methods.
- High level of understanding among volunteers and people in general.
- Active involvement of health staff at all levels.
- Continuing activity and progress towards elimination.

PROJECT GULAIMAL

Khalwa block of Khandwa district, among the most isolated parts of Madhya Pradesh, is a tribal area with rough, forested terrain and rivers and nullahs flooded during the rains. The roads can hardly be recognised as roads. The reach of the general health system and of the leprosy elimination staff is poor. The people, in scattered villages and hamlets, have a low literacy rate and

living standard, and migrate into neighbouring areas of Maharashtra for seasonal work.

The project area in Khalwa covered the Gulaimal sector consisting of 17 villages with a population of 14,701. According to the project proposal, 34 volunteers (17 male and 17 female) were to be selected and trained. Training was to be followed by an intensive 5-day detection survey. However, difficult terrain and flooding of streams compounded the problems of the supervisory staff even in the initial phase of volunteer training and IEC. They were unable to cover the whole area at one time and this project was implemented in two phases. In the first, 12 volunteers were trained to cover six villages having a total population of 5,499. This survey took place in September 1999. The rains had not ceased completely and volunteers and supervisory staff had to travel first by jeep over rough roads and then on foot across streams. A total of 3,797 persons were examined in these six villages, resulting in 61 suspected cases. Four cases were confirmed and started on MDT.

The remaining 11 villages were covered in December 1999. In all, 34 volunteers had been trained and deployed in the 17 villages. They had covered a population of 10,830 out of a total of 14,701, producing 115 suspected cases. Eleven of these (five PB and six MB) were confirmed within a week of the survey and treatment was started immediately. There were no cases of disability. Among the 11 patients, there were five men and six women.

The volunteers consisted mostly of VVWs and a few *anganwadi* workers. Selection was on the basis of names suggested by general health workers. Low literacy levels among the tribal population precluded their selection as volunteers. The VVWs were seen as being most familiar with the people they served and so likely to find acceptance.

Pre-survey IEC consisted of putting up posters, broadcasting messages from a jeep and small group meetings in the villages to be covered. Body charts were used for the survey. While the health staff were in formal charge of MDT doses, in practice up to three months' supply for each patient was given to the volunteer concerned as access was easiest for the latter.

OBSERVATIONS

This area of extreme inaccessibility provides a textbook example of the need for a special programme to reach remote hamlets. This was a major reason for the project being conducted in two phases. The difficulty was compounded by other factors: (i) The time chosen — August-September — when there was still some rain and the streams were full; (ii) inadequate coverage of the area by both the general health and leprosy staff. The BMO, Khalwa and his staff were overstretched because of the number of programmes in different areas of health that fell within their responsibility and the time taken for staff to access patients and vice versa. The DLO, Khandwa, while showing interest in the project, also appeared to be short of time. At every phase, much of the implementation had apparently depended on the experience and drive of the senior NMS, Khandwa.

More than a year after the project, volunteers showed a reasonable level of retention and understanding of what they had learnt during training, except in their inability to differentiate between leprosy symptoms and symptoms of other skin ailments like leukoderma. Either this or excess of zeal may account for the large number of suspected cases compared to the number confirmed (115-11).

There had been some difficulty in identifying an adequate number of women volunteers. Also, since the number of volunteers assigned to a village or group of hamlets depended on the population, some villages had more than two volunteers, while some had only one, either male or female. Among the volunteers, it was the *anganwadi* workers who proved most effective.

IEC activity had raised awareness and volunteers had no problems in conducting body examinations. The VVW being known to the villagers was a positive factor except in the occasional case where a VVW had lost their trust for other reasons. IEC has not been sustained after the pre-survey effort though individual volunteers say they continue to talk to the people about the causes of leprosy and its curability. There appears to be no stigma or isolation of patients. Misconceptions about leprosy are related to its cause, such as believing it to be a punishment for sin. This too, is losing ground, according to a *sarpanch* who

appeared to have retained much of the information offered during the campaign.

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.

SALIENT FEATURES

- Extremely isolated, difficult to access area.
- Reach of health staff poor.
- Low involvement of health officials.
- Though conducted in two phases, project coverage inadequate.
- Awareness campaign and training of volunteers effective.
- Detection assumed to have fallen short of actual number of cases.

PROJECT KRUSHNAPRASAD

Krushnaprasad block contains 109 villages and 46 hamlets scattered over 22 islands strung across the southern part of Chilika lake in Puri district of Orissa. The population in mid-1998 was estimated at 75,195. The people are mostly fisher-folk and a majority of the men are out on the lake in their boats from early morning to late evening. Boats are the only means of transport between islands. Kachcha roads and footpaths connect hamlets within each island. Sometimes it is easier to travel by boat along the shore than by land, between habitations on the same island. Literacy levels are low.

The health infrastructure in the block consists of one PHC at Chilika Naupada, an additional PHC (recently established) at Titipo, a hospital at Krushnaprasad and 15 HSCs. The facilities are understaffed. For example, the block has only two doctors as against the seven sanctioned and five of the 30 MPW posts are vacant. Vehicles provided to cover the area are old and in poor repair.

The SAPEL proposal for this area stated that the existing infrastructure was too poor to carry out leprosy detection and treat-

ment in a sustained manner. It offered the estimate that there were about 320 hidden cases in the block. In addition, many old cases, registered under the MLEC conducted in 1998, were not receiving full treatment. Health staff are too few for the difficult area, have to provide for all the health needs of the population, and cannot maintain regular contact with patients.

The Krushnaprasad SAPEL was organised and conducted by the MO and staff of the Leprosy Eradication Unit (LEU) Puri. Additional vehicles and staff were mobilised for the project. Intensive activity took place over 14 days in November-December 1998. Pre-survey IEC included announcements through loudspeakers mounted on vehicles or accompanied by drumbeat, folk song and dance, street plays, group meetings and display of posters. 29 leprosy workers, 33 general health workers and 203 other volunteers (of whom 52 were *anganwadi* workers) received training.

KNOW YOUR PEOPLE, TAP THEIR POTENTIAL

In this project area, recruitment of volunteers has been based on the MPW's recommendation. A young graduate with teachers' training had returned to his native village hoping to work in the local government school. While he waited for a posting he involved himself in community development projects and was a natural choice for SAPEL. An *anganwadi* worker of 20 years' experience in one village, and a young girl in another who has just entered college, demonstrate equally their understanding of the information given during training. Their memory of the facts is good more than a year after the SAPEL. The young girl was a high school student when she was persuaded by the MPW, who knew her personally, to join the survey. "I volunteered because I wanted to do some useful work apart from studying," she says. Some of the younger volunteers had also participated extensively in IEC activity. One of them, a graduate who worked with his brothers in cultivation, said he still looked out for signs of the disease among the people of his village and talked to them frequently about the need for voluntary disclosure, prevention of disability and getting rid of fears and misconceptions. It is not surprising that the project organisers have relied on the MPWs to pick the volunteers in these isolated villages and hamlets.

According to the proposal, volunteers were to be picked from a range of local groups and individuals, including *anganwadi* workers, teachers, women's groups and *panchayat* members. In practice, the choice of volunteers was based entirely on the recommendation of the local (female) MPW. Many of the volunteers were *anganwadi* workers. Others were known personally to the MPW and, in her judgement, best suited for the task. Criteria applied by the MPWs included literacy, interest in working for the community, often a history of volunteering for other health projects, having the time and ability to move around scattered habitations. The final selection did not include some of the listed groups like teachers, *panchayat* members or *mahila sangam* members; it did include older men and women with several years' experience in other health projects and educated young people eager to work for their community. 262 searchers took part in the survey. They worked in pairs of one male and one female in the house-to-house survey, while the NMSs and NMAs of the leprosy staff followed up for confirmation of suspected cases either on the same day or the next.

All 109 villages and 46 hamlets were covered in the detection survey which took place over a period of seven days. The search covered nearly 84% of the total population of 75,195. Those not contacted by the searchers included fishermen who had left very early for work and those who were away from home during the search period. In the preliminary survey, the MPWs/volunteers conducted full, or nearly full, body examination of those with patches who came forward, those whom the searchers spotted as showing likely symptoms, those whom they knew well enough to persuade to undergo examination, and most family members of suspected cases. There were 368 suspected cases, all of whom were examined again for confirmation. The total of confirmed cases was 179 (103 male and 76 female). Of these cases, 80 were SSL, 80 PB and 19 MB. Treatment with MDT was initiated immediately after confirmation.

Subsequent doses were held by the PHC and HSC staff for the patients to collect on a monthly basis. In cases where the patients did not collect the medicine on time, the MPWs visited them at home to deliver the medicine. With treatment beginning

in December, only the MB cases still needed to continue the course at the onset of the next monsoon. In a few of these cases, where access to the local PHC/HSC was difficult for the patient and access to the patient's home difficult for the MPW, more than one month's supply was given to the patient at the start of the monsoon.

OBSERVATIONS

Every village and hamlet in the project area was visited and about 84% of an estimated population of more than 75,000 was contacted. This was a major achievement in these islands where fishermen had to be reached early in the day, and where movement involved taking a boat and/or walking several kilometers. But in an intensive survey programme like SAPEL, 84% coverage raises the question whether the special inputs had been utilised to optimum effect. However, staff involved in the programme, like the MOs and MPWs, are confident that the coverage was near total because enquiries were made among family members of those absent, and IEC had been so effective that voluntary disclosure could be expected all over the project area. One MPW cited the case of a woman who had been forbidden by her husband to show her patches during the survey, but who later managed to contact the MPW on her own and got herself examined. Both the MO, LEU, Puri and the MO at Titipo PHC stated that they were confident that there were no more hidden cases in the area.

The IEC activity before the survey had been thorough and most people were aware of what the search teams were looking for. The doctors and health workers involved in this SAPEL project say general awareness has increased enormously since the survey was conducted. Most patients have been particular about getting their medication on time. Patients live with their families and there is no neglect or ostracism. In some areas people are shy of letting neighbours know that there is a leprosy patient in the family. This mostly relates to the fear that marriage prospects of the patient or patient's child may be affected.

MPWs and other volunteers retained reasonable memory of essential facts even two years after SAPEL was initiated. Those

MPWs who had in their care patients whom they provided with their monthly medicine, also remembered the types of leprosy and the treatment for each. This was, of course, outside the purview of the volunteers. Some of the latter had to be prompted to remember those signs and symptoms which were not as common as patches.

Here, too, the female MPWs have played a crucial role. Because of their familiarity with the people, they work from a position of trust both in combating misconceptions and in ensuring detection and treatment.

It follows that community awareness and participation stops with the assurance that, “yes, if I or anyone in my family have any of these symptoms, we will go to the MPW; there will be voluntary disclosure. We know this disease is curable and we will not let it develop further.” Beyond this, the less said about leprosy the better, is the common attitude.

“CHAU” IS NOT “KUSHT”

Most people in the area knew that what caused “chau” (patch) was curable. Some knew that if neglected, “chau” could result in disability and deformity. Very few acknowledged that this was because “chau” was a symptom of “kusht” (leprosy). Voluntary disclosure was acceptable as long as it was called “chau”. Identifying it with “kusht” placed it in a different category altogether. One did not then want one’s neighbours or even relations to know that one was affected by leprosy. While social ostracism or neglect by the family was a thing of the past, tolerance had its limits: marriage with a person cured of leprosy, or even with a member of his/her family, was certainly out of the question!

SALIENT FEATURES

- Difficult to access area.
- Effective IEC and good coverage in survey have resulted in much voluntary disclosure.
- Crucial role of female MPWs.
- Contribution of volunteers.
- Reluctance to identify the disease as leprosy.

PROJECT KOLLI HILLS

Kolli hills in Namakkal district, Tamil Nadu, though only 45 km from Namakkal town, is a world apart. It is an undulating plateau at an altitude of 1200 metres, reached by a ghat road which climbs steeply through forested hillsides. The 14 panchayats of Kolli hills cover 105 villages and 135 hamlets scattered over an area of nearly 300 sq km. Of the estimated population of 37,031, 94.8% is tribal. Among the criteria put forward in the SAPEL proposal were: difficult terrain, poor roads and scattered dwellings making for inaccessibility and poor communication; low literacy and income and poor socio-economic status; prevalence of stigma and false beliefs; inadequate health services due to vacancies in staff posts and poor motivation of existing staff.

The health infrastructure in Kolli Hills consists of two PHCs and 16 HSCs. Each of the latter, staffed by one VHN and one HI, covers a population of 2000 to 3000. Application of MDT under the NLEP began in Kolli Hills in 1987. A survey in June 1992 calculated a prevalence rate of 44.8. By 1999, the total of recorded cases in the area was 393 and the PR was 6.5. The SAPEL proposal, put forward in August 1999, pointed out that the initial rate of detection under NLEP was not sustained afterwards and a fresh initiative was needed.

SAPEL was conducted in Kolli Hills in November 1999. It began with IEC activities: public announcements were made about the detection campaign that was to follow; a *karakattam* (folk dance) with content relating to leprosy was performed in several villages. Jeeps with loudspeakers covered the whole area, broadcasting information and messages.

A one-day training programme was conducted for health workers and community members in positions of influence. The trainees were:

Health staff (NMS, MMA, VHN, HI, etc)	40
ICDS staff	32
Noon meal organisers	60
<i>Dhais</i> (traditional midwives)	30
Teachers of High, Middle and Elementary schools	63

Village Administrative Officers	14
Elected <i>panchayat</i> members	26
Members of <i>madhar sangams</i> (women's groups)	146
Total number of trainees	411

The training provided information about types of leprosy and their symptoms, methods of detection, modes of infection and treatment. It was emphasised that leprosy is completely curable and age-old fears and misconceptions were addressed to remove the social stigma attached to the disease. At an additional meeting preceding the inauguration of the project, health staff, consisting of Health Educators (HEs), NMSs, VHNs and HIs, were briefed on their roles in the detection campaign and the expected result.

The inaugural function, in which the District Collector, district health functionaries and DANLEP-TN representatives participated, was aimed at giving the programme high visibility and thrust. It included a mass rally to mobilise the community.

Core Committees, Advisory Teams and IEC Teams were formed. Each village had a Core Committee consisting of a VHN, a HI, elected *panchayat* members and women's group members. There were four advisory teams of two NMSs each with a vehicle at their disposal. They were to guide the core committees, providing expert knowledge and transport when necessary. The four IEC teams each had a HE, a HI and a BEE or Block Health Supervisor (BHS). They conducted elocution, essay and quiz competitions at schools, covering all the schools in Kolli Hills. They also visited all the villages and in each village were joined by core committee members in IEC work.

The intensive case detection drive which followed was conducted for five days, with the whole area being divided into four sectors. The initial enumeration and examination was conducted mainly by field health workers who showed a high level of motivation. On all five days, they set out very early in the morning, to be able to meet as many people as possible before they left for work in the fields and forest. While extra transport was made available to the teams during these five days, there were many remote hamlets which could be accessed only on foot and many of the health workers walked several kilometers a day. The follow-up to

confirm suspected cases of leprosy was done by the NMS advisory teams.

Of the total population of 37,031, the number enumerated was 32,637 (88.1%) and the number examined was 25,425 (68.65%). Population coverage was less than 90% because many of the more inaccessible areas could not be reached within the five-day period and, despite the field staff's early start, they sometimes missed those who had left for work as well as those who were away from home for more than a day or two. Some of the cases were missed by the field workers and later spotted by HEs or NMSs.

A total of 99 cases were detected during this SAPEL. Of these, 31 were SSL, 42 PB and 26 MB. Among the MB cases, there were five of first grade of disability and four of second grade of disability. For all cases, the first dose of MDT was given immediately after confirmation. The VHNs were responsible for subsequent doses for PB and MB cases. Monthly supply to the patient, which would have ensured that the first dose each month was supervised, was possible only in those cases where the patient was easily accessible (living close to the VHN's own home or within easy distance of a PHC/HSC). During the monsoon months difficulty of access was compounded. As a result, in many cases the VHN supplied the patient with medicine for three or four months together and had to depend on the verbal assurance of the patient and other family members that it had been consumed regularly. In the case of one child, it was discovered after a year (November 2000) that his parents had stopped giving him the medicine because he had exhibited an adverse reaction. Steps were then taken to begin medication again, with close monitoring and other medicines to counteract the reaction.

OBSERVATIONS

The 5-day detection programme was well organised and effective, with 99 cases being confirmed. That less than 90% of the population was covered was due to difficulties of terrain and distances. The coverage could have been greater if more than five days had been provided.

Initial IEC activities were useful in making the population aware

that a special health programme was to take place, but seem to have had no long-term effect. The *karakattam*, which was used to attract crowds at various centres, is not a folk dance native to these hills and was seen as a curiosity with some entertainment value. Many who remembered the dance commented that the songs and words were difficult to follow. Announcements accompanied by beating the drum appear to have given a clearer message.

The training programme was most effective in the case of health and welfare workers such as VHNs, HIs and *anganwadi* workers. Even a year after the training, many of the VHNs and ICDS workers showed a high level of retention and understanding of the symptoms and types of leprosy, and means of infection. The VHNs, in addition, were familiar with the course of medication for each type of the disease.

In fact, the outstanding feature of SAPEL in the Kolli hills was the dedication of the female health workers (VHNs). For some years, the health department had promoted training and recruitment of young women of tribal origin who could be posted as VHNs in their home areas. Though this had been only partially accomplished, it was obviously a positive factor in promoting trust and understanding between the concerned VHNs and the population they served.

The VHNs were also largely responsible for providing patients with their monthly medication. During the monsoon months, it was necessary to provide patients who lived in the more remote hamlets with medicine for three or four months together and then follow-up after the monsoon. A year after the SAPEL survey, and when all the patients detected and treated under SAPEL had completed their course of medicine, the VHNs were still familiar with the case histories and the personal lives of these patients. This familiarity was also exhibited by the HIs, especially those who had been leprosy workers before integration, even though they were not as much 'on the spot' as the VHNs were. Particularly, those HIs who had been part of the leprosy service before integration showed high motivation and made a notable contribution to the project.

Retention and interest was low among others who had undergone training. In the largest high school, the headmaster and assistant headmaster showed a positive attitude and talked of how they had cooperated with health department officials in educating the students about leprosy through talks, rallies and quizzes. Teachers elsewhere in Kolli Hills showed little interest in or knowledge of the subject.

The *panchayat* members apparently retained all the traditional prejudices and misconceptions, while the women's groups functioned solely as Self Help Groups (SHGs) for income generating activities and had neither time nor energy for a leprosy campaign.

While trainees from the above groups were officially part of the core committees of villages, none of them (not even the *anganwadi* workers) participated in the actual detection campaign or subsequently in spreading awareness in their villages. It has been pointed out that in all the Tamil Nadu SAPEL programmes, health staff tend to ignore local groups and adopt the attitude that only they have the prerogative and expertise to detect leprosy cases. Community awareness and participation is therefore very poor.

It follows that knowledge levels are low. Most patients accept that the disease they have contracted is curable and say that they take the medicine because the doctor/NMS/VHN whom they trust has given it to them. But do they know that the disease is leprosy? Most refer to it as "*vandu kadi*" which can be translated as a wasp sting or the bite of a beetle-like insect. Health staff have found themselves facing withdrawal and hostility when they use the word for leprosy, "*kushtam*". They have therefore concentrated on ensuring detection and cure and see no harm in using the local term for the disease. Only cases of obvious deformity are seen as leprosy and there are conflicting reports about the extent of stigma and isolation in these instances.

If the disease is not named, either by the community or by healthcare providers, it follows that IEC aimed at removing false beliefs and stigma cannot be effective or even purposefully undertaken.

There is also room for doubt about the extent to which the cases

detected have been followed-up. There is no standard procedure for RFT, it being often assumed that the patient, having taken the required course of medication, is cured. But in many cases, there is only the patient's word for it that the course has been completed.

SALIENT FEATURES

- Hilly area of difficult access, with scattered population.
- IEC initially effective, but little long-term effect.
- Good coverage in survey with high level of detection.
- Commitment and enthusiasm of VHNs and HIs.
- Many persons other than health staff trained but not used.
- Poor community participation and low levels of knowledge.
- Reluctance to identify the disease as leprosy.

CONCLUSION AND LEARNINGS

A special action project, as its name indicates, is designed to meet special needs. Through SAPEL, state health departments and DANLEP have initiated a massive effort to do just that: to reach out to disadvantaged and neglected populations in remote areas within the overall effort to eliminate leprosy from every part of the country. Levels of success in the various aspects of SAPEL vary from project area to project area. There have been lapses in training, or commitment, or community mobilisation. But in every project area, the access problem has been overcome, the majority of people have been surveyed, most if not all cases have been detected and treated, knowledge has been communicated in a move towards banishing centuries-old fears and misconceptions.

How far have the stated objectives of SAPEL been achieved in these project areas?

ACCESSING ISOLATED COMMUNITIES

This has largely been achieved because of the extra resources made available and the intensity of the detection process. Where there have been shortfalls in coverage, the main reason has been scheduling of the search immediately after the monsoon when rivers are in flood or during seasons of labour migration.

COMMUNITY PARTICIPATION

Lanji, where full community participation was achieved, is the exception. In other project areas, IEC was effective to the extent that people generally cooperated with the search teams. In some areas a considerable number of local residents participated in the search as volunteers. For the population in general, passive cooperation rather than participation has been the rule. There are indications that health personnel prefer this situation as they are able to carry through the operation efficiently in ways to which they are accustomed.

REMOVAL OF MISCONCEPTIONS AND STIGMA

IEC aimed at this objective has been successful in generally

removing misconceptions about the causes of leprosy. Isolation and neglect of leprosy patients is also becoming rare and the SAPEL process has contributed to this. But marriage with someone who has been affected or even with a relation of such a person is avoided. This remaining stigma is offered as the reason why most people shy away from identifying the disease as leprosy. Short of obvious disability, the disease is identified by other names and there is withdrawal and hostility when the word leprosy is mentioned. Health personnel tend to avoid the hostility by using the locally preferred vocabulary so that the aim of detection and cure is achieved.

KNOWLEDGE AND AWARENESS OF LEPROSY AMONG GENERAL HEALTH WORKERS

The participation of multi-purpose workers (particularly the women) in SAPEL has been a major feature in all project areas. Those who played a part in identifying cases and/or were in charge of administering treatment show a high level of knowledge and awareness. Others who underwent training but did not come in contact with confirmed cases ask for refresher courses. Where MOs and NMSs have made discussion of leprosy a part of weekly review meetings, knowledge and awareness levels are high.

OTHER LEARNINGS

Treatment providers have found direct administration of drugs at the beginning of every month impractical, especially during the rains. Where there is no responsible local volunteer to maintain contact with the patient, means of checking whether the medication is being taken regularly are inadequate. There is no set procedure for RFT.

Specific target groups for community participation, such as women's groups and teachers, have not been effectively drawn into the process, possibly because IEC has been general. In particular teachers, who form an important resource pool, have been the least interested everywhere.

The post-SAPEL sustainability of leprosy elimination in the project areas is open to question. Seen as an intensive, time-bound activity, the SAPEL focus has narrowed down to the sequence of

IEC, training, detection survey, confirmation and initiation of treatment. The end product of SAPEL is seen as the number of cases detected. It was suggested in Orissa that a second round of SAPELs, covering the same project areas about two years after the first, would make elimination more feasible. Ways could also be explored to strengthen the immediate follow-up to SAPEL.

WHAT FACTORS HAVE CONTRIBUTED TO THE VARIOUS SUCCESSES AND FAILURES OF SAPEL?

Concentration of resources, the intensity of a short-term project and the commitment of MPWs have been major ingredients of success. An exceptional case like Lanji shows how community participation can ensure success.

Short-term intensity, while contributing to success in detection, has also had the negative effect of making long-term sustainability difficult. Other negative factors have been blinkered attitudes and poor commitment of some health staff, IEC activity of limited scope not achieving community participation, under-utilisation of resources.