

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 Kodonar. 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.