



**Part Two**

# Process Documentation





## Background

The state of Tamil Nadu has made significant progress in leprosy control activities. In 1997 it was the first state in the country to integrate leprosy services with the primary health care system in rural areas, a process many states are also now beginning to start. The prevalence rate was 108/10,000 at the start of MDT in 1983. Subsequently, before the integration of the NLEP with the PHC system in rural areas, the PR had come down to 7/10,000 in 1997. More than 95% of the population was covered by the NLEP. Presently, the PR is 2.3/10,000 and the goal is to reach the elimination level of 1/10,000 by March 2004 at the state level, and by 2007 at the district level.

**Table 3: Leprosy indicators – Tamil Nadu**

PR per 10,000 population at start of MDT in 1983	108
<i>Status as of March 2003</i>	
Present PR per 10,000 population	2.3
New case detection rate (NCDR) per 10,000 population	3.9
Percentage of MB cases among new cases	23.8
Percentage of child cases among new cases	18.5
Percentage of Grade II disability cases among new cases	1.2

Although the prevalence rate in rural areas has decreased dramatically, the characteristics of urban conglomerations pose special problems for the leprosy elimination work. For instance, during April 1998 and March 1999, the highest number of new cases (2,291) and child cases (1,372) were reported in Chennai.<sup>2</sup> Furthermore, since 40 per cent of the population in

<sup>2</sup> The diagnosis of a large number of leprosy cases among children may mean several things. Firstly, it implies that there are a significant number of undetected active cases of leprosy among adults, who are passing it on to children. Secondly, it points to lacunae in routine survey activities. Women and children are more easily available for examination, while adult male members are being missed out.

Tamil Nadu now resides in urban areas, there is an urgent need to develop an urban leprosy elimination strategy. This need is clearly recognised by the state government. A government order dated 19 September 2002 authorises the establishment of primary health care centres in the six corporations and 102 municipalities in the state. It is proposed that each urban primary health centre would cater to a population of 1,00,000. The new urban health care delivery policy, again the first of its kind in the country, envisaged the reorganisation and restructuring of the urban health infrastructure and services in the corporations and municipalities in the state. This policy would have the effect of integrating leprosy services within the general health care system in urban areas, and consequently strengthening the urban infrastructure to provide sustainable leprosy services.

Complementary to this urban health system restructuring is another policy-level decision that involves the participation of NGOs as facilitators and partners in urban leprosy elimination activities. In order to harness the potential of existing leprosy NGOs in elimination activities, DANLEP facilitated a process of partnership-building between NGOs involved in leprosy work and the state government. This effort resulted in the government formulating a relocation plan for the leprosy NGOs from rural to urban areas. The NGOs were also encouraged to readjust their vertical approach in favour of a partnership with existing health care providers in an effort to integrate leprosy care in urban areas.

A formal government order to this effect was issued on 8 November 2002, which authorises NGOs to play the role of facilitators in the urban leprosy elimination programme in Tamil Nadu. The situation in the state is particularly conducive for government-NGO collaboration. There are over 31 reputed specialised leprosy NGOs with more than three decades of experience of working in different parts of the state. They have played an important role in supplementing the state's leprosy programme. They possess the necessary expertise, facilities and grass-roots networks to become partners with the government in the leprosy elimination initiative, a role they have been playing in an informal manner so far. With their expertise in IEC, capacity building and POD, they can mainstream leprosy services within the urban health system without any additional financial burden on the state.

Highlighting the differences between leprosy services in urban and rural Tamil Nadu, the State Leprosy Officer told the documenter in the course of an interview in April 2003:

*“The situation at the primary health centre is very different. There is more manpower and the female component is also present. Supervision is also better. Urban areas lack the infrastructure for leprosy. Urbanisation poses many problems, including large floating populations. Data is also not available on the higher income groups, who mostly visit private practitioners. It is difficult to involve private practitioners in elimination work. In this situation, it is good to involve NGOs. They have the expertise in providing leprosy services.”*

Examining the issue from the NGOs perspective, a member of the core consultative group coordinating the Government-NGO integration process for leprosy elimination in urban areas, explained to the documenter:

*“Around 1999, NGOs in Tamil Nadu thought leprosy work would stop. Elimination was to be achieved in 2000 and the funds were also drying up. Our organisation, the German Leprosy Relief Association, organised a meeting with prominent leprosy NGOs. Several ideas were floated like NGOs coordinating leprosy activities at the primary health centre level in rural areas. We had the experience. We also thought we could help in integration of leprosy services in urban area. We proposed to support the government. By the time the urban primary health centres are in place, elimination will have been achieved and then we can withdraw. Working in the area of leprosy is a half-way house for us.”*

DANLEP representatives in Tamil Nadu actively participated in a series of meetings convened in 2002 between the state government and NGOs to work out a common agenda of action for urban areas. While representatives from NGOs have shown their willingness to participate in leprosy elimination in collaboration with the government, they have also highlighted their limitations in terms of geographical extent, nature of expertise and source of funding. It is agreed that the prime responsibility for the programme and its sustainability rests with municipal corporations and municipal health authorities and NGOs could only play a facilitating role in identifying

stakeholders, coordinating the work of different agencies, building partnerships and networking.

A tentative list of International Federation of Leprosy Associations working in Tamil Nadu that could perform the role of facilitators in different districts was prepared by the Government-NGO Consultative Group. The ILEP agencies involved are: the German Leprosy Relief Association (GLRA), the Damien Foundation India Trust (DFIT), and the Leprosy Mission (TLM). A nodal ILEP-affiliated agency has been identified for each district to coordinate with the government in respect of the urban leprosy elimination programme. For instance, St. Joseph's Hospital is a DFIT-affiliated NGO assigned the task of coordination and networking for Dindigul district (urban). The identified NGOs have expertise in the area of leprosy and hence can be involved in all aspects of work from training to management and evaluation. They can be equal partners with the government in a joint ownership of the leprosy elimination programme in urban areas.

The main characteristics of the government-NGO collaboration are:

- The ILEP agencies working in Tamil Nadu will support the NLEP, keeping elimination as a goal within the overall framework of integration.
- The GLRA in Chennai will be the main ILEP agency spearheading the Technical Support Team.
- The Technical Support Team will facilitate the processes of capacity building, coordination and partnership building among all the agencies involved.
- Given the context of the need to focus on urban leprosy, urban leprosy elimination will be a priority of the ILEP Technical Support Team.
- The urban leprosy strategy will build on partnerships between multiple stakeholders in the urban context. The experience of integration in rural areas and DANLEP's experiences will be the points of reference for this endeavour.

- NGOs will also be involved in capacity building in primary health centres, which will strengthen the integration process already under way.

As a follow-up to this, it was decided to hold district-level sensitisation meetings between local-level leprosy health staff and the nodal NGO entrusted with the task of facilitation for that district. Between March and May 2003, it was planned to hold one such meeting in each of the 29 districts of Tamil Nadu. The aim of these meetings was to develop a local plan of action for elimination activities in consultation with different stakeholders. So far, such meetings have been conducted in 20 districts. It was anticipated that all the districts will have been covered by June 2003.

### **District Sensitisation Meeting in Dindigul District**

The documenter had the opportunity to observe one such meeting held in Dindigul district on 22 April 2003. The meeting was held on the premises of the district health department. There were around 25 participants from the government and NGO sectors, including the DANLEP state adviser. The NGOs represented were: St. Joseph's Hospital, Dindigul (the nodal DFIT-supported NGO for the district), DFIT, Chennai, GLRA, Chennai, Code (working in Kodaikanal), and Aundipatty (the nodal leprosy NGO for Theni district). From the district administration's side, important functionaries were the Deputy Director, Leprosy, the Chief Municipal Health Officer and other medical officers from different hospitals in the district. There were also a couple of paramedical workers and non-medical supervisors from the health department and NGOs at the meeting.

The representative of the local nodal NGO presented a tentative plan of action of St. Joseph's Hospital for the elimination of leprosy in Dindigul. Reiterating that the NGO would play an advisory and liaising role, he enumerated some of the concrete areas of the work envisaged:

- Establish quality MDT services in the identified area, including ensuring adequate stocks of drugs.
- Treatment would be through existing health facilities.

- Voluntary reporting through wider and intensive IEC would replace active case-finding.
- Capacity building of a whole range of medical officers from the public and private sectors.
- Assistance in the planning of special activities, wherever and whenever necessary.
- Facilitating POD activities.

The discussions that followed covered a wide array of issues ranging from indent procedures for ensuring constant MDT supply at the clinic level to the involvement of private practitioners in leprosy activities. Some of the salient issues that came up for discussion are enumerated below:

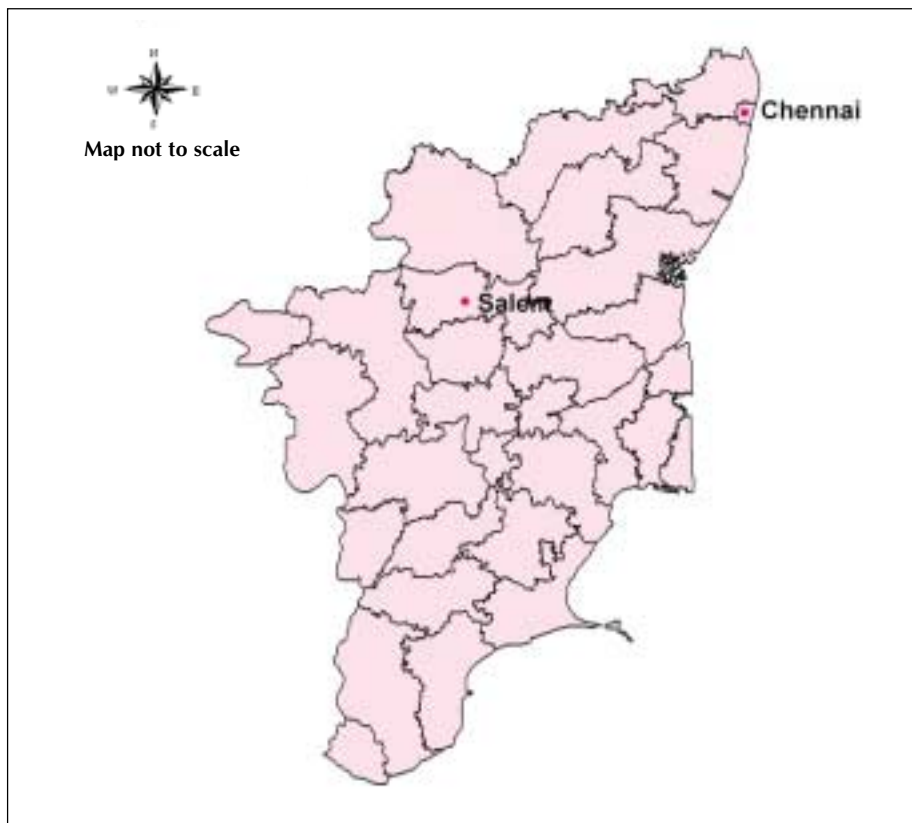
- The government-NGO collaboration needed to be given an impetus in Dindigul. It was suggested that the health department and the nodal NGO officials needed to meet on a regular basis, perhaps in the first week of every month.
- It was reiterated that the NGO would not actively engage itself in leprosy services but would function as facilitators at all urban health posts in the areas allocated to them by the government. Facilitation implied support, coordination and networking in partnership with the government.
- One participant wanted to know why it was necessary to sensitise school teachers and students on the signs of leprosy and its treatment. He wondered why incorporating diagnosis and treatment of leprosy in school health surveys was not enough. Some of the core elements of the urban elimination strategy had to be clarified to communicate the message of volunteer mobilisation campaigns and voluntary reporting of suspected cases.
- The question was raised whether only leprosy NGOs should be assigned the role of nodal NGOs in elimination activities for specific areas. What about other health and development NGOs? Could they not perform the

same functions in areas where no leprosy NGOs existed? For instance, many development NGOs were working in tribal areas. After due orientation, such NGOs could undertake leprosy work.

- The role of medical practitioners in the Indian and alternative systems of medicine (*ayurveda, unani, siddha*, homeopathy, among others) in the leprosy elimination programme also came up for discussion. Could they diagnose cases? The clarification was made that their role was confined to referring suspected cases to the allopathic medical practitioners for diagnostic confirmation and commencement of treatment. But their clinics could become drug delivery points from where patients could collect MDT, free of cost.
- The importance of IEC, especially interpersonal communication, was reiterated. It was important for all health practitioners, irrespective of the system of medicine or locus of practice, to display leprosy in their clinics. Otherwise, people would not know that treatment for the disease was available with the practitioner/service provider.
- One participant cautioned against focusing on case detection, diagnosis and treatment at the expense of rehabilitation of existing patients with deformities. It was equally important to focus on their vocational rehabilitation as well as social integration.
- It was pointed out that constituting a viable group of stakeholders, ensuring that they come for meetings, remain motivated and contribute to the elimination activities was a difficult and time-consuming process. Personal rapport and regular communication, especially through personal contact between them and the prime movers, were necessary to ensure that they remained involved. Means had to be found to make leprosy a priority for the stakeholders.

It was in this overarching context of policy changes and the partnership of government and nongovernment agencies that DANLEP piloted its urban leprosy elimination strategy in the municipal corporation areas of Chennai and Salem. They were selected since they were DANLEP-supported districts. Good response was expected from these districts.

**Figure 1: Map showing urban leprosy pilot project sites in Tamil Nadu**



### **Urban Leprosy Pilot Project in Chennai Municipal Corporation**

Chennai city is the Capital of Tamil Nadu and the largest metropolitan city in the state. The population of Chennai city was 4,253,528 (March 2001), of which 340,000 people resided in the city slums. The city is divided into four zones covering a total area of 170 square kilometres. The NLEP has been implemented in Chennai since 1988. MDT was introduced in the city in 1990 with the support of DANLEP.

**Table 4: Leprosy indicators – Chennai**

PR per 10,000 population at start of MDT in 1983	35.0
<i>Status as of March 2003</i>	
PR per 10,000 population	1.3
New case detection rate (NCDR) per 10,000 population	3.4
Percentage of MB cases among new cases	7.9
Percentage of child cases among new cases	53.9
Percentage of Grade II disability cases among new cases	0.5

Like other metropolitan cities, Chennai has a large medical infrastructure of private and public hospitals. Leprosy services are available at all public health facilities in the city. There are also four leprosy wards having around 160 beds for leprosy patients in the government and voluntary sectors. Table 5 presents an overview of the government health infrastructure in Chennai.

**Table 5: An overview of government health infrastructure in Chennai city**

Type of health facility	Total
Medical college hospitals	3
Government hospitals	16
ESI hospitals	2
Corporation dispensaries	71

The coverage of leprosy services in Chennai is divided into four zones. While zones II, III and IV are covered by the NLEP, Gremaltes, a GLRA-supported NGO, is responsible for leprosy services in Zone I comprising 40 wards and covering a population of 1,253,973.

The urban project initiative was started in Chennai in March 2002. Progress there has been relatively slow; and, as Table 6 shows, only the potential stakeholders have been identified and a small sample interviewed so far.

**Table 6: An overview of urban leprosy elimination pilot project in Chennai: March 2002- Present**

<b>Date</b>	<b>Activity</b>	<b>Responsible person/institution</b>	<b>Outcome</b>
March 2002	Meeting with Deputy Director (Leprosy) to discuss piloting urban strategy in Chennai.	DANLEP and NLEP functionaries.	Government officials show interest and are willing to cooperate.
	Identification and preparation of list of stakeholders by health inspectors of respective divisions along with their addresses.	DANLEP and NLEP functionaries.	A large and composite group of potential stakeholders distributed evenly over the catchment area, along with their occupation and contact addresses, is produced.
April 2002	Appointment of consultant.	DANLEP.	A qualified and willing candidate is available for coordinating activities.
	Compilation and consolidation of stakeholders' list.	DANLEP and Consultant.	A complete list of potential stakeholders along with their contact addresses is available for use.
	Pre-testing of questionnaire with a sample of stakeholders. Questionnaire modified after field-testing.	Consultant.	A reliable questionnaire tailored to the local context is available for use.
	Interviews with three categories of stakeholders, viz. doctors, pharmacists and general public, conducted.	Consultant.	Large number of stakeholders are contacted, give time and complete the questionnaire.
24 April 2002	Meeting of DANLEP (Delhi and Tamil Nadu representatives) with government	DANLEP and NLEP functionaries and consultant.	All persons attend the meeting, review the activities undertaken so far and make plans for future work.

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Date	Activity	Responsible person/institution	Outcome
	officials (Additional and Deputy Directors, leprosy) and consultant.		
Not available	Meeting with Collector, Chairperson of District Leprosy Elimination Society (DLES), to present urban leprosy strategy.	DANLEP and NLEP functionaries.	DLES is willing and committed to supporting the urban leprosy elimination pilot project.

Although more or less evenly distributed, the maximum number of stakeholders were from zone IV. A consultant was appointed who identified various stake-holders and interviewed them to gauge their motivation in getting involved in leprosy elimination activities.

Out of the 48 stakeholders interviewed, 13 were doctors, 20 were pharmacists and 15 were from the general public. All the stakeholders expressed their willingness to cooperate, affirming that it was their moral obligation to work for the elimination of this socio-medical problem. A majority of the doctors interviewed were private practitioners, whose understanding of the signs and symptoms of leprosy and the treatment regimen were variable. Although aware of the curability of the disease and the availability of free MDT services, an understanding of leprosy as a public health problem and the elimination strategy was not uniformly present among all the doctors interviewed. They also voiced the fear that their participation in the leprosy elimination programme might adversely affect their private practice. There was an opinion expressed that by actively participating in the leprosy programme, the stigma traditionally associated with the disease might rub onto their own practice, resulting in the loss of patients.

The interviews with pharmacists working in private medical shops showed that their understanding of the indicators of leprosy was below average. Like the doctors interviewed, they also knew about the availability of free

treatment, but they were not aware of the NLEP system. Nonetheless, they expressed a willingness to undergo training for suspecting cases, stock and distribute medicines from their shops and take part in IEC activities.

The group of stakeholders from among the general public of Chennai comprised a motley group of councillors, film directors, journalists, cinema hall owners and beauticians. Their knowledge levels were highly variable; but they knew about the availability of free treatment. Participation from civil society members and local representatives can give a fillip to IEC activities. Furthermore, like barbers, beauticians can become a good source of case detection among women after receiving some training on the rudiments of leprosy.

When the urban leprosy elimination strategy and the follow-up action were discussed with the field health staff, they demanded incentives in return for their participation. Consequently, the State Leprosy Officer requested the DANLEP Tamil Nadu unit to decelerate the work in Chennai and concentrate at Salem.

Now, Chennai has been taken up by GLRA, the nodal NGO for leprosy elimination programme, at par with other corporations and municipalities. It is proposed to invite the stakeholders, who earlier showed interest in leprosy elimination activities, for the district sensitisation workshop, yet to be held.

### **Urban Leprosy Pilot Initiative in Salem Corporation**

Salem is one of the 29 districts of Tamil Nadu. Agriculture and animal husbandry are the major occupations in its rural areas. It is also a centre for textile manufacture. The Salem Steel Plant is a major employer in the district, with a workforce exceeding 3,000 men. Thus, the district is a hub of agricultural and industrial activity.

DANLEP has been working in the district since Danida began assisting the NLEP in 1986. The Salem Corporation, the locus of the urban pilot initiative, is one of the six corporations in the state. It was established in 1994. According to the 2001 census, the population of the areas which comprised the corporation was 7,06,273 spread over 60 wards. Around 65,000 of the

people reside in slums. When MDT was first introduced in Salem in 1987, the prevalence rate was 25/10,000. Now the PR is 0.9/10,000 for the district as a whole. The PR of the Salem Corporation is 1.7/10,000.

**Table 7: Leprosy indicators – Salem**

PR per 10,000 population at start of MDT in 1987	77
<i>Status as of March 2003</i>	
Present PR per 10,000 population	1.4
New case detection rate (NCDR) per 10,000 population	2.3
Percentage of MB cases among new cases	26
Percentage of child cases among new cases	12
Percentage of Grade II disability cases among new cases	2.6

The corporation has one medical college. In addition to the government infrastructure of maternity centres, sub-centres and health posts, there are also general and specialised private hospitals and a sizeable number of private practitioners in the area. Table 8 presents an overview of the health infrastructure in Salem Corporation.

**Table 8: Health infrastructure in Salem Corporation**

Type of health facility	Total
Government Medical College Hospital	1
Government maternity centres	12
Government health Posts	7
Government sub-centres	9
Government allopathic dispensaries	4
Government <i>ayurvedic</i> dispensaries	3
Government <i>siddha</i> dispensary	1
Government <i>unani</i> dispensary	1
Private hospitals	18

St. Mary's Leprosy Centre (SMLC), the coordinating NGO of the urban pilot project, is supported by DFIT. It has been working in the area of leprosy since 1958. A religious congregation by the name of Salesian Missionaries of Mary Immaculate runs the centre. In addition to outreach clinics and

extension work, it has facilities for the rehabilitation of leprosy affected persons, including a well-equipped laboratory, a physiotherapy department and an inpatient ward with 28 beds. SMLC was inducted into the NLEP in 1975. Of the 60 wards of Salem Corporation, 40 wards comprising a population of 4,42,956 are being managed by SMLC, while leprosy work in the remaining 20 wards, having a population of 2,50,280, is being managed by the government.

Despite the fact that integration of the NLEP with the general health services occurred in 1997 in rural Tamil Nadu, the vertical system continues to be in place in urban areas. For instance, in Salem urban area, there are 15 health inspectors, two non-medical supervisors, one physiotherapist, one lab technician and one health educator. The Deputy Director of Leprosy is not only responsible for Salem district, including Salem urban, but also three more municipalities. SMLC also operates through a vertical structure corresponding to that of the government.

The pilot project was conducted in Shevapettai comprising ward nos. 28, 29 and 30. Between 1997 and 2002, a total of 58 cases was detected in the three wards. Shevapet is the hub of commercial activity in Salem Corporation. In addition to the wholesale market, goods sheds for trains and lorries are also situated in the area. It is populated by a large number of migrant workers, who are employed in various workshops and ancillary industries.

The main reason for the choice of this area is the existence of certain occupational groups who remain out of the net of normal case detection work and IEC activities, either due to their pattern of work or frequent change of residence. They are head-load workers, hotel employees, silver and gold ornament workers, auto and bullock-cart drivers, roadside vendors, scavengers and seasonal labourers such as coir workers. Head-load workers, for instance, work round the clock on a shift system. Often they do not return home on a daily basis. Fortunately, many of them have formal associations or unions through which they could be reached. In the course of the implementation of the urban leprosy elimination initiative in Salem, there was a very positive response from the head-load workers at the goods shed at Leigh Bazaar. Several groups were sensitised through personal contact at their respective places of work. In this regard, 138 auto drivers

from eight auto stands, 245 bullock-cart drivers and 1,046 silver and gold ornament workers were provided information on leprosy elimination and the role they could play in the process.

**Table 9: An overview of urban leprosy elimination pilot project in Salem Corporation: April-October 2002**

<b>Date</b>	<b>Activity</b>	<b>Responsible person/ institution</b>	<b>Outcome</b>
April- July 2002	Meeting between DANLEP representatives, Deputy Director (Leprosy), Salem and his staff and the Saint Mary's Leprosy Centre.	DANLEP, NLEP functionaries and staff of SMLC.	Discussion of the urban leprosy elimination strategy and its implementation.
	Identification and preparation of list of stakeholders along with their addresses.	SMLC and NLEP functionaries.	Initially, 99 stakeholders were identified in the three wards of Shevapet, but when the site was visited, the number of stakeholders rose to 110.
	Appointment of consultant.	DANLEP and SMLC.	Project promotion adviser of SMLC was appointed as DANLEP consultant for the Salem pilot intervention.
	Compilation and consolidation of stakeholders' list.	DANLEP, SMLC and consultant.	Done.
	Pre-testing of questionnaire and modification after field-testing.	Consultant.	Done.
	Stakeholders interviewed.	Consultant and SMLC.	110 stakeholders administered revised questionnaire as the first step towards their sensitisation.

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<b>Date</b>	<b>Activity</b>	<b>Responsible person/institution</b>	<b>Outcome</b>
	Baseline database on epidemiological profile of leprosy established.	DANLEP and consultant.	Data on disease profile for past five years consolidated ward-wise, sex-wise, age-wise and mode-wise. Epidemiological data on prevalence, new case detection and annual case detection rates also compiled for past 10 years.
	Analysis of the stakeholders, questionnaires.	Consultant.	Stakeholders' knowledge about leprosy and willingness to contribute, nature of contribution (cash, kind, personal time, etc.) were assessed.
12-13 August 2002	A series of separate workshops conducted with stakeholders. Other participants in the meeting were DANLEP (Tamil Nadu and Delhi representatives), DDL, Salem, consultant and the staff of SMLC.	DANLEP, DDL Salem, consultant and the staff of SMLC.	Objective was to sensitise them on the leprosy elimination strategy, and the role they were expected to play.
13 August 2002	Review meeting between DANLEP representatives, DDL, Salem, and SMLC.	DANLEP, DDL Salem, consultant and the staff of SMLC.	Stock-taking of work so far done and the division of responsibilities for the next phase of the pilot project.
21 August 2002	Follow-up meeting in Chennai between consultant and DANLEP state adviser.	DANLEP, consultant and SMLC.	Discussion focused on the action plan for the October 2 campaign.

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<b>Date</b>	<b>Activity</b>	<b>Responsible person/ institution</b>	<b>Outcome</b>
19 September 2002	Training of trainers workshop to equip them to train volunteers for the survey.	SMLC and NLEP.	Eleven staff members of SMLC (leprosy inspectors) and seven from government side participated.
24 September - 1 October 2002	Nine batches of volunteers trained in the participatory urban leprosy elimination strategy.	SMLC and NLEP.	These included 30 ICDS workers, 13 Goodwill Committee members, 15 members of Social Welfare and Development Society, 34 nursing aids of St. Mary's Hospital, 53 higher secondary school students and seven Nethaji scouts.
26 September 2002	Training of medical officers and multipurpose health workers also undertaken.	SMLC and NLEP functionaries.	Thirteen corporation hospital doctors and 18 multipurpose health workers of corporation dispensaries.
1 October 2002	Intensive IEC in the three wards of Shevapet. Loudspeakers and handouts were used to tell people about the programme on the following day.	SMLC, NLEP and trained volunteers.	Posters and handbills distributed, mike announcement informing about forthcoming activities.
2 October 2002	Launching of the programme in the three wards. Official inauguration followed by house-to-house search.	SMLC, NLEP and trained volunteers.	Mass rally held. Most households are surveyed. Six new cases detected and put on treatment.

Stakeholder identification was done through a multi-phase process. Two separate groups of stakeholders were interviewed. Initially, a group comprising 57 stakeholders was interviewed. The stakeholders were bureaucrats, people working in social institutions and professionals. The group consisted of 53 males and four females. Due to the focus on labourers in Shevapet, especially the head-load workers and labour union leaders, there was an over-representation of males in the sample. The educational level of the majority of the respondents (32) ranged between the sixth and twelfth standards. An overwhelming majority (93%) of them knew that leprosy was curable. The normative perception that leprosy elimination is everyone's concern was backed by a verbal commitment to be partners in the elimination process by 96 per cent of the persons interviewed. While 68 per cent wanted to be personally actively involved, the remaining preferred to contribute in a more measured fashion, either in cash, kind or limited amount of personal time. The stakeholders also evinced the desire to obtain more technical information about leprosy, its diagnosis, treatment and prevention.

Subsequently, 53 more persons were contacted. The second group of stakeholders had a more balanced gender composition comprising 29 males and 24 females. By contrast to the first group, the second group had a larger number of graduates (15). Although the majority of the respondents were willing to cooperate in the leprosy elimination effort, only 9 per cent thought it was a public health problem. With regard to aetiology, 71.8 per cent were of the opinion that leprosy was caused by a germ. Almost 90.5 per cent thought leprosy was completely curable, and 92.4 per cent agreed that early detection prevents deformity; 90.5 per cent of the respondents said they knew that the treatment was available free of cost. The higher educational level of the stakeholders of this grouping in comparison to the first group is reflected in a higher level of awareness about different aspects of leprosy, its aetiology, treatment and prognosis. Furthermore, the higher socio-economic status of the group members was also manifested by the kind of assistance they were willing to commit. More respondents offered to contribute in cash and kind rather than personal time.

A comparison between the two groups of the stakeholders of varying socio-economic and educational statuses confirms the oft-cited correlation between socio-economic status, educational levels and awareness about leprosy; but

it does not shed any light on the levels of motivation. In fact, going by the criterion of personal involvement, more persons from the first group were willing to become partners in terms of giving personal time than those from the second group.

A series of meetings of stakeholders were organised by SMLC in August 2002, after they had been individually oriented to the urban leprosy elimination strategy, with special emphasis on the roles they could play. The objectives of the workshops were to carry forward the process of sensitisation, to discuss the roles that each of them could play, and to draw up a time-bound plan of action delineating their respective functions and responsibilities. The duration of the meetings did not exceed two hours. The venue of the workshops was one of the local schools in Shevapet and the agenda was more or less the same. Presentations were made on leprosy by the Deputy Director, Leprosy (Salem) and DANLEP state representatives, with special focus on the issue of leprosy in urban areas and the urban strategy developed by DANLEP. Subsequently, there was an interactive session between the organisers and the stakeholders.

Four separate workshops were organised with the following categories of stakeholders over a two-day period:

1. Twenty ICDS workers.
2. A mixed group of 20 stakeholders comprising councillors, head-load workers' union leaders and computer professionals, among others.
3. Sixteen members of a local development organisation.
4. Fifteen members of a local women's charity group known as 'Goodwill Committee'.

Due to their ongoing involvement in health activities at the grass-roots level, the *Anganwadi* workers were quick to grasp not only the rudiments of the elimination strategy, but also the specific roles that they could play in that regard. The participants felt that they could cover 50 households for rapid survey without disrupting their other ongoing health-related work.

The second workshop was conducted with a mixed group of 20 stakeholders. After initial discussion on leprosy elimination strategy and the role of civil society members in the process, individual participants volunteered their services in various ways. For instance, the owner of a medical shop agreed to sponsor wall-writing depicting the message of leprosy elimination. A ward councillor offered to sponsor training materials, while a young computer professional offered to undertake data entry. One participant, however, provocatively asked how it was that the government did not have the resources to undertake leprosy elimination activities on its own. Given the diverse composition of the group, interesting questions were raised by the participants in the course of the workshop.

From the stakeholders, a high level of awareness about leprosy and a whole-hearted commitment to work for its elimination was expressed by the members of a local development organisation called 'Welfare Association of Youth for Social Development'. It has as its members a large number of lower-middle class youths. Most of them are daily wagers. Their motto is 'Let us unite. We shall see a new society'. Helping leprosy affected persons is one the long list of its objectives. The youth group agreed to carry out survey in one entire ward.

The workshops with different categories of stakeholders threw up some interesting lessons. For instance, it is more productive to organise meetings of stakeholders of similar socio-economic background and status, educational qualifications and lifestyles. These commonalities help enhance interpersonal communication and cement group cohesion for a common cause. Consequently, the homogeneous meeting of ICDS workers was a more enriching experience for all the participants than the second workshop in which the elite were clubbed together with head-load workers' union leaders. Secondly, much preparation has to go into focusing on the convenience of professionals and upper-income group stakeholders, not only for their availability to attend meetings, but also their ability to concretely contribute to leprosy elimination activities. Thirdly, more systematic work can be expected from organised groups than from stray individuals.

In an interview with the Administrator of SMLC in April 2003, the level of cooperation and enthusiasm of the youth group and the head-loaders' union

was repeatedly under-scored. The latter had even referred five cases for treatment. The Administrator also made a mention of the contribution of the local cine clubs. The local branch of the fan club of the well-known Tamil actor, Kamalhaasan, was especially active in this regard. Explaining the reasons for such a positive response, she said:

*“They want to do social service through which they also get social recognition. They report regularly on the work they are involved in to their head office.”*

A group that emerged as a critical partner for the urban pilot programme was the ‘Salem Shevapet Ladies Good Will Committee’. The fourth workshop was held with 15 of its members. Originally formed as a community-based organisation by the resident Gujarati community belonging to the Saurashtra region, it has now expanded to include women of other communities as well. Its motto is ‘Heal the world’. Its members are wives of local businessmen and professionals, who engage in social service activities in the areas of environment and health. In the context of the leprosy elimination project, the members agreed to carry out a house-to-house survey among the Saurashtrian community residing in wards 29 and 30 of Salem Corporation.

The documenter had the opportunity to meet the president and other members of this association during her visit to Salem in April 2003. They proudly showed the certificates they had received in recognition of their work in the October survey. They also informed her that three cases of leprosy were identified by their members, which were subsequently confirmed and put on treatment by SMLC.

Recounting her experiences, one of the members said:

*“Initially, people looked down upon us. We were doing the survey in our neighbourhood. People were surprised to see us engaged in a survey on leprosy.”*

The councillor of ward 30, who is the husband of the general secretary of the ‘Ladies Good Will Committee’ said that he had got the women together to do some social service. He took credit for organising the group, not as a political person but as a private individual. In an interview, he said:

*“They are housewives, and between the time they complete their household chores and the children come home from school, they are free. I thought they should get together and do some social service.”*

In the review meeting between DANLEP, SMLC and the local NLEP staff after the conclusion of the stakeholders’ sensitisation workshops, it was decided to launch the programme on 2 October (Mahatma Gandhi’s birthday) in the three wards of Shevapet area. DANLEP was charged with preparing IEC and training materials, the survey forms, badges and certificates for volunteers. In addition, it would also provide a digitised map of Salem Corporation, especially of the three target wards. To facilitate the planning for the survey, the Deputy Director, Leprosy (Salem) was given the responsibility of liaising with the government, including ensuring financial support for mass IEC and cooperation of Corporation dispensaries and hospitals. As the coordinating agency, SMLC would work out the logistics for the launch of the programme on 2 October 2002.

A training of trainers (TOT) workshop to train volunteers for the survey was held a fortnight before the survey at the SMLC office. In addition to familiarising the participants with the urban leprosy elimination strategy, an important aim was to design a curriculum for volunteer training. The meeting helped to facilitate interaction between the government and NGO staff brought together for a common purpose.

Initially, the plan was to conduct the training of volunteers simultaneously on the same day in different places; but since the volunteers belonged to different walks of life, such as students, daily-wage earners, housewives and ICDS workers, the training sessions had to be spread over a week and arranged according to the convenience of different volunteer groups and trainers.

In addition, training of medical officers and multipurpose health workers was also conducted. The purpose of training of health personnel was not only to sensitise them to the issue of leprosy and the urban elimination strategy, but also to train them to fill the formats and to clarify their roles *vis-à-vis* volunteers and other actors involved in the ensuing survey.

On 1 October, the three wards were visited by leprosy inspectors and non-

medical supervisors. Ninety-two streets were marked and parcelled out among the different volunteer groups for the survey on the following day.

On 2 October 2002, the programme was inaugurated officially in each of the three wards in the presence of the ward councillors, local leaders and government and SMLC officials. Voluntary reporting centres, marked by banners, were set up at five sites in each ward. Reference slips were given to volunteers to refer suspected cases to these centres.

The actual survey was undertaken in the morning between 7 and 11:30. The shortage of volunteers was keenly felt as the actual coverage number fell short of the required coverage number. Around 50 of the selected volunteers did not come for the survey. Therefore, a sizeable segment of the population in the three wards remained uncovered. There were no extra volunteers available to fill the gap.

Furthermore, it was also found that there was a discrepancy between the population figures available with the Corporation on the basis of which the survey had been planned, and the actual population of a given area. The actual numbers exceeded the expected numbers in all the three wards, because the Corporation's records had not been updated. The survey had to be carried forward and completed later. Therefore, an activity planned for a single day took weeks to complete.

Then there was the problem of covering households whose members were absent. It was difficult to make alternative arrangements to survey them because volunteers would not be available. A strategy to cover absentee households should be incorporated in the action plan from the very outset.

Seven cases, six paucibacillary and one multibacillary, were detected during this drive. The programme generated enormous enthusiasm and it received the unstinting support of the stakeholders. For instance, expenses for the mike announcements and certificates and badges for the volunteers were defrayed by private individuals.

Although 2 October, being a public holiday, is a good day for rapid survey, nonetheless, it is difficult to get government officials to inaugurate the

programme on such a day. Again, volunteers expect some recognition for their contribution, which could be in the form of being conferred the certificate of participation in the leprosy elimination campaign by an important dignitary. This is difficult to organise on a public holiday.

One of the main reasons for the successful implementation of the urban leprosy elimination in Salem Corporation was the presence of a local leprosy NGO having vast experience in leprosy work even before the start of the MDT era. Indeed, the success of the Salem pilot project may be attributed to the simultaneous existence of a credible NGO that inspires trust in the community, a solid government infrastructure and active community participation. Describing the experience of collaborating with government agencies, the Administrator of SMLC told the documenter:

*“We always work together with the government. We have no problems. It is our common programme. Public is with us. Government administration is with us. This convergence is the reason for our success.”*

Since the partners are mostly permanent residents of the Corporation area and SMLC maintains regular contact with them, not only in connection with leprosy work but in the context of its other health activities in the areas of HIV/AIDS, TB and reproductive and child health, it is hoped that the pilot project is transformed into a routine health activity with SMLC continuing to play the pivotal role.

## **Conclusion**

Tamil Nadu has performed a pioneering role in several respects with regard to the leprosy programme. For instance, urban-rural disaggregated data are available since 1997. It has taken the lead in formally involving NGOs in leprosy elimination activities in urban areas. Through these efforts, the entire state is taken care of by NGOs as facilitators to push for leprosy elimination by networking and partnership building. Thirdly, the plan to develop an urban primary health care system on the lines of the rural PHC approach would have a dramatic effect on the urban health scenario as a whole. As in the case of mainstreaming leprosy control within the general health system, the urban health policy is likely to start a trend, which other states in the country would want to emulate.



## Background

Orissa is one of the eight endemic states in the country contributing a substantial number of leprosy cases. It is divided into 30 districts. The state has 103 urban areas comprising two corporations, 28 municipalities and 73 notified area councils (NACs). The urban population accounts for 13 per cent of the state population, contributing around 17 per cent of total leprosy cases. While the PR has plummeted from 121/10,000 at the start of MDT in 1983 to 5.12/10,000 in 2003, the new case detection rate has remained stable.

**Table 10: Leprosy indicators – Orissa**

PR per 10,000 population at start of MDT in 1983	121
<i>Status as of March 2003</i>	
PR per 10,000 population	5.18
New case detection rate (NCDR) per 10,000 population	7.9
Percentage of MB cases among new cases	32
Percentage of child cases among new cases	15
Percentage of Grade II disability cases among new cases.	2

Out of the total 103 urban areas in the state, 50 have a PR higher than the state average; and out of these 50 high-prevalence urban areas, the PR in 38 areas is double than the state average.<sup>3</sup>

The urban leprosy elimination project was piloted in five urban areas of Orissa, namely, Bhubaneswar, Rayagada Municipality, Vyasnagar Municipality in Jajpur district, Rourkela and Angul NAC in Angul district.

<sup>3</sup> There are, however, wide variations within the state. The PR in rural areas is 7. In urban areas it is 13.7, while for tribal and state border areas it is 5.1 and 8.2 respectively.

**Figure 2: Map showing urban leprosy pilot project sites in Orissa**



In addition to a high PR, the choice of urban sites was made not only to ensure a geographical representativity in the state among the coastal, plains and hilly zones, but also to incorporate the different urban contexts, ranging from mega-city to municipality and NAC, that characterise Orissa's administrative structure.

What Tamil Nadu accomplished in 1997, Orissa is in the process of implementing in 2003. The vertical NLEP is being integrated with the PHC system in rural areas in a phased manner. The integration of the NLEP in the PHC system will be achieved in two phases in a district. In the process of this reorganisation in a PHC area, core NLEP activities will be carried out by male and female multipurpose health workers. They will be supported by one leprosy worker. This trial phase will last for a period of one year during which PHC staff will be technically equipped to undertake leprosy work independently. Recording and reporting systems will also be modified in accordance with the PHC context. Subsequently, during the second phase,

NLEP workers will be merged with PHC cadres and will be known as multipurpose workers (MPW). Only one non-medical supervisor (NMS) or senior PMW will be retained at the block and district levels for the overall monitoring of NLEP activities. Only one leprosy elimination unit (LEU) will be kept operational at district level to assist the Additional District Medical Officer (Public Health) (ADMO-PH) and the District Leprosy Officer (DLO) in the supervision, monitoring and reporting of NLEP work. Phase I of the integration process has been under way since 1999. For instance, general health workers have been actively involved in various modified leprosy elimination campaigns (MLECs), Special Action Projects for the Elimination of Leprosy (SAPELs), leprosy elimination campaigns (LECs) and routine case detection activities involving treatment, follow-up and monitoring. It is anticipated that Phase II will be completed by the year 2000 in all districts of the state. A formal government order authorising the dismantling of the vertical NLEP system in rural areas is awaited. It is expected that case detection and case-holding will improve with the involvement of the general health staff in leprosy work. However, in some of the urban areas, the vertical NLEP structure will continue to operate for some more time until a substantial decline in PR has been achieved.

## Urban Leprosy Pilot Project in Bhubaneswar

The population of Bhubaneswar is 710,795. Like other state capitals in the country, the city is characterised by a large number of slums, a floating population and a complex health infrastructure.

There has been a substantial decline in the leprosy PR since the introduction of MDT in 1985. Some of the important epidemiological indicators are given in Table 11.

**Table 11: Leprosy indicators – Bhubaneswar**

PR per 10,000 population at start of MDT in 1985	127.90
<i>Status as of March 2003</i>	
PR per 10,000 population as of March 2003	10.3
New case detection rate (NCDR) per 10,000 population	7.2
Percentage of MB cases among new cases	38.8
Percentage of child cases among new cases	12
Percentage of Grade II disability cases among new cases	0

Bhubaneswar has a complex health infrastructure comprising public and private institutions and multiple service providers. Major health care institutions located in the city include Kalinga Hospital, Capital Hospital, the Employees' State Insurance (ESI) Hospital, the Corporation dispensaries and the Railway Hospital.

As in the case of Chennai in Tamil Nadu, a series of meetings have been held in Bhubaneswar with identified stakeholders. The urban strategy initiative is being coordinated by the Leprosy Elimination Unit (LEU), the state Leprosy Cell and LEPR India, a national NGO. In addition to other activities, LEPR India is responsible for the training of technical personnel involved in the programme. The roster of activities undertaken so far is presented in Table 12.

**Table 12: An overview of urban leprosy elimination pilot project in Bhubaneswar: May 2001-Present**

<b>Date</b>	<b>Activity</b>	<b>Responsible person/ institution</b>	<b>Outcome</b>
19 May 2001	Meeting between government health officials and state DANLEP representatives on developing urban strategy for leprosy elimination in Bhubaneswar Municipal Corporation.	DANLEP, NLEP, general health system (GHS) functionaries and LEPR India.	After stakeholder analysis, 34 partners identified.
5 July 2001	Partners meeting on urban leprosy strategy held at Circuit House, Bhubaneswar.	DANLEP, NLEP, functionaries, LEPR India. and District Health Society.	Meeting was presided over by district magistrate-cum-collector. Action plan for leprosy elimination in Bhubaneswar developed. Core committee formed, but MOU not formally signed yet.

Contd...

<b>Date</b>	<b>Activity</b>	<b>Responsible person/ institution</b>	<b>Outcome</b>
October 2001	Sensitisation of community organisers.	MO-LEU and LEPR India.	Training was done by LEPR India in partnership with the Director of Health Services (Leprosy and TB).
October 2001	Sensitisation of sweepers of the municipality.	MO-LEU, LEPR India and municipality.	Training conducted by LEPR India in partnership with municipal health officer.
18 April 2002	Follow-up meeting of partners.	DANLEP and NLEP functionaries LEPR India and District Health Society, Khurda.	Meeting held in the office of Deputy Chief Medical Officer of Capital Hospital.
May 2002	One-day training on leprosy for medical officers of Bhubaneswar Municipal Corporation.	MO-LEU, LEPR India and municipality.	Training was conducted by LEPR India.
May 2002	Training of pharmacists.	MO-LEU and LEPR India.	Training was conducted by LEPR India.
May 2002	Training of health workers.	MO-LEU and LEPR India.	Training was conducted by LEPR India.
May 2002	Sensitisation of NSS volunteers.	School and college principals and LEPR India.	Principals of local colleges organised training.
May 2002	Sensitisation of NGOs and informal community leaders in the slum areas.	CYSD and LEPR India.	Trained CYSD members conducted sensitisation.

Contd...

<b>Date</b>	<b>Activity</b>	<b>Responsible person/ institution</b>	<b>Outcome</b>
May 2002	Sensitisation of <i>Anganwadi</i> workers.	LEPRA India, MO-LEU and CDPO.	Child Development Project Officer of ICDS coordinated with LEPRA India, MO-LEU and DANLEP.
May 2002	Sensitisation of school children.	School Authority, MO-LEU and	District Inspector of schools coordinated.
4 Oct. 2002	Training of Lions Club members.	LEPRA India and DANLEP.	Sensitisation done by DANLEP.

The members of the core team constituted to implement the leprosy elimination strategy in Bhubaneswar consists of the Deputy Chief Medical Officer of the Capital Hospital, the MO-LEU, Bhubaneswar, the Assistant State Leprosy Officer, and programme officers from DANLEP and LEPRA India. The ADMO-PH and the Medical Officer of The Leprosy Elimination Unit are responsible for coordinating all training and sensitisation activities.

During the first partners' meeting held in July 2001, an elaborate action plan was formulated which has been partially implemented, and that too at a much slower pace than anticipated. A situational analysis of the health infrastructure in the city and the epidemiological profile of leprosy have been completed. MDT is available in all health facilities, including the ESI hospital. All municipal corporation staff engaged in public health, and a number of private practitioners have been sensitised in the diagnosis and treatment of leprosy by LEPRA India. After training, sweepers of the municipality have been identified as link volunteers in their areas of operation. All schools have been surveyed. IEC has been strengthened. Special efforts have been made to build awareness and speed up case detection in slum areas. Seventy-six cases have been detected through these special activities like MLECs and LECs. The other activities listed in the action plan, such as mass rallies, house-to-house search in the slums by volunteers and evaluation of the urban strategy initiative, are yet to be undertaken. Furthermore, the sensitisation of the councillors of the Corporation has also not taken place so far as all the elected urban bodies have been dissolved.

The Lions' Club of Bhubaneswar has been actively involved in the sensitisation and survey work. The Joint Director of Leprosy and TB, herself a member of the club, personally mobilised the members to participate in elimination activities. After their initial sensitisation during October 2002, the members organised an awareness meeting that was facilitated by the Leprosy Unit and DANLEP representatives in January 2003. Some club members also attended the IEC programme and POD camps organised by LEPRO India. In addition, they also participated in the fourth state MLEC in February 2003. During the course of their involvement, three cases were detected by them and put on treatment.

Unlike Tamil Nadu, there is only one major leprosy NGO in Orissa, namely, LEPRO India, a partner of LEPRO UK. In addition to leprosy, it also works in the areas of TB, HIV/AIDS and blindness control. It is currently operating in seven other states in India. In Orissa, it is working on leprosy in Bolangir, Junagarh, Mayurbhanj, Sonepur, Bargarh, Paradip, Rayagada and Bhubaneswar. LEPRO India's main activities are case detection, IEC, capacity building and POD. As part of the urban initiative in Bhubaneswar, LEPRO India had conducted sensitisation workshops involving medical officers, *Anganwadi* workers, sweepers of the municipality, community organisers and members of CYSD.

While the majority of government health officials interviewed for the present report in the DANLEP-supported states were of the opinion that there is inadequate health infrastructure in urban areas, one Assistant State Leprosy Officer was of the opposite view. He said:

*"There is enough infrastructure. Effective coordination is the problem. Everyone is working independently. There are monitoring and coordination mechanisms, but because people have responsibilities but no accountability, the system does not work."*

It appears that there is some correlation between the size of the urban conglomeration and the facility with which the urban elimination strategy, involving networking and partnership building, can be implemented. This could be one reason for the relatively slow pace of progress in both Chennai and Bhubaneswar.

## Urban Leprosy Pilot Project in Rourkela

The population of Rourkela, the largest industrial city in Orissa, is around 500,000. Of this, 180,000 persons live in slums. The city is divided into two geographically distinct administrative areas. The Civil Township comes under the control of the state government, while the Steel Township falls under the purview of the Rourkela Steel Plant, a public sector undertaking of the Steel Authority of India. In addition to the civil and steel township areas covering 17 per cent and 50 per cent of the total area respectively, the remaining 33 per cent of the area comprises peri-urban slums. The latter houses around 30 per cent of the city's population, a sizeable section of which consists of Scheduled Tribes and Castes. The steel plant is the fulcrum of economic activity employing over 30,000 persons. Consequently, there is also a large volume of migration into Rourkela from the neighbouring districts and states for employment. In fact, 15-20 per cent of the residents are migrants.

The steel plant provides high quality health services to its employees and their families in the steel township. The Railway and the ESI hospitals also provide health care to the employees and dependants of those working in the Railways and in the organised sector respectively. The health needs of the remaining population (around 50 per cent) are met by the government infrastructure and occasional assistance from social service organisations like Lions and Rotary clubs and professional associations like the Indian Medical Association (IMA). Although the slum-dwellers are mostly deprived of quality health care, the Reproductive and Child Health (RCH) programme under the ICDS provides maternal and child health services in 120 slum areas of the city. The state health infrastructure in Rourkela includes the ISPAT General Hospital and Rourkela Steel Plant dispensaries, the Rourkela Government Hospital, the Pamposh Sub-divisional Hospital, the ESI, Railways and Fertilizer hospitals, the municipal homeopathic dispensaries, the Urban Revamping Scheme and the *anganwadi* centres.

The PR in Rourkela is 10/10,000, which is higher than the state average. The present leprosy profile is given in the following table:

**Table 13: Leprosy indicators – Rourkela**

PR per 10,000 population at start of MDT in 1994	54
<i>Status as of March 2002</i>	
Present PR per 10,000 population	10
New case detection rate (NCDR) per 10,000 population	19
Percentage of MB among new cases	19.3
Percentage of child cases among new cases	23.2
Percentage of Grade II disability cases among new cases	0

Despite the fact that MDT was introduced in Rourkela in 1994, and even though there are a large number of health care providers and institutions, accessibility to MDT was limited to the three government hospitals. The slum population was not covered and there was no involvement of the local bodies or civil society members in leprosy work. Consequently, a large number of leprosy cases continued to be detected in the urban health facilities and slum areas. The new case detection rate began to dip only after 1998. Regular school surveys and the efforts of *anganwadi* workers in case detection activities have resulted in increased case registration, both through direct search and voluntary reporting. For each 1,000 population in the slum areas, there is one *anganwadi* centre offering MDT services. Nonetheless, Rourkela continues to account for 13 per cent of the total leprosy case-load of Sundargarh district, of which it is a part.

The urban leprosy initiative in Rourkela was coordinated by the medical officer of the leprosy elimination unit with the help of the district health staff, the municipal authority and local NGOs. Table 16 depicts the chronology of events of the urban leprosy elimination initiative in the city.

**Table 14: An overview of urban leprosy elimination pilot project in Rourkela: April 2002 - January 2003**

<b>Date</b>	<b>Activity</b>	<b>Responsible person/ institution</b>	<b>Outcome</b>
April-July 2002	Meeting of DANLEP team with Medical Officer, LEU, and his staff to discuss piloting urban strategy.	DANLEP.	Consensus on implementation of urban strategy.
	Identification of stakeholders and administration of the questionnaire.	DANLEP and MO-LEU.	Ninety stakeholders administered the questionnaire.
6 June 2002	Meeting of DANLEP Orissa representatives with the local health officials, Chief District Medical Officer, District Leprosy Officer and Medical Officer, LEU.	DANLEP, DLO and MO-LEU.	Action plan discussed and sent to partners for comment.
27 June 2002	Sensitisation meeting with partners.	DANLEP, district health authority, Collector.	More than 40 partners signed the MOU at the meeting held at the Rourkela municipality presided over by the Collector. Micro-plan of action approved.
26 July 2002	Sensitisation of IMA (Rourkela branch) members on leprosy elimination.	DANLEP and MO-LEU.	Fifty-one members of IMA were sensitised.

<b>Date</b>	<b>Activity</b>	<b>Responsible person/ institution</b>	<b>Outcome</b>
July-December 2003	Training sessions on leprosy organised by partners in their respective organisations.	DANLEP and MO-LEU, Inspector of Schools and school principals, CDPO, NSS Coordinator.	Training imparted to 120 teachers, 60 community organisers, 120 ICDS workers, 180 NSS volunteers, and 52 NGO representatives. One thousand community members were also imparted IEC through IPC. Members of some religious groups and the Press Club were also oriented.
Jan 2003	IEC campaign.	DANLEP, DLO and MO-LEU.	With the assistance of the District Public Relations Department, slide shows were shown in local cinema halls and video cassettes were played on cable TV.
30 January 2003	Observation of Anti-Leprosy Day as a public event.	DANLEP, DLO and MO-LEU.	A mass rally was flagged off by the District Collector.

All the stages of the urban strategy model were successfully operationalised between April 2002 and January 2003 in Rourkela. Ninety stakeholders were originally identified and administered a questionnaire to assess their understanding of the leprosy problem and their willingness to participate in the elimination project. The questionnaire data is being analysed. A sensitisation meeting was held with the selected partners, an action plan agreed upon, and the MOU signed. As per the micro-plan, training on leprosy was imparted to a varied group of stakeholders such as teachers, community organisers, ICDS workers, health providers, headmasters of municipal and the Steel Plant schools, NSS volunteers, NGO representatives and community members. The outcome of this whole exercise was that between April and

July 2002, out of a total of 156 suspected cases, 52 were confirmed for leprosy and put on treatment.

Active search was carried out in 166 slum areas with the help of the sensitised partners and volunteers. Interactive sessions with the help of ICDS workers and community volunteers were conducted in slum areas before door-to-door surveys. MDT was distributed in major health institutions like government hospitals, the steel plant hospital and to dermatologists working in the private sector. *Anganwadi* centres had been made drug delivery points. School surveys were undertaken with the active participation of schoolteachers and children. Quizzes on the basics of leprosy and its treatment were conducted among students after their sensitisation.

The result of the partnership-building effort was that Anti-Leprosy Day on 30 January 2003 (Mahatma Gandhi's death anniversary) was observed as a major public event in the city. A huge rally was flagged off by the District Collector in which 52 schools and colleges, local youths and sports clubs and members of the tempo- and taxi-drivers' unions participated. The event was covered by the local TV networks as well. Stickers on leprosy were pasted on public transport vehicles such as buses, taxis and autos by NSS volunteers. The organisation of events on 30 January was one of the items of the action plan and its planning was entirely the handiwork of the stakeholders. It was the first time that the day was observed as a major public event in Rourkela. This enthusiasm was carried over to the state-level MLEC IV conducted in the first week of February 2003.

During her visit to Rourkela in May 2003, the documenter had the opportunity to meet a large number of stakeholders and partners who had taken part in the pilot project. Meetings with private medical practitioners brought out some interesting observations. In response to a query on the role of the general practitioner in leprosy treatment, a skin specialist at the ISPAT Steel Plant Hospital felt that both factual and cultural elements had to be incorporated in any medical training programme on leprosy. He said:

*"Frequent training is required. Doctors also have a tendency to stigmatise. Furthermore, many of them do not know the correct treatment. They have*

*no awareness about the public health aspects of the disease; that elimination is possible. They should be provided literature on these aspects. As a part of the sensitisation process, they should come to clinics like ours for simple observation. Two hours of simple observation is enough."*

Following the same train of thought, a dermatologist practising in an upmarket commercial area of Rourkela felt private practitioners (other than skin specialists) would not really be 'interested' in elimination activities. Being 'so busy', they would not have the time to maintain the registers. As proof, she showed how despite her best intentions, she herself had not been able to keep the leprosy register she had agreed to maintain up to date. She said candidly, *"We are not used to documentation."* She also highlighted the vested interest private doctors may have in not collaborating with the government in leprosy elimination activities. She said:

*"When a general physician sees a skin patch, the first thing he does is to prescribe antibiotics and steroids. That is standard practice. I get mistreated cases like this all the time. General physicians, even with training, cannot treat lepra reactions. Instead of focusing on physicians in urban areas, it might be better to sensitise doctors working in the peripheral areas from where leprosy cases are still coming in substantial numbers."*

When asked about their experience of participating in the leprosy sensitisation session of IMA members, all the practitioners the documenter met told her that they had found it an 'informative' experience, and they hoped that such sessions would not be a one-time affair. Evaluating the outcome of this sensitisation effort, it was noted that 15 cases were subsequently referred to the LEU by private practitioners who had participated in the workshop.

*Anganwadi* workers in Rourkela have attended several training sessions on detecting leprosy cases. They have participated in the MLECs and other mopping-up surveys conducted in the area. They have been supplied with registers to maintain records of all suspected cases. The case confirmation is done by the NLEP staff, who visit the *Anganwadi* centre on a fortnightly basis. The confirmed cases get MDT from the centres.

Visits to several *Anganwadi* centres in different slum areas of Rourkela revealed that the centres had displayed wall posters on leprosy, and MDT drugs were also available. *Anganwadi* workers evinced confidence in being able to suspect leprosy cases. They used terms like 'leprosy' and 'MDT' very comfortably in their description of work. Most of them had diagnosed a couple of cases correctly. When asked whether they found leprosy work as an additional burden on their existing tasks, the consensus was that it was not really a burden. However, all the AWWs interviewed categorically stated that their remuneration was not at all commensurate with the volume of work they performed, especially in urban areas where the number of persons they had to cover was higher than in rural areas. Nonetheless, they expressed 'satisfaction' at being able to 'serve their own people'.

Several stakeholders attributed the success of the 30 January campaign to the enthusiastic participation of school and college students, especially NSS volunteers and the local sports hostel inmates. Examining the categories of participating stakeholders from the perspective of reliability for contributing to leprosy elimination activities over time, it has been found that it is the institution-based school and college students and their teachers, who appear to be in an advantageous position to offer continual support. If leprosy work can be formally made a part of their curricular and extra-curricular activities, the chances of sustainability are to a large extent assured. The enthusiasm of young people, their embeddedness in families and local communities and the existence of a certain social welfare orientation in the education system can be positively channelled for leprosy elimination work.

This was confirmed by interviews with educational authorities. For instance, the District Inspector of Schools, Sundargarh, said she was the headmistress in one of the local schools when she underwent training on leprosy. After the training, she organised a sensitisation programme for teachers and students in her school. In the process, two cases were identified. When the parents were informed, they were quite 'frightened'; but the children subsequently underwent treatment and were cured. Commenting on the involvement of schoolchildren in leprosy elimination activities, she said:

*"Most of the children in our schools are from the deprived sections of society. The two cases that were identified in my school were from the*

*Scheduled Caste and Scheduled Tribe groups. After the training, several students began to examine one another, searching for patches. It was a kind of a game. Many of them are first-generation learners. If they are informed about the signs of leprosy and its treatment, they can pass on the information to their families and neighbours in the slums. But only older children from the ninth standard should be trained. I don't think it is useful to involve younger children. They won't understand."*

She also felt that it was more important to focus on parents. Sensitisation on leprosy can become an item on the parent-teacher association meetings that are conducted regularly in schools. The Inspector of Schools further added that after undergoing the leprosy sensitisation workshop, she noted in a fifth standard textbook the following factually incorrect statement: "Leprosy is a contagious disease. It spreads through touch and clothes." She said that she brought this to the notice of the Education Department, and the error had been rectified.

An important feature of the urban leprosy initiative in Rourkela is the involvement of local, non-leprosy development NGOs in IEC and case detection activities. The documenter had the opportunity to interact with the representatives of two such NGOs, *Sankalpa* and *Rourkela Swasthiya Samiti*. Both are engaged in a range of activities in the areas of health education and employment among the socially and economically disadvantaged sections of the population at the state and regional levels. They had participated in the partners' meeting facilitated by DANLEP and LEU, and had signed the MOU. When asked about their experience of working with the government, the general secretary of one of the NGOs said:

*"Government cannot do everything. We have a tendency to blame the government for everything. Each person has to think for the nation. If you are clean yourself, then the experience of working with the government can be very good. Our goals are the same if we want to sincerely work for public good."*

Another active partner is the *Jana Sansathan Samiti*, a government-funded programme of non-formal education. In addition to imparting literacy and vocational training, the organisation sponsors health camps and awareness

drives through its network of centres in slum areas. In an interview, the programme officer said:

*"We are engaged in imparting life-enrichment education in which health is an essential component. We have been conducting leprosy surveys and imparting knowledge on leprosy is also a part of the refresher course we do with Anganwadi workers in Rourkela."*

IEC is the cornerstone of a successful campaign. Awareness-generation and information dissemination are the cognitive element of this process. But real change means a change in the underlying attitudes and perceptions, which call for novel communication strategies. In an interview, the Medical Officer, Leprosy Elimination Unit, Rourkela, described the innovative IEC strategies that he had developed for his area. He said:

*"I involved the paan and bidi shop-owners. I told them: 'Every time you sell a bidi or cigarette to a customer, just say automatically 'Leprosy is curable.' I asked barbers to repeat the same message while shaving their clients. Initially, they were unwilling, saying that people would consider them mentally unstable if they made such remarks out of context. But some of them did it. And, I think, this is an effective IEC strategy."*

He also spoke of a pet project of his which he had named 'Project *Buthru*' (child). He sought to systematically survey children working in garages, *dhabas* (small roadside restaurants), shops and other establishments in the slums of Rourkela. This was not a successful venture, because as soon as a child was suspected, he would be thrown out of work. Unlike the case of school-going children where teachers could function as the link persons in case detection and medicine distribution, this role could not be expected from small-scale employers.

Despite having many of the features of mega-cities like Chennai and Bhubaneswar such as a large migrant population and a complicated health infrastructure, different stages of the urban strategy from stakeholder sensitisation to door-to-door survey have been successfully implemented in Rourkela.

## Urban Leprosy Pilot Project in Rayagada Municipality

Rayagada district is situated in southern Orissa bordering Andhra Pradesh. The area is rich in mineral resources, which has resulted in the development of several industries. Corresponding to the position of the Rourkela Steel Plant, J.K Paper Mills is the nodal industry in Rayagada which employs a large number of persons and has its own residential and health infrastructure.

About 80 per cent of the population of Rayagada is tribal. Unlike Rourkela, the literacy rate here is very low. Rayagada town, with a population of 58,000, is a busy transit point attracting a large and mobile population from areas both within Orissa and the neighbouring Andhra Pradesh.

While the leprosy prevalence rate for Rayagada district is 6.1/10,000, the PR of Rayagada Municipality is 19.7, which is tree times the PR of the state as well as the district.

There are a number of hospitals and dispensaries situated in the Rayagada municipal area, including the Rayalep Clinic for Leprosy, the District Headquarter Hospital, the J.K. Paper Mills Industrial Hospital, the ESI Hospital, J.K. Pur, Rayagada, and the Railway Dispensary.

**Table 15: Leprosy indicators - Rayagada Municipality**

PR per 10,000 population at start of MDT in 1992	62.5
<i>Status as of March 2002</i>	
Present PR per 10,000 population	19.7
New case detection rate (NCDR) per 10,000 population	9.5
Percentage of MB cases among new cases	33.1
Percentage of child cases among new cases	Not available
Percentage of Grade II disability cases among new cases	0

A leprosy NGO, HOINA Leprosy Research Trust (now known as RAYALEP) exists in Rayagada. Being a branch of LEPROA India precluded its selection as the coordinating agency for the urban leprosy pilot project. The main activities of RAYALEP are in the areas of POD, IEC and the socioeconomic rehabilitation of leprosy patients, as well as capacity building of the general health care

**Table 16: An overview of urban leprosy elimination pilot project in Rayagada Municipality: March 2002-May 2003**

<b>Date</b>	<b>Activity</b>	<b>Responsible person/ institution</b>	<b>Outcome</b>
16 March 2002	Consensus-building meeting of partners held at the Collectorate.	DANLEP, district health authority.	50 persons participated in this meeting.
15 April 2002	Training of schoolteachers.	DANLEP and RAYALEP.	50 schoolteachers sensitised.
16 April 2002	Training of NSS volunteers of Women's College, Rayagada.	RAYALEP, College Principal.	NSS volunteers trained.
17 April 2002	Training of selected members of local NGOs coordinated by PREPARE.	RAYALEP, PREPARE.	35 persons working in different local NGOs sensitised.
18 April 2002	Training of NSS volunteers of Rayagada College.	RAYALEP, College Principal.	121 NSS volunteers (both male and female) sensitised.
19 April 2002	Training of all health providers (medical officers, pharmacists), both public and private.	DANLEP, RAYALEP, district health authority.	40 health service providers oriented.
20 April 2002	Sensitisation of councillors.	DANLEP, RAYALEP, district health authority.	40 NAC councillors sensitised.
22 April 2002	Sensitisation of sweepers of Rayagada Municipality.	RAYALEP, Municipal administration.	Done.
29 April 2002	Mass rally on leprosy elimination.	DANLEP, RAYALEP, district health authority, NSS Coordinator, school and college	Over 500 persons participated, including NSS volunteers, schoolchildren, rickshaw-pullers and other

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Date	Activity	Responsible person/ institution	Outcome
		principals, NGOs.	stakeholders.
1 May 2002	MOU signed by members of Rayagada Leprosy Elimination Committee.	DANLEP, RAYALEP, district health authority.	MOU.
1-15 May 2002	Slide show on leprosy at local cinema halls. Relaying of leprosy messages on cable TV.	RAYALEP.	Leprosy information disseminated.
7-15 May 2002	Direct search in Rayagada Municipality.	DANLEP, RAYALEP, district health authority, NSS Coordinator, school and college principals, NGOs.	7,500 people surveyed, 135 cases suspected and 46 confirmed (41 PB and 5 MB).
6 November 2002	Review meeting on urban leprosy strategy held under chairmanship of Collector.	DANLEP, RAYALEP, district health authority.	Suggestions were made to extend case detection activities to several new sites such as jails, and short-stay homes.

staff, monitoring of functional integration and networking. Like its parent organisation in Bhubaneswar, its members functioned as resource persons for all the sensitisation workshops.

As in other areas, DANLEP functionaries were closely involved in the whole process of mobilisation of resources, survey and follow-up. A unique aspect of this involvement was the preparation of a three-hour video documenting all activities, including the initial contact with individual stakeholders, subsequent meetings, sensitisation workshops and a mass rally.

One of the reasons for the success of the programme was the personal interest taken by the District Collector. He issued an administrative order

instructing all government departments to provide necessary assistance and appealing to the general public to participate in leprosy elimination activities. Describing RAYALEP's experience of coordinating with the government, its Programme Officer said that the critical factor was the interest and leadership provided by the District Collector and his administration. Delineating the experience of working with various partners, he said:

*"It is not easy to work with government departments. But the Collector really gave a push to the programme. It was, in fact, his suggestion that the Telugu Association, rickshaw-pullers and vegetable-vendors should be involved. He also suggested that the participants in the rally don white caps with the inscription 'Eat MDT, Root out Leprosy'. Again, it is not only government functionaries who are difficult to work with. Members of the Rotary and Lions clubs, the Bar Association and the Chambers of Commerce are busy persons. It is difficult for them to take part due to the time factor. Schoolteachers and students and NSS volunteers are easier to work with."*

The Project Coordinator of RAYALEP said in an interview that they were facing difficulties in keeping the group of stakeholders together and maintaining the momentum of the programme. He attributed this to the fact that the charismatic District Collector and the ADMO had been transferred, and the CDMO had retired.

Following the activities undertaken during the urban leprosy elimination campaign, there was a spurt in the referral of new cases by different stakeholders. Four new leprosy cases were referred by municipal councillors in June. Three cases were referred by private practitioners during July 2002. NSS volunteers referred two cases; and three new cases came through voluntary reporting. All in all, between August 2002 and March 2003, a total of 41 confirmed cases were put on treatment. The break-up of the sources of referral of these cases is given in Table 17.

One of the most important outcomes of the urban leprosy initiative in Rayagada was that MDT services have now been extended to all health facilities in the area, including hospitals and dispensaries run by the government/public sector, NGOs and practitioners of Indian systems of medicine.

**Table 17: New leprosy cases detected in Rayagada Municipality, August 2002-March 2003**

Source of referral	No. of confirmed cases
Government NLEP staff	7
RAYALEP	13
Voluntary reporting	6
Community leaders	4
Contact cases	5
Leprosy affected persons	3
General health staff	3
<b>Total</b>	<b>41</b>

In addition to RAYALEP, two local development agencies, PREPARE and Pragatee, were identified as important partners in the urban leprosy initiative. Besides Orissa, PREPARE is also working in Tamil Nadu and Andhra Pradesh on a host of activities ranging from disaster management to income generation, education and health. In Rayagada, among other activities, it has been sponsoring scholarships for children from vulnerable sections, many of whom are working in the same areas as rickshaw-pullers and vegetable-vendors. These children participated in the rally and survey activities. Twenty-three volunteers underwent training on leprosy to work in 16 wards of the municipality. Furthermore, the NGO has also trained a number of *dais* (traditional midwives) in the area, who have also been inducted into leprosy work. All in all, 17 cases were identified by PREPARE workers and volunteers after their sensitisation.

When asked what role non-leprosy NGOs could play in the elimination work in urban areas, the PREPARE representative replied that after preliminary training such NGOs could make a significant contribution if their leaders were sufficiently motivated and committed to the cause. He said, “*Non-professionals can give better service.*” He also felt that the approach that was being piloted for leprosy elimination could also be used for the control of malaria and respiratory conditions, since the main objective was to strengthen the capacity of existing health services to deliver through community involvement and participation. Similar views were expressed by the coordinator of Pragatee, an NGO working in the area of maternal and child health in both urban and rural Rayagada since 1995.

The wife of the Project Coordinator of Pragatee is the councillor of ward No. 6 of Rayagada Municipality. Since this ward was showing a high case-load, she was requested by the Collector to play an active role in the leprosy campaign. She had attended the councillors' sensitisation meeting held in April 2002. Although she was aware that medicines were available free of cost, she had not had any personal contact with leprosy affected persons prior to the training. Consequently, she had found the sensitisation workshop quite informative.

She subsequently detected four leprosy cases in her ward. Two were put on MDT, and the other two, who had deformities, underwent reconstructive surgery. After the survey, she had organised a meeting between the residents of her ward and some leprosy patients. Both the groups sat and ate together without any discomfiture. Her participation in the survey had diminished the social stigma attached to the disease in her area. She was willing not only to sustain the programme in her ward, but also to work in other wards of the municipality.

In addition to the usual category of stakeholders comprising local health officials, members of the municipality, local NGOs, school and college students and teachers, rickshaw-pullers and vegetable-vendors also participated actively in the rally on 1 May 2002. Rickshaw-pullers who had participated in the rally at the local rickshaw stand in Rayagada town said:



Rickshaw-pullers describing their experience of participating in the rally in Rayagada to the documenter.

*“We were told to drive our rickshaws in a single file through the slum areas carrying banners and shouting slogans about leprosy and MDT.”*

One rickshaw-puller said that whenever he sees anyone with a patch on the body, he tells him to go and see the doctor. He has himself referred a few persons to the local clinic. He said he enjoyed participating in the rally and evinced a willingness to take part in such endeavours in the future as well. The RAYALEP representative, who had accompanied the documenter, said that he considered this group to be ‘reliable stakeholders’.

Nonetheless, other traditionally unreached groups remained out of the purview of the elimination activities. For instance, hotel-workers, railway-porters, transport-workers such as bus and truck drivers and gypsies were not the direct focus of the IEC and case detection drives.

NSS volunteers have been willing and productive partners in all the urban projects. Commenting on their active role in the leprosy campaign, the Principal of the Rayagada Women’s College said:

*“The girls in this college are from the poorer sections. Most of them belong to Scheduled Tribes and Scheduled Castes. Leprosy is a new concept. In their communities, it is not the stigma which is the problem but the lack of awareness. Therefore, I think the students, who volunteered for leprosy work, can play an important role in passing the message on to their respective communities.”*

With the existence of an affiliate of LEPRO India in Rayagada, and the fillip given to the urban leprosy strategy by the local administration, the chances of the urban leprosy initiative being sustained are quite high.

## **Urban Leprosy Pilot Project in Vyasnagar Municipality, Jajpur District**

Jajpur district is situated in the Central zone of Orissa. The small Vyasnagar township, the locus of the urban pilot project, has a population of 32,786. The main occupation of the people is agriculture. The area is also a centre for the ferrochrome mining industry. Consequently, the Ferrochrome Hospital, like the J.K. Mills Hospital in Rayagada and the ISPAT General Hospital in

Rourkela, is an important health care facility in the area. In addition, there are the government hospitals and dispensaries, the ESI and Railways dispensaries and a range of private practitioners. The major health facilities in Jajpur district include the Jajpur District Hospital, the ESI Dispensary, the Ferochrome Dispensary, the Railway Dispensary and the Homeopathic Dispensary.

The prevalence of leprosy in Jajpur district is 5.2/10,000. Disaggregated data shows that there are two urban endemic pockets and a few blocks accounting for a high concentration of cases. Vyasnagar Municipality is one such pocket of endemicity. The epidemiological indicators for Jajpur district are given in Table 18.

**Table 18: Leprosy indicators – Vyasnagar Municipality**

PR per 10,000 population at start of MDT in 1983	Not available
<i>Status as of March 2003</i>	
PR per 10,000 population	13.7
New case detection rate per 10,000 population	22.5
Percentage of MB cases among new cases	17.5
Percentage of child cases among new cases	18
Percentage of Grade II disability cases among new cases	0

**Table 19: An overview of urban leprosy elimination pilot project in Vyasnagar Municipality, Jajpur District**

Date	Activity	Responsible person/ institution	Outcome
25 January 2002	First stakeholders' meeting convened by chairperson of municipality and facilitated by DANLEP.	DANLEP, district health authority, MO-LEU.	Agreement to implement urban leprosy strategy.
30 March 2002	Training of NSS volunteers of Indira Gandhi Women's College.	MO-LEU, College Principal.	27 NSS volunteers and 10 faculty members sensitised.

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<b>Date</b>	<b>Activity</b>	<b>Responsible person/ institution</b>	<b>Outcome</b>
2 April 2002	Training of schoolteachers.	MO-LEU, School Principal.	42 teachers sensitised and they participated in the rallies and case-finding activities.
5 April 2002	Sensitisation of sweepers of Vyasnagar Municipality.	MO-LEU, district health authority, Municipality.	32 sweepers sensitised, 12 of whom participated in search activities in their respective areas.
7 April 2002	Sensitisation of members of the Press Club, Chambers of Commerce, truck owners' association, etc.	MO-LEU, DANLEP.	19 members participated and agreed to be involved in all planned activities.
8 April 2002	Sensitisation of Chairman and members of municipality.	MO-LEU, DANLEP.	22 councillors and the Executive Officer sensitised. They would be involved in the rally, search and interactive meetings.
16 April 2002	Training of NSS volunteers of Vyasnagar College.	MO-LEU, College Principal.	22 NSS volunteers and 12 faculty members sensitised, five of whom were involved in search activities and rallies.
17 April 2002	Training of health providers, medical officers, pharmacists and other medical professionals.	MO-LEU, DANLEP, district health authority.	28 service providers trained on leprosy diagnosis and treatment.
21-30 April 2002	Targeted IEC campaign.	MO-LEU and DANLEP.	Audiocassettes conveying message of leprosy elimination played in local betel shops; slide show organised in local cinema halls;

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Date	Activity	Responsible person/ institution	Outcome
			video cassette played on local cable network; interactive meetings held in slums.
26 April 2002	MOU signed.	MO-LEU, DANLEP.	
1 May 2002	Mass rally held.	MO-LEU, DANLEP.	All partners participated.
2-10 May 2002	Door-to-door search and voluntary reporting in the slums, <i>basti</i> and peri-urban areas.	MO-LEU, DANLEP.	78 community members participated. 17 cases detected.
2 May 2003	Evaluation meeting of the partners held.	MO-LEU, DANLEP.	All but one member from core committee who had signed MOU attended.

As in the case of the Rayagada initiative, the whole process has been videotaped. All activities were coordinated by the Medical Officer of the LEU and her staff. A meeting scheduled to sensitise members of the local IMA branch could not be held due to time constraints. A similar sensitisation workshop slated to be held with local clubs, social service groups and community-based organisations could also not be conducted. This was accomplished in the latter part of the campaign.

Unlike Rourkela and Rayagada, the Chairperson of the Leprosy Elimination Committee in Vyasnagar was not the District Collector but the Chairman of the municipality who was very enthusiastic about the urban pilot project. He took the initiative in convening a meeting of all partners to discuss the elimination strategy. Leprosy elimination was also put on the agenda in the meetings of the municipality.

The Chairman of the local Chamber of Commerce and the Bar Association has been an active partner, especially in IEC activities, among the town's higher socioeconomic groups. In an interview he said that he had organised a sensitisation meeting of both members of Chambers of Commerce and the Bar Association. When asked why he had agreed to participate so actively, he said:

*"I have to share my education. It is my duty to work for the social good. Only educated people can save the country. I am also involved in other social activities."*

The documenter visited the plot area in ward No. 24 inhabited by a large number of tribal labourers. Although an interaction session on leprosy had been held a year ago, people distinctly remembered the information on leprosy that had been communicated to them on that occasion. During the meeting, two persons of the community, one male and one female, were chosen to undertake the survey in the area comprising 50 households. Five cases had been referred by them for treatment. Both the community volunteers said that they were sure no untreated cases existed among the households in their area. When asked whether another search was necessary, the male volunteer, a teacher in the local school, said confidently:

*"No, I don't think there is any need for a search here."*

Indeed, the level of awareness about leprosy in the area was illustrated when a young woman stepped forward showing a skin discoloration on the body of her infant to the doctor accompanying the documenter. She wanted to know whether it was a sign of leprosy. This incident highlights the effectiveness of the IEC work that had been done in the area.

A distinctive feature of the urban leprosy initiative in Vyasnagar was the active participation of railway porters or *coolies*. An interactive session was organised with them by the Medical Officer of the LEU on the railway platform, and some of the porters who had watched the slide show on leprosy at the Vyasnagar railway station told that they had learned on that occasion that leprosy is curable and the medicines are available free of cost. One of them



A tribal woman holds her child up to be examined for leprosy.

said he had referred two cases among his colleagues to the government hospital. Both of them had completed the treatment and were completely fine now.

### **Partners' follow-up Meeting**

A partners' follow-up meeting was held on 3 May 2003, exactly a year after the signing of the MOU. The participants included the MO of the LEU and her staff, the DANLEP programme officer, the Executive Officer and three ex-councillors of the municipality,<sup>5</sup> the Tehsildar, the CDMO, ADMO (Public Health), the Principal of Indira Gandhi Women's College, and MOs of Jajpur, ESI and Ferochrome hospitals. A journalist from the daily *Samaj* and a local advocate also attended. All the signatories except the President of the Chamber of Commerce and the Bar Association, were present. In addition, the two tribal volunteers, whom the documenter had met in the plot area on the preceding day, were also invited.

After a brief inauguration by the Tehsildar, excerpts from the video on the Vyasnagar leprosy elimination project were shown to the participants. The MO of the LEU made a brief presentation on the epidemiological profile of

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<sup>5</sup> Between May 2002 and 2003, municipal elections have been held and some of the councillors lost their seats, including three of the councillors who participated in the review meeting.

leprosy in Vyasnagar municipality. She highlighted the increased level of case detection as a result of the campaign. The PR had dipped from 15.6 to 7/10,000 during the past year. Forty-one cases had been confirmed after the awareness and search activities in May 2002. All in all, 86 cases had been referred by different stakeholders. With minimal sensitisation, lay persons accurately diagnosed leprosy cases 50% of the time.

This presentation was followed by short presentations by each of the participants on their experiences of being part of the pilot project, and their plans for the future. The Principal of the Indira Gandhi Women's College told the gathering that sensitisation on leprosy and survey in the slum area had become a regular part of the NSS programme in her college.

The ex-chairperson of the municipality was of the opinion that in addition to the work being done by the female NSS volunteers, a special task force of women volunteers should be constituted to carry out IEC and case detection work among women in slums. The CDMO noted that children in the slums were another vulnerable group, who needed special attention.

Both the tribal volunteers were invited to address the meeting. They assured the gathering that they would continue to survey people in their area for leprosy, ensure that suspected cases were sent for medical consultation, and the diagnosed cases completed the treatment.

An important question raised during the meeting was: "Who should carry this initiative forward?" The participants' unanimous opinion was that the impetus should come from the health department; either the general health services or the NLEP. The CDMO was requested to ensure that the endeavour was sustained. One suggestion supported by all the participants was that the present MO/LEU, who had been the driving force behind the campaign, should not be transferred out of the district in the near future.

The Tehsildar said he was happy that the programme had been a success. He assured the gathering that the administration would continue to support the programme even after DANLEP had phased out its work. He said:

*“We have the expertise and the medicines. There is no need for us to depend on Danida. We can carry it forward ourselves.”*

## Urban Leprosy Pilot Project in Angul Municipality

Angul district is located in the north-western part of Orissa. Angul municipality has a population of 34,700. The presence of the public sector undertaking, NALCO, has conferred certain urban characteristics on this small town, such as densely-populated slums and a multiplicity of service providers. The epidemiological profile of leprosy in the area is given in Table 20.

**Table 20: Leprosy indicators – Angul NAC**

PR per 10,000 population at start of MDT in 1991	89
<i>Status as of March 2002</i>	
Present PR per 10,000 population	49.9
New case detection rate per 10,000 population	10.4
Percentage of MB among new cases	56.9
Percentage of child cases among new cases	Not available
Percentage of Grade II disability cases among new cases	0

There are a number of large hospitals and dispensaries in Angul Municipality: the District Hospital, the Nalco Hospital, the Police Training College Hospital, the Jail Hospital, the ESI Dispensary and the Bidi Shramik Dispensary.

As in the case of other urban areas, the urban leprosy initiative in Angul municipality began with the identification of key stakeholders. A leprosy elimination committee was formed under the chairmanship of the District Collector. The stakeholders were sensitised and the MOU signed, whereby they pledged to work for the elimination of leprosy from Angul township. The Medical Officer of the LEU is the prime mover who has been coordinating all activities in consultation with other partners. A sizeable number of stakeholders have been sensitised. People have participated in mass rallies, and case detection activities have received a boost. Table 21 presents a step-by-step account of the activities undertaken in Angul NAC.

**Table 21: An overview of urban leprosy elimination pilot project in Angul NAC: February-September 2002**

<b>Date</b>	<b>Activity</b>	<b>Responsible person/ institution</b>	<b>Outcome</b>
12 February 2002	Meeting between local health officials such as CDMO, ADMO and DANLEP Orissa representatives.	DANLEP, MO-LEU, district health authority.	42 stakeholders listed.
11 May 2002	Formation of urban leprosy elimination committee.	DANLEP, MO-LEU.	25 partners identified.
17 May 2002	First meeting of partners held under chairmanship of Collector.	DANLEP, MO-LEU, district health authority.	Cooperation for urban pilot project was confirmed and a micro-plan developed.
31 May 2002	Sensitisation of health care providers (medical officers and pharmacists).	DANLEP, MO-LEU, district health authority.	42 service providers were sensitised.
21 June 2002	Sensitisation of schoolteachers.	DANLEP, MO-LEU, school principals.	21 teachers participated.
26 June 2002	Sensitisation of municipal sweepers.	DANLEP, MO-LEU, municipality.	55 sweepers underwent training.
27 June, 2002	Sensitisation of members of Marwari Juba Mancha (Marwari women's group).	DANLEP, MO-LEU.	45 members were sensitised.
17 July 2002	Orientation of NSS volunteers of Women's College.	DANLEP, MO-LEU, NSS Coordinator.	84 female students underwent training.
1 August 2002	Sensitisation of Satyasai Seba Sangh (local religious organisation).	DANLEP, MO-LEU.	53 persons attended the meeting.
7 August 2002	Training of NSS volunteers of Government College Angul.	DANLEP, MO-LEU, NSS Coordinator.	44 students participated.

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<b>Date</b>	<b>Activity</b>	<b>Responsible person/institution</b>	<b>Outcome</b>
17 August 2002	Follow-up meeting of partners called by Collector.	DANLEP, MO-LEU, district health authority.	The progress on the action plan reviewed and future activities planned. MOU signed.
28 August-6 September 2002	School survey conducted by PMWs.	MO/LEU.	Out of the 2544 children examined in 25 schools, five cases were detected.
3 September 2002	Sensitisation of members of Press Club.	DANLEP, MO-LEU.	17 persons from the media were oriented.
17 August 2002	Meeting under chairmanship of Collector to discuss implementation strategy.	DANLEP, MO-LEU, district health authority.	20 out of the 25 persons invited participated.
4 September 2002	Sensitisation of neighbourhood committee of Urban Basic Service, Angul.	DANLEP, MO-LEU, district health authority.	26 persons participated.
14 September 2002	School rally.	MO-LEU, school principals.	Around 1050 students and teachers participated in the rally which passed through the slums of Angul.
16-24 September 2002	IEC campaign.	DANLEP, MO-LEU.	Banners and leaflets distributed. Posters displayed. Loudspeaker announcements relayed on leprosy. Slide shows in cinema halls organised.

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Date	Activity	Responsible person/ institution	Outcome
16-24 September 2002	Members of unreached groups such as railway station platform-dwellers, hotel workers, mechanics and other daily labourers examined at their place of work.	MO-LEU.	Not available
24-25 September 2002	House-to-house visits by volunteers informing about the VRCs in the area where suspect cases could be referred the following day.	DANLEP, MO-LEU, district health authority.	Not available
25 September 2002	Ten VRCs manned by PMWs and volunteers from 9 am to 5 pm.	DANLEP, MO-LEU.	A total of 140 (109 males and 31 females) persons reported for examination, out of whom five were confirmed and immediately put on treatment.

In April 2002, potential stakeholders were identified and administered the stakeholders' questionnaire by the MO/LEU. Subsequently, partners were identified among the stakeholders. The initial partners' meeting held on 17 May 2002 was attended not only by key members of the local health administration, the municipality, principals of local colleges, the Press Club and the President of the local branch of the IMA, but there were also representatives from a number of other professional and social service organisations. The presidents of the Chamber of Commerce, the Truck-Owners' Association and the Hotel Owners' Association were present. So were the chairpersons of the Rotary and Lions clubs, Naba Jeevan Mandal and Marwari Juba Mancha. Furthermore, members of the local church, *masjid*, Satyasai Seba Organisation and the Aurobindo Ashram organisation also participated in the deliberations. The training meetings

organised by various partners went on schedule, with the exception of the training of municipal councillors which could not take place due to the dissolution of the municipality. As in the case of Rayagada, the District Collector was a key figure in the implementation and success of the programme in Angul.

## Conclusion

After the piloting of the urban elimination strategy in the five urban areas described above, attempts have been made to replicate it in a number of other urban areas in Orissa. For instance, stakeholders held a meeting in August 2002 in Paradip urban area. The main partners were the MO/LEU, the municipality and the Port Workers' Union. Other areas in which the replication has been completed are: Bargarh, Jharsuguda, Sundargarh, Brajarajnagar, Chatrapur, Bolangir, Sambalpur and Jatni. Replication is also under way in Berhampur, Jeypore, Puri, Bhadrak and Paralakhemundi. The Orissa unit of DANLEP has been encouraging and monitoring these efforts.



## Background

The state of Madhya Pradesh was bifurcated in November 2000 when the new state of Chhattisgarh was formed. Madhya Pradesh comprises 45 districts, and around 26.7% of its population resides in urban areas. The decennial growth rate of the urban population between 1991 and 2001 was 31.2%.

Madhya Pradesh has been one of the high-endemic states for leprosy in the country. MDT services were initially started during 1987-88 in Rajnandgaon and Durg districts, with assistance from DANLEP. Coverage of the entire state was not completed until 1995. The current leprosy scenario is presented in Table 22.

**Table 22: Leprosy indicators – Madhya Pradesh**

PR per 10,000 population at start of MDT in 1987	43.4
<i>Status as of March 2003</i>	
PR per 10,000 population	1.9
New case detection rate per 10,000 population	2.7
Percentage of MB cases among new cases	43.2
Percentage of child cases among new cases	8
Percentage of Grade II disability cases among new cases	4

Current district-wise disaggregated data show that 17 of the 45 districts in the state have a PR of less than 1, 11 have a PR between 2 and 3, and the remaining 17 have a PR exceeding 3.

Leprosy elimination in urban areas has been a central focus of the state planning. A large number of new cases are being reported from urban areas.

A special urban leprosy elimination campaign was organised between 26 September and 2 October 2000 in the hitherto undivided states of Madhya Pradesh and Chhattisgarh. Out of a total of 13,607 suspected cases, 1,840 were confirmed and put on treatment. Thirty-nine per cent of the new cases were female, while 11% were children. Four per cent of the cases had some degree of deformity. A large percentage of cases (53.5%) belonged to Scheduled Castes and Scheduled Tribes and Other Backward Classes (OBC), while 13.6% belonged to the below poverty-line segment of society. In addition to the urban leprosy elimination campaign, other state-wide drives had also been undertaken during the past four years to mop up cases in the community. Four modified leprosy elimination campaigns and three leprosy fortnights have been conducted. Furthermore, a large number of cases have been detected through the SAPELs, numerous skin camps and school surveys.

A special feature of the Madhya Pradesh DANLEP-supported leprosy programme is the importance accorded to the triologue model.<sup>4</sup> Bringing the three principal actors (patients, service providers and community) together on a common platform of action, such as in the context of the residential Care and Concern camp, is considered to be not only a potent tool of de-stigmatisation, but also of actual empowerment of leprosy affected persons and their families through a process of psychosocial change. The triologue model encourages social integration and community acceptance by bringing together patients, providers and community as partners in a common endeavour.

Over the years, Gwalior has been the epicentre of a large number of DANLEP-supported activities. In addition to the unique *dastak* experiment, sensitisation of different social and occupational groups and patients released from treatment (RFT) camps have been a routine feature of leprosy work in the area.<sup>5</sup> Honouring leprosy-cured patients by important public

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<sup>4</sup> Extending the concept of dialogue, the triologue model involves bringing together the patients, the service providers and the community on a common platform. The POD camp is one such platform promoting triologue.

<sup>5</sup> *Dastak* (knocking on the door) is an interpersonal communication strategy in which all the households in a given area are individually contacted by volunteers in groups and are informed about leprosy, its causes, signs, symptoms and cure. During the mid-1990s the Bharat Scouts and Guides were trained in *dastak* campaigning in Gwalior city. This initiative was facilitated by the DANLEP Madhya Pradesh Unit. Consequently, the approach gained international recognition as an important IEC technique in leprosy work and was replicated in countries like Nepal, Togo and Nigeria.

dignitaries has become a regular annual feature on 2 October and 30 January (Mahatma Gandhi's birth and death anniversaries, respectively).

Gwalior has not been officially chosen as a site for experimentation of the urban pilot strategy; and given its long history of leprosy-related innovative activities, it is probably just as well. However, the same complexities that characterise other large cities also hold good for Gwalior. For instance, the large-scale *dastak* programme in the mid-1990s, and the consequent social mobilisation that it generated, has not been repeated in Gwalior city. It appeared that there were strong social networks for joint action in Gwalior city and especially in Dabra, where the influential residents are bound together by both professional association and personal ties.

The DANLEP-facilitated urban leprosy elimination initiative has taken a slightly different trajectory in Madhya Pradesh. While the pilot project was implemented in Burhanpur in accordance with the standard protocol, instead of the leprosy control unit taking the leading role, local developmental NGOs in Bhopal and Guna like Vimarsh and ISHWEL (Integrated Society for Human Welfare) have been contracted by the DANLEP state unit to initiate the pilot project. This approach is different from Salem in Tamil Nadu, where a long-standing leprosy NGO was the nodal agency. In Bhopal, Vimarsh has contacted a large number of stakeholders and developed a plan of action. In Guna, on the other hand, a number of smaller NGOs have been mobilised by ISHWEL to undertake leprosy work. For instance, a rally was held on International Women's Day in March 2003; and a POD camp was organised from 28 April to 5 May 2003. Currently, the coordinating NGO, ISHWEL, is engaged in a sensitisation drive, and a door-to-door survey of the high-endemic pockets in Guna city is also planned. The urban sites where the leprosy elimination campaign has been conducted or is underway are indicated in Figure 3.

## Urban Leprosy Pilot Project in Burhanpur City<sup>6</sup>

Burhanpur city is located in Khandwa district of Madhya Pradesh. It is a busy centre of the textile industry. Most of the residents are handloom and powerloom weavers. With a population of 3.3 lakh, the people of the area

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<sup>6</sup> A report on this initiative is available as a separate document. See "Urban Leprosy Elimination: The Burhanpur Special Initiative", DANLEP 2003.

**Figure 3: Map showing urban leprosy pilot project sites in Madhya Pradesh**



are a heterogeneous mix of Muslims, Hindus and Jains. The majority group is of Ansari Muslims. The PR in Khandwa district is one of the highest in Madhya Pradesh at 3.4/10,000 (March 2003).

In addition to the low levels of awareness about leprosy, another obstacle to leprosy elimination efforts is the practice of *purdah* (veil) observed by many women of both Muslim and Hindu communities. This is a barrier to diagnosis and treatment of not only leprosy but also other skin diseases among women.

It is due to these factors that Burhanpur was chosen as a site for the urban leprosy elimination project by the DANLEP unit of Madhya Pradesh in the second half of 2001. A pre-campaign assessment of the area further revealed the existence of a perception gap between NLEP functionaries and the general health care staff on their respective roles and responsibilities in leprosy elimination. This could be attributed to the fact that a full-time DLO for Khandwa district was appointed only in 2001. DANLEP functionaries had to make extra efforts to alter the perception of the general health care functionaries from regarding themselves as a mere adjunct to NLEP workers to accepting their role as one of the main stakeholders in leprosy elimination activities.

The documentation process of the Burhanpur project was initiated concurrently with the intervention itself. The methodology involved participatory observation and discussions with various stakeholder groups. A documenter from the NGO undertaking the documentation, Vimarsh, was present during the workshops and negotiations, and sometimes also played the role of facilitator. There was a constant feedback between project participants and the documenter so that their perspectives not only on the intervention but also on the shape of the document could be incorporated.

The high point of the campaign was the commemoration of a leprosy fortnight. The fortnight's activities began with a series of rallies by schoolchildren of Burhanpur on 30 January 2002. The rallies converged at two points in the city, where public functions were held. The participants included the Mayor, the local Member of Parliament and other leading citizens who addressed the gathering on leprosy elimination. An overview of the activities conducted during the special initiative is presented in Table 23.

**Table 23: An overview of urban leprosy elimination pilot project in Burhanpur: June 2002-June 2003**

<b>Date</b>	<b>Activity</b>	<b>Responsible person/ institution</b>	<b>Outcome</b>
24 December 2001	Sensitisation workshop.	DANLEP.	
30 January 2002	Rally by government schools.	DANLEP, NLEP.	18,980 persons attended the rally, addressed by the Mayor, local MLA and other leading citizens.
1 February 2002	Training of <i>Dastak</i> volunteers.	NLEP functionaries.	Schoolchildren, NGO functionaries, youth groups and AWWs were given a one-day training course and provided with brochures and pamphlets.

Contd...

Date	Activity	Responsible person/ institution	Outcome
2-3 February 2002	<i>Dastak</i> campaign.	NLEP functionaries.	47 LAPs admitted.
3-9 February 2002	POD camp held at Anand Bhawan owned by Sthaniwasi Jain Samaj.	NLEP functionary, students of <i>Ayurvedic</i> College and private donors.	Not available.
10 February 2002	Free skin diagnosis and treatment camp at Gandhi Bhawan.	Burhanpur Medical Shop-owners' Association.	355 beneficiaries, nine new leprosy cases detected.
June 2002	First feedback session.	DANLEP.	Postponed due to inadequate representation of stakeholders.
November 2002	Second feedback session.	DANLEP.	Questionnaire administered and filled by stakeholders.

In addition to the mainstream partners such as DANLEP, the NLEP and the health department, other partners who actively participated in the initiative were: members of Lions, Rotary and Giants' clubs, professional associations such as the National Integrated Medical Association (NIMA), community-based organizations, such as Sindhi Sewa Naujawan Mandal and Maheshwari Yuva Sangh, political organisations such BJP Corporators' Dal, medical institutions such as the Government *Ayurvedic* College and the *Unani* College of Medicine, Bharat Scouts and Guides and government schools. The partnership negotiations with these organisations and leading citizens of Burhanpur were facilitated by members of the Lions and Rotary clubs.

The special drive was carried out in a campaign mode. Since the main focus of the initiative was on awareness generation and information dissemination, IEC was the main fulcrum of activities. Almost all the materials pledged were delivered. The involvement of different organizations and institutions also ensured the participation of an adequate number of volunteers. Other

highlights of the campaign were: daily coverage of elimination activities in local newspapers, and the recording and release of an audio cassette containing a dramatic presentation on leprosy elimination.

One year after the initiative, a feedback session was organised by DANLEP with the stakeholders, who were administered a questionnaire. The purpose of the exercise was to gauge both the stakeholders' personal experiences of their participation and their assessment of the campaign endeavour in general. The stakeholders felt that awareness about the disease, its cause, the signs and the availability of MDT had increased among the people. The initiative had created a motivated local cadre of committed people who could be trusted to carry forward the elimination activities in the future. Overall, their participation in the campaign was described as a socially productive and personally fulfilling experience. Different stakeholders planned different activities. Social service clubs like the Lions, Lionesses and Rotary clubs agreed to conduct skin camps on a regular basis. NIMA proposed to adopt villages for case detection and patient care. The Deans of the local *unani* and *ayurvedic* colleges said they would incorporate case detection, registration and follow-up into their curricula.

Although the programme was largely rated as 'successful' by the stakeholders, certain drawbacks were also pointed out. There was inadequate involvement of the Muslim community, especially Muslim women. Secondly, another stakeholder that was not centrally involved in the project was leprosy affected persons and their families. While one of the main reasons given for the successful implementation of the project was the strategic role of DANLEP in bringing together the general health system functionaries and NLEP staff on a common platform focusing on leprosy elimination, the former showed some reluctance to accepting full programme ownership.

## Urban Leprosy Pilot Project in Bhopal

In addition to being the Capital of the state, Bhopal has one of the 14 municipal corporations in Madhya Pradesh. From the health perspective, it is known as the site of one of the worst man-made industrial disasters. The leakage of gas from the Union Carbide Company in 1984 not only resulted in the loss of many lives, but its aftermath is still felt in the affected areas in the form of chronic morbidities and deformities.

Like many other large cities, Bhopal has large slums, a medium level of industrial activity and a complex health infrastructure of public and private service providers. The list of the major health care facilities in the city include the Hamidia Medical College and Hospital, the ESI Hospital, the Railways Hospital, the Gas Rahat Hospital, the Bharat Heavy Electricals Limited (BHEL) Hospital and the Military Hospital.

The epidemiological profile of leprosy in Bhopal is presented in Table 24.

**Table 24: Leprosy indicators – Bhopal**

PR per 10,000 population at start of MDT in 1995	12
Status as of March 2003	
PR per 10,000 population	3.5
New case detection rate (NCDR) per 10,000 population	4.0
Percentage of MB cases among new cases	Not available
Percentage of child cases among new cases	Not available
Percentage of Grade II disability cases among new cases	Not available

In Bhopal, as in the case of Guna, an NGO, Vimarsh, has been contracted to implement the urban strategy initiative. The coordinator of Vimarsh informed that they were trying to modify the urban strategy approach to suit the local context. Forty-five stakeholders had so far been identified and individually contacted for interview. Potential partners included officials in nationalised banks, insurance companies, religious organisations like *gurudwara* and church committees and *madrassa* boards, pharmaceutical companies, and political groups such as the Youth Congress and the local Rashtriya Swyam Sevak Sangh (RSS) branches. They had a tentative plan to work with and through the DLO and his team. A training module on leprosy would be prepared and on-the-spot orientation given to medical officers working in different government hospitals and dispensaries. Among private practitioners, the focus would be on persuading dermatologists to keep free MDT drugs at their clinics. The local dermatologists and nursing homes associations had been contacted, and some pharmaceutical companies had agreed to sponsor skin camps. They planned to collaborate with the Lions Club in the IEC campaign and with NCC/NSS volunteers and scouts and guides for the door-to-door survey in 33 wards, especially in



A cured person speaking about her treatment for leprosy.

the old city area of Bhopal. A meeting with the Collector was planned for July 2003 to formalise the process.

Shuruwaat (meaning 'beginning') is primarily a health NGO with a grass-roots presence in the slum areas of Bhopal. It has a large group of local women animators engaged in IEC and case detection work on different dimensions of health, ranging from reproductive and child health to leprosy. The majority of these women are otherwise employed and work only as volunteers on social issues in their communities. The President of the organisation told the documenter that underlying all their activities was the concept of dialogue. Describing the attitude towards leprosy among the multi-lingual, multi-religious slum populations, he made the observation that in contrast to the Hindu conceptualisation of the disease as a punishment for past sins or *bad karma*, Muslim groups simply considered it a terrible affliction without moral overtones.

In the meeting with the community women organised in Malaviya Nagar by Shuruwaat workers, the documenter met a number of cured persons. When asked what the people's attitude to leprosy was in the area, a middle-aged woman, who had completed the treatment, said:

*“It is a curable disease. People know this now. If you hide it, you only suffer. I myself have completed the treatment.”*

Given the grass-roots presence of this NGO, a partnership between the Vimarsh and Shuruwaat teams could be a productive strategy to implement the urban initiative in Bhopal.

### **First Care and Concern Camp in Bhopal**

A major event in Bhopal was the first-ever seven-day mixed-gender Care and Concern camp for 50 cured patients and their attendants, organised by the Leprosy Unit with financial assistance from the Lions Club, in February 2003. The venue of the camp was the Rajiv Gandhi Vishwavidyalaya (RGV), a 100-bed *Ayurvedic* college-cum-hospital. About two thousand students of the RGV participated. The link person in the fruition of this camp was one of the non-medical supervisors, who is also a member of the organising Lions Club (Bhopal Classic). An important component of this camp was the training and active involvement of the bachelor degree students of *ayurvedic* medicine and surgery (BAMS). According to one of the Lions club members who had been instrumental in organising the camp:

*“It was a good experience for patients, their family members, the ayurvedic students and the rest of us. The patients and family members only lost their wages for the period of stay. Medical treatment, food and accommodation were free for them. The medical students were also sensitised and the general public saw that leprosy is curable. The message is spread from mouth to mouth, which is more effective than wall-hoardings or newspaper and TV advertisements. It is also a great psychological boost for the patients and their families. It is their way of coming back to society.”*

When told about the urban strategy approach being piloted by DANLEP, and asked whom he considered to be better stakeholders, the government or the NGOs, he said:

*“Leave out the politicians. They are too busy and when they do come for such meetings, they monopolise the proceedings. NGOs with grass-roots networks should be involved.”*

The present treasurer of the Lions Club (Bhopal Classic) is also the president of the District TB Society. When asked why persons like him choose to give of their time and money without any apparent returns, he explained the benefits accruing from doing such work:

*“People want to do good work. It gives one an identity. It is also a social obligation to do some good deeds. In addition to mental satisfaction, one also gets status and respect from others.”*

With regard to the choice of stakeholders, he felt that while it was important to have politicians and government officials in a larger group, the core group which provides the actual leadership should not have any political figures. Their presence obstructs decision making. The larger the group, the less effective its functioning; and the more the number of officials, the less work will get done.

The pivot of the urban leprosy elimination initiative is coordination and networking. This is easier said than done. Coordinating the work of different government, public and private sector organisations and NGOs can be as difficult as liaising between the government and the private sector. For instance, one of the medical officers, who the documenter met at the ESI hospital in Bhopal, was not in favour of turning it into a drug delivery point. He said:

*“Ours is a referral hospital. Here we are dealing mainly with problems of general medicine. We get cases from the ESI dispensaries. We do not cater to the general public. When a case is suspected to be suffering from leprosy, we refer him to the government Hamidia Hospital, or he is directly referred from one of the dispensaries which filter out cases. The non-medical supervisor comes here once a week and that is enough.”*

Encounters with a range of possible partners in Bhopal showed that there is a great potential in the community for its involvement in leprosy elimination activities, but it has to be systematically organised. That is the challenge that the coordinating agency has to rise up to.

## Urban Leprosy Pilot Project in Guna City

Guna is one of the 64 municipalities of Madhya Pradesh with a population of 137,132 (Census of India, 2001). It has gained political prominence as the district falls within the electoral constituency of the current Chief Minister. In addition to being a well-known grain market, a fertilizer and an LPG unit are also located in the area. Consequently, a large section of the population of Guna city is engaged in industrial activity. *Beedi*-rolling is also a supplementary income-generating activity for many slum women.

**Table 25: Leprosy indicators – Guna**

PR per 10,000 population at start of MDT in 1993	5.89
<i>Status as of March 2003</i>	
PR per 10,000 population	2.1
New case detection rate (NCDR) per 10,000 population	2.4
Percentage of MB cases among new cases	52
Percentage of child cases among new cases	Not available
Percentage of Grade II disability cases among new cases	Not available

In the context of leprosy, Guna is an area of low endemicity. While the official PR is around 2, the actual PR could be over 5 in the city. Guna city was chosen as a site for the urban leprosy pilot project because of its political prominence, as also the willingness of the DLO to participate in the pilot project. In addition, it has typical peri-urban characteristics of a small industrial township.

According to the figures available at the LEU, the average case detection rate is around 30 new cases per month. Between April 2002 and March 2003, 411 new cases were detected

Major health care facilities in Guna city include the District Hospital, the Railway Hospital, the Fertiliser Hospital and the Police Hospital.

For the implementation of the urban strategy initiative, ISHWEL has been contracted by the DANLEP Madhya Pradesh unit. The main objective of the project is to develop and institutionalise a participatory and structured network and coordination mechanism for leprosy among the various service providers

in Guna city. One of the first tasks of the agency was to identify issues and problems affecting the functioning of the NLEP in the urban and peri-urban areas of Guna city.

As in other areas where the urban pilot project had been implemented, the process involved the identification and involvement of strategic partners in leprosy elimination activities in a sustained manner. As a facilitator, the coordinating agency was expected to make a special effort to ensure active and sustained involvement of the government health system. In addition, monitoring and documentation of the entire process were essential components of the terms of reference. The Madhya Pradesh unit of DANLEP would provide the requisite IEC materials and assist in sensitisation activities.

Local NGOs had been sensitised. A list of over 400 possible stakeholders was prepared from the local telephone directory. The potential stakeholders included persons from a cross-section of society: persons from government and semi-government departments (health and education) and individuals from the private sector, such as grain merchants, shopkeepers, transporters and contractors. More than 200 stakeholders have been administered the questionnaire, and a list of potential partners prepared. MDT was available in two government health facilities in Guna urban. An attempt was being made to create a third drug delivery depot in the Railway Hospital. Some areas had been identified for the house-to-house survey. Table 26 summarises the activities and achievements of the intervention.

Out of the 419 stakeholders contacted, 153 agreed to contribute to leprosy elimination activities either in terms of cash, kind or personal time. The first major event organised was dovetailing of the themes of leprosy elimination and women's empowerment in the form of a mass rally on International Women's Day (8 March). Six-hundred women, including 50 female municipal sweepers, participated in this event.

The second major event involved linking up the themes of leprosy elimination and patriotism. A musical programme was organised on 26 April 2003 at Shastri Park, which included songs and dramatic presentations on leprosy.

**Table 26: Overview of urban leprosy elimination pilot project in Guna City: March 2003-Present**

<b>Date</b>	<b>Activity</b>	<b>Responsible person/ institution</b>	<b>Outcome</b>
February 2003	Identification of stakeholders.	ISHWEL.	A total of 419 stakeholders were contacted out of whom more than 70% either were not available or did not show a desire to participate.
8 March 2003	Sensitisation programme and rally as part of the local celebrations on International Women's Day.	ISHWEL, DLO and LCU Staff.	The event was coordinated by ISHWEL and involved participation of local NGOs.
26 April 2003	Sensitisation of school children.	ISHWEL.	Quizzes were held in a number of schools after a series of information sessions on leprosy.
27 April 2003	Evening of music and dance organised at Shastri Park. One of the highlights was a skit on leprosy by a local theatre group.	ISHWEL.	Leprosy awareness increased
28 April-4 May 2003	Eight day long POD camp.	ISHWEL and NLEP.	32 patients participated.
7 July 2003	Signing of MOU at Red Cross Bhawan.	ISHWEL.	A Core Committee comprising 12 members under the chairmanship of Chief Medical and Health Officer.

In addition to these public events, a coordination mechanism in the form of a core committee comprising advisory groups and ward committees had been formulated by ISHWEL to monitor leprosy elimination activities. Two advisory groups comprising health officials and members of local NGOs have been formed. While Group A would monitor the work in wards 1 to 20 of Guna city, Group B would monitor the activities in wards 21 to 37. It was planned that these groups should meet once a month to review activities and formulate sub-plans of action based on the reports from the ward committees. The advisory groups would report to the urban leprosy elimination committee which, in turn, would report on the progress to the State Leprosy Elimination Society through the District Leprosy Officer.

### **Partners' Meeting**

A meeting was organised at the district leprosy office on 27 May 2003 to acquaint the documenter with the activities undertaken so far with regard to the implementation of the urban strategy initiative. In addition to NLEP staff, a health educator from the Multipurpose Training Centre, chief functionaries of local NGOs such as Sharda Shiksha Samiti, Moti Shiksha Samiti, National Friends Club and National Young India were present. These NGOs have an exclusive local presence and are engaged in a range of social service activities in the fields of education, health and women's empowerment. A member of the coordinating agency, ISHWEL, and the local programme manager of the European Commission also participated.

In addition to reviewing the activities undertaken so far, the main issues discussed were:

1. POD camps should be funded in the manner of eye camps by the government. When eye camps are organised by NGOs, a sum of Rs. 60 per patient per day is given. For a seven-day camp, including pre- and post-operative treatment, this comes to Rs. 420 per patient. In the case of POD camps, no such provisions exist; and generating almost the entire funding is the responsibility of the community. While on the one hand this enhances community participation and ownership of the programme, it also means that eventually fewer POD camps are held.
2. Furthermore, to increase case detection and MDT coverage, skin and POD camps should be conducted simultaneously.



Beedi workers' slum area in Guna city.

A visit was made to the *beedi* workers' slum area in order to get a sense of the type of population groups who require sustained sensitisation at the grass-roots level. People were reluctant to talk about leprosy, saying that there was no one in their area who suffered from the disease. Most people said they did not know what it was. One woman said she knew someone's daughter who had white patches on her body. When asked if they had witnessed any rally on leprosy in the area during the month of March, the response was in the negative. When asked if some health workers had visited their homes and asked about anyone suffering from leprosy, again no positive response was forthcoming. A couple of women, however, said they had seen posters with the indicative white patch in public hospitals. The unwillingness to engage in an open discussion on leprosy could be linked to the suspicion that the team had come to do a house-to-house survey, and the fear of subsequent invidious labelling.

The unwillingness of the people to engage in spontaneous discussion on the issue of leprosy makes one question the reported wholehearted cooperation of the community with volunteers in *dastak* campaigns. Urban life is characterised by the predominance of anonymity and secondary relationships. Suspicion, mistrust and a general caution underlie interactions between people. The high crime rates in cities also make people wary. They do not open up with strangers quickly, especially when visited at home.

These features of urban life raise questions about *dastak* being an effective IEC strategy in urban areas.

## Conclusion

Apart from Burhanpur, the DANLEP Madhya Pradesh unit has adopted a different approach to implement the special leprosy elimination campaign in other selected urban areas in the state. In addition to working in collaboration with NLEP and general health service functionaries, local non-leprosy NGOs have been selected and contracted by DANLEP to plan and implement the urban pilot project. This is a novel experiment in community participation and ownership of the programme. The DANLEP experience in Madhya Pradesh, especially in Gwalior, Guna and Burhanpur, has shown that community resources can be successfully mobilised for leprosy elimination activities in a sustained manner.





## Background

An estimate of the leprosy prevalence rate in the areas of Madhya Pradesh that have been shifted to the new state of Chhattisgarh shows that the average PR at the beginning of MDT in 1987 was around 38/10,000. There were 15,482 registered cases in the 16 districts of the state as of 31 March 2003. Other leprosy-related epidemiological indicators at the state-level are provided in Table 27.

**Table 27: Leprosy indicators – Chhattisgarh**

PR per 10,000 population at start of MDT in 1987	38
<i>Status as of March 2003</i>	
PR per 10,000 population	7.2
New case detection rate (NCDR) per 10,000 population	8.6
Percentage of MB cases among new cases	41
Percentage of child cases among new cases	117
Percentage of cases with Grade II disability among new cases	3

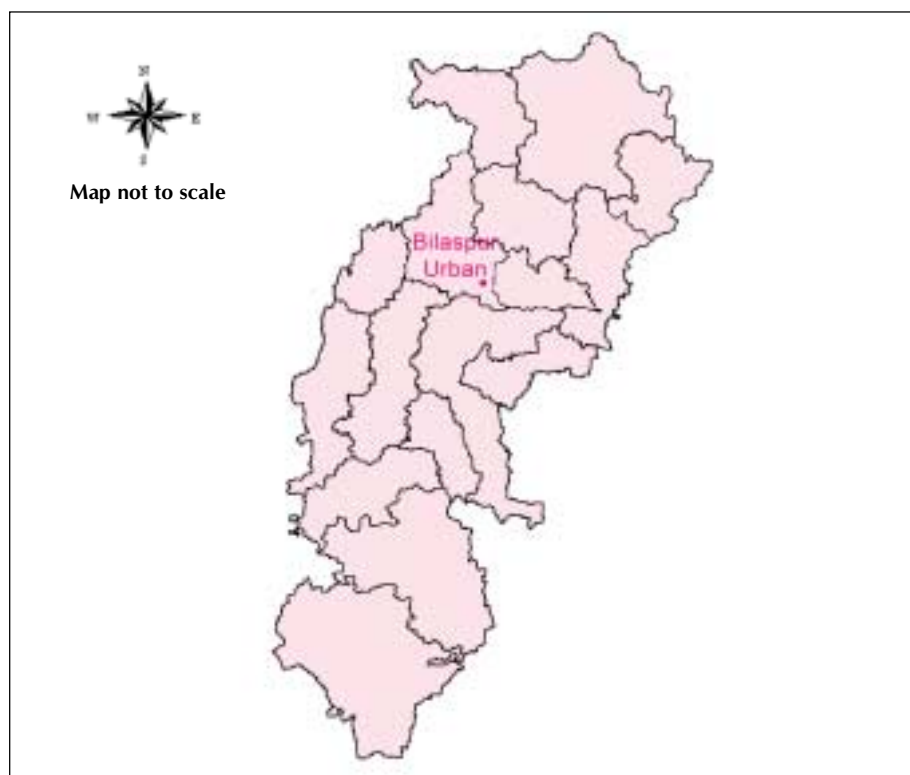
Out of the total number of new cases, around one-third belonged to Scheduled Castes and Scheduled Tribes. A district-wise analysis of the leprosy prevalence reveals that Janjgir, Mahasamund and Raigarh have PR rates of above 10, while in Dharmtari, Raipur, Durg, Kawardha, Bilaspur and Korba, the PR is between 5 and 9.9.

Approximately 20% of the total state population resides in urban areas. The main urban centres in Chhattisgarh are: Durg, Bhilai, Raipur, Bilaspur and Korba. The leprosy PR in urban areas is around 8.7. The prevalence is higher in urban centres than in rural areas. For instance, 30% of the new

cases in Durg district were reported from the slum areas of Bhalai, which, like Rourkela, is a hub of the iron and steel industry. The industrial and mining towns of Chhattisgarh, such as Bhalai, Korba, Bilaspur and Raipur, have become areas of high concentration of migrant labourers making case detection, delivery of treatment and retrieval of defaulters difficult for the health care staff. For instance, in an urban leprosy elimination campaign conducted in Raipur city during 1998, 588 cases were confirmed and given the first dose of supervised medication at their residence. Out of this, 200 patients did not report after the first pulse of MDT, resulting in a staggering 37.9% default rate. These patients not only run the risk of developing deformities, but they may also be potential sources of infection to others in the community.

As Figure 4 shows, the only site of the urban leprosy elimination project in Chhattisgarh is in Bilaspur urban.

**Figure 4: Map showing urban leprosy pilot project site in Chhattisgarh**



Like Gwalior in Madhya Pradesh, Bhilai town in Durg district of Chhattisgarh has been a site for DANLEP activity, albeit at an informal level. Some of the DANLEP representatives are former residents or employees of health care institutions in Bhilai.

With a population of six lakh, Bhilai, like Rourkela in Orissa, has the typical urban characteristics of an industrial mining town. One-third of the total population resides in the city's 26 slums. The PR in Bhilai is 7.9, which is one of the highest among urban areas in the state. In an interview, the District Leprosy Officer said that one-third of the new leprosy cases in the district were from the slums of Bhilai. Being the hub of industrial activity in the region, it attracts a large inflow of migrant labour, not only from within Chhattisgarh but also from states like Andhra Pradesh, Orissa and Uttar Pradesh. Consequently, according to the DLO, a large number of the leprosy cases in Bhilai are from among the itinerant migrant population.

Bhilai has a large health infrastructure comprising not only the leprosy control unit and private practitioners, but also large hospitals such as the Bhilai Steel Plant Hospital, the Railways and ESI hospitals and dispensaries, in addition to health facilities sponsored by the local municipal bodies. Following lobbying by the state DANLEP unit, MDT is now available at 12 dispensaries. ICDS workers have also been sensitised and are engaged in case detection work. A private dermatologist has agreed to canvass with members of the local branch of the IMA to keep MDT drugs at their clinics.

Looking at DANLEP-supported urban leprosy activities, the Bhilai Steel Plant has been an active partner in the endeavour as far back as 1988 when DANLEP started operating in Durg district (then in Madhya Pradesh). Between 1988 and 1994, the Steel Plant Hospital also ran a leprosy control unit. A computerised information and monitoring system for leprosy care was put in place at the Bhilai Steel Plant. A teaching-cum-demonstration course on reconstructive surgery involving the participation of eminent leprologists was also conducted.

Thus, there is both a need and scope for launching a special drive for leprosy elimination in Bhilai. There is a large number of potential partners who could be brought together on a common platform through an effective

coordination and networking mechanism. Again, the point is who should take up the role of facilitator for this endeavour.

### Urban Leprosy Pilot Project in Bilaspur city

Bilaspur is one of the 16 districts of Chhattisgarh. Bilaspur city was chosen for the urban strategy pilot project because it has some of the typical characteristics of an urban conglomeration such as a large number of slums, migrant population, and a multiplicity of health care facilities without proper coordination among different service providers and institutions. The project was initiated in January 2003 and many of the planned activities were under way at the time of documentation.

Bilaspur urban borders Masturi block which has a PR of 11.10, the highest among all the ten blocks of Bilaspur district. The current PR in Bilaspur district is 8.53, which, as can be noted from the indicators given in Table 28, is more than the PR of Bilaspur urban.

**Table 28: Leprosy indicators – Bilaspur district**

PR per 10,000 population at start of MDT in March 1989	66.0
<i>Status as of March 2003</i>	
PR per 10,000 population	5.2
New case detection rate (NCDR) per 10,000 population	9.32
Percentage of MB cases among new cases	40.4
Percentage of child cases among new cases	9.57
Percentage of cases with Grade II disability among new cases	3.90

The MLEC IV held in November 2002 was a major event in Bilaspur. It was organised as a major public event enlisting the participation of all levels of the government from the Chief Minister to the district collectors. A population of over 10,000 was surveyed in Bilaspur urban alone. Fourteen VRCs were set up. Out of a total of 346 suspected cases, 33 were confirmed. Organisation of house-to-house surveys, school surveys and rallies by schoolchildren were the other highlights. The event was widely covered in the local and state-level media.

**Table 29: An overview of urban leprosy elimination pilot project in Bilaspur city: February 2003-Present**

<b>Date</b>	<b>Activity</b>	<b>Responsible person/ institution</b>	<b>Outcome</b>
27 February 2003	Partners' meeting.	DANLEP, DLO and his staff.	Detailed action plan developed and MOU signed.
29 March 2003	Training of ICDS workers.	DLO and his staff and CDPO.	Training organised by the Child Development Project Officer (CDPO) for all <i>Anganwadi</i> workers in Bilaspur urban.
March 2003	Sensitisation of social work students.	DLO and his staff, Social Work Department of Guru Ghasidas University.	A lecturer in the department was a member of the core committee which signed the MOU.
25 April 2003	District-level workshop of Gayatri Parivar.	DANLEP, DLO.	Leprosy elimination activities figured on the agenda.
18 May 2003	Skin camp organised by Gayatri Parivar.	DANLEP, DLO.	Five new cases detected.
23 May 2003	Partners review meeting.	DANLEP, DLO.	Project process documented.

After the initial meetings between the District Leprosy Officer and his team and the Chhattisgarh DANLEP representatives and assemblage of epidemiological data on leprosy in the city, a detailed list of stakeholders was prepared. A large number of stakeholders were interviewed to ascertain their capacity and commitment for leprosy elimination activities.

A workshop was held on 27 February 2003 which was attended by DANLEP representatives, the Chief Medical Officer and the Mayor of the Municipal Corporation, in addition to a number of other partners and health officials. Other partners included the Secretary of the local Chamber of Commerce, representatives from the Lions Club and various local NGOs. A detailed plan

of action, involving sensitisation of health care workers in the government and the public and private sectors and students and teachers of educational institutions, was chalked out. A multi-pronged IEC campaign involving the electronic, print and folk media, direct search in slum areas, school surveys and organisation of skin camps was also planned. Table 30 shows the activities undertaken.

An interesting development in the partners' meeting on 27 February 2003 was the assignment of different wards of the city to different agencies for coordination of leprosy elimination activities. Table 30 gives the details of the area division along with the name(s) of the nearest drug delivery point(s) for referral and treatment of leprosy cases. The table also presents an overview of the major health care facilities located in Bilaspur urban.

### **Partners' Review Meeting**

Due to the existence of an organised plan of action, the second partners' meeting held on 23 May 2003, which the documenter attended, was more of a review of the activities completed so far, and a planning-out of future events in the light of the pre-existing division of labour.

In addition to the DANLEP functionaries of the Chhattisgarh unit, the participants in the meeting included three local councillors, the Child Development Project Officer of the ICDS, the District Leprosy Officer and his



A pharmacist showing MDT drugs at a dispensary in Chingrajpada.

**Table 30: Division of Bilaspur city among different partners for coordination of leprosy work**

Area	Coordinating agency	Nearest health facility
Wards nos. 5, 6, 8, 9, 18, 19, 20, 21	NSS, ICDS and Bhagani Mandal	Zila Parishad Hospital ULC
Ward nos. 7 and 10	Rotary Club	<i>Ayurvedic</i> Hospital
Ward nos. 11, 12 and 13	Rotary Club	City dispensary, Talapara
Ward nos. 1, 2, 3 and 4	Vasudha Mahila Mandal	<i>Unani</i> Hospital, Kuda Dund
Yudhunandan Nagar Tifra	Vasudha Mahila Mandal	City Dispensary, Yudhunandan Nagar
Bilaspur rural area	South Eastern Coalfields Ltd. (SECL)	SECL Hospital
Ward nos. 40, 41, 43 and 44	Social Work students of Guru Ghasidas University	City dispensary, Chingrajpada
Ward nos. 42, 45, 46, 47 and 48	Social work students of Guru Ghasidas University	<i>Ayurvedic</i> dispensary, Sukhanda
Ward nos. 49, 50, 51 and 52	Railway Hospital	Railway Hospital
Ward nos. 39, 53, 54 and 55	Railway Hospital	City dispensary Ganesh Nagar
Ward nos. 37 and 38	Railway Hospital	City Dispensary
Ward nos. 25, 26, 27, 28, 29, 30, 31 and 32	NSS	City dispensary ULC, Gandhi Chowk
Ward nos. 14, 15 and 16	Social Worker	<i>Ayurvedic</i> dispensary, Tarbahar
Ward nos. 1 and 24	Deaf and Dumb School	Municipal <i>Ayurvedic</i> Hospital
Ward nos. 32, 33, 34, 35 and 36	NSS and Scouts and Guides	Municipal <i>Ayurvedic</i> Hospital

staff of non-medical supervisors and non-medical assistants, two coordinators of the NSS, the Principal of the Deaf and Dumb School, and a lecturer from the Department of Social Work of the Guru Ghasidas University. In addition, a number of representatives from different local-level NGOs attended the meeting. An *Anganwadi* worker, who had received training in leprosy, was also present.

The meeting began with the programme officer of DANLEP giving a brief overview of the problem of leprosy in urban areas and the urban initiative that was under way in Bilaspur.

The first half-hour of the meeting was dominated by the councillors,<sup>7</sup> who, in typical declamatory fashion associated with political speeches, repeatedly said that they pledged to make the city leprosy-free. Using such terms as *prayaas* (endeavour) and *sankalp* (pledge), they reiterated that they were willing to cooperate with any persons and support any efforts in that direction. One of them proclaimed on behalf of the municipality:

*“On behalf of all the councillors, we pledge to make our city leprosy-free. We are willing to support it 200%. It is a national programme and it is a social programme.”*

The councillors speeches were directed against the inefficiency of the government’s health care facilities where the staff was accused of being lax and apathetic, that is, if and when they were present at all. Subsequently, the discussion focused on the sensitisation of the inhabitants of the low income localities in Bilaspur urban like Chingrajpada, where special efforts needed to be exerted to bring out the hidden cases. About 90% of the inhabitants were labourers and poverty and illiteracy were rife in the area.

The documenter had earlier visited the dispensary in Chingrajpada where MDT services were available, but the leprosy case-load was relatively low (only six patients under treatment).

The partners sought to work out a plan of action involving coordination between the different government departments and the NGOs operating in the area. It was pointed out that NGOs like the Grameen Sewa Sanstha and Asha Abhiyan could be linked with the *Anganwadi* workers in the area, not only in the IEC work but also in such activities as skin camps and referral and follow-up of diagnosed patients. The Grameen Sewa Sanstha had organised 20 self-help groups, each comprising ten women, who could be

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<sup>7</sup> These councillors represented city wards, which have a substantial slum population. Among the three councillors present, two were from the Muslim community.

mobilised for leprosy work. After sensitisation, they could, in turn, examine the female members of their area and refer suspected cases to the nearest health facility. The Child Development Project Officer promised the cooperation of the six *Anganwadi* centres situated in the area.

A suggestion was made to sensitise municipal sweepers on the basic facts of leprosy. Another suggestion was to provide a list of the dispensaries where MDT services were available, not only to all the partners but to all the councillors of the municipality as well. In addition to rallies and surveys, one participant suggested that cured patients should be interviewed on TV to publicise their experience of treatment and cure.

When the issue of treatment default was being discussed, one of the councillors asked the District Leprosy Officer to provide a list to each councillor with the names and addresses of defaulting patients in their respective wards. The representative would then follow up on the cases and get the patients back on treatment. Another suggestion was that a roster be prepared of the rallies and skin camps that would be organised in different wards of the city. Advance notice should be given to the councillor of the ward, who would extend all cooperation. One of the councillors said:

*“You tell us when the camp will be held. We will comply.”*

Indeed, the form of the involvement that the councillors were willing to provide appeared to be more in the nature of passive cooperation rather than active engagement.

The National Social Service Scheme (NSS) coordinators said that their students would be available at the beginning of the new academic year from July onwards. One of them told the group that in their forthcoming national-level general meeting in Delhi, he would propose that leprosy be considered a theme of special concern for all their programmes in the forthcoming year. If all the programme officers of the NSS received training in leprosy, that would give a great boost to the programme at the state and national levels.

The above account reveals that this meeting generated a lot of discussion. There were attempts at coordination and networking by the partners among

themselves and the respective organisations they represented. A number of skin camps were planned by the partners, especially after July. One concrete plan was to hold a skin camp on 15 June 2003 in ward no. 40, represented by one of the councillors present at the meeting.

One of the outcomes of the urban strategy initiative in Bilaspur urban was the increase in the number of drug delivery points from two to 14. In addition to the municipal, railway and South Eastern Coal Fields Ltd. hospitals, the delivery points include government homeopathic and *ayurvedic* dispensaries as well.

In addition to the ICDS workers, medical officers of allopathic, homeopathic and *ayurvedic* dispensaries and hospitals have also been imparted training on the diagnosis and treatment of leprosy. NSS volunteers, social work students of the local Guru Ghasidas University and schoolchildren have also been sensitised about the issue. A Social Work lecturer informed the partners that the Social Work Department of the university had adopted three slum clusters in their vicinity. Creating awareness on leprosy and conducting surveys would become a part of the assignment of the students placed for field work training in these areas.

The District *Ayurvedic* Hospital had become a drug delivery point in April 2003. The medical officer told the documenter that, on an average, he was receiving up to five leprosy patients a week. According to him, while it was good to increase the number of drug delivery points, integration was not such a wise move. He felt that leprosy had become an orphan of the public health system. While the general health workers were more concerned with reproductive and child health, NLEP staff was becoming lax due to the sudden change in their status from specialised workers to general health care workers as well as the future professional uncertainty. Shortages of manpower and heavy workloads also characterised the functioning of the primary health centres. The result was that the patients suffered. He was, however, quick to see the benefits of integration, such as the involvement of not only mainstream biomedical service providers but also service providers from other systems of medicine in leprosy work. In addition, the wider availability of MDT services was also a direct outcome of integration.

When asked about the role of *ayurvedic* doctors in leprosy work, he said:

*“All the ayurvedic doctors in Chhattisgarh have been sensitised about leprosy. There are around 670 of us, both in the government and private sector. In Bilaspur alone there are 60 doctors. People come to us for skin problems because ayurvedic medicines are blood purifiers and quite effective against skin diseases. This means that we are in a better position to detect leprosy cases. And if we have MDT with us, we can treat them.”*

## **Conclusion**

The implementation of the urban plot project in Bilaspur urban has the potential of becoming a sustainable endeavour. There is close coordination between members of the core group of influential individuals tied together by professional and personal bonds. Furthermore, they have worked out a tentative division of labour among themselves for case identification, referral, treatment and follow-up. Since the project is still under way, only time will tell how sustainable this endeavour will be, especially after DANLEP ceases to play the role of facilitator.

*Design and Printing:*

New Concept Information Systems Pvt. Ltd., New Delhi,

Phone: 26972748, 26972811