



Part One

The Strategy



Background

Leprosy Elimination in the Urban Context

The challenges in urban areas relate to the existence of multiple uncoordinated service providers, rapid population growth, industrialisation, migration and ensuing unplanned area expansion and a complex socioeconomic structure, which make access to patients difficult from a programme point of view.

Urban agglomerations are characterised by heterogeneous and highly mobile population groups. Being the centres of economic activity, cities attract a large number of migrants who come from less prosperous towns and villages in search of employment. Since employment is often short-term and spatial movement essential, frequent change of residence within the same city is a common feature of the lives of many migrant residents, sometimes called the 'floating population'. An outcome of this large-scale migration to the cities is the development of slums, the sprawling dense population clusters that mushroom in city centres and along the urban periphery with minimum access to basic amenities. Many population groups, who live in these slum clusters remain out of the reach of routine information, education and communication (IEC) and case-finding activities. Work patterns also contribute to this situation. For instance, construction workers, *rickshaw*-pullers, railway-porters and head-loaders and hotel and restaurant workers have erratic working hours, which often means that they are unavailable during case-finding activities. Beggars, pavement-dwellers and gypsies also escape the net of awareness due to their itinerant lifestyles.

It is not only the poor and illiterate urban dwellers who need to be targeted in leprosy elimination activities. It has been found that many members of the educated, middle and upper income groups also lack awareness about the basic facts of leprosy. Many of them continue to regard it as a highly

contagious disease with no possibility of cure. Partly due to the lack of basic information and partly due to the persistence of age-old stereotypes about leprosy, they also tend to stigmatise leprosy affected persons (LAPs). Although most of them have access to better health care services than the urban poor, delayed diagnosis and non-completion of the prescribed treatment have also been found to characterise the health-seeking behaviour of some leprosy affected persons even in higher socioeconomic groups in urban areas. This is because the social image of leprosy has not changed significantly over the years in these groups.

In addition to this demographic complexity is the existence of a highly complex and uncoordinated urban health care system. The urban health system in India is characterised by a multiplicity of service providers and medical systems. There are a large number of allopathic, homeopathic, *ayurvedic* and *unani* practitioners working in both the private and public sectors. There are many other agencies and organisations providing health services, ranging from municipalities to industrial corporations and corporate, private and charitable institutions. Most of these service providers and health facilities are working independently with minimal collaboration with each other and little coordination by the government.

At the policy level, there is no well-defined national urban health policy to address the specific health problems of urban areas, including leprosy. Leprosy elimination units (LEUs) have been engaged in the diagnosis, treatment and follow-up of patients, functioning more or less in isolation from other health agencies. The major focus has been on clinic-based activities to the relative neglect of outreach services. Leprosy treatment has been on the agenda of hospitals run by large industrial houses, but only so far as it falls within the target group of their workers and their families. Municipal bodies, which are primarily responsible for looking after the health needs of urban townships, are mainly involved in sanitation work and the provision of basic amenities such as roads, electricity and water supply. *Anganwadi* workers (AWWs), under the Integrated Child Development Services (ICDS), function within a different administrative structure and are not directly involved in leprosy work everywhere. It has sometimes been found that the health staff in government facilities is demotivated due to various reasons such as job stagnation, perceived

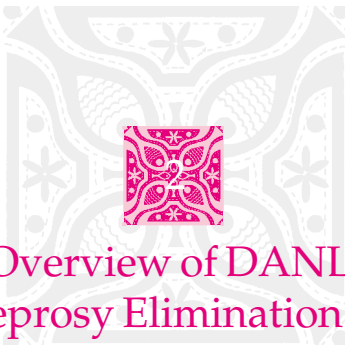
inadequate remuneration, among others. Different state health institutions under different departments have different priorities, resources and management structures. And there is often an absence of coordination, let alone partnership, between them.

To compound the situation, the lack of community awareness about leprosy, its symptoms, its curability and the availability of free treatment, and the social stigma attached to it mean that people often choose to frequent private clinics that proliferate in urban areas. Although anonymity and confidentiality are ensured in private clinics, patients run the risk of misdiagnosis and also receiving costly and sub-optimal treatment.

So, although at a superficial level, the urban health infrastructure appears quite impressive in quantitative terms, its functioning is fragmented and uncoordinated with regard to leprosy elimination work. It appears that very few have a clear idea of who is working where and doing what. The government system appears to be less interested to liaise with NGOs; and private practitioners shy away from collaboration with government agencies, since such a partnership is perceived to adversely affect their professional interests. So, there is not only an absence of information-sharing among different service providers in the same area, but lack of coordination also affects the quality of services provided by different players. Many private practitioners whose services are used both by the poor and elite sections of the population, remain ignorant about leprosy as a public health problem and the efforts to eliminate it.

According to the Indian Constitution, health is a state subject. While the functioning of smaller urban areas falls within the purview of municipal bodies, the larger ones are under the regulation of municipal corporations. These bodies have the status of local self-government. One of their functions is the provision of primary health care services within the geographical area of their operation. The main sources of finance of these bodies are local taxes and grants-in-aid from state governments, and these bodies often suffer from financial constraints which result in inefficient functioning. Furthermore, health may not be the topmost priority for these local urban bodies.

State governments have primarily focused on creating tertiary-level health infrastructure and medical colleges in urban areas rather than urban primary health care. For the implementation of health programmes, different mechanisms exist in different urban areas. Hence, it is difficult to get a clear understanding of the magnitude of health problems in large towns and cities, and there are no uniform institutional mechanisms in place to address them. Accordingly, DANLEP's approach to the challenges to leprosy elimination in urban areas has been to develop stakeholders' partnership and coordination.



An Overview of DANLEP's Urban Leprosy Elimination Initiative

The WHO-initiated final push strategy towards the global elimination of leprosy by 2005 has helped to generate the necessary political will to participate in a global coalition to free the world of this age-old scourge. The gradual phasing-out of specialised programmes has provided opportunities for advocacy at global and local levels. Broader partnerships mean the availability of greater expertise and more resources for implementing innovative strategies at local level.

Similarly, the DANLEP-supported urban leprosy elimination strategy is predicated on the ideas that partnership-building, community participation and ownership and social mobilisation will not only result in wider dissemination of information about leprosy and its cure, but the collaboration of a heterogeneous group of influential social actors would be more effective than the health system functioning alone through the conventional methods of health surveys and IEC. Increasing the participation of the community in leprosy elimination activities, it is also hoped, will contribute to transforming the image of leprosy in a more positive direction and simultaneously diminishing the social stigmatisation and discrimination of leprosy affected persons.

The essential differences between this alternative urban operational strategy and the conventional approach of case-finding and IEC are:

1. The underlying principles of the endeavour involve partnership, networking and community participation;
2. The active involvement of the non-health system administration and political leadership;

3. Peer group facilitation and local advocacy using non-traditional/non-leprosy groups and agencies;
4. The development of a plan of action by local individuals and institutions to ensure local ownership of leprosy elimination activities;
5. The signing of a memorandum of understanding (MOU) symbolically formalising the stakeholders' commitment to the programme.

Pilot Projects as the Basis for the Strategy

The urban leprosy strategy was piloted by DANLEP in selected urban areas in the states of Tamil Nadu, Orissa, Madhya Pradesh and Chhattisgarh. The following table presents an overview of the urban sites where the project was undertaken.

Table 1 shows that the urban pilot projects began at different times at different sites between 2001 and 2003. While the projects had been completed in Salem, Burhanpur, Rourkela, Rayagada Municipality, Vyasnagar and Angul municipalities, they were still under way in the cities of Chennai, Bhubaneswar, Bilaspur, Bhopal and Guna at the time of documentation.

Table 1: Project sites of the DANLEP-facilitated urban leprosy initiative

State	Urban area	Time period
Chhattisgarh	Bilaspur Urban	February 2003-July 2003
Madhya Pradesh	Bhopal	February 2003-July 2003
	Burhanpur	June 2001-June 2002
	Guna	February 2003-July 2003
Orissa	Angul Notified Area Council (NAC)	February-September 2002
	Bhubaneswar	May 2001-July 2003
	Rayagada Municipality	March 2002-November 2002
	Rourkela	April 2002-January 2003
	Vyasnagar Municipality, Jajpur District	January 2002-May 2003
Tamil Nadu	Chennai Corporation	March 2002-July 2003
	Salem Corporation	April-October 2002

While the NLEP was at various stages of functional integration in Orissa, Madhya Pradesh and Chhattisgarh, the situation in Tamil Nadu was somewhat different, since integration was implemented as far back as 1997 in rural areas. For dealing with the leprosy situation in urban areas, efforts made by the DANLEP Tamil Nadu unit have resulted in the government formulating a relocation plan for the leprosy NGOs from rural to urban areas. The NGOs had been encouraged to readjust their vertical approach in favour of partnerships with existing health care providers in an effort to integrate leprosy care in urban areas. The situation in Tamil Nadu was particularly conducive for government-NGO collaboration. There were over 31 specialised leprosy NGOs, with more than three decades of experience of working in different parts of the state. They had played an important role in supplementing the state's leprosy programme. They possessed the necessary expertise, facilities and grass-roots networks to become useful partners with the government in the leprosy elimination initiative, a role they had already been playing in an informal manner earlier. NGOs could be equal partners with the government in joint ownership of the leprosy elimination programme in urban areas. In the division of labour between the state government and NGOs, it was reiterated by both sides that NGOs would not actively engage 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 and stakeholders.

Size and Administrative Complexity of the Urban Site

The size and the administrative complexity of an urban area are important factors in determining the pace with which the urban strategy can be implemented. This is illustrated by the relatively slow progress in the state capitals, that is, Chennai and Bhubaneswar, in comparison to the time-bound completion of planned activities in smaller cities, such as Salem, Burhanpur, Angul, Rayagada and Vyasnagar municipalities. Large urban areas are characterised by the existence of multiple and complex bureaucratic networks whose functions often overlap; for example, health departments of municipal body and state government.

Given the complex bureaucratic procedures within which government organisations function, any intervention that seeks to involve different sections of the bureaucracy must make provision for handling possible inter-

and intra-departmental dynamics, both procedural and human. This would require a thorough understanding of the local bureaucratic context within and through which the objectives will be achieved.

The relatively slower pace of implementation of pilot projects in state capitals does not mean that the strategy is more appropriate or more likely to succeed in smaller towns and cities. But it points to the need to pay close attention to the size and administrative complexity of the urban area. Difficulties may arise in coordination and partnership-building in the planning and execution of the urban initiative, when both the target population and the number of stakeholders are large.



The Urban Strategy Initiative A Generic Model

The model described below provides guidelines for leprosy elimination activities in urban areas. The approach emphasises local body, institutional and peer group participation, institutionalising partnerships and developing coordinating mechanisms. Taking cognizance of the population and spatial characteristics of urban areas, the urban strategy initiative has tried to channel the utilisation of existing services and resources in leprosy elimination work through processes of coordination and networking with minimal additional financial investment. For instance, the numerous homeopathic and *ayurvedic* dispensaries in cities can become drug delivery points for MDT services.

Objectives

Overall Developmental Objectives of the Urban Strategy Initiative

1. To ensure leprosy elimination in the urban area within a realistic timeframe.
2. To generate public awareness about the curability of the disease, the availability of free and effective drugs, and to destigmatise leprosy.

Specific Objectives of the Urban Strategy Initiative

1. To develop partnerships with a variety of stakeholders, representing all known communities of the urban area, and ensure commitment at all relevant levels and develop a common work plan for leprosy care and elimination.
2. To promote participatory and structural coordination mechanisms among different service providers and agencies.

Steps for Implementation

The following table delineates the formal design of the multi-stage urban leprosy elimination strategy piloted by DANLEP. The suggested procedure is indicative and not absolute. While the time frame for the completion is of necessity flexible, a realistic time management plan is necessary to ensure optimum effectiveness. It has been found that the shorter the intervals between the different activities, the more chances there are of the entire strategy being operationalised.

It must be ensured that this approach complements the urban NLEP/GHS initiatives, and in no way creates any parallel or alternative structure to the latter. Ensuring the active involvement of the medical officers of leprosy elimination units (MO-LEUs) and local body executives is essential for the success of the initiative.

The above description represents the ideal typical model of the strategy, as it has been developed based on the experiences with pilot projects in urban areas in the four DANLEP states. However, as will be exemplified in Part Two of the document, there were important differences in implementation in different urban areas in different states, including variation in their sequence as per local conditions. Keeping these differences in mind, the above steps serve as a generic model to be carefully evaluated in planning leprosy initiatives in other urban areas and other states, and to be modified according to local needs.

Table 2: The Special Urban Leprosy Elimination Initiative

Step	Activity	Responsible persons/ institution	Outcome	Resources	Risks	Indicators for assessing outcome
1.	Selection of an urban area. Areas with a PR higher than the state average should be prioritised.	MO-LEU, DLO and other NLEP officials, local health department, especially CDMO, leprosy NGOs.	Preliminary discussions with government officials on the feasibility of the project.	1. Time 2. Decision-making power.	Lack of interest and enthusiasm to focus on urban leprosy as a priority.	1. Level of interest shown by different stakeholders. 2. Level of cooperation. 3. Level of commitment expressed.
2.	Situational analysis to get a comprehensive overview of the demographic composition, the prevailing leprosy situation and available resources in the target area.	MO-LEU, DLO and other NLEP officials, local health department, NGOs.	Statistical information on leprosy scenario in the target area and precise information on all available health infrastructure.	1. Social scientist or similarly trained person. 2. Statistical data on leprosy in the area. 3. Directory of health facilities in the area available with health department and professional associations.	1. Unavailability of reliable or up-to-date data. 2. Unavailability of a competent data analyst.	Availability of detailed baseline information on following aspects: a) demographic and socioeconomic description of the population. b) accurate data on the leprosy situation in the area and availability of treatment.

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Step	Activity	Responsible persons/ institution	Outcome	Resources	Risks	Indicators for assessing outcome
						c) number of health facilities available categorised by location, sector (public, private, NGO, industrial) and system (biomedical, ISM, other).
3.	Identification of stakeholders at policy, provider and community levels.	MO-LEU, DLO and other NLEP officials, local health department.	Listing of potential partners for participating in leprosy elimination campaign (assessment of contribution, availability of time, interest, willingness and potential drawbacks).	1. Reliable information on occupational groups, pathways of influence and health infrastructure in the area.	Important stakeholders may be left out or be inadequately represented, e.g. women, LAPs, religious minorities, migrant populations, other marginalised segments.	1. Comprehensive list of important stakeholders ranging from state health care system, private service providers, social service organisations, educational institutions, members of local municipality or corporation, community

Step	Activity	Responsible persons/ institution	Outcome	Resources	Risks	Indicators for assessing outcome
						<p>and spiritual leaders, leprosy affected persons and their families etc.</p> <p>2. Important to ensure equal gender representation in stakeholder selection.</p>
4.	Dialogue with stakeholders.	LEU, DLO and other NLEP officials, local health department, NGOs.	<p>Stakeholders are personally contacted and appraised of the project and their possible role therein.</p> <p>Questionnaire may be administered to assess their understanding of leprosy, possible contribution and willingness to participate.</p>	Personal knowledge and contacts with persons of influence in the local polity and community.	<p>1. Difficulty in meeting stakeholders because they lack time.</p> <p>2. Many stakeholders are not interested in the issue.</p>	<p>1. Large, influential and fairly representative (in terms of class, caste, gender, occupation) group of partners are mobilised for leprosy work.</p>

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Step	Activity	Responsible persons/ institution	Outcome	Resources	Risks	Indicators for assessing outcome
5.	Stakeholders' analysis and development of a stakeholder matrix.	LEU, DLO and other NLEP officials, local health department, NGOs.	<ol style="list-style-type: none"> 1. Feasibility of the group of stakeholders who have agreed to be partners to contribute to the campaign, both individually and collectively. 2. Matching campaign tasks with the availability, willingness and capacities of each of the partners, including individual strengths and weaknesses. 	Thorough understanding of the human resource component of the campaign and then matching the demand with the available human resources in the form of willing stakeholders.	<ol style="list-style-type: none"> 1. There may not be enough willing stakeholders. 2. The group of stakeholders may not be representative of influential persons. 	Ranking of stakeholders' potential participation and contribution, both individually and as a group.
6.	Partnership-cum-team-building.	LEU, DLO and other NLEP officials, local health department, NGOs.	Partnership-cum-consensus-building workshops with stakeholders to discuss the	1. Time, space and money to organise workshops.	1. Stakeholders may not attend scheduled meetings.	1. Stakeholders regularly attend the consensus-building meetings.

Step	Activity	Responsible persons/ institution	Outcome	Resources	Risks	Indicators for assessing outcome
			project, individual roles and responsibilities, and arrive at participatory agreement on support and cooperation.	2. Group coordinator such as MO (LEU) to oversee activities.	2. Negative group dynamics may disrupt consensus-building exercise.	2. They are sensitised about the importance of leprosy elimination. 3. They are sufficiently motivated and committed to partner the urban leprosy elimination initiative.
7.	Formation of Urban Leprosy Elimination Committee with MO (LEU) as secretary.	Committee is under chairpersonship of chief administrative functionary of the area, such as district collector/ mayor.	Meeting of the entire committee under chairman is held.	Time of the chairperson and core committee members.	Due to lack of time and motivation of members, committee may not get formed expeditiously.	Committee is formed under chairmanship of important administrative functionary.
8.	Finalisation of action plan for IEC and case-detection.	Members of Urban Leprosy Elimination Committee coordinated by secretary.	The committee develops action plan.	Time of the chairperson and core committee members.	Due to lack of time and motivation of members, committee may not meet.	A time-bound micro-plan of action with clear delineation of tasks, roles and responsibilities is

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Step	Activity	Responsible persons/ institution	Outcome	Resources	Risks	Indicators for assessing outcome
						produced. It is the product of a number of consensus-building meetings and workshops.
9.	Budget.	LEU, DLO and other NLEP officials, local health department, NGOs.	On the basis of the action plan, the budget is worked out.	<ol style="list-style-type: none"> 1. Cash and kind contributed by stakeholders. 2. If locally relevant, SAPEL resources may be utilised for urban leprosy elimination. 	Inadequate financial resources are available.	Financial resources available for implementing the action plan.
10.	Signing of MOU.	Members of Urban Leprosy Elimination committee coordinated by secretary.	The MOU is signed by all the committee members.	Time of the chairperson and core committee members.	Due to lack of time and motivation of members, committee may not meet. Or not agree to sign MOU.	<ol style="list-style-type: none"> 1. MOU is signed. 2. Public announcement of the programme through local media.

Step	Activity	Responsible persons/ institution	Outcome	Resources	Risks	Indicators for assessing outcome
11.	Sensitisation and training through coordination with partners.	Members of Urban Leprosy Elimination Committee, MO-LEU, DLO and other NLEP officials, local health department, NGOs.	The partners organise sensitisation workshops on leprosy in their institutions.	Motivation, ability and time to organise the sensitisation workshops.	Partners may lack enthusiasm to organise sensitisation activities and put it on the priority list of their organisations.	Systematic sensitisation of different categories of stakeholders (including health care providers, teachers, students, body of councillors etc.) on basic facts of leprosy and their role in the project and beyond.
12.	Strengthening institutional capacity.	MO-LEU, DLO and other NLEP officials, local health department, NGOs.	Drug delivery points (DDPs) are created in a large number of health facilities in the government, private and NGO sectors.	Medicines, reporting and registration formats and training on their use.	Health facilities and service providers especially in the private sector, are unwilling to cooperate.	Availability of MDT drugs, registers, reporting formats and IEC material in maximum number of health facilities.
13.	Plan of IEC campaign in the selected areas.	Members of Urban Leprosy Elimination Committee, MO-LEU, DLO and other NLEP	Rallies and other public events for increasing awareness about	Time and commitment of a large number of enthusiastic community volunteers.	1. Apathy of partners to initiate such activities. 2. Lack of community	Range of activities with community participation, such as organisation of rallies,

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Step	Activity	Responsible persons/ institution	Outcome	Resources	Risks	Indicators for assessing outcome
		officials, local health department, NGOs.	leprosy, enhancing community participation and widening case detection and treatment activities are undertaken.		participation.	setting up voluntary reporting centres for diagnosis and treatment of cases.
14.	Document process for dissemination.	MO-LEU, DLO and other NLEP officials, local health department, NGOs.	A comprehensive report for wider dissemination.	1. Availability of reliable data on the initiative. 2. Documenter.	1. Inadequate records. 2. Lack of initiative of responsible person/institution.	Detailed process documentation available.
15.	Evaluation and follow-up.	MO-LEU, DLO and other NLEP officials, local health department, NGOs.	<ol style="list-style-type: none"> Increase in voluntary reporting. A short-term increase in PR. Wider availability of MDT. Evaluation report may be prepared and disseminated. 	Time and commitment of the core committee members, and local health care functionaries.	Initial enthusiasm may fade and other health issues may take priority over leprosy.	<ol style="list-style-type: none"> Regular review meetings of stakeholders to assess project, plan for follow-up of ongoing activities and planning for future interventions. Evaluation report available.

Roles of Different Stakeholders

Nongovernmental Organisations

In the present context of the phasing out of DANLEP and the integration of the NLEP with the general health system, NGOs are essential partners for leprosy elimination. But leprosy work is no longer as professionally challenging for this sector as other alarming public health issues such as tuberculosis or HIV/AIDS. Consequently, in the context of leprosy elimination activities, a strategic effort should be made to identify and cultivate strategic NGO partners at all levels.

Local Political Representatives

A conscious attempt to involve members of the *Panchayati Raj* institutions (PRI) in leprosy work in rural areas has been quite successful. Similar attempts have been made in the urban initiative to partner members of municipal councils.

Again, it has been easier to elicit their cooperation in smaller towns like Vyasnagar, Rayagada, Bilaspur and Burhanpur than in larger towns like Bhubaneswar, Chennai and Bhopal.

From a strategic point of view, the councillors should be directly involved in a number of activities, such as case detection and IEC. For example, a roster should be prepared of rallies and skin camps that would be organised in the different wards of the city. Advance notice should be given to the councillor of the ward who should extend his/her cooperation.

However, in larger cities, the nature of involvement of municipal councillors may be more in the nature of passive cooperation rather than active engagement. It must be remembered that stakeholders also have ulterior motivations in participating in public events and campaigns like the leprosy elimination initiative. This is both natural and expected. From a programmatic point of view, it is important to take this factor into account in the planning and implementation of the strategy.

Private Practitioners: Critical Stakeholders but Unwilling Partners

The proliferation of private clinics in urban areas implies that private practitioners should be encouraged to actively participate in any health initiative in their cities. The assumption that private practitioners are crucial stakeholders but unwilling partners in government-sponsored health programmes is not entirely untrue. Private doctors may not want to take on additional responsibility, especially when it involves extra documentation and cuts into their time and profit. Firstly, it is important to disaggregate the category of private practitioners itself; for, it is a heterogeneous mix of service providers with varying qualifications and appertaining to different systems of medicine. And, not all of them have been found to be averse to participating in the urban leprosy pilot project. For instance, in both Madhya Pradesh and Chhattisgarh, private *ayurvedic* and homeopathic doctors have been referring suspected patients to the leprosy units.

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 of the elimination strategy was not evident among all private doctors in different DANLEP aided-states. Private practitioners may fear that their participation in the leprosy elimination programme might adversely affect their practice, and that by actively participating in the leprosy programme, the stigma traditionally associated with the disease might rub onto their own practice, which could result in loss of patients and practice.

In order to increase cooperation with private practitioners, it is important to involve the local branches of the Indian Medical Association (IMA), the professional body of registered biomedical practitioners, and sensitisation sessions should be undertaken with IMA members.

Though attempts at involving biomedical private practitioners in leprosy work, even when mediated through professional associations such as the IMA, in some cities may be only partially successful, private doctors form an important resource. Ensuring their involvement is essential for the success of any health intervention, particularly since private practitioners may otherwise work actively against the strategy for fear of losing patients. Innovative strategies to influence professional associations through academic and outreach programmes have to be further pursued.

Practitioners of Indian Systems of Medicine

For practitioners of Indian systems of medicine (ISM) to be partners in leprosy elimination activities can be a pathway to higher professional mobility. This probably explains the willingness of *ayurvedic* and *unani* practitioners to participate in the urban initiative, especially in Madhya Pradesh and Chhattisgarh. The first Care and Concern camp in Bhopal was held at the Rajiv Gandhi Vishwavidyalya, which is an *ayurvedic* college. Similarly, the local *ayurvedic* and *unani* colleges in Burhanpur played active roles in the special urban leprosy campaign.

The involvement of practitioners of Indian systems of medicine implies a dialogue with the leprosy elimination programme, where ISM practitioners agree to the principles of leprosy diagnosis and treatment in accordance with biomedical standards. There has long been a tradition for forming such partnerships in rural and less accessible areas with a poor health care infrastructure. The same tradition does not exist in urban areas, where competition between practitioners of different medical systems is often high. However, once collaboration is established, ISM practitioners form an important resource and may add to the coverage of people who may not routinely seek allopathic treatment as their first choice.

The ICDS Workers: A Rich Resource Base

In the process of integration of leprosy with the general health system, the onus of leprosy case detection and treatment at the micro-level falls on the multipurpose workers (MPWs) and *Anganwadi* workers (AWWs). *Anganwadi* workers have, in fact, emerged as significant stakeholders in the urban context. Most of them have undergone some amount of sensitisation on leprosy before each Modified Leprosy Elimination Campaign (MLEC). Due to frequent contact with households in their respective communities, they can be important channels for case detection, treatment delivery and follow-up. In the DANLEP context, ICDS workers have expressed satisfaction with being able to suspect leprosy cases.

However, from a strategic point of view, it is essential to assess the workload placed on ICDS workers vis-à-vis the remuneration they receive. Due to the density of population in urban areas, their workload is often higher than in rural areas. Hence, inclusion of ICDS workers should take place with due

consideration for their overall working conditions. DANLEP's health system research (HSR) studies have shown successful involvement of *Anganwadi* workers in case detection, record-keeping, reporting and treatment, including delivery of MDT.¹

Students: A Committed Volunteer Force

From the perspective of reliability in contributing to the leprosy elimination activities over time, institution-based school and college students and their teachers are in an advantageous position to offer continual support. If leprosy work can be formally made a part of their curricular and extracurricular 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. Any attempt at the replication of the urban strategy must ensure the active involvement of this group of stakeholders.

Cured Leprosy Affected Persons

Cured leprosy affected persons (LAPs) are in many ways the most convincing advocates in the IEC context, since they have undergone the trauma of social exclusion and have experienced the benefits of cure. The POD-camp approach has strategically honed in on the potential of this group for both the preventive care of recovered patients and the de-stigmatisation of community. In contemporary disability legislation in India, being cured of leprosy is classified as a distinct category of disability, at par with hearing and visual impairment.

However, it has proven more difficult to involve cured LAPs in urban than in rural settings. Reasons for this include the difference between a large city and a small rural community, where, at community level, there can be direct and personal communication with all or almost all community members, and a consensus can be reached on behavioural changes in favour of de-stigmatisation, case detection and treatment, which, in turn, leaves the LAP

¹ *Integrating Leprosy Services into the General Health Care System: Studies from Chhattisgarh, Madhya Pradesh and Orissa, India.* DANLEP, New Delhi, 2003; and *Integration of MDT Delivery for Leprosy Treatment in the General Health System: Studies from Orissa, India.* DANLEP, New Delhi, 2003.

strengthened rather than vulnerable. In the urban context, this level of consensus is difficult to reach and sustain, and care should be taken not to render leprosy affected persons vulnerable to stigmatisation in the process. At a practical level, it is difficult to access and involve leprosy-cured persons from the upper- and middle-income groups, who could emerge as equal partners. The process of involving persons who have suffered from the disease and are in a position to influence their communities in the context of low-income groups in planning and implementation should also not be underestimated. Special care should be taken to grant LAPs genuine decision-making power if involved, and to avoid tokenism. However, if this is done, cured LAPs can be vital and essential advocates for the urban initiative.

Reaching the Unreached Groups

Given the demographic complexity of larger urban areas, sometimes with a heterogeneous composition of many different social, ethnic, religious and language groups, it is necessary from the outset to produce a demographic map of the intervention area and actively identify and involve key members of the unreached groups. This may be done directly through personal contact or through their representatives, e.g. union leaders, religious leaders, community organisations, women's groups and others. While the sensitisation effort is necessary from the viewpoint of programme management, it is important to work actively against mere tokenism, since being unreached by earlier campaigns is a sign of general marginalisation from social and political decision-making. Otherwise, this marginalisation will simply be replicated in the dynamics of the group of stakeholders who organise the urban leprosy elimination initiative. There is no doubt that their participation would enhance the effectiveness of the programme, but the modalities of their involvement have to be carefully worked out keeping in mind their precarious living conditions. The issue of financial compensation has to be carefully considered.

The urban landscape throws up a wide array of unreached groups, from minorities such as Muslims, especially Muslim women, to middle and upper income groups. In the context of the urban strategy initiative under discussion, there is no doubt that representatives from these groups must be equal partners in the core team: but equally important is the need to involve individuals from these groups with real clout. Otherwise, their

presence will be merely token and the aim of reaching the unreached will remain just that.

Non-Cooperation of Upper Socioeconomic Groups

A major obstacle to the success of any people-based endeavour is the general apathy of large sections of the upper- and middle-income urban populations. Having the resources to avail themselves of the services of the private sector, be it education or health, they are often reluctant to be associated with interventions involving the general public.

During the pilot interventions, stigma was seen more among the urban middle and upper-middle socioeconomic groups as compared to rural areas, thus highlighting the point that social status and education may often correlate negatively with attitudinal change. Hence, from a strategic perspective, it should be assumed that stigma will form an important challenge for any urban leprosy intervention. However, treatment adherence may be comparatively higher in urban areas because more educated people tend to complete the course once they are aware of the treatment.

Information, Education and Communication

Information, education and communication (IEC) is the cornerstone of any successful campaign. Awareness-generation and information dissemination are the cognitive components of this process. Different media have been used to communicate the message of leprosy elimination. The choice of media depends on the target population. There is, for instance, a difference between IEC in urban and rural areas. In the urban context, mass media, including cable TV, is the most effective communicative modality for reaching the community at large if – and only if – it is combined with interpersonal communication (IPC). However, even in the urban setting, specific population groups may be systematically left out if too much reliance is placed on the use of mass media. For example, migrants from other parts of the country may prefer to watch the TV channels from their native states rather than the ones generally watched in the locality.

As part of the urban campaign, special songs and dramatic presentations on leprosy should be prepared and enacted in smaller towns and in selected neighbourhoods in larger towns. In contrast to the village milieu where it

is easier to gather people at a central location for such presentations, this is more difficult in the densely populated slums in urban areas.

Based on the identification of the specific population groups that form an urban society, there will be a need to develop specific, tailor-made IEC interventions for particular groups, such as Muslim women or tribal communities. IEC materials should be developed in close collaboration with resourceful individuals and artists from the target communities and should focus on key messages pertaining to curability, timely detection, free treatment and de-stigmatisation.

The Rehabilitation Component

The disabilities associated with leprosy impose a significant economic and social burden on the individuals affected, their families and society as a whole. Leprosy symptoms affect individuals in their most productive years of life and the disease, if untreated, runs a chronic course. People with chronic manifestations are often unable to work or marry. They become dependent for both physical and financial support, leading to further insecurity, shame, isolation and economic deprivation.

Given the intensive drive towards the elimination of leprosy, with its focus on case detection, MDT treatment and other activities, rehabilitation of the already disabled leprosy patients should not be forgotten. In addition to the importance of rehabilitation *per se*, the appeal of the urban leprosy initiative is enhanced through the incorporation of social and vocational rehabilitation.

Sustainability of the Initiative and the Issue of Leadership

Once the group of key stakeholders and partners has been brought together, a Memorandum of Understanding (MOU) should be signed to symbolise the pledge to work for leprosy elimination in the local urban area.

However, the composition of the partners' group brings to the fore the question of leadership. Who will act as the cement that will bind together the loosely-knit group of partners over time? The MOU is not a legal agreement, and participation is voluntary. Before integration, the NLEP staff under DLO would have indisputably assumed the leadership position. But

even in the context of functional integration, NLEP functionaries are being engaged in other health activities. Involving leprosy NGOs in the role of facilitator is a well-conceived option, but not all states have the required NGO expertise for leprosy work. There are, however, a large number of health NGOs which can take on the facilitation role in leprosy elimination activities after initial orientation. In the current era of disinvestment of the state in the social sector, such agencies may constitute the most viable option.