

# **The Urban Initiative for Leprosy Elimination**

Strategy and Process Documentation

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**DANLEP**

**2003**



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ADMO–PH	:	Additional District Medical Officer – Public Health
ASLO	:	Assistant State Leprosy Officer
AWW	:	<i>Anganwadi</i> Worker
BAMS	:	Bachelor of <i>Ayurvedic</i> Medicine and Surgery
BHEL	:	Bharat Heavy Electricals Limited
CBO	:	Community-based organisation
CDMO	:	Chief District Medical Officer
CDPO	:	Child Development Project Officer
CMO	:	Chief Medical Officer
CYSD	:	Community Youth for Social Development
Danida	:	Danish International Development Assistance
DANLEP	:	Danish Assistance to the National Leprosy Eradication Programme
DDL	:	Deputy Director, Leprosy
DFIT	:	Damien Foundation India Trust
DLES	:	District Leprosy Elimination Society
DLO	:	District Leprosy Officer
ESI	:	Employees' State Insurance
GAEL	:	Global Alliance for the Elimination of Leprosy

GHS	:	General Health System
GLRA	:	German Leprosy Relief Association
GOI	:	Government of India
ICDS	:	Integrated Child Development Services
IEC	:	Information, education and communication
ILEP	:	International Federation of Leprosy Associations
IMA	:	Indian Medical Association
IPC	:	Interpersonal communication
ISHWEL	:	Integrated Society for Human Welfare
ISM	:	Indian systems of medicine
LAP	:	Leprosy affected person
LCU	:	Leprosy Control Unit
LEC	:	Leprosy Elimination Campaign
LEU	:	Leprosy Elimination Unit
MB	:	Multibacillary
MDT	:	Multidrug Therapy
MLEC	:	Modified Leprosy Elimination Campaign
MO	:	Medical Officer
MOU	:	Memorandum of Understanding
MPW	:	Multipurpose Worker
NAC	:	Notified Area Council
NCC	:	National Cadet Corps
NGO	:	Nongovernmental organisation
NIMA	:	National Integrated Medical Association
NLEP	:	National Leprosy Eradication Programme

NMS	:	Non-Medical Supervisor
NSS	:	National Social Service Scheme
OBC	:	Other Backward Classes
PB	:	Paucibacillary
PHC	:	Primary health care
PMW	:	Paramedical Worker
POD	:	Prevention of disability
PR	:	Prevalence rate
PRI	:	Panchayati Raj institution
RAYALEP	:	Rayagada Leprosy India
RCH	:	Reproductive and Child Health
SAPEL	:	Special Action Project for the Elimination of Leprosy
SC	:	Scheduled Castes
SECL	:	South Eastern Coal Fields Ltd.
SER	:	Socioeconomic rehabilitation
SET	:	Survey, education and treatment
SLES	:	State Leprosy Elimination Society
SLO	:	State Leprosy Officer
SMLC	:	Saint Mary's Leprosy Centre
ST	:	Scheduled Tribes
TLM	:	The Leprosy Mission
TOR	:	Terms of reference
TOT	:	Training of trainers
VRC	:	Voluntary Reporting Centre
WHO	:	World Health Organization



Achievement of global elimination of leprosy was announced by the World Health Organization (WHO) in May 2001. However, India is among the six countries still reporting leprosy cases, making up to about two-thirds of the world's total. The National Leprosy Eradication Programme (NLEP) targets to achieve leprosy elimination at national level by 2005.

The NLEP initiated leprosy control programme through a vertical set-up. The operational units for rural areas have been districts, and for urban areas, urban leprosy control units. The vertical leprosy control structure is being strategically integrated into general health care services. This gradual process of structural and functional integration of leprosy care has been more or less achieved in rural areas through the primary health care network. Consequently, there has been an appreciable reduction in leprosy prevalence in rural areas.

Over the years, India has developed a well-structured and uniform health care system for its rural areas. India lives in villages, the rural population accounting for about 70% of the total. Therefore, the obvious priority for the state-supported primary health care system has been rural areas. In contrast, the urban health care system has grown into an unregulated, multiple and complex system that poses problems for most national disease control programmes. Leprosy elimination is no exception.

By taking the district as the operational unit, the NLEP inadvertently let urban areas go out of focus. The available NLEP vertical structure could not keep pace with the urbanization process and the population dynamics. Operational strategies missed the opportunity to involve local urban governance in the leprosy elimination initiative.

The programme also failed to ensure community support in urban areas. With inherent generic problems of health system complexities and the multiplicity of health care service providers, urban areas could not appropriately respond to support NLEP initiatives. The cumulative effect of an inadequate urban response over the years has gradually emerged as a major issue in leprosy elimination. Therefore, urban leprosy elimination programme needs to be strengthened.

Though the NLEP had identified urban leprosy as a problem, it needed a systematic approach to address the issues. In consultation with the NLEP and the partner states of Madhya Pradesh, Chhattisgarh, Orissa and Tamil Nadu, DANLEP analysed the issues and problems related to urban leprosy and developed and piloted an 'Urban Leprosy Elimination Initiative Model'.

Considering the resource constraints of most urban local bodies, the approach was based on pooling together all existing and potential resources, involving and ensuring a wide range of stakeholders' participation, developing shared local ownership and coordination and monitoring mechanism for leprosy elimination in the pilot urban areas. The concept was to supplement and not substitute government efforts. The initiative aimed at creating renewed interest to implement an intensified strategy, ensuring partner support, promoting and ensuring local advocacy and broadening partnership efforts to develop an approach to integrate leprosy care into the general health care services and the services provided by other players. The initiative had a mixed response at different locations, resulted in some success, and also provided some lessons in the process.

These experiences have been documented by an independent researcher, Dr Renu Addlakha. She has captured the DANLEP initiative in a broad perspective and from various dimensions and tried to conceptually examine the urban leprosy elimination strategy. The analysis is undertaken within the framework of the problems of urbanisation in the Indian context. A comparative analysis forms the basis for the strategic inferences drawn for future replication that are presented in the form of a generic description of the urban leprosy elimination strategy model and a set of prescriptive guidelines.

This document also reflects the detailed description of the process and the experiences of operationalising the urban strategy in the selected urban sites in the four states of Tamil Nadu, Orissa, Madhya Pradesh and Chhattisgarh. An attempt has been made to describe the actual planning and implementation of the urban strategy at the micro-level. The document not only describes the problems and the challenges faced during the implementation but also highlights the positive outcomes of the approach.

I hope the experiences and the lessons learned will be useful to the NLEP in addressing the urban leprosy problem in India and to other health programmes which pursue their objectives through partnerships.



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New Delhi, August 2003



I would like to acknowledge the painstaking assistance provided by the DANLEP teams in Delhi, Orissa, Tamil Nadu, Madhya Pradesh and Chhattisgarh. I am also grateful for the cooperation of the NLEP functionaries and other health officials in the different states. It is impossible to individually enumerate the contributions of the large number of stakeholders that I interviewed in the different states for preparing this document. The insightful comments of Dr. S.K. Mohanty, Senior Technical Adviser, DANLEP, Delhi, were very useful in writing this report. This document would never have been brought to fruition without the assistance of Dr. Jens Seeberg, HSR Adviser, DANLEP, Delhi. Apart from his patience and encouragement, he has meticulously gone through several versions of this document providing invaluable conceptual and editorial inputs.

Renu Addlakha



## Executive Summary

The widespread adoption of multidrug therapy (MDT) for the treatment of leprosy since 1983 has made the possibility of its elimination a reality. When the case-load is brought down to less than one case per 10,000 population, it is defined as elimination. Elimination has, in fact, been achieved at the global level since May 2001. Nonetheless, six countries continue to contribute large numbers of new cases; of these, India accounts for more than 66 per cent of the total global case-load.

The current epidemiology of leprosy in the DANLEP-supported states of Tamil Nadu, Orissa, Madhya Pradesh and Chhattisgarh shows that a sizeable number of new cases are being reported from urban areas. The dramatic achievements in case detection and completion of treatment made in rural areas have been difficult to replicate in urban areas. It has also been observed that leprosy cases tend to concentrate among the socially and economically disadvantaged sections of the population living in urban slums. Considering the rapid pace of urbanisation in the country, it is important to take account of the special problem of urban leprosy so as not to slacken the pace towards its elimination.

The challenges in urban areas relate to the existence of multiple service providers, rapid population growth, industrialisation, large-scale migration, unplanned area expansion and a socioeconomically heterogeneous population. These factors make access to patients difficult from a programme point of view.

In accordance with the WHO recommended strategy for the final push towards elimination of leprosy, the Government of India (GOI) has been trying to achieve the integration of the National Leprosy Eradication Programme (NLEP)

into the general health care system. Integration has been achieved to a large extent in rural areas, mainly due to the existence of a uniform well-structured primary health care delivery system.

In the absence of such a system in urban areas, integration of leprosy care with the existing complex pluralistic urban health system can only be realised by developing and institutionalising partnerships between existing service providers and stakeholders, and developing an appropriate coordination and monitoring mechanism promoted and supported by the state. Political commitment, partner support and community involvement are indispensable elements in this process.

In order to address the problems facing the leprosy elimination programme in the urban context, DANLEP has conceptualised an operational approach based on building partnerships between existing and potential stakeholders, pooling together available resources, developing and institutionalising coordination and monitoring mechanisms for leprosy elimination that supplement rather than substitute government efforts. This intervention has been piloted in selected cities of Tamil Nadu, Orissa, Madhya Pradesh and Chhattisgarh between 2001 and 2003.

The urban initiative 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. The novelty of this approach lies in the active involvement of administrative bodies outside the health system and local political leadership in the development of a local plan of action, with the aim of ensuring local ownership of leprosy elimination activities.

The overall developmental objectives of the urban strategy initiative for leprosy elimination are:

1. To ensure leprosy elimination in the urban area within a realistic time-frame.

2. To generate public awareness about the curability of the disease and the availability of free and effective drugs, and to destigmatise leprosy.

The specific objectives have been defined as:

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 develop and institutionalise participatory and structural coordination mechanisms among different service providers and agencies.

The strategy that is described in Part One of the present document provides a generic model of 14 steps to be followed. These steps describe the generic activities to be carried out in the urban leprosy initiative in terms of responsible person/institution, outcome, resources, risks, and indicators for assessing the impact.

Part Two provides a detailed process documentation of the activities in the urban pilot project areas in Chhattisgarh, Madhya Pradesh, Orissa and Tamil Nadu.



The National Leprosy Eradication Programme (NLEP) in India has been in existence since 1955. Till the 1980s the programme moved slowly within the parameters of the survey, education and treatment (SET) approach. It was the era of dapsone monotherapy, with long treatment regimens, continuing deformity and microbial resistance. It was only after the introduction of multidrug therapy (MDT) in 1983 that the programme experienced renewed interest. The possibility of a cure for an age-old disease and the prevention of the onset of disability in diagnosed cases contributed, along with innovations in information, education and communication (IEC), to changing the image of both the leprosy patient and the leprosy worker.

With the introduction of MDT in the last two decades, the national leprosy prevalence rate (PR) has come down from 57/10,000 (1983) to 2.3/10,000 (2003). Within the country, however, the cases are not equally distributed. Out of the 35 states and Union Territories, eight states account for about 70 per cent of the total cases. The high-endemic states are Jharkhand, Bihar, Chhattisgarh, Orissa, West Bengal, Madhya Pradesh, Uttar Pradesh and Uttaranchal.

The widespread adoption of multidrug therapy since 1983 has made the possibility of leprosy eradication a reality. When the prevalence rate is brought down to less than one case per 10,000 population, the chain of transmission of *mycobacterium leprae* is disrupted and the disease ceases to be a public health concern. Although elimination has, in fact, been achieved at the global level since May 2001, six countries continue to contribute large numbers of new cases; and, among them, India accounts for more than 66% of the total global case-load. Being a signatory to the

Global Alliance for the Elimination of Leprosy (GAEL), India is committed to achieving leprosy elimination by the year 2005. By March 2000, nine states had achieved elimination. The World Health Organization (WHO), the World Bank, Danida and other partners have been supporting the Central and state governments to achieve this goal.

The current epidemiology of leprosy in the DANLEP-supported states of Tamil Nadu, Orissa, Madhya Pradesh and Chhattisgarh shows that a sizeable number of new cases are being reported in urban areas. Experts point out that the dramatic success achieved in case detection and treatment completion in rural areas has not been repeated in urban areas. It has also been observed that leprosy cases tend to concentrate among the socially and economically disadvantaged sections of the population living in slums. Considering the rapid pace of urbanisation in the country (with 40 per cent of the population expected to be residing in urban areas by 2020), it is important to take account of the special problem of urban leprosy so as not to slacken the pace towards elimination at the national, state, district and block levels. Taking district as the operational unit, NLEP activities in urban areas have been rather ad hoc and sporadic. The cumulative neglect of urban areas over the years has now emerged as a major obstacle for the achievement of the elimination goal.

Since 1986, Danida had assisted the National Leprosy Eradication Programme in three states – Tamil Nadu, Orissa and Madhya Pradesh. Its activities were rooted in local communities, particularly addressing the social issues of fear and stigma associated with leprosy. In Phase III (1998-2003), DANLEP has consolidated its work through an integration and phasing-out process, to be completed by November 2003. The main focus of the activities of the Danish Assistance to the National Leprosy Eradication Programme (DANLEP) within the NLEP framework has been on integration of the vertical structure into the general health services, promoting gender equity, reaching the unreached population groups and areas, and mobilising civil society. DANLEP's main task before its withdrawal is to pass on its special skills and roles to partners, both within and outside the government, and to facilitate a smooth organisational transition without disruption in ongoing work.

Since 1995, one of DANLEP's main concerns has been the problem of leprosy in urban areas in the states in which it has been involved. A number of workshops on urban leprosy have been organised at the national and state levels. In contrast to the structural uniformity of the health care delivery system in rural areas based on the PHC system, the urban health system is very complex and involves a wide range of diverse organisations and individuals. In order to address the problems facing the leprosy elimination programme in the urban context, DANLEP has conceptualised an alternative operational approach based on building partnerships between existing and potential stakeholders, pooling available resources, and developing and institutionalising coordination and monitoring mechanisms for leprosy elimination that supplement rather than substitute government efforts. This intervention has been piloted in selected cities in Tamil Nadu, Orissa, Madhya Pradesh and Chhattisgarh during the past two years.

The drive for the integration of the vertical leprosy elimination programme with the general health services has also implied a need to shift the focus from active case finding to voluntary reporting for case detection. Political commitment, partner support and community involvement are indispensable elements in this process. Analogous with the Global Alliance for Elimination of Leprosy (GAEL) is the need for similar alliances/partnerships at local level. The urban strategy initiative piloted by DANLEP builds precisely upon such a paradigm of collaboration between different agencies and individuals within local communities.

The need to mainstream leprosy services within the general health system assumes strategic importance. Integration has been achieved to a large extent in rural areas, mainly due to the existence of a uniform well-structured primary health care delivery system. In the absence of such a system in urban areas, integration of leprosy care in the existing complex pluralistic urban health system can only be realised by promoting and institutionalising partnerships between existing service providers and stakeholders and developing an appropriate coordination and monitoring mechanism promoted and supported by the state. In some states like Tamil Nadu, DANLEP convinced the governments to work in partnership with international and national leprosy and non-leprosy nongovernmental organisations (NGOs) and other agencies. But the coordination and monitoring mechanisms were weak. In some places,

some of the NGOs still prefer to work vertically contrary to the national programme mandate to integrate leprosy care in the general health system.

This document is divided into two parts. Part One conceptually examines the urban leprosy elimination strategy developed and piloted by DANLEP. The analysis is undertaken within the framework of the problems of urbanisation in the Indian context. The strategy is based on the lessons learnt and is intended for future replication in other states. It is presented in the form of a generic description of an urban leprosy elimination model, including a series of steps for implementation, as well as a stakeholder analysis.

Part Two is a detailed description of the experiences with operationalising the urban strategy initiative in selected urban sites in the four states of Tamil Nadu, Orissa, Madhya Pradesh and Chhattisgarh. Using both documentary and interview-based data, an attempt has been made to describe the actual planning and implementation of the urban strategy at the micro-level. It is hoped that this descriptive account will pinpoint not only the problems and challenges faced during implementation, but will equally highlight the positive outcomes of the approach. Enhanced community awareness about leprosy and greater community involvement in and wider ownership of leprosy elimination activities are the broader objectives that have guided the operationalisation of the DANLEP urban leprosy elimination initiative in all the project sites.

