

Urban Leprosy Elimination

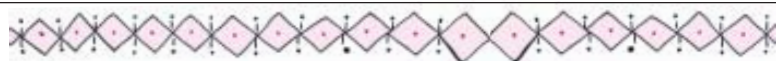
The Burhanpur Special Initiative

Vimarsh, Bhopal

DANLEP

2003

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Abbreviations



AWW	Anganwadi Worker
BJP	Bharatiya Janata Party
BMDA	Burhanpur Medical Dealers' Association
BSG	Bharat Scouts and Guides
CMHO	Chief Medical and Health Officer
DANLEP	Danish Assistance to the National Leprosy Elimination Programme
DLO	District Leprosy Officer
GHS	General Health System
GOI	Government of India
HOPE Therapy	Hydro-Olio-Physio Therapy
IEC	Information, Education and Communication
LAP	Leprosy-Affected Person
LE	Leprosy Elimination
LEC	Leprosy Elimination Campaign
MC	Municipal Corporation
MDT	Multi-Drug Therapy
MLA	Member of Legislative Assembly
MP	Madhya Pradesh
MP	Member of Parliament
MSO	Medical Shop-Owner
NGO	Nongovernmental Organisation
NIMA	National Integrated Medical Association
NLEP	National Leprosy Elimination Programme
NMA	Non-Medical Assistant
NMS	Non-Medical Supervisor
NSS	National Service Scheme
OBC	Other Backward Caste
OPD	Outpatient Department
POD	Prevention of Disabilities Camp
PR	Prevalence Rate
SC	Scheduled Caste
ST	Scheduled Tribe
ULC	Urban Leprosy Centre



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Executive Summary



The co-existence of registered and unregistered, public and private health service providers in urban areas pose a tremendous challenge for leprosy elimination (LE) in India. This problem is aggravated by rapid population growth, unplanned urbanisation and a complex socioeconomic set-up, which characterise urban areas and make access to patients difficult. Against this background, DANLEP, Madhya Pradesh, supported a special initiative in Burhanpur for the elimination of leprosy. Such an initiative promotes participatory efforts by citizens of the town drawn from different walks of life and also involves selected key stakeholders from the planning to the implementation stages. The general health system is expected to benefit from this experience which utilized resources that otherwise remain untapped.

Burhanpur, with a population of 3.3 lakh, is known for its handloom and powerloom weavers located in East Nimar (Khandwa) district. The town has a mix of Muslims, Hindus and Jains, with the largest group being Muslims. At 9.3 per 10,000 population (September 2001) East Nimar district had the highest prevalence rate (PR) of leprosy in the state. Despite the high PR, the awareness level of the local population regarding leprosy is very low. In addition, leprosy elimination efforts are affected by the practice of *purdah* (veil) observed by many Muslim women. This practice is a barrier to the diagnosis of leprosy and other skin diseases.

DANLEP, Madhya Pradesh, began facilitating the Special Initiative for Leprosy Elimination in the second half of 2001. A pre-campaign assessment in the town was carried out to identify issues that hindered leprosy elimination. This was done by discussions with local leaders and professionals, the National Leprosy Elimination Programme (NLEP) and General Health System (GHS) functionaries as well as through first-

hand observation of local conditions. A major issue identified, or rather confirmed by this exercise, was the low awareness level regarding leprosy in the population. A substantial perception gap was found among NLEP and GHS functionaries concerning their respective roles and responsibilities in leprosy elimination. An important issue highlighted by the exercise was the low priority accorded to leprosy elimination activities by the GHS. DANLEP's initial efforts were directed at convincing the health department of the validity of the concept of LE and to ensure their commitment for the use of their human resources. An additional challenge for DANLEP was to sensitise the department to change its perception from seeing itself as a mere associate to NLEP efforts to accepting responsibility as one of the principal stakeholders in leprosy elimination.

It was planned that the GHS and NLEP functionaries would provide appropriate guidance and support to various service and social work groups in the town, and that a special drive would be undertaken to eliminate leprosy in this high PR area. With the help of the Chief Medical Officer (CMO), the District Leprosy Officer (DLO) and NLEP workers, DANLEP developed a list of probable stakeholders. The list consisted of mainstream NLEP partners such as DANLEP, NLEP and the Health Department; service clubs such as Rotary, Lions and Giants; NGOs like the Red Cross Society; professional associations such as the National Integrated Medical Association (NIMA); community organisations such as Maheshwari Yuva Sangh and Sindhi Sewa Naujawan Mandal; political bodies such as the BJP Corporators' Dal; influential individuals, medical institutions such as the Government Ayurvedic College and the Unani College of Medicine, social service groups such as Bharat Scouts and Guides and the National Service Scheme (NSS), educational institutions such as Sanskrit Mahavidyalaya and a number of government schools. The team tried to assess the possible contributions these stakeholders could make. Two organisations, which helped facilitate the partnership negotiation with other institutions and citizens of Burhanpur, were the Rotary and the Lions clubs. The three distinct phases of the negotiations were:

1. Individual meetings with key/influential stakeholders;
2. Sensitisation workshop;
3. Partnership negotiation workshop.

At every stage the project tried to establish partnerships with various stakeholders in order to shift its ownership from government functionaries to the community. Attempts were made to involve the health department and the DLO at every stage. As key stakeholders they could provide a boost to the project but they could also have a negative impact on its success. However, GHS functionaries remained reluctant to accept ownership of the process. The perception among this body as well as other stakeholders was that the campaign was more a part of the DANLEP agenda.

Another issue was the inadequate involvement of an important stakeholder group, namely, leprosy-affected persons (LAPs) and their families. A serious problem consistently faced by the initiative was its inability to involve the Muslim community and bring them together on a common platform with other stakeholders. Despite the best efforts, the project did not successfully involve the Muslim community in organising the intervention. Future interventions need to have active involvement of all relevant groups and target communities at the planning stage itself and may need to be specially designed for particular communities like the Muslims or even women within the Muslim community.

The special drive for leprosy elimination was carried out as planned in a campaign mode. Since the objectives of this initiative were awareness generation and information dissemination, the greater part of the initiative comprised information, education and communication (IEC) activities. The efforts of the core group, principal stakeholders and others culminated in the commemoration of a leprosy fortnight. Almost all materials pledged towards the endeavour were delivered. Groups and institutions ensured the presence and participation of their volunteers.

On the occasion of Mahatma Gandhi's death anniversary on 30 January, 2002, two rallies were organised for schoolchildren belonging to various middle schools in Burhanpur. The rallies had children marching with placards carrying information on leprosy and chanting slogans designed by their respective schools. The rallies converged at two destinations and public functions attended by important people were conducted. The rally was the first of the many events that followed as part of the leprosy fortnight. It helped to draw the attention of the citizens of Burhanpur towards the cause of leprosy elimination. Additionally, it served as an

orientation for the school authorities regarding leprosy and laid the basis for future interactions for LE.

The other important strategy used was that of *Dastak*. *Dastak* (meaning knock) was a door-to-door interpersonal communication activity in which all households in an area were covered and informed about the disease, its causes and cure. A cross-section of people, including schoolchildren of various ages, NGO functionaries, youth group members and *Anganwadi* workers were enlisted and trained as volunteers for *Dastak*. They were given brochures containing photographs of the symptoms of leprosy and information on its treatment, along with pamphlets informing the public about the skin diagnosis and treatment camp to be held on 10 February 2002.

The prevention of disabilities (POD) camp was held in Burhanpur from 2 to 7 February 2002. All expenses for the camp were borne by various partners who also helped arrange the camp. In addition to the POD a skin diagnosis and treatment camp was held on 10 February 2002. The camp aimed at providing diagnostic and treatment services for patients having skin ailments.

Information dissemination was one of the key strategies utilised to increase people's involvement. Two activities were carried out for this purpose: 1) daily newspaper coverage; and 2) the recording and release of an audio cassette, which contained a dramatic presentation of various issues involved in leprosy elimination. The outcome of these activities and efforts went beyond the fortnightly campaign.

An important element in the entire initiative was the coordination between various members of the core group. These members put their personal agendas on hold to ensure that the campaign was not affected negatively.

However, the partners were rather concerned about the low level of participation by the Muslim community. This was in spite of the fact that the NLEP felt that there were many unidentified cases among them. The main reason was that the contacts of the main actors among partners were mainly among the Hindus and Jains and therefore their strategies tended to overlook the Muslims although that was not the intention.

While attempts were made to correct this situation in the later stages, the campaign had gained momentum and successful inclusion of the Muslim community could not be achieved.

The initiative generated substantial enthusiasm in the partnership negotiation phase, which endured even after the end of the campaign. It was an important motivational factor for various stakeholders in the campaign to participate in something meaningful and socially productive. This indicated that many individuals and institutions form a rich resource base to work for a social cause when the right platform is established.

The participants in the campaign felt that the information, education and communication (IEC) strategy made a good impact and suggested that a better-planned IEC can have a stronger effect. People have been taking up a number of activities after the end of this special drive. POD and skin diagnosis camps have been organised by some groups. It was found that one crucial stakeholder, the Health Department, was not very actively involved. Many stakeholders felt that the Health Department needed to play a more active and prominent part as they would have a pivotal role to play in the post-integration period.

Responses to the questionnaire showed that all stakeholders felt that the Special Initiative had a considerable positive impact on the awareness level of the local population regarding leprosy and its elimination. The knowledge about the signs and symptoms of leprosy and the availability and effectiveness of multi-drug therapy (MDT) had increased among the people of Burhanpur. In addition, organisations that worked on welfare issues had also become better informed about leprosy. This, in effect, created a cadre that may be useful when carrying forward the leprosy elimination work. All the stakeholders felt that such initiatives needed to be sustained in order to achieve the desired elimination target for leprosy.

