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# Communication in Public Health Programs: The Leprosy Project in India

Supriya Mukherji, Meera Priyadarshi and Suneeta Singh

March 2005



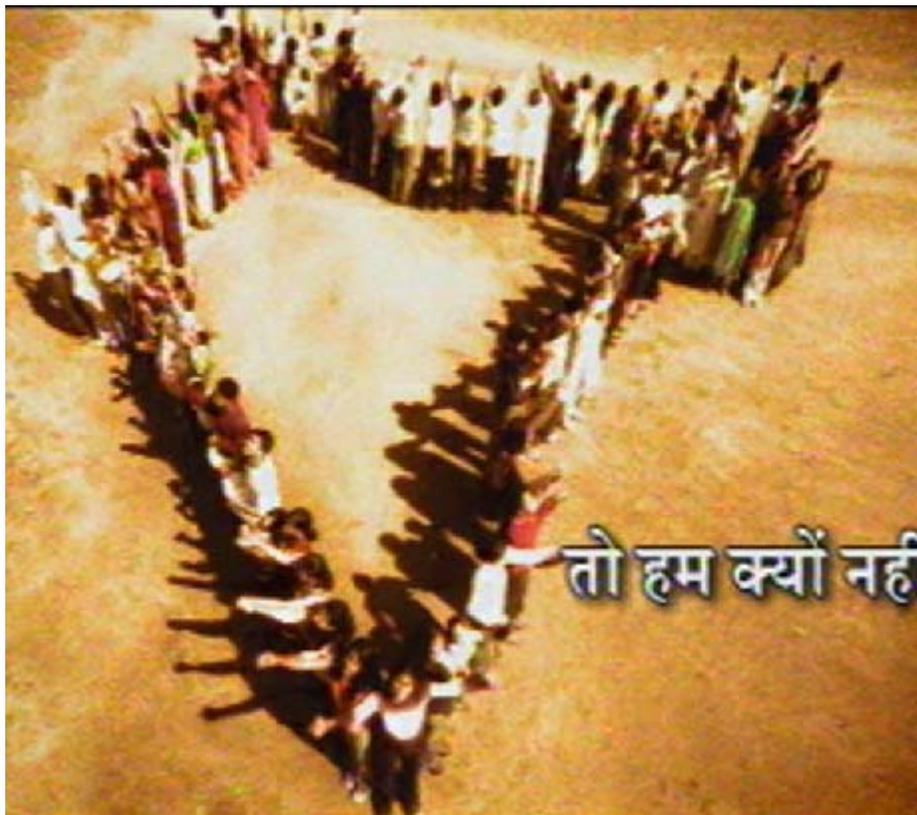
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## COMMUNICATION IN PUBLIC HEALTH PROGRAMS:

### *The Leprosy Project in India*

Supriya Mukherji, Meera Priyadarshi and Suneeta Singh



March, 2005

## Health, Nutrition and Population (HNP) Discussion Paper

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Cover picture: The nation joins hands to eliminate leprosy. (Image from a TV spot produced for India's National Leprosy Eradication Program.)

## Health, Nutrition and Population (HNP) Discussion Paper

### COMMUNICATION IN PUBLIC HEALTH PROGRAMS: The Leprosy Project in India

Supriya Mukherji,<sup>a</sup> Meera Priyadarshi<sup>b</sup> and Suneeta Singh<sup>c</sup>

<sup>a</sup> Consultant, World Bank

<sup>b</sup> Senior Nutrition Specialist, South Asia Region, World Bank

<sup>c</sup> Senior Public Health Specialist, South Asia Region, World Bank

Suneeta Singh and Meera Priyadarshi were, in turn, Task Team Leader of the Second National Leprosy Elimination Project India (which closed on 31<sup>st</sup> December, 2004). This paper was written in September 2004, with support from the South Asia Human Development Unit.

**Abstract:** The use of communication by the leprosy program in India offers valuable lessons for other programs, both in terms of its successes as well as the challenges ahead. The information, education and communication component has made a significant contribution in reducing the prevalence rate of leprosy cases. It has raised awareness about the signs and symptoms of leprosy and the importance of seeking early treatment, and reduced the social stigma associated with the disease. In recent years, the program emphasis has shifted to early voluntary self-reporting. The Government of India has set itself the goal of eliminating leprosy at the national level by December 2005. In the last vital year, cost-effective communication efforts have to be planned and sustained in collaboration with key partners to improve service delivery to hard-to-reach groups, motivate general health system staff, and ensure district-level political support.

**Keywords:** India, leprosy, communication, IEC, prevalence, treatment, elimination, International Leprosy Elimination Partnership, Multi-drug Therapy, Modified Leprosy Elimination Campaign, National Leprosy Eradication Program

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**Correspondence Details:** Supriya Mukherji, 5 Sri Aurobindo Marg, New Delhi 110016, India. Phones: 91-11-26851436, 91-11-26851451, Fax: 91-11-26569526, email: symphcom@vsnl.com

## LIST OF ABBREVIATIONS

ANM	Auxiliary Nurse Midwife
AWW	Anganwadi Worker
BBC WST	British Broadcasting Corporation World Service Trust
Danida	Danish International Development Agency
GOI	Government of India
IEC	Information, Education and Communication
ILEP	International Leprosy Elimination Partnership
MDT	Multi-drug Therapy
MOHFW	Ministry of Family and Health Welfare
MLEC	Modified Leprosy Elimination Campaign
NGO	Non-governmental Organization
NLEP	National Leprosy Eradication Program
PHC	Primary Health Center
POD	Prevention of Disability
RCH	Reproductive and Child Health
SET	Survey, Education and Treatment
WHO	World Health Organization

## GLOSSARY

Anganwadi workers	Female community level workers of the Integrated Child Development Scheme (ICDS)
Haat	Weekly village market
Haath milayen, kusht mitayen	Let's join hands to eliminate leprosy
Kalajatha	Local folk entertainment using song, dance and drama
Madrasa	Traditional Muslim school
Mahila mandal	Local women's group
Mela	Village fair
Miking	Making announcements through a public address system fixed to a vehicle
Mukhiya	Village headman
Munadi	Traditional announcement of events
Nukkad natak	Street theater
Panchayat	Village level elected body of representatives
Rath	Vehicle used for campaigns
Sarpanch	Head of the panchayat

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## **EXECUTIVE SUMMARY**

### **The leprosy program: A positive outcome**

The leprosy program has achieved a significant lowering of the prevalence of leprosy cases and deformity in the country. Between 1981 and 2004, leprosy prevalence in India fell from 57.6 to 2.4 per 10,000 population. The rate of visible (Grade II) deformity among new cases has also been reduced to less than 2 percent. The factors responsible for this outcome include the introduction of multi-drug therapy (MDT); the relentless efforts of central and state governments and an array of partners in detecting and treating cases; political will; the decentralized strategy followed by the program; and the use of a wide range of communication methods. In the same period, the project focus has shifted from active case detection to early voluntary self-reporting by patients, and the integration of the program with the general health care system has led to the involvement of the primary health care staff in leprosy diagnosis and treatment.

### **World Bank support**

Information, education and communication (IEC) has always been a component of health assistance provided by the World Bank to Indian health programs. In the leprosy program too, funds were allocated for IEC within the government program to involve communities. The World Bank's support through two projects (1993-2000 and 2001-04) has been used to pursue the goal of eliminating leprosy using a variety of case finding methodologies. In the first instance, the methodology was active case detection including campaign-style case detection. This has since evolved to the current methodology of voluntary self-reporting, and a comprehensive communication strategy and implementation plan to increase the demand for services has been implemented to this end.

### **The IEC experience in the leprosy project**

Early efforts at communication were hampered by the lengthy treatment of uncertain outcomes and limited media options. But the survey, education and training (SET) technique placed health information center stage; and the intensive campaign approach, best exemplified by the Modified Leprosy Elimination Campaigns (MLECs) scaled up interpersonal communication and began to make use of mass media in the program. Communications efforts have helped to promote belief in the curability of leprosy, increase community awareness of the free availability of treatment, and diminish the stigma associated with the disease.

The strategy has used the widest range of media available at the time and changed its focus when necessary to achieve its objectives. In the early years, communication was primarily through interpersonal communication and posters. In the later years, it also included communication through electronic media such as radio and television. The audience for IEC has included clients, providers and influencers. Beneficiaries have been reached through a well thought out, multi-layered campaign, a strategy developed by trained professionals to bring together the strengths of key partners.

Close supervision of planning and implementation has been critical. Service providers formed an important client group for IEC and were reached through mass media, training and campaign participation. Planning workshops allowed them to take control of the local IEC choices made by the program, and awards for performance provided motivation. The leprosy project also

provides an example of effective international advocacy efforts through the Global Alliance for the Elimination of Leprosy. Local advocacy formed an important part of the MLECs and continues to be an important part of the national program.

### **Lessons learnt**

The IEC experience in the leprosy program indicates the need for:

- A planned communication strategy with objectives and target groups identified and prioritized;
- A multi-layered campaign that combines methods and media to reach varied target groups;
- Inputs from communication professionals to plan and implement IEC strategy and produce quality material;
- A planned implementation strategy with intense bursts of activity for impact;
- A plan that utilizes the different strengths of key partners; and
- Close supervision of IEC planning and implementation at state, district and sub-district levels.

## 1. COMMUNICATION FOR CHANGE

*What happens when awareness is created in the community about the symptoms of leprosy and its treatment? People talk about the disease more openly, without fear, and they voluntarily seek treatment. In a village in Kheda District, Gujarat, an old man sits in a courtyard talking. A crowd gathers to listen to him. The old man has leprosy. He talks about how his illness was diagnosed, and how his treatment is almost complete. He talks without self-consciousness about the disease and the fact of his being cured. Meanwhile, far away in a school in Mahasamund District, Bihar, a group of children are in a state of excitement. They are participating in a quiz on leprosy, and so many of them know the answers! The success of IEC is evident in the day-to-day lives of real people, whether they are men or women, children or adults, well or sick.*

### **Reaching out: A perennial issue**

Every program that aims at development needs to change behavior. This is as true for programs to promote literacy and family welfare as it is for programs to reduce the prevalence of under-nutrition or polio. And every intervention to bring about such changes in behavior involves communication. The specific context of the beneficiaries needs to be taken into account, including their expectations of the program; information has to be provided; and awareness levels raised. Once the motive to change behavior has taken root in the individual and the community, it has to be sustained. Resistance, as a result of either social inequities or stigma, has to be dealt with.

**Barriers to behavior change have to be broken down before making further investments in the system.**

Communication also has to keep pace with new opportunities presented by the developing scenario – in the expanding reach of mass media, for instance. The IEC component of a program is not merely an add-on feature. It is an integral part of the program that needs to be developed from the design and planning stage to the evaluation of the outcome. Precisely because of its importance, the IEC component has to devise strategies to meet numerous challenges including addressing specific, action-oriented and realistic objectives; using available quantitative data as well as information on values and judgments; addressing local problems, developing effective leadership at all levels and local capacity; and the need to sustain the changed behavior over time.

### **The case of health communications**

Health communication efforts in India drew much of their strength from agriculture extension work. Though media reach was poor in the sixties and seventies, programs such as family planning, and later, leprosy, saw the potential value of IEC in fulfilling their program objectives (see Box 1.1). The leprosy program based its strategy on SET or survey, education and treatment. With the expanding reach of television in the eighties and nineties, government-sponsored health programs such as the universal immunization and family welfare programs began to make greater use of both government and private channels. And recognizing the importance of using communication, World Bank assistance to the GOI's health, nutrition and population programs has always included IEC as an important component. Examples of such programs include the two National Leprosy Elimination Projects, the Woman and Child Development Project, the State Health Systems Projects, the Cataract Blindness Project and the National AIDS Control Project.

### **Box 1.1 Using communication for disease control**

#### **□ Project components**

The activities in disease control projects usually include:

- Finding likely cases;
- Diagnosing cases;
- Ensuring completion of treatment;
- Recording treatment course and outcome; and
- Co-opting partners such as drug stores, labs, policymakers and private providers.

#### **□ Two examples**

- IEC can help find likely cases by addressing hard-to-reach rural areas; poor, illiterate rural communities; tribal communities; and urban disadvantaged groups.
- IEC can help diagnose cases by addressing labs and doctors, health workers and rural medical practitioners, and general duty doctors.

### **Wanted: A success story**

The field experience of programs has confirmed the critical role of IEC in initiating, implementing and sustaining project objectives. Equally, experience indicates that IEC faces challenges at every level – from its design to its ability to adapt itself to the evolving situation on the ground. The final objective of any investment in communication is a positive outcome in terms of behavior change. In this context, the Indian leprosy program provides an example of the

**The experience of IEC in the leprosy project offers valuable lessons for other programs, in terms of success as well as challenges ahead.**

effective use of IEC (see Box 1.2). The leprosy program has been successful in using professional advice and partnerships to design a carefully planned, multi-layered IEC strategy that addresses a variety of stakeholders. In fact, the IEC experience in the leprosy program offers valuable lessons for other programs – in terms of its success, and the challenges ahead.

### **Box 1.2 Behavior change through IEC**

IEC in the leprosy program seeks to bring about *behavior change*. In the initial stages of the program, the behavior change involved treatment compliance and completion. Subsequently, with a decline in prevalence, the focus has shifted to early voluntary seeking of treatment.

*Barriers* to behavior change include inequitable access to services and the stigma associated with leprosy.

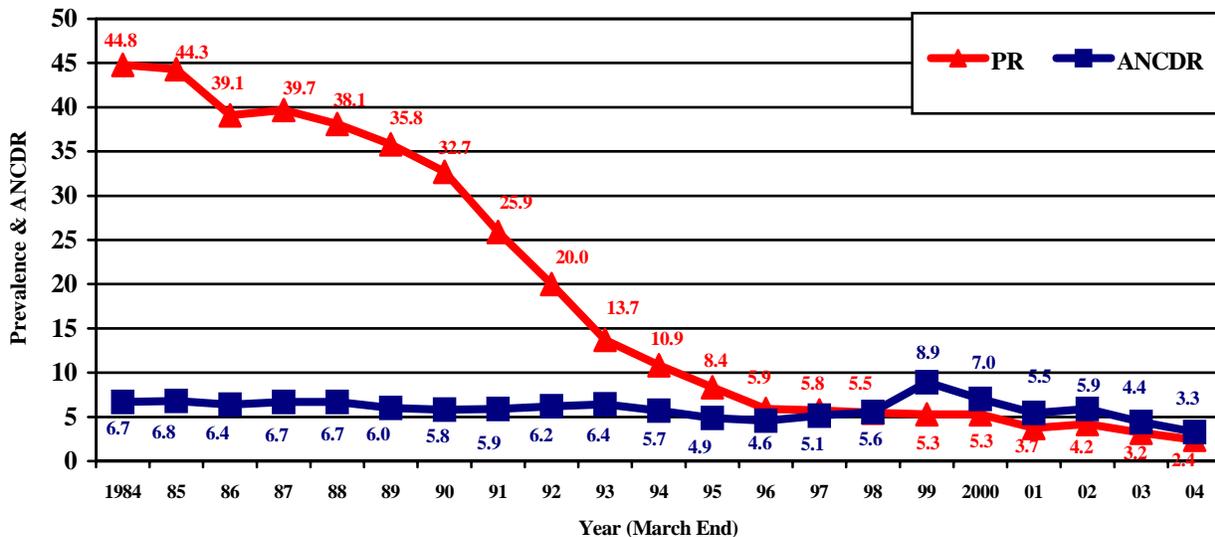
The *strategies* to break down these barriers and bring about behavior change have made use of a variety of media. For example,

- Interpersonal communication has helped to increase information and awareness and reduce stigma through one-on-one interaction.
- Radio, which is inexpensive and has good reach among the rural poor, has been particularly effective when it uses localized program content (e.g. phone-in programs)
- Local events, on World Anti-Leprosy Day, for example, have provided opportunities for advocacy with local leaders and influencers.

## 2. THE LEPROSY PROGRAM: AN IEC SUCCESS STORY

What happens when people's representatives are involved in the leprosy program? They become local level advocates for the program, and look for accountability from the authorities. In Takari Block in Gaya District, Bihar, a mukhiya sensitization meeting is taking place in a primary health center (PHC). The district program staff explain the signs, symptoms and treatment of leprosy, and distribute literature. In the question-and-answer session that follows, one mukhiya complains that a leprosy patient in his village has not been able to get leprosy drugs at the nearest sub-center for three months. The program staff look into the matter immediately.

**Figure 1: Trends in leprosy prevalence rate and annual new case detection rate (ANCDR) in India, 1984-2004**



Source: Central Leprosy Division, Ministry of Health and Family Welfare (MOHFW), GOI

### 1984 TO 2004: A SUCCESSFUL OUTCOME

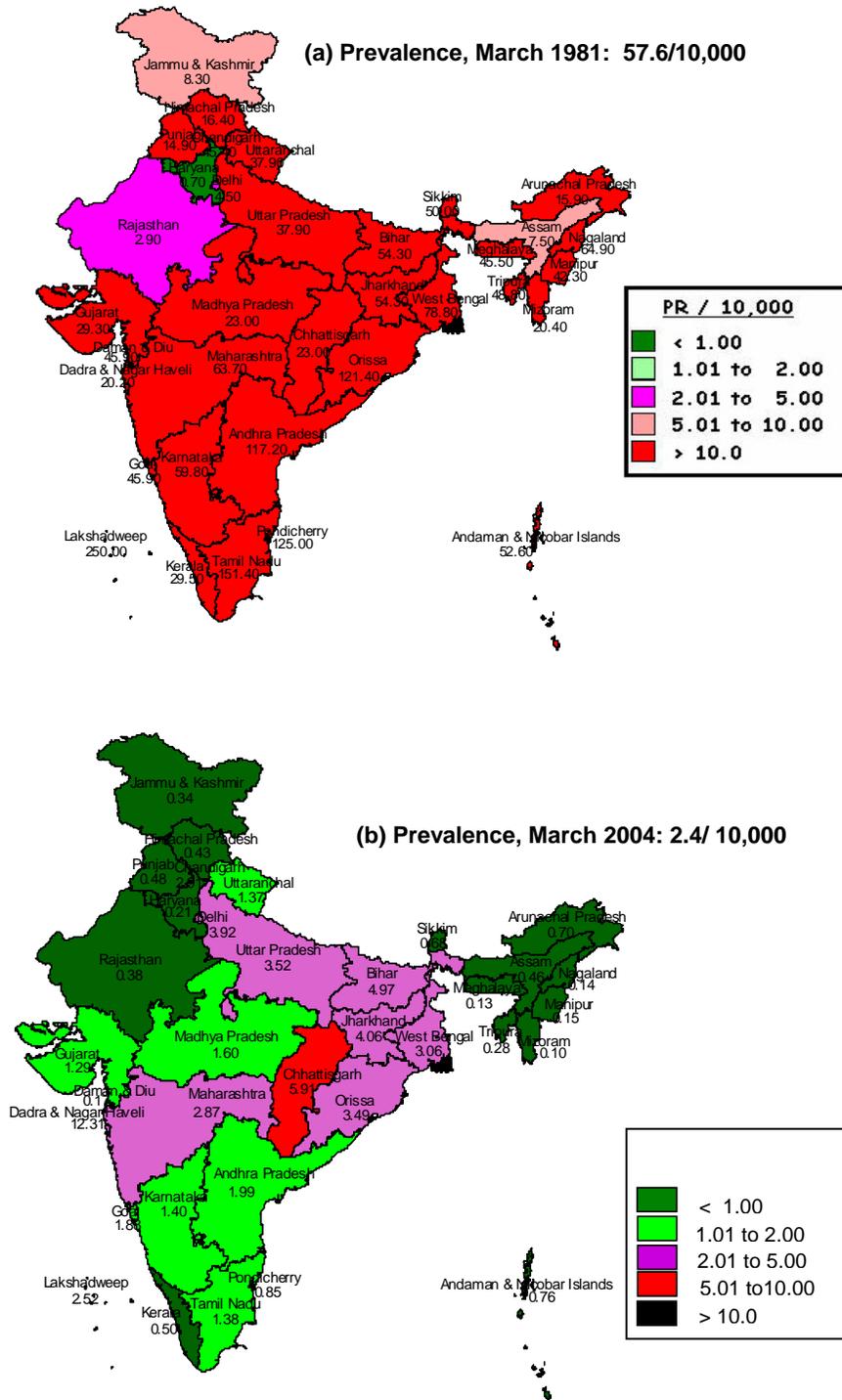
#### Lower prevalence

The leprosy prevalence figures tell the positive tale of the India leprosy project's outcome (see Figure 1). In March 1984 the prevalence rate was 44.8; by March 2004 it had come down to 2.4 per 10,000 population. Seventeen states and 250 districts have already achieved the goal of leprosy elimination (defined as a prevalence rate of less than one per 10,000 population). Another seven states are close to the goal (see Figure 2). The country as a whole is on its way to achieving the goal of national elimination of leprosy by December 2005.

#### Project achievements include:

- Lower prevalence rate;
- Grade II deformity down to less than two percent.

**Figure 2: Leprosy prevalence rate and status of elimination goal by state, 1981 and 2004**



Source: Central Leprosy Division, MOHFW, GOI

## Lower deformity rate

The most distressing forms of leprosy are associated with disfigurement and deformity – adding to the patient’s suffering and increasing the stigma associated with the disease. But with more sophisticated treatment, and with determined campaigns to search for early leprosy cases, there has been a drastic reduction in the number of cases exhibiting these forms of the disease. The rate of Grade II deformity among new patients in 1981 was 20 percent; by 2004, it was only 1.5 percent. The goal of bringing the deformity rate down to less than 2 percent by the end of the current World Bank supported project (2001-04) has been achieved. In a developing nation of more than a billion people these are indeed achievements to be proud of.

A number of factors have contributed to this remarkable progress:

- the introduction of MDT;
- the relentless efforts of the central and state governments and a range of partners in detecting and treating cases;
- political will;
- the decentralized strategy followed by the program giving autonomy of action to the states; and
- the use of communication in the program.

## GOING BACK: UP TO THE EIGHTIES

The success of the leprosy project has, of course, to be seen as the result of years of gradual change and progress (see Figure 3). How did the project evolve to its current status?

### The disease

Leprosy is a chronic, slow-developing disease affecting mainly the peripheral nerves and the skin. The patient’s suffering is caused by damage to the peripheral nerves, which leads to sensory loss, paralysis and loss of function of the hands, feet and eyes. The disease is feared because it can lead to deformity; this is also the cause of the social stigma traditionally attached to the disease. Leprosy can be multibacillary or paucibacillary. While multibacillary leprosy shows a high density of bacilli on slit-skin smear examination, paucibacillary leprosy cases show only a few or no bacilli on slit-skin smear examination.

### Prevalence

The prevalence rate of leprosy refers to the number of cases at a given point of time as a proportion of the total population. Till 1981, the prevalence rate in India was based on data collected by the decennial population census. These figures (Table 2.1) were, however, generally considered to be underestimates. They included only cases with advanced forms of the disease; there were also errors in population coverage. Most of all, the acute social stigma suffered by leprosy patients at the time affected reporting, in turn affecting data collection on prevalence. From 1983-84, more reliable data on prevalence, based on the leprosy program’s own data collection, began to be available.

**Table 1: Census estimates of leprosy prevalence, 1951-1981**

<i>Year</i>	<i>Population (million)</i>	<i>Estimated no. of leprosy patients ('000s)</i>	<i>Prevalence rate (per 10,000 population)</i>
1951	361.0	1374.0	38.1
1961	439.1	2561.6	58.3
1971	548.0	3200.9	58.4
1981	685.2	3919.3	57.2

Source: Census, various years, GOI

### **The leprosy program**

Given the prevalence rate, the GOI recognized leprosy as a national health problem, and launched the National Leprosy Control Program in 1954-55. The program gained momentum during the Fourth Five Year Plan period (1969-1974) after it was made a centrally sponsored program, thus receiving the necessary priority and funding. The program was expanded to cover additional populations in rural and urban areas at this time. To achieve this increased coverage, the involvement of NGOs was strengthened, and health education programs became a prominent component of the leprosy program. The government also encouraged the involvement of NGOs in SET activities in allotted areas through a scheme introduced in 1983.

SET centers were set up in moderate/low endemic areas and urban leprosy centers in urban areas. These centers were staffed with one paramedical worker for a population of 25,000 called a sector, and there was one non-medical supervisor for every five paramedical workers. The paramedical worker conducted a house-to-house search for leprosy patients, “surveying” the entire population in a cycle of two years.

Diagnosis followed cumbersome slit smear techniques, with treatment of confirmed cases lasting between 10 years and lifelong treatment. The leprosy program provided free domiciliary treatment in endemic districts through specially trained staff in fixed leprosy control units; and in moderate to low endemic districts, through mobile leprosy treatment units. Cases were treated at monthly leprosy clinics held at a fixed point in the village. This led to improved compliance and provided an opportunity for counseling each patient. Patients were encouraged to come to the clinics with their families, and this helped address the issue of stigma.

**Educating communities to recognize the early signs and symptoms of leprosy was an integral part of the house-to-house visits made as part of SET activities. This was probably the origin of IEC in the program.**

## **THE TURNING POINT: MARKETING THE CURE**

### **MDT: A cure at last**

**The introduction of MDT, a credible “product” to “market,” was the turning point for the use of communication in the leprosy project.**

Until the eighties, regimens for leprosy often entailed extended lifetime treatment. The skin patches would remain despite years of taking drugs every day; patients lost confidence and frequently discontinued treatment. But in 1983, there was an important technological change in treatment – the introduction of the drug Rifampicin (Table

2). With the new MDT regimens containing this bactericidal drug, the program could finally

offer shortened treatment durations and a cure. This helped increase the credibility of the program and boosted attempts to change negative attitudes to leprosy treatment. In response to this shift to MDT, the National Leprosy Control Program was re-designated as the National Leprosy Eradication Program (NLEP) in 1983. The government also introduced blister packs of MDT medication for 28 days with a calendar printed on the back. The patients found the packs attractive, easy to store and consume, and the packs also prevented spoilage and pilferage. Thus packaging helped enhance the credibility of the program among patients and the community.

**Table 2: The leprosy program: a timeline**

1954-55	National Leprosy Control Program launched
1981	Prevalence rate 57.60 in a 10,000 population
1983	Introduction of MDT Program re-designated National Leprosy Eradication Program with revised strategies for diagnosis, case detection, MDT, health education and rehabilitation, partnerships
1991	Goal of elimination adopted at World Health Assembly
1993	First World Bank supported leprosy project (Leprosy I)
1996	Campaign mode initiated through first MLEC
1997	Tamilnadu first state to integrate program with general health care system
1998-99	Rate of Grade II deformity 3.8 percent
2001	Second World Bank supported leprosy project (Leprosy II)
2003	Rate of Grade II deformity 1.8 percent Monitoring study indicates 62 percent know leprosy is curable; 63 percent know at least one symptom
2004	Prevalence rate 2.4 in a 10,000 population (March 2004) Rate of Grade II deformity 1.5 percent (June 2004) IEC focus continues on integration, voluntary reporting and hard-to-reach groups
December 2005	National elimination goal

### **A shift in diagnostic protocols**

In the nineties, a shift in the World Health Organization (WHO) recommendations on the diagnostic protocols for leprosy led to the use of syndromic diagnosis in large anti-leprosy programs, partly because the lack of trained manpower to carry out extensive and quality diagnostic skin smears was holding back some countries from the goal of leprosy elimination. The new approach allowed trained paramedical workers to “suspect” cases based on the loss of sensation in skin patches, with a doctor later confirming these cases. The approach was later to pave the way for the use of a large body of primary care workers for case detection activities.

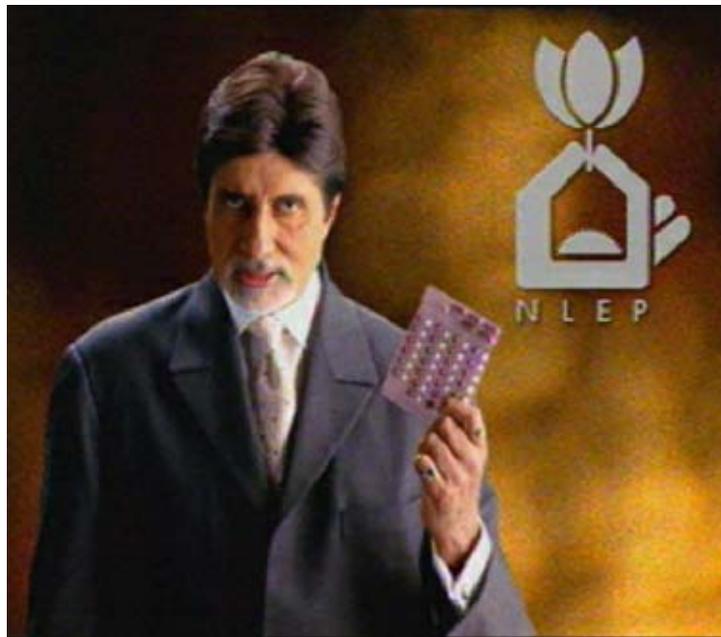
Leprosy patients rarely experience discomfort in the early stages of the disease. Together with fear and stigma this factor had, for years, been a powerful deterrent to seeking treatment. The resulting time lag between the onset of the disease and the voluntary seeking of treatment often meant that deformities had already developed. This only added to the vicious cycle of social stigma. It is in this context that the program adopted active methods of case detection.

**Figure 3: The promise of treatment**



A woman *sarpanch* makes a woman who has leprosy promise she will go for treatment, in this image from a TV spot produced for the NLEP.

**Figure 4: These pills can cure leprosy**



An icon of Hindi cinema, Amitabh Bachchan holds up a pack of MDT in a TV spot produced for the NLEP

## TOWARDS ELIMINATION

### The goal of elimination

In 1991 India made a commitment to the World Health Assembly goal of eliminating leprosy as a public health problem by the turn of the century. Elimination was defined as achieving a prevalence rate of less than one per 10,000 population. This meant reducing the number of leprosy cases by 95 percent, from about 2 million cases in 1992 to 100,000 by the year 2000 – clearly an ambitious target. Although India did not achieve this goal at a national level, 17 out of the 35 states and union territories have achieved elimination. The target for achieving the national goal is now December 2005.

### The campaign mode

In the mid-nineties, the government and the WHO realized that case detection had reached a plateau: the annual detection rate had remained almost the same for about a decade and a half. Hence, in 1996, the WHO developed a campaign mode SET technique called the Leprosy Elimination Campaign. India modified this technique to the MLECs – short, concentrated bursts of case detection activities held across the entire state/country. These campaigns, aimed at more rapid results, involved three activities:

- Orientation of all health staff, village level workers and volunteers on leprosy;
- Building community awareness of the disease; and
- Availability of free MDT services followed by a house-to-house search in the entire population for six days by the trained staff and volunteers. A doctor confirmed and treated suspected cases with MDT.

There have been five MLECs between 1997 and 2004. The first MLEC was conducted in 1997 in Tamilnadu, and campaigns followed in other states. The primary purpose of the campaigns was case detection. But by the fourth MLEC, community involvement and awareness as well as sensitization of local functionaries and influencers (for example, of anganwadi workers or AWWs) had become equally important. The MLECs were preceded by intensive IEC activities at central, state and district levels for a month before house-to-house search activities (see Box 1).

**MLECs became the focal point for social mobilization, and have probably made the most powerful use of IEC in the program.**

### **Box 1: Unleashing the power of communication through campaigns**

The IEC buildup to each MLEC included a variety of mass media and localized media such as rallies, folk media and school activities to inform people about the imminent campaign. These activities often included cured patients, arguably the most effective advocates for the program. MLECs have had a lasting impact on community awareness. Their intensive, repeated and large-scale communication efforts have made a significant contribution to increasing voluntary reporting and reducing stigma. Successive MLECs showed a gradual but significant decrease in the numbers of cases detected, indicating that awareness about the disease, and reduction of fear and stigma, have stimulated voluntary reporting. In addition, the training and focus on the program in the district during the campaign period motivated service providers at all levels. It also offered opportunities for local level advocacy since the campaign involved the district administration, and political, religious and social leaders.

The use of community volunteers who received short training in the first MLEC resulted in over-diagnosis. The declining prevalence, the massive effort demanded by the exercise and the relatively lower yields from low endemic areas prompted the government to adopt a combination of strategies from the second MLEC onwards. Active search was conducted in high endemic areas; in moderate endemic areas, temporary voluntary reporting centers were set up and IEC activities intensified. In low endemic areas, only intensive IEC activities were carried out to encourage voluntary self-reporting. At the same time, another strategy developed by the WHO to ensure underserved populations' access to services, especially in hard-to-reach areas, was put in place. These Special Action Projects for the Elimination of Leprosy have the same components as other campaigns, but they cover defined rural geographic areas and populations. The urban counterparts of these projects are the Leprosy Elimination Campaigns.

#### **The move to voluntary reporting**

With falling prevalence rates and the goal of elimination in sight, the focus of the program has shifted to voluntary reporting. This move to voluntary reporting has rendered a vertical delivery system – with a large number of workers working solely on leprosy – unnecessary and cost ineffective. In 1988, an expert committee on the involvement of primary health care in leprosy eradication recommended the gradual involvement of the primary health care staff in leprosy diagnosis and treatment, with close technical cooperation of the leprosy worker attached to the PHC. Integration has also had the advantage of increasing the reach of the program significantly, with the larger numbers of staff available through the general health care system. Tamilnadu was the first state to integrate the vertical health delivery system with the general health care system in 1997. Other states have followed over a period of time. The training of large numbers of general health care system staff to diagnose, treat and counsel patients has been one of the major tasks undertaken by the program over the last six to seven years (see Box 2).

**With the shift to voluntary reporting, the need to invest in continuous IEC inputs has grown.**

### **Box 2: Reaching out to more people through integration**

- The consensus among those involved in the program is that integration has widened the reach of IEC significantly. A State Leprosy Officer has described integration as a “spur for IEC.”
- With the general health staff now involved in IEC, there are more people available to undertake IEC activities.
- Medical Officers of PHCs are gradually taking on responsibility for all aspects of the program, including IEC, and participating actively in several states.
- It is easier to organize IEC activities for leprosy as they can be integrated into IEC activities for other health programs, such as health *melas*.

The process of integration has, however, to meet the challenge of the transition period – with the general health staff assuming the responsibility of detection, treatment, and local level IEC, and the earlier vertical staff being trained to participate in general health activities. Keeping both categories of staff motivated as they adjust to their new roles is a challenge that IEC activities will have to continue to address in the future.

### **World Bank support**

In line with its support of government policy on the control of major endemic diseases, the World Bank sanctioned a credit of US\$85 million in 1993 to accelerate the pace of the program, and help India eliminate leprosy as a public health problem by 2000. This was to be accomplished by treating 2.2 million current leprosy cases; detecting and treating 1.8 million new cases; reducing prevalence to 100,000 cases nationwide; and reducing the impact of leprosy disability. One of the five project components was promoting public awareness and community participation.

With the emphasis on community participation and awareness, funds were, for the first time, specifically allocated for this activity within the government program. This made it possible to widen the scope of IEC. The activities used till this point – health education, distributing pamphlets and posters – had shown limited impact, especially among hard-to-reach sections such as low literacy groups, particularly among women. So the program began to make use of non-formal IEC methods, such as health camps with extensive village participation and activities involving village leaders. The new IEC activities helped to increase community participation and awareness about leprosy and free MDT treatment. But these were largely restricted to support for MLECs, and other more sustained interventions needed strengthening.

**One of the five components of the first World Bank supported project (1993-2000) was the promotion of public awareness and community participation.**

The prevalence rate at the national level declined from 24 per 10,000 at the start of the first Bank supported project (1993) to 5 per 10,000 at the end (2000). Nine states/Union Territories and 137 out of 490 districts achieved a prevalence of less than one per 10,000. Close to 4.4 million patients were treated and cured. Disability among new cases declined from 8 percent in 1993 to 3.1 percent in 2000. The registered caseload at the national level was reduced from 1.2 million cases to 0.5 million cases.

Building upon these achievements, World Bank support was extended for another three years through a second project. This project (2001-04) aimed at developing a decentralized and integrated approach to the program to increase community access to MDT and eliminate leprosy as a public health problem at all levels. It sought to improve the quality of service delivery by motivating the general health staff, and involving influencers through advocacy at all levels. It supported a comprehensive communication strategy and implementation plan to increase the demand for services through voluntary reporting. The target groups identified for communication included clients (patients, their families and communities); vertical and general health care public service providers; private providers; and influencers at national, state, district and sub-district levels. The strategy included:

- Advocacy at various levels to involve influencers and create a favorable environment for the program;
- Promotion of new paradigms that ensure positive implementation by public providers and the co-option of private providers;
- A mass media component implemented by the Central Leprosy Division through a contracted professional mass media agency; and
- State and district level activities such as wall paintings, local market or *haat* activities, folk media, school-based activities and interpersonal communication.

### 3. IN THE FIELD: THE IEC EXPERIENCE

*Every place where people gather is a potential IEC opportunity, and the leprosy program has used this concept to communicate its messages.*

*In Bilaspur District in Chhattisgarh State, a large crowd has gathered to watch a puppet show on leprosy. The organizer is a cured leprosy patient, certainly the best spokesperson for the program. Meanwhile, in the Kunnoor PHC in Bangalore Rural District, another crowd waits for a street play to begin. The village elders are part of the crowd; their feedback is critical to the event's outcome. A representative from the NGO staging the play asks the audience what they have learnt. A young girl says she has learnt that free medicine for leprosy is available, and that people who have leprosy should not be discriminated against. Soon after, a mother approaches the doctor present there to examine a patch on her daughter's skin.*

#### THE CONTRIBUTION OF COMMUNICATION

##### Community awareness

There is a substantial body of qualitative data to illustrate the contribution that communication has made to the India leprosy project. In addition, several quantitative studies have confirmed that the IEC component has helped raise community awareness of the disease and its treatment, and initiated the process of attitude and behavior change. One such study was the Leprosy

**Leprosy Elimination Monitoring studies indicate the significant contribution of IEC to improving awareness of the signs of leprosy, the fact of its curability, and the availability of free treatment.**

Elimination Monitoring study conducted by the Leprosy Mission Trust India in seven states in 2002. The study found that as many as 65 percent of respondents were aware that leprosy is curable, 45 percent knew the early signs of leprosy and 51 percent knew that free treatment was available (Table 3.1). A similar study, conducted in 77 districts in 2003 by the National Institute for Health and Family Welfare (NIHFW) with support from the GOI and the WHO, also offers evidence of this improved awareness. The study results show that 63 percent of respondents knew at least one symptom of leprosy and were aware of the availability of free treatment. To achieve these awareness levels, IEC strategies have had to evolve to meet the changing needs and emphases of the program – from supporting active case detection activities to encouraging voluntary self-reporting.

### Reduced stigma

One of the greatest successes of the program, from a programmatic as well as a human point of view, has been the reduction of stigma towards those affected by leprosy. In the earlier stage of the program, stigma was acute and deep-seated. Patients were ostracized, even thrown out of their homes. The situation today is different: people are beginning to talk about leprosy openly.

**The positive effects of communication have meant a change of attitude to leprosy. With reduced stigma, the patient has begun to be part of the mainstream during and after treatment.**

And more important, larger numbers of people are voluntarily seeking treatment. Overcoming stigma also means that patients are not deprived of support from their family and community. Once cured, most of them have a greater chance of going back to a productive and dignified life.

**Table 3: The leprosy elimination monitoring study, 2002**

	<i>Total (%)</i>	<i>Male (%)</i>	<i>Female (%)</i>
Heard about leprosy	75.3	82.6	67.0
Aware of early signs of leprosy	45.0	51.7	37.1
Aware leprosy is curable	64.7	70.4	58.0
Aware of availability of anti-leprosy drugs	50.8*	56.5	44.2

\* 90.7 percent of those who were aware of availability knew that drugs were available at public health facilities.

Note: 2,527 community members were interviewed about their awareness of leprosy, in the selected seven states of Bihar, Chhattisgarh, Jharkhand, Madhya Pradesh, Orissa, Uttar Pradesh and West Bengal. 1,359 (53.8 percent) were male and 1,168 (46.2 percent) were female.

Source: The Leprosy Mission Trust India, 2002

## The strategy: Communicating through a wide range of media

To achieve these improvements, the leprosy program has used a variety of media over a period of time. Skin camps have been conducted to detect cases, and Prevention of Disability (POD) camps to counsel patients and teach them self-care. The MLECs have provided impetus to IEC activities by using a variety of media and local level advocacy to mobilize people. In fact, advocacy at all levels has been an intrinsic part of the program's communication strategy. This has resulted in the support of state and district administrations in many states, and this support has been critical to the success of the program. And given their position as influencers, religious leaders have also been co-opted into the fight against leprosy. Folk media, school activities, community meetings and *melas* have been used at the community level. Mass media campaigns developed through professional agencies have been used. Examples include campaigns by the BBC World Service Trust (BBC WST) and the advertising agency SOMAC: Lintas. There have been a number of training programs for providers in addition to recognition of their services. Thus the IEC strategy of the program has addressed clients, influencers and providers.

- The IEC *audience* includes clients, providers and influencers.
- The *methods* used include camps, *melas*, folk media, rallies, community meetings, school activities and mass media campaigns.
- *Partners* include professional agencies (such as BBC WST and SOMAC: Lintas) and NGOs.
- *Advocacy* is at all levels, and well-known figures and religious leaders have been co-opted as influencers.

## Over the years: Milestones in communication

The IEC activities of the leprosy program have grown from camps and clinical settings to folk media and interactive stalls in the local marketplace. How did these activities evolve over time? For almost the first two decades of the program, the primary focus was on clinical activities. A number of patients did not complete treatment, and the thrust of the program was to ensure patient compliance with the drug regimen.

With the recognition of the social dimensions of the problem, the objective was expanded to include community involvement. The fear of deformities as the motivator to treatment compliance gradually gave way to a more interactive community-based approach. The “health education” of the patient, his/her family and the general public became part of the strategy. The district and block level media officers of the health department were involved in health education activities for leprosy, and a nation-wide mass campaign was initiated to overcome superstitions and social stigma. Some mass media – films, posters and pamphlets – were used, but until the eighties, IEC consisted largely of the interpersonal communication that was part of SET activities. When leprosy workers went to each house they would “educate” people about leprosy, its symptoms and treatment.

The introduction of MDT made concerted IEC possible: people could now be informed that a cure was available. Thus organized IEC activities became an intrinsic part of the program. Flash cards with pictures and text were introduced to help workers explain the signs and symptoms of leprosy to the community. Since earmarked funds were not available for IEC activities within the government program, the role of NGOs became even more significant. Over a period of time

many of these NGOs, including missionary organizations, have gained the trust of communities by working closely with them.

The scaling up of vertical SET services in the public sector took place with World Bank assistance. However, by the late nineties, the MLECs became the focal point for IEC activities as the community was mobilized for these active case detection campaigns. Mass media and folk media were used during each intensive, month-long buildup to the MLEC and the possibilities for local level advocacy were tapped. Since the last of the MLECs held in early 2004, the focus of the program has shifted to sustained, voluntary reporting – making ongoing IEC activities even more important.

## **The range of IEC strategies: Field experience**

### *Camps*

One of the earliest forms of IEC, “skin camps” were used for case detection and counseling. These camps often took health services to hard-to-reach populations. At a time when leprosy patients suffered deep-seated social stigma, the camps offered relative anonymity as they were for all skin ailments, not just for leprosy. The camps were preceded by local IEC activities, mainly to announce the camp through “miking” and traditional local methods of announcement such as munadi. Skin camps are still held in some endemic areas; but with better services available and the shift to voluntary self-reporting, these camps have become less useful.

**With lower prevalence levels, skin camps may be more useful in high endemic areas. Prevention of disability (POD) camps have been useful for counseling and training in self-care.**

Camps for POD were begun to train health staff, patients and their family members in care and disability prevention. Since they were usually held over one to three days, there was enough time for interaction and counseling and the camps have proved ideal for IEC. The Danlep project of the Danish International Development Agency (Danida) enlarged the POD camp concept to

seven-day residential camps called “care and concern camps” in Madhya Pradesh. The camps tried to reduce stigma by creating an emotional bond among the community, the patient and service provider. In fact, community participation was central, since the community provided the food and the camp venue. The activities included cultural performances that combined entertainment and IEC.

POD camps are now organized by government health workers following a process of cascade training. Teams of state level trainers are trained at the Schiefflin Leprosy Research and Training Center, Karigiri. In turn, they trained district level teams, who trained teams at the PHC level. These teams conduct two camps in every block. On the first day of the camp, the general health care staff is trained by the district training team. On the second day, patients are provided with POD services including counseling and training in self-care.

## Campaigns

The one-month IEC campaign leading up to the case detection activity of the MLEC used a variety of media. A number of IEC activities were held at the district and sub-district levels. These included rallies, *munadi* and announcements, folk dances and songs, puppet shows, *raths*, *nukkad nataks*, exhibitions at PHCs, group meetings and discussions. The involvement of local leaders also presented opportunities for local level advocacy. From the third MLEC (2001-02) onwards, school quizzes and interactive stalls in local *haats* became an integral part of IEC activities. By the fourth MLEC (2002-03), mass media were handled by the Center since by then, a mass media agency was working with the Central Leprosy Division. This central effort was supplemented by state-led mass media activities – such as press advertisements, cinema slides, hoardings and wall paintings, distribution of posters and pamphlets, appeals by ministers and dignitaries, and radio and television talk shows and spots. The districts focused on interpersonal activities such as group meetings, interactive stalls at *haats* and folk shows. These activities involved local volunteer groups, social organizations, school children and panchayat members.

**The MLECs generated intensive activity involving the entire community during the campaign period. But with the shift to early voluntary reporting, sustained IEC has to replace the “campaign mode mindset.”**

IEC was essential to the success of the MLEC strategy, hence the campaign approach generated intensive activity with lasting impact. However, the tendency to focus on time-bound campaigns also meant that few IEC activities took place at other times. MLECs are no longer used, and the program focus has shifted to the encouragement of early voluntary reporting on an ongoing basis. This has shifted the challenge to sustained IEC and a change in the “campaign mode mindset.”

## Folk media

Despite the increasing reach of the electronic media, the rich traditional forms of folk culture have continued to lend themselves to communicating the leprosy message. The literacy campaign developed in the late eighties by the Bharat Gyan Vigyan Samiti in Kerala provided a model for the use of folk media to generate community demand for literacy, particularly among women. The leprosy program first used folk media through the government health education machinery. These forms of communication also became an integral part of the Danlep project in the eighties in Madhya Pradesh, Chhattisgarh, Orissa and Tamilnadu (see Box 3.1). Between 1999 and 2001, the BBC WST also experimented successfully with the use of this medium by training local troupes in some high-prevalence states including Bihar. An evaluation of the BBC WST’s use of folk shows by the ORG Center for Social Research indicates that of 1000 respondents interviewed across five states, 82 percent of respondents were aware of MDT as the cure for leprosy as opposed to 56 percent of respondents in the control group villages not exposed to the shows. Similarly, 74 percent of those who had seen the shows were willing to sit next to leprosy patients, compared to 64 percent of respondents from the control group villages.

### **Box 3: Folk media: The Danlep experience**

In 1994, the Danlep project of Danida began training NGOs and other rural groups in the use of street theatre in IEC. State level workshops were organized to train district and block level media officers. In Chhattisgarh, Danlep collaborated with the literacy mission to train several groups for a time-bound statewide tour. Since the groups were recruited from different parts of the state, they brought to the performance their knowledge of local customs, languages and dialects. Several troupes have been used in other campaigns as well. The Danlep experience indicates that street theatre is useful in introducing leprosy to the community: it generates curiosity and attracts a large audience. Basic facts about leprosy, its curability and the availability of free treatment can be woven into the dialogue; and discussion encouraged by open-ended plays and stories related to social attitudes towards leprosy patients.

Folk media performances are often held during the haats. Interactive stalls, manned by the local leprosy staff and the Medical Officer of the local PHC, are also set up to disseminate information about leprosy, examine and counsel people, and distribute pamphlets. These events are announced using local methods such as miking and munadi.

The IEC experience in the leprosy program shows that the use of folk media has several advantages. Folk media are culturally contextual, particularly in rural areas. Their flexible format

**When planned and designed well, folk media are effective local means of communication.**

can be adapted easily to program needs and local situations. They make use of simple stories and do not require demanding costumes and props, but still have a strong entertainment component.

But there are some difficulties involved in the use of folk media. They require careful planning and preparation with appropriate scripts that balance standardized messages and local needs. They also call for input and training to standardize performance quality. Quality maintenance is easier and less expensive on a small scale, as indicated by the experience of Danlep and BBC WST. The experience of the literacy program indicates that these shows are effective local means of communication. Attempts to duplicate the experience of the literacy program by managing this activity centrally and funding the districts for the purpose have, however, been less successful, as in the case of the Reproductive and Child Health (RCH) program. Stalls in haats are easier to organize and monitor. They have been particularly effective when they are attractive and when they make use of announcements, messages interspersed with films or film songs and better-printed material with more visuals.

#### *School activities*

The number of cases of leprosy among children is considered an important program indicator as it indicates the level of transmission of infection. Hence school surveys were conducted to detect child cases as a corollary to active house-to-house case detection activities. While these methods of active case detection are no longer used, the program continues to make use of the potential of children as messengers of the leprosy message to their families. For example, live quizzes in schools enthuse both the participants and the audience. Sometimes the Chief Medical and Health Officer of the district is the chief guest at the function, and he addresses the students and gives away the prizes, reflecting the true spirit of integration of the leprosy program with the general health services. Regular, simple events such as quizzes or essay and debate competitions

can thus become powerful communication tools, and they are actively used as part of program strategy. These activities are cost-effective and easy to organize through school infrastructure.

School activities are powerful tools since children are naturally curious and receptive. However, they work best when they use material specially designed for children, and when the activities are planned in such a way that they evoke interest in the children and increase the probability of their sharing the leprosy message with family members.

**School activities can stimulate the children's interest and increase the probability of their sharing the leprosy message with their families.**

### *Community meetings*

The easiest and most cost-effective way to communicate with people is to talk to them in small groups. These meetings are held with the community at large or with specific groups such as women – through mahila mandals and self-help women's groups. Cured patients have also been used effectively as advocates for the program in community meetings. Several programs, including the leprosy program, have found community meetings an effective and inexpensive means of communication. They can be organized easily and locally. But experience shows that

**Smaller, more homogenous groups lead to more effective community meetings.**

the message can be diluted in a large meeting of the entire village community. The use of smaller, more homogenous groups helps to make the meetings more focused. The use of audio-visual aids is also helpful.

### *Melas*

*Melas*, traditionally part of religious and cultural festivities in India attract large numbers of people, particularly in rural areas. As a result, *melas* have proved to be effective communication opportunities. Several health programs, including the programs for HIV/AIDS, tuberculosis and leprosy, have set up stalls in these *melas*. For example, the Sonapur *mela* in Bihar is Asia's largest fair, and it provides an ideal opportunity for the leprosy staff to answer the questions of curious passers-by and give them information leaflets.

### *Mass media*

The leprosy program first began to use mass media in an organized way during the MLECs. However, the first professional campaign on leprosy was the initiative implemented through the BBC WST from 1999 to 2001. The objective was to increase awareness about leprosy symptoms and MDT in some of the most affected states – the five focus states of Uttar Pradesh, Bihar, West Bengal, Orissa and Madhya Pradesh, and later, Chhattisgarh and Jharkhand. The BBC WST campaign also had an interesting feature: it worked in partnership, through a capacity building process, with the public broadcaster Prasar Bharati for mass media and the community media units of the Information and Broadcasting ministry. An evaluation of the campaign by the ORG Center for Social Research indicates that not only did the campaign reach as many as 60 percent of the respondents, but also that it contributed to correcting misinformation about leprosy and changing negative attitudes to leprosy patients.

**The production partnership strategy has had a positive outcome. The managers and producers of Doordarshan and All India Radio reported that they had learnt new skills and new approaches to health campaigning.**

The BBC WST's collaboration with Doordarshan centers in the five focus states was particularly

effective: Doordarshan producers made TV spots with training and technical support from BBC WST, a method that created a sense of ownership in the activity as well as the subject. To increase the reach of mass media, more than 2700 video van screenings were organized in rural areas in collaboration with the Directorate of Advertising and Field Publicity. Similarly, BBC WST partnered and supported All India Radio teams in the five states to produce a radio serial, radio spots, musical dramas, special features and phone-in programs in three languages.

The advertising agency SOMAC: Lintas, contracted by the MOHFW under the second World Bank supported leprosy project, built on the BBC WST experience. More significant, it worked at imparting the sense of a “national movement” into the extensive community education and case detection efforts of the government. A quantitative Knowledge, Attitudes and Practices study that was conducted in the high-endemic states prior to the design of the campaign strategy showed that although most people believed leprosy could be cured, they still hesitated to seek timely treatment. This finding formed the basis of the creative strategy that was leveraged across all media – press, television, radio, public relations and political advocacy. The strategy combined education, motivation, and celebrity endorsement – by the Hindi cinema icon Amitabh Bachchan – to run a synergistic campaign under the slogan “Haath milayen, kusht mitayen” (Let’s join hands to defeat leprosy). In the initial phase, a theme film launched the campaign and set the national-scale background of the elimination goal, followed by four tactical films centered on “spreading the word” about MDT. After this phase, a quantitative impact evaluation was conducted. The learning from this evaluation was translated into the concept of “reach out”: influencers such as village panchayat leaders and doctors were involved in efforts to reduce stigma and promote the seeking of early treatment.

Radio has been extensively used as part of the SOMAC: Lintas campaign. Radio spots featuring the campaign anthem, and themes similar to those used by the television campaign, were developed and used on All India Radio stations in the endemic areas, particularly Bihar.

The press was used primarily for announcements, for instance on World Anti-Leprosy Day and before MLECs. Going further, the SOMAC: Lintas campaign made extensive use of a feeder service for a number of district level newspapers to reach influencers in rural areas and district towns in the Hindi heartland. This path-breaking effort involved the development of advertisements suitable to the intended audience as well as locally saleable stories. The service combined advertisement and editorial coverage, placing the advertisement close to a relevant article based on material supplied by the advertiser at no additional cost.

The debate continues on the use of mass media, particularly television, by a development program. Available data and substantial anecdotal

**Mass media has been useful in reaching a large audience. With the program shift to voluntary self-reporting, the focus will be on localized forms of communication aimed at hard-to-reach groups in specific areas.**

evidence indicate the formidable power of television. Although its reach among the rural poor is still not high, it does reach a wide representation of rural influencers. Despite having lost some of its audience to TV, radio continues to reach people in the rural areas, and has also begun to reach the influencer groups in urban areas through the new FM channels. The press is an expensive

medium to sustain and it does not reach low literacy groups; but is useful for announcements. Campaign experience indicates that district level newspapers are also helpful in reaching rural influencers. Outdoor media (such as hoardings and wall paintings) have been used by the

program usually on government buildings and PHCs, and mainly at the time of the MLECs. If placed at public traffic points these might have greater impact, although this would be more expensive. Wall paintings are cheaper than hoardings, but they need to be designed well to attract attention and communicate the leprosy message.

In sum, in terms of persons reached, mass media are probably cheaper than interpersonal communication. But in absolute terms, mass media require a reasonably high threshold level of expenditure for the desired impact. Mass media have been particularly useful when a large audience has to be addressed to create a broad level of awareness. However, in keeping with the program strategy of shifting to voluntary self-reporting, the focus for the future will be on localized forms of communication aimed at hard-to-reach groups in specific areas.

### **Motivating and training service providers**

Service providers are central to the program. Their services include support to the process of diagnosis, treatment and counseling. Although stigma has been considerably reduced, it still exists. So do patients' fears. Fortunately, the program has developed a significant body of dedicated workers, including missionaries, who have inspired grassroots health workers with their zeal. Today, PHC workers carry out the process of diagnosis and treatment in the integrated program structure. The MLECs with their campaign style approach mobilized entire districts and contributed to the enthusiasm and motivation among providers. As part of the MLECs, general health care staff were trained over three days to identify and diagnose leprosy. This was followed by a day of training on the actual modus of conducting the MLEC. The IEC strategy of the second World Bank-supported leprosy project has specifically targeted providers in addition to clients and influencers.

In the post-integration scenario, the Chief Medical and Health Officer of the district is responsible for the program at the district level. Experience indicated that planning and implementation of IEC activities at the state, district and sub-district level need close supervision. Hence the GOI and the World Bank jointly organized a series of regional planning workshops to systematize the planning process at state and district levels, and similar workshops for district program managers. A tool to facilitate the management oversight of IEC at the state, district and sub-district levels has also been developed to strengthen this aspect of IEC in the program.

**The training and motivation of service providers is critical to program outcomes. In fact, the two are related: training motivates in addition to imparting technical information.**

In addition, the Central Leprosy Division has used recognition to motivate the providers through a series of performance awards. Awards are given annually to the best worker in the district and the best NGO. The Center also gives awards to states that have achieved elimination in all districts.

### **Advocacy at all levels**

Advocacy can be a powerful tool to attract attention to the program and the goal of elimination. The Global Leprosy Elimination Program was established in 1991 to achieve elimination by 2000. In 2000, twelve countries that had not reached this goal formed the Global Alliance for the Elimination of Leprosy. This alliance, in partnership with international agencies such as the World Bank and the WHO and international NGOs such as The Leprosy Mission, the Nippon

Foundation and the Novartis Foundation, aims to accelerate the elimination process through technical advice and a regular review of country programs.

Again, linking international and national level advocacy, the World Leprosy Congress held in Delhi in 1984 accorded the program top priority and made it part of the prime minister's 20-point program. Subsequently, a range of activities has helped put leprosy on the agenda of policymakers: a national level committee was formed to tackle the elimination goal; it sensitized politicians, which led to an increase in funding allocated. A National Leprosy Eradication Commission chaired by the health minister was set up; so was a National Leprosy Board that has functioned as a regulatory, monitoring and technical advisory body. Similar commissions and boards have been set up at the state level to make policies and review program implementation.

**With the program moving closer to the elimination goal, advocacy becomes even more important – to hold the attention of policymakers, administrators and leaders; and to maintain the focus on the district level program.**

Campaigns such as those run by BBC WST and SOMAC: Lintas have used advocacy through press conferences and press workshops, as well as regular success stories and interviews in leading newspapers. The MLECs provided impetus to local advocacy activities since they involved the local administration as well as local leaders – including members of central and state legislatures, panchayat members, religious leaders and village elders.

Advocacy at all levels has been an important factor in motivating people within the program. It has also led to greater political commitment: the support of state administrations and politicians has been a critical factor in efforts to meet program goals.

#### **4. CRITICAL ISSUES: EQUITY AND PARTNERSHIPS**

*“In the leprosy program, ordinary people are the most effective and efficient means of reaching the wider population. And to be a success, the program has to be active in seeking women’s involvement.” These statements by a representative of the Danlep project in Orissa are borne out by a real-life story in the predominantly tribal Bastar District of Chhattisgarh.*

*The woman sarpanch, Rampati, is at a kalajatha being held at the village haat. She speaks about a leprosy sensitization workshop she went to and how it has enabled her to help other women in her village. Rampati examines the women when they bathe at the village pond. She tells them about leprosy; that it can be cured, that it is not communicable, and that women with leprosy should not be afraid to come forward and get themselves treated.*

## TWO CRITICAL ISSUES

### Equity of access

Over the years, communication strategies have evolved in line with the changing needs and emphases of the leprosy program. The current phase of the program is directed towards achieving and sustaining elimination. To do this, it has to ensure equity of access to program services. It has to reach out more to the poor and marginalized, particularly among women, tribal communities and urban populations. Poor living conditions facilitate the transmission of infection, and poor access to services contributes to the perpetuation of the disease. The states

**To achieve and sustain current program objectives, IEC activities must continue to emphasize:**

- **Vulnerable groups such as women, tribal communities and the urban poor.**
- **Partnerships for innovative approaches and technical and implementation support.**

that contribute most of the patient load are among the poorest states in India. Within these states, the most socially marginalized groups – such as the scheduled castes and women below the poverty line – bear the highest burden of the disease. Not only does the disease target the poor; it is also a tremendous social and economic burden to its victims. The poor have been the central focus of the program and customized IEC strategies are directed at groups with lower access

to health services. But reaching these groups will continue to pose a major challenge for the program in the coming years.

### Partnerships

While the GOI has taken the lead in the program's IEC efforts, a number of partners, including the World Bank, NGOs, the WHO, Danida, and the International Leprosy Elimination Partnership (ILEP), have made significant contributions to this key component. These partners have strengthened the government's efforts through their reviews, their innovative approaches, development of materials, and implementation support. Some have helped to widen the reach of IEC in the community. The role partners have played is a major factor in the communication successes of the leprosy program, and their involvement continues to be critical.

## REACHING HARD-TO-REACH GROUPS

### Women

Women have undoubtedly been the worst victims of the social stigma attached to leprosy. (Also see Table 3.1, which indicates lower awareness levels among women respondents compared to men.) In its initial stages, the first World Bank-supported project found that underreporting and late detection of cases was common among women for several reasons:

- Poorer access to health services and information;
- Complete examination less likely;
- Social stigma higher; detection can decrease the probability of marriage or lead to the abandonment of married women; and
- The conditioned tendency of women to ignore illnesses till they become acute.

In this context, the program has included a special focus on women. From the third MLEC (2001-02) onwards, search teams that carry out house-to-house visits have included female members, usually the auxiliary nurse midwife (ANM) or the AWW. From 2002-03, the program has begun tracking the proportion of female cases among new cases detected. This serves as an indicator of women's access to services, as well as reduction of stigma. Several states such as Bihar, Gujarat and Maharashtra report that around 40 percent of new cases detected are female. Other states such as West Bengal, Andhra Pradesh and Uttaranchal are also beginning to show an increase in this proportion, indicating that larger numbers of women are being emboldened to seek treatment for leprosy.

**The roles of the ANMs and AWWs have been critical to addressing underreporting and late detection of female cases of leprosy. The proportion of male:female cases is now a critical program indicator, and it is regularly tracked to ensure greater access to program services among women.**

The integration of the vertical program with the general health system has increased women's access to the program. The community's first point of contact with the program is now the ANM, who has been trained in leprosy detection, treatment and IEC. As a woman it is easier for the ANM to examine women and communicate with them. The number of AWWs in almost every village facilitates reaching out to their primary target groups – women and small children. The AWWs have also been trained in leprosy case detection and treatment. Along with AWWs, community based women's organizations such as mahila mandals and self-help groups have been sensitized in successive MLECs. Women have also been used as protagonists in communication materials, making it easier for women to identify with the situations portrayed.

### **Tribal populations**

**The evidence indicates a large number of cases being detected among tribal populations. Focused communication campaigns are required to improve access to information and timely voluntary reporting, particularly in remote areas.**

The endemic states in India are home to large tribal populations, and evidence indicates that they are less likely to access timely diagnostic and treatment services than non-tribal populations. The program has developed a strategy to ensure access to services for tribal populations by improving the reach of detection and treatment services in the remote areas in which tribal people usually live; by ensuring that cases from the tribal community have no social and economic impediments to completing treatment; and by ensuring that leprosy patients remain socially and economically integrated in their communities.

A large number of tribal volunteers have been trained during the MLECs, and this has helped reach tribal populations in some states. The Special Action Projects for Elimination of Leprosy are being used to reach tribal populations in remote areas, and IEC is an integral part of these activities. But the data indicate a large number of cases being detected among these groups, and the focus on ensuring their access to services will have to continue. Focused IEC campaigns are necessary to improve access to information and timely voluntary reporting.

## Urban poor

Eliminating leprosy in poor urban settlements presents a major challenge for the coming years. Compared to the relatively well-established community health centers, PHCs and sub-centers in rural areas, urban areas lack public health infrastructure. In the case of leprosy, ensuring complete treatment over a period of six to twelve months among migrant and mobile communities poses significant challenges.

**Ensuring the complete treatment of leprosy among poor migrant and mobile communities in urban settlements poses significant challenges.**

Ensuring access to services is made more difficult by the multiplicity of administrative bodies, the unregulated growth of private providers, and the lack of support structures. Leprosy Elimination Campaigns are being conducted among the urban poor, and these campaigns have a strong IEC component to address the special needs of urban areas. In addition to the intensification of campaigns, meeting the urban challenge calls for close monitoring of leprosy cases among urban migrants, and coordination among the diverse set of administrative bodies.

## THE NEED FOR PARTNERSHIPS

### International Leprosy Elimination Partnership

The ILEP has been represented through several of its partners who have supported the leprosy program for several decades in India. ILEP partners, along with the WHO, have fielded District Technical Support Teams that support program implementation monitoring. Most partners also actively support IEC activities in the program in various ways, including carrying out community level IEC activities and funding other NGOs for the purpose. One of the partners, The Leprosy Mission Trust India, has set up a media center close to Delhi to produce audio-visual and print materials for use in the field. Apart from this, ILEP members have been running special leprosy institutions such as hospitals, rehabilitation centers and reconstructive surgery units.

**NGOs and other partners have played a significant and often pioneering role in the leprosy program in India. In the coming years, their support will continue to be critical in promoting voluntary self-reporting and treatment completion, community awareness, and the integration of leprosy patients into the community.**

### National NGOs

Over the years, several voluntary organizations have been involved in the cause of leprosy including the Hind Kusht Nivaran Sangh, the Gandhi Memorial Leprosy Foundation, and Sevagram. In 1965, the National Leprosy Organization was set up to provide a common platform for NGOs to share their experiences and problems. Almost all of these undertake IEC for leprosy. About 250 NGOs of various sizes and mandates continue to collaborate with the leprosy elimination program in India.

### Danida

Between 1986 and 2003, Danida supported India's leprosy elimination in several parts of the country. Danida provided significant assistance to IEC, supporting conventional as well as innovative IEC methods, and produced a large body of diverse IEC material, much of it

produced with active community involvement. The Danlep “care and concern” skin camps represented its active involvement in the shift to a new approach that combined education, training and treatment through a process of building community participation. In Madhya Pradesh and Chhattisgarh, Danlep developed the concept of “dialogue” among the health provider/educator, the patient, and the community as a process for breaking down barriers.

## **WHO**

In addition to supporting the District Technical Support Teams in some states and other technical assistance, WHO support for the IEC effort in the leprosy program has included the piloting of a communication approach called COMBI (Communication for Behavioral Impact) in three districts of Bihar in 2003. This approach is based on the identification of a single message that is communicated through “personal sellers” as well as other media. The behavior change objective of the COMBI plan in Bihar was CYS (Check Your Skin) for ELSI (Early Signs of Leprosy) defined as a patch with no sensation. A mix of approaches was used, including mass media (radio and print), interpersonal communication by workers from the health and social welfare departments, “point of service promotion” at service delivery centers and the use of “personal sellers” – school children between the ages of nine and fourteen. The effort carried out in the state of Bihar resulted in an increase in the number of skin cases seeking treatment at health facilities.

## **5. EXTENDING THE SUCCESS STORY: USING LESSONS LEARNT**

*What happens when the “survey mindset” gives way to encouraging voluntary reporting? Providers throughout the country feel that the voluntary reporting of leprosy has increased because of communication efforts. A paramedical worker working with an NGO in Bangalore describes the change she has seen over the years: “Earlier we used to do surveys. Nowadays MDT is kept in the centers and the patient voluntarily comes and takes it.”*

### **LESSONS LEARNT: A SUMMARY**

Despite the successes the leprosy program has achieved in IEC, there are, inevitably, tasks that remain to be completed. It is in this context that lessons learnt from past experience will help the program meet the challenges ahead. At the same time, these lessons apply to the communication effort of other development programs in India as well.

#### **Communication is an intrinsic program component**

It is always difficult to evaluate the exact impact of a component like IEC, which works in different ways at different levels, particularly without adequate baseline data. But the first and most significant learning from the experience of the leprosy program is that communication can indeed be used as an input for the achievement of program goals.

## *Strategy*

The impact of IEC is greater if a clearly articulated communication strategy is first developed, with objectives and target groups clearly identified and prioritized. This prioritization has been a key feature of the second World Bank supported leprosy project.

## *Multi-layered campaign*

In a vast and diverse country like India, a combination of strategies and methods is required to reach varied target groups. Hence the leprosy program has used many different means – from folk media and interpersonal communication to mass media – to communicate its key messages across the country. The synergistic impact of the planned use of different media is undoubtedly greater than the impact of a single medium, since the opportunities for the target audience to be exposed to the communication multiply.

## *Professionalization*

Understanding that communication is a discipline with trained professionals has enabled the leprosy program to achieve better results both quantitatively and qualitatively. The strategy and implementation plan of the second World Bank-supported leprosy project has been drawn up with the help of professionals. BBC WST brought its professional expertise to bear on the production of quality materials to good effect. SOMAC: Lintas built on this experience and crafted a strategy to increase the reach of information and change attitudes.

## *Campaign approach*

The leprosy program also provides evidence of the impact of using communication with a planned campaign approach. Research indicates that intense bursts of activity are likely to have greater impact than sparsely distributed activities. The impact of intense campaigns such as the MLECs, for instance, can still be felt in the community. The use of mass media in the campaign approach enhanced its impact.

## *Partnership*

The significant contribution of IEC towards meeting program objectives is clearly the result of concerted efforts on the part of the GOI, working in close coordination with its key partners to achieve a common goal. The partners brought their different strengths and areas of expertise to the campaign, thus enhancing the quality of IEC and widening its reach.

**The IEC experience in the leprosy program indicates the need for:**

- **A planned communication strategy with objectives and target groups identified and prioritized;**
- **A multi-layered campaign that combines methods and media to reach varied target groups;**
- **Inputs from communication professionals to plan and implement IEC strategy and produce quality material;**
- **A planned campaign approach with intense bursts of activity for impact;**
- **A plan that utilizes the different strengths of key partners; and**
- **Close supervision of IEC planning and implementation at state, district and sub-district levels.**

### *Management oversight*

Learning in a program comes from aspects that have worked, as well as those that need strengthening. The experience in the leprosy program indicates that state, district and sub-district level IEC activities need closer supervision to ensure that plans are developed and implemented with the same degree of attention across the country. Hence the GOI and the World Bank jointly organized a series of regional planning workshops to systematize the planning process at state and district levels. Similar workshops are being held in the states for district program managers. A tool to facilitate the management oversight of IEC at the state, district and sub-district levels has also been developed to strengthen this aspect of IEC in the program.

## **THE CHALLENGES AHEAD**

### *The urban challenge*

Special IEC strategies and campaigns to reach urban audiences comprise a key feature of the strategy that will soon be implemented in identified urban areas. The World Bank-funded project closed on 31<sup>st</sup> December 2004, and access to substantial funds for mass media activity in the coming years seems unlikely. Ways of reaching out to urban audiences – using cheaper strategies without loss of impact – will have to be found.

### *Other special groups*

The high rates of leprosy in some districts in low prevalence states, and the extremely high rates in some districts in endemic states, indicate the need for area-specific and target group-specific focus in the years ahead. Special efforts will have to continue to reach the poor and marginalized – women, tribal communities and other hard-to-reach groups – through customized IEC in focused areas. Effort to further reduce stigma towards women affected by leprosy and to empower them to seek treatment voluntarily will have to remain a key component of the program's IEC strategy. Equally, increasing the access of tribal groups to services and information will have to continue to be a focus of the program's strategy.

### *Early detection/POD counseling*

The disaggregated analysis of data indicates a fairly high proportion of multibacillary cases. While this could be due to various epidemiological factors, it is also possible that these cases are not being detected in time. Hence the IEC emphasis on early voluntary reporting and treatment will have to continue. Although deformity rates have come down dramatically, the high proportion of multibacillary cases calls for strengthening self-care and counseling for the prevention of disability.

### *Focus on providers*

The program's IEC strategy has addressed the need to motivate providers; nevertheless they have received less attention than other target groups. In the post-integration period, the focus has had to include improving the quality of service delivery by motivating providers and counseling patients. This is particularly applicable to the general health system, the new entrants to leprosy service delivery. Appropriate strategies and tools – such as non-monetary recognition in local events – need to be developed and implemented to recognize the contribution of providers.

## *Advocacy*

**The challenges ahead for IEC in the leprosy program include:**

- **Continued emphasis on early voluntary reporting and treatment to achieve and sustain the program goal of elimination;**
- **The need for an area-specific and target-specific focus;**
- **Finding cost-effective ways to reach poor urban audiences;**
- **Improving the quality of service delivery by motivating providers and counseling patients; and**
- **A cohesive strategy for advocacy to position elimination center stage, motivate all those associated with the program, and involve district level administrators and influencers.**

The program made advocacy efforts at national, state and local levels. These must be strengthened with a cohesive strategy for the last vital years. As the program nears its goal of elimination, advocacy efforts at the national and state levels need to showcase the imminent success of the program through identified events, positioning the issue of elimination center stage and taking the concept of a national movement further. This will help strengthen the image of the program that influencers have, and motivate people associated with the program at all levels. A significant advocacy task remains at the district level: the continued involvement of district level administrators and influencers will remain a key to the achievement of program goals.

## *Sustainability*

The IEC experience in the leprosy program holds valuable lessons for other programs. In many ways, the leprosy program has been part of the collective experience that has shown the way for other health programs, such as polio and HIV/AIDS, in which communication is a key component. That IEC has become an integral part of service delivery is an achievement the leprosy program justifiably can be proud of. At the same time, the way ahead holds some challenges. These include addressing hard-to-reach groups and finding ever more cost-effective and sustainable methods to implement IEC strategies. Most of all, ways will have to be found to retain the momentum of IEC efforts so as to achieve and sustain the program goal of elimination.

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