SERIES NO. 1

LEAP

LEPROSY
ELIMINATION
ACTION
PROGRAMME

OCT 04

TASK TODAY

WHO :
perspectives and prescriptions

GOM :
special initiatives for elimination

LEAP :
tasks ahead - 2005 and beyond

ALERT-INDIA'S
26th FOUNDATION DAY
SPECIAL ISSUE

INDEX

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FOREWORD

'Task today' is the most appropriate title when we talk of the current leprosy elimination scenario in the country and the state. I heartily congratulate ALERT-INDIA for their publication with the most appropriate title.

The country had missed the bus of elimination in 2000 and now is the do-or-die opportunity with reference to leprosy elimination by 2005. Simultaneously a serious thought has to be given to real achievements especially keeping in view that plenty of hidden cases are still there in the state so that elimination does not boomrang. The PR & NCDR the few worthwhile indicators have been almost static in the state for last 4-5 years. This needs to be thoroughly deliberated upon and action plan which will yield a significant reduction in both needs to be developed.

The exercise of integration to increase MDT access help achieve elimination in the time frame seems to be the priority concern. The consequent change of responsibility of Non Governmental Organizations and adequate channelization of their potential needs to be kept in mind.

The vision of 'Task Today' is really appreciable as not only the current scenario but also the future problems of post-elimination era have been reflected. I am happy & feel satisfied that ALERT-INDIA are fully devoting to anti leprosy activities not only in Mumbai but other parts of the state as well.

'Focus' - a booklet published by ALERT-INDIA on Mumbai programme is an excellent documentation. So also is the utility of 'Task Today'. All the burning issues like urban leprosy, special campaigns, selective special drives, integration, training, rehabilitation, role of NGOs, Block Leprosy Awareness Campaign etc. have been paid legitimate attention. I am sure 'Task Today' will turn out to be an extensively informative and educative publication.

I sincerely applaud the efforts of ALERT-INDIA towards achievement of Leprosy Elimination in state and acknowledge the same with thanks. I wish them very good luck and success-in-toto in the accomplishment of the goal of Leprosy-Free India.

Pune,
30th September, 2004

Dr. S.C.Gupta
Joint Director of Health
Services (Leprosy) Pune.

WHY 'TASK TODAY'

'Task Today' is an effort to share information and gather informed support of one and all for Leprosy Elimination Action Programme (LEAP) during integration phase. The LEAP proposals originate from two landmark events :

On 11th October, 2003, a Workshop on the – **"Strategies for Leprosy Elimination in Cities and Towns"** was held in Mumbai, on the occasion of ALERT-INDIA's 25th Foundation day. Experiences from Delhi, Mumbai, Agra, Pune, Navi Mumbai, Thane, Panvel, Miraj were presented answering basic questions which were raised related to the theme.

* How close are we to leprosy elimination? Where are the new cases coming from? Is there any change in the trend in new case detection? What should our strategy for the future be? The NCDR reported from different locations called for an action programme.

The strategy for leprosy elimination in cities and towns was discussed under the Chairmanship of Dr. Ashok Kumar, the then, Dy. Director General Health Services, Head, Central Leprosy Division, GOI; Project Director, NLEP - India (WHO). He stressed on the advantages of integration and the need for partnership between stake-holders.

On 14th – 15th October, 2003, another landmark event was GOI's National Consultation Workshop, New Delhi, to define a specific strategy for elimination of leprosy from urban areas. The recommendations of this consultation are futuristic and excellent guidelines for action. Salient proposals and relevant aspects will be incorporated into the LEAP plan, as we progress.

'LEAP' proposals are also a response to the need for a pro-active role needed today, from NGLOs, following integration of leprosy services into the general health services in Maharashtra.

The LEAP proposals are released for the perusal of all willing partners. These are aimed at developing a leprosy-affected persons'- centric and community-oriented strategy and an action programme.

A. Antony Samy
Chief Executive
ALERT-INDIA

11th October, 2004

I. WHO & others : Perspectives & Prescriptions

1. Overall Strategy

The strategy for 'elimination of leprosy' as a public health problem is quite clear in having a definite target that is not only aspirational but also managerial. The strategy focuses on :

- MDT, which together with early case-finding, is the best way of dealing with the problem of leprosy and its consequences;
- reducing the disease burden in terms of prevalence to very low levels, will lead in the course of time, to a reduction in transmission of infection and reduction of disease incidence;
- preventing the occurrence of disabilities by early diagnosis and treatment and improved management of cases with consequences;
- changing the negative image of leprosy;
- working closely with governments and every agency interested in leprosy elimination in a spirit of true partnership.

The elimination strategy is a highly relevant and sound approach to deal effectively with the leprosy problem. The key elements of the strategy require further innovative approaches, better adaptation to local realities, and greater attention to the implementation process itself.

"Leprosy elimination campaigns and special initiatives for reaching out" - published in The Final Push towards Elimination of Leprosy : Strategic Plan (2000-05), WHO

Box : 1

How does the concept of leprosy elimination differ from that of leprosy control?

Leprosy control was a more limited concept, based on strenuous - but not always successful - efforts to find leprosy cases and treat them with one or more drugs. By contrast, the concept of leprosy elimination takes advantage of the availability of the effective technology of MDT, and its capacity to reduce disease prevalence drastically, to work towards a defined goal within a specified time frame.

ELIMINATION OF LEPROSY - Questions and Answers, Action Programme for the Elimination of Leprosy, World Health Organization : Revised 1996

2. Special Campaigns to Eliminate Leprosy

A. What are Special Campaigns?

Special Campaigns are usually carried out in areas (or among population groups) presumed to have a high hidden case-load. In these circumstances, the coverage of MDT services is typically still poor, awareness about the disease is low, and the negative images traditionally associated with leprosy persist. These factors have prevented patients from coming early for diagnosis and treatment, thus increasing the risk of their becoming disabled and transmitting the disease to others. Special Campaigns are needed to focus attention and change this situation as quickly as possible.

Special Campaigns combine three objectives :

- capacity-building of general health workers to provide MDT services to the communities they serve;
- raising community awareness and encouraging participation, to promote self-reporting and remove negative perceptions about the disease;
- ensuring that all cases of leprosy are diagnosed and that patients receive a full course of treatment.

B. Where are Special Campaigns particularly needed? What population groups should be targeted?

Special Campaigns are needed in the following areas and for the following target groups:

- ***Rural areas*** **-** where MDT services are not operating effectively and there are indications that large numbers of undetected (hidden) cases exist (*e.g.* migrant labourers).
- ***Difficult access / remote areas*** **-** where MDT services are not available or easily accessible for certain population groups living under difficult conditions (*e.g.* minority groups, tribal groups, nomads, displaced people, refugees).
- ***Urban / peri-urban / urban slum areas*** **-** in these areas stigma is generally high, awareness about the disease is relatively low and MDT service coverage is poor due to the inadequate involvement of both the general health care system and the private sector.

It is also clear that, in many programmes, there is a significant "gender gap" in

accessibility to MDT services for women. Every effort must be made to ensure that this gap is narrowed.

C. Why not simply conduct house-to-house surveys to detect all cases? Why wait for people with possible symptoms to self-report?

In the ideal situation, the community would be so well informed about leprosy that anyone who develops a suspicious skin lesion would come forward for timely diagnosis and treatment. This requires both an effective communication strategy, adapted to local culture and customs, readily available and accessible leprosy services. However due to rural sociocultural factors, this approach has not resulted in achieving desired goals or targets.

By contrast, house-to-house surveys are very time-consuming and require considerable financial and human resources. Such surveys also expose new patients and their family members to unnecessarily stressful situations and may often result in rejection of the diagnosis and patients defaulting from treatment. Active search campaigns have also had a high rate of misdiagnosis of doubtful lesions.

D. What are the main challenges encountered when conducting a Special Campaign?

The problems commonly encountered in carrying out Special Campaigns are :

- ***Poor coverage*** - activities may cover only a small portion of the population in the target areas.
- ***Inadequate community awareness*** - information provided to the community may not be appropriate and the communication methods used may be unattractive or ineffective.
- ***Limited involvement of the general health services*** - the general health services may not be fully involved during and after the Campaigns, which will create problems in sustaining MDT services.
- ***Emphasis on detection*** - overenthusiasm on the part of health workers and volunteers in detecting new cases may result not only in a significant proportion being wrongly diagnosed but also in the re-registration of previously treated cases as new cases (recycling).
- ***Inadequate preparation*** - poor planning leads to the existing health infrastructure being unable to cope with the increased demand for MDT services, which in turn results in drug shortages and in patients getting irregular or no treatment.

E. What activities are carried out during the actual campaign?

The Special Campaign itself is usually of short duration and its success will depend to a great extent on how well the preparatory activities have been carried out. The campaigns concentrate on :

- case-finding through creating community awareness (self-reporting by patients) and providing clear information on where to go for diagnosis;
- starting treatment with the first dose of MDT and providing clear information on how to continue taking the treatment;
- providing enough treatment or information about where to go for continuation of treatment;
- removing negative perceptions about the disease through intense IEC activities, using various communication methods specially adapted to local situations.

F. How will the Special Campaigns be evaluated?

National programmes must ensure that every Campaign is evaluated : future activities can be improved on the basis of the lessons learned. The following indicators may be used in evaluation :

- Increase in the number of new health facilities providing MDT services on a daily basis after the Campaigns.
- Confirmation of diagnosis, classification, and recording of new cases (paucibacillary, multibacillary, women, children and grade 2 disabilities) detected during the campaign.
- Level of community participation and feedback on the Campaign.
- Number and categories of general health workers competent in and routinely providing MDT services.
- Coverage of awareness activities and impact, particularly in terms of the proportion of new cases self-reporting to the nearest health centre.

"Strategic Issues - The Elimination of Leprosy as a Public Health Problem" - WHO (2003) as published in Indian Journal of Leprosy, Vol. 75(3), July - Sep 2003

3. Leprosy Elimination Campaigns (L E C) and Special Initiatives

Leprosy Elimination Campaigns and special initiatives for reaching out :

Leprosy Elimination Campaigns (LEC) aim at accelerating elimination activities in the major endemic countries through detecting and treating patients who for various reasons have not as yet been detected. This initiative is a combination of three elements, namely : (i) promoting community awareness and participation in leprosy elimination activities; (ii) capacity building measures for local health workers to improve MDT services; and (iii) case finding and curing patients with MDT. LEC is designed as a campaign, in that all the efforts are carried out within a relatively short period of time. They cover a fairly large population and involve the maximum possible number of health workers.

Special Action Projects for the Elimination of Leprosy (SAPEL) were introduced with the objective of reaching patients living in difficult-to-access areas or among neglected population groups and thus to provide leprosy services, specifically MDT, to those patients who otherwise would never have received treatment. They include those who are geographically inaccessible, politically neglected groups, ethnic minorities and certain population groups like nomads and refugees.

Box : 2

Is the goal of elimination reasonable and feasible? What urgent actions must be taken now to ensure the attainment of the goal?

This new approach will have four basic elements : (i) the national Leprosy Elimination Campaigns (LEC) to stimulate public awareness and detect "hidden" cases; (ii) making MDT readily available at the community level; (iii) Special Action Projects to tackle difficult-to-reach areas and populations; and (iv) monitoring the impact of these activities at district, regional and national levels.

ELIMINATION OF LEPROSY - Questions and Answers, Action Programme for the Elimination of Leprosy, World Health Organization : Revised 1996

The main elements of the special action projects are : (i) innovative actions, adapted to the local culture and resources to find cases and cure them; (ii) capacity building for local health workers or volunteers (i.e. local leaders, priests, imams, teachers, etc.) with the aim of establishing sustainable MDT services; and (iii) promotion of community awareness and mobilization of their participation in case-finding and treatment activities.

These projects serve an important role in bringing services to neglected population groups and to those patients who would not otherwise be reached. Linkages with other partners in the planning and implementation of activities should be sought with a view to expanding to more underserved populations.

Year 2000-2002 :

Intensive implementation at the district level, including integration, together with close monitoring of the progress and adaptations at the local level.

Year 2003-2004 :

Phasing out and validation of elimination at national and possibly sub-national levels.

Year 2005 :

Detailed validation of leprosy elimination.

"Leprosy elimination campaigns and special initiatives for reaching out" - published in The Final Push towards Elimination of Leprosy : Strategic Plan (2000-05), WHO

Box : 3

Only development can defeat disease

President Abdul Kalam

The President at the National Conference on Elimination of Leprosy at Raipur in January 2004 said that it's only development that can defeat disease. This means better amenities, clean drinking water, better hygiene and sanitation, better education and awareness, better health care, nutritious food resulting in a livable environment. This holistic approach is vital in leprosy-endemic regions.

as reported in the Bulletin of the Leprosy Elimination Alliance, January-June 2004.

4. What is the Need of the hour?

excerpt from

Leprosy Programme in India : Anticipations and Outcomes

- Experience suggests that prevalence of the leprosy is largely under-reported and real prevalence might have been several times of the reported prevalence.

- Nobody can deny the urgency to treat the existing pool of all leprosy cases as much as the control the transmission of disease to susceptibles. The same can be achieved NOT by means of clearing of records from the registers Or by not treating the cases sufficiently or by not undertaking regular surveys. Although the presently adopted public health approach may give some relief but it artificially suppresses the problem of leprosy.

- If mid-course corrections were not applied, the problem would certainly bounce back in the years to come. One, especially public health experts, should not forget the malaria story.

- It is therefore needed now that a joint approach of culminating knowledge and perceptions about the benefits of living in clean settings alongwith the sincerely committed MDT based leprosy control approach, that has the patient in focus, is the need of the hour.

Dr. Anil Kumar, Dty. Director, Biostatistics & Epidemiology,
Central JALMA Institute for Leprosy (ICMR), Agra.

Box : 4

What epidemiological advantages over other diseases does leprosy have that make elimination possible?

The special features of leprosy are that :

(i) the infected human being is the only reservoir and source of infection;

(ii) under natural conditions, incident cases make up only a small fraction of the prevalence pool;

(iii) below a certain level of prevalence, any resurgence of the disease is very unlikely; and

(iv) unlike tuberculosis, the leprosy situation does not appear to be adversely affected by HIV infection.

ELIMINATION OF LEPROSY - Questions and Answers, Action Programme for the Elimination of Leprosy, World Health Organization : Revised 1996

5. Logical Framework for Leprosy Elimination Monitoring

Situation in a country like India has raised several important questions. Everywhere else in the world, leprosy elimination is being achieved or already achieved. But India is lagging behind too far. It is therefore essential to examine what could be the reasons for this non-achievement. The reasons can be epidemiological or operational. Logical framework is proposed for monitoring the evaluation of the situation :

LOGICAL FRAMEWORK

Descriptive summary	Objectively Verifiable indicators	Means of verification	IMPORTANT ASSUMPTIONS
Programme Goals : Leprosy Eradication	Areas free of leprosy for ____ years	Certification exercise	REGARDING RELEVANCE OF PROJECT TO PROGRAMME GOALS
Project Purpose : Leprosy Elimination	Recorded Prevalence NCDR	Surveillance data LEM LQAS	IMPACT OF SERVICES
Outputs : Case detection & treatment	LEM indicators for MDT supply & patient care + Sensitivity & Specificity of diagnosis	Surveillance data Quality Checks LEM	CONVERSION OF RESOURCES INTO SERVICE
Inputs : Personnel & support	Infrastructure Trained staff MDT availability	Routine data Data on training Sample check	AVAILABILITY OF RESOURCES

Several important assumptions are made with respect to achievement of elimination of leprosy. They call for urgent examination. It is also necessary to develop methodologies and implement monitoring and document carefully the process of implementing the elimination programme. Finally, the output and outcome need to be carefully assessed.

The pattern is seen in several other districts and states in the country. Prevalence of leprosy has fallen down by more than 90%, but new case detection remain almost static or is very slowly declining. The changing profile of leprosy can therefore be described as : lowered multibacillary proportion in the new cases, proportionate increase in paucibacillary cases, extremely low smear positives, no shifts in age specific rates and lastly important and disturbing no change in the detection rates. The present picture therefore suggests :

- New cases will continue to occur
- Profile will be mild
- Better acceptance by the community
- Integration is needed
- Patient focused management

Thus, certain issues call for urgent attention:

1. Need for clear documentation of leprosy trends globally.
2. Validation of new case detection.
3. Examination of the present strategy for leprosy control and consideration of various alternatives.
4. Continued global efforts.
5. Important research issues in view of availability of M. leprae genome, possible uniform MDT and consideration of prophylactic leprosy vaccines for certain areas.

Thus, for the last two decades, leprosy has come down substantially at the global level, but continues to be a major problem in countries like Brazil, India and Nepal. This situation calls for focused and strong efforts to achieve the final elimination from these countries as well.

"Leprosy Elimination Critical Issues : Epidemiology-Global Scenario" by M. D. Gupte (Director, National Institute of Epidemiology - Chennai),

6. The DANLEP-supported urban leprosy elimination strategy

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

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

1. The underlying principles of the endeavour involve partnership, networking and community participation;
2. The active involvement of the non-health system administration and political leadership;
3. Peer group facilitation and local advocacy using non-traditional/non-leprosy groups and agencies;
4. The development of a plan of action by local individuals and institutions to ensure local ownership of leprosy elimination activities;
5. The signing of a memorandum of understanding (MOU) symbolically formalising the stakeholders' commitment to the programme.

The urban leprosy strategy was piloted by DANLEP in selected urban areas in the states of Tamil Nadu, Orissa, Madhya Pradesh and Chhattisgarh.

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

The Urban Initiative for Leprosy Elimination, Strategy and Process Documentation, DANLEP 2003.

7. A Comprehensive Concept of POID

A comprehensive concept of POID (Prevention of Impairment and Deformity) needs to be developed involving all areas of leprosy control, including early detection, provision of MDT, nerve assessments, prevention of nerve function impairment, reconstructive surgery, rehabilitation, and the socio-economic situation of the patient. It is recommended that a common language is adhered to, based on the new ICIDH-2 (WHO International Classification of Impairment Disability and Handicap).

POID at the start of, and during treatment

Nerve function assessments should be performed and recorded adequately. It is acknowledged that the technical level of assessment may vary per region or country. The aim is to prevent (further) deterioration of nerve function. Motivation and personal attention by health care staff is essential. A mechanical test is of limited value if it is not followed by appropriate action. Impairment grading should be done before starting, and after completing chemotherapy. Reporting formats should ask for this information to be recorded. Field control cards in particular should be appropriate to POID.

Recent nerve function impairment and reactions should be treated with corticosteroids whenever possible. If the structure of a programme permits, and quality conditions are met, the provision of corticosteroids can be given at field level. Otherwise a referral system needs to be in place.

Health education, training of medical staff at all levels, and provision of sufficient resources are essential for the success of POID.

Referral options for specialist POID care are imperative to make an integrated leprosy control system work.

POID after treatment

In addition to comments made above, the following points were made :

Patients need to receive adequate health education so that they are empowered to

understand when and where to request care if complications due to leprosy arise after they are released from treatment with chemotherapy.

For high risk patients (e.g. those with initial highbacterial load), it is recommended to organize adequate follow-up after completing chemotherapy in order to recognize and treat nerve function impairment and leprosy reactions in time.

Management of people with established nerve function impairment and/or disability

People with lasting complications due to leprosy in the form of eye problems, ulcers, muscle paralysis, etc. should receive continued care. This is preferably provided at community level (community based rehabilitation), but referral for specialist care should also be available.

Alliances and partnerships

It is preferable that people with secondary complications due to leprosy are treated in general medical facilities whenever possible. Eye problems, for instance, can usually be dealt with adequately in general eye units or services.

Reverse integration is also possible, where leprosy treatment centres provide specialist care for non-leprosy patients. Examples of this principle are ulcer care for diabetic patients, and hand therapy for trauma victims.

Education about leprosy and leprosy complications should filter into general medical services at all levels in order to facilitate integration and partnerships.

excerpt from Smith, W.C.S.(1999).“International Leprosy Congress, Beijing, 7-12 September 1998. Workshop Reports” Leprosy Review 70(1):82-83.

8. Social Aspects and Rehabilitation

Major Issues

1. Equal rights and opportunities for people affected with leprosy to develop their full potentials is a matter of human rights.

2. Leprosy and its consequences are a complex human problem leading to discriminations, stigma and prejudices.

3. There is lack of complete understanding about global needs for rehabilitation.

4. Concentration on medical care of people affected with leprosy (MDT, surgery, etc.), though vastly beneficial, has led to highly inadequate psycho-socio-economic rehabilitation in a holistic manner resulting in poor quality of life.

5. People affected with leprosy have not been full partners and decision makers for their own development and lack self-confidence and opportunities for self-expression.

6. Community and health providers lack the right attitude and sensitivity, thus failing to assist in the empowerment of people affected with leprosy in an integrated manner.

7. There is insufficient coordination at international/NGOs/government levels to utilize scarce resources to allow full development of people affected with leprosy.

RECOMMENDATIONS

1. **Estimation of global needs:** using existing tools with necessary modifications, need assessment and relevant interventions in rehabilitation at global/national/field levels requires urgent attention to enable all concerned to take specific actions recognizing that not all require rehabilitation.

2. **Change in perceptions and attitudes:** using mass media and other tools like training, counselling, etc., changes in behaviour resulting in positive attitudes of communities, patients, their families and health providers are of paramount importance to ensure social amalgamation and reduction of stigma/prejudices.

3. **Empowerment:** provide information, education skills, resources and motivate people affected with leprosy to empower them to lead a dignified, self-reliant quality of life and achieve their full potential with access to equal opportunities.

4. **Community based rehabilitation:** CBR with modifications is appropriate in most of developing countries to provide sustainable self-employment and self-dependent living requiring simple skills and focusing on women who are excellent agents of change.

5. **Community action:** increase community awareness through use of better communications: field-based training and counselling to mobilize community support and participation in practical help to help people affected with leprosy in their social acceptance and rehabilitation.

6. **Referral and support services:** CBR will be successful provided diversified individual needs are met covering physical, medical and rehabilitative areas (but should avoid excessive institutional care) through referral and support services.

7. **Discriminatory legislation:** all discriminatory legislation must be repealed in countries/states where it exists. Appropriate terminology in relation to people affected with leprosy must be developed with their full consent.

8. **Multi-sectorial approach:** comprehensive rehabilitation with socio-economic emphasis is possible with involvement of relevant ministries of governments along with support of UN agencies and NGOs. The political commitment at governmental level is imperative.

9. **Non-governmental agencies:** non-governmental agencies, both at international (e.g. ILEP/ILU) and national levels (leprosy and non-leprosy) are critical in years ahead for their commitment and available resources in promoting rehabilitation. They need to strengthen their activities by acquiring well-trained rehabilitation experts and co-ordinating at field/central levels.

10. **Research:** ongoing research to find new effective and efficient rehabilitation methods, social aspect research, and market research can make significant improvements fur the future.

excerpt from Walter, C.S.(1999).“Social aspects and rehabilitation.”Leprosy Review 70(1):85-94.

9. Rehabilitation of Leprosy-Affected Persons

Planning for Rehabilitation

The immediate need is reliable information on practically all aspects of the rehabilitation of leprosy – affected – cured persons for any given area. For this purpose it is probably best to take the district as a unit. We will need to have the following kind of information:

1. **Deformity profile :**
   - Distribution of sites of loss of sensibility
   - Nature of visible impairments, State of eyes and;
   - Presence of ulcers and scars in the feet of the subjects.
2. **Demographic data** on the leprosy – affected – cured persons including
   - Their family details
   - Mode of subsistence and Sources of income.
3. **Information** about affected individuals and their families on:
   Means of assessing;
   - their overall socio-economic status and "dyshabilitation status" (or participation limitation status);
   - determining their "rehabilitation potentials" as per their perceived needs;
   - the physical consequences of the disease (such as, severity of impairments and nature of activity restriction);
   - their activities of daily life (mainly their occupation).
4. Identify and evaluate availability and usefulness of the **rehabilitation resources** in the immediate neighbourhood and in the district.
5. **Corrective Surgery :**
   - Assessment of the fitness and willingness for corrective surgery of the visibly impaired individuals.
   - Active disability prevention programme will progress when the corrective surgery and rehabilitation programme is initiated.
6. The rehabilitation project should be **well planned, a time-bound and target-oriented** programme and should also **cover the "unrehabilitable"** to ensure a minimum level of economic security, including food security for this group.

7. Simultaneously a semi-permanent, extensive and initially intensive social awakening programme, using all available strategies and resources, to ensure restoration of normal social identities of disabled persons in general and leprosy-affected persons – irrespective of their disabilities – in particular, and expanding their level of inclusion in society, should be carried out to touch all levels of the society.

Rehabilitation activities will have to address three different issues, namely;

(1) impoverishment of the affected individual and his/her family,

(2) activity limitations of affected persons and;

(3) participation restriction involving the affected persons and their families.

abridged from "Rehabilitation of Leprosy-Affected Persons"- Dr. H.Srinivasan in Indian Journal of Leprosy : April-June 2003

Box : 5

Nerve damage sets leprosy apart from other diseases

- Nerve damage and the consequences of nerve damage set leprosy apart from other diseases. The irreversible motor and sensory impairments caused by leprosy lead to increasing secondary impairments long after the disease process has been arrested. Interventions that prevent, reverse or limit the impairments resulting from leprosy are, therefore, of the highest priority.

- Self-care has been demonstrated to be an effective means of preventing secondary tissue damage, and its implementation must now be encouraged within the framework of basic health care.

- Currently, a comprehensive effort has been made to address all dimensions of impairment of nerve function and its consequences, from prevention of both primary and secondary impairments to interventions in long-term nerve damage.

excerpt from Smith, W.C.(2000)."Review of current research in the prevention of nerve damage in Leprosy." Leprosy Review 71(Suppl):S138-44; discussion S145.

10. BBC World Service Trust Leprosy Campaign

The BBC World Service Trust (BBC WST) is an independent NGO within the BBC World Service, established in 1999 to promote development through the innovative use of the media. The Trust currently works in 23 countries, tackling health, education and good governance issues.

The Health Unit of the BBC WST works in partnership with local and national media to implement health promotion campaigns. The Health Unit has conducted more than 20 large-scale health campaigns in 15 countries, focusing largely on leprosy, trachoma and HIV/AIDS.

In September 1999, the BBC WST, in partnership with Doordarshan TV and All-India Radio, launched a 16 month leprosy campaign in the 5 most endemic states of India. Uttar Pradesh, Madhya Pradesh, Orissa, Bihar and West Bengal. The campaign funded by the Department for International Development (UK) was designed to encourage those with leprosy to report for treatment and to reduce stigma toward those with leprosy.

The campaign consisted of 50 TV programmes and 213 radio programmes, produced in 21 languages/dialects. These were broadcast some 800 times on TV and 6000 times on radio. In remote areas, the campaign comprised 1727 live drama shows, 2746 video-van screenings and 3670 public events or competitions.

A longitudinal panel study was undertaken in November 1999. March 2000 and September 2000 to measure changes in knowledge, attitudes and practices (KAP) in the target population. The radio and TV spots were seen by 59% of the total population (467m people) of the 5 states, i.e. 275m people. The impact on stigma was dramatic the proportion of the total population believing leprosy is hereditary fell from 56% to 32% (after Phase 1) to 19% (after Phase 2). This means some 172m people changed their attitudes on this issue over the 12 month period. The percentage of people believing leprosy is communicable disease fell from 52% to 37% to 27%. The proportion who claimed they would not sit next to a leprosy patient fell from 47% to 33% to 27%. The percentage who claimed they would eat food prepared by a leprosy patient rose from 32% to 43% to 50%. The proportion who believes that leprosy is caused by bad deeds in a previous life fell from 37% to 29% to 12%.

A follow-up longitudinal study was carried out in June 2003 to measure the sustainability of the campaign. The results of the sustainability study indicate the following three conclusions regarding long-term impact. First, nearly half the respondents with access to TV and over a third with access to radio recalled TV and radio sports respectively (when prompted) 2 ½ years after the campaign finished. Second, those exposed to the campaign demonstrated higher levels of awareness of the symptoms and causes of leprosy in comparison to those unexposed. Third, there were no appreciable differences in the majority of impact indicators with regard to BBC WST spots that were aired 2 ½ years back and those that continued to be telecast until 1 ½ years ago.

From the Executive Summary by : Lori McDougall, BBC World Service Trust, January 2004.

Box : 6

Central Purpose of Mass Communication

The central purpose of mass communication should be to give leprosy a new image :

- create awareness about leprosy - its symptoms, infectivity, curability;
- remove misconceptions,
- explode irrational myths and stigma,
- generate a more leprosy friendly environment and demand for leprosy services.

The purpose of IEC should be :

- to educate the community including the policy-maker the medical profession, the lay public, as well as the leprosy affected individual and family in the true facts about leprosy;
- to discourage discrimination against the leprosy affected and their displacement from their homes, jobs, residential areas, schools, marriage, etc;
- to encourage and ensure the leprosy affected person's self-acceptance and acceptance in the family and the community;
- to spread awareness about early signs and symptoms of leprosy and treatment and rehabilitation facilities.

"Rehabilitation in Leprosy" by Dr. S. D. Gokhale (Chairman ILU, Pune) and Neera K. Sohoni (Consultant, ILU, Pune) in Human Face Of Leprosy

11. Peoples' Participation in Leprosy Elimination

There are different ways and methods in which people can participate in the Leprosy elimination programmes.

- Leprosy Patients come from all the walks of life and are found in all the strata of the society. Leprosy must be everyone's concern. The master key of the problem lies in the health educational aspect of it. Communication skills play a vital role in these health education programmes.

- As a good salesman the health functionary has to sell the idea that Leprosy is curable. Effective health education programmes give knowledge to the people and change their attitude and behaviour for good. This musters peoples' participation to a great extent.

- All types of media are to be involved depending upon the requirement of the local people. However, word of mouth has no alternative. Print media are useful among literate people and radio, TV, films etc. will be effective among illiterate people.

- Health education should be undertaken by all cadres of workers in such a way that good public opinions are created.

- Health education helps in case detection, case holding, and drug compliance (regularity of treatment) prevention of dehabilitation and in actual rehabilitation.

Mere progress in the technology will not help eliminate the problem. The people at large will have to be alerted to feel the importance of the problem and to take initiatives to solve them with their own resources. For this to happen, a trilogue between the patients, providers and people is necessary.

('Anubhav' : Experiences in Health and Community Development (January 03), Voluntary Health Association of India)

II. Special Campaigns : Initiated by Govt. of Maharashtra

Jt. Director of Health Services (Leprosy) MS

12. Urban Leprosy Elimination Project

- Formation of Urban Leprosy Elimination Committee under Chairmanship of Commissioner Municipal Corporation.
- Memorandum of Understanding (MOU) to be signed between DLO and MOH.
- Case detection and treatment by Municipal Corporation / Gen. Hosp. / Pvt. Hosp.

Activities to be undertaken

- LEC for slum-area.
- Special IEC drive in low PR area with the help of GHCs and NLEP staff (VRC approach).
- Rapid Survey in high PR area with the help of NGO (SET pattern).
- Validation of 100% Cases by MO SULU, DTST.
- Cleaning of Registers.
- MDT Stock as per revised guidelines of GOI.
- Sensitization of Private Practitioners.

13. Block Leprosy Awareness Campaign (BLAC) in Identified High Endemic Blocks

Jt. Director of Health Services (Leprosy) MS

BLAC will be implemented in high endemic blocks (PR>5) of districts with high and medium PR.

BLAC should not be treated as another MLEC.

Objective : The special Block leprosy awareness campaign through Inter-personal Communication (IPC) approach will have the following objective.

i) To carry out intensive awareness campaign about leprosy involving community.

ii) To provide leprosy service extended from PHC to the sub centres for 2 days for people who wish to avail the facility nearer to their home.

Strategy of Campaign

- Leprosy Awareness Drive : 15 days intensive IEC through IPC and Mike announcement regarding. i) Leprosy disease and cure; ii) Availability of free MDT; iii) Dates of Leprosy Diagnosis Counseling Centres at nearest sub-centres.

14. Orientation of Medical College Faculty, Students and Interns in NLEP

Jt. Director of Health Services (Leprosy) MS

It has been observed that newly appointed medical officers in the state services do not have sufficient knowledge and skills to adequately contribute to the task of Leprosy Elimination. This has an adverse impact on the programme and scores of deficiencies are observed at primary health centre level.

Under the Directorate of Health Services, training programmes are being organized to properly orient them in the necessary knowledge and skills required under all national health programmes including NLEP.

However, the schedule of training is many times delayed. The district authorities have been instructed to organize at least a day's training for the new entrants immediately on recruitment. But to nip the problem in the bud, it is necessary to ensure that the faculties as well as students from medical colleges are oriented to the new concepts in Leprosy Elimination.

WHO and GOI also stress that every doctor, under-graduate or intern should have an update knowledge about leprosy elimination and MDT.

Under the above background, the Director, Medical Education & Research was approached by the Joint Director Health Services (Leprosy) Pune to organize 3 hours' Orientation Training in Leprosy Elimination at all the medical colleges of the state in collaboration with NGLOs. It is heartening to note that there was an immediate response by the D M E R through his instructions to all the Deans of Govt. Medical Colleges vide his letter no. Leprosy/Training/7-A dated 21/9/2004. Deans of the Govt. medical colleges under the State are being contacted and the orientation course will be organized after finalization of dates in the month of Oct. 04 accordingly.

The orientation sessions shall include the following aspects of leprosy :

1) Details of NLEP with recent modifications & important definitions including record keeping.
2) History in brief.
3) Leprosy trends & statistics - World, India, Maharashtra.
4) Epidemiology in brief, classification, clinical briefs with demonstration of cases.
5) Management of cases including reactions.
6) MDT stock management.
7) Disability prevention & Rehabilitation.
8) Integration and progress towards elimination.
9) Questions & answers.

Brief notes developed by Joint Director of Health Services (Leprosy) Pune with assistance from ALERT-INDIA shall be distributed to all the participants. ALERT-INDIA has kindly consented to support the above orientation sessions with necessary audio-visual equipments.

Dr.S.C.Gupta
Joint Director of Health Services (Leprosy) Pune

15. Leprosy Counselling Centres (L C C)

Jt. Director of Health Services (Leprosy) MS

i) Formation of LCC at every sub-center for consecutive 2 days.
ii) LCC manned by 5 persons viz. MO / Senior NMS, HS, MPW (F), MPW (M) and 1 village volunteer.
iii) LCC will attend cases under treatment, validate recent cases, counsel defaulter case for better case management and POD.
iv) MO / Senior NMS, HS will attend the persons reporting the centres, keep record, provide counseling and start treatment.
v) MPW (M & F) and volunteer will move house to house and motivate the people with suspected skin lesion, patients whether regular or irregular in taking MDT to report to the centres for diagnosis, reassessment and counseling.

Important Activities

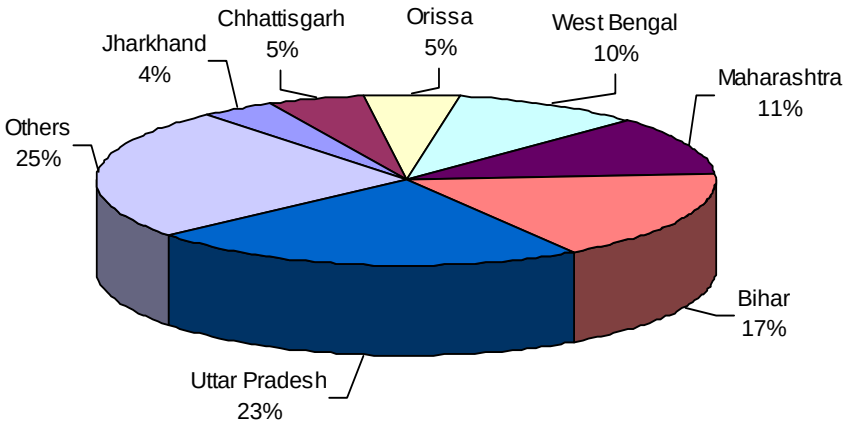
- Validation of 100% New Cases Detected. • Management of MDT stock at District HO and peripheral level. • Guidelines regarding cleaning of registers should be strictly followed. • Timely RFT of patients. • Records and registers of leprosy to be maintained by General Health Care Staff.
- Implement remaining POD Camps.

Box : 7

Disease burden as on 31st March 2004

A total of 3.45 lakh cases are on record as on 1st April 2003, thereby making the prevalence rate (PR) of only 3.23 leprosy cases per 10,000 population. The national PR in March 1981 was 57.6 leprosy cases per 10,000 population while the PR on March 2002 was 4.2 per 10,000 population and on March, 04 was 2.44.

PERCENTAGE OF CONTRIBUTION OF ACTIVE CASES OF 7 STATES AS ON 31ST MARCH, 2004



Central Leprosy Division, Directorate General of Health Services, Nirman Bhavan, New Delhi - 110011.

Geographical Distribution	Registered Cases			Prevalence Rate (per 10,000 population)		
	1981-82	2002-03	2003-04	1981-82	2002-03	2003-04
WORLD	12 million (1985)	5,23,605	4,41,992	N.A.	0.8	N.A.
INDIA	39,53,700	3,45,189	2,65,781	57.7	3.23	2.44
MAHARASHTRA	3,12,871	29,680	29,497	62.4	2.95	2.87
MUMBAI	43,892	2,402	1,838	60	2	1.5

III. LEAP : Tasks Ahead - 2005 and beyond

16. NGLOs' Role : During the Process of Integration and Thereafter

Dr. V. V. Dongre, Hon. Secretary, The Society for the Eradication of Leprosy, Mumbai

(Presented on the occasion of ALH RRE Society's 34th Foundation Day on 9th June, 2004)

"Inauguration of a Leprosy Hospital is not a big thing, I will come to close it", so said the MAHATMA**.** These words echo our feelings and spirit in the process of Integration.

A. Concept of Integration as Compiled from Different Central and State Governments' Documents :

e.g. Reports / circulars of

1. Swaminathan committee, Gavai committee, Workshops at New Delhi, JDHS Leprosy (MS) and EHO-MCGM, International Leprosy Conferences.
2. Integration means to merge together or to bring together to make one like interwoven fabric.
3. During and after integration there is still lot of anti - Leprosy Work for the NGLOs.

B. Milestones of Leprosy Programme in India :

- 1955 - National Leprosy Control Programme (NLCP)
- 1980 - Political "will" for eradication of leprosy by 2000 A.D.
- 1981 - Introduction of MDT
- 1982 - NLCP re-designated as National Leprosy Eradication Programme (NLEP)

- 1994 - Concept of elimination
- ***Elimination : Less than 1 case in 10,000 population.***
- ***Eradication : Zero number of cases at any given time in any area.***

C. Necessity for Integration :

1. Eliminating Centres exclusive for leprosy treatment will minimize social stigma attached to leprosy.
2. Integration will lessen the stigma and will help social acceptance of the patients.
3. It is cost effective.
4. There will be more population coverage and making services more accessible.
5. There will be more comprehensive care of the leprosy patients.
6. Decreased prevalence and less number of deformed patients of leprosy will lead to normalisation and social assimilation of lives of leprosy patients.

D. Synergy of NGLO with Stake-Holders (Patients, Providers and People) :

There will be a joint action by all the stake-holders in the Integration process for leprosy elimination. **Initial steps :**

1. Training & capacity building of staff of GHS will be undertaken. They will suspect and make diagnosis of obvious cases of leprosy.

Box : 8

Fear and social prejudices still conspire

Indira Gandhi gave a boost to Leprosy Work. In her address to the World Health Assembly in May 1981, Mrs Gandhi said,

"In India, we have undertaken a national campaign against Leprosy, but fear and social prejudices still conspire to prevent large number of patients from seeking treatment. In this, the time is an all-important factor. The disease must be permanently consigned to the limbo of history".

HEALTH FOR THE MILLIONS, January-February 2001

Their leprosy consciousness will be enhanced.

2. Transfer of knowledge & skill about leprosy elimination will take place.
3. Validation of new cases and "cleaning of registers" will improve the quality.
4. NGLOs will co-ordinate, monitor the work done by GHS with close rapport.

- The following activities are expected to be taught by NGLO to health post staff who in turn will carry on the same in the day to day work.

5. Multi - Drug - Treatment.
6. Self care for insensitive limbs, eyes and nose.
7. Dressings of wounds and vegetable oil massage to fingers and toes along with simple exercises of the fingers and eyes.
8. Treatment of lepra reactions and neuritis.
9. Counselling of patients, their family members for regularity of treatment etc.
10. Simplified Information System (SIS) will motivate the GHC staff to report the local PR.
11. Indent and maintenance of stock of drugs.
12. Submission of monthly and annual reports of activities to the Municipal Corporation.

E. Functions of NGLO After Integration :

1. Inter-Personal Communication (IPC) and IEC (Information - Education - Communication) activities with the help of NCC, NSS, Scouts, School children and women groups.
2. Awareness to be created about leprosy in the community with the help of literature, posters as per local language and culture.
3. Involvement of the mass media for the same.
4. Continuing Medical Education (CME) of General Medical Practitioners (GMPs).
5. The medical students to be involved in the leprosy elimination programmes.
6. Hidden cases to be detected by focal surveys as well as by specially surveying hard to reach population including migrants, floaters, slum dwellers, fishermen and high income group people.
7. School surveys to be undertaken during rainy season.

8. Survey of family contacts of leprosy patients to be undertaken.
9. Skin Smear, Biopsies, Electro Myography (EMG) studies to be undertaken for cases that are difficult for diagnosis.
10. Simple measures to achieve POD and POWD : such as physiotherapy exercises, self care to be taught. Provision of MCR footwear, Crutches, Goggles, Splints for all deformed patients.
11. Complicated cases of re-current lepra reactions, neuritis, trophic ulcers to be treated.
12. Surveillance of RFT (Released From Treatment) cases to be undertaken.
13. Deserving cases to be referred for Re-Constructive Surgery (RCS).
14. Socio-Economic Rehabilitation (SER) and Community Based Rehabilitation (CBR) to be undertaken.
15. Welfare schemes to be extended and self help groups of patients to be created.
16. Treatment defaulters to be retrieved.
17. Gender issues to be given more attention.
18. Referral centres to be created for due consultation.
19. Help to maintain central registry.
20. Linkages to be established with the service clubs for financial help to the leprosy patients.
21. To correct the legal discords, advocacy will have to be done, on behalf of leprosy patients with the law givers.

POD : Prevention Of Deformity; **POWD :** Prevention Of Worsoning of Deformity;
MCR : Micro-Cellular Rubber (protective foot-wear for insensitive foot)

Box : 9

Why Leprosy should have a stigma?

- "The word 'leper' has a bad odour".
- "Why Leprosy should have a stigma?"
- "Opening a Leprosy hospital is not a big thing. I will come to close it".
- "Leprosy work is not merely medical relief, it is transforming the frustration in life to the joy of dedication; personal ambition into selfless service".

Mahatma

F. Important issues for successful integration :

1. Leprosy consciousness or leprosy mindedness will have to be enhanced in the stakeholders, so that suspects will be referred to the nearby health centre.

2. A leprosy patient will not be made to run from pillar to post for diagnosis and treatment.

3. Atmosphere at the treatment centres should be patients' - friendly.

4. Innovative non-survey techniques will have to be evolved.

5. A repeated trilogue between people, providers and patients will have to be created which should be backed up by political "will".

6. Successful integration will change quality of life of leprosy patients for good.

7. Leprosy patients should become partners of national progress.

8. A feeling of "with the patients" will have to be created instead of "for the patients", amongst the workers.

9. For amelioration of physical, mental, social, financial sufferings of leprosy patients, a joint action by NGLOs with Govt. Organisations, Para Govt. Organisations (Zilla Parishad, Mun. Corpn.) Non Govt. Health Organisations and Non Govt. Non Health Organisations (Multi- Sectoral) will have to be undertaken.

10. This will help elimination of leprosy and social assimilation of leprosy patients in the mainstream of the Society.

11. Convergence and confluence of common interest of leprosy elimination of the stakeholders will go a long way towards leprosy eradication.

17. L E A P :
Leprosy Elimination Action Programme

by ALERT-INDIA

These proposals are aimed at developing a leprosy-affected persons'-centric and community-oriented strategy and an action programme during integration phase. These proposals are released for the perusal of all willing partners.

A. LEAP : Leprosy Elimination Action Programme :

"LEAP" is a strategy for joint action in the making. Primary objective is to facilitate the integration process with the community-based approach, in the interest of leprosy - affected persons.

B. "LEAP" is a programme aimed …

1. **To evolve a leprosy-affected persons'- centric and community-oriented strategy and an action programme that would facilitate the changeover from vertical system to an integrated system.**

   Continuity of service to the leprosy - affected persons in this transition is the prime concern. Programme is aimed to respond with positive interventions needed to strengthen the process of integration.

2. **To formulate guidelines for action for "vertical NLEP staff" (doctors/ paramedicals) to actualise the goals of integration.**

   The different levels of expertise and specialisation available today with 'vertical staff' can adequately be reoriented to take up the tasks needed for actualisation of objectives of LEAP. This is an advantage, which needs to be utilised to realise the goals of integration.

3. **To develop a feasible, replicable alternative methodology to strengthen integration and to sustain the chain of leprosy care services in collaboration with the multiple partners (Leprosy NGOs/Health NGOs/CBOs).**

   Such an effort alone can pave way for a long-term sustained strategy for work to achieve the target of elimination.

4. **To help the public health personnel by direct & indirect supportive actions and programmes to detect, treat and cure leprosy on par with other diseases in the general health system.**

Offering practical (technical) help in diagnosis, treatment, follow-up and care of leprosy-affected persons. This is the only way to strengthen integration.

5. **To bring together leprosy NGOs and other partners to define collectively the future strategy and work independently for a common purpose.**
   Pooling of strengths and resources will definitely make a difference in the present context.

6. **To arrive at a common plan of action with all willing partners who are ready to implement programme at the community level.**
   Take up tasks (relevant activities) for the benefit of leprosy-afflicted persons that can directly or indirectly promote integration.

C. Proposals for Action :

1. **Adequate training of Full Time Medical Officers (FTMOs), HP staff and Medical Officers (MOs) – (Dispensaries of Municipal Corporations) – in Mumbai,** at Acworth Municipal Hospital for Leprosy (AMHL) – a short certificate course, with expertise drawn from different units – following the training need assessment, in addition to adequate induction on new SIS.

   Official certification will provide recognition and help in the capacity building exercise. This is the need of the hour.

2. **Special orientation cum training of CHWs (Community-based Health Workers) attached to HPs of the corporation/s and NGOs on their role.** Enhancing the knowledge, awareness and skill of health workers and other such functionaries at the local community level is essential for reporting leprosy cases at an early stage. A sustained effort will result in greater number of referrals to HP / PHC.

   It is a pre-requisite to effect a long-term impact – a crucial task, but difficult to achieve, needs to be done. Diverse approaches and strategies need to be adopted to make this possible.

3. **Establishing reliable specialised / referral centres / services for diagnosis of difficult cases, management of recurrent and difficult to manage lepra reactions ('recalcitrant lepra reactions'); disability / deformity**

prevention (POID); care after cure and SER activities at regional / zonal levels managed either by NGOs or Medical colleges (Dermatology Depts.) or Hospitals.

The referral centres can also impart practical training to medical officers in treating lepra reactions and other such episodes that occur during the course of leprosy.

Addition of this important component to the integration plan will help in transfer of skill and expertise gained over decades to a young generation of medical fraternity in public health.

4. **Strengthening and updating the knowledge and skills through Continuing Medical Education (CME).** Medical colleges and others can offer specialised guidance and practical training to private medical practitioners and the public health medical personnel from various specialities. Such an effort helps develop application of their specialities in service of the leprosy patient who needs care.

   - Leprosy is one of the new additions to the public health programme (HP / Municipal Dispensary) – hence the necessary knowledge and skills required for diagnosing the disease, specially in dealing with lepra reactions and early neuritis, may not exist. Public health doctors can suspect leprosy and treat it, provided continued education, interaction and exchange of knowledge between the periphery level and the specialised centers is planned and achieved.

5. **Develop and Sustain Specialised Care and Support Services to**

   - Treat complications that occur among patients with leprosy - impairment of sensation in the hands, feet or eyes. These often lead to disability and handicap.
   - Provide disability management to prevent worsening of disability through well-guided self-care practice and use of appropriate aids and appliances that can help leprosy-affected persons lead a normal life.
   - Provide facilities or refer patients to established centres for restoration of functional ability through corrective surgery to enable the leprosy-affected persons to get on with activities of daily life.
   - Help develop exchange programmes with public health facilities like physiotherapy and surgical units in public hospitals to train equip the specialist with requisite experience in disability management.

6. **Establish a Central Registry to monitor and document the progress. Epidemiological surveillance - unit to study the impact and analysis of interventions under "LEAP". This is essential to know the ground reality.**

Periodic feedback and analysis of the impact will also help to formulate, make necessary changes in the strategies for leprosy elimination in future.

Box : 10

REFERRAL SLIP – a tool for transfer of knowledge !

The vertical Leprosy Control Programme is now integrated into the General Health Services (GHS). So far, it is the NGLOs / SULUs that have been identifying and treating leprosy patients in the community. With integration in Mumbai (from 1st July 2004), the diagnosis and treatment will be the responsibility of the GHS, i.e. the MOs at Municipal dispensaries, Health Posts (HP) and Hospitals.

At this stage, our inputs are necessary for the staff of the GHS to carry out leprosy treatment effectively. NGLOs are called to play a supportive role and provide all assistance.

The Referral Slip (RS) is to be considered as a tool for education, transfer of knowledge and expertise. Regular briefing of the diagnostic details of the cases who come to our Referral Centres, give us an opportunity to share our knowledge and experience with public health doctors and other functionaries.

This provides simple linkage between the referral centres and the proposed treatment centres for the patients.

When the patient reaches the HP/PHC seeking MDT, the RS will provide all essential information to the MOs and other health staff that can facilitate a "hands on experience" in leprosy diagnosis and treatment. Further, detailed information about the diagnosis and the recommended treatment and other notes will help in follow-up of the patient by HP staff.

A duplicate of the RS is to be kept at the NGLO / SULU for record and follow-up of patients to the extent possible. Follow-up of MB cases by the NGLOs / HP staff is recommended.

(To be used by NLEP institutions to refer new cases to GHS doctors.)

7. Selective Special Drives (SSDs) in specially selected pockets – such as HPs with high prevalence and other such relevant criteria under the leadership of reoriented PMWs and NMS of NLEP institutions.

Recent experiences prove this to be very effective in unearthing new cases in the community.

The strategy is to select, train and engage CVs, CBOs and CHWs as leprosy campaigners. CBOs, CHWs and CVs will continue to be the guides and spokesmen in the community, even after the special campaigns. They will form the nucleus for a long-term community awareness needed to promote voluntary reporting.

8. Targeted Special Drives (TSDs)

Humans are the only reservoir of the leprosy infection. The multiplicity of human migration throws challenges in containing the spread of leprosy. Any effort to take care of the stable population, urban or rural, cannot alone solve the problem. Elimination requires specialised strategies to tackle the various migratory populations in cities and towns. Considering that people migrate for various social, economic and personal reasons.

To mange this massive phenomenon effectively, a multi dimensional planned approach is required. The mainstay of such a strategy would be to track the location/s from where the infected person has originated. Further, methods of reaching out to the affected in the identified locale (family, village, *basti*, construction site, industrial unit, brick kiln, etc).

9. Joint LEC campaigns at community level by specially trained teams of community-based volunteers (CVs) to promote voluntary reporting – covering all regions, with special focus on slum communities.

With special re-orientation and training of community-based volunteers (CVs) can do a better job - under the leadership of re-oriented PMWs of the NGLOs and SULUs of the GOM in Greater Mumbai. Special emphasis on IEC methods, tools that are relevent to specific socio-economic and cultural context of specific community group will be an essential component of LECs.

Community awareness is the pivot of voluntary reporting, which is the pivot for successful integration.

D. Plan of Action to launch "LEAP"

Preparatory Phase : January 04 – December 04

1. "LEAP" to start pilot projects in different locations and organisational / institutional settings based on the proposed action plan to gain an adequate understanding of the requirements for launching a long term programme.
2. To record and validate the approaches, difficulties in implementation, shortcomings and results achieved in actualising the objectives set for each action under "LEAP" programme.
3. To review and record the progress in order to gain inputs to finalise a strategic plan - phase wise : **Phase I : 2005 – 07 (3 Years) (Annual Reviews); Mid-Term Review (External); Phase II : 2008 – 10 (3 Years) (Annual Reviews).**
4. Formulating, finalising the methodology, guidelines and develop an operational manual for each action project under "LEAP" is one of the main objectives of this draft proposals.
5. Create a decentralised structure for an effective working of multiple partners guided by a common vision. (It can be a federal set up with operational, administrative independence keeping intact the individual identities of projects/units).
6. Establish, develop an appropriate nucleus as "Nodal Agency" or a mother NGO or any other appropriate structure or framework to coordinate and monitor different projects and with all willing partners who join "LEAP". **"LEAP"** is the common programme of action proposed - it needs a common organisational context. This is essential to plan to execute a long term collaboration with the multiple partners under a common programme (2005 - 2010).

Finance for a larger, long-term plan from 2005 to be raised, disbursed and monitored from one point. This is crucial to sustain a large programme with multiple interventions and partners.

A Vision document and a Strategic Plan for Leprosy Elimination are proposed to be released by **11th October, 2004.**

Let us work together to make leprosy elimination a reality !

18. Selective Special Drives (S S D)
an outline

A Proposal for community-based action programme

A. Integration of leprosy into General Health Services : guidelines

- World Health Organization (WHO) has set the goal of 'Elimination of Leprosy' by December 2005. The goal is to reach a Prevalence Rate (PR) of one case per 10,000 population.

- As per GOI's instructions it is necessary to ensure integration of the vertical programme of Leprosy Control with general health services and move towards elimination of Leprosy.

- Integration means that all the anti-Leprosy activities will be carried out by the public health facilities like Government, Municipal Hospitals, Health Posts and Dispensaries on par with other diseases.

- Integration of leprosy with the general health should be everywhere and this integration should be sustainable.

"All the health facilities including the Government and private sector should be able to manage leprosy-diagnosis, management and treatment of complications i.e. Leprosy should no longer be a special disease, treated at special centres but it should merge with the existing health infrastructure."

(Director General of Health Services, Nirman Bhavan, New Delhi : 30th April 2003 : No.T-16011/6/2002 – Lep. Coordn.)

The vertical leprosy programme with SET methodology under NLEP is no longer needed in the event of reaching the goal of elimination. It does not make social or economic sense. NLEP should become horizontal programme like all other public health programmes.

B. Integration is aimed to achieve the following results :

(a) "Isolated" special vertical programme is one of the causes of the social stigma attached to leprosy. Integration will lessen the stigma and will help social acceptance of the patients. Successful integration will change the lives of leprosy patients.

(b) Since the general Public Health service personnel will undertake diagnosis and treat leprosy, leprosy patients need not run from pillar to post. Public health personnel and facilities will be equipped to provide comprehensive health care to the leprosy sufferers.

(c) Involvement of general health services will result in a larger population coverage and availability of anti-leprosy treatment.

C. Directives for action :

(i) "Recognizing the urgency of the situation in view of the approaching target date of December 2005, (the National Conference) urges the National and State programme - to develop strategies in collaboration with all stake-holders to identify and focus on specific geographic areas or populations of high endemicity and ensure that more intensified, decentralized, time bound plans are developed and implemented on an urgent basis."

("Raipur Declaration" - National Conference on Elimination of Leprosy, 27th to 30th January 04.)

(ii) **"Withdraw finally from (vertical) clinics and undertake :**

- special drives for detecting hidden cases in endemic and high risk pockets.
- Special attention on migratory population, work sites, slums, labour populations at brick works, building sites etc.
- and awareness generation and involvement of school children."

(Jt. DHS - Lep. - Pune : 11/02/2004 : D102/2604-743/2004)

(iii) "It is expected from GHS staff in NLEP that in order to conduct New Case Detection, the entire Health Post population should be surveyed once a year to update records. At the same time the School surveys should be conducted from June to September."

(ADHS - Leprosy - MUMBAI : 15th July 2004 : 483-495/04)

D. Selective Special Drive (SSD) :

Keeping in mind the above directives, Special Drives could be conducted for detecting hidden cases of leprosy in any geographical area or any segment of population, carefully SELECTED based on certain relevant, definite criteria, that suggests the possibility of finding new leprosy cases.

To strengthen Integration and to move towards elimination a joint action by all the stakeholders, namely public health functionaries, NGOs, Community Based Organisations, and the community is needed.

1. Objectives :

(1) to detect all hidden cases, 'detecting patients who for various reasons have not yet been detected' through community awareness and participation.

(2) to confirm disease burden (PR) in a given geographical location in the city, town or district based on specific selection criteria.

(3) to promote community awareness through involvement of CBOs and community groups in community level campaigns that will result in voluntary reporting.

(4) to undertake capacity building of local health care staff in general health care system, voluntary sector and community groups to promote community level referrals of new cases and strengthen integration.

2. Rationale :

Selective Special Drives are an important tool to detect new and hidden cases in the community, for several reasons;

(1) The long incubation period of leprosy will bring forth new cases wherever the chain of infection continues.

(2) Following integration, public health personnel will not be taking up active case detection activities but will totally rely on voluntary reporting and referrals. Late detection of cases, specially cases of significance (MB cases and cases with nerve involvement and deformities) need to be identified and treated for epidemiological and social reasons and for their consequences.

(3) Trouble free nature of the disease coupled with ignorance of early signs and symptoms augment the possibilities of late detection and deformity.

3. Strategies :

The SSD Strategy will include;

(1) **Training and Involving** Community-based Volunteers (CVs), community based - health workers (CHWs) as community level spokesmen for leprosy from **different segments** of the society.

(2) **Educating and Leprosy Elimination Campaigning** in local communities to create leprosy awareness for voluntary reporting of leprosy.

(3) Careful **search for new cases/hidden cases** among segments / groups in selected pockets in a city/town where there is a reason to anticipate hidden new cases.

4. Details :

(1)
- Selection / identification of a cluster or an area;
- a specific socio-cultural economic group or a segment of population in a given area for SSD is the crucial first task.
- Selection should be based on valid reasoning and justification.

(2) **Additional factors that can help in selecting an area :**
- The location chosen for SSD in a city / town may be a slum or a cluster in it;
- EWS / LIG (Economically Weaker Section / Low Income Group) colony or a sector in it;
- village/s surrounding the city / town or a school / college within the municipal limits of a corporation.
- Public health authorities of the respective locality to be informed and involved to the extent possible in the drive.
- The geographical municipal boundaries need to be ascertained for the purpose of referring suspected / detected patients.
- The reference point should be one or several specific public health facilities in the vicinity.
- A public health facility where MDT is available must be the reference; which can be a Government / Municipal Hospital, Health Post and Dispensary where MDT is available.
- The public to be given specific information about the same during SSDs.

(3) **Involving and Training local CVs :**

- The SSDs are to be undertaken by carefully selected and oriented CVs (Community-based Volunteers).
- The selection, orientation and implementation of the drive should always be under the guidance, training and direction of experienced leprosy workers available today.
- Volunteers from the local community or CHWs (Community-based Health Workers) from the Health Posts, NGOs, (Community Based Organisations (CBOs) - mahila mandals, youth / sports club members) can be trained to participate in the drive.
- All of them should get practically equipped to be a guide and spokesmen in the community even after the drive is completed.
- The same is possible with the involvement of students, scouts, guides, teachers, anganwadi workers etc. the specific module for training of CVs, CHWs, students should be followed.

(4) **Involving Community Health Workers (CHWs) in the drive :**

- SSDs can facilitate integration by involving the Health Post staff in Mumbai like metropolis, where the special community out reach programmes in the slum/EWS/LIG communities is undertaken through CHWs, as far as possible.
- The CHWs are generally women from local communities. They have a greater opportunity to detect, refer, and follow up leprosy cases from the limited number of households entrusted with them in a specific locality during various routine health drives, as a part of their duty.
- This is not an immediate possibility in several areas but a definite step towards community outreach efforts planned under LEAP, with long term impact and results.

(5) **Other components of SSD**

- SSD activities also include the activities outlined by WHO for Special Campaigns.
- The SSDs will be evaluated on the basis of indicator for evaluation proposed by WHO for 'Special Campaigns'.
- IEC will be an integral part of SSDs.

- The pilot SSDs will be undertaken based on the guidelines evolved on the basis of LEAP strategy and methodology by specially trained teams.

The programme will be piloted in Mumbai Corporation and extended to other areas with willing partners for LEAP.

Box : 11

Criteria for selection

Criteria for selection / identification of a cluster / area / specific groups or a segment of population for SSD:

These can be used with modifications based on specific assessment in a given geographic area / population group.

1. Health Post or PHC data shows a pocket having Prevalence Rate (PR) above 1/10,000 (higher PR).
2. Pockets having MB and / or smear positive cases.
3. Any area where more child cases are detected (through school surveys).
4. Clusters with new job-seekers; migrant contract workers' settlements or new slum colony or a new addition to an established slum.
5. Pockets with high number of deformed cases reported in the recent past.
6. Areas with large number of Voluntary Reporting of new leprosy cases.
7. Pockets not surveyed for past 3-5 years and with new additional population where no other Leprosy related activities have been taken up.
8. Any other relevant criteria as decided by the Health Posts / NGOs or Health Authorities.

19. Targeted Special Drives (TSD)
an outline

1. Rationale :

An important aspect of public health concern is the movement of people.

Broadly, the migration of rural folks to urban areas and of movement within different urban areas in search of livelihoods. The movement is seen in agricultural and non-agricultural sectors. The migration spans various time periods from short term casual employment to many years of migration to urban cities and towns.

Understanding large scale movement of population from one locale to another is not complete, without inclusion of movement with in rural areas. Migration of rural poor for agriculture related or EGS (Employment Guarantee Scheme) driven mobility or draught and other natural disaster driven displacement of population, seasonal employment to agriculture intensive districts (like sugarcane, cotton or rice growing belts) are also very common phenomena.

Humans are the only reservoir of the leprosy infection. In the multiplicity of human migratory patterns throw challenges in containing the spread of leprosy. Any effort to take care of the stable population, urban or rural, is inadequate to achieve elimination. Elimination requires specialised strategies to tackle the various migratory populations in cities and towns and within rural areas. Considering that people migrate for various social, economic and personal reasons.

To manage this massive phenomenon effectively, a multi-dimensional planned approach is required. The mainstay of such a strategy would be to track the location/s from where the infected person has originated. Further, to device methods of reaching out to the affected in the identified locale (family, village, *basti,* construction site, industrial unit, commercial centres, brick kiln, etc).

2. Purpose :

To fully realize the goal of leprosy elimination in the current phenomena of large scale movement of population, tracking down the sources or origin infection should be the ultimate aim of TSDs. This inturn will contribute to breaking the chain of transmission.

3. Objectives :

1. To detect all hidden cases in the operational area by identifying the migratory populations within.
2. Examination of the identified segments of the population to detect early leprosy.
3. To provide special arrangements for regular supply of MDT and other required services.
4. To trace the origin of the leprosy affected person in order to examine the local constituency/community/contacts.
5. Network with mechanism like DTST and other specialised leprosy service providers that are operative in that locality.

4. Strategies :

i. Identify clusters of migrants for new case detection.
ii. Training volunteers and program personnel on intervention among migrants.
iii. Engage / motivate educators (culturally suitable facilitator) appropriate to socio-cultural context of the affected persons in the city and their place of origin.
iv. Create an enabling environment through networking with affected group at place of work / stay and place of origin.
v. Network with Govt. and private service providers to ensure the provision of services to those affected by leprosy.
vi. Conduct operational research on the movement of migrants and leprosy.

5. Tasks :

(i) Identification of target population
(ii) Training of culturally suitable volunteers / facilitators
(iii) Training and sensitisation of GHS and other related officials.
Conduction of community based IEC Programmes
(iv) Tracing origin of infected migrant.
(v) Providing treatment.
(vi) Advocate with Dist and State govt. and private networks to ensure leprosy services to the population in the place of origin.
(vii) Establish Monitoring systems.
(viii) Documentation of the process and programme.

The program will be piloted in Mumbai and Thane Districts in the first year of LEAP.

Call of the hour

The partners who have a stake in the elimination of Leprosy - such as international agencies like WHO, Federal and State Governments, community-based organisations and those affected by Leprosy must network and understand the strengths and weaknesses of each other. During this process, we have learned several lessons that helped in redesigning not only the mission but also the methodology.

Need for a new approach

- Support early identification and voluntary referral through a systematic campaign.
- Raise awareness about the reasons for stigma and its resulting trauma to the victim.
- Be a partner with local, national and international groups.
- Update legislation and vigilant enforcement to assure the rights of those who are affected.
- Orient action to prevent disabilities and dehabilitation.
- Strengthen the family network.
- Arrange meetings of people's representatives to build political will.
- Develop training modules and kits for front-line workers.
- Undertake and support research evaluation and documentation.

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