LEAP

LEPROSY
ELIMINATION
ACTION
PROGRAMME

Evolution of LEAP Strategy

ALERT INDIA

2004-2007

LEAP Publications

Evolution of LEAP strategies

2004 - 2007

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PART ONE

ALERT-INDIA'S VISION
The Role of ALERT-INDIA as an NGO

October 11, 2004

From 'Vision 2010 : ALERT-INDIA' Silver Jubilee Commemorative Document titled "towards community partnership for leprosy elimination : 1978-2004" (Chapter 5) relased on October 11, 2004

Preface

For centuries, the scourge of Leprosy has been a huge socio-economic problem for those afflicted by it – patients and their families, and the communities prone to the disease. Leprosy then was characterized by deformity and mutilation. As identified by modern medicine through anaesthetic patches or early nerve involvement, Leprosy has proven to be a treatable and even curable through multi-drug (chemo) therapy (MDT). If the drugs are taken early, there are good chances of preventing visible deformities, which have been the root cause of the stigma attached to the disease.

With modern drugs it has been possible to launch control programmes and bring the disease to the level of treatability and curability just like with any other disease, without labeling it a public health problem.

Concerted efforts by international agencies, national governments and voluntary institutions have rendered this possible. It is therefore but natural for the government to roll back the "vertical" leprosy programme – and integrate it with the general health care services.

Since the means of transmission of the disease is not completely understood, and since the disease sometimes results in complications, it is felt that leprosy-specialising personnel in the government and in the voluntary sector will continue to have a role in leprosy-related issues.

ALERT-India, a prominent NGLO in Mumbai, has, during the last 25 years, shown sensitivity in dealing with leprosy not merely as a vertical issue but also in attempting to merge it with other urban-related health issues. . Great emphasis has been placed on involving community health volunteers attached to the health posts of the Municipal Corporation of Greater Mumbai.

It is therefore desirable that the 25 years of experience should project the phases after integration is effected. This document has tried to take stock of leprosy-related issues and the role ALERT-India has played as a partner in leprosy control.

The first chapter projects the issues as have been discussed in global and national foras. The second chapter summarizes the work of ALERT-India over the past 25 years. The third chapter provides a vision for the next ten years. I am sure the document will provide food for thought and reflection about the evolution of leprosy programmes as conceived and implemented, as well as project a vision of the scenario for the near future.

September 5, 2004 Prof. R K Mutatkar

Epilogue

Till 1955, there was no extensive leprosy field work in Mumbai, though Allbless & Acworth Leprosy Home existed since 1885 and 1890 respectively. The Greater Bombay Leprosy Control Scheme (GBLCS) came into existance in 1955 under the auspices of Acworth Leprosy Hospital, wherein 13 Health Visitors and two Non-Medical-Assistants were appointed who undertook field work in whole of Bombay and treatment centres were opened-up in all the then teaching medical colleges in Mumbai.

On account of job hunting and other facilities like good treatment for all the diseases, there is an influx of people in Mumbai from other parts of Maharashtra State and other States of India, till today. Bombay gives 1/3 revenue of the whole country to GOI, this indicates sources of business. The Secretariat, Govt. of Maharashtra State is in Mumbai. Being connected by sea, rail, roads to the whole country, entry is made easier for the people in Mumbai. Population explosion has become phenomenal. Paucity of good houses, has added to the accommodation problem, therefore, slums are overcrowded, footpath dwelling has increased. This has brought about the atmospheric congestion and low profile of socio-economic conditions, creating a good ground for breeding of all kinds of communicable diseases, including leprosy. Urban leprosy problem has been recognised as a special national problem of public health and was thoroughly discussed at an international platform in 1974 in Mumbai under the auspices of ALH-RRE Society and IAL.

In 1976, GLRA started 4 field projects in Bombay, namely, Bombay Leprosy Project (BLP), Lok Seva Sangam (LSS), VDC (Vimala Dermatological Centre) and MLSM (Maharashtra Lokhita Seva Mandal). In 1977 and 1978 two more projects - Society for Eradication of Leprosy (SEL) and ALERT-INDIA came in to existance respectively. Realising the importance of urban leprosy the State Government started 4 SULUs in Bombay in 1984-85 and the MCGM enhanced the field work by giving 16 more trained workers to A.L. Hospital for more field work in 1978-79. However, because of the peculiar course of leprosy and ever increasing population of Mumbai city, the disease could not be eliminated even with the advent of MDT. Since 1997, LEC, MLEC, VRC and SAPEL types of Programmes were undertaken, yet till today elimination level could not be achieved. Moreover, multiplicity of service providers does not give correct information on PR.

Since July 2004, integration of leprosy services has taken place with GHC system of MCGM. All the stakeholders are involved and with special drives and focal-surveys, it is but natural that the hidden cases will get surfaced. This will help to a greater extent to attain elimination level. The CBR, POD programmes will certainly help in reducing stigma attached to the disease along with integration process. The 'vision' is a 'path' revealing document from that point of view. It will help all the concerned, in the present transitional phase to create awareness, detect cases, treat them with MDT and target the much awaited elimination level !

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

ALERT-INDIA's Vision
The role of ALERT-INDIA as an NGO

1. The role of ALERT-INDIA as an NGO

There will be very few NGLO players in the field after integration – ALERT will be one of those few. ALERT INDIA's intersectoral holistic vision goes beyond leprosy in the arena of general health, poverty alleviation and development, more precisely women's development and will continue to play a creative role in leprosy related issues during and after the Integrated scenario.

The process of Integration of leprosy does not warrant to close down the NGOs engaged in vertical programme or to abandon the existing treatment centres established to provide care and services for leprosy patients. It also does not call for reducing the vertical staff or for finding an alternative work to compensate the work load. The need is for absorbing new strategy for interventions by the NGOs in tune with the Integration policy recommended by the Government that would strengthen the process of integration. In order to fulfil this, ALERT INDIA has envisioned its future programme called **LEAP, "Leprosy Elimination Action Programme",** which is based on a community partnership strategy. The primary objective of LEAP would be to meet all the needs of leprosy affected persons through a community partnership. A well defined road map has been drawn out after due consideration of the priority issues to be addressed during Integration and Elimination and also taking into account of all the spheres of leprosy activities in the form of Vision Statement.

2. Integration for Leprosy Elimination is the focus

It has been now realized that the Integration of leprosy programme will pave a way to achieve the goal of leprosy elimination within a set timeframe by pooling all the health resources to tackle the disease burden that prevail in a given community. The strategy for Integration implies that leprosy will no longer be dealt by specialized centres exclusively working for leprosy. However the focus of the leprosy integration must include urban areas to achieve the desired goal of elimination. More so, the treatment will be dispensed through public health network in the cities and towns of Maharashtra and through PHCs in rural areas. The process of Integration has been already initiated in the Maharsahtra State since July 2004. The transfer of responsibility from the vertical programme to the General health Care system is taking place in a phased manner.

3. Leprosy scenario after Integration – Advantages & disadvantages

Today the integration makes for the first time in history the drugs that can cure leprosy are made available through a large network of public health outlets. The entire medical fraternity especially medical personnel in public health are made responsible to treat leprosy. Rough estimation of leprosy (however, defective and inaccurate) in region wise is now available, though no estimation is available on the actual number of patients treated by private health sector, particularly General practitioners and Practising Dermatologists all over the country. There is also a new thrust to incorporate leprosy as a public health issue in medical teaching and curriculum, though there is a long way to go.

During the Integration phase, active early case detection is officially given up – we do not have definite answer to

the questions like will not this lead to late detection – more deformed patients, with gross deformities – misery for the individual - more social visibility - reinforcement of stigma and fear? The poverty condition in which most of the leprosy affected persons dwell leads to gross deformities resulting in economic loss, unemployment and occupational hazards. The consoling factor is "gross deformities" are not common. The fear is will this scene be maintained during integration phase? Public visibility of leprosy – socially known leprosy patients are at the root of social stigmatization, fear and ostracism.

3.1 Community awareness and Education : ALERT INDIA proposes to strengthen the IEC (Information–Education-Communication) activities with the help of NCC, NSS, Scouts, School children and women groups using Inter-Personal Communication (IPC) techniques. An effective awareness campaign about leprosy will be carried out in the community with the help of hoardings and pamphlets prepared in local languages and suitable to local socio-cultural beliefs as well as by involving mass media communication tools.

3.2 Advocacy and communication campaigns : ALERT INDIA proposes to organize Workshops and Seminars focussing the new approaches for leprosy elimination through integration by involving all the partners of LEAP to reinforce liaison with the Government health agencies. Advocacy and consultative meetings with the Health Programme managers of various health sectors will facilitate smooth implementation of the programme. Various publications and News letters will be brought out to improve the communication skills.

3.3 Capacity building of General Health personnel and Medical fraternity : It is mandatory that the skills of the vertical manpower need to be transferred to the general health personnel in order to maintain the quality of services to the leprosy patients. ALERT INDIA recognized the need for conducting a task-oriented certified short term training at periodical intervals during the integrated phase emphasizing mainly on diagnosis of early leprosy cases, treatment and management for FTMOs and MOs dispensary/hospitals in the urban areas and the MOs of hospitals and Health Centres in rural areas. A standard training curriculum is being formulated by drawing on the expertise available with NGLOs. Continuing Medical Education (CME) is one of the LEAP strategy. ALERT INDIA supports the initiative by the Joint Directorate of Health Services (Leprosy), Government of Maharashtra. Special training programmes for General Medical Practitioners (GMPs) including the medical interns in Medical colleges will also be part of this initiative. This is aimed to cover all the medical fraternity in the Sate of Maharashtra in a phased manner. The medical students can be involved in the leprosy elimination programmes.

3.4 Community approach for leprosy elimination : The greatest challenge in urban areas is the difficulty in detecting all the hidden cases in the growing slum areas and tackling the migrant population. ALERT INDIA has proposed a strategy for detecting new cases by specially surveying hard to reach population including migrants, floaters, slum dwellers, fishermen and high income group people. These campaigns are to be carried out by deploying trained community level volunteers and the various health personnel in the Health Post or Urban health Post and PHC and village level health workers who are part of the health delivery system in the rural areas. Even after such campaigns, these community level trained personnel will continue to act as a guides and spokesman who will promote spread of awareness and encourage voluntary reporting in the long run.

Besides, school surveys with a special focus on children as an epidemiological indicator to be carried out during rainy season. Priority to be given to schools located in slums and economically weaker sections housing areas. Experience shows that the high incidence of new cases among the contacts, hence survey of family contacts of leprosy patients have to be undertaken. As a good proportion of cured leprosy cases are likely to develop

post-treatment complications, it requires active vigilance of RFT (Released From Treatment) cases. Retrieval of defaulters at the local Health Post level need to be promoted.

3.5 Creation of district and state level Referral centres : ALERT INDIA recognizes the need for establishing referral centres / facilities for confirmation of diagnosis, management of reactions, physiotherapy and care at regional / district / zonal levels at various locations in the cities, towns and also in rural areas. Simple POD measures such as physiotherapy exercises and home self care will be taught. Assistive aids such as MCR footwear, Crutches, Goggles and hand Splints will be provided to all the needy deformed leprosy patients. Technical guidance to manage complications such as of re-current lepra reactions, neuritis, trophic ulcers will be offered. Suitable and eligible cases for corrective surgery will be referred to the collaborative Re-Constructive Surgery (RCS) Units with due consultation. Specialized services such as Skin Smear, Biopsies, EMG studies will be undertaken for cases that are posing difficulty in management.

3.6 Strategies for strengthening Integration : Re-planning and effective deploying of the leprosy specialized man power available today (medical & paramedical) for training, supervision and coordination of referral centres, deformity prevention and control, training of community level volunteers and health personnel, organizing awareness campaigns at community level is crucial in the first phase of integration, when the learned contingent of experience and manpower is available. If not appropriately and adequately reoriented and deployed this manpower will not be available after five years. NGOs (both leprosy specialized and others) come together to form a consortium with specific objectives and strategies to work together and strengthen the process of integration. A common strategy and a common plan of action, short term and long term will set the direction for achieving the goals of integration through public health system and the community participation.

3.7 Central registry and Epidemiological Monitoring Unit : NGOs should augment and compliment the efforts taken by the Govt. and the Municipal Corporations at the District level towards leprosy elimination in a perspective. Throughout the *integration phase*, more than it was required in the previous decades, the epidemiological trends viz. new cases, child cases, deformity, ulcers of the disease and community participation need to be documented/studied and results are to be reported, besides for the purpose of basic monitoring (MIS).

This perspective is i) to streamline an authentic recording and reporting system to avoid duplication and re-cycling, ii) to review the progress and provide feedback, iii) to analyze and study the interventions and their relevance in the integration phase and iv) to study and evaluate the outcome and impact. To accomplish this, ALERT INDIA has established an Epidemiological and Monitoring unit in collaboration with the District Leprosy Society, BrihanMumbai Municipal Corporation and other NGOs, wherein all the information from the health functionaries are collected and computerized. This unit will provide feedback to the stake holders and guide them in planning future perspective of LEAP.

3.8 Social concerns assume special significance : Socio-Economic Rehabilitation (SER) and Community Based Rehabilitation (CBR) requires investigations and initiatives to suit the need of those who are afflicted. Welfare schemes have to be an add-on to these rehabilitation schemes. Priority should be given to the self help groups of patients.

Linkages to be established with the service clubs for financial assistance to the need based programmes benefiting the leprosy patients.

Gender issues (The special problems related to women

leprosy patients) deserve special attention. A social advocacy and campaigns are required to correct the legal discords on behalf of community in the best interest of leprosy patients to banish legalized ostracisms.

4 Special drives in the community

Integration is based on achieving a sustained new case detection and treatment of all leprosy cases by the General Health System. Voluntary reporting from the community is pivot for the success of Integration. Voluntary reporting cannot happen in void without community awareness and their active participation. Promoting voluntary reporting through community level campaigns with full involvement and guidance of leprosy personnel available today is one of the ALERT INDIA's strategy. Selected Special Drives (SSDs) and the Targeted Special Drives (TSDs) are the new tools designed to achieve the elimination target in the integration scenario. The criteria for selection of focus areas to implement these special drives should comprise of selective community groups or urban pockets where multibacillary leprosy (infectious) cases are reporting or new migrant settlements in cities and towns or areas with large number of child cases. All these special drives must be accompanied with community level awareness campaign, which will ensure sustained voluntary reporting of new cases.

5 Partnership for LEAP

In the process of integration the key to success lies in building partnership with the community, NGOs, CBOs, concerned public health functionaries and above all the NGLOs. The geographic reach and the scope of operation will be determined by creating linkages with them. Every partnership and linkage will be promoted and assisted to enhance the continuity of the service and care for the leprosy affected individuals. The partners with their roots in a given geographical location and socio-cultural context will be the best suited service providers. All those who share the concerns of LEAP will be the partners. Pooling and sharing resources together with partners will be key to an effective implementation of a common programme for action. Appropriate organizational structure will be developed for coordination and monitoring of the programme.

The ultimate goal of leprosy elimination is the eradication of fear of leprosy and its consequences, in terms of ulcers, deformity and threat of dehabilitation. If the community can be involved in suspecting the early signs of leprosy including nerve involvement, voluntary reporting will eradicate the fear and stigma. The information about diagnosis and treatment of leprosy has to become the common knowledge of the community, which is only possible through community action in leprosy elimination.

VISION STATEMENT

ALERT INDIA
will strive **towards**
programmes focussing on
community partnership strategies
to achieve the goal of **leprosy elimination**
during the integration phase,
in alliance with all stakeholders,
to make elimination a reality for people.

PART TWO

LEAP : Tasks Ahead - 2005 and beyond

NGLO's Role : During the Process of Integration and Thereafter

June, 2004

1. Task Ahead - 2005 and beyond : NGLOs' Role
2. LEAP : Leprosy Elimination Action Programme
3. Selective Special Drives (SSDs) an outline
4. Targeted Special Drives (TSD) an outline

June 2004

1. LEAP : Tasks Ahead - 2005 and beyond

NGLOs' Role : During the Process of Integration and Thereafter

June, 2004

Dr. V. V. Dongre, Sr. Consultant , LEAP

(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.

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)

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.

2. LEAP : Leprosy Elimination Action Programme

Proposed by ALERT-INDIA

June 2004

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.

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, difficul-

ties 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 !

Box :

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.

3. Selective Special Drives (S S D)

an outline

June 2004

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 evaluationproposed 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.

Criteria for selection of areas for SSD

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.

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.

HEALTH FOR THE MILLIONS,
January-February 2001

4. Targeted Special Drives (TSD)

an outline

June 2004

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.

PART THREE

Framework for Leprosy Elimination Action Programme (L E A P) 2005 - 2010

October 2004

Executive Summary

1. A Leap Towards Leprosy Elimination
2. Historical Perspective
3. Reign of MDT and the Ground Reality
4. An Overview of Leprosy Situation in India
5. The Path to Leprosy Integration and Elimination
6. Challenges in Leprosy Elimination
7. Aims of Leprosy Elimination Action Programme
8. LEAP - Strategies
9. LEAP - Activity Phases

Executive Summary

1. Introduction

Leprosy has been known to mankind since ancient times the world over. Though the perspective has changed over the ages from being God's retribution, to a disease caused by germs, and a public health issue. Today the Leprosy Elimination Programme has reached an important milestone, wherein it has determined its way to eliminate leprosy as a public health problem. This junction is the stage when the vertical leprosy programme will start to fade out, making scope for leprosy care to be integrated into the general health system.

2. Historical Perspective

The earliest records of 'leprosy like' disease came from Egypt, dating as far back as 1400 B.C. The Ayurvedic writings describe the affliction as 'kustha' and this word is till today used to describe leprosy in South East Asian countries like Nepal, Indonesia, Malaysia and India. In almost all cultures that had leprosy, it was considered as the flail of God's wrath, or the result of sin and lechery.

The status of leprosy worldwide has undergone phenomenal change over the past 20 years. This was largely due to the application of MDT which began in 1981, as well as the global effort towards eliminating leprosy, spearheaded by WHO from 1991. WHO has set a target for elimination of leprosy as a public health problem by 2000 at national level every where.

3. Reign of MDT

Dapsone or DDS was introduced as a single drug therapy in the 1950s and it held centre stage until Multi-Drug-Therapy (MDT) became an effective line of treatment in 1982. MDT is based on two or three drugs (Dapsone, Rifampicin and Clofazimine or CLF), used in combination and is highly effective in curing the disease and also in rendering patients non-infectious within a very short time.

4. An Overview of the Leprosy Situation in India

India carries the biggest burden of leprosy in the world. India finds it difficult to eliminate leprosy since leprosy has existed for several centuries and further, socio-economic underdevelopment has continued to have serious consequences on health. With efficient implementation of well-planned efforts since 1953-54, India has substantially controlled leprosy. The current prevalence rate being 2.44 per 10,000 population and current case detection rate of 3.37 per 10,000.

Leprosy in Maharashtra

Maharashtra with a population of 100.74 million had 29,680 registered cases and a PR of 2.95 in the year 2003. Though Maharashtra does not fall in the high endemic states with a PR of more than 5 per 10,000 it has small isolated pockets of very high endemicity.

Leprosy in Mumbai

Mumbai, in Maharashtra with a current population of more than 12 million has had a long history of leprosy. The government initiated the leprosy control programmes in 1950s and most work till the 1970s was inthe form of mandatory institutionalisation and rehabilitation. In the 1970s and 1980s leprosy NGOs where engaged in specialised urban leprosy control work. In the 1990s Modified Leprosy Elimination Campaigns (MLEC) were implemented at various locations with the aim of covering the total population of the city. Recognising that urban centres like Mumbai have unique problem of slums, migrants and industrial workers, appropriate strategies have to be developed / formulated to provide effective coverage for all groups of people and covering inaccessible areas.

5. The Path to Leprosy Integration and Elimination

A number of factors have contributed to the decreased prevalence of leprosy in India brought about by the NLEP. The decreased prevalence rate is a significant indicator leading to elimination and thus paving the way for integration. Yet, one cannot undermine the role played by an environment of political willingness and the availability of resources, mostly from the World Bank, WHO and international NGLOs.

6. Challenges in Achieving Leprosy Elimination (1/10,000) target

Following challenges and suggestions in eliminating leprosy are discussed :

- New and hidden cases, treatment of relapse, reactions and deformed cases, indicators for measuring elimination of leprosy, issues and questions related to measuring elimination, MDT alone cannot achieve elimination. Attention is needed to social aspects of leprosy elimination.
- Some of the practical difficulties that were the reasons for the goal of elimination not being realized in 2000 in India still persist in certain situations and need to be addressed, the relationship between poverty and leprosy, tackling urban leprosy problems and the need for a post-elimination strategy.

7. Aims of the Leprosy Elimination Action Programme (LEAP)

1. To evolve a 'patient-oriented', community-based strategy that would facilitate the transfer from vertical system to an integrated system.
2. To formulate guidelines for action for 'vertical NLEP staff' (doctors, paramedics) to actualise the goals of integration.
3. To develop a feasible, replicable alternative methodology to strengthen integration and to sustain a chain of leprosy care services in collaboration with multiple partners (Leprosy NGOs/health NGOs/ CBOs).
4. To help the public health personnel by direct and indirect supportive actions and programmes to detect, treat and cure leprosy on par with other diseases in the general health system.
5. To bring together leprosy NGOs and other partners to define future strategy collectively and work independently for a common purpose.
6. To arrive at a common plan of action with all willing partners who are ready to implement programmes at the community level.

8. Strategies of LEAP

1. Case detection and focus on geographical endemic areas
2. Appropriate diagnosis & compliance to MDT
3. Focus on incidence of leprosy among children.
4. Use of IEC / awareness generation
5. Disability management programme
6. Rehabilitation programme
7. Monitoring, surveillance and evaluation of elimination programme
8. Capacity building of GHS
9. Provision of referral services
10. Involvement of NGOs in leprosy elimination.

9. LEAP Activity Phases

The LEAP is envisaged for a period of 6 years until 2010 with a preparatory period until 2004. The period up to 2007 will see the development of programmes and systems for integration of leprosy services in the GHS. The period soon after that will be to study and consolidate the elimination process through well-documented strategies and successful activities.

1. A Leap Towards Leprosy Elimination

Leprosy has been known to mankind since ancient times the world over. The perspective though has changed down the ages from being God's retribution, to a disease caused by germs, to a public health issue.

India too has gone through various stages of treating leprosy patients. Today it has reached an important milestone, wherein it has determined its way to eliminate leprosy as a public health problem. This junction is the stage when the vertical leprosy programs will start to fade out, making scope for leprosy care to be integrated into the general health system. The advantages of this are immense, including a major achievement of doing away with segregation, thereby increasing the acceptance of leprosy care and the leprosy patient.

Yet the process of integration is not a simple task. It will envisage the dismantling of a large vertical system, retraining and relearning is expected of the GHS staff and the transfer of knowledge from the vertical program to the GHS. This calls for an effective co-ordination at all levels between the vertical and general health staff as well as for making the programme more decentralized.

Treatment for leprosy over the years has engulfed the care of the physical, psychological and social aspects of the problem. This will have to be continued even beyond achieving elimination. The task to accomplish on all these fronts in the context of integration pose different kind of challenges as compared to those faced in running vertical programs. Partnerships will have to be forged between different types of service providers; Governments and NGOs, as well as between Government agencies and civil society organizations to provide comprehensive treatment and care to leprosy patients.

In order to contribute and to ensure that integration of leprosy into the GHS takes place successfully, ' LEAP' is being envisioned. This LEAP strategy forms a part of the endeavour to promote integration and contribute to the process of achieving leprosy elimination by 2005. LEAP is the co-ordinated effort of all those who have been exclusively working in leprosy control to integrate leprosy care into the GHS with the continued focus on the individual leprosy patient. The strategy is based on the integration of the vertical leprosy program that was in place for the past 50 years. The process of LEAP acknowledges the potential of the resources available with the vertical system, in the form of knowledge, skills, technology and personnel, accumulated over the years by implementing vertical programs. LEAP will assist in taking forward these resources towards integration and elimination of leprosy in India. It will ensure that services for the leprosy affected will continue in this phase of transition without interruption without adversely affecting the individual leprosy affected person at whichever stage of treatment he/she is being administered.

2. Historical Perspective

The earliest records of 'leprosy like ' disease came from Egypt, dating as far back as 1400 B.C. In China and India the first records appeared in the 6th century B.C. In China it was known as 'li' or 'lai'. Sushruta, Charak and others in ancient India listed 18 kinds of 'Kushtha' including one for signs and symptoms resembling what modern day leprosy stands for. These Ayurvedic writings describe the affliction as 'kustha' and this word is till today used to describe a leprosy patient in South East Asian countries like Nepal, Indonesia, Malaysia and India.

Leprosy is most prevalent in tropical countries. This is not due to the climate since leprosy was found all over the world until the 1900s, including cold countries. Leprosy is commonly found in central Africa and South-East Asia. And although most leprosy sufferers live in Asia, the prevalence rate is highest in Africa. Due to the increasing movement of people, e.g. immigrants, refugees, etc., leprosy can today occur, at least occasionally, anywhere in the world.

In almost all cultures that had leprosy, it was considered as the flail of God's wrath, or the result of sin and lechery. This caused great physical, mental, social and financial suffering to leprosy patients. Leprosy was noted for its potential to cause permanent and progressive physical disability and disastrous social stigma and discrimination. Thus, patients of leprosy became objects of terror and pity. As a result they were ostracized, condemned and driven away from homes and communities and denied their human rights and privileges. As long as human memory can recall leprosy was associated with being a 'leper', poor, blind, crippled and segregated from society and 'normal people".

The incidence of leprosy sufferers becoming beggars was a well-known phenomenon. In India there were laws to keep leprosy patients segregated until the leprosy Act of 1898 was repealed in the 1980s (Maharashtra 1984) in different states of India. Leprosy is linked to poverty. Poverty was a cause of leprosy because the poor were more prone to suffer from leprosy as they lived in overcrowded settlements resulting in higher risk of contracting the disease. Leprosy led to greater poverty, as it was a leading cause of permanent disability in the patients. The chronic symptoms often afflicted individuals in their prime, productive years and imposed significant economic and social burden on their families and society at large.

The status of leprosy worldwide has undergone phenomenal change over the past 20 years. The number of leprosy cases has fallen from the 1985 peak of 5.4 million to one- ninth of that figure of less than 6 lakhs in 2001. This was largely due to the application of MDT which began in 1981, as well as the global effort towards eliminating leprosy, spearheaded by WHO from 1991. The World Health Assembly had resolved in 1991 that leprosy should be eliminated as a public health problem (elimination means a prevalence rate of less than, 1 in 10,000 population) by 2000. The achievements were so impressive that it enabled WHO to announce in May 2001 that the goal of leprosy elimination had been attained at the global level. But at the national level some countries still had to meet the goal and WHO consequently set a new target for elimination by 2005 at national level everywhere.

3. Reign Of MDT And The Ground Reality

Since the vedic times and until the early twentieth century Chaulmoogra oil, the ayurvedic medicine was the only recognized treatment for leprosy. Dr Gerhard Hansen discovered the bacillus Mycobacterium Leprae and introduced the germ that caused the disease to the world in 1873. The introduction of the single drug Dapsone or DDS from 1950s in India made leprosy workers euphoric and it held centre stage until Multi-Drug-Therapy (MDT) became an effective line of treatment in 1982.

MDT was developed against a background of growing primary and secondary resistance to dapsone. It is based on two or three drugs (Dapsone, Rifampicin and Clofazimine), used in combination to prevent the development of resistance. Once-monthly treatment with an antibiotic (Rifampicin 600 mg) is the cornerstone of all MDT treatment regimens. In its current regimens MDT is highly effective in curing the disease and also in eliminating infectivity of patients within a very short time.

In certain geographic areas, MDT has demonstrated the possibility of reducing the incidence of leprosy suggesting that it has the capacity to eliminate the sources of infection effectively. Its efficacy has also influenced the disability situation, particularly through the reduction of disability among newly detected cases. In addition its other features are: reduced relapse rates, negligible side effects, no reported resistance to the combined drugs, health workers can be easily trained to administer the drugs, easy to administer as it is taken orally, conveniently available in blister packs of 4 weeks' treatment and it can be stored under ordinary storage conditions (WHO, Final Push Strategy to eliminate leprosy as a public health problem, 2003).

The advent of MDT has directed the elimination strategy more clearly by being able to directly affect disease burden elements, most prominently bring the prevalence down to 1/10,000 population. This target of prevalence was considered to be sufficiently low so that the disease will no longer pose a significant problem either in terms of its size or its potential for transmission. Assuming this, there will be a steady decline in leprosy prevalence and ultimately near disappearance of the disease.

The decline of prevalence achieved by the SET pattern implemented by the vertical specialised programme at the national level coupled with MDT treatment is only a means to an end. It cannot be an end itself. The end – the real elimination of leprosy and the subsequent eradication can be achieved only by disappearance from the environ of the germs causing leprosy. Hence, elimination of poverty conditions in which majority of our people live in urban rural India is a necessary pre-condition. Only development can defeat the disease!

4. An Overview Of Leprosy Situation In India

4.1 Leprosy, a chronic bacterial disease with a long incubation period between 9 months and 20 years after infection affects across all age groups. The severity of the disease and the clinical manifestations vary between Paucibacillary to multi bacillary depending upon the degree of the patient's immunity to M. Leprae. Although 95 % of the people in India are naturally immune to leprosy, in India, some 400,000 new leprosy cases are detected. A large number of people suffer from deformity and disability, which is the main consequence of the disease due to the consequential nerve impairment as the disease was not detected and treated promptly and appropriately. The nerve impairment results in loss of sensation on the body, including hands, feet and eyes. Injuries to these anaesthetic parts lead to disfigurement.

A WHO report in 2003 stated that there were 523,605 cases registered in the world, which made the global prevalence at 0.84 per 10,000. Out of these 76.4% are in Asia, 8.6 % in Africa and remaining 15 % in other continents. India carries the biggest burden of leprosy followed by Brazil and together account for nearly 80 % of the global burden of leprosy. India finds it difficult to eliminate leprosy since it has existed for several centuries and further, socio-economic underdevelopment has continued to have serious consequences on health. Although India has made phenomenal progress in containing the disease and reducing the burden there still remain significantly large numbers yet to be tackled.

India has implemented nation wide leprosy control and elimination programs. These were vertical programs considering the volumes and the adverse socio-cultural impact it had on the population and nation at large. With efficient implementation of well-planned efforts since 1953-54 India has substantially controlled leprosy. During 1981 the country recorded a prevalence of 51 cases per 10,000 population whereas in March 2002 it had come down to only 4.2 per 10,000 population. 12 states/UTs have achieved the status of elimination (PR <1 per 10,000) and four more states/UTs are very near to this goal.

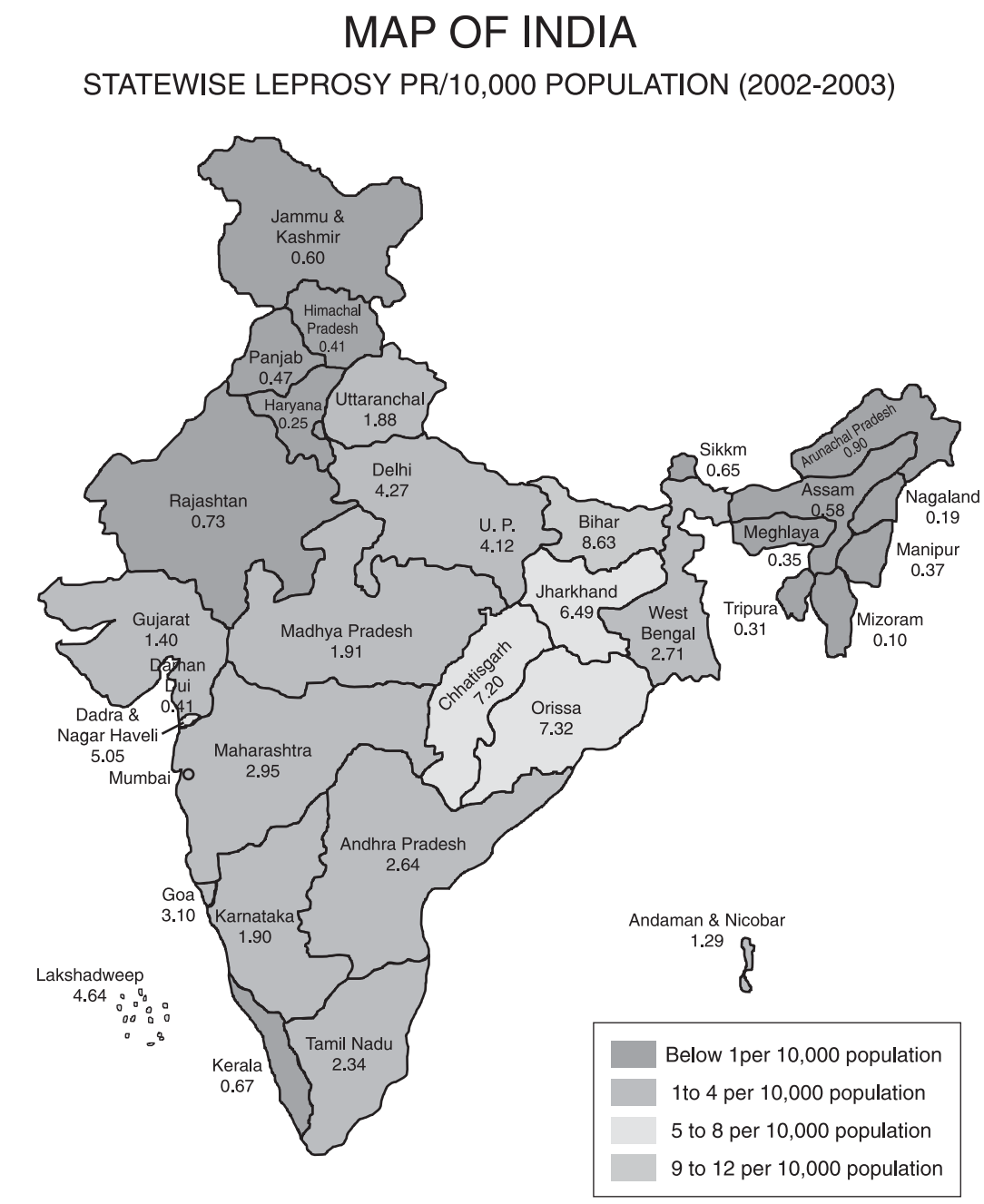
The graph 4.3 : p-12 shows the changes in the rate of prevalence since 1991. New cases detected over the years have varied between 0.4 to 0.6 million with the number of new cases detected from April 2002 to March 2003 being 0.48 million. The fluctuations in the number of new cases from year to year appear to be mainly due to operational factors such as extension of services to new geographic areas, intensification of activities and launching of special; drives including LEC.

Figure 4.1

Source : Leprosy in India, CSSRL, 1992

In 2003 India reported 344,377 registered cases with a PR of 3.3 per 10,000. In March 2004 the Government reported further improvement in the situation. The total number of cases dropped by further 22.7 % since the previous year with the current prevalence rate being 2.44 /10,000 population. The number of new cases in the country also dropped by 22.9 % with a current case detection rate of 3.37 per 10,000 population based on some 367,000 new cases (*Bulletin of the Leprosy Elimination Alliance, January - June 2004).*

Figure 4.2



Source : GOI, 2003.

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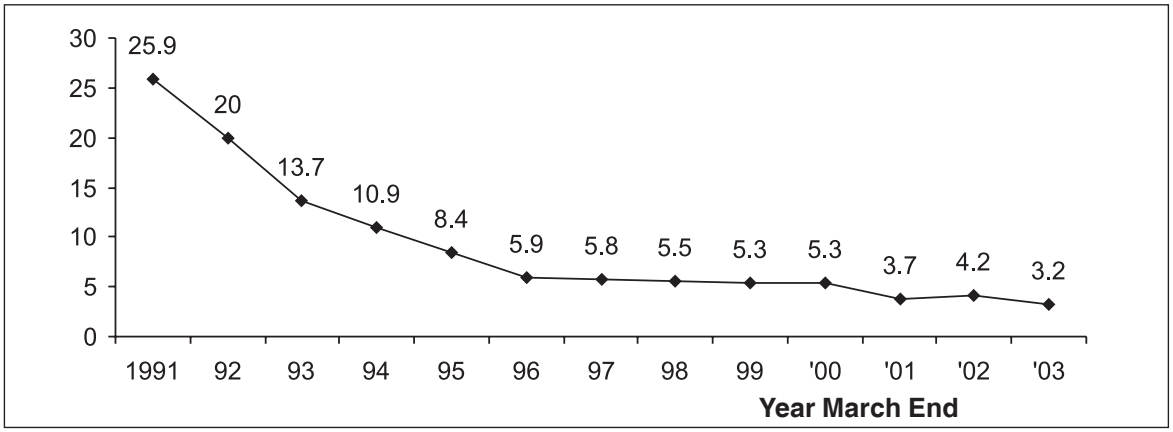
Figure 4.3

Trend of Leprosy Prevalence Rate /10,000 Populations in India



Bulletin of Leprosy Elimination Alliance – June 2003

Table 4.1 Leprosy Prevalence in 11 Endemic States (March 2003)

State	Populations (millions)	Leprosy cases on record	PR/ 10,000	Total districts	Noof dist. With PR		
					<1	1-5	>5
Bihar	87.07	74,871	8.60	37	0	0	37
Uttar Pradesh	173.77	71,647	4.12	70	8	33	29
Maharashtra	100.74	29,680	2.95	34	0	30	4
Orissa	37.8	27,660	7.32	30	0	13	17
West Bengal	82.87	22,432	2.71	19	3	13	3
Andhra Pradesh	77.7	20,483	2.64	23	2	21	0
Jharkhand	28.04	18,207	6.49	22	0	9	13
Tamil Nadu	63.43	14,813	2.34	29	1	27	1
Chhattisgarh	21.49	15,482	7.20	16	0	7	9
Karanataka	54.42	10,353	1.90	27	8	18	1
Madhya Pradesh	63.04	12,027	1.91	45	10	35	0
Total	**790.37**	**317,655**	**4.02**	**352**	**32**	**206**	**114**

Bulletin of the Leprosy Elimination Alliance, Jan-June 2004

The top fives states with the largest number of cases in 2004 are UP, Bihar, Maharashtra, WB and AP and the top five in terms of intensity of the disease (prevalence rate), continue to be Chhattisgarh, Bihar, Jharkhand, Uttar Pradesh and Orissa. Progress towards leprosy elimination, in terms of reduction of leprosy prevalence, has been varied. While Orissa showed the largest reduction of 52.3 %, west Bengal showed an increase by 15.9 %. Bihar, TN and Jharkhand performed very well with reductions of 42.2 %, 41.0 % and 38.2 %, respectively. Maharashtra, UP and MP did not do so well with limited reductions of 2.7 %, 14.6 % and 16.2 % respectively.

4.2 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.
- 1997 – Leprosy integration initiated in Tamil Nadu.
  - ➢ Eradication - Zero number of cases at any given time in any area.
  - ➢ Elimination - Less than 1 case in 10,000 population.

4.4 Mumbai - Urban leprosy control programme

Mumbai, with a current population of more than 12 million has had a long history of leprosy. With its large slums and a migratory population the anti-leprosy workload in Mumbai is five times that of any average sized MDT district. Rapid industrial growth, improved educational and job opportunities, better transport facilities-these factors have drawn rural populations to urban areas like Mumbai resulting in big, unmanageable increase in population in towns and cities. The congested living space act as focal point for transmission of disease such as TB, HIV and leprosy.

The unique demographic characteristics of Mumbai, having its impact on anti-leprosy activities are as follows :

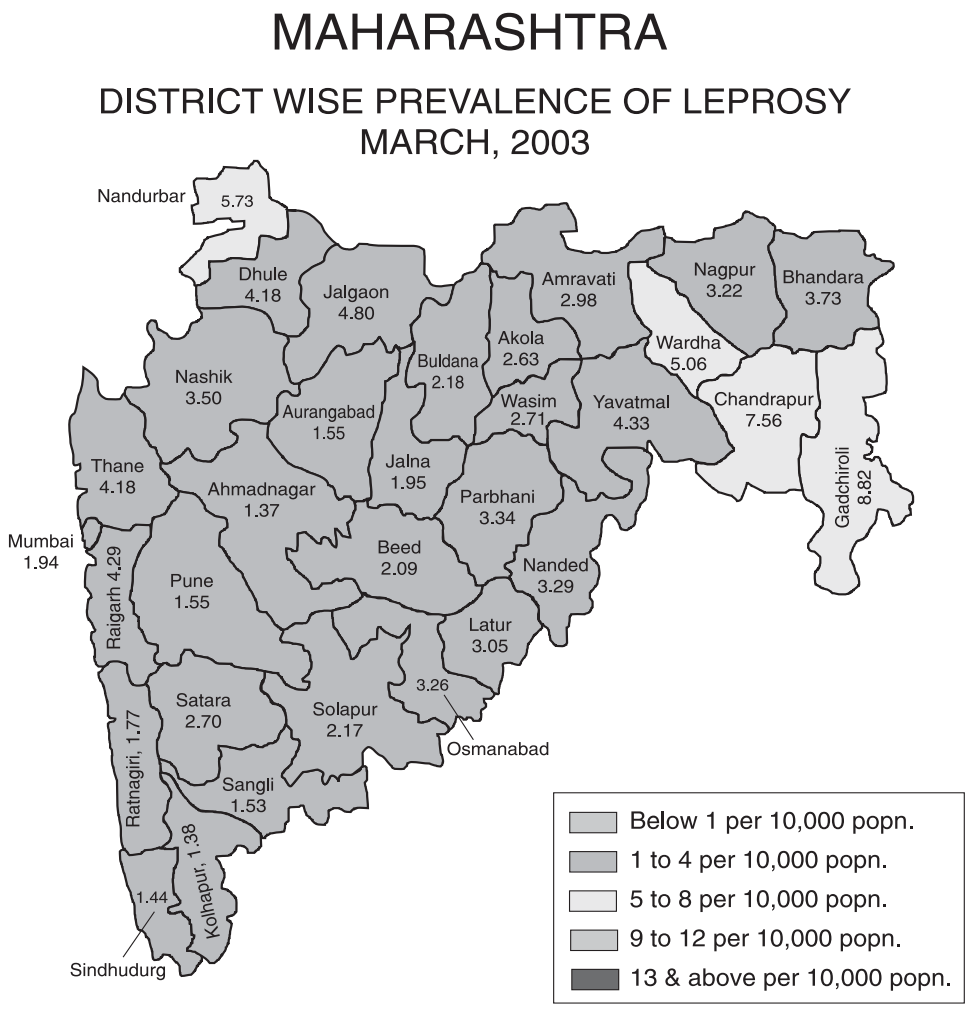
- Huge population of 12 million, almost equivalent to 5/6 districts.
- Over 70% population live in slums.
- Wide difference in socio-economic status.
- Difficult to cover high middle class and upper class population living in elite areas.
- Heavy influx of population from other parts of Maharashtra and India leading to continuous growth in slums.
- Internal movement of people within the city – from dwelling place in the suburbs to work place in the city. Tendency of people visiting their native place periodically thus affecting regularity of treatment.
- Day migration from nearby districts for occupational reasons.
- Large sector of practicing dermatologists in the city treat sizable number of leprosy patients in their own ways.

The earliest treatment in the city of Mumbai was started in the JJ Dharmshala in 1870. Well-organized anti-leprosy work was started with the inception of the Albless leprosy hospital in Trombay in 1885 and five years later in the Acworth Leprosy Hospital in Wadala. (These were leprosy homes to isolate leprosy patients) The government initiated the leprosy control programs in 1950s and most work till the 70s was in the form of mandatory institutionalisation and rehabilitation. Several voluntary organisations started work during this period. In the 1980s the draconian Leprosy Act was repealed as well as MDT was introduced through voluntary organizations. The formal MDT programme according to government guidelines was initiated in the city in 1991-92. This saw a dramatic change in the way leprosy was approached as a health problem.

Presently, the National Leprosy Eradication Programme, based on Survey, Education and Treatment, is implemented in the city by seven voluntary organisations, four supervisory urban leprosy units of the state government and the Acworth Municipal Hospital for Leprosy (Bombay Municipal Corporation). For operational purposes, municipal wards have been allocated to these anti-leprosy agencies as project areas. About 65% of the city is covered by voluntary organisations while the remaining 35% is shared

4.3 Leprosy in Maharashtra

Figure 4.4 Map of Maharashtra showing endemic sites 2002 - 2003



Source : Office of ADHS (Leprosy) Mumbai

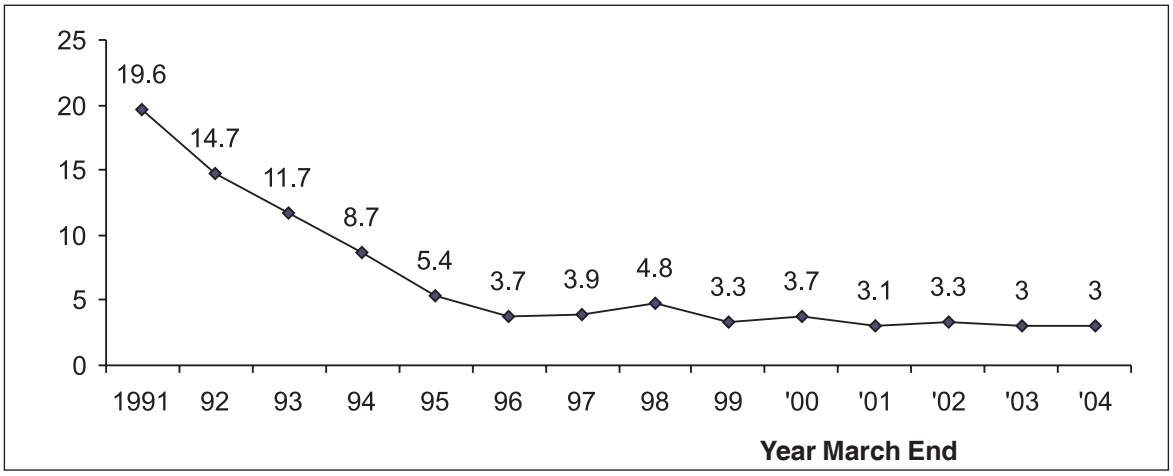
Maharashtra with a population of 100.74 million had 29,680 registered cases and a PR of 2.95 in the year 2003. New cases in 2002-2003 were 48,549 and the detection rate of 4.82 per 10,000. Though Maharashtra does not fall in the high endemic states with a PR of more than 5 it has small isolated pockets of very high endemicity.

between the BMC and the state government units.

Since the inception of the MDT programme, there has been a steady fall in both annual new cases and active balance cases, thereby bringing down the prevalence rate from 12 / 10,000 (1991-92) to 2.3 (1999-2000). However, analysis of cases shows that there is uneven distribution of leprosy cases in municipal wards.

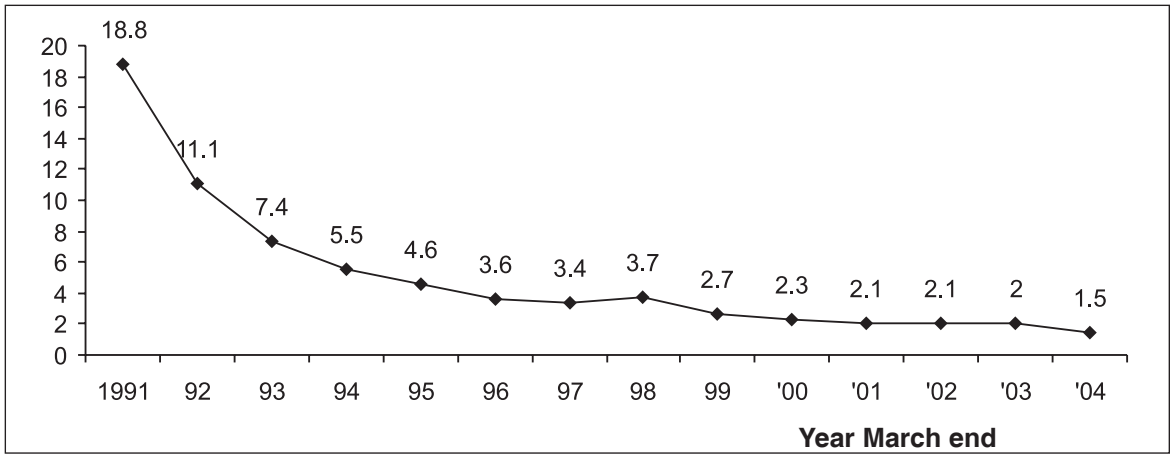
Inspite of the myriad problems, leprosy control program was managed successfully for the last 4 decades, bringing down the leprosy caseload substantially in the city. Even though MDT was introduced in the city in 1980, its impact on prevalence and incidence was seen much later in the early 90s as shown in the graph below. Modified Leprosy Elimination Campaigns were implemented at various locations with the aim of covering the total population of the city.

Figure : Trend in leprosy prevalence in Maharashtra 1991-2004



Source: office of ADHS (Leprosy), Mumbai

Figure : Trend in leprosy in Mumbai 1991-2004



Recognising that urban centres like Mumbai have unique problem of slums, migrants and industrial workers appropriate strategies have to be built to provide effective coverage for all groups of people and covering inaccessible areas.

5. The Path To Leprosy Integration And Elimination

5.1 Achievements of the NLEP

There was an imperative need to create a vertical structure to control leprosy in the mid fifties, for the twin reasons that the number of leprosy patients during that time, needing a specialized army to combat leprosy was so large and the general health services were mentally unwilling to accept leprosy as part of their responsibility, a vertical programme was called for a definite period and was not meant to be continued for decades. The vertical program was the NLEP implemented with Central Government assistance throughout the country.

A number of factors have contributed to the decreased leprosy prevalence in India brought about by the NLEP. The decreased prevalence rate is a significant indicator leading to elimination and thus paving the way for integration. MDT is the unchallenged hero of the sum of these factors. Yet, one cannot undermine the role played by an environment of political willingness and the availability of resources, mostly from the World Bank, WHO and international NGLOs. Noteworthy of mention among the NGLOs is the Nippon Foundation, ILEP agencies, and Novartis which provided uninterrupted free drug supply to the Government and have relentlessly urged the Government and local communities to establish and sustain leprosy control programs over the years.

The Government's NLEP has been a 100% centrally sponsored scheme with financial support from the World Bank. The first phase from 1993 to 2000 was at a cost of Rs 550 crores. The second phase from 2001 for three years involves a cost of Rs 249.8 crores with World Bank assistance of Rs 166.35 crores. This phase also includes a provision of free drugs costing, Rs. 48 crores from WHO.

Until now, the vertical programs for Leprosy were managed in a comprehensive way through:

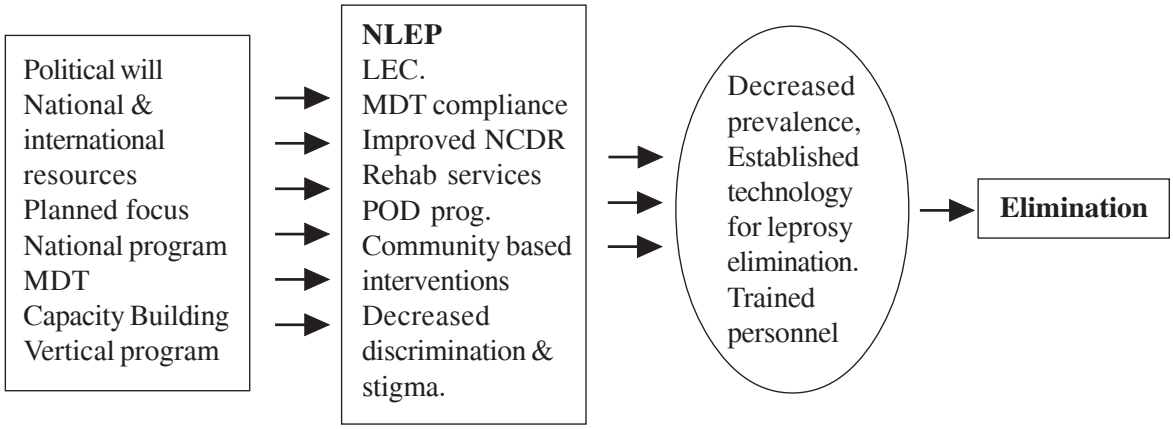
- MDT with fixed duration.
- Physiotherapy and care of anesthetic limbs, affected eyes and nose.
- Reconstructive surgery (RCS) for cosmetic purpose and for corrective purpose.
- Population and other surveys.
- Examination of family contacts.
- Prevention of dehabilitation.
- Rehabilitation.

5.2 Objectives and tasks of NLEP

The National Leprosy Control Program was started in 1955 and was renamed the National Leprosy Eradication Program (NLEP) in 1982. The Objectives and tasks have evolved over the time with the success of MDT and currently focus on :

- Reaching out to population groups in difficult/ inaccessible areas, slums and migratory population.
- Improving quality/ skills of GHS system in diagnosing and treating leprosy.
- Ensuring availability of MDT services at PHC/ dispensaries/hospitals
- Conducting needs assessments and setting up services for prevention and care of disabilities.
- Setting up monitoring infrastructure through SIS
- Management of stock and supply of MDT
- Tackling urban leprosy.

Figure 5.1 Path to leprosy integration and elimination



• Building capacity of private medical practitioners in detection and management of leprosy.

• Community education and mobilization.

• Involving Panchayat Raj systems, schools, opinion leaders as partners in the battle against leprosy.

• Securing co-operation of NGOs and medical colleges.

5.3 MLEC

The NLEP was implemented through MLECs since 1997. MLEC with the package of teaching/training, intensified IEC, case detection and prompt MDT were put together and implemented in the entire country to facilitate efforts toward leprosy elimination. States were categorized into endemic, low/moderate endemic and very low endemic states for implementation. There were SAPEL for rural and urban areas since the past three years (2001-2004) and the second phase of the NLEP is moving towards decentralization, integration and achievement of elimination by the end of the project by 2005. The strategies include:

1. Decentralization of NLEP to states and districts.
2. Integration of leprosy with General Health care System.
3. Leprosy training of GHS functionaries.
4. Surveillance for early diagnosis and prompt MDT, through routine and special efforts.
5. Intensified IEC using local and mass media approaches.
6. Prevention of disability and care.
7. Monitoring and evaluation on regular basis as well as with special efforts such as independent evaluation, LEM, Annual survey and validation of elimination, etc.

5.4 Some issues on the path to elimination

Policies are made based on the state and national figures; and these may have limitations. Range and prevalence would give better information than average since there are pockets of high prevalence even in low endemic states. These pockets could be the focus for the further spread and re-emergence of the disease.

When WHO had previously set an elimination of leprosy by 2000 AD, some practical difficulties made this unachievable. These were; the neglect of the difficult – to-access areas and population, 'simplistic' form of integration resulting in a much more difficult route of achieving elimination, insufficient IEC to create awareness of the disease and to propagate health seeking behaviour at the earliest and to let people know that treatment was available. These difficulties, which still exists must be carefully considered for future success, to make it to the 2005 deadline.

Debates continue to arouse uncertainty about the policy of elimination and its achievements, and there continues to be uncertainty about the future of leprosy control strategies and the role of leprosy workers and researchers after 2005.

5.5 The WHO approach to elimination

- The national LECs to stimulate public awareness and detect 'hidden' cases.
- Make MDT available at the community level.
- Special Action Projects to tackle difficult to reach areas and populations.
- Monitoring the impact of these activities at district, regional and national levels.

(Elimination of leprosy-Questions and answers, Action Program for the Elimination of Leprosy, WHO: Revised 1996)

5.5.1 WHO push strategy for 2000- 2005

1. MDT and early case finding
2. Reduction in prevalence will lead to reduction in incidence.
3. Early diagnosis and treatment will prevent deformities.
4. Change the negative image of leprosy.
5. Call for global coordinated efforts.

5.6 Initiating integration on the right presumptions

The proposal for integration in the 1990s, was reflected on the view that during the post elimination period, voluntary agencies and leprosy workers would be required to share a heavier load of patients, in the 21st century. According to projections based on Government prevalence figures, the numbers of leprosy patients in India during post 'elimination' era would be less than a lakh, which is an insignificant number. But studies carried out subsequently in the early 90s had observed that the actual prevalence was always three or four times of what was declared by the Govt. for a particular area. Thus, it was assumed that at the beginning of the 21 century the figures would be estimated at 3-4 lakhs. And rightly, today there are more than 344,377 registered cases at a prevalence rate of 3.3 %. Figures that are very significant and need to be taken up seriously.

5.7 Integration policy of Government of India

Integration of leprosy within general health services is more than merely involving general health services in leprosy work. It is really a transfer of ownership of leprosy elimination to general health services at all levels and dismantling of most of the vertical elements. The system should not slide into a trap of half-measures that jeopardize the very effort towards integration. Unless integration is accepted by one and all in letter and spirit, progress towards leprosy elimination will be hampered.

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."

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

Table 5.1 Magnitude of urban centres to initiate integration in Maharashtra.

	Category of city - towns	Numbers of urban centres
1	Mega and metropolitan (above 25 lakhs population)	3
2	Medium sized city (above 5 lakhs - 25 lakhs population)	12
3	Medium sized towns (above 1 lakh - 5 lakhs population)	27

5.7.1 Line of action suggested by the government

The integration of leprosy in the GHS was initiated by the Government some couple of years ago, mostly in the rural areas. This was possible since the NLEP was being implemented by government agencies in the rural areas unlike in the urban areas where NGLOs were dominant.

Having successfully integrated leprosy treatment into the GHS in the rural areas in India, The Government of India on the recommendation of the National Workshop for defining Specific Strategy for Elimination of Leprosy in Urban Areas formulated Line of Action for integrating the leprosy elimination program into the GHS in urban centres. The guidelines are more administrative and leave a lot to be done in implementing the technical aspects of patient care and logistics. However, it suggests actions for three categories of urban centres namely: mega and metropolitan cities, medium sized city and townships. All these centres will be supported by the District Leprosy Society under Chairmanship of the District Collector or Executive Officer of Zilla Parishad. After integration, the MO of the PHC will be the nodal officer for implementation of the NLEP in PHC area. The public and private health care centres have been asked to play a role as well as NGOs. Urban leprosy elimination committees have been called to be formed at each of these levels to plan out activities and to share resources and responsibilities.

And going by the categories included there will be large numbers of towns and cities that would be initiating integration soon.

The integration will :

- Lead to the leprosy patient's assimilation in society as against the 'isolation' that was a consequence of the vertical program, thus lessening stigma associated with the disease and changing the lives of leprosy patients.
- Make available leprosy services under one roof by making health facilities equipped to provide comprehensive care to leprosy sufferers.
- By the involvement of the GHS a larger population will be covered, increasing availability and economizing costs.
- The strategy for integration would work best when the leprosy patient is in the centre of focus and when all the facets of leprosy management are taken into account.

The integration of leprosy will be successful when implemented phase wise and in accordance with the capacity of the GHS and with the involvement of the multiple stakeholders.

In conclusion the document states that the Line of Action suggested is not exhaustive and additional items may be drawn up by implementing agencies suitable for urban locality. Overall, to develop a coordinated system of MDT services involving all willing partners and organisations, keeping in mind the sustainability even after elimination.

6. Challenges In Leprosy Elimination
(1 per 10,000 population target)

6.1 Case Detection

6.1.1 New and Hidden cases

The assumption is that at very low levels of prevalence, the disease will be unable to sustain itself, and peter out-provided patients continue to be detected and treated (Noordeen 2004). Success in checking the spread of the disease depends upon the efficiency of case detection (and not merely a reduction in prevalence rates). Unearthing "hidden" new cases, characterised by uneven distribution, very typical of leprosy, throws up greater challenges in the elimination program. While some states in India can take pride in successfully controlling leprosy the situation in certain districts, talukas and pockets is not so good. Thus, it may take 5-10 years to achieve the target of elimination as a public health problem. Trends in new case detection have declined in India over the years from 51/10,000 in 1981 to 3.2 /10,000 in March 2003 and yet there has been little change in figures of annual new case detection despite the MDT campaign. This could be attributed to the operational reasons as well as hidden sources.

6.1.2 Treatment of relapse, reactions and deformed cases

The challenge of follow up of default, relapse and reaction cases will have to be taken up. While emphasis is laid on case detection and NCDR, adequate facilities should monitor and treat relapse cases and treatment of reactions and deformities to ensure comprehensive solutions to leprosy problems.

6.2 Debate on Indicators for measuring elimination of leprosy

Experience suggests that prevalence of leprosy is largely under-reported and real prevalence might be several times of the reported prevalence. There is an urgent need to treat the existing leprosy patients as well as to control the transmission to new susceptibles. Promoting clean living environments along with sincerely committed MDT based leprosy control approach keeping the patient in focus, is the need of the hour.

Although leprosy prevalence is currently considered the best composite indicator of progress in the anti-leprosy drive, case detection can be useful as an additional indicator. The concept of disease burden is best reflected through the use of prevalence. Others are in favour that in certain areas adding another useful indicator such as case detection to monitor progress towards leprosy elimination should be explored so that the situation can be better understood.

For arriving at case detection rates, the relevant population covered for detection and the denominator assume significance. Consider the following :

- If the Census figures are used as a denominator there can be an underestimation and if special detection in high endemic areas are used then there can be an overestimation.
- Another reason is the intensity of case detection activities, as it is believed that in high endemic areas there are substantial cases with 'minimal disease' which otherwise would be spontaneously healed. Frequent detection/examinations of these self-healing evanescent lesions would add and thus inflate detection figures.
- Quality of diagnosis plays an important role in case detection and depends upon training, level of expertise and skills. Thus, some epidemiologists argue against using case detection as an indicator of measure towards elimination since it can give rise to underestimation or over estimation, as the case might be.
- Lastly, the absence of programs in certain areas or regions have led to an 'absence of data' showing false prevalence.

While the recently observed quick decline in prevalence has been largely due to the cure of all or nearly all detected cases, the stagnation in figures of new case detection is due to several factors:

- Aggregating figures at the regional and national levels is one reason where averages include areas where new case detection is on the decline as well as areas where the opposite is true.
- Areas that had started implementing MDT early and where the coverage had been consistently good have shown clear declining trends; where as where MDT had been introduced relatively late and where the coverage had been rather slow have shown the opposite picture. Combining information from a mix of these areas masks the true situation and the real trend of leprosy.
- There is also the increasing tendency of leprosy workers to detect what they consider 'early' cases. These include a high proportion of non-cases, self healed cases and even some previously treated and healed cases. This happens due to case detection pressures, over zealous workers, target setting and sometimes the fear that they might loose their jobs if leprosy becomes a relatively insignificant problem.

6.2.1 Issues and questions related to measuring elimination

Issues relating to case detection that need to be addressed at the macro level:

- 60% of the people are aware of the disease, but many of the cases reported voluntarily have disabilities
- Though prevalence rates have fallen, the number of new cases detected does not show a corresponding fall.
- How to obtain information on incidence?
- Validation of new cases detection.
- What should be the impact indicators?
- What level should diagnosis be done?

Issues relating to case detection that need to be addressed at the micro level :

- How to suspect an early infectious case presenting without anaesthetic patches?
- What is the extent of additional detection that can be done during diagnosis through nerve examination and smear examination?
- What proportion of cases will be missed if anaesthesia in the patch is used as the only criteria for diagnosis?

6.3 MDT is not the sole answer for achieving elimination

Although MDT has helped to achieve 90% of cases to be cured it has not reinforced the reduction in new cases being detected over these years. One continues to see the NCDR at about 5-6 /10,000 persons since 1988. Secondly. MB disease load has not declined over the years.

6.4 Attention to social aspects of leprosy elimination

By reviewing historical careers of other disabling conditions, experience suggests that technical solutions alone bring only partial success. They must be backed up individual and family self-help, community participation in service provisions, and a redeployment of professional expertise, what the NGLOs can attempt in the light of integration. Studies of similar disabling diseases that have social stigma attached have shown that elimination can raise issues of resilience. Thus, while perceiving to eliminate leprosy and integrate it into the GHS would seem to disregard the problem of social ignorance and stigma attached. Since the health system (more so allopathic) leaves little scope for addressing the social and rehabilitative aspects of the problem.

Early signs of leprosy can be misleading to the untrained eye, give no trouble and hence go undetected for years. When detected patients may not come forward for fear of stigma and discrimination and will do so only when it is quite late because by then the disease has progressed, deformities have developed, most probably the person has lost his/her job, driven off from the family and community and also given the infection to a few others. This is a vicious chain which gives rise to numerous social problems. There are social overtones in any chronic disease, but in leprosy, their immensity and severity have been aggravated due to ignorance, fear and stigma. Thus, a program of elimination without considering social aspects of treatment would be tremendously incomplete. The focus cannot only be the individual affected but would have to encompass the family or immediate contacts and the community for proper rehabilitation.

6.5 Practical difficulties

Some of the practical difficulties that were the reasons for the goal of elimination not being realized in 2000 in India and persists even now in certain situations :

i. Delayed introduction of MDT in the states.

ii. Delayed expansion to all geographical areas within the states.

iii. Insufficient resources for operational activities in support of MDT implementation.

iv. Drug supply problems including logistics, particularly in the early days.

v. Inadequate priority for case detection activities particularly in the early phase of MDT implementation

vi. Neglect of difficult –to- access areas and populations.

vii. Insufficient IEC to create community awareness about leprosy, the curability of the disease through MDT, and the availability of services and drugs free of cost.

viii. Poor health infrastructure to handle even the simple aspects of MDT implementation.

ix. Inadequate allocation of resources for MDT by donor NGOs in comparison with their allocation to other activities.

x. Late recognition of the need to fully integrate leprosy within the GHS and make GHS to own leprosy work.

6.6 Poverty and leprosy

Leprosy is a leading cause of permanent disability in the world. Although leprosy is not fatal, the chronic symptoms often afflict individuals in their most productive stage of life and therefore impose a significant social and economic burden on society. In addition to its economic impact, leprosy imposes a heavy social burden upon affected individuals and their families. Patients are often shunned and become isolated within their communities. Mocking and social stigmatisation are frequent behaviours toward affected individuals. Because persons with chronic manifestations of the disease are often unable to work or marry, they become dependent for care and financial support leading to further insecurity, shame, isolation and consequent economic loss.

In his address to the National Conference on Elimination of Leprosy January 2004, President Abdul Kalam stated that only development can defeat disease. Better amenities, clean drinking water, better hygiene and sanitation, education and health care, nutritious food and a livable environment are vital in leprosy endemic regions.

The path to eliminating leprosy is going to be tedious considering the above. A complex, gigantic task is ahead as India stands 127 in the Human Development Report Index (HDR 2004) out of a total ranking of 177 nations. With a total population of more than one billion just 28 % have sustainable access to improved sanitation, 21% of the population being under nourished, an adult literacy rate of 61 .3 %. And to top it all less than 1 % of GDP spent on public health.

6.6.1 Urban problems

Urban problems include the absence of uniform primary health care services in the urban area and the implications for monitoring and coordinating the multiplicity of service providers and medical systems-allopathy, homeopathy, unani etc. Leprosy reporting is not part of the general reporting system. Additionally, the SIS for leprosy reporting has yet to be established and with its many recording and reporting formats, and the overall perception that the PHC is not comfortable with treatment of leprosy doubles the problems of integration at the PHC level.

Prevalence and incidence of leprosy as in most communicable diseases in an area are directly related to population density i.e. crowding. More than 60 % of smear positive cases in Mumbai are those of migrants/ commuters from neighbouring districts/states. For example, sustained effort through campaigns in the slums

of Dharavi, in Mumbai, which houses more than 4 lakh people in a compact area, reduced new cases from 178 (1980) to 32 in 2002, while skin smear positive cases fell from 62 (1979) to 5 cases in 2002 (Ganapati, 2002). These observations indicate that disease transmission can be reduced appreciably with current MDT schedules. However, early detection of imported or migrant leprosy cases, especially of infectious types, remains a considerable operational challenge for health workers.

An examination of 72,436 migrant population groups to different cities/towns in western India revealed a detection rate of 194 per 10,000 even though the overall PR was coming down in 32 cities/towns (NLEP –Maharashtra, 1998).

6.7 Need for post-elimination strategy

Leprosy is a very unevenly distributed disease and thus when the disease burden lessens this will not be uniform. It is likely that leprosy will retreat itself to some of its strong but small pockets and persist for quite some time necessitating identification and dealing with them effectively in a focused manner. It is likely that significant numbers of new patients will continue for many years. Leprosy control activities must therefore be sustained.

In view of the elimination deadline of 2005, experts say that the elimination strategy will have failed if leprosy disability is not prevented after it has been declared eliminated. And in order to ensure that the leprosy patient is not 'sacrificed' after elimination has been declared, it is important that a powerful post elimination strategy is discussed and created before 2005. This strategy aims to prepare for a scenario when leprosy would become a disease that affects a few and not large populations. To help and support those 'few' people and to ensure that the individual is not sacrificed for the benefit of the population, to ensure that each person with leprosy continues to be given the best opportunity to be a 'whole', healthy member of his/her community.

6.7.1 Major findings of the 2003 LEM indicators

- The prevalence rate satisfactory, mostly below one, the disability rate among new cases was low at around 2%. However, discrepancies existed in prevalence figures of state and district reports.

- The integration indicators showed three-fourths of the general health facilities diagnosed and treated leprosy and accompanied MDT was practiced more than 50% of the facilities and the level of integration varied widely in the states.

- The quality of MDT services showed a high level of cure rates at 84% and 94% and defaulter rates of 10% and 4% for MB and PB respectively, and about 9% instances where criteria for maintaining patients on the register were wrongly applied. There were wide variations with regard to MDT drug stock and quality of blister packs.

- Only two-thirds of the health facilities were using the SIS.

- There was reasonable level of leprosy awareness in two-thirds of the community members.

It is clear that leprosy will continue to exist as a limited problem after achieving elimination. So ant-leprosy activities will have to continue without any break. But such activities will have to be more focused and more integrated within general health services, and secure good referral support.

7. Aims of Leprosy Elimination Action Programme (L E A P)

For Maharashtra elimination and integration have taken equal significance at this point of time. Integration is being used as a strategy towards achieving elimination. Therefore, the successfulness of the integration of leprosy care will determine the success of leprosy elimination. This LEAP strategy forms part of the endeavour to promote integration and contribute to the process of achieving leprosy elimination.

To evolve a 'leprosy patient-oriented', community based strategy that would facilitate the changeover from vertical system to an integrated system.

To formulate guidelines for action for 'vertical NLEP staff' (doctors, paramedics) to actualise the goals of integration.

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

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

To bring together leprosy NGOs and other partners to define future strategy collectively and work independently for a common purpose.

To arrive at a common plan of action with all willing partners who are ready to implement programs at the community level.

Issues for discussion

Social

Deformities that cause stigma and social fear are not totally eliminated in the MDT era

Late detection is not the only reason for gross deformities - economic status , occupation and employment are the direct contributing factors.

The consoling factor is "gross deformities" are not common. Hence, there is less public visibility – less number of patients under treatment today are socially known leprosy patients. But the poor patients often are unable to protect themselves from ulcer, mutilation due to type of employment and living conditions.

POID (Prevention Of Impairment and Deformity) is priority at this phase of integration of leprosy with public health system. Is the system equipped to provide appropriate and adequate care?

Active early case detection is officially given up – will it not lead to late detection – more deformed patients, with gross deformities – misery for the individual - more social visibility - reinforcement of stigma and fear?

Legal

Repealing of Indian Lepers' Act of 1898 by all States in India has not made any significant impact on the 'ground level'. An unofficial, social stigma imposed social isolation, segregation and institutionalisation in the name of "self settled colonies", "shelter for poor or beggars" "rehabilitation institutions". This reality differs region to region, state to state at varying numbers.

All Matrimonial Acts (except the Parsee Marriage Act) continue to allow certification of one of the partner suffering from leprosy as a ground for divorce. We do not have figures of separation families.

Employment Rules have not changed. Deformed leprosy patients employed in public places are exceptions.

Antony Samy, Issues for discussion, Media Workshop, Raipur 2004

8. LEAP – Strategies

Having understood the need to integrate leprosy services into the GHS and recognized the challenges therein the focus now is on what will make this process most successful. Over more than 50 years of vertical leprosy programs that attempted control and later eradication and then elimination, have brought out many exercises that have failed and succeeded. The expanse of services of leprosy treatment involved strategic planning, fund raising, drug therapy and administration, POID and rehabilitation, research and survelliance, monitoring and evaluation.

All these have been well documented and the field still has many of the experts from down the years eager to use their intelligence and technologies to reach a new horizon- integration and elimination of leprosy. The LEAP is a collection of the approaches and strategies that have brought out best results. Some of the past experiences have had to be adapted to suit the new context. 10 such strategies are outlined to pave the way for integration.

8.1 Case detection and Focus on Geographical endemic areas

As the PR has decreased over the years there will be still lesser cases spread out over larger areas. Due to the integration of the leprosy into the GHS there will also be a decrease in community intervention and focus will be more on self reporting.

Leprosy situation is said to be the result of a dynamic process where there is a steady flow of new cases and discharge of cured cases. An intensive case-detection campaign is very useful in mopping up undetected cases of leprosy. New case-detection, treatment delivery and case-discharge should go together in order to ensure a declining trend.

Formerly, the success of NLEP activities was largely dependent upon active case-detection as the percentage of voluntary reporting was still only about 33% in India as a whole(DGHS, 1999). Awareness of leprosy is not adequate to motivate the patients to report voluntarily and complete their treatment. This is evident from the findings of MLEC I in Andhra Pradesh and Tamil Nadu where for every confirmed case about 10-19 suspected cases respectively were found to exist. But since the majority of the patients came from rural, economically backward areas, they expressed wage loss, traveling costs and the painless nature of the patch as reasons for not approaching the health delivery system. This underscores the need for continuation of active case-detection programs.

8.1.1 Endemic areas and Reaching the unreached

Concentrated leprosy elimination campaigns and rapid surveys may be needed in areas known for high endemicity, and in areas of high labour and fresh migrant populations.

Campaigns are also needed in uncovered areas and difficult to reach groups: people isolated because of poor transport/communication facilities or isolated for several months in a year during monsoons, floods, snow; people living in border areas, or between states/districts, people living in conflict or war affected areas; nomadic populations; urban slums; floating populations in urban cities and metros.

8.1.2 New case detection and transmission

'New Cases' include 'incident cases' (where the patient has just been afflicted with leprosy) and cases where leprosy occurred earlier but is detected now. If India is to attain the goal of a caseload of less than 1 per 10,000 population by 2005, then the new case detection rate will have to be decreased to one –fourth its rate of 4.4 reported in 2003. For this tried and tested methods of LEC and special initiatives recommended by WHO will have to be implemented.

Long term observations in Mumbai Slums (Ganapati 2002) show that it is easier to check transmission if the population is localised, in spite of the high magnitude of the reservoir on *M leprae*.

A Identify the unreached in rural, tribal and slum areas and plan SAPEL/LEC projects as necessary.

B Establish an efficient mechanism to appropriately link these people with PHC.

C Promote MDT in areas that remain cut off during rains, floods or snow, promote MDT also among migratory population.

D Encourage industrial health care institutions to provide orientation and training on diagnosis and MDT among industrial workers.

E Get cadets from NCC, Scouts, NSS and similar institutions as well as teachers and students from schools, to take part in special camps to reach the unreached.

Dr Ashok Kumar, Dy. Director General Health Services, Bulletin of the Leprosy Elimination Alliance, Vol.2, Nos 2, April -June 2002

8.1.3 WHO LEC and special initiatives

Leprosy Elimination Campaigns (LEC) cover a fairly large population and involve the maximum possible number of health workers. They 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.

The Special Action Projects for the Elimination of Leprosy (SAPEL) were introduced by WHO 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.

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 mobilisation 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.

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

Detecting every leprosy affected person, at an early stage, particularly, from those being in endemic and difficult areas to reach will be possible through adopting different approaches. Experiences demonstrate that the LEC, special drives and campaigns will enhance the large numbers of persons who will be motivated to seek treatment voluntarily.

8.2 Appropriate Diagnosis & compliance to MDT

Since leprosy elimination is based on early case detection and treatment, the diagnosis is required to be made in the field and thus has to be clinical. The 'cardinal signs' in use for clinical diagnosis are :

1. Skin lesion/s with sensory impairment.
2. Thickened or enlarged peripheral nerve.
3. Acid- fast bacilli in skin smears.

Any one of the above or third alone in suspected cases have been taken as diagnostic for leprosy. It is estimated that using the first two cardinal signs singly or together, a large proportion of cases could be diagnosed correctly, indicating a high degree of sensitivity. Slit smears for AFBs – the third cardinal sign, is a laboratory investigation with almost 100% specificity. In MB patients, not only skin smears help in diagnosis, but also to monitor the progress under treatment. Skin smears are useful in differentiating reactions from relapse in MB patients and are essential for diagnosis of relapse in bacteriologically positive patients. While 70 % of leprosy patients can be diagnosed by a single sign of skin patches with sensory loss, patients with suspicious lesions that are not anesthetic would have to be referred appropriately for diagnosis.

Diagnosis of leprosy in the field is essentially through clinical examination. The simplified classification has done away with skin smears due to the poor dependability of the procedure when carried out in the field and, this has greatly facilitated widespread application of MDT and enhanced the progress towards leprosy elimination. It is important that clinical examination is carried out systematically, starting from inspection of skin to palpation of nerve trunks to testing for sensory loss. In order to facilitate this process a flow chart has been developed depicting clinical action, clinical findings, and clinical conclusions.

8.2.1 Validity of leprosy diagnosis

The most important part of the LEM exercise related to the validation of the diagnosis of leprosy. Validation becomes critical so as to derive accuracy for the data of the patients diagnosis, since it has a direct bearing on the prevalence indicator towards elimination. The issues in validation are wrong or over-diagnosis, re-registration, wrong grouping or classification and non-existing patients.

8.2.2 Ensuring availability of MDT

MDT blister packs in adequate number should be available in all treatment facilities and dermatologists' clinics. The local program officer should monitor the utilization of MDT packets, cases registered and cured through simplified recording and reporting system.

8.2.3 Treatment & follow up

The treatment of leprosy patients is largely based on the guidelines laid down by WHO from time to time. In order to simplify the therapy in an effort to increase the compliance in the patients the WHO has from time to time shortened the duration of MDT, especially for the MB patients encouraged by the low relapse rates in different studies. The induction of MDT has reduced the duration of follow up of patients. In the dapsone days lepromatous patients and tuberculoid patients were followed up for life or at least 10 years respectively, While for MDT the follow up is reduced to 5 and 2 years, respectively. Even if according to WHO guidelines, a patient is removed from the MDT register, patients of certain category should be followed up for relapses, detection and management of late reactions, identification of drug resistance and management of disability.

Appropriate diagnosis, systematic validation, prompt treatment and ensuring the compliance for treatment are the key to achieve the goal of leprosy elimination.

8.3 Focus on Children

WHO Status report 2001 and 2002 shows South East Asia had 18% of children under 15 of the total of 606,647 new cases. The highest proportion globally, with Africa second with 11%. According to Lechat (2000), the relatively high proportion of children affected under 15 years of age in the countries with high detection rates is a worrisome observation, since that suggests evidence of relatively recent transmission.

The frequency of occurrence of leprosy among children is an important epidemiological index for determining the level of transmission of the disease. School screening is an effective and efficient method of case detection for leprosy, especially in hyper-endemic areas. Maharashtra has 3 districts falling within this category as well as small pockets in urban centres justifying that this method with appropriate innovations and use of minimal resources should be continued albeit the integration process.

The most famous Indian project with children is the Leprosy-free school project at Chengai MGR district. Between May 1991 and December 1993, more than 750,000 school students from 2,800 odd schools covering five education districts were screened for leprosy. Nearly 7,400 suspected case were referred to the health centres and the schools were declared leprosy free. This idea of leprosy-free schools was replicated in other parts of India and abroad and is still popular.

Small armies of Indian children, Bharat Souts and Guides from schools have served as foot soldiers in the war on leprosy. They have been organising awareness marches, seminars, essay and quiz contests, exhibitions, street plays, songs, poster shows, slogans and puppet shows. Such initiatives have urged the international World Scout Bureau to initiate similar activities in other leprosy endemic countries. The process involves educating themselves, their families and people in the neighboring localities.

The involvement of children in leprosy detection and care has two fold advantages. One, 'catch them young' and the other is empowering them with an education to help detect the disease in themselves and others around them through leprosy educations. A method that combined awareness creation with screening of high school students by their peers and teachers conducted in Karigiri, Vellore, India is worth replicating.

The incidence of leprosy among children is one of the important epidemiological characteristics for determining the level of transmission of the disease. Educating and detecting leprosy among the children are appropriate tools for 'catching them young' for treatment and for empowering the future generation for elimination.

8.4 Use of IEC/ Awareness generation

Leprosy is considered to cause more social than medical problems. Leprosy elimination cannot be achieved in the absence of social awareness and action. It can be achieved by providing basic and positive information about leprosy aimed at changing people's attitude from fear to understanding and from apathy to participation so that early diagnosis and modern treatment can be used to provide cure. Now that leprosy care is being integrated into he GHS, emphasis should be given to IEC so that persons cured of leprosy, especially those with deformities, receive acceptance in society.

'Voluntary reporting is the key to successful integration of leprosy into the GHS'. This can happen when people are adequately made aware of the disease and the consequences of delayed treatment. Focus is also needed on the social aspects of stigma and discrimination. This can be tackled through IEC and awareness, to motivate people to access health services and overcome fear and ignorance. For this, major festivals especially those observed through community gatherings, can be utilized for message delivery and awareness generation. LEC can be dovetailed to the celebrations like Durga Puja and Ganesh Utsav.

Education of the community on leprosy should be part of the overall health education efforts including school health education. Special education efforts on leprosy may be needed during LEC.

IPC for awareness and social issues, especially in difficult to reach locations, in urban slums, tribals who live in mountains, and forests difficult to access and people who line on border areas. Such places where the mass media

Health education is not merely imparting information on health and disease to the community. It must aim at encouraging participation of the community in the health program concerned. Thus, "the objective of health education is to evoke in the public at large and the patients and their relatives, a reasoned attitude towards leprosy which neither exaggerates the dangers of leprosy nor minimizes them"

(Rio Congress, 1963)

doesn't affect or touch people who don't read or listen to radio or watch T.V. More efforts are needed through interpersonal communications and activities such as puppet shows, song, dance which deliver messages orally and visually.

IEC can play a major role in drawing GHS professionals to treat leprosy patients through technical education and mass media advocacy. Urban health program managers should ensure IEC materials, pocket guidelines for quick reference and technical updates wherever necessary. Sustained interaction with professional bodies such as dermatologists and medical associations including non-allopathic systems, should be drawn into the integrated leprosy program to practice national guidelines.

IEC is instrumental in bringing about awareness, that aims at reducing stigma and discrimination thereby motivating more people to seek treatment. Communication, (mass or interpersonal) is a good channel for doing away with myths and misconceptions about leprosy.

8.5 Prevention of Impairment and Disability (POID)

The components of disability prevention are detection of disability, its measurement and management. The early diagnosis and treatment of cases, neuritis and reactions are essentials of a well run elimination program. Yet, the current concept of elimination (PR of 1/10,000) will not have much effect on tackling disability and impairments. The policy of fully releasing patients following short regimens of treatment may be inducing a large contingent of disabled individuals (Virmond 2002). WHO Status report 2001 and 2002 shows South east Asia had 3% disability from the total of 606,647 new cases. Almeida (1993) reports, in an estimation that is relevant to a high endemic region of India, that the final number of patients and ex-patients in need of some sort of medical attention 18 years after starting MDT treatment to be about 125% greater than the initial number of cases. Which means that large number of cases released from treatment will need leprosy – related medical care in the long run. Many treated cases will show some sort of impairment in the future that may lead to disability or handicap. A study in Brazil (1994), considering global data for 1992, showed 24.75 % of patients with disability out of the 79.66 % evaluated from a total of 34,451 newly detected cases. Further, in 1994 in the city of Sao Paulo, the most affluent in Brazil, had the following to report of patients with disabilities being released from treatment.

Srinivasan (2004) says that this stage of integration is the best time to re-orient perspectives from 'preventive medicine' to 'curative medicine'. Disability management should be regarded as an integral part of management of leprosy. Health care providers at different levels should become familiar with principles and practices relating to management and prevention of disabilities in leprosy patients. The problem can be broken up into manageable units of : organize crash program for all fit and willing persons through reconstructive surgery camps, identify organizations at district and state level to manufacture and provide protective footwear at affordable prices, crash program to deal with all persons with ulcers in a given area and carry out a program to empower leprosy affected persons, especially those with loss of sensitivity and muscle weakness or paralysis and train them and their family in disability prevention practices.

The components of disability prevention are early detection of disability, its management within their local environment. Activities aimed at tackling disability and impairments should go hand in hand with MDT to make leprosy treatment more comprehensive.

8.6 Rehabilitation program

One should not consider leprosy merely as an infection of skin or nerves and treat it by mere pill prescription. The consequences of leprosy extend far beyond this to affect lives of individuals, their families and society at large. A' three tier consequences of disease' has been developed by rehabilitation scientists as :

1. Impairment
2. Disability
3. Handicap

Leprosy would hardly be the disease as it is if it was not for its potential to disfigure and disable. WHO status

reports for 2001 and 2002 reported that 3% of total new cases in SE Asia had disabilities. The disability caused by leprosy is progressive in nature and thus raises many issues.

In the international Classification of Functioning, Disability and Health (ICF), 'Impairments' are defined as 'problems in body function or structure such as a significant deviation or loss. A 'deformity' is a structural, usually visible, impairment. A 'defect' could be either a functional or structural impairment. In the ICF, 'Disability' is used as an umbrella term for impairments, activity limitations and participation restrictions. And the WHO grading system grades impairments rather than the overall disability status of the person. The objectives of this grading, specifically meant for leprosy, are :

- To assess the disability burden attributable to leprosy in the community so as to plan the necessary action.
- To use it as an indicator for assess the performance of the elimination program
- To grade the potential for preventing disabilities in individual patients.

The most recent and currently practiced grading by WHO is the 3 point grade established in 1988.

1. Normal sensation, no visible impairments.
2. Impaired sensation, no visible impairments.
3. Visible impairments/deformities.

This grading is frequently used for 'delay in case finding' an indicator for delay in presentation.

The matter of leprosy rehabilitation has gained tremendous significance today because the future of 'leprosy work' is seen to lie in the area of 'rehabilitation'- in the broad sense of 'solving all leprosy related , not necessarily medical, problems'- rather than in the traditional areas of case finding- treatment proving case holding (Yuasa, 2000). The 'early diagnosis and treatment remedy of prevention of disability' will not hold good in situations where persons have already developed some impairments and disabilities. In India, at present, such persons outnumber leprosy patients needing or under treatment by a factor of five, if not more. One should also keep in mind that most leprosy affected persons with impairments have already developed some impairment by the time their disease was diagnosed and only a small proportion from the remaining patients develop impairments for the first time, after starting treatment.

The term dehabilitation was developed for leprosy to describe the process of down grading of the patient's status within their families and societies. The end stage being of isolated or being driven away to destitution. Different actions are needed for preventing and reversing this process on the one hand and dealing with the end stage. The actions for reversal and arresting the process of dehabilitation as a consequence of disability lay with the health sector while rehabilitating the dehabilitated leprosy affected person is part of the much bigger issue of rehabilitation demanding different kind of expertise. The former depends on early detection and prompt multi drug therapy, counseling, prevention of complications, good ulcer management programs, provision of suitable footwear and disability prevention and management. Rehabilitation requires skills in assessment of the extent of dehabilitation, assessment of family resources and marketable skills available with the affected persons and their families, entrepreneurship, public relations, management, identifying and mobilizing resources for rehabilitation activities and helping the affected persons to have access to income generation schemes of the Government and other organisations besides actively promoting 'inclusion' of the affected in various contexts.

8.6.1 Patients who need rehabilitation

Limited data is available regarding the size of the socio-economic problems due to leprosy in a given study. A summary of the findings from an early study conducted in 1967 (Srinivasan & Noordeen) show that 30% of adult males (15-60 years) out of the group of 409 examined, complained of economic worsening due to their having leprosy and about 85 % of them had ceased to be self – supporting. Prevalence of economic worsening due to leprosy in the population studied was about 20/10,000 and prevalence of economic dependency was about 16/ 10,000. More recent studies though not comparable, give a rough idea of the ground situation :

Table 8.2 People with leprosy having socio-economic problems

Year	Researcher	% having economic or socio-Economic problems due to leprosy
1993	Sivkumar & Srinivasan (unpublished)	45 % of 671 patients
1995	Kopparty et al	21 % of 500 families
1997	Gopal	35% of 53,550 patient responders

It is incorrect to assume that all patients with deformities or only those with deformities require rehabilitation. Many do not realize that a substantial proportion of leprosy affected persons in dire need of assistance (for preventing dehabilitation) do not have disabilities, but are getting dehabilitated because of societal prejudice against them as leprosy affected persons. A study of the process of dehabilitation conducted by the International Leprosy Union (ILU) in two different states of India found that about 43 % of 1071 dehabilitated leprosy affected persons (i.e. displaced from their homes) had no disability when they left their homes. Such persons will not qualify for the concessions related to employment, etc accorded to the disabled because they do not have the requisite' percentage of disability' as defined in the "Persons with Disability Act" (Act I of 1996) of the Government of India, although they are greatly handicapped by their being labeled as 'leprosy patients' or 'leprosy cured'.

Little or no data is available to confirm, if deformity correction is essential for rehabilitation. Further, disability is not an essential pre-requisite for leprosy affected persons to be dehabilitated, as pointed out earlier, and there are large numbers of leprosy affected who have disabilities but are not dehabilitated. It appears that atleast 50% among those with WHO grade 2 disabilities may belong to the last category.

Assuming that little has been studied in the field of rehabilitation Srinivasan (2002) suggests to gather information to develop a plan :

1. The disability (grades 1 & 2 of WHO classification) load and its profile in the given community.

2. The demographic profile of this population, including family size and what proportion feels it is handicapped because of leprosy and its consequences.

3. The effect of leprosy on the economic status of the affected individuals and their families (economic worsening or impoverishment vis-s-vis the local population).

4. The effect of leprosy on the social status of the affected individual and family (level and contexts of discrimination, participation restriction and loss of social status).

5. The 'rehabilitation potential' of the diversely affected individuals and families.

6. The available local 'rehabilitation resources' in the given area in the Government/NGO/VO/private sector.

7. Among those with impairments and disabilities, a list of those who are fit and willing to undergo corrective surgery & the resources that exist in the area for carrying out a time-bound reconstructive surgery program.

8. The magnitude of the different kinds of possible solutions to the problem of ; impoverishment of the affected individuals/families and promoting 'inclusion' of the affected.

9. The measures needed for enhancing the self-esteem of the affected persons and their families.

10. The attitudes of the local opinion leaders and service organisations regarding their willingness and ability to assist in the rehabilitation of the needy leprosy affected persons in their locality.

8.6.2 PHCs and rehabilitation

The participation of PHC in rehabilitation services has remained very limited (WHO, 2001, WHO/ILO/UNICEF/ UNESCO/UNHCR, 2001). The reasons mentioned for lack of rehabilitative services through PHC include :

• Insufficient coverage of PHC services.

• Lack of sufficient staff and structures in PHC systems.

• Lack of time by PHC staff.

• Vertical programs and special campaigns, by providing incentives to get more attention from PHC staff, leaving less time for other activities.

• Lack of training on rehabilitative aspects in the training curriculum of primary health care workers.

8.6.3 Community Based Rehabilitation

CBR approach has been shown to be effective in promoting holistic rehabilitation and empowerment of persons with disabilities. The WHO manual of CBR (Helander et al, 1989) has three specific modules on 'persons with lack of sensation; that provide information about prevention of disabilities and simple measures for preventing worsening of existing disabilities. In addition, other modules of the manual, especially those dealing with difficulty in movement and preparation of simple mobility aids are also useful for persons with leprosy-related disabilities.

Rehabilitation of leprosy patients is a shared responsibility and integration of leprosy into the GHS is the future of rehabilitation (Virmond, 2002). WHO has already mentioned this path while stating that solutions to the problem of leprosy affected persons should be viewed in the general context of development. Access to all existing programs of poverty alleviations and development, welfare and/or rehabilitation, including community based rehabilitation, should be made available to leprosy affected persons as well (WHO 1998).

It is assumed that 70% of people with disabilities can be handled at the community level, while the remaining 30%, comprising people with severe and multiple disabilities require specialist intervention that are not available at this level. CBR was promoted to achieve wider coverage at costs that were affordable. Thus, a CBR approach is the best way for the vast majority of leprosy affected disabled in India.

Specific rehabilitation infrastructure working only for leprosy affected persons can play a key role in the initiation and extension of CBR programs. Within this, organisations of leprosy affected persons still play a limited role in the rehabilitation initiatives directed at persons with leprosy related disabilities. Rehabilitation projects will need to strengthen such organizations and create equitable partnerships with them.

The consequences of leprosy may extend far beyond the medical realm. Therefore, a holistic care of those affected by leprosy should encompass social, economic and emotional well-being. Thus, the design of rehabilitation programs should be need based and localized.

8.7 Monitoring, surveillance and evaluation of elimination program

Several important considerations are to be made for the achievement of leprosy elimination. Part of these are appropriate methodologies and implementation of monitoring and documentation of the process of the elimination program. This will enable the assessment of the outputs and outcomes. Trends in the past years have shown no decrease in case detection rates and new cases will continue to occur. Validation of new case detection methods must be established and documented. The models for elimination such as integration and its processes require to be studied, documented and justified for replication, if found successful. The potential of information technology should be harnessed to establish an effective surveillance system in order to identify specific problems, including identification of leprosy pockets at sub-national levels.

8.7.1 NLEP and LEM

NLEP is already equipped with an inbuilt information system for concurrent monitoring and feedback for timely corrective measures at various levels of program implementation. This has further evolved into the SIS to stand the test of integration, wherein all those newly oriented into the leprosy program from the GHS will find it easy to implement. The system of LEM is required to assess the performance of leprosy services and envisages to collect key information on issues of integration, quality

of leprosy services like diagnosis and treatment (MDT), drug supply management, IEC, etc. The first LEM exercise was carried with WHO support in 2002 in 12 states (74 sample districts) and is planned to be repeated at the national level for the next three years. The major indicators being prevalence, new case detection, delay in diagnosis, integration indicators (MDT provision in GHS and availability of blister packs) and quality of MDT services. In 2003 a similar exercise but expanded to cover 77 districts and additional indicators of implementation of SIS, community awareness and validity of diagnosis was conducted.

It is important to be aware that we need to continue to look for leprosy cases or we may make it disappear by ceasing to look for it, a danger that leprologist have been cautioning against. This is where Surveillance assumes significance. Surveillance is defined in terms of disease reporting for action . Specifically, it is the routine, systematic collection of morbidity and mortality data, its compilation, interpretation and dissemination and finally the necessary action based on these data.

Simplified Information System (SIS) is the 'New' surveillance systems are being established to ensure that the appropriate information on leprosy patients is collected and managed after integration. Even after elimination surveillance never goes away; it is an essential part of public health practice. If leprosy cases increase then this needs to be noted and checked. This can only happen when there is a surveillance system.

There are many factors that affect the case detection of leprosy so that transmission can be broken and elimination of leprosy achieved such as awareness programs, active case detection and socio-economic factors. The establishment of a sentinel surveillance system along with a computerised SIS will ensure operational efficiency.

8.7.2 Case validation for diagnosis

Cleaning of registers' exercises are important for case validation to eliminate over-detection, under-detection and mis-diagnosis. A review of registers in Tamil Nadu indicated that about 38.8 % of cases should not have been on the registers. Most of these cases had completed the treatment and should have been struck off the registers. Similar register-cleaning exercises were carried out in several countries of Africa with WHO assistance in 2001 and 2002. Similar results as found in TN were present in African countries (30-35 %). Thus, programs should carry out systematic validation exercises and sensitise health functionaries at various levels on the need to address the problem.

The exercise of validation was undertaken for the first time in India in 2003 . There were 12 states covering 2,541 new cases of which 1,503 were actually examined by the validators. The findings were very significant reflecting the corrections required for proper diagnosis and the immediacy for it too. The conclusions of the 2003 LEM, particularly from the case validation are :

- The Indian program has a serious problem of over reporting of prevalence and case reporting (40 % of over-reporting).
- Estimation of underreporting could not be made with the current methodology and some rough methods need to be developed to assess the level of underreporting.
- Delhi, Karnataka and WB have a serious problem of over-reporting.
- MP, Maharashtra and Orissa have problems of over diagnosis.
- Maharashtra and Tamil Nadu have problems of maintaining patients under treatment beyond the stipulated period.
- Remedial actions are urgently required in Delhi, MP, Maharashtra, Karnataka, Tamil Nadu, West Bengal and Andhra Pradesh.

8.7.3 Validation of elimination

To assess the progress of leprosy elimination activities more effectively, data needs to be collected separately for urban and rural areas while preparing district/state reports. The DLO/DHO/municipal health officials should try to collect information also from private hospitals, dermatologists, etc to assess prevalence and detection more accurately.

Twelve states/UTs have so far reached the goal of

elimination i.e. PR of less than 1/10,000. There is no standard method to assess low levels of leprosy prevalence in a population for certifying achievements of elimination level. On the suggestion of WHO Technical Advisory Group, a pilot testing of validation of elimination of leprosy by Lot Quality Assurance Sampling Technique was undertaken by the GoI in Himachal Pradesh and Meghalaya through the Central Leprosy Teaching and Research Institute, Chengalpattu, TN in 2002-3. It is important to develop a procedure for monitoring and certification of elimination of leprosy. A new indicator should be developed in conjunction with other essential indicators to show whether or not leprosy elimination is sustained.

The development of a suitable epidemiological indicator that would reflect the true magnitude and the disease morbidity in the community along with a computerised SIS will ensure operational efficiency of the elimination process. A system to provide ongoing feed back for mid course corrections should be inbuilt. It is important to develop a procedure for monitoring and certification of elimination of leprosy.

8.8 Capacity building of GHS / training of GHS staff

The current medical education leaves much to be wanted where leprosy is concerned. This scenario will have to change in order that all GHS personnel obtain adequate knowledge on leprosy and its care. In a survey of 106 medical colleges in India, it was found that the average time spent on leprosy is 4 ½ hours during three years (McDougall & Wendal, 1980). There were also serious defects in the teaching of leprosy in India. One can anticipate the inadequacy in a scenario where the GHS personnel who have graduated from such medical institutes will be expected to treat leprosy patients. Probably motivated trainers and specialist on the subject do exist in the vertical programs. And with the help of these persons appropriate modules can be developed for health care providers training in leprosy treatment. Till formal curriculum is added through instituting new medical education policy, a transfer of knowledge and skills program will be a stop gap arrangement to ensure that personnel in the GHS have minimal skills in leprosy care.

The medical students provide a large and important "captive audience" in medical schools who can be trained in the basic aspects of leprosy, including development of a positive attitude towards the disease and clinical contact with patients (McDougall, 1986). Though repeated attention has been drawn to the lack of proper teaching-learning modules in leprosy-endemic countries, no satisfactory module exists (McDougall, 1986). Keeping in view these facts, Karthikeyan and Thapa (2003) drafted a suitable module that could be used to teach the undergraduate students about leprosy in a simple and comprehensive manner. They conducted two types of modular training for undergraduate medical students on leprosy. The modular teaching program was an interdisciplinary approach to impart comprehensive and holistic knowledge of the disease to the students as per the new guidelines of the Medical Council of India. The modules were designed to supplement and reinforce the importance of knowing and having a total concept about leprosy-a public health problem. Both the modules were different in certain aspects, but the basic concepts were the same. Module A had more time, and hence certain practical aspects were also discussed. Improvements in post test scores over pre-test score were marginally different at 17 and 15 for modules A and B respectively. It proved that both the modules were effective in conveying the core message about leprosy.

A patient survey of MLEC in TN and AP (Subramanium, et al 2003) brought out the various obstacles in voluntary reporting. It brings forth the need to involve other medical personnel in addition to the public health system, to be sensitized to suspect leprosy while examining patients. The study showed 48% of people with leprosy were aware of the disease but do not perceive the presence of the patch on their body as early stage of leprosy or do not approach the health delivery system due to socio-economic reasons. Yet about one third of the patients had visited a general hospital for other reasons within the previous one year.

The successful launch of the integrated programme needs formal training in leprosy to all categories of staff and

they should be informed more about the concept of integration and new job requirements. Managers need clear understanding of the priorities to place equal emphasis on leprosy and other priority programmes. Supervisory staff need orientation in understanding the community's response to the changed situations, and in maintaining the records in a comprehensive manner. Field workers need to improve self-confidence about the quality of their services. This needs special attention while developing guidelines and the motivational component of the training, considering the difficulties voiced by them. The requirement of physical space is to be looked into wherever needed.

Urban health program managers should ensure facilities for training and retraining. Vertical programs should take active steps to transfer simplified field knowledge and skills to urban primary health care personnel. Technical guidance will have to be sustained to manage difficult cases, tackle complications, handle disabilities, check over-diagnosis or misclassification. The experience of Myanmar in integrating MDT in the Basic health services (BHS) successfully, shows how the BHS staff had undergone clinical and managerial course for leprosy control and obtained support from the vertical leprosy program. Similarly, the training of GHS staff in Maharashtra should be task oriented and should take support from the leprosy vertical staff which has immense expertise on the subject.

Thus, the elements of capacity building will encompass :

The launch of the integrated programme with formal training in leprosy through transfer of skills and knowledge to all categories of staff wherein they will be informed more about the concepts of integration and new job requirements to achieve the goal of leprosy elimination.

Programme / Health Managers are to be given clear understanding of the priorities to place equal emphasis on leprosy and other priority health programmes.

Supervisory staff need orientation in understanding community's response to the changed situations, and maintaining the records in a comprehensive manner.

Basic Health System Field workers need to improve self-confidence about the quality of their services.

Special attention to be given while developing guidelines, and motivational component of the training, considering the difficulties voiced by them.

Reviewing the issues concerning infrastructural and logistical needs of the training program will strengthen capacity building.

8.9 Provision of Referral services

Assuming that the Government health services will provide free diagnosis and MDT, the other equally significant elements of leprosy elimination and control, such as awareness, counseling, physiotherapy and rehabilitation services need to be provided. A system of special services /referrals need to be developed with pooling of resources between partners, from the government, NGOs and other private health agencies.

A detailed list of services need to be drawn up and sites/ agencies mapped out in the locality where the MO can refer cases to. The MO and other personnel must be oriented to the fact that a leprosy patient may need different treatment in addition to MDT and where that service can be available. Follow up should be ensured through the PHC linking up with these agencies and the case progress should be recorded.

The General health services of the Government will provide free diagnosis and MDT. The other equally significant elements of leprosy elimination and control, such as awareness, counselling, physiotherapy and rehabilitation services need to be provided through an institutionalized system by special referral services.

8.10 Partnerships and NGO Involvement in leprosy elimination

NGOs have been involved for the cause of leprosy elimination for many decades and their contributions have made a positive impact in reducing the prevalence of leprosy. It has been well recognized that the voluntary or NGO sector has much more credibility where leprosy care at the individual and community level is concerned. 60 % of the leprosy care and management in India is done by the NGO sector and the rest by the government. Most of these NGOs have been working as partners along with the Govt under the SET (Survey, Education and Treatment) Scheme.

The Line of Actions for Integration outlined by the Govt suggests that partnerships for implementing the elimination of leprosy be created and MOUs be signed with them, NGO can thus be concerned with providing diverse support to leprosy elimination like: Develop Capacity building programs, undertake training and CME, develop effective communication strategies, provide referrals services including management of complications and reconstructive surgeries, provision of foot wear and assistive devices, socio-economic rehabilitation, facilitation in drug compliance and early case detection.

The perspectives of the GHS in the treatment of leprosy will be different from that of the NGLOs before integration. These roles will stand apart since the Government will be concerned with treatment to patients to bring down numbers in terms of prevalence and incidence, making leprosy a no risk in term of public health- A question of handling of the disease. Whereas, the voluntary agencies are committed to the welfare- physical as well as social of every patient approaching it. Hence their function does not cease when the numbers come down to a minimum level, but their role is there as long as even one patient exists who has medical, physical, social and vocational problems to overcome.

More than 290 NGOs are working in the field of leprosy through out the country and they have been encouraged to play key roles on various leprosy elimination related activities. ILEP, an international NGO has been supporting 13 states with 138 District technical support teams and their role has been redefined recently to assist in the integration of leprosy services with GHS and their capacity building. (Ashok Kumar, Dy. Director General and Project Director NLEP GoI, 2002). While the process of preparation of the GHS to develop a willingness to undertake leprosy treatment takes its time, the NGOs can assist in the assimilation of leprosy treatment into the GHS. There will also be the issue of the voluntary sector continuing to undertake rehablitation services to the patients and ex-patients, a service not offered by the govt. sector. Thus, the role of the NGO sector is widened by the integration to assist in transfer of knowledge and skills through capacity building of GHS staff and providing referral services.

The Modified SET scheme of the GoI has outlined the following activities for NGOs :

• Planning., • Surveillance and information system.

• IEC. • Capacity building. • POID. • Rehabilitation

• Referral. • Advocacy • Case Detection and MDT delivery •District Technical Support Teams.

Although NGLOs would be in a better position to contribute to the process of elimination of leprosy, other health NGOs too have a scope through the integration process. Networking of NGOs too could broaden the base of communities to provide an increased outreach for IEC and referral services.

It has been well recognized that the voluntary or NGO sector has much more responsibility and credibility where leprosy care at the individual and community level is concerned. And yet the Government is relied upon for its extensive service reach, infrastructure and resources. Collaborations, partnerships and co-ordination between the different service providers alone can give the best treatment and care to those affected by leprosy.

9. LEAP – Activity Phases

The LEAP is envisaged for a period of 5 years with a preparatory period until 2004. The five years will have a good system of monitoring and will be evaluated mid-term in 2007 on various indicators of integration.

The period up to 2007 will see the development of programs and systems for integration of leprosy services in the GHS. The period soon after that will be to study and consolidate the elimination process through well documented and successful activities.

Preparatory Phase : April 04 – March 05

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 - phasewise : 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" as partners. This is essential to plan to execute a long term collaboration with the multi partners under a common programme (2005 - 2010).

"LEAP" is the common programme of action proposed - it needs a common organisational context.

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

PART FOUR

Focus on task based activities under
Leprosy Elimination
Action Programme
(L E A P)

March 2005

1. purpose
2. an epidemiologists' point of view
3. integration : advantages and challenges
4. basis for LEAP strategy
5. LEAP : a strategy for integration
6. LEAP : goals & specific objectives
7. selective special drives
8. continuing medical education
9. referral & special guidance centres
10. epidemiological reporting & monitoring
11. leprosy: too complex a disease
12. for a simple elimination paradigm
13. WHO & NLEP : recommendations

The Purpose

The process of Integration is not an 'all-or-none' event: hence the manpower and expertise available within the vertical programmes should seek out ways and means to promote decentralized interventions through the wide network of general health care services, both public and private.

ALERT-INDIA proposes a strategy called LEAP as a direct response to leprosy patients needs in the future. LEAP is aimed to reach out to the leprosy affected persons through community approach and appropriate activities during Integration phase.

This issue of "FOCUS" provides an overview of LEAP strategies with specific interventions proposed under LEAP that would complement the tasks and ensure achieving the goal of leprosy elimination. Practical application of interventions are suggested in brief to fulfil each specified task.

It is hoped that the LEAP will greatly facilitate the Integration process by practical support based on a feasible strategy enabling both the health care providers and the community to make the goal of leprosy elimination a reality for people.

ALERT INDIA invites all the stakeholders to take active part in this concerted effort to ensure a better use of resources available with all of us today and work with the general health sector and contribute to the success of Integration.

A Antony Samy
Chief Executive, ALERT INDIA

NB : The LEAP publication titled 'FOCUS' Series No. 3 is completely reproduced as the issue is out of print and is relevant for the current period

Integration : advantages & challenges

The policy today . . .

The **structural integration** has taken place making the diagnosis and treatment facilities for leprosy available through a large network of PHCs & health posts in most of the states in the country. Thus the entire General Health Care (GHC) system is made responsible to treat and cure leprosy.

The very **purpose of Integration** makes it imperative that the responsibility of the leprosy treatment must lie with the GHS staff. Hence, the **focus on Integration** demands improved logistics, changing attitude of the people and training of general health care personnel.

However, the Govt. of India's (GOI) has declared that the National Leprosy Eradication Programme (NLEP) will continue its leprosy elimination activities with the same vigour till the end of 10th Five Year Plan, i.e. March 2007.

LEAP is possible . . .

Rationale for LEAP

Rationale for LEAP is to bring together all the prospective partners, reorganise the existing **assets**, reorient to make best of the **potentials** and **opportunities** we have today. All partnerships and linkages will be promoted and assisted to enhance the reach and the quality of the services to the leprosy-affected individuals.

Asset

The expertise available with the vertical leprosy staff need to be transferred with appropriate orientation and inputs to the GHC staff by an effective practical process. Trained manpower available today with Government & NGLOs can be re-oriented and redeployed effectively for achieving this goal. The expertise and experience of NLEP manpower could be revitalized for strengthening the Integration. Hence, utilizing the vertical leprosy staff for TB & AIDS activities is unwarranted at this stage.

Potential

A large number of public health functionaries and resources are available with the GHC system. They have a potential to become a reliable ally in the course of time to make integration a success. Hence, it is necessary to train and work in partnership with all the GHC personnel to detect, treat and cure leprosy. This includes specialists, medical students of all disciplines and other health professionals including private medical practitioners. Health administrators and policy makers also need to be sensitized to make this process smoother.

Opportunity

Efforts to pool all the resources available in the present vertical system and working in partnership enlisting involvement of all the health care providers cannot yield the desired results without community partnership. The success of Integration largely depends on the community involvement and education to promote voluntary reporting of cases in the absence of active surveys. Integration provided this opportunity.

Basis for LEAP strategy

Government of India has recommended many positive steps and guidelines for NGLOs to strengthen the process of Integration. ALERT INDIA supports integration in letter and spirit and it has envisaged a complementary programme called **LEAP : "Leprosy Elimination Action Programme",** which is based on a community partnership strategy to help in achieving the goal of leprosy elimination.

The primary objective of LEAP would be to meet all the needs of leprosy affected persons by building partnership with the community, NGOs, CBOs, general health care system and above all the NGLOs. The following are the basis for LEAP:

1. Detecting all new leprosy cases, at an early stage, particularly those from endemic and inaccessible areas. This will only be possible through adopting different approaches. Experiences show that during the Modified Leprosy Elimination Campaigns (MLEC) when an active search was undertaken to detect new cases, it encouraged more number of people to seek treatment voluntarily at the Voluntary Reporting Centres (VRC). Therefore, the need today is for a sustained campaign with active community participation.
2. Appropriate diagnosis, prompt & uninterrupted MDT delivery and case holding to ensure the compliance for treatment are the key to achieve the goal of leprosy elimination. Laying foundations for such a practice in general health care need to be a continuous task of NGLOs for the coming decade or more.
3. Early detection of disability and its proper management will prevent deformities. Services for prevention of disability and impairments should go hand in hand with MDT services, to make leprosy treatment more comprehensive. Participation of public and private health care givers is crucial for the future.
4. The consequences of leprosy extend far beyond the medical realm. Therefore a holistic care of leprosy affected by the NGLOs should encompass physical, social, economical and emotional well-being. Special community based efforts, institution supported care and vocational rehabilitation need to continue.
5. Information, Education and Communication (IEC) is instrumental in bringing about awareness, that aims at reducing stigma and discrimination thereby motivating more people to seek treatment. Communication (mass & inter-personal) is a good channel for doing away with myths and misconceptions about leprosy.
6. Suitable epidemiological indicators need to be used that would help to assess the true magnitude and the disease morbidity in the community. These will ensure operational efficiency of the elimination process at all levels.

LEAP : a strategy for integration

"LEAP" is a strategy for a joint action with all stakeholders and partners to facilitate the integration process through a community-based approach, in the best interest of leprosy affected persons.

LEAP is 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 during 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/ multi-purpose workers) 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 goals. This is an advantage, which needs to be utilised to realise the goals of integration.***

3. **To study the lacunae and to develop a feasible, replicable, supportive methodology for strengthening integration as well as to sustain the provision of leprosy care services in collaboration with the multiple partners (NGLOs/ 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 assist the public health personnel by direct & indirect supportive actions and programmes to detect, treat and cure leprosy on par with any 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 NGLOs and other partners to work independently for a common strategy.** ***Pooling strengths and resources will definitely make a difference in the present context.*** *Take up tasks (relevant activities) for the benefit of leprosy-afflicted persons that can directly or indirectly promote integration.*

Views. . .*that matter*

Anti-leprosy activities will have to be continued without any break

It is clear that leprosy will continue to exist as a very limited problem in several countries even after 2005. This means the anti-leprosy activities will have to be continued without any break. However such activities will have to be more focussed, more integrated within general health services and should have good referral support.

Excerpt from the article on "Vision beyond 2005" by SK Noordeen, Indian J Lepr., Vol. 76 (2), 2004, p 171

The Holistic principle

It includes activities that address every aspect of life of leprosy affected persons. It requires teamwork of different professionals towards prevention of disability, elimination of dehabilitation and achievement of social integration. Rather than creating special services for people affected by leprosy, one should use existing services through networking.

Excerpt from the article on "Social and economic rehabilitation of leprosy patients" by SD Gokhale, Health for the millions, Jan - Feb 2001, Vol. 27 (1), p 13.

Participation of the people

Leprosy is a people's problem and people have to solve it. Once we can get the participation of the people, it becomes people's programme. So along with community participation, we will give the promise to our generations, a leprosy-free world.

Excerpt from the article on "Drawbacks of Integration" by Sumit Talukdar et al, Indian J Lepr., Vol. 76 (3), 2004 p. 270

Need for a comprehensive approach

Successful launching of the integrated programme needs formal training in leprosy to all categories of staff and they should be informed more about the concept of integration and new job requirements. Managers need clear understanding of the priorities to place equal emphasis on leprosy and other priority programmes. Supervisory staff need orientation in understanding community's response to the changed situations, and maintaining the records in a comprehensive manner.

Excerpt from the article on "Integration of the leprosy programme into PHC: A case study of perceptions of primary health care workers" by MS Raju & V V Dongre, Indian J Lepr, Vol. 75 (3), 2003, p 257

LEAP : GOALS

1. To strengthen the process of Integration through a community partnership approach.

2. To involve all the stakeholders as partners in LEAP to achieve the goal of leprosy elimination.

LEAP : Specific Objectives

1. To reach out to all new leprosy patients through intensive community level IEC campaigns and selective special drives - specially in the endemic areas.

2. To augment the capacity building efforts of GHC personnel by imparting Continuing Medical Education to all medical professionals and health care functionaries.

3. To offer timely and comprehensive care to all leprosy patients during Integration phase, through a network of Referral Centres (RC) or specialized service centres of NGLOs and NLEP Institutions, in collaboration with the public & private health care providers / Institutions for specialized services by Capacity Building.

4. To monitor and evaluate the outcome and the impact of all interventions proposed, supported and supplemented under LEAP.

Views. . .*that matter*

Provide basic positive information

Leprosy elimination cannot be achieved in the absence of social awareness and action: however it can be achieved by providing basic positive information about leprosy aimed at changing people's attitude from fear to understanding and from apathy to participation so that early diagnosis and modern treatment can be used to provide cure.

Excerpt from the article on "People's perception of leprosy - A study in Delhi" by Harvinder Kaur & Anjali Gandhi, Indian J Lepr, Vol. 75 (1), 2003

Case detection influenced by leprosy elimination campaigns

The village leader and village paramedical workers held gatherings of residents in their villages to inform them where, when and how to obtain leprosy services free of charge. Individuals with suspected leprosy could go to the nearby township hospital or village clinic for examination. Because the village leader and village paramedical workers knew the villagers well, there was no house-to-house search for leprosy, except follow-up of household contacts. Due to improved community awareness and increase service coverage, many self-reported cases were detected by health services during and after the LEC.

Excerpt from the article on "Trends in case detection influenced by leprosy elimination campaigns in certain areas of China" by Shen Jianping et al, Indian J Lepr, Vol. 76 (1), 2004, p 41.

Easily accessible target group for education or intervention programmes

Enhancing the community awareness about leprosy is vital to the early reporting of cases. It is imperative that all categories of society, such as teachers, school children, village leaders and communities, get involved in the early reporting of 'suspect lesions'. Since school-going children account for roughly one-third of the population and will become the future generations of society, creating awareness among them would have a long lasting beneficial effect. They are an easily accessible target group for education or intervention programmes.

Excerpt from the article on "Leprosy case detection using school children" by G Norman et al, Lepr. Rev., Vol. 75 (1), 2004, p 34

Specific Objective : 1

To reach out to all new leprosy patients through intensive community level IEC campaigns and selective special drives - specially in the endemic areas.

Rationale

1. Routine surveys are discontinued due to low yield of new cases and increased cost. This calls for a renewed strategy. However, the continued detection of significant number of new cases with early deformities and disabilities call for an intensive community awareness programme involving larger participation for wider reach.

2. Invariable incidence of new cases (NCDR) and reduction in prevalence of active leprosy cases (PR) calls for special interventions during the Integration phase.

3. Continuing ignorance about basic scientific information on early signs of leprosy and socio-religious myths need to be countered consistently in the general community to promote voluntary reporting.

4. Constant migration of population from the leprosy endemic areas into urban and semi-urban areas makes the task difficult for the health service providers to break the chain of transmission.

Tasks

1. Promoting voluntary reporting of new cases through effective Information Education & Communication (IEC) campaigns with multiple communication tools at community level to spread Basic Scientific Information (BSI) and counter Socio-Religious Myths (SRM).

2. Undertaking Selective Special Drives (SSD) by identifying and focusing on the community in a given geographic area for new case detection based on specific epidemiological indicators.

3. Organizing Targeted Special Drives (TSD) focusing floating population - migrant labourers, seasonal agricultural labourers, including nomads in cities and rural areas, if new cases are detected among them.

4. Pursuing Extended Targeted Special Drives (ETSD) to reach the place of origin of new cases identified from migrant groups.

Specific Objective : 1

Task 1

Promoting voluntary reporting of new cases through effective IEC campaigns with multiple communication tools at community level to spread Basic Scientific Information and counter Socio-Religious Myths.

Task Based Activities

Identify a localized community from where more number of new leprosy cases had reported in the recent past. Involve the local Community Organizations and motivate volunteers to undertake IEC campaigns to sensitize the community. On identifying the community, undertake the following activities:

1. Identify the locally and culturally relevant IEC tools to conduct IEC campaigns in the specified community.
2. Identify and sensitize the local NGOs, Community Based Organizations (CBOs) and other groups in the community.
3. Conduct orientation training programmes for selected members of the community and involve them as volunteers in IEC campaigns.
4. Conduct mass awareness activities with the help of community groups using either Inter-personal Communication, one to one & group approach using flip charts, slide / film shows, leaflets, street plays, etc.
5. Use suggested slogans to convey messages on Basic Scientific Information (BSI) and counter Social-Religious Myths (SRM) about leprosy in all IEC tools to counter the misconceptions and spread scientific facts in the community.
6. Display banners & hoardings at prominent public places / Offices / Institutions / Schools & Colleges / Hospitals / Nursing Homes / Private clinics with messages on signs and symptoms about leprosy.
7. Display posters or stickers on leprosy in all the public transport services like local trains, buses, taxi & autorikshaws.
8. Write short messages about leprosy on the notice boards of any community organization during community meetings and celebrations.
9. Distribute pamphlets or leaflets on leprosy in the vernacular language through the school students [NSS, Scouts & Guides] or community based volunteers.
10. Organize slide shows, street plays, cultural programmes, rallies, exhibition at public places with the help of the local Organizations and community groups.
11. Contact local cable network and convince him to show messages or short films on leprosy and related issues.
12. Give positive messages about leprosy using human interest stories in the local newspapers & newsmagazines.

Specific Objective : 1

Task 2

Undertaking Selective Special Drives (SSD) by identifying and focusing on the community groups in a given geographic area for new case detection based on specific epidemiological indicators.

Task Based Activities

Select epidemiologically significant zones in slums or villages and undertake Selective Special Drives - (i) identify a geographical area or (ii) a specific pocket in it or (iii) a population group in it (e.g. ragpickers or recent settlers or economically backward community) - based on the criteria, which suggests the possibility of detecting new leprosy cases and carry out the following:

1. Sensitize the local community leaders, opinion makers, elected representatives etc., about leprosy and gain their support to reach the local community and inform them about the objectives and methodology and the need for active community participation.
2. Obtain or collect a list of all organised & unorganised, registered & unregistered, formal & informal groups [e.g. ICDS and CDPO Network, Anganwadi Teachers, Mitra Mandals, Mahila Mandals, School teachers, Religious & cultural groups, etc. including NGOs & CBOs involved in health and community organization work] and organize meetings with the representatives of each of these groups and appraise them about the programmes.
3. Identify and motivate volunteers from these organizations & community and organise training programmes according to the training module for the identified volunteers. Inform them about their role in the programme and involve these volunteers in undertaking IEC programmes for spreading Basic Scientific Information (BSI) to counter Socio-Religious Myths (SRM) through Inter-Personal Communication (IPC) & group awareness activities in the community.
4. Suspect cases of leprosy in the selected area within a time frame by involving the selected/ trained community volunteers. Wherever possible, (specifically in areas of NGLOs & NLEP Units already working for leprosy) deploy or engage a trained leprosy worker and make him responsible for implementing the SSD, to guide and train the volunteers as well as monitor the SSD activities in the area along with the concerned ANM / MPWs to the extent possible.
5. The leprosy worker of Govt. & NGLOs need to coordinate with the local health worker of Health Post or PHC in organizing referrals & follow up of all the suspects identified by the volunteers for

Specific Objective : 1

Task 2 (cont.)

Task Based Activities (cont.)

confirmation and treatment of leprosy at the respective Centre of the GHC system.

6. All attempts to be made to utilize the resources and facilities available with the community groups and local Organizations (resources could be in kind, manpower or time) for conducting IEC activities during SSDs.
7. Encourage trained volunteers to motivate other peer groups in the local community who will continue to do IEC activities and suspect new leprosy cases and refer them to the nearest GHC centre even after the SSD campaign is over.
8. Ensure sustained contact with the local trained volunteer by way of periodical feedback meetings / supply of new campaign materials for sustained campaign.
9. Do make it a point to felicitate the volunteers with due public acknowledgement - certificates - for their contribution to the community. Involvement of local leader do help.

Select schools in epidemiologically significant zones and undertake SSDs - identify the school from where more number of child leprosy cases reported in the recent past and carry out the following activities:

1. Obtain permission from the concerned Education Department and liason with the local school authorities.
2. Identify and motivate the teachers and train them in IEC activities and to suspect case of leprosy among the school children.
3. Select a group of senior level students among the students of the school as 'peer educators'.
4. Trained teachers and the local volunteers will train these peer educators and they will undertake IEC programmes in school.
5. Refer the student who report with signs and symptoms of leprosy to the nearest GHC centre for confirming diagnosis and treatment.
6. Maintain liason with school for assisting in implementation and give necessary feedback to the respective general health care centre on the cases detected among children referred by school.
7. Promote awareness among the students through inter-school competition in essay or slogan writing and drawing posters and other such participatory initiatives.
8. Encourage the teachers and students to carry out exhibitions on leprosy during the functions organized by the school or conduct rallies for public awareness in the local community with the help of the local NGLOs or NLEP institutions.
9. Felicitate the school students & teachers at an appopriate time for their involvement in awareness campaigns and for their contribution in participating in the drive.

Specific Objective : 1

Task 3

Organizing Targeted Special Drives (TSD) focussing on floating population such as migrant labourers, seasonal agricultural labourers including nomads in cities and rural areas, if new cases are reported from them.

Task Based Activities

In order to conduct TSD, identify a cluster of migrant population who will be either staying temporarily in the project area or available only at specific time or seasons and undertake the following activities.

1. Target a population group where new leprosy case has been reported, for e.g seasonal, industrial, construction and agricultural labourers and those people who are working in workshops, commercial units, restaurants as well as people who are displaced due to civic eviction and manmade or natural disaster.
2. Identify and sensitize person(s) from such population groups having same socio-cultural background and engage them as 'Peer educators' or as 'facilitators'.
3. Train them to conduct IEC programmes and also to suspect new leprosy cases among his own population groups and refer to the nearest health centre for diagnosis and treatment.
4. Maintain linkages with these peer educators in order to get feedback and also establish network with the local health centres for providing treatment.

Specific Objective : 1

Task 4

Pursuing Extended Targeted Special Drives (ETSD) to reach the place of origin of new cases identified from migrant or settlement population.

Task Based Activities

Identify the origin of new leprosy patients reporting from any migrant population / groups (recently moved into the area) from other States by undertaking the following activities:

1. Trace the place of origin [He may be from any other District or State] of population group of any migrant patient (s).
2. The identified 'peer educator' from the same group who will visit the respective village or the area from where these patients originated and will examine the population to suspect new leprosy cases with due information to the local health centre / district health officials.
3. The Peer Educator need to establish a liason with the general health service providers or with the District Technical Support Team (DTST) of that region to ensure diagnosis, treatment and management of all new cases.

Views. . .*that matter*

Supervisory capabilities should be built up

Integration requires critical planning and selection of suitable areas for integration bases on set criteria. Training of PHC staff is a key component of integration and must precede implementation. Since supervisors play a most important role in the success of the integrated system, supervisory capabilities should be built up. A specialized component of MDT services is required at the district level to handle complicated cases.

Excerpt from the article on "Study on integration of the NLEP into PHC services: A pilot project" by Inder Prakash & PS Rao, Indian J Lepr, Vol. 75 (1), 2003, p 34

Disseminating appropriate information on leprosy elimination

Capacity building for undertaking elimination activities will be done through simple, task-oriented, self-learning and user-friendly materials made available at local level. National training centres, educational institutions and local NGOs will play a key role in disseminating appropriate information on leprosy elimination.

The Final Push Towards Elimination of Leprosy, Strategic Plan : 2000 - 2005 WHO/CDS/CPE/CEE/2000.1/Page.11

Training of PHC functionaries

Reorientation training of PHC functionaries through sector meetings at the PHC level is suggested to strengthen their knowledge in operational aspects of the integrated leprosy programme for sustained MDT services. This will further improve communication between health care providers and the community and help in early diagnosis, case-holding and regular treatment.

Excerpt from the article on "Perspectives of leprosy patients on MDT services after integration of NLEP functions into primary health care" by T Sahu, NC Sahani & SK Sahu, Indian J Lepr, Vol. 75 (3), 2003, p 225

'Captive Audience' in medical schools

It becomes important to train medical students in developing countries, as they will play an important role in the community level activities against leprosy in future. Moreover these medical students provide a large and important 'captive audience' in medical schools who can be trained in the basic aspects of leprosy, including development of a positive attitude towards the disease and clinical contact with patients.

Excerpt from the article on "The medical student and leprosy" by AC McDougall, Leprosy Review, 57, p 97

Specific Objective : 2

To augment the capacity building efforts of GHC personnel by imparting Continuing Medical Education to all medical professionals and health care functionaries.

Rationale

1. An appropriate and updated knowledge & skills to diagnose and treat leprosy for medical and paramedical staff of GHC system is a need of the hour.

2 Lack of scientific knowledge and approach to leprosy treatment and care among the various indigenous and traditional medical practitioners.

3. Apprehensions about reaching the set target for leprosy elimination has created an uncertainity in the minds of budding doctors who are reluctant to take up leprosy as their career.

4. The absence of emphasis on leprosy in medical education has been largely responsible for depriving the essential services for leprosy patientss on par with other diseases.

Tasks

1. Training all the health personnel (especially MOs) of the GHC system to improve their knowledge and skills to diagnose and treat leprosy by offering practical & task-oriented training programme including para-medicals, nurses and others, indigenous and traditional medical practitioners.

2. Specialized Guidance Centres (SGC) to manage difficult and problem cases through imparting practical clinical guidelines to all practitioners. (apart from Referral centers)

3. Develop exchange and interaction between SGC and medical students as well as specialists like Surgeons, Ophthalmologists, Physiotherapists and others in the general stream to make the management of leprosy, a common knowledge and not an exclusive specialization.

4. Continuing dissemination of information through updates on clinical and epidemiological aspects to medical fraternity of all hues.

Specific Objective : 2

Task 1

Training all the health personnel (especially Medical Doctors) of the GHC system to improve their knowledge and skills to diagnose & treat leprosy.

Task 2

Offering practical and task-oriented training programme for all medical fraternity including medical, para-medical professionals, indigenous and traditional medical practitioners.

Task Based Activities

1. Enumerate all the medical and paramedical personnel working in the area or region. List all the nursing schools and other such medical / paramedical training centres, indigenous and traditional medical practitioners for providing orientation and training on leprosy.
2. Appraise and obtain necessary permission from the concerned Authorities and arrange for 2 day official deputation for training.
3. Select and depute staff for Training of Trainers (TOT).
4. Finalize the dates for the training in consultation with Master trainers.
5. Organise a 2-day Certificate course for Training of Trainers (TOT) according to the set module or invite faculty from other organisation or district, already trained to be Master Trainers.
6. A guide for Public Health Doctors (Published by ALERT INDIA) will be provided to all the trainees as a training & reference material.
7. Information about the MDT and Referral centres at District or Regional level need to be provided to all the trainees during the training programmes.
8. TOT for NGLOs and NGOs staff giving adequate knowledge and skills to train their health functionaries (other than Doctors) in their respective area or even in other area. (A model curriculum is available with ALERT INDIA)
9. If required, the Expert Team of trainers from LEAP will assist, guide and train the local Trainers team in the training of health functionaries in their area of work.
10. Organize training for members of the local branch of Indian Medical Association (IMA) on any convenient day mutually agreed.
11. Plan for a feedback on the training and follow-up on the impact of training refresher based on their need after a reasonable interval.

Specific Objective : 2

Task 3

Specialized Guidance Centres (SGC) to manage difficult and problem cases through imparting practical clinical guidelines to all medical practitioners.

Task 4

Continuing dissemination of information through updates on clinical and epidemiological aspects to medical fraternity of all disciplines.

Task 5

Develop exchange and interaction between SGC and medical students as well as specialists like Surgeons, Ophthalmologists, Physiotherapists & others in the general stream to make the management of leprosy, a common knowledge and not an exclusive specialization.

Task Based Activities

1. The existing treatment centres of NGLOs or Leprosy Institutions with thier experienced leprologist, surgeons and clinicians can act as a Specialized Guidance Centres (SGC).
2. These Centres can give clinical guidance to other specialist / medical consultants on the correct line of treatment to manage most difficult and problem cases.
3. Publications containing periodic updates giving information on clinical and epidemiological aspects can be made available to all the medical fraternity in Medical Colleges as well as to private medical practitioners.
4. Provide opportunities for medical professionals of any discipline who are willing to contribute their special skills for offering services to leprosy patients through exchange and interaction programmes with SGC.
5. The interested professionals can interact with the identified Special Guidance centres and exchange their expertise. eg. a general surgeon or a physiotherapist can learn skills from leprosy specialists through an exchange programme or specific placement for a specified period.
6. Organize special internship training for students of any medical discipline on the clinical management of leprosy at selected leprosy centres or Hospitals. (ALERT INDIA also promotes such an opportunity).
7. Specialized guidance on the management of leprosy can be made available to any individuals or to any Centres / Hospitals / Insitututions from anywhere in the World through Internet.

Views. . .*that matter*

Key Issue

When the disease burden goes down, it is likely that leprosy will retreat itself to some of its strong but small pockets and persist for quite sometime necessitating identification of such pockets and dealing with them effectively in a focussed manner.

Excerpt from the article on "Leprosy Elimination in India - Key issues" by SK Noordeen, Book on 'Leprosy Elimination - Critical Issues', Round Table Conference Series, No. 10, September 2002, p 220

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.

Excerpt from the book titles "The final push towards elimination of leprosy : Strategic Plan 2000-2005", WHO/CDS/CPE/CEE/2000.1

Finding segments of the population left out

Population coverage is never 100%. Always one finds segments of the population left out because of various reasons. Increasing the coverage would increase case detection. The only way of ensuring all new cases are detected as soon as they occur is to improve the coverage by involving the community for identifying and referring suspects.

Excerpt from the article on "Case-detection and diagnosis" by P Krishnamurty, Indian J Lepr., Vol 76 (2), 2004, p 154

Tribal villages

The tribal villages are small, scattered and difficult to reach by Jeep. In such areas the stress was to visit weekly market places, known as 'haats', which the tribal population invariably visits to sell its forest produce and purchase its daily household requirements. The 'haats' are located in an easily approachable central place and are held on a particular day of the week. The teams visited 'haats' and propaganda was carried out. All suspected cases and newly detected leprosy patients were started on appropriate MDT.

Excerpt from the article on "'Instant' new leprosy case detection: An experience in Bihar State in India - Strategy in tribal areas" by T Prabhakar Rao et al, Indian J Lepr, Vol. 75 (1), 2003, p 12

Specific Objective : 3

To offer timely and comprehensive care to all leprosy patients during Integration phase through a network of leprosy referral centres (LRC) or specialized service centres of NGLOs and NLEP Institutions in collaboration with the public & private health care providers / Institutions for specialized services by Capacity Building to improve the quality of life for leprosy afflicted.

Rationale

1. Lack of facilities at the GHC system to offer comprehensive care / specialized treatment for the leprosy patients, specially for those with disabilities and deformities.
2. Poor, delayed and inadequate management of leprosy related complications [reactions / neuritis] will result in disability.
3. Services for deformity prevention, management, vocational training to be located at regional/ district for easy accessibility to patients equipped with appropriate equipments and trained manpower.

Tasks

1. Establish NGLOs / NLEP units as 'Referral centres' at District and regional level to offer support services to leprosy patients who are referred by the general health care centres (MDT Delivery Centres).
2. Strengthening the existing referral centres of NGLOs, Dermatological departments (Private / Government Medical colleges) and Government Hospitals as 'Specialized Centres' - equipped for multiple services.
3. Creating effective linkages with the existing specializations at the Medical colleges, Hospitals and Institutions who can offer specialized services such as surgery, aids & appliances and vocational rehabilitation.

Specific Objective : 3

Task 1

Establish NGLOs / NLEP units as 'Referral centres' at District and regional level to offer support services to leprosy patients who are referred by the Primary Health Care centres (MDT Delivery Centres).

Task Based Activities

1. Collect all the information on all the services available for leprosy patients with the existing specialized centres of NGLOs and other institutions in any given zone / region or district of your operation.
2. Assess the needs of the leprosy patients who require specialized services such as physiotherapy, ulcer care, aids and appliances and surgical intervention and decide on the additional requirements to fulfill the needs of patients in the area.
3. Equip the Referral Centre with necessary facilities for the patients.
4. Reach out to the nearest surgical / hospitalization centers and establish liaison and linkages for referral and also initiate referral system to other Rehabilitation Institutions for specialized services to the needy leprosy patients.
5. Maintain individual patient records of all the patients referred by the GHC to monitor the progress after interventions.
6. Provide a feedback to the concerned Health Post / PHC from where the leprosy patient was referred for special services and ensure regular follow up of the patient.
7. Train and motivate the staff of the general health care system to treat the leprosy patients with complications and deformities as part of their routine work.
8. If such centres are not in existence, propose a suitable place for establishing a new Referral Centre, which must be accessible to most leprosy patients from the surrounding area - **if need for one exists.**
   (i) Initiate and acquire requisite permission from the respective authority for establishing a 'Referral centre' in the existing health centres.
   (ii) List the necessary equipments & supplies required to offer specialized services to leprosy patients at this Referral centre.
   (iii) Recruit / depute necessary personnel such as trained Medical Officer, trained Physiotherapist or Para-medical worker and an assistant.
   (iv) Provide specialized services including counselling and education for leprosy patients and their families.

Specific Objective : 3

Task 2

Strengthening the existing referral centres of NGLOs, Dermatological departments (Private / Government Medical colleges) and Government Hospitals as 'Specialized Centres' - equipped for multiple services.

Task Based Activities

1. Identify the needs of the existing referral centres of NGLOs and NLEP Institutions for offering specialized services to leprosy patients and raise them to the level of specialized centres.
2. Create a network of such specialized centres to share their resources and facilities that are available for leprosy patients through induction, training and exchange programmes.
3. Make efforts to reach all professionals like Surgeons, Physiotherapist, Ophthalmologist, Dermatologists and Rehabilitation Experts in public and private health care who are willing to cater to the specific needs of leprosy patients.
4. Equip them to adopt and practice at their respective place of work (private / public institutions) to provide specialized services.

Specific Objective : 3

Task 3

Creating effective linkages with the existing specializations at the Medical colleges, Hospitals and Institutions who can offer specialized services such as surgery, aids & appliances and vocational rehabilitation.

Task Based Activities

1. Identify other specialized centres in Medical colleges, Hospitals and Institutions that are offering specialized services such as surgery, aids & appliances and vocational rehabilitation in the public health system.
2. Take appropriate steps for extension of their services for leprosy with adequate induction and training needed for the same by the existing specialized centres.
3. Meet the concerned authorities of these existing Institutions and convince them to absorb leprosy patients in their routine system to render necessary services.
4. Create a linkage through a feasible arrangement with these Institutions and ensure follow-up of the patients referred to such centres / Institutions.
5. Identify leprosy patients requiring such specialized services and refer them to the appropriate Centres or Institutions.
6. To begin with, refer the leprosy patients to plastic Surgeons and Physiotherapists identified in these public and private facilities.

Views. . .*that matter*

Identify the underlying epidemiological and operational reasons

LEC - Lessons learned: The fact remains, however, that one or more successful campaigns should be able to detect most hidden cases in the community. If the programme continues to detect high number of new cases, despite the LECs, there is clearly something wrong with the way in which campaigns are conducted. A more in-depth analysis of the situation is called for, to identify the underlying epidemiological and operational reasons for this.

Excerpt from the "LEC : impact on case detection", WHO Weekly Epidemiological Record", 17 January 2003, Vol. 78, p 9 - 16

Identification of leprosy pockets at sub-national level

Any negligence in the operational efficiency of case detection and treatment would lead to accumulation of a large number of hidden cases in the community. It is important to develop a procedure for monitoring and certification of elimination of leprosy at least in areas where leprosy work had been in operation since 1991.A new indicator should be developed in conjunction with other essential indicators to show whether or not leprosy elimination is sustained. The potential of information technology should be harnessed to establish an effective system in order to identify specific problems, including identification of leprosy pockets at sub-national level.

Excerpt from the article on "Leprosy situation in endemic states of India and prospects of elimination of the disease" by M Subramanian et al, Indian J Lepr, Vol. 75 (4), 2003, p 344

Highlights of India's strategy for leprosy elimination

Some highlights of India's strategy for leprosy elimination: decentralization; integration of leprosy with health services; training of GHC and NLEP staff; surveillance for early detection and prompt MDT treatment; special projects for urban slums, remote areas etc.; information campaigns through selected and mass media; disability prevention and care; monitoring and evaluation.

Excerpt from the article on "Leprosy elimination in India"

by GPS Dhillon, Bulletin of the Leprosy elimination Alliance, January - June 2004, p 7

Specific Objective : 4

To monitor and evaluate the outcome and the impact of all interventions proposed, supported and supplemented under LEAP.

Rationale	*Tasks*
1. Simplified Information System (SIS) need to include all essential epidemiological indicators for long-term monitoring and disease control.	1. Maintaining Central Registry using appropriate computer software to avoid re-registration / re-cycling of leprosy cases.
2. GHC staff need to report on essential indicators required for monitoring the programme in their respective area.	2. Establishing 'Epidemiological Monitoring Units' [District and State level] to study the short & long term trends and outcome/ impact of all interventions under the programme.
3. Review and evaluation of the outcomes of all interventions during integration is essential for improvement and change in strategy to enhance the quality of the programme.	3. Collecting information on a standard reporting form from the respective Programme Managers and providing feedback to them.
4. Need to provide scope for doing operational research in leprosy by the medical students who would like to specialize in leprosy.	4. Undertaking research studies that are relevant to provide cues for policy priorities and programme objectives.

Specific Objective : 4

Task 1

Maintaining Central Registry using appropriate computer software to avoid re-registration / re-cycling of leprosy cases.

Task 2

Establishing an 'Epidemiological Monitoring Unit' [District and State level] to study the trends and outcome/ impact of all interventions under LEAP.

Task 3

Collecting information on a standard reporting format from the respective Programme Managers and providing feedback to them.

Task Based Activities

1. Collect all the necessary data on a pre-designed standard format based on the Simple Information System (SIS) recommended by the Government from all the respective Programme Managers at periodical intervals.
2. Feed the information into a simple computer data-entry software which will help to verify the information of new leprosy patients with the information of the old or existing cases registered already and thereby avoid re-registration or recycling of cases.
3. Generate periodic reports and analyse the trend for micro monitoring and give feed back to the agencies through periodical district or block level meetings of the respective programme managers.
4. Establish an 'Epidemiological Monitoring Unit' in the districts, where the prevalence is high.

Specific Objective : 4

Task 4

Undertake research studies that are relevant to provide cues for future policy priorities and programme objectives.

Task Based Activities

1. The LEAP Epidemiological Monitoring Unit (LEMU) will undertake research studies on the various programme interventions being carried out by the partners focussing on the relevant issues that would provide cues for making future policy priorities and programme objectives.
2. The interpretation of the data analysis and the documentation of these studies will be done by the LEMU and a feedback will be sent to the concerned LEAP partners.
3. Involve medical college students or student volunteers as investigators for undertaking specific studies.
4. The scientific relevance of these studies will be published in the respective medical journals.

Leprosy: too complex a disease for a simple elimination paradigm

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Introduction

Leprosy is caused by *Mycobacterium leprae* and manifests as damage to the skin and peripheral nerves. The disease is dreaded because of the damage that occurs in weak and anaesthetic hands and feet, as well as in blindness and facial disfigurement. Worldwide 2 million people are estimated to be disabled by the consequences of leprosy. Multidrug therapy (MDT) for leprosy is highly effective in curing the mycobacterial infection, but treating the nerve damage is much more difficult. In 1991, the World Health Assembly set a target for the "elimination of leprosy as a public health problem" by 2000 (*1*). Elimination was defined as a prevalence of less than 1 case per 10,000 population. Many people found this definition difficult to understand. The "elimination of leprosy" slogan has galvanized activities worldwide but has also dominated the priorities in leprosy work. Here we argue that elimination is not an appropriate goal for leprosy and it is better seen as a chronic disease that requires long-term planning and control. The new challenge is to build on the success of the leprosy campaign and deliver sustainable care for leprosy patients.

The new challenge is to build on the success of the leprosy campaign and deliver sustainable care for leprosy patients.

The concept of elimination

The success of multidrug therapy provided the basis on which the concept of elimination developed. Multidrug therapy was introduced by WHO in 1982 (*2*). Under this programme, patients are classified as having one of two types - paucibacillary (PB) and multibacillary (MB) - and receive either the combination of rifampicin and dapsone (known as paucibacillary multidrug therapy or PB-MDT) or the triple drug combination of rifampicin, dapsone and clofazimine (known as multibacillary multidrug therapy or MB-MDT). The rifampicin and part of the clofazimine component are taken monthly under supervision. PB-MDT is given for 6 months and MB-MDT for 24 months (*3*) or 12 months (*4*). Relapse rates are low (0 to 2.04 per 100 person-years) with the 6-month PB-MDT regimen and the 24-month MB-MDT regimen (*5*). Throughout the 1980s and 1990s the Leprosy Unit at WHO led a successful campaign to implement multidrug therapy worldwide. Nongovernmental organizations (NGOs) were instrumental in supporting government's commitments to implementing multidrug therapy. Vertical leprosy control programmes were used to identify and treat patients. Between 1994 and 1999 the worldwide cost of multidrug therapy was borne by the Nippon Foundation in Japan (through the Sasakawa Memorial Health Foundation). More than 13 million cases were detected and treated with multidrug therapy between 1982 to 2002 (*6*).

Prevalence and new-case detection rates

Prevalence figures were used to measure progress, and the number of patients with leprosy has fallen from an estimated 12 million in 1985 to 0.6 million in 2002 **(Fig. 1)** (*7,8*). Disease prevalence is measured by counting all patients receiving treatment at a defined moment and expressing this as a ratio using the population as the denominator. Prevalence figures are therefore affected by operational aspects of programmes, such as the length of treatment; for example, halving the

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duration of treatment for patients receiving MB-MDT from 24 months to 12 months halves the prevalence figures for that group. Additionally, the means of administration may also affect the numbers; for example, patients receiving single-dose treatment (rifampicin, ofloxacin and minocycline) for single skin lesions do not appear in prevalence figures nor do patients who received their 6-month course of PB-MDT early in the calendar year since only patients registered on 31 December are counted for that year.

In 1985, 122 countries in the world had leprosy prevalence of >1 case per 10,000 population. This prevalence fell to 24 countries in 2000, to 15 countries in 2001 and to 12 by 2002. The largest number of leprosy cases are concentrated in seven countries: Brazil, India, Madagaskar, Mozambique, Myanmar, Nepal and the United Republic of Tanzania (*8*), with India alone accounting for 64% of the prevalence of leprosy and 78% of new cases detected worldwide (*9*).

The picture is different when new-case detection rates are used instead of prevalence figures. The new-case detection rate is better indicator of disease because it is not affected by changing case definitions or duration of treatment. Comparing the data from India using these two different types of measurement shows that although prevalence has fallen dramatically, the incidence figures have remained almost constant **(Fig. 2)**. **Fig. 3** shows new-case detection rates for the countries with the highest rates of leprosy over the past 8 years. In all of these countries new-case detection rates are stable or increasing. There may be operational explanations for these trends, such as increased detection activities, and more people may be presenting for treatment because they have learnt that leprosy is curable. New-case detection rates taken together with the proportion of cases treated with MB - MDT and the high rates among children (about 17%) indicate that leprosy continues to be transmitted in the community (*6*).

Proportion of cases treated with MB - MDT and the high rates among children indicate that leprosy continues to be transmitted in the community.

Fig. 1. **Global prevalence and new-case detection rate for leprosy, 1994–2003**

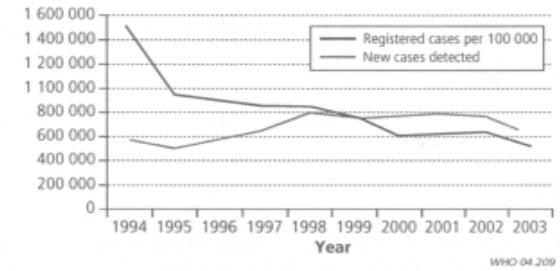


Fig. 2. **Prevalence and new-case detection rate for leprosy in India, 1984–2002**

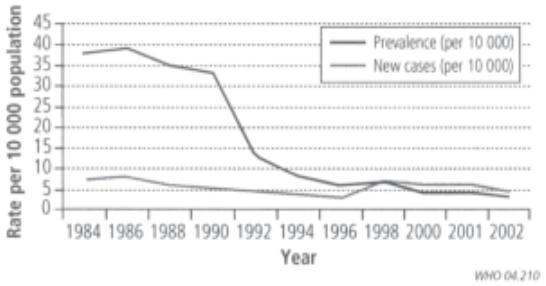
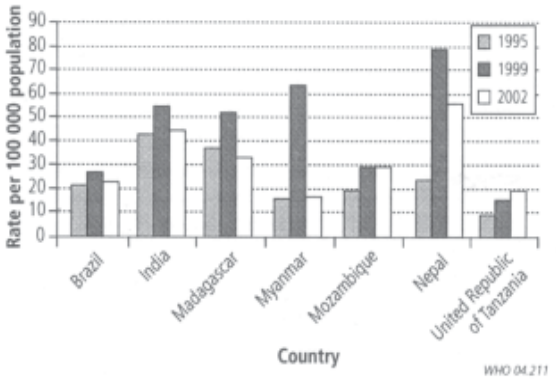


Fig. 3. **Cases of leprosy detected in seven countries where rates of endemic leprosy are highest, 1995, 1999 and 2000**



The idea of elimination was based on the hypothesis that at a prevalence of < 1 case per 10 000 population the transmission of leprosy in the community would be interrupted. The International Leprosy Association's Technical Forum noted that there was little evidence to support this hypothesis but also acknowledged

that when new-case detection rates do decline it is often not clear why that decline has occurred (*10*). Leprosy has a long incubation period, ranging from 2 to 20 years (*11*). Patients newly diagnosed with leprosy may have transmitted the disease to others in their family or community long before their disease is detected. Using WHO's definition, South Africa attained elimination in 1924 but new leprosy cases continue to be detected in the northern Transvaal (*12*).

Patients newly diagnosed may have transmitted the disease to others in their family or community long before their disease is detected.

Biological features of *Mycobacterium leprae*

M. leprae is a hardly organism and can survive outside the body for up to 45 days (*13*). In countries where leprosy is endemic, such as Ethiopia and Indonesia, up to 5% of the population carry *M. leprae* DNA in their noses, often transiently and with no evidence of overt disease (*14*). In Ethiopia the organism was found in the nasal passages of 5.9% of the villagers in an area where multidrug therapy has been used for the past 16 years (*15*). *M. leprae* is shed from the nasal mucosa of untreated lepromatous patients and probably survives in the environment before infecting the next host. The only significant animal source is the nine-banded armadillo, which lives in the southern United States in Texas and Louisiana; no animal vectors have been identified elsewhere (*16*).

The combination of epidemiological and biological evidence suggests that leprosy cannot be eliminated by multidrug therapy alone (*17*). This analysis is supported by recent mathematical modelling of leprosy indicators that suggests leprosy is slowly declining but that the rate of decline remains uncertain and a sustained leprosy control effort is required (*18*). Despite the evidence collected and published by WHO that leprosy is far from eliminated, especially in the areas that have the highest rates of endemic leprosy, in May 2001 WHO announced that leprosy had been eliminated as a public health problem at a global level. This was achieved by including in the denominator of the prevalence - the populations of all countries that reported even a single case of leprosy.

Mathematical modelling of leprosy indicators suggests leprosy is slowly declining but that the rate of decline remains uncertain and a sustained leprosy control effort is required (18).

Vaccines

None of the vaccines against leprosy give high levels of protection. But many randomized controlled trials and case-controlled studies show that bacille Calmette-Guerin (BCG) gives variable protection against leprosy (20% in Myanmar, 80% in Uganda) (*5*). In Brazil, neonatal BCG vaccination has been shown to protect against leprosy (*19*). Since this vaccine is already widely used in leprosy-endemic countries, the routine use of BCG could be part of WHO's anti-leprosy strategy.

Political effects of elimination

Success of elimination

The advantage of an elimination campaign was that it mobilized people and resources. Governments and NGOs worked together in campaigns during which leprosy teams and local experts screened thousand of people; in 1998 in Orissa state in India, a week-long campaign detected 62 804 confirmed cases (*20*). Leprosy monitoring was done well (*21*). Leprosy attained a high profile, and this is a credit to the Leprosy Unit at WHO.

Downsides

The elimination campaign, however, has also had negative effects on issues such as planning to meet the future challenges of leprosy, the place of leprosy on the research agenda and on the interaction between different leprosy service providers. A major worldwide problem is that people,

Problem is that people, including health planners and those who fund health care, have not understood the concept of elimination

including health planners and those who fund health care, have not understood the concept of elimination to a prevalence of <1 case per 10 000 population, thinking instead that it means an absence of cases.

The prospect of elimination has also inhibited leprosy research, with some notable exceptions such as the sequencing of the *M. leprae* genome. Important research sources of funds, such as the Bill and Melinda Gates Foundation, have decided not to fund leprosy research because they no longer perceive it to be an important problem. It is difficult to attract postdoctoral students and clinical fellows to leprosy research: who can build a career on a disease that is perceived as being eliminated? Yet there remain many important research questions that could affect practice and policy.

Effects on partners

NGOs have made a major contribution to the provision of leprosy services. In 1999 the Global Alliance to Eliminate Leprosy (GAEL) was formed as a multisectoral partnership that had the goal of eliminating leprosy. GAEL comprises WHO, the Nippon Foundation, the International Federation of Anti-leprosy Associations (ILEP) and the Novartis Foundation. GAEL mobilized political commitment and created partnership that ensured a supply of free medicine and was available in difficult-to-reach areas (GAEL evaluation, unpublished data, 2003). Tensions developed in this partnership and ILEP was asked to leave the alliance in 2000. At the beginning of 2003, WHO invited Richard Skolnik and a team to perform an independent evaluation of the GAEL alliance (*22*).

The evaluation noted the strengths mentioned above but also observed that the alliance was failing because WHO ignored the concern of its collaborators. These included concerns over the use of prevalence data and the introduction of new regimens that gave patients all their doses of multidrug therapy at their first visit, thus losing the supervised component of the administration of medicine. These tensions arise partly from differences in perspectives: WHO has a public health perspective whereas the leprosy NGOs focus on the individual (*23*). The evaluation also recommended that the World Health Assembly should pass a resolution that made clear to the world that leprosy had not been eliminated. Key players, such as Trevor Durston, head of Leprosy Mission International, are now suggesting that it is time to focus on bringing together all parties in a way that best meets the needs of people with leprosy (*24*).

Concerns over the use of prevalence data and the introduction of new regimens that gave patients all their doses of multidrug therapy at their first visit

Contemporary challenges

Molyneux has argued that leprosy should be seen as one of a group of chronic stable diseases that are being successfully controlled (*25*). However, he cautions that it is vital to maintain the activities that brought these diseases under control. For leprosy this means continuing case detection, providing treatment and meeting the long-term challenge of preventing disability. There are also important research questions to address, such as determining the best way of detecting and treating nerve damage and understanding transmission.

It is vital to maintain continuing case detection, providing treatment and meeting the long-term challenge of preventing disability activities.

Integration

Many governments are now moving leprosy programmes away from vertical specialized programmes to an integrated approach in which primary health care workers diagnose and treat patients with leprosy. The integrated approach has many advantages including widening the health-care network, thus bringing the diagnostic and treatment services closer to the patient.

Integration is a cost-effective mode for delivering leprosy services given the present levels of

prevalence. This advantage could be nullified, however, if there are no staff in primary health care centres. Additionally, there must be a sufficient number of health centres available. For example, in Bihar, India, there is only one health facility per 200 000 population compared with 1 per 30 000 in southern India (*26*). Effective referral systems are also needed so that complicated cases can easily be sent to specialist centres.

Integration is a cost-effective mode for delivering leprosy services. This advantage could be nullified, however, if there are no staff in PHC centres.

Surveillance and training

Surveillance must be undertaken in an integrated setting using clinically relevant indicators. The number of new cases will probably drop as integration occurs, and it is critical to establish whether patients with leprosy are being missed by the surveillance system (*27*). **Special surveillance areas could be set up in regions where integration has occurred; these areas should use active case finding so that an accurate picture of key indicators is maintained.** For example, disability rates give an approximate indication of the time to diagnosis, so if these rise it would indicate that there is diagnostic delay. India has low disability rates, and it would be sad were these to rise. Addressing these issues request effective leadership from governments and WHO. When integration occurs there will be a significant demand for training in countries such as India. Training place a critical part in ensuring the success of diagnosis, treatment and preventing nerve damage and disability. NGOs have previously worked with vertical programmes and will now need to define new roles for themselves within the framework of an integrated setting.

NGOs have previously worked with vertical programmes and will now need to define new roles for themselves within the framework of an integrated setting.

Diagnosis

The diagnosis of leprosy is simple but it requires skill to differentiate skin lesions and recognise nerve involvement. Diagnosis based on an anaesthetic patch is likely to miss about 30% of the MB cases (*28*). **Paramedical workers in the field need to be trained to identify at least two cardinal signs of leprosy : anaesthetic skin lesions and enlarged nerves. This involves training, supervising and monitoring primary health care staff as well as offering refresher training.**

Treatment

There are important issues in the treatment of leprosy that require additional research and evidence to guide policy-making. For example, a small percentage of patients have a high bacterial load; they are probably responsible for maintaining infection in their community. Data from India and Mali suggest that relapse rates are high among this group even when they are treated with 24 months of multidrug therapy (*29*). Discovering the optimum way of identifying these patients and providing appropriate treatment should be a public health priority.

Patients' adherence to treatment is problematic in disease like leprosy and tuberculosis because they require long periods of therapy. Offering supervised monthly doses provides an opportunity to directly observe the treatment as well as educate the patient about the need to take doses regularly and complete the course of treatment. The move to implement accompanied multidrug therapy in which the patient is given the entire 6-month or 1-year course of treatment at the first visit could prove counterproductive. This regimen contrasts with that of tuberculosis treatment programmes where the move has been away form unsupervised regimens towards DOTS; this change occurred after unsupervised regimens led to an increase in treatment failure. The use of uniform short-course multidrug therapy for all patients is being assessed. It is vital that relapse rates are assessed 5 years after treatment in order to detect late relapses.

Reactions and nerve damage

In leprosy, reactions are acute immunological phenomena that occur during the normal course of the disease. Reactions can be disastrous: they cause acute nerve damage. It is important to recognise reactions early and initiate treatment with steroids; this treatment improves outcomes for about 50% of patients. Almost 30% of MB patients develop reactions during the course of their disease. Reactions may occur at presentation, during treatment and after treatment. It is essential that primary health care staff are trained to recognise and treat reactions early. Steroids should be made available at primary health care centres. Clear referral systems should be established to enable primary health care workers to prescribe steroid therapy to patients or refer them to centres for assessment and steroid treatment.

> Referral systems should be established to enable PHC workers to prescribe steroid therapy to patients or refer them to centres for assessment.

Preventing disability

Preventing patients with nerve damage from progressing to disability and deformity is a challenge that will last for the patient's lifetime. Patients with anaesthesia and muscle weakness need to be taught how to care for their hands and feet: they should inspect their limbs daily and attend to any injuries promptly. Specialist footwear needs to be provided for patients with deformities of their feet to prevent ulceration. Ulcer management forms a large part of any leprosy service. Staff need to work with patients to prevent ulceration from recurring by identifying the cause of the initial injury preventing disability is critical to the success of a programme. We need to understand the routes that lead to disability.

Leprosy and stigma

Socio-economic rehabilitation is another important component of caring for patients. Many patients are marginalized by their communities after being diagnosed (*30*). Stigmatisation continues and it needs to be combated using community-based approaches.

Leprosy and poverty

A link between leprosy and poverty has long been suspected, but is difficult to demonstrate at national, community or even individual levels. A study in Malawi showed that at the individual level living in a crowded household was a risk factor as was a lack of education (*31*). A community-level study from Brazil has shown that in an area where the prevalence of endemic leprosy is high, higher levels of inequality were associated with higher levels of leprosy (*32*). Leprosy should be included in the portfolio of diseases associated with poverty, and leprosy work (including detecting and treating cases and reducing disability) should be incorporated into poverty-reduction programmes (*33*).

Role of private practitioners and dermatologists

Private practitioners and dermatologists throughout Africa, Asia and Latin America treat leprosy patients. Although they serve a significant segment of society they have not been included in leprosy programmes and often use non-standard treatment regimens. Leprosy care will be improved if these practitioners are sensitised to leprosy and trained in its diagnosis and management, including how to recognise and manage nerve damage.

> Leprosy care will be improved if these practitioners are sensitised and trained in diagnosis and management, including nerve damage.

Research

A vital question that needs to be addressed is why multidrug therapy has not interrupted transmission. We need to find new approaches to understanding transmission. Chemoprophylaxis may be another useful tool, and several trials of potential agents are in progress.

A better understanding of the pathogenesis of nerve damage would also facilitate the move towards better treatment.

Reflection on the leprosy elimination campaign

The leprosy elimination campaign has important lessons for everyone. It was perhaps inadvisable to choose a disease with a biology that does not lend itself readily to elimination. The elimination campaign did, however, achieve great success in terms providing free multidrug therapy worldwide. Nonetheless, there was an under appreciation of the complex problems that leprosy patients present with during treatment and of the long-term needs of patients with disabilities. WHO missed an opportunity to be intellectually open when it failed to acknowledge that leprosy is not going to be eliminated by multidrug therapy alone. If WHO had been able to discuss this with its partners it might have opened up a dialogue leading to new and creative solutions.

We endorse the recommendations of the GAEL evaluation to make it clear that there will continue to be new cases of leprosy, that a range of leprosy activities will need to be carried out, and that governments need to be accountable. We also support the recommendation that the World Health Assembly should pass a resolution that addresses leprosy activities beyond 2005.

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WHO recommended activities for intensive implementation and the special efforts needed to intensify the leprosy elimination strategy

- enabling all health facilities in endemic districts to diagnose and treat leprosy;
- ensuring easy and uninterrupted access to free MDT drugs;
- ensuring high cure rates through flexible and patient-friendly drug delivery systems;
- promotion of case-finding by informing the public about the disease and encouraging individuals with suspicious skin lesions to come forward for treatment;
- sustaining high geographic coverage with MDT services over 3 - 5 years;
- sustaining interventions for the prevention and management of disabilities;
- closely monitoring progress towards elimination at district level;
- changing the community image of leprosy through information, education, communication and advocacy.

Recommendations of the NLEP : Good referral system

"Development of good referral system is the need of the future. Leprosy services at the grassroots level will be entirely managed by the GHC staff. ILEP support in this context to build up capacity and equip properly identified Medical colleges / District Hospitals, particularly in the high-endemic states, should be decided urgently"

NLEP Meeting of Govt. of India, Goa, 2004
Bulletin of the Leprosy Elimination Alliance, Jul-Dec 2004

Handing over

"Referral centres will also support the general health services in diagnosing difficult and in providing certain specialized care to patients with complications"

The Final Push Towards Elimination of Leprosy, Strategic Plan : 2000 - 2005
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PART FIVE

LEAP

Leprosy Referral Centres

October 2005

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4. LEAP
5. Overall objective
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7. LRCs are 'signposts' recognized by patients/ public
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LEAP
Leprosy Referral Centres

1. The Context

NLEP *(National Leprosy Eradication Programme)* has been a great success with MDT, curing over 11.5 million leprosy patients in the country during 1984 to 2005. The new policy of integrating leprosy services into public health services is a long-term process to achieve the goal of leprosy elimination (defined as a registered prevalence rate of less than 1 case per 10,000 population).

The Government of India's policy is categorical in asserting, *"for reaching elimination of leprosy in most of the districts, it is necessary to extend the NLEP up to March 2007, i.e. till the end of 10th Five Year Plan" and the programme will continue with NLEP partner organizations such as WHO, ILEP, Sasakawa Memorial Health Foundation (SMHF), The Nippon Foundation (TNF) and NOVARTIS *.*

The **structural integration** has taken place making the diagnosis and treatment facilities for leprosy available through a large network of primary health centres (PHC) & urban health posts (UHP) in most of the states in the country. According to GOI, *"during the last 3 years, integration has made progress. Currently, the diagnosis of leprosy is made and the treatment initiated in 80% of the health facilities, providing MDT services are provided on all working days, in 90% of the health facilities. The treatment register is maintained at almost all health facilities"*.* Thus the entire GHC services are made responsible to treat and cure leprosy.

** NLEP, Programme Implementation Plan, (PIP) 2005-2007, Govt. of India*

2. The Need

Despite bringing down the overall prevalence of leprosy, new cases continue to surface. Among the new cases, a substantial number of them are detected / reported with early disabilities and deformities. We also have backlog of cured patients with disabilities and deformities in addition to deformity prone patients. This calls for a practical intervention strategy. In this context, the policy of GOI envisages to *"develop a suitable referral services for providing services to complicated cases, reconstructive surgery system, capacity building of needy professionals and supply of footwear by involving established NGO Institutions"*

3. Strengthening integration

As we approach towards the target date for elimination, new issues and challenges are arising. Although we are able to conquer the disease, it has left its consequences in the form of grievous disability and deformities in significant number of cured persons. Therefore it is essential to sustain the specialized leprosy centres at Govt. and NGO units, preferably located at general health facilities. Eventually, this will enable the general health care services to tackle all the leprosy related problems.

The weakness of integrating leprosy services with the GHC services is that its personnel are not fully equipped both technically and operationally. The need for reorientation and training is to be accomplished. It is evident that additional inputs and resources are required to address the problems related to consequences of leprosy during post elimination period. This is possible

by partnership approach with the specialities that exists in the public health services.

The Govt. of India's policy recommendations to establish **Leprosy Referral Centres** (LRC) at district and regional levels is a major step, if undertaken with adequate resources and personnel. It will provide quality of services and strengthen integration of leprosy elimination activities within the general health care services.

4. LEAP *(Leprosy Elimination Action Programme)*

LEAP promoted by ALERT-INDIA, aims to bring together all the prospective partners, and to re-organize the existing manpower resources and to make best of the **potentials** and **opportunities** that are available today with the vertical leprosy agencies, and to assist the GHC services and to enhance the quality of the services to the leprosy-affected individuals. LRC is a strategic plan that can help promote integration on long-term basis coupled with Continuing Medical Education (CME).
Following from the above, the immediate tasks are establishing / strengthening of LRCs to respond positively with appropriate interventions needed in different regions. LRCs are proposed to be established in urban and semi-urban areas and at district levels and special endemic zones with an active collaboration of district level units, municipal councils, corporations, public and private hospitals (Dermatology departments), medical colleges, teaching hospitals, physical medicine and rehabilitation institutions, specialized leprosy institutions and hospitals, NGLOs and health NGOs.

5. Overall objective

To offer timely, comprehensive quality service and care to all leprosy patients during Integration phase, through a network of Leprosy Referral Centres (LRC) in partnership with the public & private health care providers by NGLOs and NLEP Institutions.

6. Specific Objectives

i. **To assist** the public health personnel to diagnose and treat leprosy when required and provide comprehensive care.

ii. **To receive** referrals of leprosy cases from GHC services and other health facilities for treatment of complications - such as lepra reactions, neuritis early disabilities, deformities and ulcer care.

iii. **To provide** comprehensive services for care of the cured, if needed.

iv. **To act** as reverse referral unit of new leprosy cases to the GHC for MDT services and to specialized medical, surgical and rehabilitation institutions for specialized services.

v. **To serve** as a publicly known 'signpost' for patients seeking treatment and guidance and provide required services.

vi. **To offer** guidance and counseling to patients in addition to information, education and serve as a nucleus for socio-economic rehabilitation.

vii. **To impart** and exchange information, knowledge and expertise with public health personnel and other specialists for better clinical management and care of patients.

Task 1 - Establish NGLOs / NLEP units as 'Referral centres' at District and regional level to offer support services to leprosy patients who are referred by the GHC system (MDT Delivery Centres) and those living in the nearby areas.

Task Based Activities

1. Collect all the information on all the services available for leprosy patients with the existing specialized centres of NGLOs and other institutions in any given zone / region or district of your operation.

2. Assess the needs of the leprosy patients who require specialized services such as physiotherapy, ulcer care, aids and appliances and surgical intervention and decide on the additional requirements to fulfill the needs of patients in the area.
3. Equip the Referral Centre with necessary facilities for the patients.
4. Reach out to the nearest surgical / hospitalization centers / Rehabilitation Institutions and establish liaison and linkages to initiate referrals for specialized services to the leprosy patients.
5. Maintain individual patient records of all the patients referred by the GHC to monitor the progress after interventions.
6. Provide a feedback to the concerned Health Post / PHC from where the leprosy patient was referred for special services and ensure regular follow up of the patient.
7. Train and motivate the staff of the general health care services to treat the leprosy patients with complications and deformities as part of their routine work.
8. If such centres are not in existence, propose a suitable place for establishing a new Referral Centre, which must be accessible to most leprosy patients from the surrounding area - **if need for one exists.**
    (i) Initiate and acquire requisite permission from the respective authority for establishing a 'Leprosy Referral centre' in the existing health centres.
    (ii) List the necessary equipments & supplies required to offer specialized services to leprosy patients at this Referral centre.
    (iii) Recruit / depute necessary personnel such as trained Medical Officer, trained Physiotherapist or Para-medical worker and an assistant.
    (iv) Provide specialized services including counselling and education for leprosy patients and their families.

Task 2 - Strengthening the existing centres of NGLOs, Dermatological departments (Private / Government Medical colleges) and Government Hospitals as 'Specialized Centres' - equipped for multiple services.

Task Based Activities

1. Identify the existing MDT centres of NGLOs and NLEP Institutions offering services to leprosy patients and raise them to the level of specialized referral centres.
2. Create a network of such specialized centres to share their resources and facilities that are available for leprosy patients through induction, training and exchange programmes.
3. Make efforts to reach all professionals like Surgeons, Physiotherapist, Ophthalmologist, Dermatologists and Rehabilitation Experts in public and private health care who are willing to cater to the specific needs of leprosy patients.
4. Equip them to adopt and practice at their respective place of work (private / public institutions) to provide specialized services.

Task 3 - Creating effective linkages with the existing specializations at the Medical colleges, Hospitals and Institutions who can offer specialized services such as surgery, aids & appliances and vocational rehabilitation.

Task Based Activities

1. Identify centres in Medical colleges, Hospitals and Institutions that are offering specialized services such as surgery, aids & appliances and vocational rehabilitation in the public health services.

2. Take appropriate steps for extension of their services for leprosy with adequate induction and training needed for the same by the existing specialized centres.
3. Meet the concerned authorities of these existing Institutions and convince them to absorb leprosy patients in their routine services to render necessary services.
4. Create a linkage through a feasible arrangement with these Institutions and ensure follow-up of the patients referred to such centres / Institutions.
5. Identify leprosy patients requiring such specialized services and refer them to the appropriate Centres or Institutions.
6. To begin with, refer the leprosy patients to Surgeons and Physiotherapists identified in these public and private facilities.

7. LRCs are 'signposts' recognized by patients/ public

A LRC needs to be a 'signpost' located in a place that is publicly known. It should be easily accessible and have a patient friendly environment complemented by quality care.

Before Integration, in the vertical programme, most NGOs and NLEP units were providing comprehensive care to all leprosy patients through specialized leprosy treatment centres or clinics. Ideally, these can be restructured as LRC utilizing the available leprosy manpower during Integration phase.

In places where such specialized centres do not exist, it is necessary to establish new LRC. LRC should be need based and can be located at block or district or regional level. All necessary infrastructures needed to offer specialized services should be ensured.

8. LRC should promote partnership with GHC

At the district level, the facilities available with the existing general hospital should be availed. The expertise available with GHC can be utilized for LRC by exchange and/or interaction. This will pave way for continuation of services to the leprosy affected in the general health sector and provide for sustainability. The dependence on specialized leprosy personell should be eventually minimized.

9. LRC: basic functions and operational guidelines

9.1. Confirming diagnosis of leprosy in difficult cases

Basic task:

1. Confirmation of difficult-to-diagnose cases by clinical examination.
2. Counsel for regular treatment with MDT.
3. Refer all confirmed new cases to the PHC / Health Post with a referral note for MDT.
4. Perform or refer for (if not available at LRC) skin smear examination, if needed and advised by the Medical Officer (Refer box 1 for policy guidelines).

Rationale:

At present the GHC personnel are not adequately trained and equipped to provide all comprehensive services to the leprosy affected persons. Important of all is to diagnose and treat adequately. The GHC services need expert guidance in diagnosis of difficult cases and clarity on grouping new leprosy cases for MDT.

Guidance is essential especially for patient presenting with uncertain cardinal signs such as early lepromatous cases, pure neural cases (without any skin patches). In order to confirm the diagnosis, these cases need to be subjected to a detailed clinical and laboratory examination* by trained health personnel. These

laboratory investigations may also be required to diagnose 'relapse' in certain cases and will help to advise appropriate treatment (Refer box 1).

Box 1**: * Skin smear examination is not mandatory to start MDT**

When does one require skin smear?
When you suspect a person to be suffering from leprosy - multiple skin patches with intact sensation or without skin patches presenting the signs of early lepromatous leprosy with manifestation of smooth, oily and shiny skin. This cannot be diagnosed unless M.leprae is demonstrated in the skin smears. Presence of M.Leprae inskin smears is one of the cardinal signs of leprosy.

Further in advanced lepromatous cases with nodules, skin smear is essential for making differential diagnosis and confirm the diagnosis of leprosy cases from that of other similar skin conditions.

Additionally skin smears helps diagnosing 'relapse' cases and to certify a person fit for work as per employment rule.

What is the frequency? *Only in case of above type of patients*: at the time of diagnosis.

What is the policy guideline? Majority of the leprosy cases can be diagnosed without skin smears. Skin smear examination is not mandatory to start MDT. NLEP no longer routinely advises skin smear examination in the leprosy control programme.

If you suspect leprosy without sensory loss or have any doubts, skin smear examination can be done at any LRC or general hospital, which is equipped with reliable laboratory facilities and trained technicians.

Rationale:

The MDT has been made available at all health facilities in the GHC. Such facilities are easily accessible to leprosy patients and can ensure greater compliance. However some patients would prefer to take treatment at the centre of their choice for reasons of convenience or social consequences. Such a choice should be respected.

Since many new leprosy patients might be reporting voluntarily to the existing leprosy clinics upgraded into LRCs, the LRC team should refer back the new patients to the nearest health centre for MDT. The LRC team should also ensure the availability of MDT and treatment compliance to achieve 100% cure rate. This can be done by the Paramedical Worker (PMW) / Leprosy Technician (LT), who will visit the GHC centres and confirm the details of new patients registered with GHC and provide necessary assistance needed.

9.3. Management of leprosy related complications

Basic tasks:

1. When a patient with complications is referred by the GHC services diagnose & ascertain the cause and the nature of complication.
2. Assess the patient for nerve function impairment and record the findings.
3. Treat the patients with complications using steroids / Clofazimine / antibiotics, etc.
4. Initiate & refer back to PHC / HP with a note for continuation of treatment, if the facility is confirmed to be available at the place from where the patient was referred.
5. Counsel the patient and advise to report on occurrence of any problematic events.

Rationale:

LRC should assist the GHC personnel to provide treatment and manage leprosy cases with complications such as lepra reactions and neuritis, early NFI (Nerve Function Impairment) etc as their routine practice. However the LRC may take this responsibility initially till the GHC medical personnel acquire skills in managing such complications. The LRC team also should ensure the progress and response to the treatment given.

Patient suffering from severe form of reaction or recurrent reactions may be referred to the specialized centres or hospitals for hospitalization and for special anti-reaction drugs, if required.

9.4. Preventing disability among newly detected leprosy patients

Basic tasks:

1. Undertake regular nerve function assessment (sensory and motor) to identify any nerve function loss and record the same.
2. Provide relevant physiotherapy for patients with complications if needed. Teach self-care and provide information and demonstrate exercises to be carried out at home.
3. Counsel the patient
4. Undertake home visits to confirm the service compliance and ensure family support.

Rationale:

The risk of developing new nerve function loss and eye problems during and after treatment cannot be ruled out. It is necessary to screen all the 'risk prone patients' (normally patients with more than 5 skin lesions) using a standard nerve function assessment tool to identify nerve function impairment at an early stage. All the risk group patients must be assessed periodically for nerve function at LRC.

If any recent nerve function loss is detected, the LRC team should provide appropriate treatment to prevent the onset of disabilities. Wherever indicated, the patient may be referred to the specialized surgical or ophthalmologic centres at the general hospitals for special intervention / care.

9.5. Preventing the worsening of disability/ deformity among leprosy cured persons

Basic tasks:

1. In any given region or block or district enlist all patients with existing deformities and group them into i.e. Grade I & Grade II.
2. Maintain individual patient record and enter the type of deformities and other problems.
3. Prioritize them according to the frequency of follow-up needed (Refer box 2)
4. Provide relevant physiotherapy for patients with deformities and ulcers.
5. Teach self-care and provide information and demonstrate exercises to be carried out at home.
6. Maintain and update records for evaluation of patients under POID / POWD services.
7. Follow-up of all deformed patients as per the requirement/ frequency suggested.
8. Provide health education and counselling of all patients on every visit to LRC.
9. Liaise with GHC staff and ensure follow-up of all disabled patients periodically at LRC

Rationale:

The primary objective of disability prevention is essentially to minimize and avert deterioration of the impairment status of leprosy affected persons with established

disabilities and deformities.

The geographic distribution of the leprosy patients needing long-term care for their disabilities is not known. Hence, it is important to collect information about all the disabled leprosy affected living in the community and assess their current disability / deformity status.

Appropriate physiotherapy services such as wax-therapy, muscle stimulation and other such physical therapy should be made available at LRC. Further provisions of aids and appliances such as splints, special footwear (MCR), dressing materials for ulcer care should also be made available to those leprosy patients who require them. The LRC team should encourage leprosy disabled to actively participate in the disability prevention activities.

Box 2**: Suggested frequency of services at the LRC level**

Complications & deformities	Services offered	Frequency
1. Lepra reactions (Type I & II) with or without early muscle weakness	Steroid therapy & exercises, Muscle stimulation	Weekly
2. Anaesthetic disabilities (All Grade I)	Advise and demonstration of self-care	Quarterly
3. Claw-hand, Ape thumb,Wrist drop, Foot drop	Wax-therapy, Splints and exercises	Monthly
4. Lagophthalmos	Self-care and Exercises	Quarterly
5. Trophic ulcers	Dressing	Weekly / fortnightly

9.6. Health Education /Counseling for self-care

Basic tasks:

1. Assess all the cases referred with socio-psychological disturbances / obsessions.
2. Plan and conduct sessions for education & counseling (peer groups / families).
3. Educate and counsel all the deformed patients for self care at home.
4. Undertake / assist community level education campaigns to promote voluntary reporting.

Rationale:

Most of the disabilities are avoidable. Some are reversible (the early disabilities and deformities) with simple self-care measures. Hence an emphasis on teaching self-care methods by LRC team is essential. It is also essential that the family members, co-workers and friends are encouraged to assist the patient in practicing preventive measures.

The LRC team should also make sustained efforts of public education campaign to promote social acceptance of leprosy as a curable disease and promote voluntary seeking of treatment.

9.7. Establishing linkages with GHC services and rehabilitation facilities

Basic tasks:

1. Prepare, maintain and regularly update a list of local hospitals / institutions / Vocational Training and Rehabilitation Centres that offer special services aids and appliances, vocational, surgical, rehabilitation services in the region for leprosy cured.
2. Liaise with those agencies who can offer care and services to leprosy patients.
3. Identify for referral those who need special services.
4. Refer displaced patients with socio-economic problems to specialized rehabilitation centre.
5. Keep an update of all Govt. schemes and

welfare measures offered for the leprosy cured with specific eligibility criteria and the requisites for obtaining benefits under such schemes.

6. Maintain a record of patients referred to different agencies for follow-up and for feedback to the institutions / authorities offering rehabilitation services.

Rationale:

It is necessary to ensure equal opportunities and full social integration of all leprosy cured persons with disabilities. They may require highly specialized services such as Reconstructive surgery, histopathological examination, Vocational training, Socio-economic rehabilitation etc. The LRC team should identify such centres / hospitals / institutions located in the nearby area and institute an effective referral service.

9.8. Monitoring and evaluation

Basic tasks

1. Plan all LRC activities on monthly / quarterly basis with – necessary analytical data.
2. Conduct monthly review visit / meetings of all concerned functionaries and prepare quarterly reports of LRC activities (Refer box 3) for the concerned district authorities or to LEAP Support Team (LST-LEAP partners).
3. Undertake specific small analytical studies of special group of patients or specific interventions or results of special schemes promoted.

Rationale:

The purpose of monitoring is to measure the outcome and the impact of the services provided through LRCs. It is recommended to have periodical monitoring of results of activities and their impact to evaluate the quality of patient care. The LRC team should follow-up all the patients who received services at LRC at periodical interval as necessary for that specific intervention.

The analysis of the findings and the possible solutions should become the basis for amending approach and altering or continuing of interventions. The same should be discussed with the concerned district authorities or LEAP Support Team (LST-LEAP partners). Only relevant reports and records should be maintained as an evaluation tool.

Box 3**: Suggested Records, registers and reports**

Prepare, maintain and regularly update the following registers in LRC or one / two register containing all details by the PMW with the help of GHC staff / LRC team.

A. *One Register or multiple registers containing the details of :*

1. Known cases, 2. RFT cases, 3. Contact examination,4. Suspects & observation 5. Patient follow-up notes

B. *One Register or multiple registers containing the details of :*

1. Deformity & POD services, 2. Clinic attendance,

C. *One card with folds or inserts containing the details of :*

1. Individual's clinical & deformity status and assessment and 2. treatment

D. *Records to be kept :*

1. Drug Indent / Stock, 2. Aids & Appliances - Intent / Stock

9.9. Health personnel required for LRC:

An ideal LRC should consist of GHC personnel and trained leprosy technicians / workers. The LRC team should consist of a minimum of one Medical Officer (M.O), one Physiotherapist (PT), two Paramedical Workers (PMW), one Health Educator (HE) and one Laboratory Technician (LT). Besides these health

personnel one Programme Officer (PO), one Rehabilitation Officer (RO), one Dresser (DR), a Social Worker / Counsellor may be included wherever possible. It is recommended that all these personnel are leprosy oriented and have received elaborate training in providing comprehensive management of leprosy.

9.10. Suggested activities by PHC / HP staff at the community level

Basic activities:

Promoting referrals to LRCs:

1. Refer leprosy suspects difficult for diagnosis
2. Refer cases of consequence for smear examination
3. Identify & refer high risk patients for nerve assessment and necessary physiotherapy services
4. Refer for advice / treatment / management cases with complications (lepra reaction / neuritis).
5. Refer cases with complications on steroid therapy, if they develop any serious side-effects
6. Follow up on advice received from LRC

Promoting awareness in the community:

1. Health education and IEC in community

Involving general medical practitioners

1. Contact the PMPs in the area and inform them about the services available in LRC.
2. Paste posters & stickers in the PMPs clinics.

Situation analysis and need based assessment

1. Visit all beneficiaries (leprosy cases: active/RFT/ RFC) & identify their problems and needs.
2. Enlist cases from the area needing LRC services
3. Classify beneficiaries based on priority

Field level follow-up

1. Ensure regular follow up by home visits of complicated cases to confirm regularity of treatment & advice
2. During patient follow-up educate the patients and their families about leprosy
3. Refer the leprosy affected for Aids & appliances (if required) and follow up
4. Health Education to the leprosy affected with disability on self care
5. Periodical visit high risk cases to detect early signs of complications (Reactions / neuritis/ NFI) & refer to LRC if any
6. Home visits to confirm regularity of treatment and advice and ensure family support for the patient.
7. Identify patients who need rehabilitation services and refer to LRC
8. Follow-up to know if patients have reached the centre where he/ she had been referred and has been provided the services needed.

10. Anticipated Outcome

1. Enhanced capacity of the public and private health care personnel to ensure timely treatment and sustained comprehensive quality care to the leprosy affected.
2. Resulting in effective transfer of the existing leprosy expertise to the specialities in public and private health sector.
3. Estabilising network of specialised services and socio economic rehabilitation for leprosy cured.
4. Effective disability management and reduction in deformity rate among new cases, leading to reduction in social stigma.

LRC REFERRAL SLIP (LRS) – a tool for transfer of knowledge

Since 2004, ALERT-INDIA has been promoting LRCs in its urban areas in Mumbai and Navi Mumbai and other extended suburbs under LEAP. The following LRC Referral Slip (LRS) is being used effectively in all the urban centres of NGLOs, Govt. and Municipal Corporation in Mumbai and Navi Mumbai.

With a view to support and build capacity of the General Health Services (GHS) personnel LRS can be used - to provide technical and clinical inputs necessary for correct diagnosis, treatment and better care of the leprosy affected.

NGLOs are called to play a supportive role and provide all assistance. This is a specific practical assistance that can go a long way in strengthening integration.

Hence, the LRC Referral Slip (LRS) is to be considered as a tool for education, transfer of knowledge and expertise. Regular briefing of the diagnostic details of the cases that come to the LRCs, will give an opportunity to share knowledge and experience.

When the patient is referred to the PHC / HP by LRC for MDT, the LRS will provide all essential information to the MOs and other health staff that can facilitate a better understanding of leprosy diagnosis, treatment and management. The GHC - MO has a "hands on experience" on treating leprosy for the first time in decades. Further, detailed information about the diagnosis and the recommended treatment and other notes will help in follow-up of the patient by PHC / HP staff.

A duplicate of the LRS is to be kept for record and follow-up of patients to the extent possible at the NGLO / SULU (Supervisory Urban Leprosy Unit) / Hospital where the LRC is located.

Note: *The LRS can be used both for the patients who report* ***directly*** *to the LRC and are* ***referred back*** *to the respective GHC-PHC / HP for MDT and also for patients* ***referred by*** *the GHC-PHC / HP for confirmation of diagnosis / opinion / physiotherapy / ulcer care / smear etc.* ***as a feedback note*** *to inform the details of management to the concerned MO or health personnel who referred the patient.*

LEAP : ALERT-INDIA

From :

LRC REFERAL SLIP (LRS)

To : Medical Officer,

_____

Municipal Dispensary / Health Post

Date_____

Referring Mr./Mrs/Miss_____Age_____

residing at_____for

Leprosy Treatment : MB ☐ **PB** ☐ **MDT** [A] [C] ***Kindly do the needful***

No. of skin lesions : (up to 10) :_____

_____

_____

Loss of Sensations : Light Touch ☐ Pin Prick ☐ Hot & Cold ☐

Trunk Nerves : Ulnar [R] [L] Median [R] [L] Radial [R] [L]

LP (CP) [R] [L] PT [R] [L] Facial [R] [L]

Cutaneous Nerves :_____

Nerve Details : Thickened : Yes ☐ No ☐ Tender ☐

Nodules (Abscess) ☐

Neuritis : [Yes] [No] Tingling [Yes] [No] Numbness [Yes] [No]

Muscle Weakness :_____

Deformity : Ulnar Claw ☐ Median Claw ☐ Total Claw ☐ Wrist Drop ☐

Foot Drop ☐ Lagophthalmos / Facial Palsy ☐ _____

Duration of deformity : < 6 months ☐ 6 months - 1 year ☐ > 1 year ☐

Needs : Steroids ☐ Active Ex ☐ Massage ☐ MCR ☐ Splints ☐ EMS ☐ RCS ☐

Care of : Eye ☐ Hand ☐ Foot ☐ **Reaction :** Type - I ☐ Type - II ☐

Remarks :_____

_____

_____

_____

_____

Medical Officer

ALERT-INDIA:LEAP(04/05)

PART SIX

Leprosy Referral Centres:

An intervention vital to sustain elimination and support integration

Leprosy Elimination Action Programme
ALERT-INDIA, Mumbai

October, 2006

1. The Context
2. Epidemiological point of view . . .
3. Operational point of view . . .
4. Integration point of view . . .
5. Social commitment point of view...
6. Capacity building point of view...
7. Policy point of view . . .

Leprosy Referral Centres: An intervention vital to sustain elimination and support integration

A. Antony Samy, LRC: An intervention vital to sustain elimination and support integration. Journal of Communicable Diseases, 38, 1, 2006, 15-23

"Leprosy Referral Centres together with Continuing Medical Education, Information, Education & Communication, Selective Special Drives and Epidemiological Monitoring & Evaluation are identified as scheme of interventions under LEAP."

Summary:

LRC (Leprosy Referral Centre) centered activities are aimed to augment the services for leprosy affected persons by involving the GHC system to sustain leprosy elimination activities during integration phase.

The LRC activities are focused to promote the integration of MDT services within the general health services, strengthening surveillance and monitoring at the local level, supporting special surveys among specific groups of population, enhancing community participation and social communication to increase awareness, entwined with capacity building of the GHC personnel, promotion of prevention of disabilities and rehabilitation activities.

1. The context

The 'intermediate goal' for elimination of leprosy, defined as 'reducing the registered prevalence rate to less than 1 case per 10,000 population' by the end of December 2005, has been achieved at the national level. '*This of course does not mean that all supportive components will disappear. It will be important to maintain an effective network of supportive and referral services within the health system to support general health workers in maintaining an acceptable quality of services'* [1] assure the experts. This assurance needs to be translated into a policy driven action on the ground to benefit patients through out the length and breadth of the country.

After five decades of intensive specialised leprosy control efforts, the major thrust on elimination gave birth to the policy of integration. The structural integration of leprosy services into general health care (GHC) system has taken place. The entire GHC service in the country is made responsible to detect, treat and cure leprosy. The availability of MDT through a large network of Primary Health Centres (PHCs) and Urban Health Posts (UHPs) in most parts of the country is a boon to the leprosy patients and will help to reduce social ostracism in due course of time. Indeed, this is a reliable long-term process to achieve the goal of leprosy elimination, provided an active investment is made on priority for capacity building of the GHC personnel, both medical and paramedical to diagnose and treat leprosy.

The intermediate elimination target reached need to be ascertained and sustained in all regions of the country in the coming years. In this context, transfer of responsibility to the GHC system is only a partial solution. We also need to find ways and means to ***'maintain an acceptable quality of service'*** for all the leprosy afflicted. This is a monumental task yet to be realised. A serious consideration of this task from all 'points of view' is needed to arrive at a practical and viable answer.

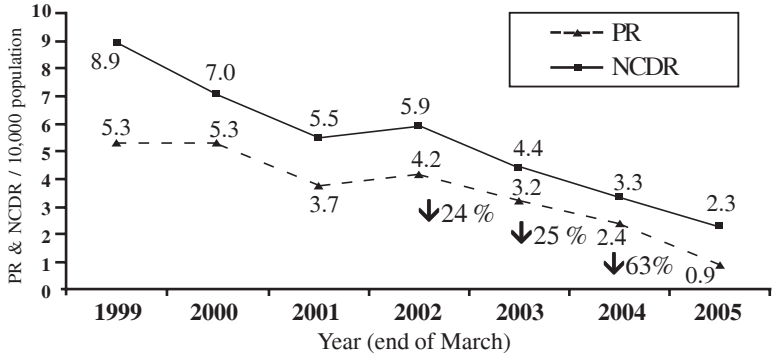
2. Epidemiological point of view . . .

Experts say that *'mathematical modelling of leprosy indicators suggests* ***leprosy is slowly declining*** *but that the* ***rate of decline remains uncertain*** *and a sustained leprosy control is required'* [2]. However, *'the picture is different, when NCDR is used instead of PR figures. The NCDR is a better indicator of disease, because it is not affected by changing case definitions or duration of treatment* [3]. WHO presume that, '*from an epidemiological standpoint, an increase in new case detection is compatible with progress towards elimination, however sustaining leprosy control activities in the context of low prevalence conditions will continue to be a challenge in the coming years'* [4].

It is difficult to measure the leprosy incidence accurately due to operational and social factors, specially the effectiveness of case finding methods, social stigma and ignorance about leprosy. There may be areas reported 'zero' case detection, but it does not mean 'zero' incidence of leprosy. Whatsoever these indicators do not characterize the leprosy burden in a given population and must take into account disability related parameters to judge the efficacy of leprosy elimination programmes.

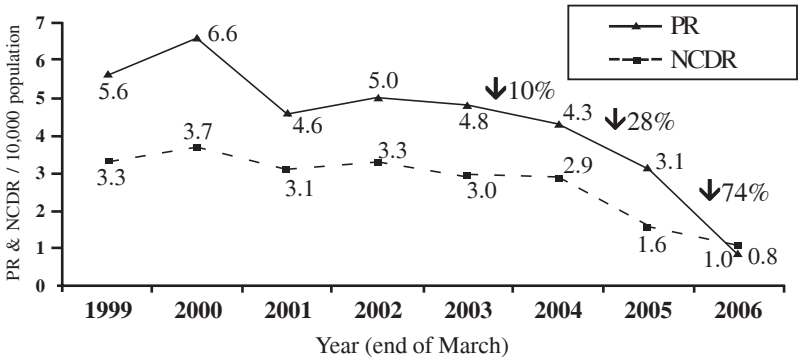
According to WHO*, a number of countries have demonstrated that a significant decline in the annual new case detection rates can be achieved after wide scale application of MDT for several years. The paradoxical trends with relatively stable detection rates reported in some major endemic countries (notably India, which contributes 78% of the global annual case detection) could be the result of several operational and administrative shortcomings, rather than epidemiological factor*[5].

Chart 1: The trend of PR & NCDR in India [6]



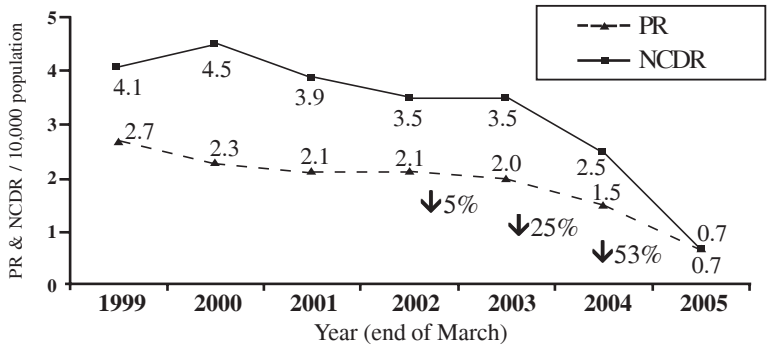
NB: Please note the sharp fall in Prevalence Rate (PR) between 2004 and 2005

Chart 2: The trend of PR & NCDR in Maharashtra state [7]



NB: Please note the sharp fall in Prevalence Rate (PR) between 2004 and 2005

Chart 3: The trend of PR & NCDR in Mumbai [8]



NB : Please note the sharp fall in Prevalence Rate (PR) between 2004 and 2005

Granting operational and administrative shortcomings, one finds it extremely difficult to agree with the policy makers that the decline in epidemiological trend of the disease has fallen to the aspired limit in prescribed time span at all levels to meet the intermediate goal set for leprosy elimination.

The charts examine the policy driven decline of PR and NCDR from 2004 to the deadline of December 2005 in the country, Maharashtra and Mumbai. In an epidemiological situation, where the knowledge about the **specific clusters of population, where new cases occur** is limited, such a decline is unprecedented and sudden. This calls for an independent validation.

The possible empirical reasons for the sudden decline are (i) discontinuing active search for new leprosy cases and (ii) the policy directives, such as registering new leprosy cases only after the validation by the designated authority; not registering single lesion leprosy cases and deleting the patients name from the treatment register as soon as the patient receive the last pulse dose of MDT, issued to the health workers in several states.

a. Undetected new leprosy cases contribute to leprosy transmission

The incidence of new leprosy cases are geographically varying in different regions across the country. *'It is a fact that leprosy patients newly diagnosed may have transmitted the disease to others in their family or community long before the disease is detected'* [3]. WHO asserts that *'a lack of appropriate tools makes it impossible to measure the true incidence of leprosy, which would be the best indicator for monitoring the impact of elimination efforts on leprosy transmission in the community'* [4].

The GOI recommends intensive Information, Education and Communication (IEC) activities to promote voluntary reporting of new cases in the integration phase. However, lack of skills, manpower and education materials to carry out effective IEC campaigns defy easy answers to educate the community about leprosy.

This calls for special interventions during Integration phase in the absence of active case detection activities. However, one cannot expect voluntary reporting of new leprosy cases will happen to its fullest extent in the given socio-economic situation in which the rural and urban poor live.

Even with the entire anticipated positive outcome from integration, the GHC system is overloaded with number of other public health priorities and will take a long time to play a 'primary' role in timely detection of new leprosy cases in the community. Hence, the integration phase requires reliable intermediary steps that will help to sustain elimination.

LRC linked Selective Special Drives (SSDs) to reach out to all the latent cases among the new migrant population to the cities and towns, urban and rural pockets, remote tribal areas and other such population groups with high prevalence will ensure early detection, diagnosis and prompt treatment with MDT [9].

b. Significant number of new leprosy cases detected among contacts

On examining the contacts of all new leprosy cases detected in 3 wards of Eastern suburbs of Mumbai (ALERT- INDIA's project area) during 2003 to 2005, it was revealed that more number of new leprosy cases are detected among the 'family contacts' than general population (Table 1). Although, the overall NCDR in the entire project area is only 0.9 / 10,000, the NCDR among the contacts is 71 / 10,000 during 2005.

LRC linked surveillance of all new leprosy cases and their contacts definitely help to unearth a reasonable number of new leprosy cases. LEAP plans to reach out to such known potential population group with the help of Mumbai Corporation, Government and Non-Governmental Organizations (NGLOs).

c. Accumulation of disabled persons due to leprosy

Government of India (GOI) reports that '*there are 6.7 lakhs (5.8%) out of 11.5 million leprosy patients registered during the last 3 decades (1984 to 2005) had visible (Grade II) disability in India'* [10] Increase in the proportion of disabled among the new cases detected during 2004-2005 (Table 2) is causing a concern.

The reason for the above situation is obvious. Even during decades of intensive surveys, the detection has been

Table 1: A comparison of NCDR in general population and among healthy contacts in ALERT-INDIA Project areas

General population	**2003**	**2004**	**2005**
Population covered	2,80,036	2,85,746	2,23,085
New leprosy cases detected	279	310	113
NCDR / 10,000	**10**	**11**	**5**
Healthy Contacts of new cases	**2003**	**2004**	**2005**
Healthy contacts examined	5,654	4,687	2,686
New leprosy cases detected	62	43	19
NCDR / 10,000	**110**	**92**	**71**

Table 2: Comparision of disabled cases and NCDR trend in India

Year	NCDR per 10,000 (% of change)	Disabled among new cases
2000-01	5.5 (21%) ↓	12,955 (2.5%) ↓
2001-02	5.9 (0.07%) ↑	12,951 (2.1%) ↓
2002-03	4.4 (25%) ↓	8,545 (1.8%) ↓
2003-04	3.3 (25%) ↓	5,302 (1.4%) ↓
2004-05	2.3 (30%) ↓	4,145 (1.6%) ↑

delayed due to reasons of inadequate coverage and persisting ignorance of early signs of disease in the community. Now the indications are that the disabled among the new cases would be higher in the coming years in the absence of active early case detection. *'It is vital to maintain continuing case detection, providing treatment and meeting the long term challenge of preventing disability'* [3]. Hence, the continuation of intensive public education linked to LRC is all the more necessary to promote early reporting of new cases voluntarily.

3. Operational point of view . . .

The WHO believes that, *'the problems facing disabled people at the community level need to be considered in their entirety, whatever the primary cause of the disability. Thus, access to all existing programmes that provide for the social and economic welfare of the disabled, including community-based rehabilitation, should also be available to leprosy-affected persons'* [12].

This is ideal, but the ground reality is different. Equipping the GHC personnel with adequate knowledge and skills especially at the district level hospitals and institutions is a long term objective to be accomplished.

Disabled leprosy patients today cannot wait until the GHC system is fully enabled to cater the needs of leprosy patients with disabilities and deformities. LRC will serve as a 'vehicle' located amidst GHC facilities as a 'reliable expertise' and 'multi-service unit' for prevention and care of deformities in addition to confirmation of diagnosis (when needed), smear facilities, management of complications (reactions / neuritis) today and equip the GHC personnel for tomorrow [2].

4. Integration point of view . . .

Effective partnership can help to sustain leprosy elimination during integration phase. Considering the huge

magnitude of post-elimination problems to be tackled, there is a need for sharing the knowledge and resources. There is a need to end the legacy of vertical programme by strengthening the partnership with the public health system to sustain the leprosy elimination activities. Creating effective linkages with the existing institutions who offer specialised services such as surgery, aids & appliances and vocational rehabilitation will also substantially help to meet the needs of the leprosy affected persons. LRC can act as a 'catalyst' for partnership with medical, surgical & rehabilitation institutions, interact with GHC personnel, exchange the expertise available at GHC & private sector in to meet the special needs of leprosy afflicted persons [12].

5. Social commitment point of view...

From the social point of view, 'm*any leprosy patients are marginalised by their communities after being diagnosed. Stigmatization continues and it needs to be combated using community based approaches'* [3]. It is totally unjust to leave the leprosy disabled today at the 'mercy' of the presently available services in the public health system for disability prevention and care. The system is largely inadequate and unprepared. The public health system is already over burdened with multiple disability loads. The net result will be additions to the leprosy colonies and rehabilitation institutions. Hence, there is a need to create a network of referral services for long term care of all disabled due to leprosy to protect and restore functional abilities. LRCs are required to be established at regional and district levels to provide adequate care and services to a large number of leprosy patients living with disability today and the additions to the pool every passing day.

Leprosy patients must have equal access to appropriate treatment on par with other diseases. Services for early diagnosis, management of complications and disabilities through trained manpower are made available at places, easily accessible for patients. LRC can serve as a 'sign post' for the public and patients during integration phase, located in publicly known places, providing comprehensive and quality care to all leprosy patients in a patient-friendly environment [12].

6. Capacity building point of view...

Specialised centres in the public health system need to be fully utilized for the management of chronic reactions, plantar ulcers, ophthalmology and hospital care with appropriate orientation and training in leprosy. LRC can become the mainstay of an effective linkage between the leprosy patients and the specialists / institutions, located at the existing municipal, government and private health facilities. Departments of Dermatology in teaching Medical colleges can be enabled to function as LRCs with appropriate training and manpower. Capacity building through CME programmes with specific placement / exchange programmes at leprosy specialised centres is essential.

Physical and surgical needs can also be effectively met by the mainstream of Physical Medicine and Rehabilitation (PMR) department in medical colleges and government institutions in the country. However, the need to change the curriculum of rehabilitation professional courses in tune with leprosy disability services is yet to be realised. Following the recent interactions with PM&R professionals through a National Workshop at Mumbai in 2005, recommendations for curriculum change in medical education and related professional courses were suggested. The recommendations are likely to become part of Sixth Five Year Plan.

7. Policy point of view . . .

WHO recognizes the *'need for "referral" services to sustain quality services in the integrated setting'* [4]. GOI proposes *'to develop a suitable referral system for providing quality services by involving established NGO / Institutions'* [11]. One takes consolation by the fact that the GOI's policy is categorical in asserting that '*it is necessary to extend the NLEP up to March 2007 for reaching elimination of leprosy in most of the districts, i.e. till the end of 10th Plan and the programme will continue with NLEP partner organizations'* [11]. The activities proposed under this

plan will be crucial to sustain the intermediate goal achieved with lot of extraordinarily active official policy changes and interventions.

Ideally, at least one LRC need to be established at regional and district level in the country. The existing NLEP units and NGOs working for leprosy can facilitate establishing new LRCs to offer timely, comprehensive & quality services to leprosy patients during integration phase and beyond.

Need for a practical intervention strategy

Despite bringing down the overall prevalence of leprosy, new cases continue to surface. Among the new leprosy cases, a significant number of them are detected / reported with early disabilities and deformities. There is a huge backlog of leprosy cured persons with residual disabilities and deformities in addition to leprosy patients prone to develop new disability and deformity.

WHO admits that *'the main principle of leprosy control is "morbidity control", i.e. timely detection of new cases, their treatment with effective chemotherapy in the form of multi-drug therapy (MDT), prevention of disability and rehabilitation. This will not change over the coming years. The emphasis will remain on providing diagnostic and treatment that are equitable distributed, affordable and easily accessible'* [12].

Therefore, *'elimination' is not an appropriate goal for leprosy and it is better seen as a chronic disease that requires long-term planning and control. The new challenge is to build on the success of the leprosy campaign and deliver sustainable care for leprosy patients* [3]. Continuing transmission and increasing burden of disability due to leprosy will remain as a challenge for many years to come unless a renewed strategy with active approach to leprosy management is pursued by all stakeholders.

Leprosy Elimination Action Programme

This calls for a practical intervention strategy that supports integration and sustains leprosy elimination in a real sense of the term. Leprosy Eliminaton Action Programme (LEAP) promoted by ALERT-INDIA during integration phase, is a planned transition from the predominance of vertical leprosy programme and services to an action programme, focussing on community partnership strategies. The objective of LEAP is to meet all the needs of leprosy affected persons by utilising the best potentials available today with the NLEP and dovetail with the services and facilities in the public health system through a partnership approach.

Leprosy Referral Centres (LRCs) together with Continuing Medical Education (CME), Information, Education & Communication (IEC), Selective Special Drives (SSD) and Epidemiological Monitoring & Evaluation (EME) are identified as scheme of interventions under LEAP [13].

Establishing LRC in partnership with public and private health care providers, NGLOs and NLEP institutions is an immediate possibility to meet the needs of leprosy patients in the present phase. LEAP promotes such partnerships. LEAP promoted and assisted Government, Municipal Corporation and other NGLOs to establish seven LRCs in urban, rural and tribal areas of Mumbai, Thane and Raigad districts based on the principle of sharing resources, expertise and manpower.

In future, LEAP proposes to establish LRCs in four backward and tribal districts of Maharashtra in partnership with district NLEP units. ALERT-INDIA has also established, in its project areas at Mumbai and Navi Mumbai, six LRCs since 2004, out of which five are located in the municipal hospitals / dispensaries and medical colleges.

8. The Future

LRCs can help us make a difference for the patients of today and tomorrow. In places where such services do not exist, LRCs need to be established. LRC should be need based and can be located at block or district or regional level. All necessary infrastructures needed to offer specialised services should be ensured. At the district level, the facilities available with the existing general hospital should be availed.

LRC should promote partnership with GHC. The expertise of professionals such as surgeons, ophthalmologists, dermatologists, physiotherapists and rehabilitation experts available with GHC can be utilised for LRC by exchange and / or interaction programmes.

This will pave way for continuation of services to the leprosy affected in the general health sector and provide for sustainability. The dependence on specialised leprosy personnel should be eventually minimised.

In fine, LRCs can help us to make leprosy elimination sustainable and enduring.■

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Specialized element for leprosy

World Health Organisation (WHO) has accepted the principle of integrating leprosy control into general health services wherever possible, whilst at the same time, underlining the importance of maintaining a vertical specialised element at various levels of the programme, for supervision, referral facilities, drug supply and financing.

Integration will help in maintaining MDT services at the peripheral level, especially in areas where prevalence is declining. Several national programmes, even in countries with very high prevalence, have integrated leprosy services, mainly because of the urgent need to expand MDT coverage.

However, it is important to have an element of a specialized programme in all endemic countries, either at the central level or — in some larger countries — at intermediate level.

This specialized element for leprosy will be needed for providing technical guidance, for monitoring and evaluating the progress of elimination, for training and for research purposes.

Referral centres will also support the general health services in diagnosing difficult cases and in providing certain specialized care to patients with complications.

Source: Handing Over. WHO, SEARO; New Delhi. Website: http://w3.whosea.org/leprosy/theplan.htm

Disabling conditions in South Asia : The hidden factors with implications for Leprosy

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"The specialists and referral centres that should have been developed to support the front line have often fallen victim to 'anti-institutional' rhetoric of the 1980s and 1990s."

Elimination of leprosy "as a public health problem" may be achievable in South Asia through Multi-Drug Therapy, within a few years. Management of disability in cured leprosy patients will nonetheless continue through the 21st century, probably with some stigma. Disabilities in leprosy are targeted for eradication or severe reduction, using affordable surgery or preventive measures; yet this have proved unexpectedly resilient. Experience suggests that technical solutions alone bring only partial success. They must be backed up by individual and family self-help, community participation in service provisions, and a redeployment of professional expertise.

In the current South Asian population of c. 1400 million, the WHO-backed target would be reached by bringing the number of registered 'active' leprosy cases down below 140,000. Yet even if that occurred, and the data were genuine, the visible human "problem" of leprosy would take at least a further century to disappear, with the eventual death of people who had leprosy-related disabilities and who could not, or did not wish to, gain access to rehabilitative care. Such outcomes, though feasible, are hardly the sharp, clear-cut, objectives that would be politically attractive.

Conflicts between vertical and horizontal approaches have appeared not only in the health field but also in disability services. Some people place Community Based Rehabilitation (CBR) in opposition to institutions or centres, though the WHO CBR scheme makes clear the need for referral centres with specialised skills.

After many futile struggles it has become clear that the knowledge, skills and design accumulated under careful scrutiny in the best of the specialised approaches are vital to the success of the best integrated community-based approaches, while the community resources and links are vital for disseminating knowledge, skills and design to people in the community. Thus, the expertise of people who have been working for 30 years in vertical leprosy schemes, for example, should neither be dispersed nor ignored.

It needs to be adapted and applied in the newer policy, so that people who have spent 30 years in primary health care schemes need not spend years discovering for themselves all the complexities and peculiarities of leprosy. Better results come by enlisting and sharing the existing information resources, and being open about the knowledge gaps.

"Leprosy-expert" staff and "CBR-expert" staff should observe, value and acquire one another's skills", and also makes clear that the cumulative experience of people with leprosy, and their own organisations, now make a valued contribution to the sum of "expertise".

The specialists and referral centres that should have been developed to support the front line have often fallen victim to 'anti-institutional' rhetoric of the 1980s and 1990s. In the long run it must be these human resources that tackle the social problems that continue after technical solutions have been applied to leprosy and other disabling diseases and conditions.

This has been seen elsewhere in the world where people often had narrower and shallower historical cultures on which to draw, but applied themselves successfully to improving the social context and facilitating inclusion of those with disabilities. ■

Source: Miles. M., Knowledge and management of disabling conditions in South Asian Histories: Implications for leprosy futures. Indian J Lepr., 75 (2), 2003, 153-167 (Extracts)

Special attention to prevent deformities, blindness and damage to insensitive areas

Consultations for specialized care

Dr. Ramaratnam Sridharan

"Physiotherapy and occupational therapy are essential in patients with paralysis because of neural involvement. In patients who undergo rehabilitative surgery, such as tendon transfers, muscle-reeducation exercises are essential."

Surgical care

- A multidisciplinary team comprising a leprologist, a neurologist, physical and occupational therapists, and a surgeon with experience in peripheral nerve surgery is needed.
- Surgical treatment of an acute nerve abscess is careful incision of the nerve sheath and draining the abscess. Surgical neurolysis or even fascicular dissection has been advocated to relieve intraneural pressure.
- Surgical treatments for eliminating anatomically restricted areas (constrictions) improves sensation in selected patients and often prevents further deterioration. Optimal timing for nerve decompression needs to be established.
- Nerve decompression is used when signs of entrapment have not cleared after 3-4 weeks of steroid therapy, when function deteriorates despite steroid therapy, or when signs of nerve abscess or chronic entrapment are evident.
- Posterior tibial neurovascular decompression by release of flexor retinaculum with systemic administration of steroids may be beneficial in early acute or silent neuritis. Distal compression of plantar branches should be relieved by slitting the calcaneal bands and ensuring free passage of the plantar branches to the sole of the foot. Nerve function (particularly autonomic and sensory modalities) can recover considerably. In some cases vascular decompression may help heal chronic plantar ulcers and prevent recurrence.
- Peripheral nerve reconstruction performed by using denatured muscle autografts may help to restore protective sensation in hands and feet.
- Nerve grafts may be helpful for patients with localized nerve lesions.
- Cosmetic surgery may be contemplated after leprosy is medically controlled. Procedures include excision of redundant skin in ear lobes and eyelids, excision of excessive breast tissue in gynecomastia, implantation of islands of scalp hair to replace lost eyebrows, and nasal reconstruction.
- Facial-nerve palsy with associated lagophthalmos may be corrected by performing tarsorrhaphy or canthoplasty to prevent exposure of cornea or by tunneling a slip of temporalis muscle attached to tendon through the lid and attaching it to the inner canthus. Re-education involves closing the jaws to effect eye closure.
- Tenodesis to stabilize joints, arthrodesis to correct clawing, and tendon-transfer surgery may be considered. Tendon-transfer procedures may be used to replace paralytic muscles with functioning ones, especially to restore action.

Source: "Neuropathy of Leprosy" by Dr. Ramaratnam Sridharan, HOD, Neurology, Apollo Hospital, Chennai, India, http://www.emedicine.com/neuro/NEUROMUSCULAR_DISEASES.htm.

Consultations

Patients with leprosy are best referred to specialized centers with expertise in leprosy management.

- Consultation with an orthopedic surgeon is recommended for the management of trophic ulcers and for tendon-transfer surgery.
- Consultation with an ophthalmologist is recommended for the management of ocular complications.
- Consultation with an otorhinolaryngologist may be helpful for patients who have nasal symptoms.
- Reconstructive surgeon with special interest in leprosy and nerve surgery may be of assistance.
- Specialists in physical medicine and orthotics should be consulted.
  - Physiotherapy and occupational therapy are essential in patients with paralysis because of neural involvement. In patients who undergo rehabilitative surgery, such as tendon transfers, muscle-reeducation exercises are essential.
  - The most effective healing tools for plantar ulceration are the total contact cast and the posterior walking splint. Alternatively pressure-relieving or healing devices can be made, modified, or augmented to reduce loads on foot.
  - Heel ulcers are common in those with an insensitive foot and who need long-term bedrest or positioning during surgery. These ulcers can be located on the medial, lateral, or posterior aspect with a plantar component.
  - A boot is cut to appropriately relieve the area. When the wound closes, permanent footwear and orthotics are fitted to prevent reulceration.
  - All options used for the wound-healing phase and initial ambulation after wound closure must include use of an assistive device for partial weight bearing, preferably with crutches or a walker.
- Consult a psychologist to deal with the social aspects of the disease. ■

Have we won the first battle against leprosy?

It seems like, we are entering a new phase in leprosy control.
But without the largesse of governments, without the consensus of stakeholders,
without the continued, unified effort of those in the programme, and without the persisent pursuit of 'quality'
as the centre-stage of all actions, the "clear-sky" optimism will remain at best a self-indulgence and
we will be prevailed upon to remain on the battle ground for a long, long time.

Dr. Krishnamurthy P., Have we won the first battle against leprosy?.
Indian J Lepr 78: 2, 2006, 103-104.

PART SEVEN

Integration of leprosy rehabilitation services into the mainstream of physical medicine and rehabilitation

Recommendations

National Workshop

10th October 2005

Jointly Organised by

ALERT - INDIA & AIIPM&R, Mumbai

National Workshop

Recommendations

10th October, 2005

The following recommendations were made and unanimously approved by a panel of experts.

The recommendations were divided into two parts:

I. Integrating leprosy rehabilitation services into the mainstream of PMR services

1. The integration of leprosy services into the mainstream of PMR services should be done gradually and in a coordinated manner with all those concerned with the rehabilitation services including NGOs and private health sector.
2. The leprosy patients having various functional and structural deficits would require interventions to prevent activity limitations at the personal level and participatory restrictions at the societal level and such interventions should be made available at all the PMR institutions.
3. A directory containing the details of the services that are available with the PMR institutions for leprosy affected persons should be made available with the health workers at the PHC level.
4. The Leprosy division of Govt. of India should conduct a regional level meeting with the PMR experts and the State Leprosy Officers and include PMR experts as a part of the District Leprosy Nucleus team.
5. A realistic estimate on the magnitude of the leprosy related disabilities including the grade 1 disabilities (WHO, 1988) should be collected at the taluka level to plan the necessary interventions.
6. Integration of the leprosy rehabilitation services should be made at all the level of general health care delivery system and not only at the GHC level.
7. The health workers at the GHC system should be trained in the early identification and simple intervention of leprosy related disabilities and their rehabilitation.
8. The leprosy institutions providing tertiary care to leprosy affected persons should extend their services to the persons with other chronic disabilities due causes other than leprosy.
9. The media should be adequately used to achieve integration of patients in the community and to dispel the misconceptions about the fear on infectivity.

II. Review and propose modification in the training curriculum for medical and paramedical graduates.

1. The trained rehabilitation manpower as well as the PMR institution is limited hence it cannot meet all the rehabilitation needs of leprosy affected persons. Therefore the teaching of disability prevention and rehabilitation with focus on leprosy rehabilitation should be included at under graduate level.
2. At the post-graduate level, (MD / DNB) for the doctors, PMR curriculum approved by Medical Council of India (MCI) / National Board of Examinations (NBE) is already inclusive of leprosy rehabilitation. Surgical skills should be enhanced at this level. The medical specialists working in PMR already should be given training in the surgical skills on appropriate reconstructive procedures for leprosy.
3. Training of medical officers at PHC and district level should be done as is being under RCI programme to bridge the gap of requirement of available resources keeping in view of the paucity of the PMR institutions in the country.
4. Paramedical courses such as Physiotherapy, Occupational Therapy and Prosthetic and Orthotic curricula should include adequate coverage of leprosy rehabilitation components.
5. The training programmes organized by the Rehabilitation Council of India (RCI) for the medical officers working in the general health sector should include leprosy rehabilitation services.
6. The professional bodies such as Indian Association of Physical Medicine & Rehabilitation (IAPMR) in coordination with the MCI need to review the existing curricula for medical and paramedical undergraduates and suggest suitable curriculum with more focus on leprosy rehabilitation.
7. The Leprosy division of Govt. of India in coordination with the PMR experts should recommend a revised curriculum on leprosy rehabilitation to the MCI for MBBS and other paramedical courses by forming a Consultative committee and through a Curriculum Development Workshop.

PART EIGHT

Is integration a leap forward?

Implications of integration
on quality care in leprosy

Recommendations

National Workshop
11th October, 2006

Organised by
ALERT - INDIA, Mumbai

National Workshop

Recommendations

11th October, 2006

In order to sustain quality services to all leprosy patients at different levels we need to have clear directives from Central Leprosy Division (CLD). Hence the following recommendations are submitted for consideration and appropriate action by CLD.

1. On registration of new leprosy cases for MDT.	We call upon GOI-CLD to issue specific directives to all the States on the criteria for diagnosing and registering new cases (WHO criteria for 'a case of leprosy') for MDT services at all GHC centres, Leprosy Referral centres, Public and Private Hospitals and Medical colleges. Registering new patients with 'Zero" number should be forbidden. Recording and reporting all new leprosy cases should be the norm.
2. On setting targets	We strongly advocate GOI-CLD to discontinue setting targets to achieve the goal of leprosy elimination at sub-national level (district and block level), even by way of 'expected outcome'. A clear and specific instruction to all the States to this effect is urgently needed.
3. On establishing Leprosy Referral Centres	We advise GOI-CLD to ensure sustainable leprosy control activities that are carried out within the integrated set up, which includes establishing leprosy referral centres at the block and district level mainly to manage leprosy-related complications including the cured leprosy patients with visible deformities.
4. On providing POID & POD services	We recommend GOI-CLD to develop a 'formal' and 'recognized' training course for Medical and Supervisory staff at GHC on the identification of leprosy-related complications and to treat / refer all new and cured leprosy cases with deformities. This should complement the training on diagnosis and treatment for leprosy undertaken for all GHC staff. This will help in identifying early nerve damage and provide appropriate care / necessary referral.
5. On sample survey to determine epidemiological situation of leprosy	We urge GOI-CLD to encourage as a policy for continuous monitoring of new case detection (Sample survey) using specific indicators as a part of routine supervision on sampling basis. Epidemiological data collected at the district / region level need to be validated without any prejudice and provide feedback to the programme.

6. On integration of leprosy into general PMR & rehabilitation institutions

We propose GOI-CLD to support the supply of protective aids and footwear to all the needy leprosy patients through specialized leprosy institutions and other PMR departments in general rehabilitation institutions as a part of their routine services with specific linkages with the local leprosy referral centres.

7. On the need for skin smear in leprosy control

We request GOI-CLD to issue an explicit guideline to all the State Leprosy Officers on the need for undertaking skin smear examination at the referral centres and Medical colleges, where proper microscope and trained technician is available, as it is the simple tool available to detect early lepromatous cases. Skin smears for leprosy can become a part of the RNTCP microscopy centres.

8. On leprosy curriculum in medical teaching institutions and ensuring uniform MDT regimen

We advocate GOI-CLD to acknowledge and convince the MCI to develop a training curriculum on leprosy for under-graduate medical students (all pathies) as a part of routine medical education in the country and ensure by directives to make the medical colleges and other public health institutions adhere to the appropriate (MDT) treatment recommended by WHO to all leprosy patients.

9. On legal and social problems

We recommend GOI-CLD to actively promote consultative meetings with the legal experts and the social scientists to amend all the existing derogatory laws pertaining to leprosy affected persons and ensure dignity and basic human rights. An official endorsement by the GOI-CLD will make a major difference.

10. On the protocol for surgical interventions for rehabilitation (SIR)

We suggest GOI-CLD to adopt and communicate officially, the guidelines for selection suggested by ILEP and procedures for pre & post operative therapy as a part of Disability Prevention and Medical Rehabilitation (DPMR) of GOI. Corrective surgery should be done only on patient's informed consent and to whom it will make a difference in the activities of daily life and enhance functional ability. This will help to dissuade unnecessary surgical interventions at the camps. Compensation for loss of wages must be provided during the post-operative period including hospitalization care as a part of routine programme.

PART NINE

LEAP: a strategy to sustain leprosy control during integration phase

October, 2007

1. Key milestones in the development of leprosy control strategies: 1948 to 2005

2. In search of a relevant strategy for leprosy control during 'Post-Elimination' period

3. 'Leprosy elimination' - Need for sample survey

Key Milestones
in the development of leprosy control strategies: 1948 to 2005

A. Antony Samy, Joy Mancheril and S. Kingsley

Part of the paper presented at the International Symposium on "Remaining Challenges in Leprosy" Kathmandu, Nepal, September 2007.

World Health Organization (WHO) acknowledged the magnitude of leprosy in 1948 and enlisted leprosy control work as the sixth priority. In 1952, the WHO Expert Committee advocated the *'abolition of compulsory isolation of leprosy patients and recommended a strategy based on early detection and regular treatment for all leprosy patients on ambulatory basis'* [1]. The age old strategy based on isolation policy came to an end.

As early as in 1955, the Govt. of India (GOI) had launched the National Leprosy Control Programme (NLCP) based on - Survey, Education and Treatment (SET) strategy at the national level. Dapsone (DDS) monotherapy was the only weapon in the hands of doctors and paramedical workers engaged in leprosy control. The leprosy trained paramedical personnel constituted the core of the programme. Dapsone was indeed a proven effective drug. The prolonged treatment and the scientific evidence on emergence of dapsone resistance by *M. leprae* led to the advent of MDT. Following the *'first attempt to provide realistic figure of the number of leprosy cases in the affected countries of the world'* in 1966, [2] the WHO Expert Committee advised the countries with limited resources to concentrate their efforts on *'treatment and follow-up of infectious cases and on surveillance of their contacts'* [3].

In 1966, ILEP adopted the strategy recommended by WHO and *'worked in accordance with the national strategy'. However, special attention was on 'compassion towards leprosy sufferers and therefore has a long experience in rehabilitation activities including physical, vocational, economical and social'* [4].

The most important changes in leprosy control have occurred because of alterations in knowledge about the disease and the treatment. In 1981, WHO recommended the *use of MDT as a standard treatment for leprosy in leprosy control programmes* [5]. Since then, WHO provided technical support and ensured uninterrupted supply of MDT drugs free through its global partners to GOI. Supervised MDT was adopted to circumvent the limitations of dapsone era drug delivery system. The domiciliary treatment with dapsone monotherapy came to an end.

In 1983, the GOI renamed the 'National Leprosy Control Programme' as the 'National Leprosy Eradication Programme' (NLEP) and continued with SET strategy based on early detection of cases by population surveys, school surveys, contacts examination and treatment with MDT. Registration of all new cases and prompt treatment with MDT and compliance reached record levels.

a. WHO sets target date for leprosy 'elimination'

In 1991, the success of MDT propelled the WHO to propose a global strategy for 'elimination of leprosy as a public health problem' [6]. It aimed to reduce the prevalence of leprosy to less than 1 case per 10,000 population by the end of 2000. The GOI in turn adopted several operational strategies to intensify MDT coverage to endemic regions by engaging casual workers and creating mobile treatment units and achieved 100% coverage in 1996. This has helped to cure a large number of leprosy patients without disability and deformity in a short time.

b. First attempt by GOI to reach the leprosy elimination target

GOI introduced Fixed Duration MDT (6 months for PB and 12 months for MB) in 1996 and undertook 'cleaning of register' exercise during 1996 – 1997. This curtailed off all extended treatment and the number of active cases on record. WHO recommended specific strategies for undertaking special campaigns such as Leprosy Elimination Campaigns (LECs) and Special Action Programme for Elimination of Leprosy (SAPEL) to detect all the backlog of cases involving the GHC workers in 1997 [7].

Since 1998, GOI launched Modified Leprosy Elimination Campaigns (MLECs) with an emphasis on public awareness and promotion of suspects for voluntary reporting for examination. MLECs were an attempt to reach out to the community and enhance early detection of hidden cases. One million new leprosy cases were detected in all 5 MLECs. Simultaneously single dose treatment for single skin lesion leprosy was introduced to accelerate the 'leprosy elimination' target by 2000. However the target could not be met in India at the national level as the prevalence rate of leprosy was 5.2 per 10,000 population by end of 2000.

c. WHO deferred the target date for leprosy elimination

The failure to realize the target date for 'elimination' in India and in several other countries, made WHO to propose a strategic plan called 'Final Push': 2000 to 2005. Thus the target date was shifted from 2000 to 2005 [8]. The key elements of the 'Final Push' strategy were: 1) Integration of leprosy services into the general health services to improve access to treatment; 2) Capacity building to enable general health care staff to diagnose and treat leprosy;3) Improve logistics to ensure adequate stocks of MDT at health centres; 4) Change society's perception of leprosy and motivate people to seek timely treatment; 5) Ensure high cure rates through flexible and patient-friendly drug delivery systems and 6) Simplify monitoring to keep track of progress towards elimination. With this plan, all endemic countries including India were pushed to 'perform' and meet the revised deadline.

d. Second attempt by GOI to reach the leprosy elimination target

In 2001, the GOI revised its strategy based on 'Final Push' strategy. Revised Project Implementation Plan focused on leprosy training of GHC personnel; validation of new cases by special teams; intensified IEC campaigns and prevention of disability through surgery and POD camps. In 2002, the National Health Policy (NHP) of GOI expressly set the goal for leprosy elimination by the end of 2005. The GOI introduced validation exercises under Leprosy Eliminating Monitoring (LEM) on an annual basis. The PR began to decline at the rate of 25% per year at the national level. ILEP supported GOI with District Technical Support Teams (DTST), especially in capacity building of GHC personnel to deliver MDT services and assisted in supervision of LEM and simultaneously sustaining the leprosy control units and hospitals.

e. Leprosy elimination target propelled integration

With LEM, the GOI began the process of integrating the leprosy services with the general health care services in 2002, initially in the rural areas. The aim was to enhance universal accessibility of MDT services, to minimize the stigma and to make the programme cost-effective. The integration in the urban areas was undertaken in 2004. To actualize the process of integration, GOI carried out a large scale training of GHC personnel emphasizing on awareness campaign to promote voluntary reporting.

f. Final attempt by GOI to reach the leprosy elimination target

During 2004 – 2005, the GOI has drawn a strategic plan of action with the focus on endemic districts through Focused Leprosy Elimination Plan (FLEP) and on endemic blocks through Block Leprosy Awareness Campaigns (BLAC). While the GOI was keen on

achieving the goal of leprosy elimination, all the thrust has been on reducing the Prevalence of leprosy.

In the beginning of 2005, the supplementary policy directives issued by GOI based on 'Kathmandu recommendation' [9] has changed the course of leprosy control work at all levels.

- Stop all active search for new case detection
- All new cases detected to be registered and given MDT only after validation by authorities in each area.
- Delete names of the patients from the registers as they receive the last pulse.
- Do not register single lesion leprosy (SSL) cases for now.

These recommendations were strictly implemented and thus India has achieved the goal of leprosy elimination by the end of 2005 at the country level. ■

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Developing a framework for a strategy to sustain elimination: 2006–2010

- It is important that efforts be made to sustain such achievements, to reduce the disease burden still further, and to make MDT services easily accessible to communities in which new cases of leprosy will continue to be detected. **There will be no advantage in continuing to use elimination as an indicator or in defining another numerical target or timeframe for the period beyond 2005:** the most important indicator for monitoring the leprosy situation will be the declining trend in new case detection.
- The key issue will be to integrate all essential components of leprosy control, including the referral facilities, within the existing primary health care system or another relevant programme.
- The main concern, at least in some large vertical programmes, will be the reallocation of existing personnel, in order to provide technical support, monitoring and supervision. It will be important to build up the capacity of both vertical workers and general health workers to take on new responsibilities.

Source: *Excerpts from the Report on the sixth meeting of the WHO Technical Advisory Group on Elimination of Leprosy, Geneva, February 2004, WHO/CDS/CPE/CEE/2004.41,P. 15*

In search of a relevant strategy for leprosy control during 'Post-Elimination' period

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Part of the paper presented at the International Symposium on "Remaining Challenges in Leprosy" Kathmandu, Nepal, September 2007.

The remaining challenges in leprosy need a careful examination of the strategies adopted over the past five decades in India as against the present leprosy situation. The reflection of success and failures are the direct results of policies and strategies of the past. We present a historical recount of the strategies that led to drastic decline in the prevalence of leprosy prior to 'elimination in 2005' and the present strategies pronounced by major players and ALERT-INDIA's strategic action plan for leprosy control during the post-elimination and integration phase.

The milieu

In India, poverty is the root cause of all health problems and leprosy is no exception. Despite five decades of successful vertical programme, a large segment of population continues to be stigma ridden and ignorant. The continued transmission of leprosy infection, occurrence of new cases and the burden of patients with disabilities and deformities also pose a challenge. The overburdened public health system is entrusted with the responsibility to deliver leprosy services. The public health system can definitely rise up to the task. Sustaining early new case detection and providing quality care during this 'transition phase' is a matter of concern for all of us. The duration of this phase and the outcome largely depends on how relevant is our strategy.

Achieving the intermediate goal of leprosy elimination is not an end to the problem of leprosy. Now, the search is for a futuristic long-term leprosy control strategy that can effectively address the remaining challenges in leprosy. We at ALERT-INDIA are convinced that any new strategy cannot ignore the primary goals of disease control.

Goals of disease control

Any disease control strategy should aim to achieve three specific goals:

- decrease the prevalence of existing disease;
- decrease the incidence of new infection and
- decrease the morbidity and mortality rates due to the disease.

Further, the disease control strategy should be based on the ground reality in terms of the current epidemiology of disease; the available technology and tools to control the disease; the assessment of the disease burden; the logistics needed to operationalize the strategy within the public health care system; the resources available and the specific socio economic context of the population. With this view, we need to consider the tasks remain to be addressed.

Overview of current strategies for leprosy control

The following are the salient aspects of current strategies pronounced by the key players - The World Health Organization (WHO) with its global partners, member organizations of International Federation of Anti-leprosy Associations (ILEP) who supports the country wide efforts of National Leprosy Eradication Programme (NLEP) of Govt. of India (GOI).

i. Post-elimination strategies : WHO

In mid 2005, WHO proposed a global strategy for 'further reducing leprosy burden and sustaining leprosy control

activities: 2006 to 2010' [1]. This strategy recommends strengthening the referral network in order to support integrated leprosy services with an emphasis on quality care. This is to be achieved by (i) appropriate training of staff at every level, (ii) regular technical supervision and (iii) monitoring of key epidemiological indicators. WHO also recommended the country governments to prepare an action plan for leprosy control based on the global strategy.

ii. Post elimination strategies - ILEP

ILEP support to India is in line with global strategy specifically sustaining quality leprosy control activities during 2007- 2012. This is envisaged in the following thematic areas:(a) Monitoring and supervision; (b) Capacity Building; (c) Support to DPMR; (d) Operational research; (e) Support to local NGOs; (f) Socio-economic rehabilitation and (g) Community participation. ILEP proposed to constitute a national forum for partners in NLEP to review the progress and needs of the programme and to discuss technical issues with the GOI [2].

iii. Post elimination strategies - GOI

Upon achieving the intermediate goal of leprosy elimination at the national level, the GOI initiated a Programme Implementation Plan (PIP): 2005 - 2007 [3] with a focus on achieving the goal at the sub-national level. In late 2006, the GOI has promoted a Disability Prevention and Medical Rehabilitation (DPMR) programme to involve and strengthen the institutions providing reconstructive services to cater the needs of disabled leprosy patients [4]. The GOI is expected to endorse WHO's global strategy and propose a plan of action as recommended by its expert group including the ILEP in the 11th Five Year Plan (2007 – 2012).

Recently, the GOI has rightly taken a midcourse correction and issued guidelines by setting New Case Detection Rate (NCDR) as an indicator for quarterly assessment of NLEP instead of Prevalence rate (PR) and promoting special efforts to bring out hidden cases. These steps will go a long way in reverting the 'target oriented performance appraisal' to actual new case detection and pave way for leprosy elimination in real terms.

ALERT-INDIA's strategy for leprosy control during 'integration phase'

In India, we had a 'cut-off' date both for 'Integration' and 'Elimination' of leprosy. In fact, following the announcement of 'elimination' as an achievement of intermediate goal and 'integration' as policy frame for future leprosy work, we have entered a new phase in the leprosy control in India. At this stage, the strategies adopted cannot be determined by unilateral actions by the leprosy relief agencies. The main players are the public health care system and the community who can accelerate the successful realization of the objectives of this phase.

ALERT-INDIA believes that the integration and elimination are a process that can be realized by sustained interventions over a period of time by all of us. Therefore, ALERT-INDIA has evolved a feasible strategy for the leprosy control during integration and post-elimination phase. Moreover, future leprosy control work, beyond 2012 or 2020, depends on the efforts and progress made in the next five to ten years.

ALERT-INDIA refined its vision statement in 2004 [5]: ***'to strive towards programmes focussing on community partnership strategies to achieve the goal of leprosy elimination during the integration phase, in alliance with all stakeholders, to make leprosy elimination a reality for people'***.

Based on this vision, ALERT-INDIA formulated a strategic plan called **"Leprosy Elimination Action Programme: 2005 - 2010" (LEAP) [6].**

LEAP promoted by ALERT-INDIA* aims to make best of the **potentials** and **opportunities** that are available today with the specialized leprosy agencies by bringing

together all the prospective partners to assist the GHC system and to enhance the quality of the services for the leprosy-affected individuals.

Plan of action

A plan of action based on LEAP strategy, was developed to set up a programme with diverse initiatives involving multiple partners through the general health care system and community participation. In 2005, the first phase of LEAP was launched in urban areas of Mumbai and in backward districts of Maharashtra in partnership with various stakeholders. We are at the third year of the first phase. Learning from our own experience and of other players in the field, we are also preparing for the second phase to be launched in 2008.

Overall objective[7]:

LEAP aims "to strengthen the integration and to sustain the leprosy control activities through a community partnership approach by involving all stakeholders".

Specific objective 1: To reach all new leprosy patients through intensive community level IEC campaigns and **Selective Special Drives (SSDs)** - specially in selected endemic areas.

Rationale:

a. Routine surveys are discontinued due to low yield and increased cost. Special campaigns were discouraged as it was counterproductive. The previous active case detection methods did not involve community groups or organizations.

b. Continuing ignorance about basic scientific information on early signs of leprosy and socio-religious myths need to be countered consistently in the general community to promote voluntary reporting.

c. Constant migration of population makes the task difficult for the health service providers to identify the source of infection and to break the chain of transmission.

Action plan:

a. Developing appropriate education materials with simple and positive information for leprosy affected persons and community to remove the misconceptions about leprosy using different media as well as sharing these with all stakeholders.

b. Mobilizing the community potential and developing community spokesperson for sustained campaigns.

c. Selecting / training / equipping community volunteers with primary knowledge of signs and symptoms to suspect leprosy in their own locality / population covered as a part from their regular duty in epidemiologically significant areas identified, based on specific criteria** for **Selective Special Drives (SSDs)**.

d. Engaging community volunteers to involve various sections of community groups (such as CBOs / health workers of Govt. & NGOs / anganwadi workers & teachers and other health & development workers etc. who are in regular contact with people) in practically organizing and participating in leprosy awareness campaigns. These volunteers are encouraged to multiply such efforts on their own even after the drive.

SSDs are conducted in urban slums of Mumbai and rural districts of Maharastra by ALERT-INDIA *and other partner organizations – Leprosy and Health NGOs. The result is many spokesmen for leprosy in the selected community groups, who promote referrals in addition to voluntary reporting of new cases. Results are very encouraging as SSD bring out multibacillary (MB) leprosy cases at different stages. Such community partnerships in areas known as endemic for leprosy can help promote early new case detection and minimize disease morbidity.*

Specific objective 2: To augment the capacity building efforts of all GHC personnel, medical professionals and health care functionaries through **Continuing Medical Education (CME)** programmes.

Rationale:

a. Lack of appropriate knowledge & skills to diagnose and treat leprosy by the GHC personnel. The medical professionals in the public and private health sector of all disciplines need to be involved as active 'partners' in leprosy control.

b. Absence of emphasis on integrating leprosy services with the medical and surgical institutions has been largely responsible for depriving the essential services for leprosy patients on par with other diseases.

Action plan:

a. Developing suitable training modules and practical guides for transferring the knowledge and skills on leprosy to various categories of health personnel working in GHC system.

b. Offering practical and task oriented training to the GHC personnel in diagnosing and treating leprosy as well as its complications effectively.

c. Continuing dissemination of information through updates and publications on clinical and epidemiological aspects of leprosy to medical students and professionals of all disciplines including general medical practitioners.

d. Campaigning for curriculum change in medical and paramedical courses in tune with the recent development in leprosy control

Several categories of GHC personnel – Medical doctors and health workers of Urban Health Posts of Municipal corporations in Mumbai and Thane districts and Primary Health Care Centres in rural districts of Maharashtra - and medical professionals – Medical students of all discipline, paramedical and Private Medical Practitioners - trained through CME programmes carried out under LEAP.

A simple practical guide to equip the public health doctors is made available in English and Hindi. This has resulted in increased referrals of leprosy cases for confirmation of diagnosis, management of complications and disability care. These efforts are ultimately aimed to facilitate the GHC personnel and other medical professionals to treat leprosy on par with other diseases.

Specific objective 3: To offer timely and comprehensive care to all leprosy patients through a network of **Leprosy Referral Centres (LRCs),** in collaboration with the public & private health care providers / Institutions for specialized services.

Rationale:

a. Lack of skills to detect early nerve damage and manage leprosy complications by the GHC personnel [reactions / neuritis] would result in development of new disability.
b. Lack of facilities to offer comprehensive care / specialized treatment for the leprosy patients, especially for those with disabilities and deformities.
c. Referral services for counseling, prevention and management of deformity including the provision of protective aids and rehabilitation services need to be located at district level for easy accessibility to patients equipped with appropriate tools and trained manpower.

Action plan :

a. Establishing new or strengthening the existing referral centres of various partners at the sub-district level preferably located at the GHC facilities.
b. Offering practical guidance and technical assistance to the GHC personnel in making accurate diagnosis of difficult cases; refer or manage leprosy complications and providing physical care of all those affected by leprosy.

c. Training and utilizing the experienced leprosy personnel for providing comprehensive care to all leprosy patients referred by the GHC system at the LRCs involving the public health personnel.
d. Counseling to patients and their family and serve as a nucleus for identifying socio-economic rehabilitation needs in addition to information and guidance.
e. Creating linkages and exchanging expertise with the specialities from medical colleges and institutions for providing specialized services including surgery and ophthalmic care to all the needy leprosy affected persons through a planned coordinated effort.

New LRCs, established at the block level under LEAP, in collaboration with local Government, Municipal Corporations and leprosy NGOs at the GHC facilities are easily accessible and serve as a 'signpost' for most leprosy patients seeking treatment and guidance. Collaboration involves (i) hands-on training for leprosy and GHC staff on nerve function assessment and management of complications and (ii) supplying with necessary physiotherapy equipments (Muscle stimulator and Wax-bath) and protective aids (Splints and MCR footwear). A full fledged Footwear, prosthesis and splint unit caters to the needs of NGLOs and Govt. units.

37 LRCs (11 urban & 26 rural) are assisted and promoted under LEAP in Mumbai & Navi Mumbai and five districts of Maharashtra state and one in Baster district, Chhattisgarh state.

The locations of LRCs at and the involvement of public health care personnel in PHCs / Rural hospitals in providing specialized services to leprosy patients can alone minimize the dependency on the vertical leprosy agencies and their staff and ensure sustained care in future. A small, but definite beginning. Miles to go.

Specific objective 4: To monitor and evaluate the outcome and the impact of all interventions proposed, supported and supplemented under LEAP.

Rationale:

a. The present Simplified Information System (SIS) is inadequate and need to include all essential information useful for long-term monitoring of patients as well as the disease control programme. Reviewing and evaluating the outcome of all interventions is essential to make appropriate change in strategy to enhance the quality of the programme.

b. Need to continue the surveillance and monitoring systems. This will provide the programme managers and health administrators to have a clear understanding of the priorities in the integrated set up.

Action plan:

a. Maintaining a central registry for recording and analyzing the trend of epidemiological indicators that helped to measure the true magnitude of the disease and the disease morbidity in the community.

b. Undertaking specific studies through operational research to ensure the efficiency of the leprosy control and providing feedback to all stakeholders for mid course corrections.

c. Conducting epidemiological validation drives, as an inbuilt component of monitoring and sustaining the gains made so far in achieving the goal of leprosy elimination.

LEAP has established a 'Central Registry' to record all new cases in Mumbai and assists one in Thane along with the Government and Corporation authorities. The epidemiological validation drive to assess the leprosy situation in Mumbai through a 'sample survey', [9] carried out in collaboration with leprosy NGLOs authorized by Municipal corporation, reveal that the actual new cases recorded is thrice than the reported figures in our project areas. The drive is in progress.

The monitoring and validating key epidemiological indicators in Mumbai have helped to overcome operational fallacies and measure the impact of leprosy control activities by multiple partners.

The prospect

LEAP is a proactive programme to strengthen the process of integration and has made a small beginning to address the remaining challenges in leprosy during the post-elimination period. It basically promotes community participation and public health involvement for leprosy control. LEAP aims to make a difference by involving various stakeholders as 'partners'. It believes in pooling strengths and resources can take us closer to the goal. Hence, it enlists service providers who were kept outside the purview of leprosy control in the past.

It primarily attempts to address all the needs of the leprosy affected through a patient-centric approach and minimize the socio-economic consequences to the extent possible. Leprosy patients of today and yesterday have rights to quality services. It is our endeavour to reach out to them through planned interventions under LEAP.

* **LEAP,** as developed and implemented by ALERT-INDIA is endorsed and supported by Aneswad Foundation, Bilbao, Spain.

** **Criteria:**
Areas endemic for leprosy - specific pockets reporting more number of new cases, specially MB cases
Areas with special population groups (migrants, socio-economically and backward community groups in slums / tribal pockets / new settlements). ■

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'Leprosy elimination' - Need for sample survey

A. Antony Samy

Letter to the Editor; 'Leprosy Elimination – need for sample survey', Lepr Rev, 2007; 78: 2, p167 – 169.

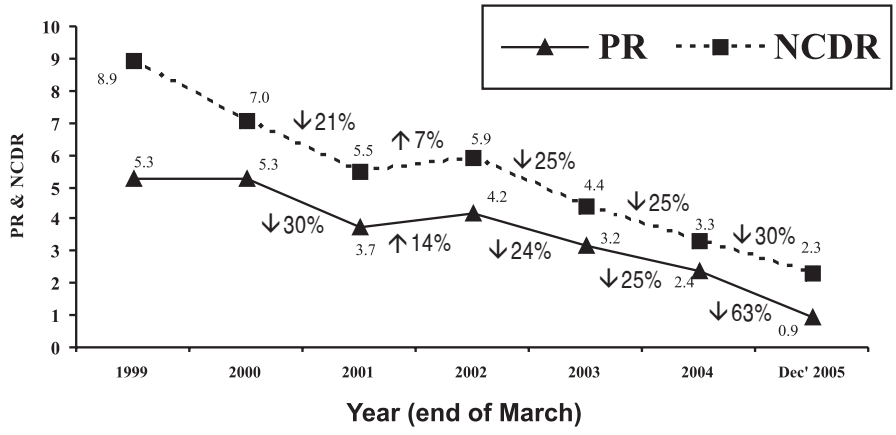
With the announcement of achieving the intermediate 'target for leprosy elimination' *(defined as a prevalence rate of less than one case per 10,000 population by the end of 2005)* by the Govt. of India (GOI), a new optimism of eradicating leprosy has become a talking-point in various forums.This declaration has also greatly influenced the public perception about the leprosy burden and has *adversely affected the ongoing leprosy control efforts in terms of programme priorities, manpower utilization and resources*.

The National Leprosy Eradication Programme (NLEP) is 'continuing the efforts to achieve elimination of leprosy through existing MDT services in the remaining districts and blocks as a strategy for the future'.[1] This has guided the programme managers at the state and district level to apply their own 'criteria for registration of new cases' in order to sustain or reduce below the target level. Such misinformed policy perceptions and measures can only lead to an upsurge of the problem in future. This has led to serious setbacks in sustaining leprosy control measures and strategies for quality care at the field level.

WHO has rightly maintained that the 'given consistent procedures for case detection, figures for a period of several years will show whether there is an increase or decrease in numbers, which may indicate whether activities aimed at controlling the disease are effective'.[2] A careful observation of the trend (see graph) for the past 6 years shows a sharp decline in the reported point prevalence rate (PR) in India from 24% in 2003 to 63% in December 2005.[1] Similar trend was also observed in the prevalence rates reported from Maharashtra and Mumbai during the same period.

Is it a decline propelled by the change in policy and operational practices or an epidemiological phenomenon? What additional inputs to the programme have brought in such a decline in the reported prevalence is not known.

The tremendous progress towards leprosy elimination made due to the introduction of MDT is unquestionable. The question is how far the reported figures today reflect the true situation. In 2003, WHO opined that the 'case detection trends in India are not showing any appreciable decline and there is no clear explanation for the persistence of this situation in spite of the highly



specialized and expensive vertical programme in operation for close to 50 years'.[3]

Recently, in 2006, the Technical Advisory Group (TAG), WHO 'reviewed the figures based on data reported by countries (including India) and identified a number of issues, which need further analysis, particularly disparities between new case detection and registered prevalence'.[4] It is pointed out that 'the over-emphasis on early diagnosis and the absence of robust criteria and methods for diagnosing early leprosy compounded by 'target pressures' have made leprosy statistics on case-detection generally less accurate'. Therefore, *'it is not easy to directly interpret changes in case-detection as an attribute of changes in transmission of the disease'*.[5]

The fact that new cases continue to occur across the region in the country and with high proportion of MB cases, calls for an in-depth assessment of the situation and appropriate action plan. We lack knowledge about the specific regions or the population groups, where new cases surface. It is 'extremely difficult to agree with the policy makers that the disease has declined and shown unprecedented and sudden change in epidemiological trend within a prescribed time span set by WHO', leaves one to wonder, the manner in which the disease has behaved.[6]

Routine surveys to detect new cases were considered as time consuming, uneconomical and less productive particularly in low incidence phase of leprosy. No one can question the wisdom of this. Unfortunately, this has resulted in 'all or none' policy as regards the efforts to detect new cases at an early stage from the selected areas that are identified to harbour new cases.

Present policy insistence on the new case detection of leprosy should only be relied on the awareness campaigns aimed to promote self-reporting. WHO has cautioned that 'the 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'*.[7]

Further, WHO has also clarified that 'it seems likely, however some new cases never come for diagnosis and treatment, so the *number of cases detected is lower than the number of incident cases*'.[2] All these cautions have gone in the wind with the euphoria of leprosy elimination and the talk of eradication.

Sample Survey – a strategy for epidemiological surveillance

WHO has strongly advocated that 'special monitoring exercises may be carried out periodically to *validate case-detection and quality-of-care indicators*, as part of routine supervision or *by independent teams on a sampling basis'*.[2] 'If the population of the area is known, it is possible to calculate the case detection rate (the number of new cases per 100,000 people) which can be compared with other areas'.[8]

From the human rights point of view, 'for patients, it is important that the diagnosis of leprosy should be made as early as possible so that effective treatment can be started and steps taken to prevent nerve damage'.[9] The reduction in the number of new cases with disabilities and its consequences is directly attributed to the 'early' case detection. WHO emphasized that 'there is an urgent need to identify, through independent (and rapid) assessment, *geographic areas where the transmission of leprosy is high'*. WHO also admits that 'there are no tools at the moment to carry out such an exercise and *existing epidemiological surveillance systems are not yet sufficiently effective*'.[10]

In the absence of any rapid diagnostic test available for mass programme, one would really wonder how this can be accomplished by any means other than a sample survey in different geographical areas where new cases continue to occur. Sample survey is an effective tool for disease surveillance and for detecting hidden cases. However,

the policy hurdles on the need for sample surveys is yet to be overcome! ■

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Our challenge

"Our challenge is to ensure that all persons affected by leprosy, wherever they live, have an equal opportunity to be diagnosed and treated by competent health workers, without unnecessary delays and at an affordable cost.

We need to ensure that the achievements made so far in controlling leprosy are sustained, that the burden of the disease is further reduced, and that affected communities continue to receive quality leprosy services as long as they are needed.

At the same time efforts to increase community awareness are required so that we can put an end to the prejudice and discrimination still faced by affected persons and their families in many societies."

Dr. Pieter Feenstra & Dr. Vijaykumar Pannikar,
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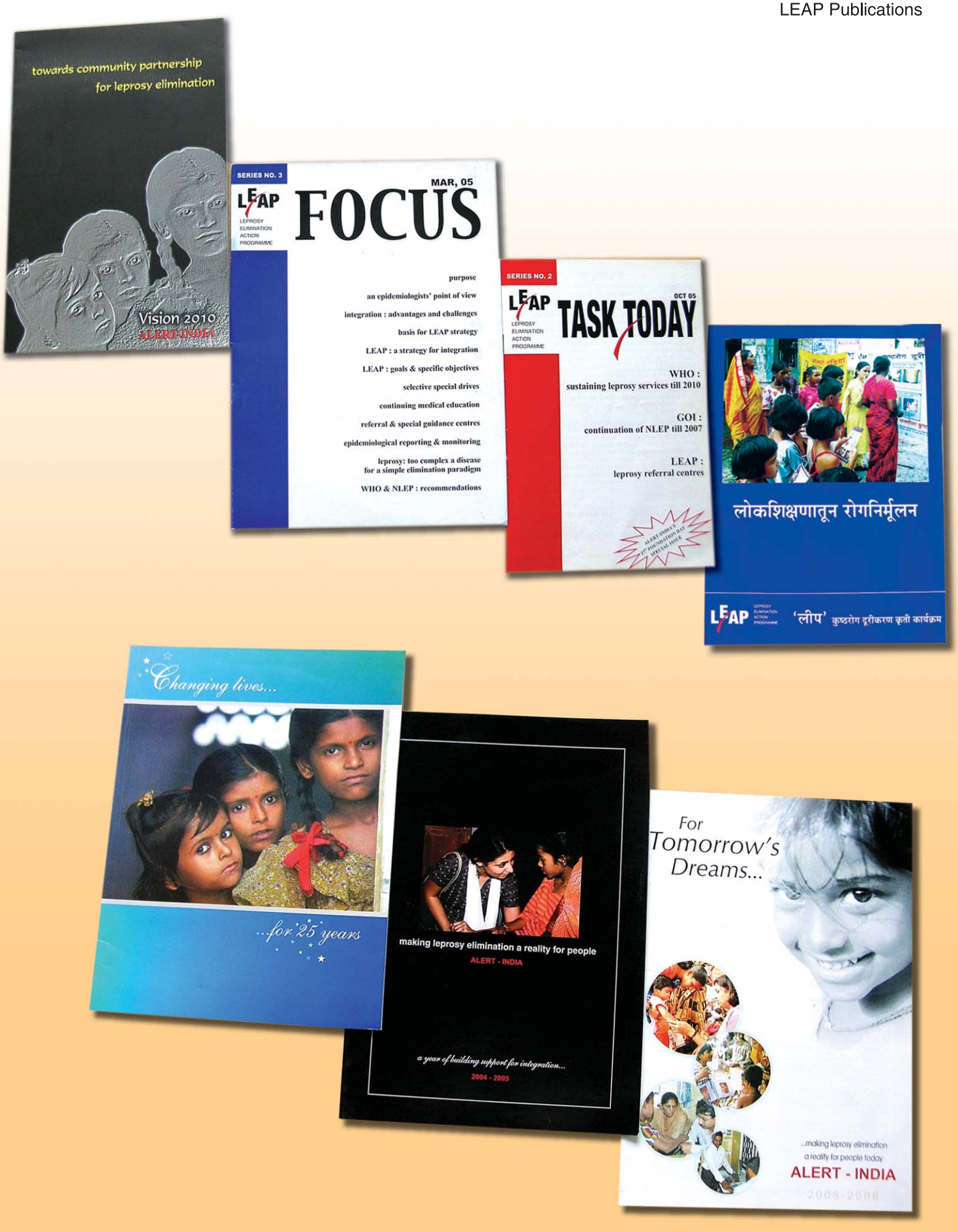
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