SERIES NO. 2

LEAP

LEPROSY
ELIMINATION
ACTION
PROGRAMME

OCT, 04

FOCUS

a leap towards leprosy elimination

historical perspective

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Focus on Leprosy Elimination Strategies in the Integration Era

Framework for

Leprosy Elimination Action Programme (LEAP)

2005 - 2010

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FOREWORD

I am extremely happy to learn that ALERT-INDIA has completed 26 glorious years while carrying out excellent work in its war against leprosy. The decline in the leprosy figures are a proof and testimony of the dedicated and sincere efforts. The social stigma and apathy towards the sufferers of leprosy makes the treatment modalities difficult. The tireless efforts of dedicated work has made the dream of leprosy elimination a real possibility.

Mr. Antony Samy, Chief Executive, has designated a weapon through the publications of LEAP to make people aware of the drugs and services available. The message is loud and clear that the leprosy which was a disease of the developing countries can be tackled by proper planning and implementation.

Mr. Antony Samy, Chief Executive, and his team deserve an applaud and sincere appreciation for bringing out the publications in an educative way by listing the facts and planning for the future.

I congratulate the author for his endeavour.

Prof. S. G. Damle
Joint Municipal Commissioner
(Medical Education & Health),
Municipal Corporation of Greater Mumbai.

Towards A Partnership Programme

This issue of 'Focus' presents the basis for the action programme LEAP (Leprosy Elimination Action Programme), outlined in 'Task Today'.

It sums up the thoughts, perspectives in a historical context to guide our action today, in favour of those afflicted with leprosy.

It also spells out the framework for the programme and a policy perspective for actions planned in the integration phase.

LEAP is also an expression of ALERT-INDIA's vision and commitment for leprosy elimination into action. We cannot carry out this task alone. We can do it in partnership with others with similar vision.

This issue of 'Focus' along with 'Task Today' is an open invitation to all willing partners to join hands in LEAP to make integration a reality for the leprosy afflicted persons, through community partnership.

11th October 04

A.Antony Samy
Chief Executive

Acknowledgement

We gratefully acknowledge the technical assistance rendered by Ms. Smriti Acharya, a Health Consultant, in preparing this document.

— A. Antony Samy, Chief Executive, ALERT-INDIA

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 in the 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.

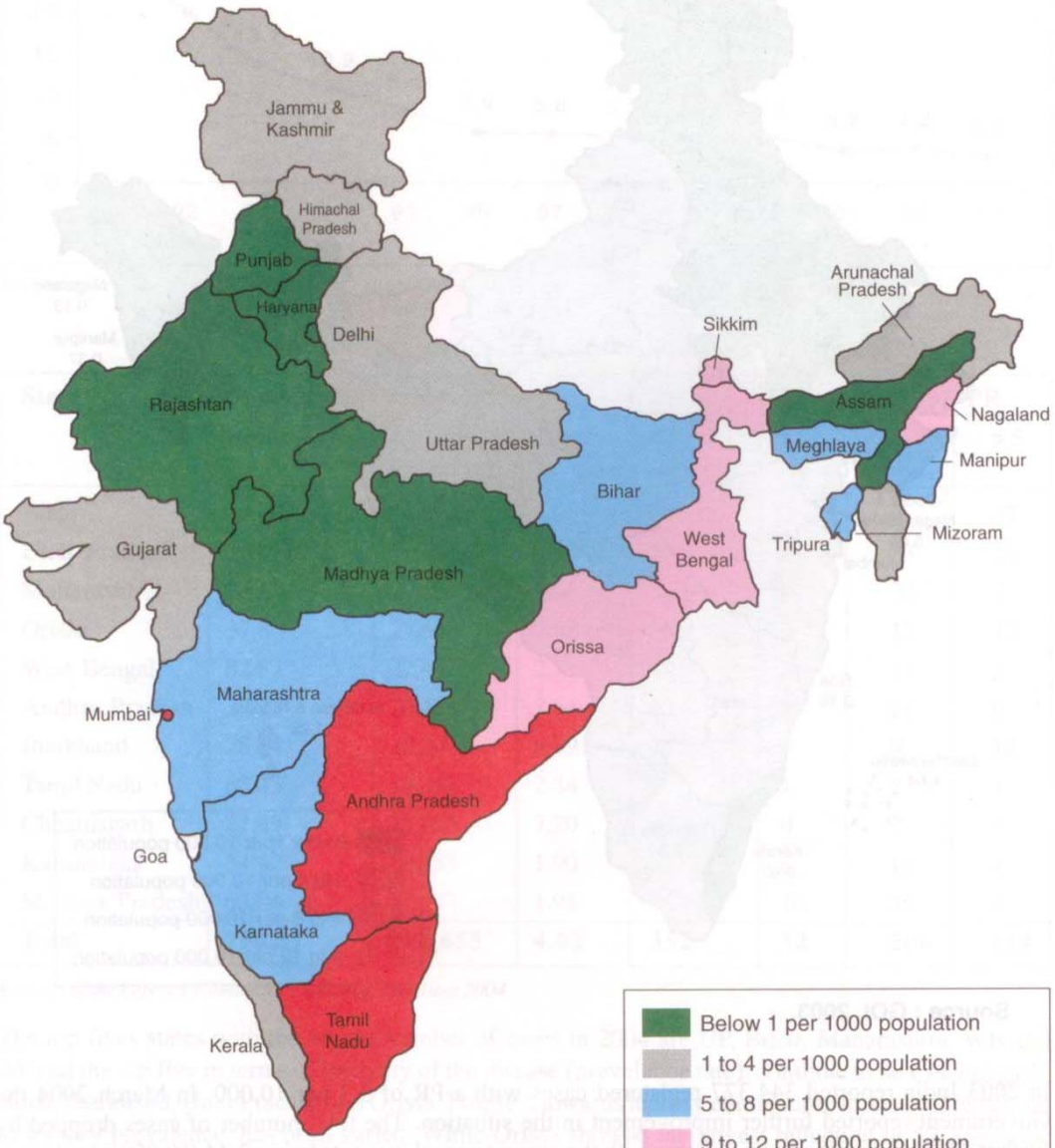
India has implemented nation wide leprosy control and elimination programs. These were vertical programs considering the volumes and the adverse socio-cultural impact it had on the population and nation at large. With efficient implementation of well-planned efforts since 1953-54 India has substantially 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

MAP OF INDIA

STATE WISE PREVALENCE OF LEPROSY IN INDIA IN 1980-81

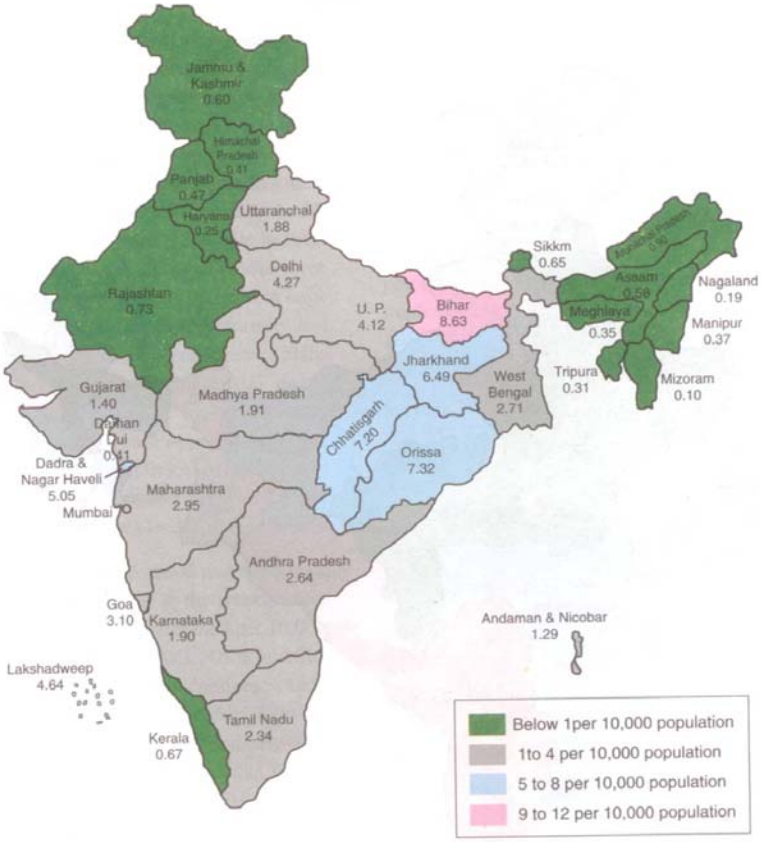


Source : Leprosy in India, CSSRL, 1992

Figure 4.2

MAP OF INDIA

STATEWISE LEPROSY PR/10,000 POPULATION (2002-2003)

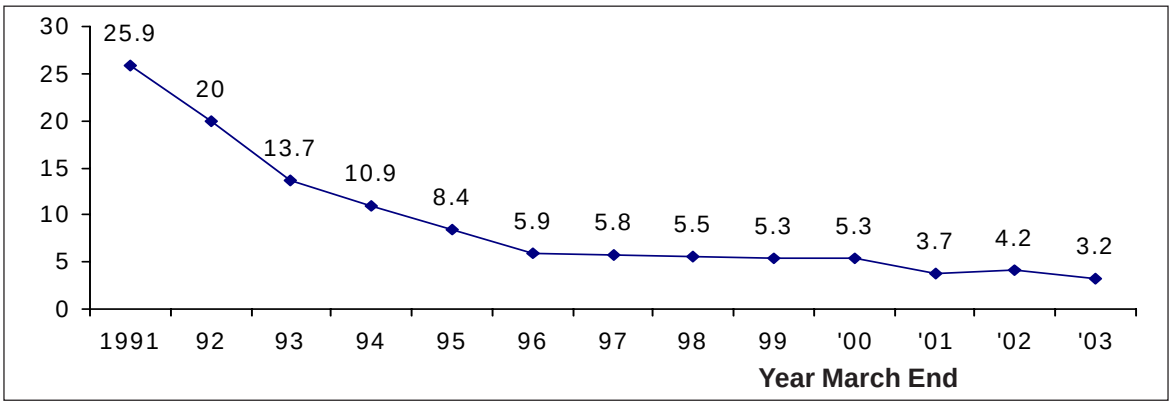


Source : GOI, 2003.

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 4.3

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 :

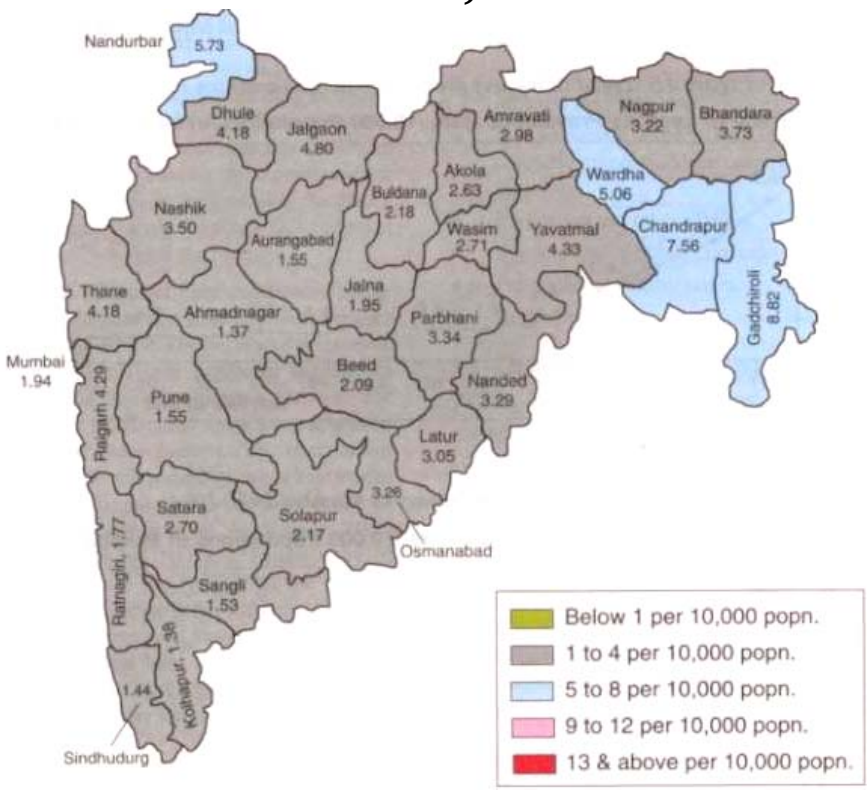
- Huge population of 12 million, almost equivalent to 5/6 districts.
- Over 70% population live in slums.
- Wide difference in socio-economic status.
- Difficult to cover high middle class and upper class population living in elite areas.
- Heavy influx of population from other parts of Maharashtra and 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

4.3 Leprosy in Maharashtra
Figure 4.4

MAHARASHTRA
DISTRICT WISE PREVALENCE OF LEPROSY
MARCH, 2003



Source : Office of AHDS (Leprosy) Mumbai

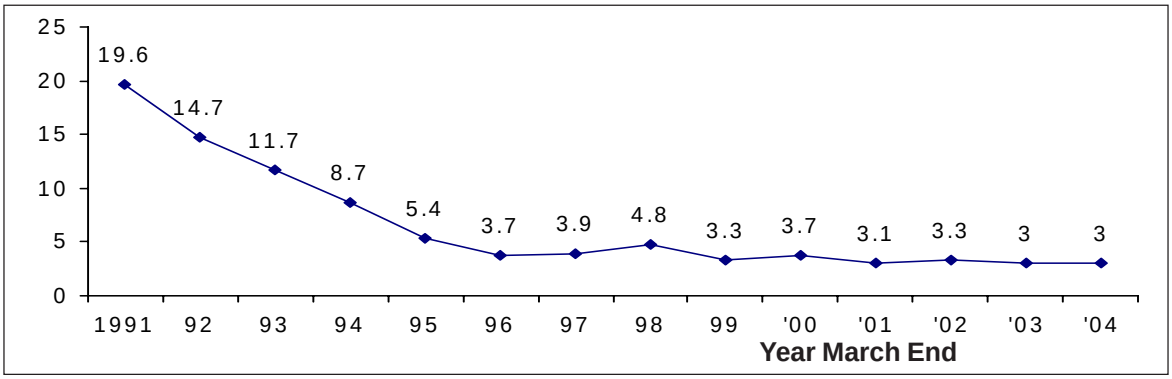
Maharashtra with a population of 100.74 million had 29,680 registered cases and a PR of 2.95 in the year 2003. New cases in 2002-2003 were 48,549 and the detection rate of 4.82 per 10,000. Through Maharashtra does not fall in the high endemic states with a PR of more than 5 it has small isolated pockets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

35% is shared 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.

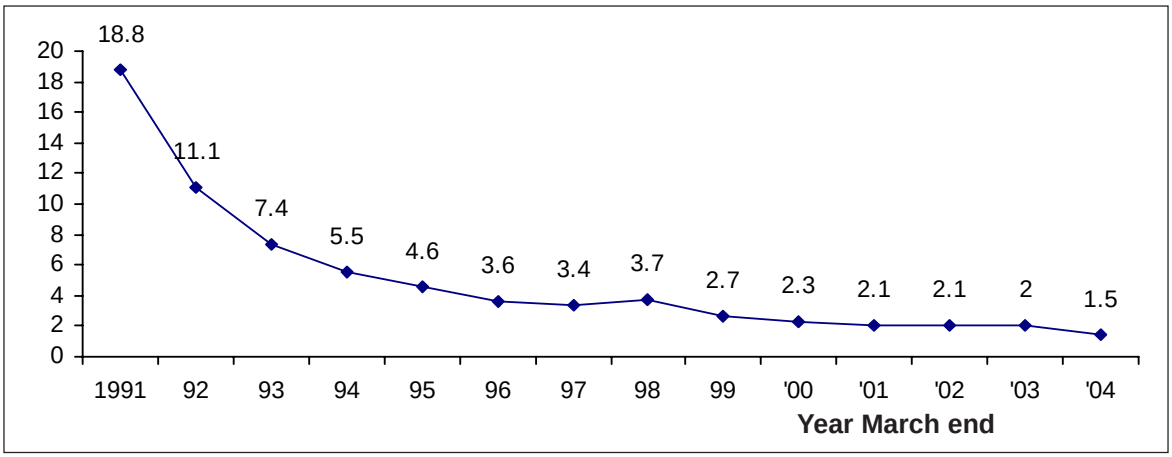
Inspite of the myriad problems, leprosy control program was managed successfully for the last 4 decades, bringing down the leprosy caseload substantially in the city. Even though MDT was introduced in the city in 1980, its impact on prevalence and incidence was seen much later in the early 90s as shown 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 4.5 Trend in leprosy prevalence in Maharashtra 1991-2004



Source: office of ADHS (Leprosy), Mumbai

Figure 4.6 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:

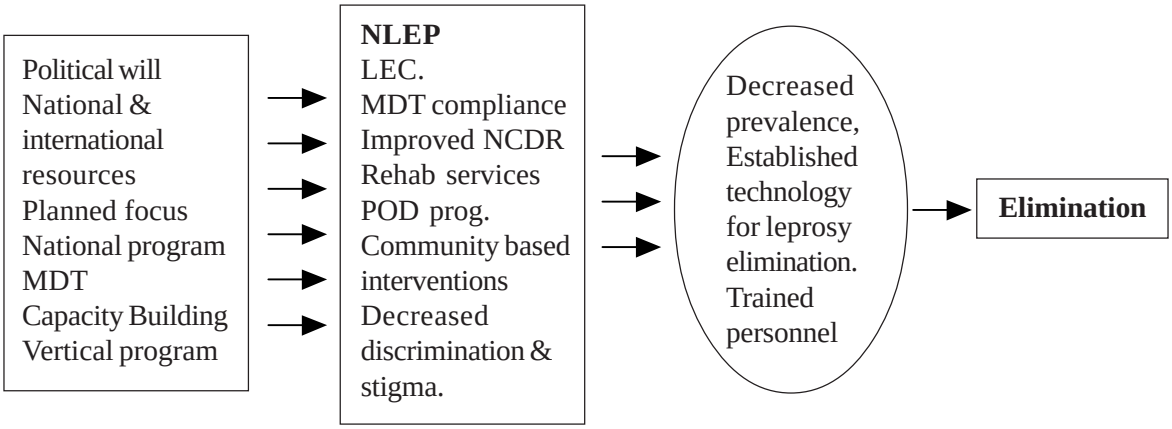
- MDT with fixed duration.
- Physiotherapy and care of anesthetic limbs, affected eyes and nose.
- Reconstructive surgery (RCS) for cosmetic purpose and for corrective purpose.
- Population and other surveys.
- Examination of family contacts.
- Prevention of dehabilitation.
- Rehabilitation.

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.

Integration Lessons from Myanmar

"Field outreach for case detection continued with integration"

India may stand to learn some basic rules in the process of integrating the MDT leprosy into the GHS. In 1991 Myanmar integrated the MDT into its Basic Health Services (BHS). The authorities there decided on a package of implementation measures that consisted of administrative steps, capacity building program for leprosy staff and BHS personnel, setting up of a monitoring and supervisory system, establishment of referral areas to manage complications with leprosy, Improved community based rehabilitation in selected areas and strengthening of supportive and technical assistance services by leprosy control staff. Noteworthy of mention is that field outreach continued for case detection, MDT treatment and community based rehabilitation and how their midwives or 'red angels" were a key to the success of the program.

Five guidelines were given at the BHS centre :

1. All leprosy workers must be oriented in leprosy elimination
2. All BHS staff should be equipped with a manual and guidebook on leprosy elimination.
3. Health centres should be equipped with adequate MDT facilities.
4. IEC materials such as pamphlets and posters should be properly distributed.
5. Patient charts, patient registers and monthly reports should be updated.

Bulletin of the Leprosy Elimination Alliance, Vol.2, No 4, Oct –Dec 2002

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.

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

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.

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 surveliance, 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.

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)

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 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 and 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.

Urban Initiative for leprosy Elimination

In order to address the problems facing the leprosy elimination program in the urban context, DANLEP has conceptualized an operational approach based on building partnerships between existing and potential stakeholders, pooling together available resources, developing and institutionalizing coordination and monitoring mechanism for leprosy elimination that supplement rather than substitute Government efforts.

This intervention is piloted in selected cities of Tamil Nadu, Orissa, Madhya Pradesh and Chhattisgarh between 2001 and 2003.

DANLEP 2003

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.

10. MILESTONES IN LEPROSY WORK IN MUMBAI

1870	Leprosy patients treated by Dr Bhau Daji Lad at the J. J. Dharamshala.
1873	Dr Henry Carter, after meeting Dr Hansen, demonstrated *M. Leprae* at the J. J. Hospital, Bombay, to colleagues
1885	The Albless Leprosy Hospital for indoor patients established at Trombay.
1890	The Homeless Leper Asylum founded by H. A. Acworth, Municipal Commissioner of Bombay, at Matunga. Fifty patients were initially sheltered. *(One of the reasons was to get vagrant lepers off the streets and out of public places).*
1904	Name changed to the Acworth Leprosy Asylum.
1911	The Indian Leprosy Act, 1898, applied to the "town and island of Bombay". The Acworth Leprosy Asylum appointed for the maintenance of leprosy patients committed under the act.
1912	Name changed to the Acworth Leprosy Home. Bed-strength gradually raised to 350, by 1920, and to 500 by 1935.
1939	Out-patient department (for diagnosis and treatment) and laboratory commenced. *(Till then, an OPD was run at the Haffkine Institute).* Leprosy training to J. J. Hospital students begun.
1942	6 health visitors appointed for contacts' examination in AL Home.
1946	Promin, a sulphone compound first used at the Acworth Leprosy Home in injectable form.
1949	Positive bacillary findings in contacts of lepromatous cases: Figueredo, Desai in Bombay
1950	Oral Dapsone (mono-) therapy begun.
1955	The Greater Bombay Leprosy Control Scheme (GBLCS) initiated Five peripheral clinics in general hospitals established to provide diagnosis and treatment. Domiciliary treatment started. Name changed to the Acworth Leprosy Hospital. Number of clinics under the GBLCS raised to ten to cover all Bombay by end - 1970.
1956	Cultivation of the Indian Cancer Research Centre (ICRC) bacillus by Dr Khanolkar at the Cancer Research Institute, Parel, Bombay
1961	The Tata Department of Plastic Surgery started at the J. J. Hospital by Dr N. H. Antia
1965	The University of Bombay arranges a symposium on Leprosy in collaboration with the Tata Department of Plastic Surgery (TDPS) in J. J. Hospital.

1969	Re-constructive surgery dept. at A. L. Hospital begun
1970	The Acworth Leprosy Hospital Society for Research, Rehabilitation and Education (ALH-RRE) founded
1973	The ALH-RRE Society celebrates the centenary of Dr Hansen's discovery of *M. Leprae*
1971	School Surveys begun, initially in small pockets; subsequently covering all Municipal and many private schools.
1974	House Surveys to detect leprosy begun in slums. Seminar on Urban Leprosy under the ALH-RRE Society and the Indian Association of Leprologists (IAL).
1975	• Chemo-prophylaxis trials with DADDS injectable in collaboration with the Haffkine Institute in A.L. Hospital • The Foundation for Medical Research founded by Dr N. H. Antia
1976-78	• Several voluntary organisations begin leprosy work on SET pattern. • Vimala Dermatological Centre (VDC), hospital at Varsova inaugurated.
1979	Human trials with ICRC anti-leprosy vaccine begun.
1978-80	Seven NGOs undertake leprosy work according to the SET pattern (Survey-Education-Treatment) along with the Bombay Municipal Corporation's own efforts and those of the Government of Maharashtra (Supervisory Urban Leprosy Units – SULUs). Municipal Wards allocated among the above (NGOs, BMC, GoM) as project areas.
1981	Newer drugs like Clofazimine and Rifampicin included in treating leprosy along with Dapsone *(Multi-drug regimen begun).* Use of multiple drugs begun in all organisations. The Gavai and Swaminathan Committees established by the GoM and GoI, respectively.
1982	• GoI changes the National Leprosy *Control* Programme (NLCP) to the National Leprosy ***Eradication*** Programme (NLEP), emphasising multi-drug therapy (MDT) and regularising dosage and duration. • Special ophthalmological and Dentistry Unit at VDC, Varsova.
1983	• 13th Biennial IAL Conference in Nair Medical College, Consensus on Indian classification of leprosy at Bombay. • SHARE (Support the Handicapped's Rehabilitation Efforts) started MCR foot wear unit at J.J. Hospital supported by GLRA.
1984	The Indian Lepers Act, 1898, repealed from Maharashtra. Bed-occupancy at Acworth Leprosy Hospital starts coming down. "Eradication of Leprosy by 2000 AD" slogan coined by the late Prime Minister Mrs Indira Gandhi. All leprosy patients gradually put on MDT and mono-therapy (DDS) stopped.

1986	Mobile Surgical Unit by Dr. Antonio Salafia supported by GLRA : Carrying out surgeries in Varsova, Trombay.
1987	Seminar on the legal aspects of leprosy, under the auspices of the Society for the Eradication of Leprosy (SEL).
1990	*The Acworth Leprosy Hospital celebrates its centenary.*
1992	The Acworth Leprosy Hospital taken over by the Municipal Corporation of Greater Bombay and renamed as Acworth Municipal Hospital for Leprosy. The District Leprosy Society established to monitor all NLEP activity according to Central government guidelines. Duration of MDT gradually reduced, drastically bringing down the case-load.
1997	Leprosy Elimination Campaigns (LEC) in the city.
1998	Central Government-sponsored Modified Leprosy Elimination Campaign (MLEC) organised. ROM (Rifampicin, Ofloxacin, Minocycline) treatment for single-lesion leprosy cases started. Newer methods of surveys to cover uncovered populations undertaken.
1999	MLEC-II organised by the Government of Maharashtra.
2000	• MLEC-III organised with a different strategy. (1) Training of general health-care staff in leprosy; (2) Centres for voluntary reporting of cases (VRC); (3) Survey of high-risk slum populations. • ALERT-INDIA takes over the management of MCR foot wear unit at J.J. Hospital from SHARE.
2001	MLEC-IV organised through VRCs. Leprosy task-oriented training to all municipal medical officers and health workers. (1) to diagnose and treat all uncomplicated cases of leprosy; (2) to identify complications early and refer them to special referral centres; (3) to maintain minimum essential records for submission of reports.
2002	• MLEC-V organised through VRCs; and two LECs implemented. • The MCR foot wear unit at J.J. Hospital was shifted to AMHL, Wadala. Jointly managed by ALERT-INDIA and ALH RRE Society.
2003	MLEC-VI organised through VRCs, manned by trained MOs, PHNs, ANMs, MPWs and CHVs working under the supervision of the NLEP staff. Implemented six LEC projects.
2004	Integration of the NLEP with general health services from 1st July, 04. Establishment of district-level leprosy Epidemiological Monitoring and Central Registry Unit (EMCRU) at Acworth Hospital, Wadala, from 27th August. 04. *Compiled by Drs W. S. Bhatki, Secretary RRE Society; V. V. Dongre, Hon. Secretary, Society for Eradication of Leprosy and the ADHS (Leprosy), Mumbai.*

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Abbreviations

ANM	Auxiliary Nurse Mid-wife
CBO	Community Based Organisation
CHW	Community Health Worker
CME	Continuing Medical Education
DOTS	Directly Observed Treatment Scheme
EWS	Economically Weaker Sections
FDT	Fixed Duration Treatment
FTMO	Full Time Medical Officer
GHS	General Health System
GMP	General Medical Practitioner
IEC	Information, Education, Communication
IPC	Interpersonal communication
LEAP	Leprosy Elimination Action Programme
LEC	Leprosy Elimination Campaign
LEM	Leprosy Elimination Monitoring
LEP	Leprosy Elimination Program
LIG	Low Income Group
MB	Multi-bacillary
MCR	Micro-Cellular-Rubber
MDT	Multi-Drug-Therapy
MLEC	Modified Leprosy Elimination Campaign
MO	Medical Officer
NCDR	New Case Detection Rate
NGLO	Non Government Leprosy Organisation
NGO	Non-Government Organisation
NLEP	National Leprosy Eradication Program
PB	Pauci-bacillary
PHC	Primary Health Care/Primary Health Centre
POD	Prevention Of Deformity
PR	Prevalence Rate
RCS	Reconstructive Surgery
RFT	Released From Treatment
SC & ST	Scheduled caste & Scheduled Tribe
SER	Socio-Economic Rehabilitation
SET	Survey, Education and Treatment
SIS	Simple Information System
SSD	Selective Special Drive
UHP	Urban Health Post
VHW	Voluntary Health Worker
VO	Voluntary Organisation
WHA	World Health Assembly
WHO	World Health Organization
ILEP	International Federation of Anti-Leprosy Associations
NFI	Nerve Function Impairment
POID	Prevention Of Impairment and Deformity
SSL	Single Skin Lesion

A novel approach to leprosy elimination programme in the urban context

The urban initiative emphasises local body, institutional and peer group participation, institutionalising partnerships and developing coordinating mechanisms. Taking cognisance of the population and spatial characteristics of urban areas, the urban strategy initiative has tried to channel the utilisation of existing services and resources in leprosy elimination work through processes of coordination and networking with minimal additional financial investment. The novelty of this approach lies in the active involvement of administrative bodies out side the health system and local political leadership in the development of a local plan of action, with the aim of ensuring local ownership of leprosy elimination activities.

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

1. To ensure leprosy elimination in the urban area with a realistic timeframe.

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

The specific objectives have been defined as :

1. To develop partnerships with a variety of stakeholders representing all known communities of the urban area and ensure commitment at all relevant levels, and develop a common work plan for leprosy care and elimination.

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

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