Integration of leprosy in the GHC system in cities and towns

Integration of leprosy in the GHC system in cities and towns

- Experiences and Lessons

National Seminar

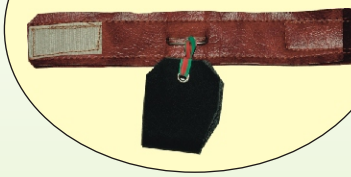
11th October 2004,

Mumbai

Splints for prevention and correction of hand deformities

Finger loops

Opponnens loop



Finger gutter

Adductor band

Available in different sizes
Durable and easy to use
Appropriate for hand exercises

Prosthesis and orthosis for foot deformities

MCR Insole

Foot-drop spring

Malleoli cap

Foot prosthesis

Foot orthosis

Moulded shoe

PROCEEDINGS

Integration of Leprosy in the GHC System in Cities and Towns
- Experiences and Lessons

Proceedings of the National Seminar
held on 11th October 2004
at
Mayfair Rooms, Worli, Mumbai

ALERT-INDIA
26th Foundation Day Commemorative Seminar

Supported by

Anesvad Foundation

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Published by ALERT-INDIA, B-9, Mira Mansion, Sion (West), Mumbai - 400 022

Printed at: Printania Offset Pvt. Ltd., D-20/21, Shalimar Industrial Estate, Matunga (East), Mumbai - 400 019

PREFACE

NLEP is a great success. The total number of leprosy cases in the country have been brought down by early case detection and effective treatment programmes, over the past five decades. The prevalence has been brought down to 1 case per 10,000 population in most parts of the country. However, the reduction in prevalence as a measure of success is questioned by many. Today the actual situation can be ascertained only by the number of new cases.

Despite curing 14 million cases with MDT, new cases continue to surface. The occurences of new cases are not restricted only to endemic districts of the past or present. It is widespread throughout the country. However, it is difficult to narrow down all specific locations of transmission in the country. The best we can say today is that we are somewhere near to elimination (i.e. 1 case per 10,000 population), which can be achieved, provided leprosy control activities are sustained.

At this critical juncture, the leprosy control programme has been integrated into the general health care (GHC) system. Integration is a process and long-term goal worth the efforts. It is extremely important to take stock of the present situation in order to focus on achievement, limitations and lessons learnt by all who have begun the integration process in cities and towns across the country.

Towards this end, ALERT – INDIA organized a National Seminar on **'Integration of Leprosy in the GHC System in Cities and Towns: Experience and Lessons'** on 11th October 2004 in commemoration of its 26th Foundation Day.

The proceedings of this Seminar have brought out several issues related to leprosy elimination, particularly in cities and towns, and also highlighted the positive outcomes as well as the shortcomings. I hope this is of interest for all those who are concerned about leprosy control in cities and towns.

23 May 2005

A. Antony Samy
Chief Executive, ALERT INDIA

Sharing of Experiences

A. Antony Samy
Chief Executive,
ALERT INDIA

ALERT-INDIA has been focussing on urban leprosy elimination programmes by supporting NLEP initiatives and developing an appropriate approach to integration.

The strategy for integrating the leprosy programme into the GHC system is yet to be implemented in urban areas. The overall urban situation is complex. Problems are related to multiplicity of health care providers and administrative complexities compounded by several issues specific to urban areas.

Other operational factors such as migration, displacement and ever growing urban slums pose a greater challenge to all who strive to achieve the goal of leprosy elimination.

To reach the goal there is an urgent need for planning and a special urban strategy at the micro-level. Unfortunately, the process of integration is at different stages in different regions or States and suffers lack of a unified approach and action.

Hence ALERT-INDIA has undertaken this Seminar to exchange the experiences of integration with special reference to cities and towns as a prelude to exploring a methodology to implement integration at various levels.

Trends of leprosy in a few selected cities and towns in Maharashtra for the past 5 years were analysed in details at a Workshop on 'Strategies for leprosy elimination in cities and towns' organized by ALERT- INDIA on 11th October 2003 in Mumbai.

Secondly, there was an urgent need to analyse the issues and review the problems related to urban leprosy in order to develop an appropriate perspective.

Towards these twin objectives, ALERT INDIA had organized a national Seminar on **"Integration of Leprosy in the GHC system in Cities and Towns: Experiences and Lessons"** on the occassion of its commemoration of 26th Foundation Day in Mumbai on 11th October 2004.

Experts and representatives from the Central and State Government, Municipal Corporations, ILEP Agencies and local NGOs participated in this Seminar with presentations specific to the cities and towns where they work.

This report presents the details of delibrations at the Seminar that confirms the need for a specific strategy and special efforts that can take us closer to elimination. ■

Inaugural Function

The Inaugural Function was attended by
Chief Guest: Dr GPS Dhillon, DDGHS (Leprosy), GOI, New Delhi

The Guests of Honour were :
Dr SG Damle, Dr SC Gupta, Dr BK Girdhar, Dr RK Mutatkar, Mr V Ranganathan, Mr Ramesh Narayan and Ms Dolly Thakore.

The invocation song by
Ms Surekha Joshi,

The Guests and the delegates were welcomed by Mrs Veera Rao.

Mr Joy Mancheril introduced the guests.

Thereafter, Dr SC Gupta delivered a lecture on the status of leprosy in the State of Maharashtra.

Dr VV Dongre spoke about the leprosy situation in the city of Mumbai.

Prof. RK Mutatkar explained the workings of ALERT-INDIA and spoke about the vision document.

Mr A Antony Samy explained the significance of celebrating the 26th Foundation Day of ALERT-INDIA. He further requested the dignitaries to release the three publications of ALERT-INDIA, namely, Vision 2010, Focus Series No.2 explaining LEAP and Task Today.

Dr BK Girdhar dilated upon the subject of the theme of the Seminar. Dr GPS Dhillon thereafter, gave his key note address. A short film on ALERT-INDIA was projected. Mrs Stella Mancheril proposed a vote of thanks.

Leprosy in Maharashtra

Dr. S.C. Gupta
JDHS (Leprosy)
Government of Maharashtra

"We have problems of urban, rural and tribal leprosy. The problems of infrastructure are everywhere, especially in urban areas. We have started integration of leprosy with the General Health Care System at all the levels in the state, though we did undertake occasional active surveys in certain areas of Maharashtra.

Looking at the co-operation that we are getting from all the Municipal authorities in the state, I feel confident that by the end of 2005, we will certainly eliminate

leprosy. We will have to pay more attention to tribal areas and urban areas."

"We have realised that the General Medical Practitioners have a great role to play in the elimination of the disease. Hence we have decided to involve them in the programme by arranging meetings with them on the said subject. I have approached the Director of Medical Education for the involvement of faculties and students in the medical colleges in the state.

The vertical leprosy staff will not undertake routine work of detection and treatment of leprosy patients, instead they will concentrate on leprosy awareness programmes in the state. The print media and the press should bring leprosy to the forefront, every now and then."

"I have to bring to your kind notice that the authorities of all the Municipal Corporations including that of Mumbai have extended all the cooperation in the process of integration though they have certain administrative problems."

"With the support of every concerned authority and agency, I feel confident that we will achieve the goal of elimination of leprosy through the process of integration by end of December 2005." ■

Leprosy in Mumbai

Dr. V.V. Dongre
Senior Consultant, LEAP
ALERT-INDIA

A group of 7 islands that were given as a dowry to the King of England by the King of Portugal in the 17th century, has grown into a super urban situation that is city of Greater Mumbai.

In 2001 the population of Greater Mumbai was 11.5 millions. 69 % of the population lives in slums and on footpaths. The total area is 600 sq. kms. The population per sq. km. is 16,500. There is migration of people from all the states of India and from all the districts of the state. Nearly 300 families per day come to Mumbai. 1/3 of the national revenue is collected from Mumbai. It indicates its pulsating business. People come for medical treatment, in search of jobs and for politico-administrative work.

In 1982 NLEP was conceived. In July 2004 integration of leprosy services started in Greater Mumbai.

The District Leprosy Society is very active and guidelines are given by the JDHS (L) and the Jt. Commissioner of MCGM for integration. 172 health posts are involved in the process. 1 health post consists of 1 full time medical officer, 1 public health nurse, multi purpose workers and community health workers.

ALERT-INDIA in collaboration with RRE Society and AMHL has already started a Central Registry for the leprosy patients from Mumbai to avoid recycling and re-registration of leprosy patients.

We are going to train all the medical officers of MCGM and we have plans to train health functionaries of MCGM as well as Municipal Corporations of KD and Ulhasnagar along with Navi Mumbai.

7 NGLOs are covering 65 % area for leprosy control. 4 SULUs are covering 25 % area of Mumbai and AMHL is covering 10 % area of Mumbai for leprosy control. Now the respective health posts will undertake routine work of case detection and treatment.

In 1981 there were 44,000 leprosy patients in the city of Mumbai when PR was 60 / 10,000. As of 1/10/2004 there are 1484 active cases and the PR is 1.19 / 10,000.

We have a long way to go because Mumbai city is cosmopolitan and there are providers from multiple systems of medicine, such as allopathy, homeopathy, naturopathy, ayurved and unani. There is a large group of skin specialists. Leprosy patients from higher income group go to these practitioners, hence we cannot have exact PR of Mumbai city as patients taking treatment from private practitioners are not included in our statistics.

Integration in Mumbai is only 100 days' old so it is in its infancy and is undergoing teething troubles. Today we have a great opportunity to learn from our colleagues working in different mega cities and towns for leprosy elimination through integration. We look forward for the same.

On ALERT-INDIA's Vision, 2010, Dr. Mutatkar, Hon. Prof. of Anthropology, School of Health Sciences, Pune University :

"ALERT-INDIA in the last 25 years has gained experience while working with the people. They really have intersectoral approach for the programme. They are running the programme by involving the patients, the providers and the people. Their vision for work in future is totally based on community with the patient as the nucleus." ■

On 26th Foundation Day Commemoration

A. Antony Samy, Chief Executive, ALERT-INDIA

26 years back we were carrying on control programmes. Today we are talking about elimination of leprosy. This can be achieved by joint-action with the willing stakeholders as partners. We have planned the Leprosy Elimination Action Programme (LEAP). The documents throwing light on this subject are being released right now. Focus No.2, Task Today and The Vision document are going to project our views, thoughts and ideas about the much-deliberated subject of elimination of leprosy through the integration process.

Integration of Leprosy into General Health Services

'Have we reached the stage for integration? It is important to have knowledge of actual case load'

Dr. B K Girdhar
Deputy Director,
Central JALMA Institute for Leprosy,
AGRA, India

How important is leprosy to the States? States have their own **priorities** related to health. Often the priorities shift and the financial and human resource is re-channelized.

We have come a long way in our efforts in overcoming leprosy. During the last two decades, there has been a marked decline in leprosy case load and as per 2003 figures, there were only a little over **half a million active cases** in the world against over 10 million in the early eighties. Like elsewhere, in our own country too there has been a marked reduction in the case load, there being around 0.34 million cases on the active case registry, with a prevalence rate of 3.3 / 10,000 population.

Where there has been a significant decline in prevalent cases, **NCDR and reporting of new cases** at the treatment centers has shown only a marginal i.e., insignificant decline. On the basis of this, the State figures on active case load have been questioned by some workers. However, there has been an undeniable shift in the disease profile. The improvement in the leprosy situation has not been uniform or similar in states of the country. Some of the States with higher political will and better administrative set-up have done well both in terms of leprosy control and also over all human development. In comparison some of the North Indian states have lagged behind. States such as U.P., Bihar, West Bengal, Orissa, Chattisgarh, Jharkhand and Delhi account for over 60 % of the total leprosy case load of the country with an over all PR of 5.9.

When one looks at the distribution of the patients, it is often seen that there is clustering of cases with neighboring villages/ panchayats / blocks being totally free of leprosy problems. This is true for urban areas also, where leprosy continues to be a significant problem. This is attributed to several factors. There has been and continues to be a **migration** of large populations of rural people, mostly manual workers of low socio–economic status, into the cities in search of jobs. This has resulted in not only diagnosed or undiagnosed patients, or those incubating leprosy moving into the urban areas, but also in creating slums with very high population densities with consequent higher risk of contracting infections like leprosy. Special measures, vertical programmes and continued and dedicated work by NGO's and municipal / state health workers has

greatly benefited the patients, the community and the NLEP (in these pockets).

The achievements in leprosy i.e., **decrease in total case load**, trend towards fall in NCDR and lower deformity rates etc. have been possible only on account of a structure committed to leprosy work which had been energized with the introduction of MDT. The National Leprosy Elimination Programme had been responsible for creating leprosy awareness in the community, for early detection of cases – both by active search and voluntary reporting and seeing or ensuring that the patients get cured with minimal disabilities, all with the ultimate aim of reducing and blocking the transmission of leprosy in the community.

The success of the programme in detecting and treating patients together with cleaning of the registers of all old patients who have been continuing on the active case lists has resulted in rapid decline in patient numbers to the present figures. Since the 1980's, it has been argued that if MDT is applied all over and to all cases, there is bound to be a reduction of the case load with resultant reduced transmission in the community.

This state **of elimination** i.e., PR <1 patient / 10,000 population, could be reached by the year 2000. If that could be ensured, from that time onwards, sustainability of leprosy services would not be needed. Indeed as per official figures we have reached this stage in several parts of the world including many states in India.

With **success** of the programme, utility of continuing with the vertical services may not be the best way. With declining case load and simplified recommendations on diagnosis and treatment, it is considered that the care of leprosy patients should be the responsibility of the GHS. This is likely to be beneficial not only to the health system but also by bringing the services nearer to the leprosy patients and reducing the stigma.

This involves integration of the leprosy programme into the general health care system. This is desirable in view of cost effectiveness of the integrated services and decreasing funds for leprosy – no longer making leprosy a major problem. Theoretically, committed non plan budget in maintenance of primary health care set-up may thus be advantageous to the leprosy population.

With all this in mind, the right decision for **integration of leprosy services** into the general health care system was taken at the highest level. In several countries it has already been acted on. Tamil Nadu has been the first state in our country to have implemented the scheme and others are in the process of doing the same. In Tamil Nadu, this was a sudden change, without adequate planning or ground work – including training and logistical support.

Obviously few questions come to mind. How has it worked? Have the patients benefitted, in terms of diagnosis and care? And what have been the difficulties and the shortcomings? Thus, there are quite a few lessons to be learnt for what should be done in the future.

Before we indulge ourselves in this, few issues need to be looked into:

1. Have we reached the **stage for integration?** It is important to have knowledge of actual case load. How reliable are the figures given by the States? Intensified case detection activities, MLEC or Modified MLEC have indicated that a lot of undetected patients continue to live in the community. Even in states like Tamil Nadu, where sustained anti-leprosy work has been going on from the beginning, a large number of new cases have been found. Work done by independent groups have found very high

prevalence of leprosy in officially pronounced low endemic areas in UP. Similar observations have been made in several urban units.

2. Till now, the NLEP has been mostly a centrally sponsored programme with assistance from national and /or international agencies. The issue is whether all the states are willing and in the position to shoulder the **extra burden** consequent to integration? Financial health of the States is not known.

3. How important is leprosy to the States? States have their own **priorities** related to health. Often the priorities shift and the financial and human resource is re-channelized. With family planning, maternity and child health, AIDS, tuberculosis, malaria, infectious diseases and GI problems, often in epidemics, dominating the scene, leprosy may not get enough attention. Further, is the present level of political and administrative commitment for leprosy going to be there at least for some more years?

4. Does the GHS have the capacity to take up the **additional responsibility** of care of leprosy patients? Though some States have well developed and functional PHC setup, in some lot of improvement, both in infrastructure and trained manpower, is required. System of supervision and checks of PHC functioning are not only important, but need to be in place.

5. **Willingness** of the PHC staff to take up leprosy work is crucial. Conversely, leprosy workers' motivation for general health work is essential. This may require lot of explanation regarding concept, rationale, benefits and the need for integration. Fear of losing seniority, additional work load and responsibilities and displacements need to be allayed. Arrangements for training and retraining of staff and intensive supervision at least for initial years has to be made.

6. Are there time, **expertise** and infrastructure for leprosy services at the PHC level? The, recording system needs to be looked at to make it simpler and more feasible for completion and reporting within the limited time available. Likewise, are we ready with adequate training material and at least the personnel who can initiate training at various levels i.e., training of the trainers?

7. Leprosy is a chronic slow motion disease, taking time to manifest following infection, a relatively long period of treatment and in many cases requiring a still longer follow-up. Even when the patient self reports to a health facility, he needs **personal attention,** a lot of explanation regarding treatment, reactions, prevention of deformities and subsequently frequent visits for monitoring of therapy and follow-up. He may need psychological support and social help. We need to consider these aspects. This is essential because the patient is the focus of the service.

8. Years of **prejudice against leprosy** together with visible deformities have kept these patients more or less away from the main stream. It is expected that the limited social stigma remaining now would be considerably reduced with integration. This would happen only if the mind-set of the workers at the GHC center changes and leprosy sufferers are attended, investigated and treated on par with patients with other diseases.

9. Whereas most leprosy patients can be managed at the PHC level, a few need care of experts. Therefore, there is a need to maintain or even establish **referral services** at the divisional or state level. This requires that leprosy trained and experienced doctors and supporting staff

be stationed there and not moved frequently. Would the States be continuously willing to maintain and support creation of such infrastructure, if not existing already?

As stated earlier, **integration of leprosy services** has been effected in Tamil Nadu and has been in practice since 1997. What are the experiences and lessons from the States? Leaving administrative issues aside, the impact on the patients and the epidemiological parameters is more important to us. An evaluation study has been done by SLR&TC in two blocks of Gudiyatham Taluk.

Touching only on some main issues, integration seems to have resulted in reduced case detection. Whereas **voluntary reporting** was not affected, as against 613 patients detected by surveys in the earlier 4 years, only 33 were diagnosed in the 4 years following integration. Even if adjustment is made for decreasing the incidence of the disease, this clearly reflects that a large number of patients remain undiagnosed and therefore untreated.

The consequence of this i.e., large load of remaining or hidden cases, and the dangers / risk to the community are obvious. Again the **higher deformity** rate among the new patients diagnosed following integration indicates delay in seeking treatment, adding to the prolonged risk of the spread of the disease.

How much of this is relevant to **urban settings**? The unique nature of migratory population, enormous over-crowding and sub-human environmental conditions, as prevalent in slums where a majority of people with low **socio-economic conditions,** live pose a challenge of a different nature.

In contrast, as against the countryside population, higher literacy rates, better awareness and easy accesses to health facilities make the task easier. Availability of leprosy trained / untrained medical personal of all cadres, including leprosy experts and dermatologists, within reasonable distances and State / private hospitals providing free or at nominal cost secondary and tertiary care do help in this regard.

On the other hand **multiplicity of agencies** involved in each urban area and in particular NGO's working for leprosy in the region call for more considerations. For them, how they can also help in the final push towards elimination and also shifting to other health related fields (Communicable diseases, such as Tuberculosis, Malaria and HIV / AIDS) requires lot of discussions within the boards as also with the staff currently involved in leprosy activities.

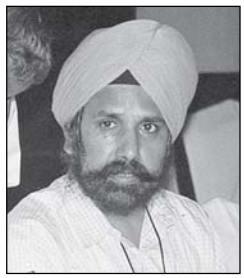
All along, case load has been the main criteria. When new patients continue to appear, almost in the same numbers, are we happy with discussions based on total case load, which according to reported figures is decreasing? It is worth mentioning that even in Tamil Nadu, in each of three MLEC, almost 12,000 new **leprosy patients** were detected and diagnosed. What would happen if these extra efforts, as being made under the vertical programme, are not under taken?

All these issues, do not mean that integration is not required or is not feasible, but only emphasize that proper preparation and **detailed planning** is required together with in-depth consultations between the Center and the State governments. Adequate planning and step-wise activities are required even to ensure that during the transition phase, leprosy patients do not feel neglected or have interruption in treatment. ■

Progress of Leprosy Elimination

Excellent progress in the field of leprosy elimination particularly during the last decade.

Dr. G. P. S. Dhillon
Deputy Director General of Health Services (Leprosy)
Govt. of India, New Delhi



Non availability of Primary Health Care System and also multiple service providers in urban areas have made things difficult.

It is really a great pleasure to be here today on the occasion of the 26th Foundation Day of ALERT-INDIA, wherein leprologists from all over the country have assembled to share their experiences gathered during the last 25 years to draw up plan for the coming months. The Association has remained committed to the Leprosy Control Programme in the country particularly in the urban areas since 1978. This long **partnership** has helped the State Government in their fight against leprosy in urban areas. I hope ALERT-INDIA will continue to support the programme for a few more years even after the Leprosy Elimination Goal is achieved at the National level by December 2005.

As you are aware, the country is making excellent progress in the field of leprosy elimination particularly during the **last decade.** Before the first World Bank Project was started, the prevalence rate was 20 / 10,000 as on 31st March 1991. The same has **reached 2.3/ 10,000 as on 31st July 2004 showing reduction of 88.5%**. This is really very encouraging. This shows that the strategy developed for the first Project and followed with few modifications in the 2nd National Leprosy Elimination Project with World Bank assistance has really paid rich dividends to the country.

Talking about the **strategies,** decentralization of the Leprosy Control Programme from the Centre to the State authorities with flexibility in approach and also the Integration of leprosy services with General Health Care Services were two key points that helped a lot. Of course availability of MDT to treat the leprosy cases in a short period of 6 months to 12 months has changed everything very quickly. You might be aware that only **by the year 1996 the whole country was brought under the MDT** Programme.

Integration was designed to change over from service delivery through the vertical leprosy staff and specialized leprosy hospitals to that of the General Health Care Services. This had a number of benefits like

i. increase in the **number of centres** from where the patient can freely go and receive treatment,
ii. patients can collect medicine and consult the Medical Officer on **all working days** rather than on a particular fixed day at the clinic,
iii. patients can collect medicine in a more **friendly atmosphere** of a Health Centre like any other patient that helps in increasing self confidence and reducing stigma,

iv. **associated training** given to the General Health Care Staff and volunteers like Aanganwadi Workers, Community Health Volunteers and some teachers has helped in spreading the messages about leprosy, its curability and drug availability in the health centres much faster than previously. Although integration has done wonders in the rural setup, much more is yet to be achieved in the urban localities. **Non availability of a Primary Health Care System** in urban areas and also **multiple service providers** have made things difficult here which needs to be addressed separately and that too very quickly.

A **Leprosy Elimination Monitoring** (LEM) exercise was carried out in 13 states during May – June 2004 followed by a validation of leprosy diagnosis study in June-July 2004 through the NIH&FW, New Delhi with independent evaluators from all over the country. The **study has shown certain good and certain not so good results**. I would like to cite a few:

A. Integration Indicators

Proportion of health facilities visited that had:

i. MDT available through GHC staff – 80%
ii. Available on all working days – 89.6%
iii. Available 3 months stock of MDT – 16.7%
iv. Median distance travelled by patient to collect MDT – 2 Kms.
v. Median money spent for travel cost – Rs.10/-
vi. Accompanied MDT provided – 59.9%

Integration process was observed to have progressed satisfactorily, yet the level of integration varied from state to state and needed to be looked into.

B. Quality of MDT services

i. Cure rate : MB – 83.9%; PB – 93.4%
ii. Defaulter rate : MB – 6.5%; PB – 3.7%
iii. Cases continuing treatment : MB – 1.3% after completion of MDT PB – 1.6%
iv. Discrepancy in records & reporting (% of health facilities visited)
   – high in nearly all states except AP
   – Under reporting : 23.5%
   – Over reporting : 24.3%

C. Implementation of Simplified Information System (SIS) in the Health facilities visited

i. Availability of SIS guidelines - 47.1%
ii. Availability of Patient Cards - 94.6%
iii. Availability of Treatment Register - 94.9%
iv. Availability of SIS MDT Register - 84.2%
v. Availability of SIS reporting format - 98.0%
vi. At least 3 NLEP indicators calculated - 33.8%

D. Elimination Indicators

i. Median delay in diagnosis – 7 months
ii. Proportion among new cases: Child – 14.7%; MB – 38.3%

E. Status of Community Awareness

In general the awareness of community members about the causes of leprosy was low in all the states. Information, Education & Communication (IEC) and Inter Personal Communication (IPC) should focus in spreading clear and crisp messages regarding signs, symptoms of leprosy, leprosy being curable, leprosy treatment being available free of cost and correct cause of leprosy (germ / microbiological agent).

F. Validation of Diagnosis

i. Proportion of wrong diagnosis – varies from 3.7% in Chattisgarh to 19.0% in Madhya Pradesh
ii. Proportion of re-registered cases varies from 4.3% in Madhya Pradesh to 45.5% in Tamil Nadu
iii. Proportion of wrong grouping varies from 0% in TN to 40.6% in West Bengal.

The results of the LEM study shows us **areas of weakness** where action is required. But one should not take any results independently to take any decision. It is better to study the situation in the state in totality.

Coming back to **Urban Leprosy Control,** on the

basis of the guidelines issued to the states early this year, the states have started preparing a plan for urban leprosy control in their respective states. The Central Leprosy Division has received such plans from a few States and is expecting plans from the others shortly. You may also keep liaison with the respective State Leprosy Programme Officers and assist them in preparing such action plans based on the guidelines. Identification of the urban localities is of paramount importance. The **plan should be drawn up keeping the present leprosy situation in mind and the need for providing future leprosy services to the people which should be easily available regularly**. Govt. of India is willing to provide some funds for urban leprosy control to the states separately from the regular district budget. This should help in speedy implementation of activities.

Problems like re-registration of cases because of circulation of the same patient from one health institution to another **is a big problem in major cities**. How to solve this problem is a issue for your discussion. Another type of re-registration is for **migratory old patients from rural areas** who again approach health institutions in urban areas expecting better treatment. These are old cases and not to be recorded as new cases. But their treatment can be given as required. This should be made very clear to all concerned that while providing treatment is the responsibility of all health institutions, proper registration is also equally important to the National Programme.

So far, 18 States/ UTs have achieved leprosy elimination. Seven states viz. Andhra Pradesh, Madhya Pradesh, Gujarat, Uttaranchal, Goa, Karnataka and Tamil Nadu are having PR between 1 and 2. With increased supervision and monitoring planned, it is expected that these states reach the goal by end of the current financial year in March 2004. The remaining 10 States/ UTs need to work hard in a planned way. A meeting was held on 30th September – 1st October 2004 at Goa to review the programme in these high endemic states. After identification of 88 high and 86 medium priority districts and **836 high endemic blocks (PR > 5/ 10,000), Strategic Action Plan** has been developed for these areas. Let us hope that the states carry out the plan meticulously and go ahead with the goal of leprosy elimination.

I would like to urge you all also to help the urban area nodal coordinators to carry out microanalysis of the situation in their respective localities and go for focused action to derive maximum benefit.

A few words of caution:

- At this stage of elimination let us be sure of **providing quality services** to the people.
- Only **definite cases** of leprosy should be recorded as new cases.
- MDT should be provided on a **regular basis** and treatment completed on 6 months for PB and 12 months for MB.
- Cases should be **released** from treatment on completion of fixed doses of treatment with MDT.
- **Active survey** in any form should be discouraged as it brings chances of wrong diagnosis.
- MDT is available **free of cost** for every patient but the same should not be wasted.
- Proper **counseling** is to be provided to all patients, family members and community leaders.

The 2nd National Leprosy Elimination Project comes to an end on 31st December 2004. But the programme does not end with it. The Govt. of India has decided that the **National Leprosy Eradication Programme** (NLEP) will **continue with the same vigour even after the project ends at least till the end of 10th five year plan i.e. March 2007**.

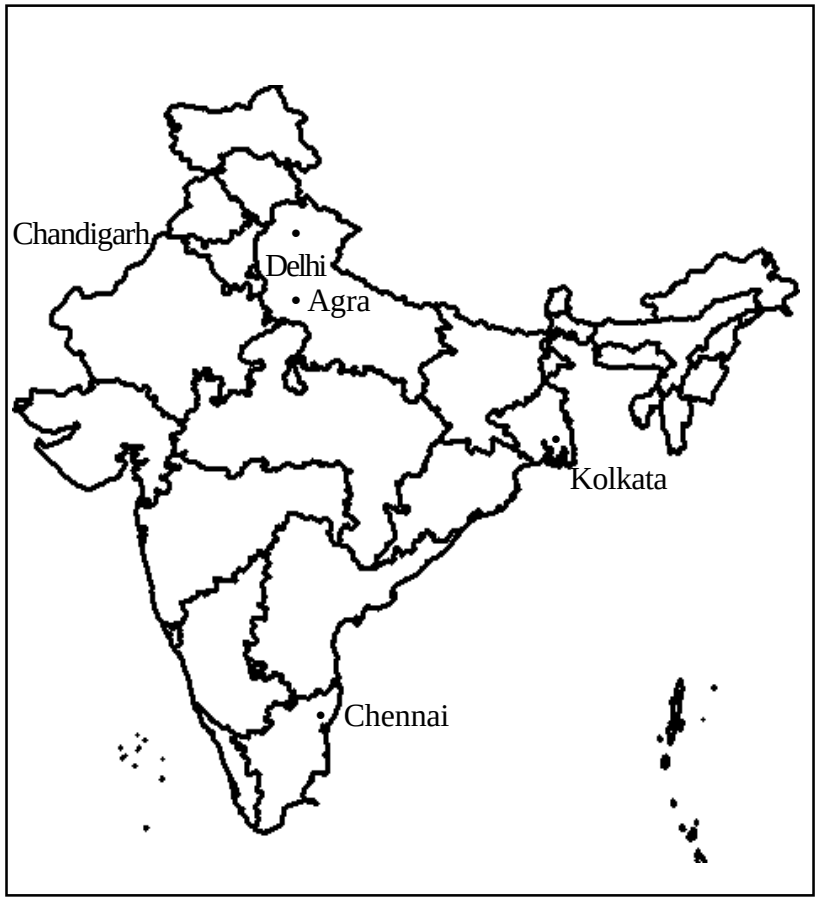
I would request you all also to keep your participation at the same high level and assist the states in achieving leprosy elimination not only at state level but further down the line in districts/ blocks and towns. With all of us working together as partners let us achieve the goal in time. ■

Session - I

Cities : Chennai, Delhi, Kolkata, Chandigarh, Agra

Chairman :
Dr. P Krishnamoorthy,
Secretary,
Damien Foundation India Trust,
Chennai

Co-Chairman :
Dr. R P Mall,
State Leprosy Officer,
Govt. of Uttar Pradesh



Panel :

Dr. P. K. Oommen
Director, Central Leprosy Training & Research Inst., Chingleput, Tamil Nadu

Dr. D. Porichha
Ex. Director, Regional Leprosy Training & Research Institute, Aska, Orissa

Dr. R. K. Chaurasia
District Leprosy Officer, Bhopal, Madhya Pradesh

Dr. Sadulwar
Asst. Director of Health Services (Leprosy), Mumbai

Presentations

Chennai : Dr. T. Kirubakaran,
Regional Secretary (South), G.L.T.R.A, Chennai

Delhi : Dr. K. S. Bhagotia,
State Leprosy Officer, Delhi

Kolkata : Mr. Sudhakar Bandyopadhyay,
Regional Secretary (East) G.L.T.R.A & Swiss Emauss

Chandigarh : Dr. Bhushan Kumar,
Prof. and Head, Dept. of Derm. PGIMER, Chandigarh

Agra : Dr. Anil Kumar,
Dy. Director, Central JALMA Institute for Leprosy, Agra

Rapporteurs:

Dr. Sachin R. Salunkhe, Project MO, ALERT-INDIA
Mr. Kingsley, Consultant - Physiotherapist, Bombay Leprosy Project
Ms. Daisy Gangurde, Social Welfare Officer, ALERT-INDIA

In Tamil Nadu, the goal of leprosy elimination is achieved only quantitatively but not qualitatively after the integration

Dr. T. Kirubakaran
Regional Secretary (South),
German Leprosy & Tuberculosis Relief Association, Chennai

The integration of leprosy by Government Organizations (GO) and Non-Government Organizations (NGO) was achieved through a collaborative project : **Urban Leprosy Elimination Programme** in Tamilnadu.

The objective of the project was to establish quality, sustainable MDT services in identified urban areas resulting in mainstreaming of leprosy cases into GHC system, utilizing the services of NGLOs. There are 28 districts and about 650 health care facilities in Tamil Nadu.

Tamil Nadu is the first State in India to practice integration of leprosy services into the GHC system since 1997. Integration was implemented in rural areas initially and in urban areas since 2003. Multi-sectoral health services with different objectives are functioning in urban areas. It is stated that 42% of population is living in urban areas and about 20% of the case load is from urban areas.

During the preparatory phase, meeting with the stakeholders, formation of special committee for planning and monitoring, orientation of NGOs to act as facilitators, establishing zonal level support system, identification and authorization of NGOs, sensitization of GHC staff and multi-sectoral health departments were carried out at the State and District level. The results of this Project were measured in terms of:

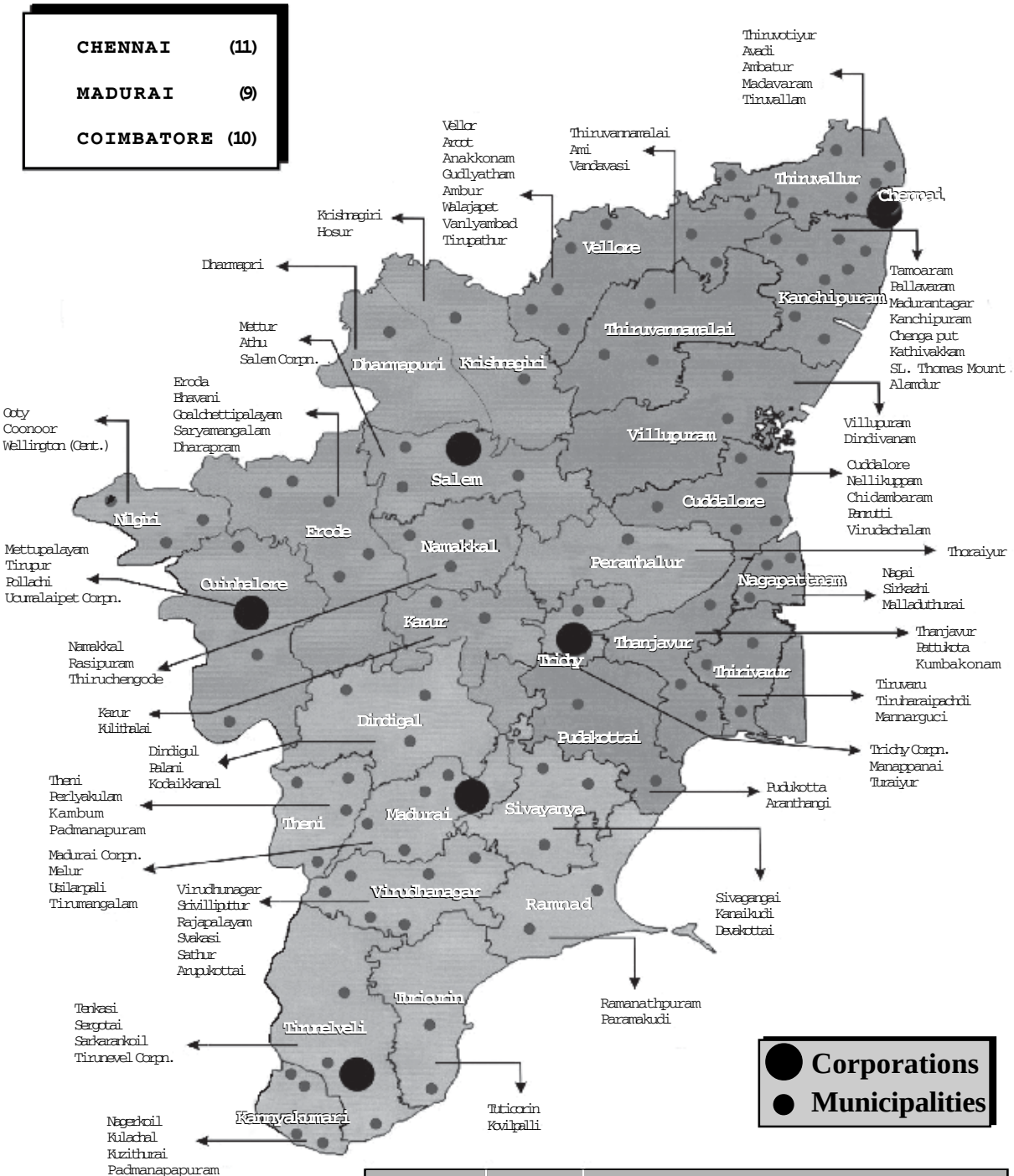
1. Capacity building,
2. Delivery of MDT drugs,
3. Information, Education & Communication (IEC),
4. Advocacy,
5. Prevention Of Disability (POD) and
6. Coordination activities.

The following are the key factors that were necessary for building a partnership with the GHC system to implement this project.

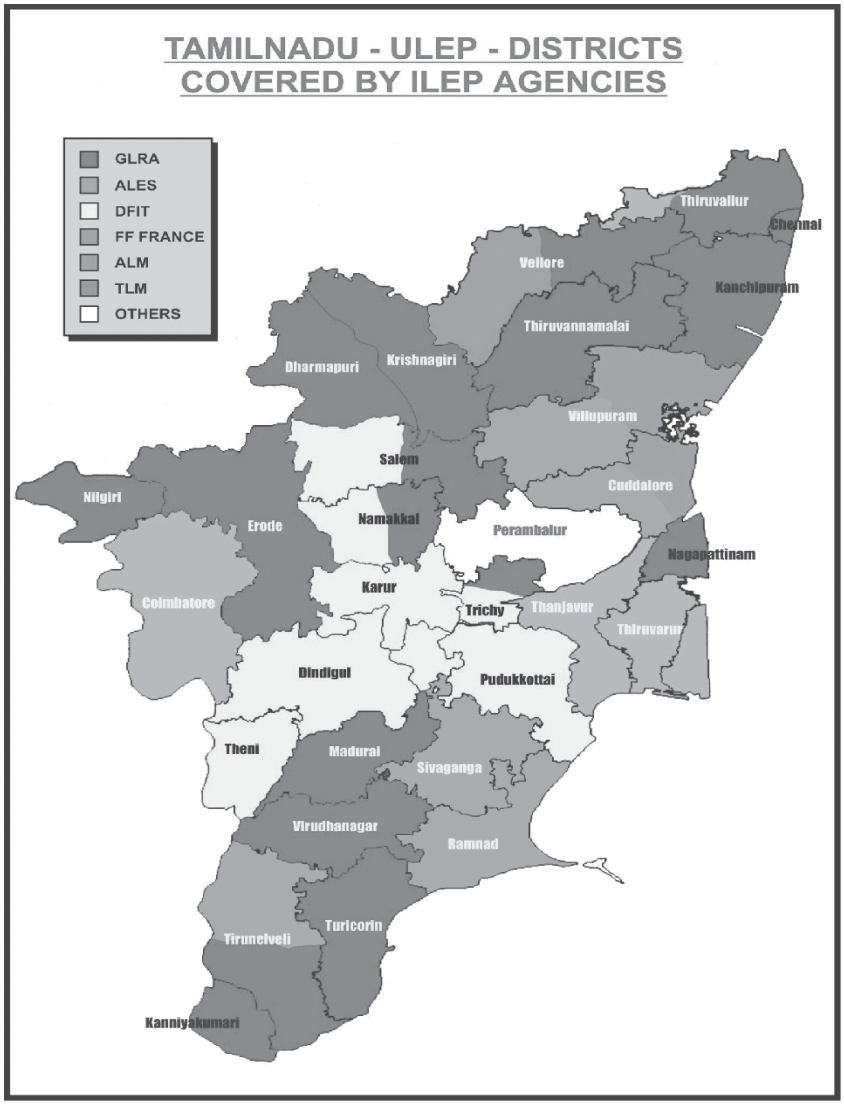
1. Issue of Government Order
2. Agreement Sign (MOU) with major partners
3. District Committee formation.
4. Common objectives as per guidelines
5. Common POA and allocation of duties (Plan of Action Model)
6. A.T.P. to all partners
7. Weekly discussion with Executive Members
8. Monthly reporting of activities - major issues identified, action planned, etc.

Sharing the expertise to more number of general health care personnel will result in more coverage and better quality of services.

NLEP - TAMILNADU
ZONAL MAP SHOWING URBAN AREAS



State	No. of Districts	Population as per 2001 census			
		Urban	%	Rural	Total
Tamilnadu	30	27,241,814	43.85	34,869,025	62,110,839



1. Know who is in the team.
2. Role of each member
3. Strength and Weakness of each member
4. Common goal
5. Direction and Pace
6. Acceptance & Respect
7. Participation

The following are the advantages and disadvantages of team work:

Advantages

1. More strength of personnel
2. More coverage
3. Better Quality
4. Expertise Shared
5. Local resources tapped

Disadvantages

1. Slow in decision making
2. Time Consuming
3. No co-ordination
4. Domination of Member
5. Individual priority

Results achieved at the District level

1. **Capacity Building:** Majority of the urban Medical Officers and other staff are oriented.
2. **MDT drugs:** Stocking MDT drugs / Register (SIS) done in almost all urban Health Posts.
3. **IEC:** Low cost IEC & No cost IPC is in full swing.
4. **Advocacy:** Implemented in all urban areas by GOs / NGOs.
5. **POD:** Initiated and in progress.

The process involved in transfer of ownership of the leprosy programme from the vertical structure to the integrated structure is to be meticulously planned and implemented in a phased manner. It is also necessary to ensure that this transfer would take place smoothly by keeping in mind the interest of leprosy patients. For any reason, if this process of transfer does not happen in a coordinated manner, then the end sufferer would be the leprosy affected persons.

Since this project has multiple partners, a true spirit of team work was maintained and the following points were seriously adhered to for successful implementation of the activities without compromising on the quality of services being rendered after the process of Integration.

Enough caution is to be taken about the overlapping of others role and the need to involve the community leaders and local bodies as well as groups. Regular monitoring of the programme needs to be assessed on the basis of quantitative and qualitative parameters. ■

'In Delhi, special surveys of target population in focal areas are needed'

Dr. K. S. Bhagotia
State Leprosy Officer,
Government of Delhi

Re-organization and decentralization of vertical leprosy care services will strengthen the process of Integration.

For planning and developing a suitable strategy to implement any developmental programmes, the urban agglomerations of cities and towns have been defined and grouped based on the size of population during the census 2001.

Definition for Towns:

1. Population more than 5000
2. Density of population > 400 persons/sq km
3. At least 75 percent of work force engaged in non-agricultural pursuits.

Size of Population:

1. Mega Cities : > 10 Million **(Delhi, Mumbai, Calcutta)**
2. Metros : > 1 Million **(11 Metro cities)**
3. Cities : > 100,000 **(379 Cities)**
4. Towns : > 5,000 **(3985)**

Grouping of urban agglomerations & towns:

S No.	Class	Population size	Towns
1.	Class I	100,000 & above	393
2.	Class II	50,000-99,999	401
3.	Class III	20,000-49,999	1151
4.	Class IV	10,000-19,999	1355
5.	Class V	5,000-9,999	888
6.	Class VI	<5000	191
7.	Unclassified	Unspecified	10
	Total		**4378**

The issues and problems related to urban leprosy are mainly (i) administrative, (ii) technical, (iii) operational and (iv) social. The components of these issues are:

Administrative:

- Multiplicity of authority & lack of coordination and cooperation
- Large number of service providers
- Lack of involvement of municipalities
- Rapid urbanization and settlement of new colonies
- Non availability of organized GHC
- Unidentified catchment areas

Technical:

- Adhoc reporting, analysis & monitoring
- Case detection through active search, which is not cost effective
- Poor utilization of cable network
- Lack of Interpersonal Communication
- Untrained manpower in GHC System

Operational:

- Poor involvement of Community and NGOs
- Need of area specific plans, IEC, Case Detection & Case Holding
- Poor involvement of ISM & H Institutions & Medical Colleges
- Lack of uniform mechanism for referral & defaulter tracing
- Non availability of Records, Reports and MDT Drugs

Social:

- Migration, frequent shifting of residence and floating population
- Poor accessibility and coverage of slum populations
- Presence of stigma even amongst educated and elite people
- Temporary settlers like building construction/ brick kiln workers

Considering all the above issues and problems, the following needs are identified as important factors that would **help us to achieve the goal of leprosy elimination** in urban areas.

Resource and Support:

- MDT services in urban areas through Urban Leprosy Centres, Temporary Hospitalization Wards, Leprosy Treatment Units,
- Some areas are adopted and supported by the NGOs
- Need to redefine the role of NGOs in view of the policy of Integration
- MDT delivery through the General Health Care System
- Urban areas still lack clear cut policy on MDT Services

Authority and Accountability:

- Programme was centrally controlled & centrally sponsored
- Mainly implemented through District Leprosy Societies
- Relative non-involvement of state headquarters
- Limited development of technical and supervisory capacity at state level
- Formation of SLS in 2nd phase of NLEP leading to state accountability

Experience of Leprosy Integration in Delhi

Profile – Delhi

Population	: 1,54,19,155
Area	: 1483 Sq. Kms
Number of Districts	: 9
Number of sub-divisions	: 27
Statutory towns	: 3
Urban villages	: 165
Slum population	: > 40,00,000

Leprosy Status - Delhi

MDT programme implemented since 1989

PR at start of MDT(April 1989)	: 17/10,000
PR as on 31st March 2003	: 4.27/10,000
PR as on 31st March 2004	: 3.92/10,000
New cases (April – August 2004)	: 2,088
MB among new cases	: 1,099 (52.6)
Children among new cases	: 111 (5.3)
Females among new cases	: 395 (18.9)
Deformity among new cases	: 46 (2.2)
Cases as on 31-08-2004	: 5,847 (3.79)

Major challenges that were encountered in Delhi to achieve leprosy elimination are:

- Multiplicity of Authority in Health Sector
- Migratory Population (> 40 %)
- High Prevalence in neighbouring States and countries
- Low priority over other health programmes
- Patients reporting directly to Tertiary Care Hospitals
- Lack of well organized reporting system in the Integrated set-up
- Peripheral units not having financial powers
- Lack of availability of proper addresses of patients
- Newly formed district units are functioning with skeletal staff

There are more than 4030 health care facilities and 11 Urban Leprosy Centres (ULC) in Delhi. The role of NGLOs is now redefined and they are assisting the DLOs by providing 'District Technical Support Teams' (DTST).

Since 2003, all the nine districts in Delhi were adopted by the following International leprosy agencies.

1. East: The Leprosy Mission
2. North-east : The Leprosy Mission
3. North : Netherlands Leprosy Relief Assn.
4. North-west : German Leprosy Relief Association
5. West : Netherlands Leprosy Relief Assn.
6. South-west : Damien Foundation India Trust
7. South : Netherlands Leprosy Relief Assn.
8. New Delhi : Netherlands Leprosy Relief Assn.
9. Central : Netherlands Leprosy Relief Assn.

The following are the steps taken by the Government to strengthen Integration and to improve the effectiveness of the programme in Delhi.

- Decentralization through formation of 9 DLSs
- Dismantling of all 5 MLTUs
- Redefining the role of NGOs
- Formation of District Nucleus and SSAU
- Decentralization of MDT supply
- Implementation of SIS System
- Mandatory District Master Register
- Computerization of Records

Re-organization of the Vertical Structure

- Three MLTUs (SLS) staff sent to District Nucleus
- Two MLTUs (HKNS) converted to SSAU in Delhi
- NGOs other than ILEP to support in IEC Activities

District Nucleus consists of a Public Health Nurse, a Pharmacist, Contractual Paramedical Workers and a Peon, which assists the District Leprosy Officer (DLO) in implementation of NLEP in the district. MDT supply has been decentralized and made available in all Govt. Hospitals and dispensaries.

Fig. 1 **Trends of Leprosy Indicators During the Last 5 Years (2000 – 2004)**

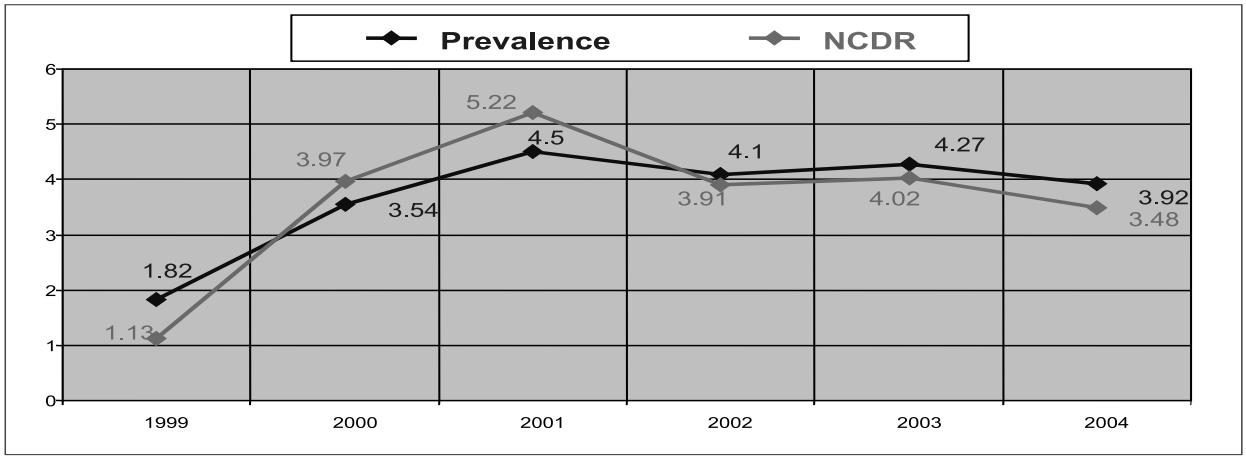


Fig. 2

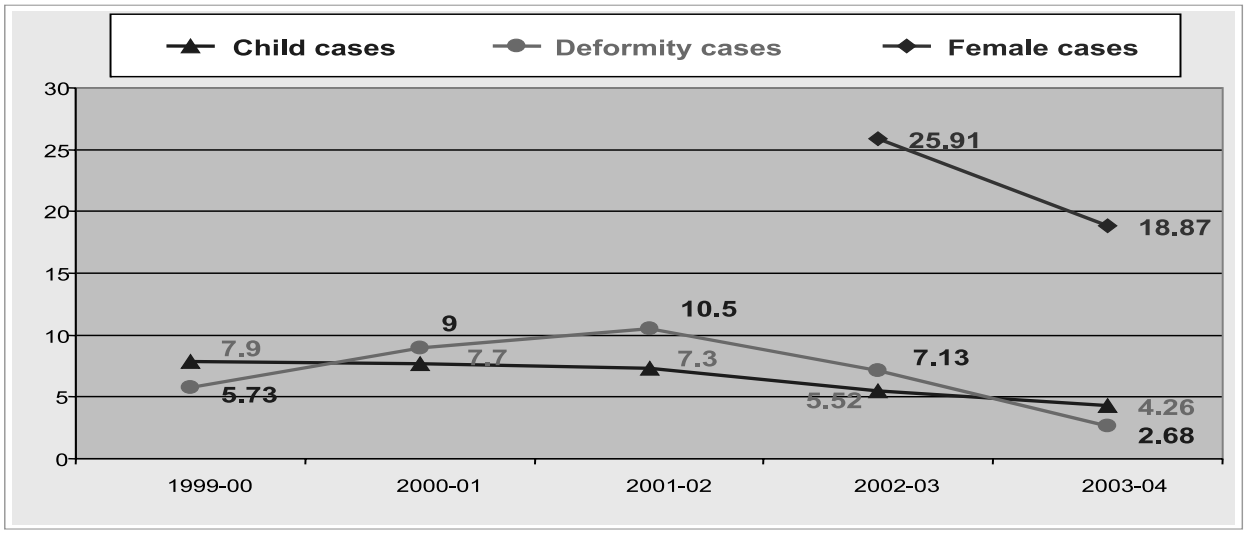
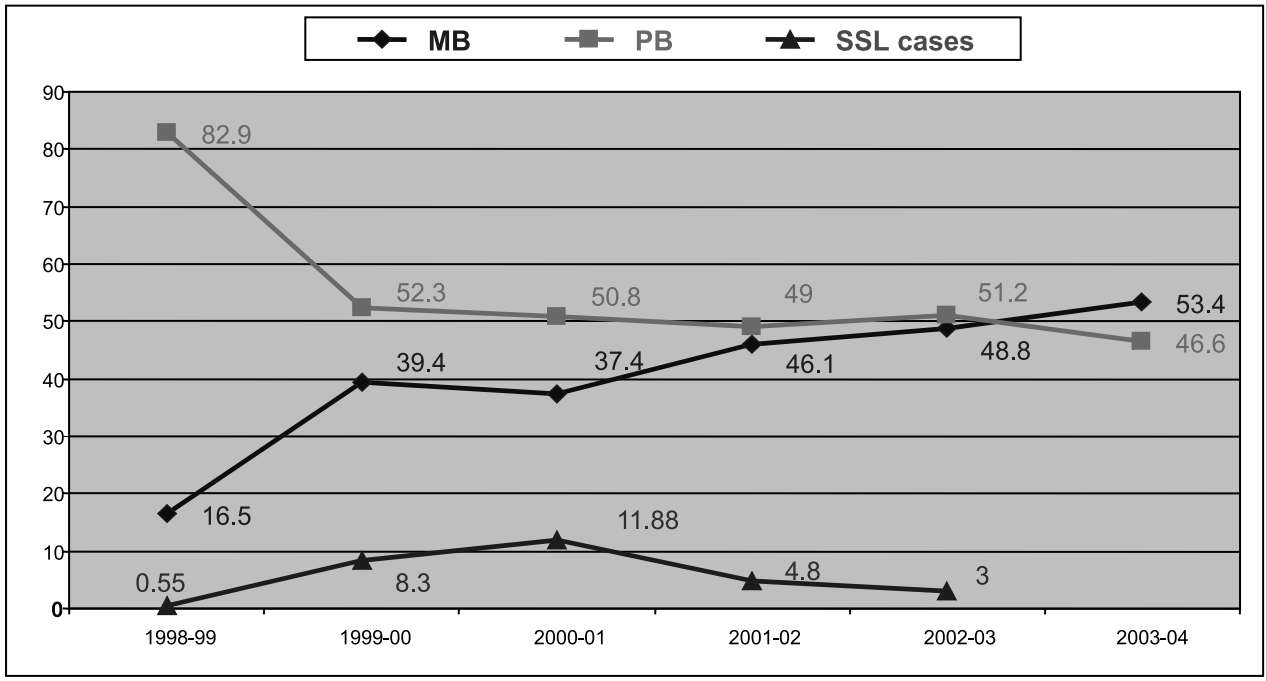
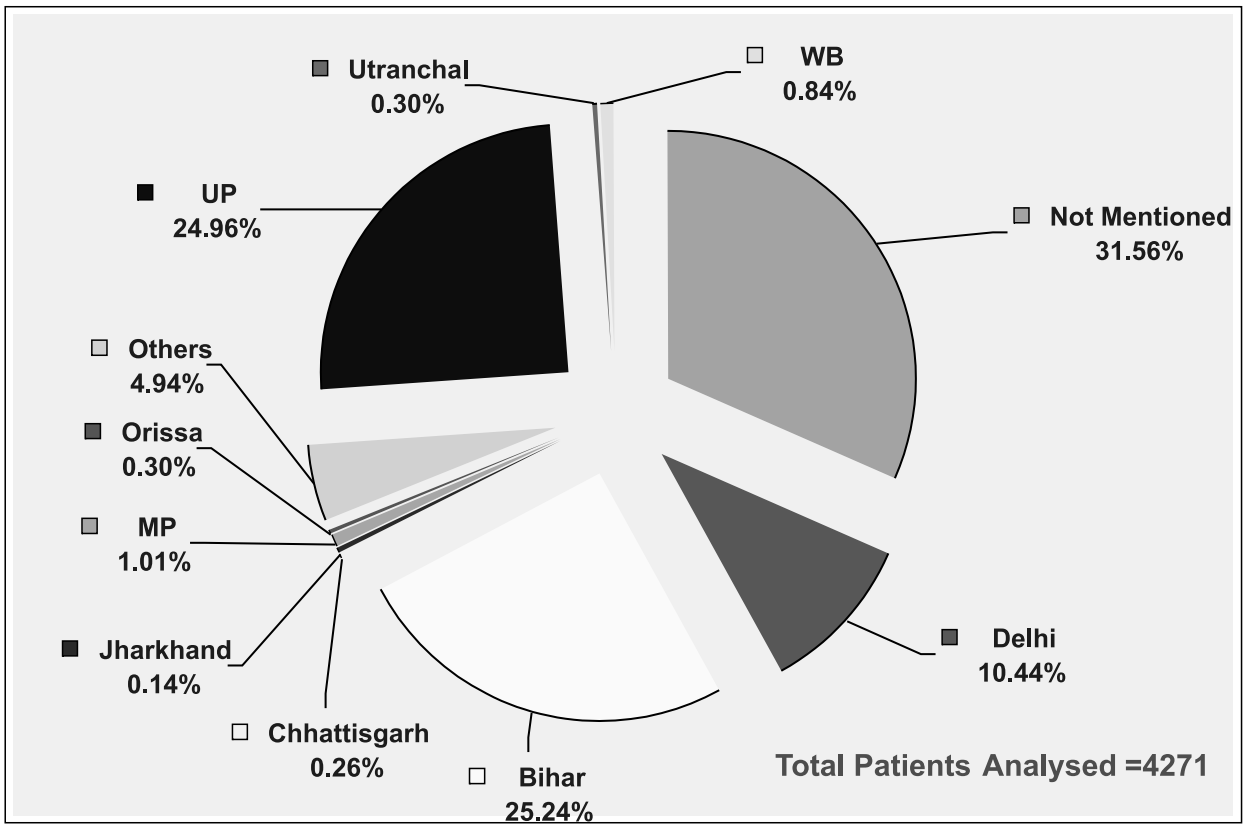


Fig. 3

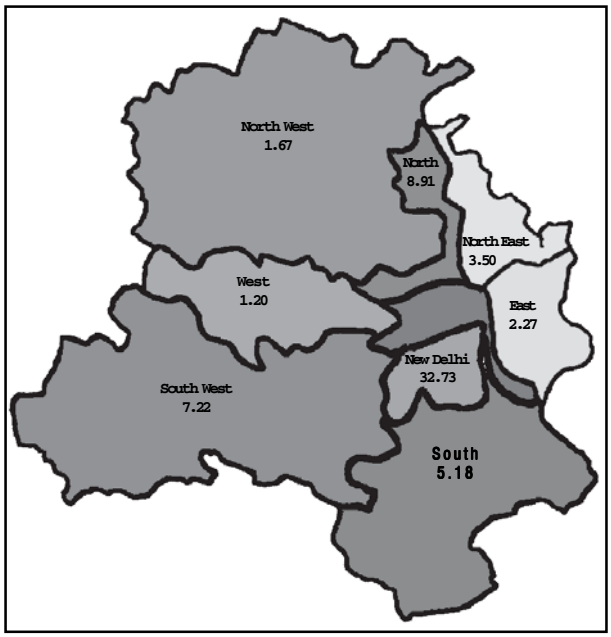


Proportion of Leprosy Patients Migrated from Other States

Fig. 4



Prevalence of Leprosy in Delhi



March 2003

August 2004

The following activities other than MDT delivery were carried out in collaboration with the Government and Private hospitals as well as NGOs.

1. Performed Reconstructive surgery: 612 patients
2. Training of health personnel:

   i. Leprosy training (1 day)

   a. Doctors : 1479

   b. Paramedical staff : 1742

   c. Anganwadi /Community volunteers: 4492

   ii. POD training (3 days)

   a. Doctors : 383

   b. Paramedical staff : 343
3. Rehabilitation assistance to leprosy patients : 4000
4. Conducted IEC campaigns

Leprosy services such as training needs, availability of IEC materials, skills of the medical staff to diagnose and treat leprosy and the infrastructure of the health facility providing MDT services in Delhi was evaluated in 2003. Based on this evaluation report it is felt that there is a need to give more emphasis on the following factors, which has led to the success of the leprosy elimination programme in Delhi :

- Ensure availability of MDT drugs.
- Diagnostic facilities in all Health Care Institutions.
- Involvement of NGOs, Resident Welfare Associations in Anti Leprosy Activities.
- Involvement of treated patients.
- School survey, Employees survey, Targeted intervention.
- Participation in big social & religious gatherings.
- IEC activities in vernacular language & display in the offices.
- Messages in Newspaper, TV, Radio and Telephones.
- Training of all Health Care Personnel.
- Reporting of cases to DLOs & State Health Directorate.
- Computerization of Patients' records.
- Assisting mobility of monitoring staff.
- Evaluation, feedback and revised action.
- Incentives, Awards and Recognition to good workers. ■

'IEC strategy is the greatest casualty of the leprosy programme during integration era'

Mr. Sudhakar Bandyopadhyay
Regional Secretary (East),
German Leprosy & Tuberculosis Relief Association, Kolkata

Need to plan support services for the next five years through the NGOs as the integration will take its own time to deliver quality services to leprosy patients.

The prerequisite for integrating the leprosy programme with the general health care programme is:

- Viable Health Infrastructure
- Program acceptance in management level
- Program acceptance & motivation in service delivery level
- Program planning
- Training of Program Managers, Medical personnel/Health workers
- Logistics Supply
- Advocacy & Sensitization
- Program Execution

Based on the above, the level of success in terms of fulfilling the set prerequisite for Integrating Leprosy Elimination Programme in Kolkata Municipal Corporation, the only health agency providing leprosy services, must consider the following problems:

Problems and Existing Health Infrastructure:

1. Assigned with multifarious activities, not yet found viable for NLEP.
2. Appreciable program acceptance in management and Medical Officers level.
3. Program acceptance & motivation not up to the mark in service delivery level.
4. Program planning is appreciable but execution is not viable.
5. Training for Medical Officers has been completed.
6. Training of Health workers is still to be started, skills not yet developed.
7. Logistic supply i.e. Medicines and Reporting formats supply is appreciable.
8. Advocacy & Sensitization Program of councilors have been done once.
9. Service delivery is once a week, which is against the concept of Integration.
10. Providing essential services i.e. POID, IEC & SER still rests on NGOs.

Role of Medical Colleges & Hospitals:

There are 4 Medical Colleges, 5 Government Hospitals & 1 School of Tropical Medicine in Kolkata. These Institutions provide daily services for Leprosy as per the Government guidelines; however the services are restricted to diagnosis & treatment only.

Role of Supportive Organizations:

Support is being provided in the form of District Technical Support Teams funded by International Association for Leprosy Elimination Programme (ILEP) through two NGOs: Greater Calcutta Leprosy Treatment & Health Education Scheme (GRECALTES) & BAM – India in Kolkata for assisting the GHC system of KMC.

The roles of **DTST** are:

1. Capacity Building
2. Monitoring & Supervision
3. Case – validation
4. Advocacy / Sensitization
5. Reporting

The activities of **NGOs** are:

Independent Services:

- Information, Education & Communication (IEC)
- Prevention of Impairment and Disability (POID)
- Socio-Economic Rehabilitation (SER)
- Advocacy & Sensitization (Community & Institutions)

Supportive Services to KMC

- Diagnosis
- Treatment
- Management of Complications
- Capacity Building
- Defaulter Tracing, Motivation & Counseling

Problems After Integration

The following are the observations and problems experienced in the Kolkata Municipal Corporation (KMC) area after the leprosy programme was integrated with the GHC system.

1. In KMC clinics, weekly once service is available which should have been six days.
2. Lack of coordination among the KMC, Medical Colleges & Govt. Hospitals.
3. Reporting systems are not streamlined and are yet to be improved.
4. Early Case detection activities are withdrawn, and it is a problem area.
5. Defaulter tracing is not done, and it is a problem area.
6. Diagnostic accuracy & Treatment of complications in KMC clinics are to be improved.
7. Expectations of incentives by Health workers.

Consequences of the Problems

In view of these above problems, the possible consequences that might happen are:

1. Mobility of undetected cases in community
2. Continuing transmission process
3. Increase in deformity rate in future years
4. Further damage to existing deformed cases
5. Increase in Neuritis and other complications

Action Needed to Improve the Quality

Hence the following actions are suggested in order to improve the quality of leprosy services and to sustain the efforts towards achieving the goal of leprosy elimination:

1. To complete the Training of all Health Workers.
2. To start 6 days Service delivery from KMC Clinics
3. To set up a High-level committee for Coordination including representatives of Govt. ILEP & NGOs
4. Intensive IEC for new case detection
5. Target period for capacity building
6. Defaulter tracing, motivation & counseling should be the responsibility of KMC Health workers for their Clinics
7. Defaulter tracing system needs to be developed by the Medical Colleges
8. To convene periodical meetings

Role of NGOs in Post-Integration Scenario

The suggested roles which the NGLOs that are working in urban areas can play in the Integration scenario are as follows:

1. Program-planning in coordination with the KMC, Govt. Medical Colleges & ILEP agencies.
2. Strengthening the independent components.
3. Continuing supportive services for at least next 5 years.
4. Undertaking responsibilities of defaulter tracing for Medical Colleges.
5. Reporting to the Coordinating body. ■

'Process of integration does not address the problems and apprehensions of the vertical staff who find themselves in a very new situation'

Dr. Bhushan Kumar
Prof. and Head, Department of Dermatology
Post-Graduate Institute for Medical Education & Research, Chandigarh

IEC should focus mainly on positive health (general) seeking behaviour and the focus on leprosy should be minimal

Over the past decades the number of new leprosy patients detected worldwide has been more or less stable (WHO, 2002). In 2001 more than 750,000 new patients were diagnosed (WHO, 2002). It is very likely that a significant number of new cases will continue to occur for many years. Hence, leprosy control activities should be sustained, and to guarantee sustainable leprosy services they should be integrated within the general health services (International Leprosy Association, 2002). The change from a vertical to an integrated program is far from easy and cannot be accomplished overnight (Soutar, 2002). Experiences with integration processes in several countries reveal that successful integration requires good preparation and planning, and the addressing of several hurdles, many of them specific to the local context.

Definition and Rationale of Integration of Leprosy Services

Integration has been defined in different ways, varying from the collaboration with other programs to the full absorption of leprosy services into national health systems, without leaving any room for leprosy-specific elements. Consensus now exists that integration of leprosy services within the general health services means that leprosy control activities become the responsibility of the general health services, i.e., involving multipurpose, continuous, and comprehensive services which are as close to the community as possible (Feenstra, 1993). Integration does not imply that specialized elements are unnecessary. On the contrary, to a certain extent specialization is needed for policymaking, training, supervision, and referral. Some of these tasks need to be performed by a central unit in the Ministry of Health, others at the intermediate (regional/ provincial) level.

During the **16th International Leprosy Congress in Salvador, Brazil, the consensus about integration was confirmed by an ILA resolution** (ILA/TF, 2002). Vertical services have become expensive and can usually only be maintained with considerable donor support. Moreover, in areas where prevalence is declining, integration will help in sustaining the Multi-Drug Therapy (MDT) services (Neira & Daumerie, 2000).

Recent Developments Facilitating Integration of Leprosy Control

An important argument for the integration of leprosy control

is to enhance the sustainability of leprosy services (ILA/TF, 2002). Though the basic arguments for integration justify in most settings a process towards the integration of leprosy control, this is reinforced by several recent developments, both within and outside leprosy control programs (Feenstra & Visschedijk, 2002).

- While the number of newly detected cases is more or less stable, the registered prevalence of leprosy has been reduced substantially
- Despite the reduced prevalence, cost-effective and accessible leprosy services (diagnosis, treatment, prevention of disabilities, disability care, rehabilitation) have to be sustained for decades to come
- The relative simplicity of the application of MDT facilitates its use by general health workers and, thus, the opportunities for integration
- The WHO campaign to eliminate leprosy as a public health problem has raised commitment for integration
- Economic crises in several countries and the consequential adjustment had a negative impact on health care and on other poverty-related diseases, including leprosy
- To remove stigma attached to leprosy so that it becomes an "ordinary" disease, which does not warrant special services and approaches

Experiences with Integration of Leprosy Control

As indicated above, several developments in leprosy control and the health sector justify the need to integrate leprosy services. As a result, several countries have already embarked on a process to integrate leprosy control into the general health services (Feenstra & Visschedijk, 2002).

The Process Towards Integration

The mode of implementation has varied between countries and States. In some settings such as Sri Lanka (Kasturiaratchi et al., 2002) and Uttar Pradesh in India (MOH/UP, 2001), the process included the whole country or State from the start. In other countries a pilot was launched first. In Ethiopia, for instance, the combined tuberculosis and leprosy control program started in 1997 with integration in one district called Arssi (Fekadesillassie et al, 1999). All experiences reveal that proper planning and preparation have to precede the actual implementation of the integration process. In some countries, such as Ethiopia, a step-by-step approach was spelled out in detail, in which all the consecutive steps were indicated (Fekadesillassie et al., 1999). Other important aspects in the planning and preparation phase include a realistic situation analysis, commitment building, formulation of a clear plan for integration, training of health workers, and provision of adequate and timely information to the public.

These experiences indicate that the building of adequate human capacity through training is one of the most important factors for successful integration. Such training should not only include the transfer of skills and knowledge, but should also create a positive attitude of health workers towards leprosy and leprosy patients (Asnake et al, 2000). In several integrated programs (Nigeria, Sri Lanka, Myanmar) the cure rate has been kept at acceptable levels (Barua et al, 1999; Kasturiaratchi et al, 2002; Namadi et al, 2002). In most settings in which leprosy control was integrated, accessibility increased substantially. However, concerns have been raised about quality of leprosy services (Naafs, 2000).

Current Status of Leprosy in Chandigarh

Total cases on record as of 31st July 2004 is 286 with prevalence rate of 2.96 per 10,000 population and ANCDR being 3.3 per 10,000 population.

Strategies for Services Delivery

- All general health care staff have been trained in Chandigarh.
- Paramedical worker will include leprosy work in his activities with emphasis on survey, defaulter identification and health education at village and sub centre level and refer cases if necessary.
- They will advise new patients and provide POD services. General Hospital, CHCs, PHCs and Dispensaries will offer leprosy diagnosis and treatment facilities.

Challenges and Action Plan

a. The problem regarding leprosy in Chandigarh is due to frequent movement of migrants not only from the 8 high endemic states but also from the 3 neighbouring states of Punjab, Haryana and Himachal Pradesh, between which the city is sandwiched.
b. Because of the higher prevalence among migrants, more of the local population is beginning to get infected.
c. Another challenge is to hold the cases. Therefore, regular follow up and finding defaulters is an important part of the programme.
d. Need for prevention of deformities and rehabilitation.

Integration

All general health care staff has already been trained in detection and treatment of leprosy. Latest training has been done on 20-22 September 2004, where the remaining staff was also trained. Till date total staff trained is 2670. With the efforts of Director, Health Services, the Municipal Corporation, Chandigarh has agreed to join hands with Health Department in removing leprosy. They have sanctioned Rs.1,14,000/- towards remuneration @ 1000/- per head per month for 6 community workers. These workers have been selected for 6 target areas.

They work in close liaison with the medical officer in charge of the area dispensary and report to the district leprosy society once a month. Their duty is to create awareness regarding leprosy, suspect new cases, confirm diagnosis and follow up treatment. They have to advise new patients, check defaulters and provide advice about prevention of deformities. After this experiment for 1 year, this project of recruiting community workers shall be extended with further opening of 4 more clinics in rest of the urban slums.

Along with 5 hospitals for specialized care, 10 more peripheral centres shall be looking after detection and treatment of leprosy in Chandigarh. All medical officers in-charge shall be given reference cards. They shall detect cases and send them to specialized leprosy clinics for confirmation and treatment. In next phase these dispensaries would also be handed over the medicines for distribution (presently with major hospitals and leprosy specialists).

Lessons Learned

- Rehabilitation of disabled leprosy patients and eye care for leprosy patients should also be integrated into general health services and facilities
- Integration requires careful and adequate advance planning and should be introduced on a step-by-step basis (phasing in place, time, and activities)
- Integration must be context-specific and is important to achieve early results. This is necessary to maintain commitment
- Special initiatives such as LECs can be used as opportunities to begin or strengthen the integration process
- Decentralization of responsibilities can enhance the ownership of leprosy control at the lower levels
- It is important that the various agencies involved in leprosy control collaborate and coordinate their activities, in order to increase their effectiveness
- All experiences reveal that proper planning and preparation have to precede the actual implementation of the integration process

Conclusion

Integration of leprosy services into general health services is necessary to sustain leprosy services and to render them more equitable. Based on recent experiences and developments, it has been demonstrated that integration is feasible in most settings. Of critical importance is that integration is well prepared and planned, and that certain preconditions are met. Although there is no blueprint for integration and every setting requires its own approach, common characteristics in the process can be identified. The prevalence of leprosy in cities like Chandigarh will not decline until leprosy is eliminated from the high endemic neighboring states of the country which act as feeders for the migrants. ■

'Before Integration, there is a need to explore the efficiency of the GHS to achieve the programme goals'

Dr. Anil Kumar
Deputy Director
Central JALMA Institute for Leprosy,
Agra

PHC system in leprosy endemic States (East & Nort-East) needs a complete overhauling, so that it can serve the people effectively and effeciently. However, it needs vast resources and teamwork.

The Leprosy scenario is reportedly changing the world over. This is true in some areas, but in some, extensive investigations are required to know the reality of the situation. India alone contributes about 60% of the total leprosy cases reported in the world. The latest situation at the district level reveals that out of 352 districts, 9.1% (32) had already achieved leprosy prevalence of <1 / 10,000, 58.5% (256) have prevalence of 1-5 and 32.4% (114) districts still have prevalence of >5 / 10,000[1]. However one of the districts (Agra) has a reported prevalence of about 0.5/10,000 since 1998, but the current prevalence is 16.4/10,000 based on 3.61 lakh population examined from over 300 villages randomly selected from all the 26 blocks and many urban areas[2]. Interestingly, about 85% of the cases had no history of treatment and were thus new cases.

Prevalence in Agra city came out to be 14.4 during 2003[3]. Another district (Kanpur) has reported prevalence of 4.7, but studies in progress there have shown a prevalence of >10 folds (unpublished). Therefore, it seems a challenging task to validate prevalence figures especially in northern states endemic for leprosy. Theoretically speaking, the current leprosy scenario does not at all fit into the transmission dynamics model. For example, if prevalence of leprosy (meaning force of infection) has been declining over the years then why has the new case detection rate (proxy for incidence) not shown a similar decline, at least a few years later? It is a question bothering every one concerned with the leprosy control and assessment work. Lacunae in the understanding does not seem as much as being projected. One of the reasons is, even today we have not a single large population closely and completely followed for years to assess prevalence and incidence of leprosy, fitting into the model of transmission dynamics. However close **assessment in Agra reveals that for every 1 case passively reported, there are 7-8 cases undetected in the population.** If detected patients are followed up regularly, only about 75% could be completely treated. However, about 99% of the completely treated and about 30% of patients with incomplete treatment get cured (including self-cured). This leaves about 15-20% detected patients uncured and needing treatment. However, some of these are bound to face a situation of deformity.

Integration of Leprosy Programme with General Health Services:

The current idea of integrating leprosy services with the General

health care services is really a brilliant thought since it will greatly reduce the cost of providing services to leprosy patients who can seek services from the wide network of PHC's (Primary Health Care) across the country in rural areas and from urban health units in all urban areas. However it raises several basic points of enquiry:

1) Is the PHC (GHC) system in its existing condition ready to take up this additional responsibility?
2) What is infrastructure and material requirement to comply with this need in addition to the existing responsibilities?
3) Is the concept of low prevalence and thus low case load a reality?
4) What infrastructure exists and how effectively are services provided for whom it was created?

A survey conducted in 90 demographically weak districts[4] in India, majority belonging to leprosy endemic states, revealed interesting facts. Only 14.4% of PHC's in these districts have a Labour room (6.3%) or/and Operation Theatre (8.1%), 20% PHC had no medical doctor posted, 64.1% had 1 medical doctor and the rest with ≥2. Nurses were posted in 3.3%, ANM in 73.5% and LHV (Lady Health Volunteer) in 15.9%, only 10.6% were conducting deliveries. Beside this, what proportion of the posted staff is effectively serving at the place of posting is another question.

Experience suggests that a good number of PHC's do not provide any health input to the communities where they are located on account of their faulty functioning. Therefore, it seems that the PHC system, at least in leprosy endemic states (also include areas of east and north east) needs a complete overhauling so that it can serve the population effectively and efficiently. However it needs vast resources and an effective team of program managers to see its implementation. This brings us back to the question that "Should the existing vertical programme be merged with the PHC system?" Or is there a severe need to revitalize its functioning to effectively deliver? Obviously there is not an easy answer to these questions.

Historically, many health programmes like Malaria control, Filaria control, TB control, Family welfare, Immunization (except Polio drops) and others could never come up to expectations and thus problems remained almost as they were. In view of the facilities and programme implementation and outcomes, **the fate of the leprosy control programme can be anybody's guess!**

Another Controversial Decision:

Public health programmers, which include WHO, argue that vertical programmes cannot be continued due to the huge cost involved to maintain them, and since the case load has declined significantly, passive voluntary reporting by leprosy patients is to be encouraged. World Health Assembly (WHA) had emphasized that prevalence needs to be brought down to <1/10,000 by the year 2005[5]. While emphasizing on passive voluntary reporting, the programme has to wait for the patients, so what would happen to the recommended action to 'bring down prevalence? Will the cases reported be taken as prevalent cases? Many studies[6,7] have clearly indicated that **even the existing vertical system has poor case detection** and thus very low reported prevalence at the district level.

In Agra city, a recent survey indicated that only 8% of patients (23/287) had history of taking treatment from speciality or Government hospitals (unpublished). This **survey highlighted that 92% (1 Prevalent: 11.5 new cases) of the detected patients never approached any so called "passive voluntary reporting" system**. Thus data from 'passive voluntary reporting' seems to be nowhere close to actual. A recent study[8] too has revealed limitations on integration.

'Elimination' is not 'Eradication':

The current figures of registered cases and new cases detected show that about 500,000 - 700,000 leprosy cases needed to be treated annually. However in real terms, we are far away from the magic 'cut-off' of <1/10,000. **Even if leprosy prevalence of 0.9 (being <1) is achieved at country level by the year 2005, it only means that India alone would have about one lakh new leprosy patients per year** to be treated (Present population is about 1100 million). Thus leprosy services would need to be sustained for longer periods in a way that they can deal effectively.

What Should Have Been Done?

Experience of nearly two decades suggests that MDT has effectively treated millions of leprosy patients around the world. Although there have been problems of defaulters, relapse rates are very low (<1%).

1. Treatment regimen: ROM for Single lesion leprosy, 6 months PB MDT for PB Leprosy and 12 months MB MDT for MB leprosy should have been continued, to create sustainable effect on transmission. We must remember that single lesion leprosy accounts for 30 - 40% of all cases and ROM has been effective.
2. Effective vertical system should have been maintained. This failed to happen for whatever reasons and way out is seen to close this. Efforts were required to explore the potential of survey teams and in extending complete treatment.
3. Before thinking of integration of leprosy services with the General Health System (GHS), serious attempts were necessary to explore the efficiency of GHS to meet out these needs and also those districts (preferably PHC areas) reached close to the leprosy prevalence at elimination level (P<1/10,000) with reasonable confidence.

PR/Criteria for PHC/Ward	Action Before Merger	Decision
≤ 1 / Efficient & ready	None	Must be merged with GHS
≤ 1 / Ready but not efficient	Remove the fallacies to improve efficiency	May be merged with GHS once fallacies are removed
> 1-3 / Ready and efficient	Quick case detection activities like MLEC	May be merged with GHS, when PR remained <1 for 2-3 years
> 1-3 / Ready but not efficient	Quick case detection activities like MLEC, good TT coverage & remove fallacies to improve efficiency	May be merged with GHS, when PR remained <1for 2-3 years and GHS is efficient to serve
> 1-3 / Ready but not efficient	Repeated case detection is required along with good treatment coverage & assessment of GHS	Wait and watch approach along with extensive efforts to achieve PR <1 & efficient GHS for 3-4 years

If such exercises are done before hand, chances of failure is likely to be rare. Whereas the presently adopted approach of deleting names of patients who default may give some short term relief, as it artificially suppresses the problem of leprosy, untreated infectious patients would continue to transmit the infection. If mid-course corrections are not applied, the problem would certainly bounce back in the years to come. One, especially public health experts, should not forget the malaria and Tuberculosis story[11] in the 60's, and now decades later we are facing more complex problems. Also needed now is the joint approach of culminating knowledge and perceptions about the benefits of living in clean settings along with the sincerely committed MDT-based leprosy control approach. Case detection & MDT Delivery may be in partnership with committed voluntary organizations, which has leprosy patient in focus, was the need of the time.

Is the Current Leprosy Scenario a Challenge or a Warning?

In reality, the current leprosy scenario is very challenging and the options are either to face it and correct the mistakes or to close one's eyes from this warning. However, ignoring this warning would 'gift' us certainly another failure of controlling a communicable disease and this seems to be unavoidable.

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Decline in New case detection after Integration

Dr. S.P.Kulkarni
Assistant Director of Health Services (Leprosy),
Government of Maharashtra, Pune

The Pimpri-Chinchawad Municipal Corporation is one of the largest Corporations in Mahatrashtra. There are 23 Municipal Dispensaries in each of the 23 Wards, covering a population of 1,06,275 as of March 2004.

Before Integration, the National Leprosy Eradication Programme (NLEP) was carried out by one Supervisory Urban Leprosy Unit (SULU) of the Government of Maharashtra and Ashwin Medical Foundation, an NGO, each adopting a population of 6,55,976 and 4,53,542 respectively. These Units were running 13 SET centres, which are managed by 2 Medical Officers and 15 paramedical workers. The prevalence of leprosy in Pimpri-Chinchawad Municipal Corporation area was 12.15 during 1981-1982 and declined to 1.9 / 10,000 population during 2003-2004.

Performance Before & After Integration

The key indicators were compared before and after integration to judge the performance of NLEP activities.

Indicators	7/03	3/04	7/04
Active cases	203	185	207
PR / 10,000	1.9	1.77	1.94
New cases	246	85	108
NCDR/100,000	2.3	0.81	1.01

It was observed that, although there was no significant change in the prevalence rate, there was significant decline in the new case detection rate after Integration. However, there has been slight improvement in the new case detection when compared to the corresponding period before and after Integration. This was mainly due to the increase in more infrastructures in terms of the number of health personnel and treatment centres available with the GHC system. Facility for diagnosis and treatment were made available daily at all dispensaries. Recently two orientation programmes for the GHC staff working in Pimpri-Chinchawad Municipal Corporation was undertaken by the ADHS and SULU staff. Leprosy awareness programmes were undertaken along with the other health programmes in all dispensaries.

Initially the health personnel at GHC system were reluctant to undertake leprosy elimination activities

Problems and Suggested Actions

Initially the health personnel at the GHC system were reluctant to undertake leprosy elimination activities and the treatment records were not updated. More priority was given to other health programmes by the GHC staff. Hence the following actions were suggested:

- Training of all medical and paramedical personnel working in GHC system.
- Monthly review of NLEP activities by Corporation authorities and feed back to dispensaries.
- Follow-up of defaulters must be undertaken by the staff of GHC system. ■

Bhuvaneshwar

'Though the goal of leprosy elimination seems to be at sight at the country and state level but it does not appear to be achieved in urban areas'

Dr. D. Porichha
Ex. Director, Regional Leprosy Training & Research Institute,
Aska, Bhuvaneshwar, Orissa

Problems faced in a city have been enumerated in more than one occasion. But things do not seem to move and a suitable integrated model is yet to emerge.

Bhuvaneshwar belongs to a medium class city with population of around 7 lakhs, and like other cities, shares the above problems. Some of the demographic information of the city is as follows:

1. Population : 7,10,975
2. Slum population : About 2 lakhs
3. Number of wards : 47
4. Number of slum : 185
5. Number of health units : Dispensary-17
   Hospitals - 6
6. Leprosy colonies : 5

1. The Problem

Though elimination of leprosy seems to be at sight in the state and country level, the problem in the urban areas does not appear controllable. As per the last census, about 27 % of the population in India lives in cities and towns and in different cities, slum population constitutes 30 to 50 %.There are about 4300 urban conglomerations and towns in the country and this is in sharp rise. The PR NCDR of leprosy in some of the mega cities fluctuates around 4, which is higher than the country level figure. Urban areas are thought to contribute to about 30% of the case load to the country.

2. Hurdles in the Path of Elimination

Various factors, which are hurdles for elimination are long back realised. These are:

- Large percentage of floating population.
- Mushrooming of slums with frequent shifts.
- Over-crowding.
- Inadequate and heterogeneous health facilities.
- Absence of streamlined health structure.
- Inadequate involvement of teaching institutions, PPs and other private health units.
- Lack of coordination.

Two important aspects to be tackled in this city are total MDT coverage and POD care.

3. Trend of Leprosy in The Past 4 Years:

Year	NC	DR	CR	MR	PR	NCDR
2001	1333	1.8	10	28	13.3	11.0
2002	778	1.3	19	29	9..9	7.5
2003	687	0.7	13	27	9.3	11.3
2004	633	0.5	7	34	6.9	6.4

Key: NC - New case; DR - Disability rate; CR - Child rate; MR - MB rate; PR - Preval rate; NCDR - New Case Detection rate

4. Status of POD Service

Total cases registered for POD - 392
Average monthly disability clinic - 6
Economical rehabilitation assistance - 6
Social rehabilitation - 2
Reconstructive Surgery performed - 17

5. Training Status

Municipality personnel trained are: Health workers and inspectors (40), Safaiwala (11). This category of staff mostly reside in the slums, hence many of them who are interested in the disease are trained. ICDS workers (61), Community opinion builders (42) have also been trained on different occasions. In addition, doctors and paramedical workers of all health units have been repeatedly trained prior to MLEC. In spite of training in several occasions the motivational aspect is still to improve. In many workers, personal involvement is inadequate.

In the past, attempts have been made by the state govt. officials, district health authority, LEPRA India, DANLEP and other agencies to bring all the health units of the city in one forum and evolve a comprehensive strategy to manage the leprosy related problems in the city and hasten the process of elimination. But the results were not as per expectation.

Our interest in the urban leprosy problem in the past was rather patchy due to our preoccupation with the rural problem. Now that prevalence rates in many areas have come down, it is time to have a fresh look into the problems in the rural areas. Hence in the line of the suggestions extended in various fora in the recent past, a tentative plan is proposed.

6. Proposed Plan

6.1 Objectives

The principal objectives are similar to what has been followed in the entire country and mainly consist of early detection by all possible means, ensuring complete treatment of cases and providing POD services.

6.2 Designing the Administrative Hierarchy.

In a district, there is a uniform pattern with a district hospital at the district HQ, CHC and PHC in block followed by sub centres bellow. Then there are village health guides in villages. The equivalent of such a pattern is absent in cities and towns though in the recent past a similar health delivery structure has been proposed in the National Health Policy. The health delivery units run by both govt. and private sectors are heterogeneous and do not function according to a common standard strategy.

Each agency does not cater to the health needs of an identified and demarcated area, and there is neither responsibility nor accountability. There is no step-wise referral system. Most importantly, these units do not function under the administrative control and guidance of a single authority. Hence the first task is to formulate an apex body under which the entire urban leprosy elimination programme should function. Designing an administrative head / steering committee to coordinate the entire MDT service may be through the following body/bodies, either individually or in combination:

a. Local urban administrative unit, either municipality, corporation, notified area council (or)
b. An agency formed out of functioning health units (or)
c. A prominent NGO + Government institution (or)
d. Combination of all.

The last is probably a better option.

6.3 An Ideal Committee Would Include

- Municipal Commissioner- Chair person
- Municipal Health Officer- Member Secretary
- Members: SLO, Heads of important health units delivering primary health care, Heads of NGOs, Professional bodies and Representatives of community organisations.

7. Functions of the Apex Committee

- Situation analysis
- Identification of health units
- Allotment of areas to identified health units
- Formulation of broad action plan
- Establish linkage with district and state authorities
- Preparation of a training curriculum
- Monitoring the programme and
- Identification of referral centres, region-wise

8. Reorganisation of the MDT Service.

a. **Identification** of MDT delivery units and Referral Institutions

b. **Mapping** the entire city indicating the problematic areas:
   - identifying high risk groups which include migrants, pilgrims
   - Leprosy settlements and other uncovered areas
   - Stratification of the city as per epidemiological parameters

c. **Equipping** the health facilities/ capacity building by Training of workers, MDT supply, supply of uniform IEC material, Registers and formats and latest NLEP operation guideline

d. **Deciding** on the mode of case detection. In an urban situation, survey in identified pockets should continue. Bhuvaneshwar is a city drawing considerable number of tourists and pilgrims. A mobile unit will take care of the tourist spots and places of worship.

e. **Deciding** the strategy of IEC activities.
   - Involvement of the youths. (NCC, NSS, Bharat Scouts and Guides) have contributed a lot in several areas, resulting in increased awareness. Activity like 'Knock at the door to knock out leprosy' has proved effective.
   - Inter Personal Communication (IPC)
   - Sensitisation meetings with community members, community opinion builders.
   - Spread of the message through bodies such as IAL, IMA, PPs, Dermatologists, Health staff of other systems of medicines, Nursing homes.
   - Though most of the health officials are trained, there is no adequate involvement as they are overburdened in several situations.
   - On the other side there are a large number of health workers catering service related only to family planning and immunisation. some redistribution of jobs may help.

f. Identifying a Monitoring body- Preferably SSAU for: Validation of diagnosis, ensuring flow of reports and periodic evaluation and data generation

g. Identifying referral units to take care of management of complications, POID, RCS and rehabilitation

h. Creation of an urban technical support team with functions similar to that of DTST.

9. Who Is to Initiate This Process?

Problems faced in a city have been enumerated on more than one occasion. But things do not seem to move and a suitable integrated model is yet to emerge. The international NGOs who are extending a lot of support to the programme in districts are probably the best hope to be the prime initiator for another attempt in some city of the state where they are coordinating the DTST teams. ■

'All the OPD cases are screened for leprosy by the Medical Officers of GHC system'

Dr. Bhandarkar
Assistant Director of Health Services (Leprosy),
Government of Maharashtra, Nagpur

Leprosy PR of Nagpur Municipal Corporation is 1.79 per 10,000 population as of 31st March 2004 and the PR ranges from 0.5 to 3.1 in the 127 Municipal wards. There are 10 Nagar Nagar Parishads in Nagpur District and in each Parishads there is a Primary Health Care (PHC) Centre or Rural Hospital (RH).

Training of GHC Staff

The Non-Medical Assistants (NMAs) – vertical leprosy workers – are engaged in IEC activities, follow-up of defaulter cases, referal of new cases for diagnosis and providing POD services. 3-day training to all the categories of GHC staff and 1-day training was given to all Medical Officers of ESIS / CGHS / Railway. 1-day refresher training to all community health workers was given. All the private medical practitioners are given one day training.

Leprosy Situation in Nagpur City

PR / 10,000 population	: 1.5
NCDR / 100,000 population	: 1.06
Child Rate	: 15.55
Deformity Rate	: NIL
MB %	: 45.30
Female %	: 46.60
Balance cases (August 2004)	: 316

Activities at Dispensary Level

The following activities are carried out by the GHC staff at the Municipal Dispensary after Integration.

- Examination of all suspects & passive surveillance for leprosy cases in OPD
- Medical Officer– Examine & confirm diagnosis and start MDT
- Pharmacist – Issue MDT drugs & maintain the stock book (working days)
- Ensure treatment regularity

Outcome of Special IEC Activity

A special IEC activity – Interpersonal Communication – was conducted during April to June 2004, when 1,70,424 people were motivated to inspect their body with the help of a mirror, or relatives have resulted in detection of 19 new cases among 58 suspected cases.

Problems

After Integration, the Doctors of Govt. Medical Colleges do not write the complete address of leprosy cases on patient cards.

Results Achieved

- ESIS /CGHS Hospitals & Private skin specialists are providing MDT services in their clinics as per GOI guidelines.
- All the OPD cases are screened for leprosy by the MOs and new cases are diagnosed & treated at the dispensary level.
- GHC workers conduct IEC activities to promote voluntary reporting. ■

Doctors of GHC do not write complete address of leprosy cases on patient cards.

'Surveys by unconventional methods will help in early case detection'

Dr. R. K. Chaurasia
District Leprosy Officer
Bhopal, Madhya Pradesh

The status of understanding about leprosy among experts and awareness about leprosy among the community in Bhopal of Madhya Pradesh State before 1987 was very undesirable. Empowerment measures initiated by DANIDA assisted National Leprosy Eradication Programme (DANLEP) have brought definite changes among the health service providers as well as among the patients and community. As a result of these innovative programmes, the following changes have been observed:

Providers of Health Services:

- Developed skills which are service oriented and patient friendly
- Job profile extended to address personal – social issues
- Developed community approach
- Integrated into community network

Leprosy Affected Persons

- They are integrated into the community
- Regained self-esteem and dignity
- Championed the cause of leprosy

People Around are Having Concerns (Community)

- Educated about the health conditions
- Changing attitude towards leprosy and patients
- Mobilized themselves to accept persons with leprosy
- Changed their normative expectations

Status of Health System in Bhopal

Medical Colleges	: 8
a) Allopathy	: 1
b) Homeopathy	: 4
3) Ayurvedic	: 1
4) Dental	: 2
Civil Hospitals	: 10
Dispensaries	: 21
Nursing homes	: >75
Private Hospitals	: >10
Private practitioners	: >300

No order of committment and lack of coordination of various government and private health sectors

Leprosy Status in Bhopal

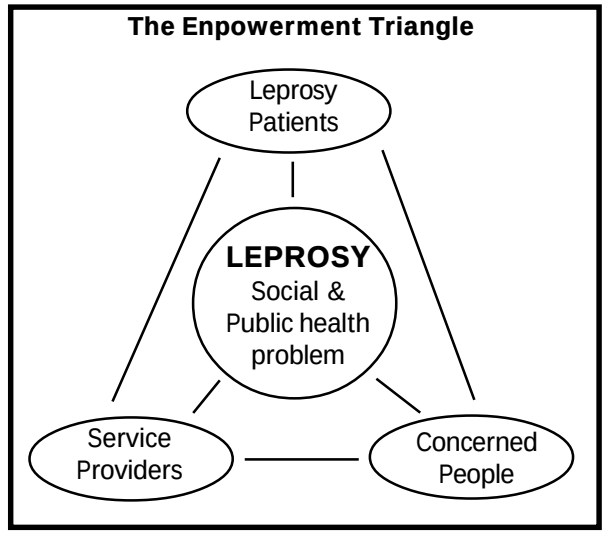
Details	'00	'01	'02	'03	'04
Pop. (lakhs)	19.4	20	20	18.3	19.8
Bal. cases	476	409	593	641	451
New cases	626	546	748	759	547
MB %	56	62	57	52	64
Child %	8.4	5.1	4.6	12	6.7
Disabled %	2	1.8	2.9	3.4	2.3
PR/10,000	2.45	2.4	2.96	3.4	2.38
NCD/10,000	3.2	2.7	3.7	4.2	2.7

Awareness About Leprosy Among the Experts and Community

Concept	Disease	Curse
Cause	Bacteria	Mysterious
Contagious?	No	Yes
Deformity	Avoidable	Infection
Curable?	Yes	No
Treatment	MDT	Segregation
Cure	Bacterial kill	Becoming normal

Innovative Activities and Benefits Obtained :

1. **New case detection** – Organized skin camps – Increase in awareness
   a. **Self survey** – Leprosy workers did house-to-house survey – Detected new cases
   b. **Screening of healthy contacts** – Leprosy worker did examination by home visits – Patient was entrusted with the responsibility of surveillance.
   c. **School surveys** – Leprosy worker examined school children – Children became aware of the signs of leprosy.
2. **MDT delivery** – Leprosy worker delivered MDT at home or at DDPs – Solidarity between community, patients and workers was reinforced.
3. **Deformity prevention and ulcer care** – Leprosy workers taught hydro-olea physiotherapy to leprosy patients with deformities – Patients gained confidence and practiced self-care regularly. Community observed touching the leprosy patients and changed their attitude.
4. **Health Education** – Promoted group interaction, Live case demonstration, experience sharing – Dependence of group learning increased. Embedded in the social and cultural fabric of the community.
5. **Community participation** – Organized Janbhagidari – Community contributed in kind and became powerful link between patient and leprosy worker.



Problems Faced While Undertaking the Above Programmes

- Absence of strong paramedical network
- Reluctance of urban population in Janbhagidari
- Development of slum area with unhygienic conditions
- No commitment from Government health sector
- No coordination between Government and NGOs
- All the health institutions are working independently
- Out of 400 health centres, only 5 are having facility for leprosy diagnosis and treatment

Suggestions to Improve the Quality of Leprosy Services

- 100% validation of all new cases
- Cleaning of registers
- Implementation of SIS
- Orientation training for all GHC staff
- Evolving regular monitoring system
- Coordination among various health institutions
- Mandatory reporting system by all Govt. & Private health sectors ■

Thane

'No uniform infrastructure or logistics for urban areas, pose problems'

Dr. S. M. Sakpal
Assistant Director of Health Services (Leprosy), Government of Maharashtra, Thane District

Thane is the fast growing industrial city in Maharashtra State, and it has a combination of both extremes of situation like: well planned cosmopolitan cities and remote tribal hilly areas. The current prevalence of leprosy is 4.25 per 10,000 population as of September 2004, which is highest in the State. The city has the largest migratory population coming from within districts, and outside the district or state in search of jobs in the construction and industrial sector.

The unique features of Thane district are:

- 2nd largest district in terms of population and urbanization
- Population growth from 1991 to 2001 – 54.8% and urban – 73.8%
- Highest migratory population from within and outside district.
- 6 Municipal Corporations and 9 Municipal Councils
- 77 Primary Health Centres; 11 Community Health Centres (Rural and Cottage Hospitals)
- 33% of PHCs are having leprosy PR > 10/10,000 populations.

Integration of Leprosy into GHC in Thane

The integration was completed in all the six Municipal corporation areas in a phased manner. Following the integration, a gradual fall in the PR was observed in all the Municipal Corporation areas except Navi Mumbai as on August 2004.

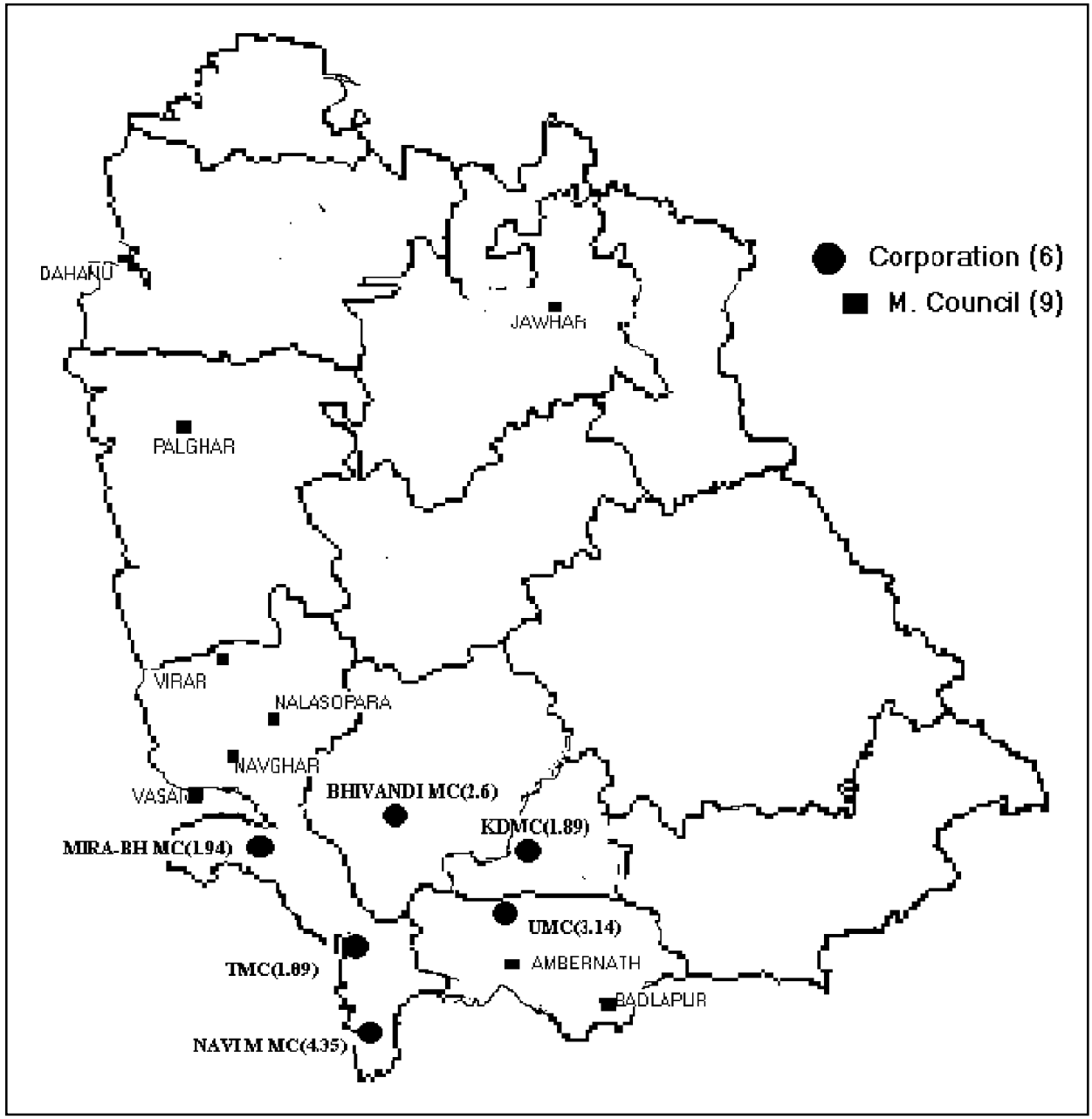
Problems after Integration

The following were the problems that were affecting the outcome of NLEP activities after Integration in Thane district.

- Shifting / excluding villages from one Corporation to other for political convenience.
- No uniform infrastructure and logistics for Urban Health Posts
- Many Municipal Councils have no health infrastructure (Out of 9, only 2 have their own infrastructure).
- A few PHCs are catering to 1-2 lakhs population instead of 30,000 as per the norms
- Non-cooperation of GHC staff (Pharmacist union)
- Frequent turnover of medical officers especially in tribal areas.
- Some resistance from the staff during the initial phase

IEC & focussed campaigns involving NGOs are needed in high endemic and difficult areas

Corporations & Municipal Councils of Thane District



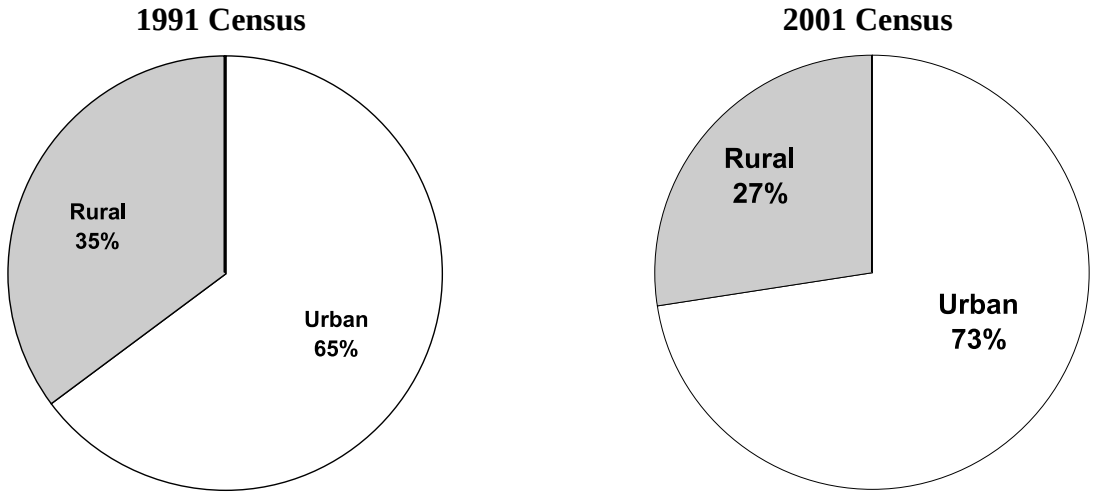
Need for Special Case Detection Activities

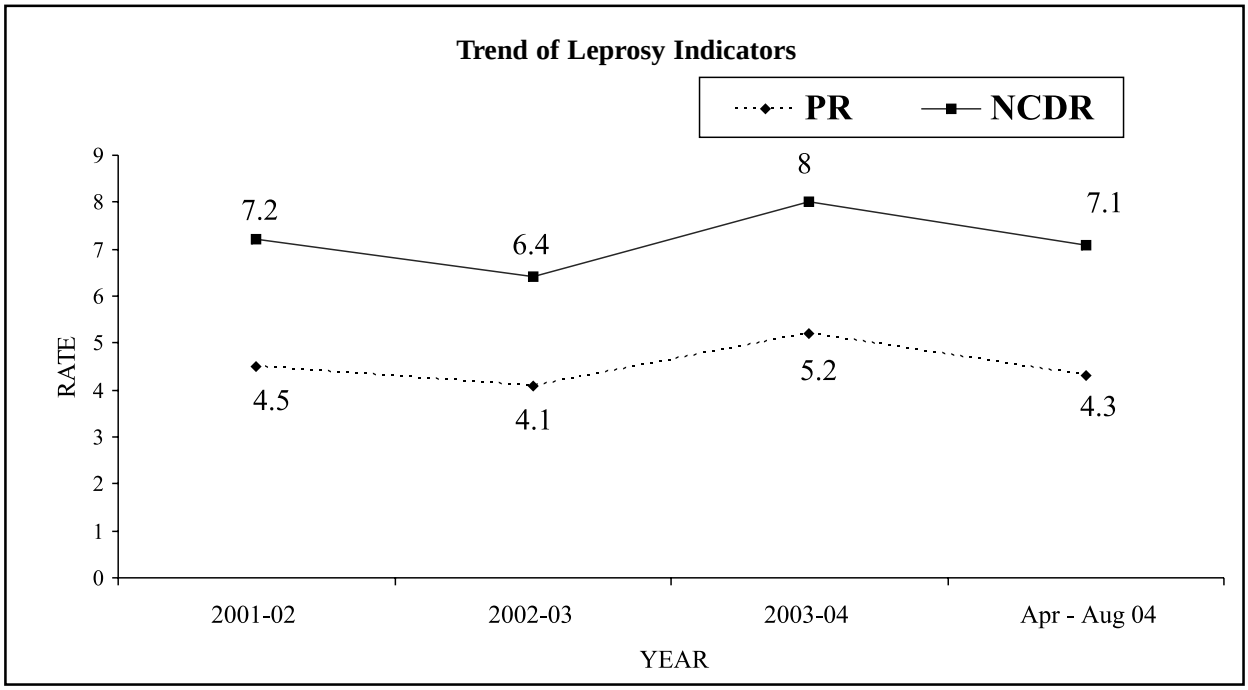
The Integration process was completed in Thane District in a phased manner, and there is a decline of PR in most areas, except areas under Navi Mumbai Corporation-The last corporation integrated. The Municipal Councils do not have out-reach staff, hence there is a need for carrying out special case detection activities like SAPEL, LEC, MLEC and VRCs. It is important to validate all the new cases detected by such special campaigns before starting the treatment to avoid over or wrong diagnosis.

Special campaigns for new case detection:

Several special activities for new case detection were carried out in the district during 2003 – 2004. All these activities revealed a high PR after the special campaigns. This shows that there are still hidden new cases of leprosy living in the community not reporting voluntarily for diagnosis and treatment.

Population : Urban vs Rural





Change in the PR before and after Integration

Corporation	Population (in lacs)	No. of UHP's	Integration completed	PR / 10,000	
				Before	After
Thane	12.62	25	April 2003	2.5	1.9
Kalyan-Dombivili	11.93	12	April 2003	2.5	1.9
Ulhasnagar	4.73	6	April 2003	4.6	2.9
Bhiwandi	5.98	12	April 2003	2.6	2.6
Mira-Bhayender	5.20	7	June 2004	1.7	1.9
Navi Mumbai	7.04	13	June 2004	3.1	4.5

Activity	Area	Population	Cases detected			PR / 10,000	
			PB	MB	Total	Before	After
SAPEL	Wada	71,417	41	9	50	10.3	17.3
LEC	Ambernath	1,34,446	53	13	66	4	7.1
MLEC	Urban (VRC)	56,79,189	105	51	156	4.5	5.6
	Rural (Survey)	25,20,743	802	226	1028	4.5	5.6
SPL. IPC	Sonawala PHC (Ambernath Block)	39.823	92	14	106	11.2	45.2
	Turbhe UHP (NMMC)	49,850	34	16	50	N.A	10
		TOTAL	1127	329	1456		

SAPEL - Special Action Programme for Elimination of Leprosy
LEC - Leprosy Elimination Campaign
MLEC - Modified Leprosy Elimination Campaign
SPL. IPC - Special Inter-Personal Communication (Special IEC drive)

Modified Leprosy Elimination Campaign (MLEC)

5th MLEC was carried out in urban (VRC) and rural (Survey – active search) areas during 6th to 12th February 2004, which has resulted in detecting 1184 new cases in the district. Following the MLEC the PR rose from 4.5 to 5.6 case per 10,000 population. Not a single leprosy case was detected through the VRCs during the MLEC in the areas of Navi Mumbai Corporation. Hence, a Special IPC Campaign was carried out in the Turbhe slum areas and detected 50 new leprosy cases within 4 days of the special IPC campaign (16th to 20th March 2004). Out of 1184 new cases, 538 (45.4%) cases were validated by State and District Teams. 4.3% cases were found to be invalid cases.

In addition to the above MLEC all cases detected in SAPEL (50 cases), LEC (60 cases) and special IPC (156 cases) were registered only after validation by the District Team.

Validation of new cases detected during MLEC:

Number of new cases detected	:	1184	
Homes visited for validation	:	1010	(85%)
Number of cases validated	:	538	(45.4%)
a. Wrong diagnosis	:	9	(1.6%)
b. Re-registration	:	5	(0.9%)
c. Misclassified	:	10	(1.8%)

Suggested actions

In order to strengthen the urban health infrastructure, activities like organizing **massive IEC activities** with the help of new projects such as IDSP (Integrated Disease Surveillance Programme) and RCH - Phase II to be carried out on par with other health programmes (Pulse polio & HIV/AIDS), intensify case detection through IEC and IPC, **focused campaigns in high endemic and difficult areas and involving all NGO**s in IEC, training and rehabilitation will help to sustain the efforts of integration. Let us join hands for elimination of leprosy in Thane district. ■

Kanpur

'Leprosy services are confined only to MDT distribution after Integration'

Dr. R.P. Mall
Epidemiologist, Sample, Survey & Assessment Unit, (SSAU)
Government of Uttar Pradesh

Case card of all leprosy patients must have full address of house and work place as well as the type of job.

In Kanpur, leprosy treatment was delivered through DDP services before Integration. The services at DDP centres were available only for a short period and it perpetuated stigma as the persons are identified as a case of leprosy. The programme was fully dependent on vehicles for mobility. After Integration, the time for which the leprosy services are available to the leprosy patients has increased but compliance is very poor. Most leprosy patients prefer to go to a general hospital and there is also less dependence on the vertical staff. The profile of the Kanpur district is as follows:

Population : 42 lakhs
Urban : 27 lakhs
Rural : 15 lakhs
Density: : 1074 per Sq. Kms
Area: : 3030 Sq. Kms
Literacy Rate : 77.6%

Problems

The problems faced after integration consist of both administrative and technical issues:

a. Administrative

- Migration within the city
- Uneven distribution of health facilities.
- Non cooperation by the GHC staff
- More stigma in urban areas
- Functional integration is not achieved.
- Lack of coordination with other government health sector

b. Technical

- High % of over-diagnosis (Child cases).
- Non-adherent to guidelines (new case).
- Drug delivery system is unsatisfactory.
- Treatment confined only to MDT distribution.
- Provision of physiotherapy service is poor.
- Poor follow-up due to other health priorities.

Solutions

The strategy focused mainly on migratory patients and advocated Accompanied MDT (A-MDT) to ensure treatment compliance. It has been suggested to include the occupation and address of the patient, both residence and working place, in the Patient Card, and to consult the patient to inform the health facility before migration. Other strategies that were practiced for the success of Integration in urban project, Kanpur are (i) Sensitization of GHC staff, District Administrative staff and the local municipal corporators; (ii) Training of Medical Officers, Paramedical staff, Anganwadi workers including Scouts and Civil Defense staff; (iii) Wide publicity about the availability of MDT services including on holidays and (iv) Monitoring the progress of NLEP by the Urban Leprosy Committee. ■

'Team work between the NGO and the Government during the Integration phase is the key for success'

Dr. S. Srikanth
Specialist, Community Health Department
Schiffelin Leprosy Research & Training Centre, Karigiri, Tamil Nadu

Urban health staff showed great enthusiasm and interest in learning about leprosy and also suspected a few new leprosy cases

An **URBAN LEPROSY ELIMINATION PROGRAM (ULEP)** was implemented in Vellore district of Tamil Nadu with the objective to work in partnership with the Govt. of Tamil Nadu in facilitating establishment of sustainable leprosy elimination services in urban areas of Tamil Nadu. SLRTC, Karigiri has been selected as a Nodal Agency and facilitated this project. The components of this project are:

- Capacity Building of all urban health staff
- IEC in all the areas of the Municipalities
- Establishing MDT centers in the Municipalities to make MDT more accessible to the patients in urban areas

Population : 35,00,000
No. of Municipalities : 9
Urban Population : 14,00,000 (40%)

One-day training programme was organized for all the following stakeholders and all categories of health staff. The methodology used was Lecture, Case Demonstration and Evaluation – pre and post test.

Stakeholders: Municipality Chairman / Councilors; Maternity Staff; Sanitary Staff

ICDS Staff; Noon Meal Organizers; Municipality School Headmasters / Teachers; NSS / NCC Students; Rotary Clubs & other NGOs; Ward Task Force Members; Local Volunteers & Self Help Groups & Factory Workers

The Case Detection activities were carried out through organizing medical camps in the wards, slums and factories, School Health Check-ups and voluntary reporting of the patients. Sensitization meetings were held in the Municipalities to create awareness among the Municipal Commissioner, Chairman, ward councillors etc. and other stakeholders like local NGOs and Govt. Hospital staff.

Awareness Programmes

A cultural troupe trained in leprosy is being used to create awareness among the public through street plays. Awareness campaigns were also organized using

- Handbills / Bit Notices
- Cable TV
- Theatres
- School Rallies & Prayer Meetings

- Banners
- Public Slide Shows
- Advertisement on the Walls
- Propaganda through Autos

Strengthening the MDT Services in GHC System

All the health posts in the municipalities have been identified and supplied with sufficient quantity of MDT drugs. Supportive supervision of the urban health staff in record keeping of leprosy cases / suspects was carried out.

Experiences and Problems

It's a new experience – working with the urban health and municipal staff. There are no municipal health officers in eight out of the nine municipalities. Urban health staff, though new to leprosy, showed great enthusiasm and interest in learning about the disease and participating in the program. In fact some of them have identified a few new cases and suspected cases. Municipal Chairman & Councillors were fairly co-operative. The NGO has to ascertain that all the urban health staff should undergo capacity building. NGOs must dispense all their expertise and the infrastructure for strengthening the process of Integration. Supportive supervision along with in-service training (coaching) is important. The Urban community is still not aware about leprosy services in municipal health posts and Govt. hospitals.

Role of NGOs in Integration

There should be team work between the NGO (playing the facilitator role) and the Governmnet (playing the technical role) during the Integration phase. A joint ATP between the Government and the NGO working in the respective area is a must for implementing any programme. It is also important to review the activities through monthly review meetings of all the stakeholders and suggest improvements.

Possible Solutions

Possibility of DOTS centers as MDT centers can be considered**.** A lot of groundwork had to be done to arrange for the sensitization meetings in the municipalities and the IEC programs in the wards. Sometimes there were delays in fixing up of the programs due to different activities in the municipalities – routine and special. The ideal time to meet all the councillors is on the day of their council meeting. Joint planning of the action plan between the stake holders, especially nodal agency and Govt., is very critical to the success and sustainability of the program. Supervision of the health posts should be carried out periodically. Street play programs and screening camps cannot be conducted in all the wards in the municipalities. Instead a media which can cover a vast population can be used to disseminate the messages on leprosy, and it has to be a continuous process. ■

Cultural troupe training

Street play

Session - III

Chairman: Dr GPS Dhillon, Dy. DGHS (Leprosy), GOI, New Delhi
Co-Chairman: Dr R Ganapati, Director, Bombay Leprosy Project, Mumbai

Panel Members: **Dr Koparde,** Municipal Corporation of Greater Mumbai
Mr Uday Thakar, Hon. Secretary, Kushtrog Nivaran Samiti, Panvel
Dr SC Gupta, Jt. Director of Health Services (Leprosy), Pune
Dr WS Bhatki, Secretary, ALH RRE Society, Mumbai
Dr Anil Kumar, Asst Director, JALMA, Agra
Dr S Srikanth, Specialist, SLRTC, Karigiri, Tamil Nadu

Dr R Ganapati: Strengthening of integration has begun. From all the presentations, it is clear that the problem is still more in Kolkata and Chennai. Delhi seems to do well. In Mumbai, we are happy in one sense and of course the problems related to POD, patients care and field monitoring is yet to be strengthened. So far the integration in Mumbai has achieved diagnosing leprosy cases and distribution of MDT, but not the treatment of complications. I think in Mumbai, it seems that we are in the right direction.

Dr WS Bhatki: In regard to the process of integration of the leprosy programme with the General Health Services, i.e. Municipal Corporation of Greater Mumbai (MCGM). I would say, as far as the official order is concerned, a communication has been sent to all the authorities in MCGM. One senior authority, the Assistant Municipal Commissioner of MCGM who is in charge of the health programmes in Mumbai has already briefed all the municipal health authorities and sensitized the policy makers about the integration. This includes Joint Municipal Commissioner, Executive Health Officer, Assistant Health Officers and Medical Officers of MCGM, who are the administrators of health programmes in Mumbai, and all of them have accepted integration. The Medical Officers of Municipal dispensary and Health Posts are doing well but the experience is very limited as Integration has started just a couple of months ago (July 2004). Now the situation is, I would say, the existing NGLOs are reluctant to leave the responsibility of the leprosy programme. However this is now achieved and we do not know whether 100% of the programme has been taken over by the general health care staff. There are several elements like trade unions are posing hurdles, and at least the Medical Officers have accepted as this may not be a problem for them to

deal the less number of leprosy cases in each health centre. At the paramedical level, who are ultimately going to treat the leprosy cases and prepare reports, there is a 'fuss' among them due to unions. Yet this is not uniform all over Mumbai and observed only in some wards, and in the rest of the wards, Integration is going on smoothly. It has been our experience that whenever any new programme is introduced, there is some resistance from the staff. This was the case even when RNTCP was introduced and now they are doing well. Probably this is the style of working, by showing initial reluctance and gradually taking over.

Dr Koparde: There is some aprehension that some NGOs are not willing to part with their responsibility and some Health Posts are not willing to take up the responsibility. We also had a meeting with the representatives of the union and their grievance is that we have not taken into confidence. This is to be tackled gradually and there is an element of ego. They agree scientifically but still consider this as extra work. Now we are calling for a meeting of the Health Post staff to give a message that this is not a work burden or a risky job. About the infrastructure, there are 163 Municipal dispensaries and 168 Health Posts under MCGM. About the manpower, there are about 300 Medical Officers, 1500 paramedical workers and 3,400 Community Health Volunteers working with MCGM. I only wish the timely induction of these work forces will help to achieve the Integration of leprosy programme in Bombay. The problem is most of the Medical Officers are not sensitized or oriented about leprosy and now we are planning a 2-day training programme for all the Medical Officers with the help of ALERT-INDIA.

Dr PK Ommen: Integration is a fact we have to accept and it is going to happen and we have to achieve somehow or the other. As Dr Anil Kumar presented, he got down to the actual baseline of the ground reality in Agra city. I have been training lot of doctors and paramedical workers and the unfortunate thing is a good number of doctors refuse to touch and examine the patients, which results in over or under diagnosis. About the Simplified Information System (SIS), it is too simple and we do not record grade 2 disabilities. **We want to see that we should identify the grade 1 disability and see to that they do not get grade 2 disability.**

Dr GPS Dhillon: Interation is not possible and now the problem is whether it will change by itself or we need to enforce it so that we can proceed. It is to be done for the benefit of the public and the leprosy patients. It has two major advantages. First is the patient will have more access to the treatment and secondly the stigma will get reduced. Similarly, the first priority is to identify and treat grade 2 patients and then grade 1 patients. We have reduced the grade 2 patients from 9% to 5.2%. We have to reduce the grade 1 also and that is the next step.

Dr V V Dongre: Integration is a fact we all have to accept. But the misconception about leprosy is still prevailing and the doctors are not ready to even touch the patients or palpate their nerves. The syllabus on leprosy in the medical curriculum is insufficient and leprosy is not a priority for the current generation of medical students. There is a need to change the syllabus/curriculum on leprosy for medical students in the context of integration of leprosy with GHS. Involvement of other systems of medicines will be helpful for the leprosy programme. Therefore somehow or the other we must inculcate interest about leprosy among medicos because they are the budding doctors, and the general medical practitioners are the pivot for every programme which we are undertaking.

Dr SC Gupta: Even Indian Medical Association, Medical Council of India at the central, labour officers, ESIS and multiple agencies and authorities need to be approached and educated. Concepts and strategies mentioned in books like FOCUS & TASK TODAY (Published by ALERT-INDIA) can be followed by anyone in the country.

Dr Bhushan Kumar: As leprosy people, we are all committed to the cause of leprosy. Now the problem is we are involving and transferring the programme to other health people who have to be our successors.

Dr GPS Dhillon: DTST is not only for rural areas but also for urban areas, and ILEP agencies must come forward to extend DTST services to urban areas.

Dr R Ganapati: Has any order from the Government has been issued to the Municipal Authorities of Kolkata regarding Integration?

Dr GPS Dhillon: Integration in Delhi is not by an Order of any Authority, but in Kolkata, Integration has started by an order from the Authority.

Mr Sudhakar Bandyopadhyay: The local authorities (KMC) did not accept the Order as the ruling party is different from the one ruling in Centre.

Dr GPS Dhillon: From the reports of 12 cities in India presented, it seems that services are not still reaching the patients, particularly in cities like Agra. There should not be euphoria regarding elimination.

Mr Uday Thakar: The Government of India has recently revised the grant-in-aid structure for the NGOs and this was announced during the NGO Conference held at Raipur. This is a welcome step and will benefit institutions like Kushtrog Nivaran Samiti, Shantivan.

Mr Sudhakar Bandyopadhyay: The grant-in-aid sanctioned for a PMW is Rs.1,800, which is insufficient. POD parameters for grant-in-aid are applied in rural areas but not in urban areas. This disparity needs to be corrected.

Dr GPS Dhillon: General Medical practitioners must be made aware that MDT will be made available to them, provided they follow WHO regimens.

Dr Anil Kumar: New case detection activities must be continued even during the Integration phase.

Dr GPS Dhillon: During intensive focal surveys and following IEC activities, the number of new cases is bound to increase. There is a need to redefine integration and understand its right perspective.

Concluding Remarks by Mr. A. Antony Samy:
Integration is a positive public health measure – but hasty steps have given discouraging results. Time is not yet ripened for integration, in terms of preparedness and capacity of GHC system.

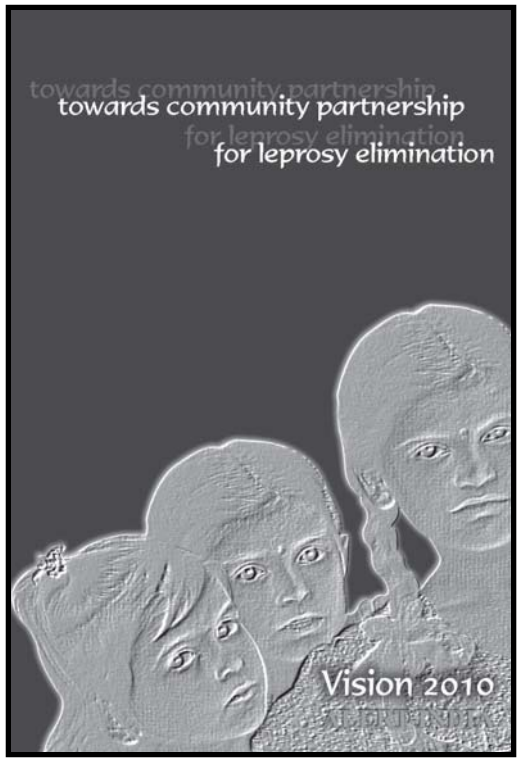
The mental attitude of the vertical staff to give up routine leprosy work is not positive and the preparedness of public health staff to accept leprosy work is not encouraging.

The NGLOs feel that they have no work to perform, whereas the horizontal staff feel that they are over-burdened because of leprosy work.

NGLOs need to find all means to strengthen Integration and sustain quality care for leprosy patients.

- Vote of thanks was proposed by Mr. A. Antony Samy. ■

The Government of India has proposed to integrate leprosy services with the general health services. As we take steps towards integration, there is need to transfer the wealth of expertise gained by leprosy workers to the general health personnel. These publications of ALERT–INDIA are aimed to fulfill this objective. Several aspects of leprosy control are discussed in addition to a proposal for LEAP (Leprosy Elimination Action Programme) in these publications.

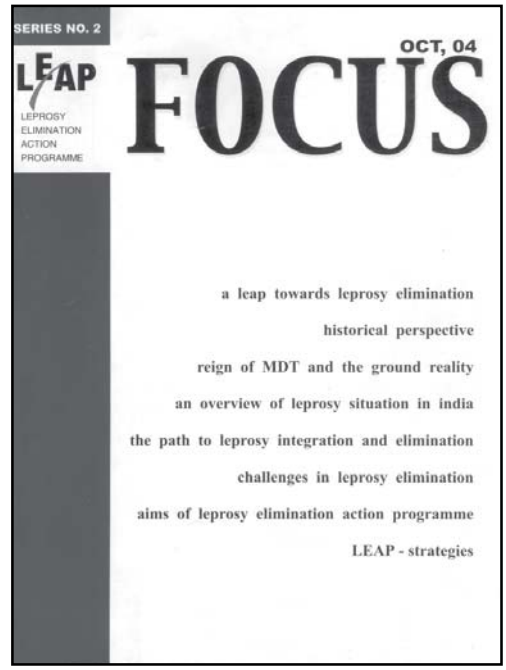


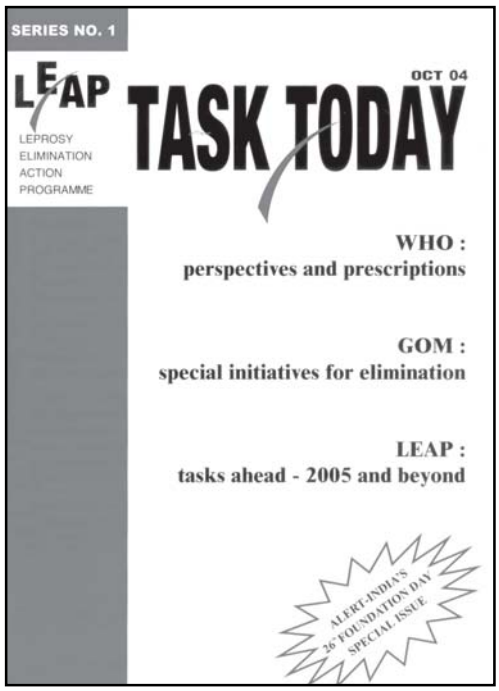
VISION 2010

The first chapter presents an overview of the leprosy elimination strategies with special reference to urban situations. The second chapter outlines a consolidated account of ALERT–INDIA's achievement over the past 25 years of leprosy control work. Experience of ALERT–INDIA's community health programmes is described in the third chapter. The fourth chapter is a synopsis of recommendations for leprosy work during integraion. The fifth chapter is a summary of ALERT–INDIA's vision to strengthen integration to achieve the goal of leprosy elimination.

FOCUS - Series No.2, October 2004

This issue presents a logical framework and strategy of Leprosy Elimination Action Programme (LEAP) proposed by ALERT INDIA. A brief note on the histrorical aspect of leprosy and the MDT era is also discussed. Achievements of NLEP and the major challenges in leprosy elimination is discussed and strategies needed for the future is summarised. It also includes an overview of the leprosy situation in India with recent statistics from different states and districts in Maharashtra.





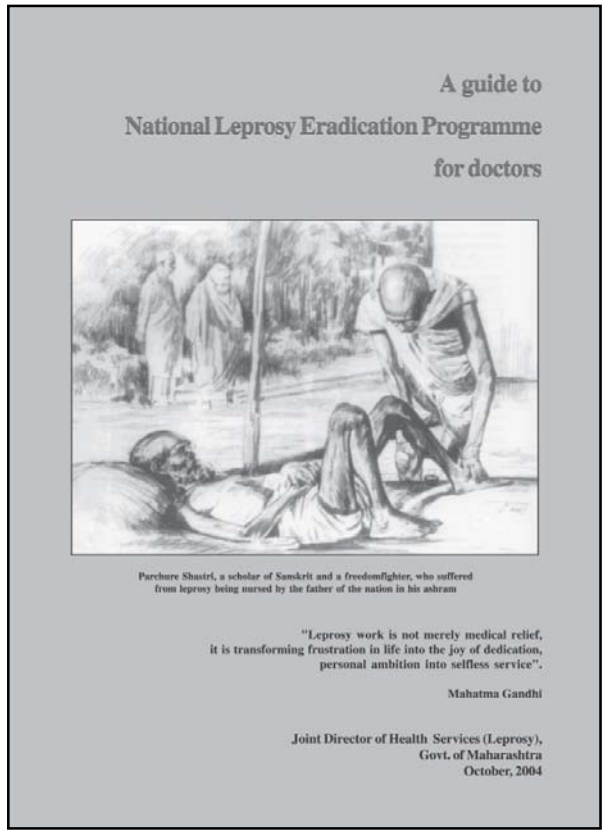
TASK TODAY - Series No.1, October 2004

This special issue outlines the need for a new strategy to achieve leprosy elimination during the Intergration phase. It also reviews references to elimination strategies adopted by WHO, GOI and other agencies in the past. LEAP is proposed as a strategy for the integration phase. The role of NGLOs during the Integration phase is spelled out. The LEAP goals and proposal for action are detailed.

Views by Dr SC Gupta, JDHS (Leprosy), GOM, Pune:

The 3 publications of ALERT-INDIA released today are very informative and specific, particularly the FOCUS series. I must appreciate the team who compiled such useful information and presented in a nutshell and I complement all of them. The Task Today gives the realities and very important references, which may be relevant to the current situation. The vision document gives an account of ALERT's experience.

I am editing a booklet titled "A Guide to NLEP for doctors" for the use of Medical colleges, which will be published by ALERT INDIA. That booklet will be distributed to all Medical Colleges in Maharashtra.



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Session-I : *Panelist [L to R] Dr. Sadulwar, Dr. R. K. Chaurasia, Dr. P. K. Oommen, Dr. P. Krishnamoorthy (Chairman), Dr. R. P. Mall (Co-Chairman) and Dr. D. Porichha*

Session-II : *Panelist [L to R] Dr. T. irubakaran, Mr. Sudhakar Bandyopadhyay, Dr. B.K. Girdhar (Chairman) and Dr. Bhushan Kumar (Co-Chairman)*

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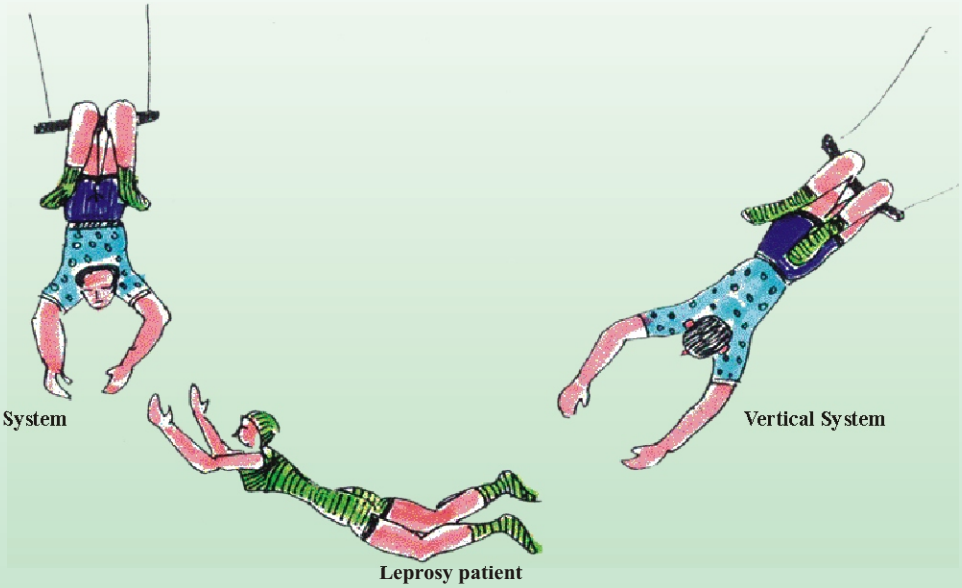
Integration Scenario Today



"Leprosy paitent transferred from the vertical system
is yet to be received by GHC system"

Cartoon courtesy : Dr Kirubakaran, GLRA, Chennai

LEAP
LEPROSY
ELIMINATION
ACTION
PROGRAMME

ALERT-INDIA
strives towards
programme focussing on
community partnership strategies
to achieve the goal of leprosy elimination
during the Integration Phase,
in partnership with all stakeholders,
to make elimination a reality for people.

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