Is integration a leap forward?

Implications of integration on quality care in leprosy

ALERT - INDIA

28th Foundation Day

Commemorative National Workshop

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National Workshop

on

Is integration a leap forward ?

Implications of integration on quality care in leprosy

LEAP
LEPROSY
ELIMINATION
ACTION
PROGRAMME

ALERT-INDIA

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Purpose

ALERT-INDIA has been organising national level deliberation under LEAP on issues that concern leprosy control work - mainly policy related issues to programme implementation. This workshop on ***"Is integration a leap forward? Implications of integration on quality care in leprosy"*** is third in the series.

The purpose was four fold:

The *first* and foremost purpose of this workshop was to counter *the public perception* that leprosy has cease to be a problem in our country following the Government of India's announcement of leprosy elimination in our country.

The *second* purpose is to examine *our own perception* - the perception of leprosy organisations on the programme needs.

The *third* purpose was to understand *the real situation of the integrated setting and the tasks* needed to strengthen integration.

The *fourth* purpose is to share the views and experiences and *to reach a consensus on the perspective for leprosy work beyond 2007* in response to the needs and the problems faced by the leprosy affected persons today.

A. Antony Samy,
Chief Executive,
ALERT - INDIA

Is integration a leap forward? Implication of integration on quality care in leprosy

Dr. K. V. Desikan
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(Read by Dr. V. V. Dongre)

Prelude

I thank the organizers of this Workshop for inviting me to participate in this meeting and for providing me the opportunity to discuss with members of this august audience a big challenge before us. Let me take up the challenge first.

The Challenge

The theme of this workshop is an extremely important subject – a burning issue drawing the attention of every one involved in leprosy work. Two words are top most in the minds of health providers – "Elimination and Integration". We are gathered here to discuss the two challenges. At the end of the day, we hope to get a better understanding of the challenge and consider the strategies to combat it. Today's subject has two aspects. The first is whether integration is a leap forward. Secondly what are the implications in quality care in leprosy? I wish to deal with these two aspects separately.

Is it a LEAP forward ?

We should consider whether integration is a leap forward or a leap backward or no leap at all. To discuss about it, I would like to go back to the old days when it was first considered to take up leprosy work as a public health problem against the then practice of sheltering the patients in asylums. The real solution to control the disease was to take it as a public health problem and this had to be done. I am the best person to talk about it because we were the first to put up a field trial of control of leprosy way back in 1952 under Gandhi Memorial Leprosy Foundation. Subsequently, the government of India adopted it. Those were the days when leprosy was considered a curse, the disease greatly feared, and the patients abhorred and ostracized. To deal with the disease as a public health programme, we had to go into the community to trace and treat the patients. I was the first person to take the risk and intrude into the privacy of each home to carry out house-to house survey. Using paramedical workers, we developed model control units, which became the basis for NLEP. The NELP had to become a vertical programme because of the severe prejudice against the disease.

I must mention here that the persons to be blamed most were the doctors. There was tremendous discrimination against leprosy patients. The leprosy patients were not allowed an entry into a general dispensaries or hospitals, let alone their being examined for any general ailments. I would go to the extent of saying that some doctors were actually propagating this fear and prejudice. The best example was in this very city at the Acworth Leprosy Hospital where the leprosy patients were subjected to severe restrictions by the leprophobic doctors. I can give any number of examples of ill treatment of leprosy patients by doctors. Some hospitals however, accepted leprosy patients, but they were isolated in a remote corner with no nursing and no specialized treatment. Under the circumstances, the NLEP took up the work as a vertical programme, involving several NGO's. The Government did an excellent job. All the endemic districts were covered by leprosy control units and SET centres with active case detection, treatment and follow up of patients.Results were very encouraging. While all this was going on, we always considered integration. It was our dream in those days that leprosy patients should one day be able to sit with patients of other diseases in a general hospital and avail treatment in any medical specialty. We often considered the possibilities. In fact, once we had a symposium on integration in CLTRI, Chingleput. There were serious discussions in its favour, but we realised that it was not possible in those days. Apart from the prejudice in the society and in the medical profession, the numbers were huge. Many of the endemic districts had a prevalence of more than 50 per thousand (or 500/10000). In the village

where I was working in Andhra Pradesh, we had 15000 patients in our register! In the village where I was living, there were 250 patients in a population of 3000; that means one in every 12 persons was a leprosy patient. Imagine patients from 10 such villages attending a PHC!!

In view of the above constraints, vertical programme was the only solution. It was certainly amounting to discrimination, but the patients were receiving good treatment, and the prevalence was coming down. Now the day has come to introduce integration. Is it not a leap forward?

Surely a LEAP forward

There has been a total change as far as leprosy is concerned, thanks to the effective vertical programme. The numbers have fallen by over 90%. The stigma against leprosy is very much reduced. Doctors are enlightened and willing to treat leprosy in their clinics. Even the pattern of leprosy has changed. More than all, the political will which was the real strength behind the NLEP, continues with equal zeal. Integration at this stage is definitely a leap forward. Basically, the leprosy patients can maintain their self respect and feel that they are not victims of an accursed disease. At the general hospitals, they can get treatment not only for leprosy but also for any other ailment from a concerned specialist. It encourages self reporting so that early cases will have no inhibition to seek treatment. What we old workers had dreamed in the past has been realised.

Implications on quality care

Any strategy would have some implications when applied and executed. Integration would also have its short comings. It is necessary to recognize these short comings and try to correct them to the extent possible. With regard to integration, there are general implications and also those specifically against leprosy elimination.

General Implication

1. With integration, active case finding by house-to-house survey is stopped. Although I started such a survey and was a strong protagonist of it, I am now fully convinced that it has to be stopped. People should recognize their problems and come out on their own. We have done enough to cajole them. However, health education and IEC activities should continue about leprosy along with other communicable disease.
2. Under the vertical programme, the patients received a greater attention with regard to care and treatment. The quality of care is bound to come down under integration. It cannot be avoided and some compromise would be necessary.
3. On technical grounds, the general practitioner might face difficulties in diagnosis of doubtful cases. Also the support of skin smear examination is not available. Management of severe reactions might pose problems. The solution for all these would be to provide referral services in each district.

Implications in Context of Elimination

If statistics are true and reliable, the official figures present a rosy picture. On country level, the PR on 31-03-2006 has been declared as 0.84/10,000. Further details are: a) 5 major states have achieved state level and district level elimination. They include Andhra Pradesh and Tamil Nadu. b) 5 major states have achieved state level elimination but not at district level. They include Maharashtra, MP & Gujarat. c) 6 major states are still to achieve even state level elimination. They are Bihar, UP, West Bengal, Orissa, Chattisgarh and Jharkhand. A real elimination would be achieved if it is brought down to the block level. It is obvious from the above data that is there a lot of work to be done to achieve a true elimination. If the general instructions given by the Government of India are truly followed, there is certainly a possibility of achieving true elimination. Unfortunately, certain dubious methods are being followed at the district level due to pressure inflicted unofficially by the higher authorities for political reasons. When genuinely new cases are detected or referred, they are not registered for treatment because the PR will go high. This is unethical and against national interest. The PR of 1/10,000 is an arbitrary figure.

What harm is there if the PR oscillates slightly above or below that magic figure? In order to maintain the sanctity of that figure the patients are denied treatment. The implication is that the infectious cases would continue to spread the disease and elimination will be reversed. What the government should concern is truth and health of the community and not undue publicity.

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A perspective for leprosy work beyond 2007

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

ALERT-INDIA has been organising national level deliberation under LEAP on issues that concern leprosy control work - mainly policy related issues to programme implementation. This workshop on *"Is integration a leap forward? Implications of integration on quality care in leprosy"* is third in the series. The purpose was fourfold:

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The *fourth* purpose is to share the views and experiences and *to reach a consensus on the perspective for leprosy work beyond 2007* in response to the needs and the problems faced by the leprosy affected persons today.

Firstly, the public perception . . . .

The widespread public opinion is that leprosy is no more a public health problem in our country. There is no need for continuation of leprosy services or specialized leprosy agencies / programme interventions. As a result, the public support is also dwindling.

We have taken a futuristic step by integrating leprosy into public health care system. At present, leprosy is expected to be treated on par with other diseases. The integration is the new weapon in our hands to change the exclusive leprosy services perpetuated by the vertical system for more than five decades. This is also aimed to helps to combat the social stigma.

Today, the leprosy control work needs greater community involvement as the responsibility lies entirely with them for seeking treatment voluntarily. It is a fact that only a well informed and educated community can take advantage of integration. But, equal access to leprosy services is the basic rights of all patients.

Mobilizing strong community support will promote social assimilation of the leprosy affected persons. This is a long drawn task; nevertheless it has to be consistently attempted, if we have to successfully conquer the disease.

The fight against leprosy is far from over. Leprosy continues to affect people, as it has been, all through the centuries. It continues to infect, incubate and manifest in the same way. The status of environmental hygiene and health care has not improved for majority of our people. Yet, the number of new cases has reduced drastically.

The intermediate goal of leprosy elimination, i.e. 1 case in 10,000 population, set by WHO is achieved nationally and not at sub-national level – as we still

** These highlights can be found discussed in detail : Lockwood DNJ and Suneetha S, "Leprosy: too complex a disease for a simple elimination paradigm", Public Health Reviews, Bulletin of the WHO, March 2005, 83 (3), 230-235*

have endemic districts and blocks. The numbers cannot represent the actual situation on the ground. Considering the total population of India, we still have approximately one lakh leprosy cases registered for treatment at this point of time.

The leprosy 'elimination' does not mean leprosy 'eradication', like small pox eradication, which meant an end of infection in the community. The new cases continue to occur and there is no evidence that transmission is curtailed or the disease is confined to specific geographical locations or population groups.

The public is unaware of the fact that leprosy infection still prevails even after achieving 'elimination' and greatly influenced by the statements that appear in the media. The perception of the public about the disease needs to be changed positively. Building the community support should be the cornerstone for our leprosy control work and there is no alternative to this.

Secondly, our own perception . . . .

Following integration, we – the non-governmental leprosy organizations (NGLOs), both national and international and the Govt. (both local and at central level) – are inclined to believe that the primary focus of our work for the past five decades has reached its culmination by achieving the intermediate goal of leprosy elimination i.e 1 case in 10,000 population. This perception is shortsighted and reflects in our policy formulations and programme priorities.

We promptly seem to have accepted that, after integration, all forms of new case detection activities should come to a halt. The community, which we have been repeatedly tracking for several decades, to unearth new cases of leprosy, is expected to understand its role and become conscious and responsible for reporting voluntarily.

If this were to happen, the entire society would have to become leprosy conscious and we would have been in a much comfortable situation today.

Unfortunately, even today, it is a fact that more and more new cases are detected early only when special drives coupled with target specific intensive education programmes are undertaken. We cannot rely on the decades of our good work under vertical set-up and expect the results – specifically voluntary reporting of all new cases at an early stage – in the new policy framework of integration. However the current programme objectives cannot be changed drastically today.

We will be in no way justified to let the leprosy patient reach us only when they realize the need for diagnosis and treatment. The consequences of these are well known to us. We also have a large number of backlog leprosy cases who need sustained care. Leprosy patient remains undetected until deformity sets in and a proportion of them spread the disease in the community.

Let us not ignore the warnings from the concerned epidemiologists and leprologists*.

- Leprosy is slowly declining but the rate of decline remains uncertain and a sustained leprosy control effort is required.
- Patients newly diagnosed may have transmitted the disease to others in their family or community long before their disease is detected.
- NGOs have previously worked with vertical programme need to define new roles for themselves within the framework of an integrated setting.
- It is vital to maintain continuing case detection, providing treatment and meeting the long-term challenge of preventing disability activities.
- Finally, special surveillance areas should be set-

up in regions where integration has occurred; these areas should use active case finding so that an accurate picture of key indicators is maintained.

Hence, are we not duty bound to promote interventions in the integrated setting to detect all hidden leprosy cases, while continuing awareness efforts at the community level? We believe that both these efforts are needed simultaneously in addition to providing quality care to those already affected by the disease. Only if we accept these facts of the real situation, we will look for appropriate programme interventions.

Thirdly, understanding the real situation of the integrated setting and the tasks . . . .

The general health care system, which we kept at arms length for decades, is now asked to take up tasks of leprosy and manage effectively.

In Government sector, the leprosy staff have been inducted as multipurpose workers and engaged more in other public health priorities like Polio, Malaria, Dengue, Chicungnia that have become their main priorities.

Justifiably so, leprosy does not kill. The medical professionals in the general health care system who had the shortest orientation and exposure to leprosy are called upon to acquire clinical acumen in short time.

The magic wand of integration cannot turn the public health staff as fully leprosy oriented and made to care for the leprosy patients amidst their other health priorities. All this is expected to happen with very little input from us – the vertical leprosy agencies.

In short, we have consigned leprosy patients to equal advantages or disadvantages that exist in public health system on par with other ailments. Can this anyway help us to achieve the long-term goal of leprosy eradication?

On the other hand, the NGO sector is busy in learning and implementing RNTCP and AIDS control in order to gainfully deploy leprosy trained staff. Re-training, re-orienting and redeploying all the expertise available today (the leprosy workers and medical doctors) at the service of leprosy related tasks is declining.

The major tasks related to continuing medical education (CME), training community health volunteers, appropriate IEC campaigns, special interventions that can detect hidden cases and sustaining quality care to all leprosy affected persons need resources.

Today the policy is guided more by the available resources than the need of the programme. The worker and the patient ratio have considerably reduced, but the reduced numbers of patients are expected to be reached by the vast network of public health personnel. Who will guide the patients to reach them?

Let us not declare ourselves redundant, well before the public health system makes us so.

Integration needs more specialized inputs and interventions to become viable and an alternative to the vertical programme. The Disability Prevention and Medical Rehabilitation (DPMR) programme proposed by the GOI supported by ILEP is only a part of the answer.

Surgery and POD camps are not an answer without pre and post operative care by trained physiotherapist. Surgeons do have a role, but all surgeons will agree that care after surgery is as important as the surgery by itself.

The question that arises here is; do we have a planned programmes, personnel and resources needed to help the general health care system; to train and equip the medical fraternity; to fulfill the special clinical needs of the patients with reactions, nerve involvement and

the deformities of – old and new patients? This calls for a practical intervention strategy that support integration and sustain quality care during the integration phase.

Fourthly, the need to reach a consensus on the perspective for leprosy work beyond 2007 . . . .

Today, we have a consensus for the global strategy proposed by WHO by collective action to sustain the leprosy control work. This is accepted and promoted by all international leprosy relief agencies. We have a general purpose and a clear direction in the strategy document. It is essential that we have a common programme for action.

Leprosy Elimination Action Programme (LEAP), promoted by ALERT-INDIA during integration phase, is a planned transition from the predominance of vertical leprosy programme to an action programme for the integration phase, focusing on community partnership strategies.

The objective of LEAP is to meet all the need of leprosy affected persons by utilizing the best potentials available today with the NLEP and dovetail with the services and facilities in the public health system through a partnership approach.

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

This sets the future direction of leprosy control work. Our experiences of past two years are briefly presented in the activity report to be released today. However, all of us have our own experience behind us as we discuss the theme of the Workshop today.

The purpose of the today's Workshop is to reflect our own experiences in our real situations and make suggestions on the future strategy for our country. I call upon every one of you to be specific to the reality of the situation in your region focusing on the **policy directives and programme implementation from the disease and patient point of view,** while answering the questions raised during the Workshop deliberations. Hope we can attempt to make consensus statement at this Workshop!

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Is integration a leap forward?

Dr. P. K. Krishnamurthy
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Chennai, Tamil Nadu

Integration: layman's term:

- The act or process of combining two or more things so that they work together
- Combining one thing with another to form a whole
- Intermixing of things which were previously segregated

Integration: programme concept:

- Brings together inputs, organisation, management and delivery of particular service functions
- Brings together common functions within and between organisations and uses common technologies and resources to achieve shared vision and goals.
- To improve efficiency and quality of service provision
- To provide optimum level of care

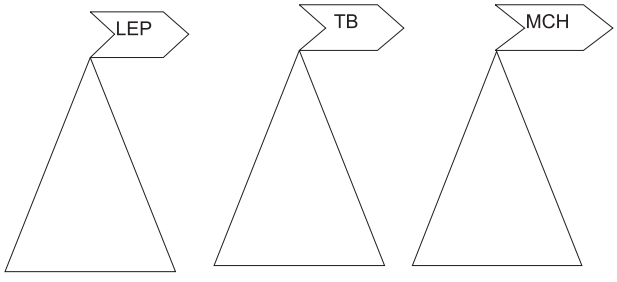
Integration-3 levels:

- **Functional-** integration of service tasks within a given setting (MPHWs providing primary care also offer leprosy service)
- **Integration of management and support functions-**integrated planning, training, MIS
- **Integration of organisational components-** coordination committee in urban, district hospital as part of GHS

Vertical-pitfalls:

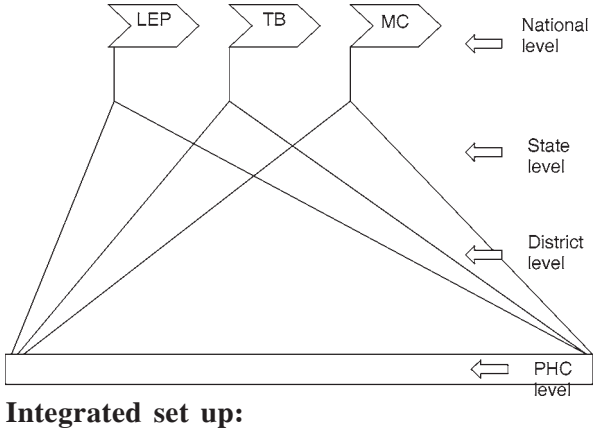
- Useful when fast, focused action is needed
- Generally it is a resource guzzler
- Limited coverage
- Fragmentation of effort
- Inefficient use of resources
- Not sustainable
- Distorted view of health and disease

Vertical- fragmentation:



Fragmented approach

Integration- crown of life:



Integrated set up:

- Does integration improve efficiency and quality?
- Assumption- functioning general health
- Wider coverage, better accessibility
- Minimal or holistic (curative, rehabilitative)?

What does it mean?

- A person with leprosy has the same opportunity as those with other diseases to attend health services that are consistent, comparable across space and time and compatible with other systems and are sensitive and responsive to the needs of the leprosy affected.

Reproduce from the PPT Presentation

The success story

- Vertical-Semi vertical-horizontal
- Search to reach
- Anonymous DDPs to PHCs
- Complicated to simplified
- Rigid, regimented, programme- oriented to flexible, patient-centred approach
- Quality- centre stage of actions

Assess integration in service delivery- 8 elements

1. Planning and budgeting processes;
2. Internal organisation;
3. Staff roles and responsibilities;
4. Training;
5. Supervision;
6. logistics and vehicles;
7. MIS and Monitoring;
8. Client services (quality)

What needs to be done?

- Involvement of all the major stakeholders in the policy formulation for consensus building
- Formulation of global action plan with specification of assignment of activities and budget-sharing
- Developing a strategy that deals with the leprosy affected as a person, not as a "case to be diagnosed, treated and reported"
- Target-free approach
- Development of comprehensive operational guidelines that deals with all the problems related to leprosy identifying sites of management
- Synchronization of all major players in the system through networking, linkages and encouraging dialogue between them.
- Redefinition of the job responsibilities of various categories of GH staff
- Introduction of integrated training through existing GH training institutions- capacity building of trainers, curriculum formulation
- A support system for building and sublimating competence levels
- Establishment of a functioning referral mechanism- inventory of specialist service providers by category and location with a map of population coverage of each
- Infrastructural support to district programme officers. Gradual phasing out of the DN. Integration at all levels.
- External support mainly for structural strengthening and key operational areas (training of trainers, tertiary care, research)
- Introduction of zonal concept of integrated supervision and monitoring and on the job competence building to identify gaps and provide immediate redressal
- Establishment of pyramidal information system as part of GH reporting
- Operational research to identify key strategic interventional issues
- Identification of surveillance centres for monitoring trends
- Creation of forum which enables all major stakeholders to participate in decision making
- Leprosy should not be allowed to remain the protected domain of leprosy 'specialists', NGO or GO.

Conclusion:

In high endemic situations there is no option other than Integration to improve coverage and accessibility of MDT service. Leprosy control stands as a good example of reasonably successful integration. Success breeds success.

Let us hope that the programme will triumph over the remaining challenges and be a model for others to emulate.

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Plan Perspective for Leprosy Control in India beyond 2007

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Background :

India achieved the goal of leprosy elimination as a Public Health problem (Prevalence Rate of <1 case/ 10,000 population) at National level in the month of December 2005 as set by National Health Policy 2002. As on 31st December 2005, the recorded Prevalence Rate of leprosy at National level was 0.95/10,000 population. The country could achieve elimination mainly because of integration of leprosy services with General Health Care System, repeated Modified Leprosy Elimination Campaigns, training and re-training of General Health Care staff, intensified IEC activities and co-ordinated support from WHO, ILEP and various NGO's. Availability of free MDT supply greatly helped the programme in this achievement. Integration of leprosy services with GHC System was initiated in 1999 and by 2003-04 has been completed in almost all the States/UTs. Now diagnosis & treatment services are available free of cost from all Health facilities. General Health staff has been trained to provide quality leprosy services.

As on 31st August 2006, the Prevalence Rate has reduced to 0.88/10,000 population. 27 States/UTs have already achieved elimination status and another 6 States/UTs having Prevalence Rate of 1-2 are close to achieve elimination. 2 UTs i.e. Delhi and Dadar & Nagar Haveli still has Prevalence Rate of more than 2. As on March 2006, 74% of districts and 70% of block had achieved elimination and the Annual New Case Detection Rate (ANCDR) was 14.27/100,000 which declined by 39% from previous year.

National Leprosy Eradication Programme was funded with World Bank loan support from 1993 to 2004 after which it is being continued with Govt. of India funds with additional support from WHO and ILEP organizations as partners. Even after leprosy elimination, the programme focus will continue for elimination in remaining States/UTs, districts and blocks. The gains achieved so far will have to be maintained and there should not be any place for complacency at any level.

Objectives of NLEP beyond 2007 :

- Continue efforts to achieve elimination of leprosy in remaining States/UTs, districts and blocks where elimination is yet to be achieved which will further reduce the leprosy burden in the country.
- Provision of quality leprosy services for all patients through General Health Care System.
- Enhanced Disability Prevention and Medical Rehabilitation (DPMR) services for deformity in leprosy affected persons.
- Enhanced advocacy in order to reduce stigma and stop discrimination against leprosy affected persons and their families.
- Capacity building among Health Service personal in integrated setting both for Rural and Urban areas.
- Strengthen the monitoring and supervision component of the surveillance system.

The System of setting target for leprosy has been discontinued, but PR and ANCDR are now used to measure level of achievement. It is expected that by March 2012 (i.e. by end of XI five year plan) the PR should fall below 1/10,000 not only in all States but also in all districts and block and the ANCDR at National level should fall below 10/ 100,000 population.

Strategies of NLEP beyond 2007 :

Infrastructure support

The state leprosy societies and district leprosy societies are to continue. Limited number of staff which are presently on contract basis may continue for some more time period. District Nucleus will be the backbone of leprosy programme in the next five years.

Integrated Leprosy services

This will continue through all the Primary Health Care facilities and will be further strengthened. Emphasis will be laid on providing quality leprosy services and strengthening of existing referral system. Free supply of MDT to patients is to be maintained for which NOVARTIS has agreed to supply MDT till the year 2010.

Information, Education and Communication (IEC)

Certain level of awareness has developed in the communities but now coverage will have to move from high risk centric areas to general community at large. More emphasis will be laid on Inter – personal Communication (IPC) with target groups to bring in attitudinal changes in public mind leading to further reduction in stigma and discrimination.

Training & Capacity building

Training has to remain a continuous process for ensuring sustainable leprosy services. Induction training and orientation training for Medical Officer, health Supervisors, Health Workers and Laboratory Technician of General Health staff as well as vertical staff will remain a major activity. Training can be jointly conducted under National Rural Health Mission (NRHM).

Disability Prevention and Medical Rehabilitation (DPMR)

It is proposed to give more emphasis on the Disability Prevention and Re-Constructive Surgery (RCS) services for the newly detected leprosy patients. Although the number of visible deformity in leprosy affected persons has reduced substantially yet quit a backlog exist which requires specialized care to remove their deformity. Such efforts also will help in regaining the status of the leprosy affected in public mind thereby reducing the stigma to the disease.

- **Prevention of Disability :** Health workers will suspect cases of reaction, relapse, insensitive hands & feet and also empower patients with self care procedure. These suspected cases will be diagnosed and treated by PHC Medical Officer who will also refer complicated cases to District Hospital. MCR footwear will be supplied to all needy patients by the District nucleus.
- **Medical Rehabilitation :** Grade – II deformity patients will be referred from PHC to District Hospital/District nucleus for further assessment. Cases fit for RCS will be referred to tertiary level hospitals for operation.
- **Reconstructive surgery:** RCS is being carried out in 33 ILEP supported institutions, 2 Central Govt. Leprosy Teaching & Research Centres and JALMA (ICMR). About 41 Physical Medicine and Rehabilitation (PMR) centres have the facility for providing services to leprosy patients as well. About 16 of these PMR centres and Medical

Colleges are being facilitated for providing RCS services. Aids & appliances will be supplied to the patients.

- **Disabled Cases:** For clearing back log of deformity cases in selected 155 districts of 11 states, 39 institutions that are already providing RCS services have been supported with a scheme of patient mobilization by general health care system from where the patients will be referred to these identified institutions for RCS. The states have started action on this plan.

Urban Leprosy Control

Leprosy is more prevalent in urban localities where the people migrate for livelihood. Problem of detection of all cases and thereafter particularly completion of treatment persist in urban situations. Urban Leprosy Control activities were initiated in 2004-05 in 422 localities. These activities include MDT delivery & patient follow up, IEC and providing supportive medicines. Under this plan integrated leprosy services through all available government and non-government hospitals and dispensaries is being carried out.

Training of Medical officers working in all Govt. & Non- Govt. institutions are conducted to facilitate quality services. Monitoring, supervision & co-ordination is carried out through a nodal agency. The Urban Leprosy Control Programme will be expanded to cover all cities & towns.

NGO Services

Under SET scheme services of approximately 40 NGO's will be continued in future. The services include disability prevention & ulcer care, IEC, referral of suspect cases, referral for RCS and rehabilitation. NGO services can be extended to ensure follow up of under treatment cases particularly in urban localities. ILEP also support nearly 130 NGO's and the support will continue as per state Govt.'s need.

Under SET scheme, Govt. of India will release funds to State Leprosy Officers. Proposals from NGO's will be recommended to the State Leprosy Officer who will release funds to NGO and will monitor their activities.

Modalities to improve efficiency and quality of services :

Regular supervision by district nucleus and from district, state & centre level through analysis of routine reports and field visits and on spot corrective action wherever needed will be carried out.

Programme review meetings are to be held periodically at Central, State and District level. At central level, annual review meeting for the State Leprosy Officers is to be held every year. At state level quarterly review meetings for the District level officers are to be held every year and at district level monthly review meetings are to be held. For monitoring the programme a component of Independent Programme evaluation through a hired agency has also been proposed.

Support from WHO & ILEP is required in monitoring and technical aspects for some more time period. ILEP has expressed their willingness to continue their support further.

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Implications of integration for quality care in leprosy control

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Integration has been defined in different ways, consensus now exists that integration of leprosy services within the general health services means that leprosy control activities become the responsibility of General Health Services. It also means full absorption of leprosy services into national health systems. However, integration does not mean that specialized attention towards leprosy as a disease is not required anymore. On contrary, emphasis should not be shifted from leprosy programme till the benefits of integration are observed in wide geographical areas of its implementation. World Health Organization (WHO) has accepted the principle of integrating leprosy control into general health services wherever possible, whilst at the same time, underlining the importance of maintaining a vertical specialized element at various levels of the programme, for supervision, referral facilities, drug supply and financing.[1]

Integration of leprosy into general health services is not a new concept. It has been advocated many decades before. It was advocated even during pre MDT era. The vertical Leprosy control programme was launched in India in 1955 as it was also started in other parts of the world around the same time. It was dapsone mono therapy era as it was the main drug available for therapy. However, by 1958 itself, [2] there were suggestions for leprosy programme to be integrated into general health services In India, one of the proposals for integration of leprosy into general health services was made in 1969.[3]

In 1978, in regards to the proposal of integration of leprosy control work with general health services in Maharashtra, it was mentioned that the time for such integration of leprosy is ripe and after successful training leprosy workers can be used as multipurpose workers.[4] However the introduction of Multi drug therapy for leprosy in 1982 has given a boost to the leprosy programme and the vertical programme of leprosy was maintained and strengthened. In 1983, leprosy eradication was established as a high priority by the Prime Minister and the National Leprosy Control Program was renamed the National Leprosy Eradication Program (NLEP). MDT coverage to various part of India was initiated over the years and by 1996 all the states in India have achieved full coverage of MDT, with Jharkand being the last state to be covered by MDT services. The success of leprosy control and the significant reduction in the prevalence of leprosy in India is due this very successful vertical leprosy programme.

The World Health Organization (WHO) Expert Committee on leprosy in 1998 has emphasized in its seventh report that integration could improve local community awareness, case finding, and patients' accessibility to MDT, and could help to ensure the regularity of treatment. The important argument for the integration of leprosy control is to enhance the sustainability of leprosy services.[5] Vertical leprosy workers have to travel long distances for relatively few patients. Vertical services have become expensive and can usually only be maintained with considerable donor support. [6]

It was felt that a fully integrated programs would be more effective in strengthening leprosy elimination activities than vertical programs. Furthermore, vertical services often serve to maintain the stigma that is usually attached to leprosy.[7] However, it should be noted that it is the success MDT vertical programme for leprosy, which has significantly brought down the sigma associated with leprosy as even a layperson became aware that leprosy is treatable and importantly a curable disease. Through integration, it is hoped that leprosy becomes an "ordinary" disease, which does not warrant special services and approaches.

At the same time, there are workers who express apprehensions on rapid integration of leprosy services.[8] It is felt that Integration should be a gradual and slow process. At the same time it has some negative aspects, the quality of care may deteriorate, records and reports will be affected, there will be more re-cycling, and leprosy workers may relax if they feel that someone else is dealing with the problem.

Quality care in leprosy:

The Global Strategy document of WHO of 2006, emphasizes quality leprosy services as an essential component of an effective leprosy programme.[9] Quality is based on appropriate training of staff at every level, regular technical supervision and monitoring of key indicators. The pursuit of quality assumes the willingness of staff to make changes aimed at improving their skills and the functioning of the health services in which they work. Most important parameters in maintaining quality of services mentioned are:

Accessibility of services to all who need them with proper coverage of MDT treatment at all health units; accurate and timely diagnosis and prevention of disability by carrying out interventions appropriately and finally referral for complications and rehabilitation.

Now, lets examine the existing infrastructure into which the leprosy services are being integrated**.** In the year 1998, there were 137,006 sub-centers, 23,179 Primary Health Centers (PHC) and 2,913 Community Health Centers (CHC) in India. This figure has not changed much over the years. At present there are about 24, 000 PHCs functioning in India. District health administration in India on average oversees between 10 and 15 hospitals, 30 to 60 primary health centers and 300 to 400 Sub-centers. Percentage of these adequately staffed is only 38%. Up to 30 % of these PHCs are without services of even one medical officer.[10]. In some states it is as high as 50%. Based on data collected by the National Family Health Survey II 1998-99 (NFHS II), in terms of population coverage, only 13 percent of rural residents had access to a primary health center, 33 percent had access to a sub-center, 9.6 percent had access to a hospital and 28.3 percent had access to a dispensary or clinic.[11] By above figures it can be concluded that the Primary health care system (PHCs, CHCs and Sub-centers) in India is not robust and is in need of significant improvements.

Care of leprosy patient:

Integration will mean that all health facilities of the general health care system should be able to provide leprosy services on all working days, not only on fixed days as organized by the vertical staff. This means that the medical officer of the system makes the diagnosis, classifies the patient and initiates the treatment, and subsequent doses are distributed at the health sub-center level, close to the patient's home.[12] Each subcentre is advised to/should stock all types of blister packs, PB, MB, child etc., sufficient for about 3 months. However, in a study conducted in Chhattisgarh, none of the health facilities had 3 months' stock of all types of blister packs, as per the guidelines. And none of the sub-centers was involved in MDT delivery. This study emphasized the need for better management of MDT drug stock.[13]. Apart from these observations made in the above study there is another important parameter to be considered. Will it be technically possible to stock such MDT medicines in all 1,37,000 sub-centers with the reduction in the budget for leprosy? One can note that the total number of subcenters supposed to hold the stock of MDT for a minimum period of 3 months is more than the number of leprosy patients prevalent in India as per 2005 figures. To be fair, they cannot and need not. Approaches and guidelines for areas of the country with higher prevalence need to differ from those formulated to cater to very low prevalence areas/states of leprosy.

The Global Strategy document of WHO (2006) also specifies measures to increase self-referral by people to promote early detection. This is to be done by increasing awareness of the early signs and symptoms of leprosy among the population by public information campaigns using a variety of media, including traditional means of communication. These are expected to help in allying misconceptions, stigma and fear among people about leprosy.

However, if has been observed over last few years that public information campaigns regarding leprosy has decreased significantly through audio visual media such as TV and/or Radio programmes. Even hoardings emphasizing the importance of suspecting leprosy in a pale or numb patch of skin are not seen any more. There is an urgent need in this era of 'no active search for leprosy' to improve public information regarding leprosy to encourage voluntary reporting. Other wise, such a voluntary reporting of leprosy patients remains a wishful thinking, especially in rural areas where surveys for leprosy have been abandoned.

After integration, the responsibility shifts from central government to state government as functioning of PHCs is a State subject. And it means that the fortunes of leprosy programme will be dictated by the functioning of PHC health care system, which was not the case till now. Integration should never mean hands off policy by the central government, especially when it comes to communicable disease such as leprosy. A special dispensation needs to be made in the case of five highly endemic states: Uttar Pradesh, Bihar, Jharkhand, Chattisgarh, and Orissa. Unfortunately, these states are not only poor but also their other state-run programs are unimpressive. An inter-state comparison clearly shows that since 1981 these states have not shown expected reduction in prevalence. Can and should the central government run a program where the responsibility lies with the state? This is difficult to answer. However if gains are to be sustained, an exception is required in these five cases, as handing over the program will surely be a setback. Considering that just five of these states contribute 62 % of cases and many laborers from these states migrate seasonally to other states, it will be advisable not only to maintain centrally funded vertical structures but also to strengthen the staff component by diverting excess staff from low endemic areas. [14]

Presently, the indicators for monitoring quality of leprosy services are based on the proportion new cases detected (correctly) and of defaulters, number of relapses and number of suspects referred by field worker. However, there is no mention of number of patients missed in the allotted area / zone or the number of patients reporting with deformities for the first time (which indicates the time lag between onset of disease and the time patient is reporting for the treatment) as an indictor of quality of services. The programme should also be able to address the problem of how to reach patients in the era of no active search for leprosy. It should be a proactive approach, not merely mentioning "early voluntary reporting should be encouraged" in print. Every attempt should be made to not to miss patients of leprosy in the specified areas and if they happen, they should be considered as an indicator for monitoring quality of leprosy services.

If we impartially look at our health care system, especially at our PHC system, we find that there is an ample room for improvements in primary health care. Quantity i.e., number of population catered to is the buzzword not quality, at least in primary healthcare. As leprosy is one of the many diseases to be attended to in the PHC health care system where family and child welfare is the priority, there is apprehension that the motivation to work further towards elimination of leprosy decreases or hindered. There is a real risk of leprosy becoming a non-priority disease and the gains in the control of the disease achieved till now getting nullified. It will be relevant to remember that the final goal is not to reach the WHO target of elimination of leprosy (which is to bring down prevalence of leprosy to less the 1 per 10,000 population) but to really eliminate leprosy from India.

When we look at Brazil, which is similar to India in its economy and resources where leprosy is an important endemic disease, the integration of leprosy into general health services has been initiated in 1980s. They were highly successful in bringing down leprosy number over last two decades. The important feature of their programme of 2005 is that the investments made by the ministry of the health in leprosy have almost doubled, increasing from R$ 7.7 million in 2004 to R$ 13.1 million in 2005 in an scaling-up which was started in 2003. Another advancement presented by the Ministry of Brazil was that the reduction in the incidence and number of cases was

accompanied by the expansion of the leprosy diagnostic network.

This is in stark contrast to programme of leprosy in India. The integration of leprosy in to General Health Services in India is accompanied by reduction in funding and curtailing of diagnostic network, laboratory facilities and trained staff. In fact, reduction in funding or making the programme more financially sustainable is the one of the important reasons mentioned in favor of integration. As we are nearing our goal of total elimination or eradication of a disease, it is imperative that we provide more inputs and more funds in to the programme to reach its culmination. Albeit, it appears that it is not the case with leprosy.

The integration of into General Health Services is not going to be without hitches or its share of problems. To make a success of the leprosy integration into General Health Services, the programme managers should keep note of past experiences and instances of failure in similar programmes after they were made non-priority and efforts diluted due to various reasons. It should not be assumed that integration of leprosy will automatically result in success of the programme and further elimination of leprosy would be achieved. Reaching WHO target of elimination means nothing, if it is not pursued vigorously till real elimination of the disease from India. To ensure its success, we should watch out for complacency in the programme management in this post integration era.

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Is integration a reality in Maharashtra? Present status, advantages, lacunae and problems

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Due to successful implementation of MDT in Maharashtra since 1981-82, prevalence rate of leprosy drastically came down from 62.4 per 10,000 population in 1981-82 to 3.32 by end of March 1999. This was the unique achievement of NLEP as the vertical programme. The subsequent decline in State PR was not as significant as observed till then as the State PR was almost static for next few years. This had also resulted in low work-load to leprosy technicians (PMWs under NLEP). It came to be realized that any further decline in leprosy may not be feasible without real integration of the programme. Besides Elimination, Integration of NLEP in GHC was the most important objective of W B assisted NLEP Phase II. Considering these facts & the guidelines from Govt. of India, it was decided to integrate NLEP into General Health Care Services. Integration of the programme further ensured the universal access to MDT and coupled with intensive IEC, the State achieved leprosy elimination (PR 0.99 /10,000) in the month of September 2005.

Need for integration :

1. Vertical Programme has limited no. of workers and is justified when there is a high prevalence.
2. Vertical Programme accords a special status to the disease and is one of the causes of social stigma attached to leprosy.
3. Integration certainly helps lessen the stigma attached to leprosy by disintegrating the special status of the disease and helps social acceptance of the patients.
4. It is cost effective especially when the prevalence rate has drastically been brought down.
5. Integration ensures better population coverage, increased acceptance to programme services through GHC i.e. Universal access to M.D.T.
6. More comprehensive care can be provided to the leprosy patients.
7. Services under disability & rehabilitation can be reached to the needy on time and more efficiently.
8. Services of vertical staff can be spared for capacity building & awareness generation.

Meaning of integration:

- Instead of providing leprosy detection, t/t, rehabilitation etc. by separate staff, all staff including doctors, nurses, compounders, MPWs, ANM, HA etc. should be able to provide these services.
- Leprosy patients should not be required to stand in a separate queue but in the same queue as patients for other diseases.
- He/She must not be examined and treated separately or on fixed days. He should receive examination, treatment etc. as any other patient coming for any other ailment.
- Drugs on leprosy should be stocked in the general pharmacy section and should be dispensed by the same person who is dispensing other drugs.
- Leprosy patients should be encouraged to report voluntarily for treatment and services should be provided on any working day between any working hours.
- MPWs (M & F) during their house to house visits should identify suspect cases of leprosy and refer them to M.O. for confirmation of diagnosis. MOs should confirm the diagnosis at the earliest and start MDT for confirmed cases.

Present status / Achievements :

- 3-day modular leprosy Technical training to GHC

Staff : MOs 5601 (5809), HAs 8847 (9152)

MPW(M) 9553 (9748), MPW(F) 11619 (11854)

- One day reorientation training to GHC Staff

  MOs 4066, HA 3061 HW 9534

- Training of NLEP staff in GHC services for 3 months. LT 998 (1416)
- Re-deployment of existing district & divisional level NLEP infrastructure is being given final touch by the State Government.
- Functional identity of SET Centres, LCU & ULCs is abolished.
- Only 2 Temporary Hospitalization Wards and 2 Leprosy Training Centres (One each of Nagpur and Pune) retained.
- Strengthening of Urban infrastructure by transferring NLEP staff (165 NMS and 474 LTs) in the Urban Area :
- Deputation of staff to Zilla Parishad : vide G.R. dated 6/11/2000 & 28/6/2002: 505 state cadre LTs and 126 NMS shifted to Z.P.
- Anti-leprosy drugs made available with pharmacist at all Civil Hosp., R.H., C.H., and PHCs
- Anti leprosy services through all corporation health posts, dispensaries and hospitals:
- NGOs working in corporation area and concerned ADHS have trained corporation health staff .

Observations of Internal Evaluation

In order to assass status of Integration, Internal Evaluation was carried out during period Oct. 05 - Dec. 05, with the deployment of 23 teams, each team comprised of MO-1, NMS - 1, LT/NMA - 1. 165 PHCs & 60 UHPs were evaluated. Findings of Internal Evaluation as under:

- IEC activity which is about 88 to 89% speaks itself for the leprosy awareness after integration.
- More than 76% of GHC staff has reasonable knowledge about leprosy.
- Record keeping and reporting has gained substantial ground after integration.
- Substantial number of suspects detected by HWs & 5.4% of these found to be new cases of leprosy.
- MDT & supportive medicine available in most of PHCs
- Wrong diagnosis, wrong classification, re-reporting, percentages in the case validation activity found to be in the acceptable limits (3.2%).
- Barring a few exceptions GHC staff i.e. HA share the full responsibility of NLEP vertical staff being utilized for other programmes.

Above facts show that integration is indeed a reality.

Advantages of integration :

1. Destigmatisation is quite evident which is proved by LEM Findings.
2. Patients accessibility to MDT Services has been greatly increased. Problem of disability has been greatly declined contributing further to destigmatisation.
3. Community awareness about leprosy has expanded so much that leprosy is no longer recognised as a dreadful disease.
4. MDT is available at each & every health facility, on every day giving rise to easy accessibility to each patient.

Lacunae / problems :

1. Structural integration is in process.
2. Integration in tribal and remote rural areas needs improvement.
3. Knowledge about NLEP among GHC staff needs further improvement.
4. IEC in general needs improvement and increased flow of funds.

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Is Integration a reality in Delhi?

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Introduction:

The capital of India, National Capital Territory (NCT) of Delhi, is situated in the northern part of India, over the west bank of river Yamuna. Surrounded by the states of Haryana and Punjab in the west, Haryana and Uttar Pradesh in the south, Uttar Pradesh and Himachal Pradesh in the north and Uttar Pradesh, across the river, in the east. NCT of Delhi has been divided into 9 revenue districts as shown below:

As per 2001 census, NCT of Delhi had 13,782,976 population, which has increased to estimated 16,616,477 by March 2006 within an area of 1483 square kilometers. NCT of Delhi has the highest population density in the country harboring 9,294 persons per sq km.

Administratively, NCT of Delhi has three local controlling autonomous bodies namely i) New Delhi Municipal Council (NDMC) ii) Delhi Cantonment and iii) Municipal corporation of Delhi. Major area of NCT of Delhi is covered by MCD.

Basic responsibility and functioning of these agencies MCD, NDMC and Cantonment board mentioned above is to provide civic amenities like water supply, electricity, cleaning etc. These agencies are also providing general health care services through their respective hospitals and dispensaries. Directorate of health services under state ministry of health is also providing health services and their hospitals and dispensaries are interspersed in MCD and NDMC areas.

All the 9 districts of NCT of Delhi have been provided with District Technical Support Teams (DTSTs) by International federation of Ant-leprosy associations (ILEP). Main function of these DTSTs is to support and strengthen provision of leprosy services through general health care staff of these dispensaries and hospitals. Out of 9 districts of NCT of Delhi, 5 are supported by Netherlands Leprosy relief (NLR), India Branch. Data presented in this article are collected by NLR DTSTs covering these five districts.

Leprosy situation in NCT of Delhi:

With population of 16616477, NCT has 3221 cases as on 31st March 2006 with a prevalence rate of 1.94 per 10000 Population. 3705 cases were detected between April 2005 and March 2006 with an Annual New Case Detection Rate (ANCDR) of 2.2 per 10000

Population. Out of the detected new cases 57% were Multi-bacillary (MB), 18.5 % were females and only 4.6 % were children. 3.2% of new cases presented with Gr. II disability.

It is difficult to comment on prevalence and new case detection rate in a city like Delhi as we are not sure of the actual number of cases (numerator) because of lack of information on the cases reporting from Delhi, migrated from other states and cases reporting to private practitioners. Comment is also difficult because of floating or unstable population (denominator).

Steps taken to strengthen MDT services:

NLR provided Two DTSTs comprising of 2 medical officers and 5 paramedical workers, each having their own mobility, and were deputed to cover 5 districts of Delhi. Government run General Health Care dispensaries and hospital were roped in to provide leprosy services. Class room and on the job trainings were provided to Doctors to strengthen their capacity to diagnose and manage leprosy cases. Identified staff (Pharmacists, Staff nurse etc.) of the dispensaries and hospitals was trained for recording, reporting and drug supply management.

IEC activities were supported in the surrounding areas of hospitals & dispensaries to provide knowledge about facts of leprosy and availability of services in these dispensaries and hospitals. Pamphlets were distributed with area wise addresses of the dispensaries.

Special IEC activities like magic shows, Nukkad Natak, puppet shows were supported on special occasions i.e. Festivals, Anti–leprosy day/week/ fortnight. Motivation, Education, counseling, of the patients, was encouraged at the time of first contact. Flexible in drug delivery was also encouraged.

Recording of Correct patient's address was emphasized for Cross notification of migrating patients, Postal reminders. Absentee tracing/ monitoring of migrant patients was encouraged. Special emphasis was given to follow Govt. of India guidelines for registration of leprosy patients. Enhanced follow up of patients through various means like telephone, community volunteers, postal services etc. was used.

Involvement of non - leprosy NGOs and general practitioners is being practiced for referral and follow up. This can be seen as under:

- Absentee Retrieval through Telephone
  - Patients Contacted – 80
  - Reported for treatment – 35
- Retrieval Through Postal Reminder
  - Inland letters sent – 334
  - Patients reported for treatment – 46
- Reverse Referral using Referral Slip (Hospital to Dispensary) – 11

Integration is a reality in Delhi:

In NCT of Delhi the Integration of leprosy services into general health care, started in the year 2000 and gradually, with the help of DTSTs, more and more general health care dispensaries and hospitals were strengthened to handle leprosy cases, maintain record, prepare report independently. By the year 2006 we have come so far which can be seen from the following tables:

Table I : **General Health Care Facilities (HCF) providing leprosy services**

Agencies	Hospitals			Dispensaries		
	No.	Identified	Providing MDT	No.	Identified	Providing MDT
Delhi Govt.	14	13	13	74	74	74
MCD	07	06	06	28	26	26
NDMC	Nil	Nil	Nil	07	07	07
Other (ESIC, Railways etc.	16	11	11	99	06	06
Total	**37**	**30**	**30**	**208**	**113**	**113**

It can be seen from table-I that majority of hospitals are from Delhi Government/Directorate of health services or from MCD, and few from NDMC and other category of agencies. To avoid duplication due to proximity of dispensaries and hospitals less than the existing number of hospitals and dispensaries have been identified for strengthening of services so that quality could be maintained. Some of the dispensaries of CGHS, Jal Board, ISM, State bank etc were not roped in as they were not willing and also they provide services to their own employees/beneficiaries.

Table II : **Involvement of General Health Services**

Proportion of HCF	Hospitals n = 30	Dispensaries n = 113
Involved in NLEP	All	All
Where records are updated by GHC Staff	83%	80%
Where reports are prepared by GHC staff	60%	71%
With adequate MDT	93%	88%
Where complications are treated	93%	40%
No. MOs diagnosing / confirming new cases	74 of 75	197 of 209

It can be seen from table II that all the dispensaries and hospitals, which have been identified and are involved in the programme in various grades in relation to recording reporting and treatment of complications. Complication management is obviously more in hospitals than in dispensaries. It can also be seen that quite a large number of doctors in hospitals and dispensaries are capable of diagnosing and treating leprosy.

Table III : **Cases Detected & Cured (2005-2006)**

Type	Hospitals		Dispensaries		Completion Rate
	Registered	RFT	Registered	RFT	
MB	821	567	97	55	38% (2003-04)
PB	734	409	107	72	52% (2004-05)
Total	1555	976	204	127	44% (Average)

highlight that not only the hospitals are involved in case detection and treatment but quite a number of cases are being detected & treated through General Health Care dispensaries. Cases registered and cured are in the year 2005-06 while the cohort analyses have been tried for the cohort of 2003-04 and 2004-05, while the. This cohort analysis depicts that completion rates are far from satisfactory.

Table IV : **Validation of New Cases (2005-06)**

Findings	LEM – 2004	2005 – 2006
Correct cases	52%	87.8%
Correct Classification	89%	99.2%
Re-registration	36.2%	07.6%

To assess the quality of services and to assess the competency of the Medical Officers validation of cases is continued, which shows that there is lot of improvement between 2004 and in the year 2005 – 2006. This improvement could be attributed to transfer of skills by the DTSTs.

Lacunae & problems in Delhi:

As mentioned in the introduction also, NCT of Delhi has Multiple administrative agencies with their own staff and control. They have their own dispensaries and hospitals providing general health care services in their control areas.

There is lack of co-ordination among these service providers as they follow their own mandate and service rules, which leads to difficulty in agreeing to Delhi government guidelines, in collection of reports and drug supply management.

GOI guidelines are not followed in majority of the hospitals e.g. no agreement for 6 &12 pulses, also for recording of cases, which leads to double registration or re-registration of cured patients.

Another major problem is Immigration and emigration, which leads to over treatment and defaulters. To avoid stigma or ensure treatment, patients also sometimes

hide their correct addresses. Sudden dislocation of slums also leads to defaulting. In an urban setting it is difficult to say with certainty about the true prevalence and new case detection rates because of variable numerator (cases) and denominator (population).

Though the district nucleus is formed, still monitoring and supervision in its true sense is inadequate. Monitoring and supervision is also inadequate by the supervisors of GHC system or by the supervisors of MCD, NDMC.

Recommendations for Urban Leprosy

- GOI guidelines be made available and followed in all the health facilities.
- At first contact, importance of detailed history taking and counseling should be emphasized .
- Non leprosy NGOs, volunteers should be involved in follow up of cases.
- Close liaison should be maintained with MCD and NDMC (advocacy required).
- Limited and motivated Private practitioners be involved.
- Consensus building/Advocacy with dermatologists and private practitioners to follow WHO, GOI guidelines.
- Drug supply to be maintained through channels of GHC i.e MCD, NDMC, Delhi administration channels as for general drugs.
- Reorientation of Pharmacists for drug supply and logistic management.
- Staff should be identified at hospitals for maintenance of records and reporting.
- If possible, computerized data should be maintained to check double registration like PNR number is used in railways.
- Monitoring & supervision be given the top priority.

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Is Integration a leap forward in Tamil Nadu?

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Background and Chronology

- N. L. E. P. in Tamil Nadu was launched in 1954 - 55, treatment with Dapsone tablet only till 1982.
- Multi Drug Therapy was launched in 1983 in a phased manner and a complete geographical coverage for Tamil Nadu was done in 1991.
- Prevalence which was 118/10000 in 1983 was brought down to 0.85 in March 2005 only after the integration in 1997.
- The WHO fixed the Goal of Eliminating Leprosy as Public Health Problem in December 2000. This means bringing down the prevalence to 1/ 10,000. But we have achieved this as on March 2005 ie., 0.85 /10000 population.

Integration on N. L. E. P. with Primary Health Care Services:

During August 1997, the amilnadu Government was the first state to Integrate Leprosy Service with PH care services and this resulted in the following:

- Leprosy services to be available in all PHCs
- Scope to treat leprosy like any other disease
- Increase in voluntary reporting
- Integration was done only in Rural areas
- Action is taken to Integrate Leprosy Services even in the Urban areas with the help of GLRA as facilitators.

Integration of Leprosy in Tamilnadu

Tamilnadu crossed the boundaries of verticality way back in July 1997 by integrating Leprosy service with that of Public Health. The ownership of leprosy was handed over to Public Health System. The Vertical Staff of erstwhile leprosy service were placed under the Public Health Programme officers to continue their leprosy work at PHCs and in due course to take care of other Public Health services. This resulted in opening many service points at village level with increased experienced man power. Leprosy service was made available on all days at all times at PHCs. Leprosy services have now been made available nearer to Patients living places.

Problems Faced at the time of integration :

- Knowledge on the diseases & Programme implementation were found to be lacking among PHC staff and therefore had to be persuaded to understand the need for integration.
- General public were not aware of the early signs of leprosy and were victims of deformity and disability caused by this curable disease. They did not know where to report for diagnosis and treatment.
- Resistance on the part of vertical staff for integration due to lack of understanding of the benefits of integration.
- Administrative constraints and delay in distribution of erstwhile vertical staff to GHS pattern and time lag in adjustment to new administrative and structural set up.
- Another major constraint in the vertical set up was the non availability of female component. Without female health staff, it was very difficult

to reach all sections of the community, particularly the women.

Challenges faced

The vision we had at the time of integration helped us achieve elimination in such a short period. Some of the objectives set are discussed below:

- Improving access to leprosy services by enabling all health facilities in endemic districts to diagnose and treat leprosy.
- Since leprosy can be diagnosed on clinical signs alone, it is possible to empower multipurpose health workers to diagnose and treat leprosy after minimal training.
- Ensuring availability of free MDT drugs at health centres through improved distribution and logistics.
- Encouraging people to seek timely treatment by creating better community awareness of the early signs and dispelling fear of the disease since the disease generates irrational fear, prejudice and intense stigma.
- To minimize delay in seeking treatment by the people for fear of its social consequences, which in some communities are extremely grave.
- Ensuring high cure rates through innovative and patient friendly drug delivery systems. Many patients have to interrupt their treatment because of lack of drugs or because the health services are inaccessible due to rains, poor road condition for other social reasons.
- Innovative solutions in line with the local field reality had to be adhered to overcome such obstacles.
- Active monitoring to keep track of progress towards elimination and taking timely corrective steps to tackle the remaining problems.

Activities planned based on the identified problem:

Integration of leprosy services with General Health Care system has been operationalized with availability of diagnostic services and drugs at all PHCs /Sub Centres. Integration of MDT services in the General Health Services has become the key element to sustain leprosy control activities in a sufficient high level in the post elimination phase. General Health care System functionaries have been trained in leprosy in all the districts & urban areas of the country. The activities carried out since Integration was in line with achieving the above objectives. Capacity building was the core activity which is an ongoing process so that the objective of reaching every village and each individual is fulfilled.

Sl. No.	Health Functionaries Trained	2004-05	2005-06
1	PHC Medical Officers	1011	590
2	Health Assistants	3130	447
3	Health Workers	1775	2480
	Total	**5916**	**3517**

Capacity Training has been given like

- Training to all categories of PHC staffs
- MLEC Training
- RPOID Training
- Self Help Group / Mahila Mandals are trained and used to detect new cases.

Sustinance – Orientation on Leprosy to the staff as and when required. Orientation to General Health Staff involving Dermatologist / Leprologist / District Health Officials.

Special Case detection activities carried out

Greater emphasis was laid on voluntary reporting. To achieve this, efforts were taken for effective IEC/ IPC methods after integration. MLECs provided the best opportunity to gear up IEC/IPC activities, which paved the way for IEC/IPC as an ongoing daily process through which we can motivate people

towards voluntary reporting and continuity in treatment.

Strategy followed:

1. Case detection only by passive methods
2. Increase voluntary reporting by IEC /IPC
3. Strengthening urban leprosy programme with NGOs as facilitators

The SSAU team attached to the State Unit under the overall control of the Director of Public Health & Preventive Medicine takes up review of N.L.E.P Programme in 2 Districts every month on :

Case Holding

- Registration
- Drug Distribution
- Drug Management (Monitoring)
- Counselling to patients / family

Carried out by : PHC- HIs, VHN, & NMS

Case detection –Methods

- Photo Survey
- Rapid Survey
- Saturday Survey
- MLEC II, III, IV & special programmes like SAPEL, ULEC.

All these active survey are stopped. Now we encourage passive voluntary reporting by means of IEC

T. N. was the pioneering state to conduct 4 Modified Leprosy Elimination Campaigns MLEC I in Feb.1997, MLEC II in Jan 2000, MLEC III in Oct 2001, MLEC IV in December 2003. The outcome of the campaigns is shown in the table below:

	Year	SSL	PB	MB	TOTAL
MLEC I	Feb 1997	4039	7533	1058	12630
MLEC II	Jan 2000	3886	6785	1932	12603
MLEC III	Oct 2001	2525	5950	1662	10137
MLEC IV	Dec 2004	1432	4018	701	6151

Sectors in Population Totally covered :

- Schedule Caste (SC)
- Schedule Tribe (ST)
- Female
- Slums
- Fisherman Colony
- Tribal Population & Minority Groups

All health posts in the state were equipped with free MDT drugs, be it in the rural or urban centres. The distribution system in the state was streamlined with a central monitoring mechanism at the State Leprosy Office.

Monitoring & Evaluation

Monitoring and evaluation was another area which was concentrated upon.

- Conducting Periodical Review Meeting at PHC, District, State Levels,
- Special Reviews & interaction with the district programme managers for Health Facilities on Priorities,
- SSAU visiting identified problematic areas based on essential indicators,

Thus Periodical review meetings, interaction with the district programme managers and visits by the State officials enabled speedy implementation of this method as an effective tool to measure the pace of elimination.

The Sample Survey and Assessment Unit (SSAU) at the state level was reorganized based on the suggestion of the Government of India and this too helps in monitoring the progress and sustainability of elimination of leprosy in Tamil Nadu.

The newly formed Sample Survey and Assessment Unit consist of

1) Medical Officer in carde of Joint Director
2) Statistical Assistant -1
3) Non Medical Supervisor -2
4) Para Medical Worker - Health Inspector Grade I B - 4
5) Epidemiologist - 1
6) Data Entry Operator -1

Objective of the SSAU Unit:

1) To assess continued availability and quality of leprosy MDT services through GHC delivery (Primary Health Care) System.
2) To assess implementation of IEC activities in the community and.
3) To assist State Leprosy Officer in all the work related to epidemiological analysis of NLEP data and suggest corrective action.

Methodology of SSAU Unit:

The SSAU will prepare its monthly advance tour programme (ATP) as per the (Annexure II) and submit to the SLO, and D.PH & PM, with a copy to the selected district by 15th of each month. The visit planned in such a manner that one district is visited in each fortnight and the data collection is completed in about six working days in each districts. Any data collection if remains incomplete the same may be completed during the mop-up visit for 2-3 days.

The SSAU should conduct visit to randomly selected (atleast) two district in each month and in each district from Primary Health Centres in different directions and in each PHC atleast 2 subcentres and 2 villages to be covered. In all in each month atleast 2 districts, eight PHcs, 16 subcentre and 16 villages are to be visited by SSAU in Tamil Nadu.

- Regular and continuous data flow from PHCs to the State through District administration.
- Feedback from State to Districts / PHCs.
- Special Focus on ULEC Activities (Coordination with Urban Health Facilities).

IEC – IPC

IEC is considered as every ones responsibility. IEC is a need based activity / differ from place to place (Tribal/ Urban/ Rural).

Major IEC activities consists of

- Group Meeting
- School IEC
- Folk dance
- Wall Paining
- Rally
- Quiz
- Advocacy etc.,

At present no active survey is engaged all the new cases are reported Voluntarily.

Effective IEC resulted

Improvement in

- self reporting
- compliance
- treatment completion rate
- patient acceptance by the community
- proportion of Females covered
- proportion of Marginalised groups covered

IPC – interactive

- Working within & with the community participatory approach
- "HAATS"
- Quiz Programme

IEC activities – 2005-06:

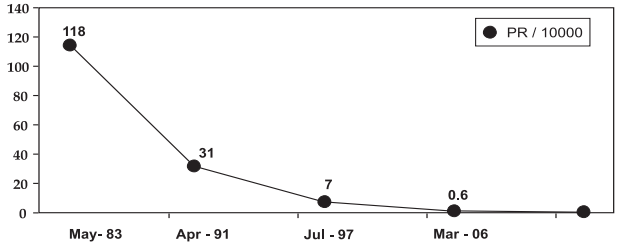
S. No.	IEC Activities	Planned	Executed
i)	IEC / IPC activities are carried out in schools to create awareness about leprosy.	**2917**	**2885**
ii)	Distribution of pamphlets	**606037**	**657063**
iii)	Leprosy PVC stickers printed	**14305**	**14515**
iv)	Local cable TV advertisement	**60**	**57**
v)	Preparation of wall hangings	**6466**	**5998**

State Profile of Tamil Nadu:

1.	Population revised (Mar-2006) (in Lakhs)	654.73
	Urban	261.89
	Rural	392.83
2.	Number of Districts	30
3.	Number of Health Unit Districts	42
4.	Number of Blocks	387
5.	Number of Primary Health Centres	1416

6.	Number of Health Sub Centres	8682
7.	Number of Corporations	6
8.	Number of Municipalities	102
9.	Number of Deputy Director of Medical Services(Leprosy)	14 / 24
10.	Number of Deputy Director of Health Services	42

Landmarks – Tamil Nadu State:



Details	Year	PB	MB	Total	PR/ 10,000
Date of Start of MDT	May-83	292401	287880	580281	118
State Fully covered by MDT	Apr-91	119874	53153	176027	31
Integrated with Primary Health Care	July-97	31114	13175	44289	7
Present Status	Mar-06	4255	2399	6654	0.60

Epidemiological Status for the Year 2005-06:

Balance Cases	3919	PR: 0.60
Total New Cases	6654	NCDR: 1.01
MB Cases	3332	36.05%
Deformity Cases	141	2.119%
Child Cases	1134	17.04%
Female Cases	1629	24.48%
SC Cases	732	11.00%
ST Cases	63	0.94%

Current Scenario of NLEP in Tamilnadu:

Since the PR of Tamilnadu was 7 /10000 in the year 1997, the Government of Tamilnadu integrated the leprosy programme with the General Health Care Services to achieve the Goal of Elimination ie., Bringing down the PR to less than 1 /10000 , by the end of December 2000 .

As on March 2003, State PR - 2.3 / 10000

As on March 2004, State PR - 1.4 / 10000

As on March 2005, State PR - 0.85 / 10000

As on March 2006, State PR - 0.60 / 10000

Tamilnadu achieved elimination as on 31st March, 2005, at State Level.

Referral Services in Support of Leprosy Elimination :

Referral services are necessary to provide quality care to leprosy patients. The activities which require referral, to support leprosy elimination are identified and referred to a sustainable referral and therefore it is made available within the general health care services itself. The level where these referral services available are :

- Medical colleges
- District Head Quarters Hospital
- Taluk Hospitals wherever dermatologists are available.
- NGO Centres

Role of NGOs:

- On the job training to the PHC staff
- Offer expertise in handling complications
- Introduce the concept of POD and self care at the PHC level
- Involve the Grass root level development staff, community leaders for creating awareness on leprosy
- Provide services to fill the gap to maintain the quality

Activities carried out involving NGOs from 2001-02 to 2005-06:

RCS Operations Performed				
2001-02	2002-03	2003-04	2004-05	2005-06
309	228	131	57	33
MCR Footwear distributed				
2001-02	2002-03	2003-04	2004-05	2005-06
8177	8669	5314	2208	4116

POD Camps

Two to three camps planned for each block. By this method PHC staff are all trained in preventing disability.

Block level planned & undertaken during 2005-06:

No of camps planned	–	110
Camps undertaken	–	155

Camps proposed to be undertaken in 2006-07:

Urban	–	125
Rural	–	387
	Total	**512**

Integration – a leap forward indeed:

Integration of leprosy services with the GHS in Tamil Nadu has not only hastened elimination but also help in sustaining elimination. It could be seen from the fact that elimination was achieved as early in March 2005 at the state level (0.85/10,000). All the 30 districts in the state achieved elimination as on March 2006 (0.6/10,000) (as on August 2006 0.53/10,000).

The social mindset on the disease has undergone a dramatic change due to combined efforts of all GHS staff. Besides this, the mindset of the health workers has also changed in terms of their concept of the disease, detection, treatment and the usefulness of the leprosy elimination programme.

NGOs were functioning independently with their own programme pattern and agenda before integration. Their contribution to elimination efforts is laudable. It was only after integration, their role and specific area of work were defined after prolonged dialogue and discussion with various NGOs. The Government of Tamilnadu has defined a clear policy as to the role of NGOs which has helped the system and the NGOs to understand their complimentary role and work together towards the common goal of elimination.

In the first stage, the ownership of the leprosy programme was transferred from the vertical programme to the entire GHS staff. Thus, instead of the lone District Leprosy Officer to monitor the programme, we now have more than one programme manager (DD-L and DDHS) who work in close coordination. In the new set up, all are accountable to the system for the progrmme implementation. No one segment can claim to be experts in diagnosis and treatment. This trend has been demystified by capacity building measures extended to all GHS staff.

Mission with a vision

In the final stage, our perspective is to sustain the elimination achieved by constant vigil, monitoring and evaluation. In this task, we shall endeavour to involve all stake holders and work in a steadfast manner without giving room for any complacency. While constantly educating the general public about voluntary reporting will be continued, no effort will be spared to bring out all the hidden cases and treat them. According to the need of the time, the method of detection and treatment has to be evolved.

Our dream is to create a state without leprosy. No individual should suffer the stigma, deformity or disability caused by this curable disease. To achieve this, each member of the community has to be the protagonist of the programme. It is possible only when the ownership of the programme is in the hands of the community. We shall strive to make this a reality in the near future.

Integration of leprosy service with the GHS has indeed been a success and a big leap forward in Tamil Nadu!

Integration of NLEP Services in Karnataka

Dr. H. Siddappa
Representative, Joint Director (Leprosy) &
State Leprosy Officer, Karnataka

NLEP

- 1981- MDT was introduced
- 1985- Vardha
- 1986- In Karnataka

- in phases to cover all the Districts during 1992-93

Integration of NLEP Services in Karnataka:

- During April 2002 Leprosy Services have been integrated into General Health Services in Karnataka and functioning as per Government of India Guidelines.
- 75% of the NLEP staff -merged with GHS & 25% staff working under District Nucleus & Block Level for monitoring/evaluation/supervision of NLEP activities.

Why integrate leprosy into the general health services?

- Integration means to provide "comprehensive" essential services from one service point
  - to improve patients' access to leprosy services and thereby ensure timely treatment
  - to remove the "special" status of leprosy as a complicated and terrible disease
  - to consolidate substantial gains made
  - to ensure that all future cases receive timely and correct treatment
  - to ensure that leprosy is treated as a simple disease

Advantages of Integrating Leprosy Services

- Patients detected early
- Patients treated early
- Transmission of infection interrupted early
- Development of deformities prevented
- Stigma reduced further

Why coverage is important?

- Good coverage means that:
  - health facilities are easily accessible to every member of the community
  - health services are provided on a daily basis
  - health workers are able to diagnose, treat and provide basic information about the disease
  - health facilities are distributed equally in all areas
- urban/rural, male/female, poor/rich, tribal/others, etc.

Disadvantages of Integrating Leprosy Service:

- Less importance to particular programme - Leprosy
- All the programmes have to be monitored by the GHS
- Equal importance to be given to all the programmes

NLEP in Karnataka as on 31/3/1986:

- Population: 37135714
- No. of Districts: 20
- Cases on Hand: 151301
- PR: 40/10000
- NCDR: 7.6
- Deformity Rate: 17%

- Child Proportion: 15
- MB Proportion: 22
- PR > 10 - 15 Districts
  5-10 - 2 Districts
  2-5 - 2 Districts
  1-2 - 1 Districts
  < 1 - 0 Districts

NLEP in Karnataka as on 31/7/2006:

- Population: 55289574 (mid year Popn)
- No. of Districts: 27
- Cases on Hand: 3059
- PR: 0.53/10000
- NCDR: 0.26
- Deformity Rate: 0.45
- Child Proportion:12
- MB Proportion: 58
- PR > 10 - 0 Districts
  5-10 - 0 District
  2-5 - 0 Districts
  1-2 - 1 Districts
  < 1 – 26 Districts

Where are we today?

CHANGING ATTITUDE & IMAGE

- Complex to simple
- Easy to diagnose
- Easy to treat and cure with MDT
- MDT is avaialable at all health centres
- Treatment is free
- Early detection and MDT treatment prevents deformities
- Social discrimination has no place
- Join hands to achieve the goal and eliminate leprosy

Training for the District Nucleus Staff

The District Nucleus was formed after the Integration of GHS - 2002District Nucleus Team Consisting of

District Leprosy Officer – 1

Medical officer – 1

Sr.NMs – 1

PMW – 1

Have been trained during December 2005 – All over the State.

Rehabilitation measures:

- Re-Constructive Surgery to the needy – free of cost- Orthopedic Surgeon and Ophthalmic Surgeon.
- Supportive Measures- providing Splints & Crutches, MCR Foot Wears, Goggles, Woolen blankets.
- Housing, Loans from banks to make a living, namely for rearing of Sheep, Poultry, Auto Rickshaws etc.
- Pensionary benefits - Oldage and physically handicapped.
- Self Employment Training like e printing, Tailoring, leather products making etc.
- 5% Reservation of Jobs for Group 'D' Employment in DH & FWS for those who are cured have grade II Deformities.

The goal of National Leprosy Elimination Programme is to bring the PR <1/10000 population.

Government of India:

- Prevalence Rate as on 31/3/2006 – 0.84/10000 population.
- New Case Detection Rate – 1.43/10000
- MB Proportion – 45
- Female Proportion – 33
- Child Proportion – 10
- Deformity – 1.9
- Cases on Hand – 95000
- New Cases Detected – 1,61,000

Government of Karnataka:

- Prevalence Rate as on 31/7/2006 – 0.53/10000 Population
- New Cases Detection Rate – 0.26/10000
- MB Proportion – 58
- Female Proportion – 35
- Child Proportion – 12
- Deformity – 0.45
- Cases on Hand – 3059
- New Cases Detected – 1518

KDP Report for the month July 2006

Strategies to eliminate Leprosy at each level:

- Decentralization and Institutional Development
- Strengthening and Integration of Service Delivery
- Disability Care and Prevention
- Information, Education and Communication
- Training

Decentralisation and institutional development:

- Integration of NLEP Services in Karnataka
- During April 2002 Leprosy Services have been integrated into General Health Services in Karnataka and functioning as per Government of India Guidelines

Strengthening and integration of service delivery:

- Integration means to provide "comprehensive" essential services from one service point
  - to improve patients' access to leprosy services and thereby ensure timely treatment
  - to remove the "special" status of leprosy as a complicated and terrible disease
  - to consolidate substantial gains made
  - to ensure that all future cases receive timely and correct treatment
  - to ensure that leprosy is treated as a simple disease

Disability Care and Prevention:

- Prevention of Deformity (POD): Orientation Training Camps for Prevention of Deformity have been conducted for Medical Officers and Health Workers
- Reconstructive Surgery
- Supply of MCR Foot wears
- To Develop Referral Centers

IEC Activities:

- IEC/IPC – to create awareness among Public (ie., Exhibition, Haats, Folk Media, Quiz, ALL India Radio, Television, Newspapers, Posters, Handbills, etc.,)
- Anti-Leprosy Month during the month of January every year.

Training:

- The MOs, Pharmacist, HAs, School Teachers, Anganwadi workers, Mahila Mandal, Village Panchayat Leaders, ZP Panchayat Members – given Orientation Training in Leprosy- to create awareness in leprosy
- Capacity Building of DHOs and other Prog. Officers
- POD Training for Health Staff
- ULEP Strategy

Inter Sectoral Co-ordination:

- Involving – All NGOs, Railway, Rotary, Lions, Municipal Corporation, Medical Colleges, Mahila Mandals, etc.,) – All over the State.
- MDT Drugs are available free of cost – in all the Govt. Medical Institutions, Pvt.Medical Colleges, Pvt. Hospitals, Clinics.
- To interact with the Information and Publicity Department, Education Dept, Women & Child Welfare, Social Welfare Dept, etc.

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Is integration a reality in Madhya Pradesh? Present status, Advantages & Lacunae

Dr. K. L. Bhandarkar
State Co-ordinator, M.P.TST

Introduction

Integration is aimed at

- To sensitise and involve all stake holders and the General health staff. Both involve and run the programme. Also
- It is the widening of the scope of involving more human power, making more hands available. Making it a part of routine

In my opinion success of integration depends on :

- Whether the programme manager has imbibed the concept of integration.
- Has he ever given a thought of planning so that leprosy can be accommodated among other programmes?
- Where the planner does keep leprosy programme priority wise among other programmes.
- Support by outside agency.
- Whether efforts have been put forward to involve community.

The integration of leprosy services was introduced looking to the following advantages.

- Sustainability of leprosy services in a cost effective manner.
- Additional hands, skill and experienced personnel will be available.
- PHC system with its wide network could augment reach of leprosy services.
- Comprehensive provision of both leprosy and GH services by same system – Convenient and Beneficial for the patient.
- Screening of leprosy patient will be possible from general OPD.
- Leprosy service more accessible to women.
- Reduction in stigma –pre integration period the home visit by a leprosy worker.
- Inclusion of leprosy services in GHS makes it more comprehensive.

Present Status:

- Diagnostic facility is available on all working days but due to rush of patient in general OPD the medical officer can not give sufficient time for confirmation of a case.
- MDT is now available practically in all health facilities wherever cases of leprosy are there.
- The indent of MDT is done as per the need of a health facility.
- Supply of MDT is also done as per the case load of a particular HF.
- Near expiry drugs are used first because of the lesson learnt from previous wastage of drugs.

Clinical skills of the Medical Officer:

- In most of the health facilities Medical Officer are now diagnosing cases. How ever they seek the help of the NLEP staff to confirm their diagnosis.
- The health facilities where, either MO is not in position or is not available, the leprosy work is looked after either by the dresser or the ward boy.

Advantages:

- Self reporting of the suspect cases has increased due to nearness of the HFs.
- Stigma is gradually reducing, now a patient of leprosy can get treatment for other ailments while he is visiting health facility for collection of MDT.
- Stigma among the General Health care staff and Medical Officer has also been reduced because more opportunities are now available for direct involvement of these Medical Officer of PHCS in leprosy activities. Reaction cases are now reported to HFs.
- NLEP staff could only talk about leprosy during his visits but after integration the GH staff can tell about more diseases and information about leprosy can now be sand witched in between.
- Defaulter rate has considerably decreased because the GH staff while routine home visits can build 'family pressure'. She/he also gets more time to listen from leprosy sufferer during her visits.
- IEC materials are now available practically in all Sub Health centers. Which give more opportunity for discussions.
- The cure rate/the treatment completion rate has considerably increased due to establishment of a process cross notification among the SHCs, PHCs in the sector meetings.
- Referral system has now been strengthened because of the referral of the suspects from SHC to PHC Similarly the referral of complication has also increased Since POD camps are now organized at sector level. There are instances that patient is now bringing new patient which never happened before.
- Follow-up of the patient is now possible during the home visit by the health worker, which a NLEP worker could have never done.
- Now PRI members are also coming forward to get involved in leprosy activities i.e. Zero case Panchayat function has now been initiated by MP TSTs.

Lacunae:

- Medical Officer still is not very confident about his diagnosis and still takes assistance of NLEP staff for case confirmation.
- The NLEP staff now has been given a larger area and hence he is not in a position to carry out systematic follow up of the patients.
- The NLEP staff has been entrusted with responsibility of other programmes even before the GH staff could fully take over the responsibility of the programme.
- The District leprosy Officer has also been entrusted with large number of programmes and hence he can not devote much for leprosy.
- The programme vehicle has now been taken over by CMHO of the district and hence there is no vehicle for field monitoring by DLO.

- Leprosy is the last priority for the CMHO and hence the field monitoring of the program is practically nil. Similarly there is no monitoring of the programme in the monthly meetings held at district level.
- There is no healthy contact examination as was done before. The result is, the detection of hidden cases among the contacts is very low.
- Responsibility/Accountability of the programme is swinging between the NLEP staff & GH staff. Since there is no clear-cut sharing of responsibility.
- Monitoring of the drug stock and purchase of supportive drug has now become the responsibility of the CMHO. .On the other hand DLO is still asked to look to the programme that doesn't have any financial power – The result is the drugs are purchased/ stocked with out looking in to the need or the justification for such purchase.
- The simplified information system does not provide sufficient information about the status of a registered leprosy case. Due to which the field staff can not carry out systematic follow up of patient as regards.
  - ➤ Progress of the disease
  - ➤ Probability of getting complications
  - ➤ Exact deformity /disability status
  - ➤ Master register not maintained at district level to ensure timely discharge of cases
- Reaction Management and treatment of complication is still centralized.
- Proportion of female cases should have increased after introduction of integration due to the availability of more number female staff but truly speaking it has not.
- Leprosy NGOs were previously getting the Anti leprosy drug for the patient they have been treating. But after the introduction of integration, this has been stopped. These NGOs who have got good reputation about leprosy services in the society, because they have been working in the field of leprosy for quite a long time even before the NLEP programme started functioning. These NGOs are now required to send cases, which report to them, to near by health facilities for registration and seeking treatment. In this process when the patient has got more faith in these NGOs if referred to Govt. Institutions, many a times such patients are lost on the way.
- The temporary hospitalization wards (THWs) have now been closed after the integration has set in. These were the only rescue points for patients with deformity or ulcers.

The programme intends that the cases with ulcers or complications should report to district hospital. These district hospitals are ideally not equipped for such services. Even if these were equipped, the specialist's services would not be available to them since they have not yet make up their minds to provide services to the leprosy affected persons, since their priorities are different.

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A perspective on integration of leprosy disability with PMR services

Dr. T. Sreedhar
Chief Medical Officer (NFSG),
All India Institute of Physical Medicine and Rehabilitation,
Mumbai

National Leprosy Eradication Programme of Govt. of India:

- Developed a Programme Implementation Plan (PIP) for continuation of NLEP during 2005 - 2007.
- Since 2005, the NLEP is fully centrally sponsored scheme with GOI funds till the end of 10th plan.
- The Central Leprosy Division will maintain its present strength till the programme achievement is consolidated.
- The Central Leprosy Training & Research Institute and 3 Regional Leprosy Training & Research Institute will support programme in management of complicated cases, prevention of disability and care and Re-constructive surgery in their allotted districts / States.

Ref: PIP for continuation of NLEP from 2005 - 2007, Ministry of Health & FW.

Background:

Prevention of deformity was all along an integral part of the National Leprosy Eradication Programme (NLEP) in India. Focus of attention, however, varied during the last two decades as the national programme passed through various phases of implementation.

Objective:

- To streamline the POD services with aim to prevent new deformities / disabilities and also to prevent worsening of existing range of disabilities.
- To provide reconstructive surgery services from increased number of specialised centers to make them more accessible to patients from all states/ UTs.

Strategy:

- Provision of prevention of deformity/ disability and rehabilitation services from three level of primary, secondary and tertiary care units.
- Upgrading of institutions on need basis after assessment by experts.
- Training to all the category of staff at all level with appropriately revised training manual.
- Strict supervision and monitoring of the programme, with periodic evaluation for corrective action.
- Programme to be conducted jointly through central, state and NGO institutions, fully coordinated by the state leprosy societies through the district leprosy units.

Rehabilitation activities supported by Central Government:

- Prevention of disability camps at block level.
- Supply of MCR footwear to needy leprosy patients.
- Provision of materials for ulcer care.
- Re-constructive surgery to perform in GOI's approved institutions.
- Above services will also available through ILEP supported 122 referral hospitals.

Goal:

- To clear backlog of leprosy disabled persons who need medical rehabilitation services.

Reproduced from the PPT Presentation

- To provide to the leprosy disabled persons on need basis materials like MCR footwear, grip aids, self care kits, splints for hands and feet etc.

Services rendered by PM&R Institutions:

- Aids and appliances
- Treatment of tropic ulcers
- Special footwear
- Reconstructive surgeries for deformity correction
- ADL training and adaptations
- Physiotherapy for post-op cases
- Vocational training

NLEP – Proposed plan for Disability Prevention and Medical Rehabilitation (DPMR):

Now, that the country has achieved the primary goal of leprosy elimination as a public health problem, it is felt that prevention of deformities and disabilities need to be given higher emphasis during the 11th Five Year Plan period (2007 - 2012). The services are to be provided through the following infrastructures existing in the country.

A. **Primary level care** – all primary health centres, community health centres, sub-divisional hospitals & urban leprosy centres.

B. **Secondary level care** – all district hospitals and temporary hopitalisation wards.

C. **Tertiary level care** – (1) Physical medicine and rehabilitation (PMR) units; (2) 41 specialised leprosy hospitals under NGOs; (3) State govt. hospitals (LRPUS) and medical colleges and (4) CLTRI, RLTRIs and Jalma (ICMR).

Partnership with ILEP agencies assisting NLEP:

- MOU for collaboration between with GOI and ILEP for the period 2005-2007.
- On the principle of supporting the national goal of NLEP and sustaining effective leprosy services after integration into GHS.
- GOI will ensure adequate drug supply for the treatment of leprosy and management of complicated clinical conditions in leprosy cases.
- The expected annual expenditure of the collaborative activities will be Rs.71.28 crore.

Ref: MOU signed on 8th February 2005 at New Delhi between GOI and ILEP

Rehabilitation activities undertaken by NGOs:

Establishing Leprosy Referral Centres (LRCs) and providing

- Technical assistance to GHC staff in diagnosis and treatment of complications.
- Appropriate aids and appliances for prevention of disabilities.
- Reconstructive surgery for correction of the deformities.
- Vocational training to and socio-economic assistance to leprosy affected persons.
- Capacity building of GHC staff.

Group meeting of leprosy experts from Govt. & NGO was organized by GOI:

The participants were divided into three groups and the following terms of reference were assigned:

Group - I:

- To suggest a system for management of reactions.
- To treat relapses without any residual disability from first, second and third level of leprosy service providing centers.

Suggestions:

- To prepare list of major components.
- To describe activities for each component (training requirement, logistics/supply, referral – coordination/linkages, supervision and monitoring, etc.)

- To identify the functionaries responsible for each of the activities in the first, second, and third level of service providing institutions.
- To prepare job responsibilities of above functionaries in relation to the subject under consideration.
- To list out the resources required.
- To mention time frame wherever applicable.

Group –II:

- To suggest a system for providing assistance to all persons with disabilities due to leprosy.
- To prevent further worsening of their disability from first, second and third level of leprosy service providing centers.

Suggestions:

- To prepare list of major components.
- To describe activities of each component (training requirement, logistics/supply, referral-coordination/linkages, supervision & monitoring, etc.).
- To identify the functionaries responsible for each of the activities in the first, second and third level of service providing institutions.
- To finalise training manuals for tertiary/ secondary / primary level care institutions.
- To start training for each category of staff.
- To finalize recording and reporting system including indicators to be followed under the programme.
- To complete logistics and supply requirements.
- To start providing services on the proposed line.

Group – III:

- To suggest a system to make RCS services easily accessible to majority of persons in need through well distributed specialised centers (Govt. & NGO).

Suggestions:

- To prepare list of major components.
- To describe activities of each component (training requirement, logistics / supply, referral-coordination / linkages, supervision & monitoring, etc.).
- To identify the functionaries responsible for each of the activities in the first, second and third level of service providing institutions.
- To prepare job responsibilities of above functionaries in relation to the subject under consideration.
- To list out the resources required.
- To mention timeframe wherever applicable.

Major components

1. Identification
   - (a) Awareness
   - (b) Suspect
   - (c) Referral
   - (d) Diagnosis
2. Management
   - (a) Counseling
   - (b) Initiation of treatment
   - (c) Follow up treatment
   - (d) Recording

Awareness: education of the patient at the start, during and at the end of leprosy treatment by MO, pharmacist and health worker.

Suspect and referral by health worker: (reaction and relapse) training of health worker by district nucleus or MO PHC during routine meetings. Health worker may be provided flash card, symptom guide and referral slips.

Diagnosis: diagnosis of reactions can be made by

MO of PHC. A symptoms and signs guide will help him in distinguishing mild from severe reactions and also in suspected relapses may be referred to referral units. MO of PHC will be trained and provided learning materials / treatment protocols for managing patients.

Recording: At the PHC level a small change can be introduced in the existing patient card.

Management:

1) Counseling – guideline to be provided.
2) Mild reaction cases are managed symptomatically and severe cases are given 2 to 3 days of steroids and referred with referral slip; treatment given – steroids/others.
3) Follow-up of cases referred back by specialist
4) Recording - PHCs should have prednisolone, referral slips, treatment protocols and training materials.

Secondary referral level:

- Diagnosis and management of cases with reactions / suspected relapses reporting directly or referred by the PHCs.
- Patients are referred back to PHC with instructions for follow-up treatment.
- Adequate supply of steroids and loose clofazimine.
- Materials like slings, splints, pop should be available.
- Laboratory facility for smear examination.
- The services of dermatologist / physician / ophthalmologist / orthopedic surgeon and physiotherapy technician may be availed whenever required.
- The facility should have learning materials, guidelines, and treatment protocols.
- The specialists in these units may be given appropriate training.
- Separate case card with all requisite details and also register for managing the referred cases should be available.
- Medical officer of District Nucleus will coordinate and develop linkages.

Tertiary referral level:

- Patients with reaction not responding to routine treatment should be referred to this unit.
- Suspected relapse should be referred to this unit.
- Diagnosis and management of cases with reactions/suspected relapses reporting directly or referred by the PHCs/secondary referral level.
- Services like nerve decompression, treatment with thalidomide may be available at this unit.
- Record, case card, drugs, guidelines or learning materials, treatment protocol should be available.
- Adequate supply of steroids, loose clofazimine and thalidomide.
- Materials like slings, splints, POP should be available.
- Laboratory facility for smear examination.

Group III Discussion and suggestions:

- Plans to clear the backlog in 5years.
- Methods of surgical procedures to be trained at least 2 in hand and feet for 3 months.
- Appoint trained Surgeons on contractual basis.
- Physiotherapy back-up in all the centers performing surgeries.
- Identification of referral centers.
- Identified 40 ILEP centers performing surgeries along with 4 national centers for the RCS.
- Identified all National PMR centers Medical colleges and strengthen the services for RCS in form of training manpower, material, OT facilities.
- Facilities in CHC hospitals or private nursing home/trust hospitals/mission hospitals at district level for conducting RCS.

2007-2012: 11th Five Year Plan period - Objectives:

- To strengthen services provided by each level of service providers.
- To develop supervision mechanism to identify deficiency in service to take remedial action quickly. Mobile teams may be formed with one disability specialist and physiotherapist for this purpose which will be attached to the district leprosy society.
- To introduce camp approach, to gather old deformed patients for motivating them for reconstructive surgery and refer the patients to the tertiary care institutions.
- To conduct joint evaluation of DPMR programme under NLEP during 2008-09.
- To follow up actions on recommendations of the evaluation teams.
- To re-assess achievements under the DPMR programme during the year 2010-11.

2006-2007: Preparatory Phase:

- To finalise the disability prevention and medical rehabilitation (DPMR) plan under national leprosy eradication programme.
- To identify the leprosy specialised institutions (tertiary care) and area of coverage for each.
- To upgrade each institution as per need basis by the concerned organisation ILEP/Govt. of India / state govt.

Final Draft from the Experts group for consideration for 11th Five Year Plan:

- To strengthen the services provided by each level of service providers.
- To develop supervision mechanism to Identify deficiencies in service to take remedial actions quickly.
- To introduce CAMP approach to gather old deformed cases needing RCS & motivating them for RCS.
- To plan preparatory activity from 1st January to 31st March in selected centers in performing RCS & providing other Rehabilitation services to project in 11th Five Year Plan.
- To establish linkages with social sector.
- To strengthen PMR services in each Zone to start the training Doctors and paramedical for RCS at Tertiary level.
  - ***North:*** *PMR Depts, Safdarjung Hospital, New Delhi & KJ Medical College, Lucknow*
  - ***East:*** *PMR Depts, Kolkata Medical college, Kolkata & Patna Medical college, Patna*
  - ***South****: Central Leprosy Training and Research Institute, Chengalpattu & Christian Medical College, Vellore (KARIGIRI)*
  - ***West:*** *All India Physical Medicine & Rehabilitation, Mumbai & Plastic Surgery Dept of J.J. Hospital & Grant Medical College, Mumbai*
  - *And 40 ILEP centres performing RCS*
- To develop Training Module for Doctors, Physiotherapists (PT), Occupational Therapists (OT) and Orthotist by a 3 member team lead by Dr. P. Krishnamoorthy of Damien Foundation India Trust, Chennai.
- To appoint contractual Surgeons to carry on RCS and similarly other trained Paramedical staff.
- To sensitize all State & District Leprosy officers in RCS & Rehabilitation activities - to identify old cases to clear back log and flow of these cases to secondary & tertiary level centers for RCS and follow up through their MPHW workers and other PHC staff.

- To prepare job responsibilities of above functionaries in relation to the subject under consideration.
- To list out the resources required.
- To mention timeframe wherever applicable.

Implementation phase:

The Govt. of India is the owner of the programme strategy and implementation. The central leprosy division, GOI, New Delhi will coordinate the implementation. One POD consultant on contractual basis will assist in this programme. Partners in the DPMR programme will be ILEP, PMR institutions and state Govts.

Constitution of Core group:

A core group of RCS and PMR experts was constituted:

1. To develop general guidelines for referral of new leprosy patients from PHCs to PMR institutions and for identifying patients with deformities in the community for RCS.
2. To develop general guidelines for involvement of all PMR institutions for providing primary rehabilitation services to leprosy patients referred from PHC.
3. To develop general guidelines for RCS in leprosy.
4. Identify the PMR institutes in each state based on the deformity load to provide RCS.
5. To identify visiting surgical teams for each PMR institutions for training the Surgeons and Physiatrists of PMR institutions.
6. To identify Para medical Team of PT/ OT /P&O for training.
7. To submit report of individual PMR Institutions.

Identification of PMR institutions for involvement in RCS training

- Assam: Silchar Medical College, Silchar
- Chattisgarh : JNM Medical College, Raipur
- Karntaka: MR Medical College, Gulbarga
- Kerala: Calicut Medical College, Calicut
- Madhya Pradesh: GMC, Bhopal
- Maharashtra: AIIPMR, Mumbai
- Orissa: NIRTAR, Olatpur
- Rajasthan: SMS Medical College, Jaipur
- Uttar Pradesh: K G Medical University, Lucknow

PMR Institutions facilitated by ILEP doing RCS:

- Bihar: Patna Medical College & Dharbhanga Medical College.
- Orissa: Cuttack Medical college & Berhampur Medical college
- Jharkhand: RIMS, Ranchi
- Delhi: Safdarjung Hospital
- West Bengal: NIOH, Bonhoogly, Kolkata

Final recommendations by core group for 11th Five Year Plan for RCS:

- Reviewed the reports of PMR institutions and recommended to strengthen the PMR institutions for RCS as per the new guidelines evolved
- General guidelines for RCS in leprosy
- General guidelines for involvement of all PMR institutions identified for RCS
- General guidelines for referral and identification of cases for RCS and follow up after treatment
- Support provided by NLEP for RCS –one time and recurring expenditure to clear back log cases.
- Guidelines for various surgeries
- Proforma of reporting by District Nucleus
- List of instruments for RCS
- Registers for referral and action taken
- Record of RCS done
- Individual patient disability assessment forms

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Is elimination a reality in UP ? Efforts and strategies adopted to achieve the goal of leprosy elimination?

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Leprosy continues to be one of the major public health diseases in many countries including India which contributes to about 2/3rd cases of leprosy reported the world over. The disease requires special mention due to stigma and gender bias attached to the disease in many societies. Although effective treatment in the form of multi-drug therapy (MDT) is available free of cost through out the globe but many issues, regarding the disease, remain to be debated.

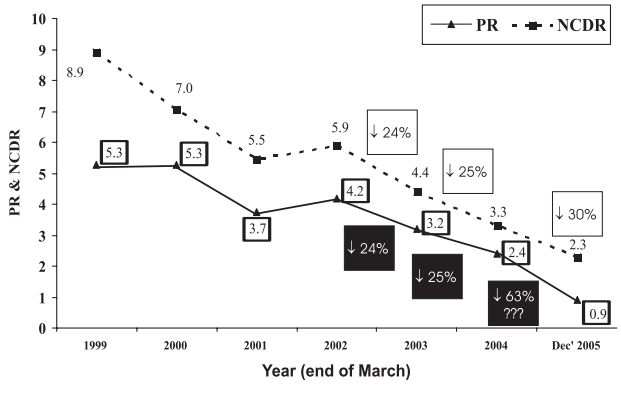
Among many important issues to be debated at national, sub national and across the globe are about its actual PR at all levels. PR currently made available is from the registration system since active field detection of leprosy cases is stopped at Government level, all over the country and programme now fully depend upon the General Health System (GHS) for detection of leprosy cases using IEC activities and for treatment delivery at its outlets like PHC/CHC and other Government hospitals. The advantages and disadvantages of the leprosy services and delivery through GHS are discussed elsewhere[1]. This paper examines the magnitude of decline in leprosy trends, its causes and efforts made to achieve this decline and if the reported decline has any basis.

To discuss the issues, we first touch upon the situation at national level then at State level and present a complete picture at District level, particularly for Agra District based on our experience.

1. Leprosy trend at National Level

The reported leprosy prevalence (prevalence or PR) at national level was 5.3/10,000 in the year 1999 declined to 3.7/10,000 by 2001 (decline of 30%). The PR during 2002 to 2005 has recorded significant decline; 24% during 2002 to 2003, 25% during 2003 to 2004 and mopping 63% during 2004 to Dec 2005- largest ever during any year. The new case detection rate (NCDR) during this period also has recorded

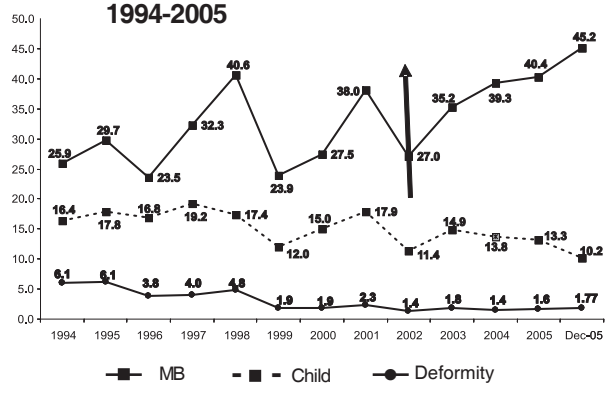
Fig. 1 : **Leprosy Trends in India**



similar pattern of decline[2] but remained always higher than leprosy PR in the country (Fig.1).

The trends in multibacillary (MB) leprosy rate, child rate (% leprosy among persons aged <15 years) and visible deformity (Grade ≥2) rate for the country as a whole are shown in Fig.1a. The data on MB rate shows increase over the years while child rate had declined to some extent. The deformity rate although observed to decline since 1994 to 2002 but then gone upward.

Fig. 1a: **Proportion (%) MB, Child, Deformity among New Leprosy cases, India, 1994-2005**

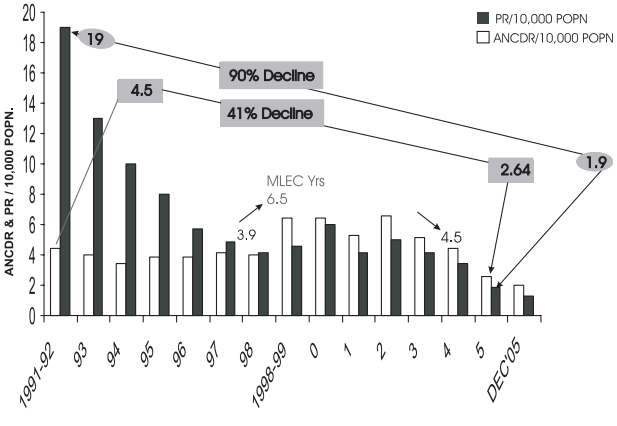


2. Leprosy Trends in Uttar Pradesh

The state of Uttar Pradesh being one of the largest states of the Indian union always has focused attention on its health status issues so also on the leprosy scenario.

The reported leprosy PR in the state[3] has declined by 90%, from 19/10,000 in 1991-92 to 1.9/10,000 in Dec'2005. Over this period, NCDR had declined by only 41%; from 4.5/10,000 to 2.6/10,000 (Fig.2).

Fig. 2: **Leprosy Trends in U.P. 1991- Dec.' 05**



One of the important observations is that PR and NCDR both have increased during the time (1999-2003) when modified leprosy elimination campaigns (MLEC) for detecting hidden leprosy patients were undertaken. The PR and NCDR during the so called MLEC years, increased to 1.5 times to 2 times higher than the PR/NCDR during the time before MLEC activities, indicating 'the wholes' in the claims made in achieving decline of PR and NCDR. However, over optimisms of these trends was the study of causes of over reporting leprosy cases but no body attempted to study the extent of under reporting of leprosy at national, state and district level. A question that anybody would like to ask as what will happen to PR/NCDR if MLEC's are repeated once again?

Extent of Over-reporting and possible causes

A study conducted during 2003 to examine the extent of over –reporting of leprosy cases in the country, revealed that about 28% of the reported cases are being over reported. This was on account of wrong diagnosis (9.4%), Re-registration (13.5%) and Non-cases (5%)[2]. For the state of Uttar Pradesh, these figures were 8.9% as wrong diagnosis, 12.5% as Re-registration and 7.7% as non cases. Another study[3] conducted by DTST in U.P. during 2005 revealed much lower (11.2%) over-reporting of leprosy cases (Table 1).

Table 1: **Case Validation by DTST - U.P. Jan - Dec 2005**

Type	Number Validated	Not a case	Wrong* Type	Re-registered
MB	3595	112 (3.1%)	201 (6.1%)	200 (5.6%)
PB	3954	180 (4.6%)	62 (1.7%)	84 (2.1%)
Total	7549	292 (3.9%)	263 (3.5%)	284 (3.8%)

* Excluding Re-registered cases and wrong diagnosis.

One of the issues which is not understood here is, why have they included those cases as over –reporting under the category of wrong diagnosis (PB as MB or vice versa) when they were actually leprosy cases and should not have been classified as over reporting

the PR or NCDR for the year. Secondly, can there be such a significant difference in figures of over-reporting (29.1% vs. 11.2%)? Does this amounts to over emphasis to show the achievements in the programme over the years?

Target Setting for Leprosy Indicators in Uttar Pradesh

Usually exercise of target setting is done based on certain programme output indicators to monitor its progress over the years. In leprosy control programme too, it is done to monitor the progress (particularly decline) in PR and NCDR and also in parameters like Child rate, MB rate and (visible) deformity rate. All the later parameters should show decline if the first two declines. The target milestones for Uttar Pradesh are shown in Table.2.

Table 2: **Targeted Milestones - U.P.**

Indicators	December 2005	
	Target	Achievement
PR / 10,000	<1	1.3
ANCDR / 10,000	2.8	2.02
MB Proportion ????	43%	42%
Disability Proportion	1.2%	0.94%
Female Proportion	40%	30%
No. of districts with PR <1/10,000	60%	27%

The state has 70 districts and 27% had already achieved the level of elimination (PR <1/10,000) by the end of year 2005 i.e. in 19/70 districts. If one looks carefully on the data presented in Table 2, it is difficult to understand how one would target to achieve a increasingly higher level of MB proportion and female proportion in any programme. Epidemiologically, high MB proportion leads to higher transmission and must give rise to high PR, high NCDR and also the high Child rate. If programme fails to catch the diseased individuals fairly early, it would also give rise to disability proportions. Secondly, target must be set when correct leprosy situation is available and understood properly that a particular intervention could help to achieve a particular target. Interestingly, whole leprosy control programme wishes to achieve every thing without a solid strategy to do so, other than the 'ones that has stopped active surveys' to find cases in the community. A deeper look into programme strategy suggests that other than the limited emphasis on IEC for cases to report to GHS, no other approach has been attempted. No body has thus far even evaluated the effectiveness of the existing IEC strategies if it really helps to attract leprosy cases to the GHS, where ever it may be properly functional.

3. Leprosy Trends in Agra District

The Agra leprosy project (ALP) was started in 1999. Initially only some selective areas were surveyed which revealed a very high prevalence[4]. During 2000-01, most of the blocks headquarters and some part of Agra city were surveyed, examination of 60,179 persons suggested a prevalence of leprosy (of semi-urban areas) as 33.9/10,000 persons examined with 84% new cases[5]. In the years 2001-03, a survey was conducted to actively detect cases in sampled areas all over the district. The prevalence was observed to be 16.4/10,000 persons examined with 88% new cases[6]. Another rapid survey during 2004-06 has suggested a prevalence of 6.1/10,000 persons examined with 97% new cases (unpublished).

The comparison of prevalence during the period of 2001-03 to 2004-06 (3 years time lag) has noticed a decline of 63% and decline in PR levels can be seen in almost all the blocks in the district (Table 3). The data during this period has also shown decline of 24%

in multibacillary leprosy (MB) type from 22.3% to 17.0%. The pattern of decline in MB% in all the blocks confirms to the pattern of decline in PR at block level. Secondly, in each survey more and more new cases are detected indicating the utility of active field surveys. These observations clearly suggest that active work, that include detection of cases at early stage and their treatment, in the community would certainly bring in the desired decline in leprosy indicators. However, one should not expect a magic change in the leprosy scenario over the smaller period of time.

Table 3: Leprosy Trends in Agra District

Block	Prevalence /10,000 Population			Change in PR during Two surveys
	Govt. Data, 2005	Active Survey, 2001-03	Rapid Survey, 2004-06	
1. Etmadpur	0.49	16.9	5.3	Declined
2. Khandoli	0.61	15.2	5.1	Declined
3. Acchnera	0.05	11.6	4.2	Declined
4. Fatehpur Sikri	0.20	1.3	1.5	Slight increase
5. Jagner	0.47	7.2	0.8	Declined
6. Kheragad	0.06	4.2	2.1	Declined
7. Saiyan	0.37	11.8	2.7	Declined
8. Akola	0.07	4.2	1.4	Declined
9. Bichpuri	0.55	-	2.8	-
10. Baroli Ahir	0.35	-	4.7	-
11. Agra	0.47	14.7	11.1	Declined
12. Shamsabad	0.56	38.5	7.3	Declined
13. Fatehabad	0.15	23.1	15.1	Declined
14. Pinahat	0.40	16.4	5.7	Declined
15. Bah	1.38	25.9	15.1	Declined
16. Jetpurkalan	1.29	46.1	15.9	Declined
All above	0.38	16.4	6.1	Declined by 63%
Population examined	None but included whole	361121	1779187	
MB%		22.3	17.0	Declined by 24%

But Agra District achieved elimination long ago:

In contrast of the above data that shows the PR in Agra district during 2004-06 as 6.1/10,000, the reported PR at district level has shown tremendously low levels of PR. In 1998-99, Agra district was one of those 5 districts in the state of Uttar Pradesh that achieved elimination (PR=0.55/10,000). The reported PR in Agra district during next few years was 0.56 by March 2004 and further declined to 0.36 by March 2005.

Indications from other Districts in U.P:

This institute (JALMA, Agra) has an ongoing activity on undertaking field detection of leprosy cases as its commitment to the cause of leprosy in the state of Uttar Pradesh. As part of this commitment, JALMA runs a regular free OPD for leprosy patients who may be from any part of the country and in addition, conduct community surveys to detect leprosy cases and provide treatment.

In parallel to this objective, JALMA has field based projects in Ghatampur Tahsil of Kanpur Nagar District. In this, PR of leprosy was observed[7] to be 156.2/ 10,000 during 2003-04 as compared to about 5/10,000 reported from Government system (>30 folds). Similarly in other field area i.e. District Firozabad, ongoing survey in 2006 suggested that actual PR may be about >20 folds.

Concluding Observations:

It is seen that reported prevalence of leprosy has declined over the years since horizontal programme has been integrated with GHS but such a decline has been much faster during the recent years and particularly during 2004-05. Although areas where field based activities are continuing, like in Agra District, PR has declined but it has happened so in all

related indicators like MB%. However, trend from GHS reported data shows and target for higher MB% to be achieved. A study has clearly demonstrated[8] that if MB% rises from about 22% to 45%, under such a programme conditions, about 78% of leprosy cases may not approach the General health System (GHS) and thus would be missed out from treatment services. It is therefore being realized that if more MB cases are being registered at GHS, could only be the result of late reporting. This would give rise to cases of deformity along with higher transmission in the community. The continuing higher new case detection rates (NCDR) are the clear indications. However, it is not known if suppressed registration of leprosy cases in the past also contributed to this phenomenon. Some indications from U.P. are already there that more and more cases are now being reported in GHS enforcing PR to increase (unpublished Monthly data, UP).

One can draw a conclusion today with sufficient confidence that currently reported leprosy elimination picture in the state of Uttar Pradesh is certainly far away from reality, if data from 3 districts are indicative.

It may also be useful to highlight here that it is ill understood that a programme having no solid strategy to control disease, achieves miraculously just in a few years. Fear that was underneath is now so clear as evidenced from some field based surveys (Actual PR could be 20 to 30 folds higher than GHS reports) that leprosy is going to be a much serious public health problem in years to come than it is now. It is therefore recommended that remedial measures are a must to explore the real leprosy situation at all levels and concerted efforts to contain transmission.

On Civil Registration System (CRS):

It may be examined historically, if any disease, even births and deaths, are fully reported to health system of any Indian state, leave aside the leprosy. To collect information for health planning, health and family surveys are being conducted nationwide even repeatedly. National Family Health surveys (NFHS)-1 and 2 are the current examples. In addition, the Registrar-General office periodically conducts sample surveys to assess the change in required parameters of importance. Why should then we have so much dependence and exert pressure to achieve targets on leprosy indicators based on incomplete data from civil registration under GHS and ignoring all the hard core reality being reported from studies based on active surveys.

What needs to be done?

The available data from field based active surveys and experience of MLEC activities clearly suggest that information on leprosy available through CRS is far away from reality and actual leprosy prevalence is expected to be many folds (15-30) at district level. Some exceptions,however, are possible on either side but may be just a few. Majority of patients do not self report unless disease is really troublesome and this problem is confounded with factors of community confidence in state sponsored health services, its functioning etc in some of the states. It is therefore recommended that district level leprosy evaluation must be done nationwide using qualified and experienced persons. Further leprosy control planning must be based on the suggested evaluation if we wish to get rid of the leprosy as a public health disease. Otherwise public health programme would have to face the repercussions of neglect now.

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Is elimination a leap forward in Bihar?
Efforts and strategies adopted to achieve / sustain quality care in leprosy control

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State Profile:

Number of Medical Colleges	6 + 2
Number of Divisions	9
Number of Districts	38
Number of District Hospitals	23
Number of Sub Divisional Hospitals	25
Number of Primary Health Centres	398
Number of Community Health Centres	101
Number of Additional PHC	1,100
Number of Health Sub-Centres	7,013
Number of Panchayats	8,471
Number of villages	45,100
Literacy rate	47.53%
Per Capita Income	Rs.2122
Sex Ratio – Male:Female	921/1000

Is elimination a reality in Bihar?

- Bihar is the third largest populated state with 94 million population.
- Bihar contributes 12% of total country's case load.
- Bihar has not yet achieved the elimination goal but near to achieve the goal.
- MDT started in Bihar in a phased manner.
- Whole State was covered under MDT in late 1996.
- At the beginning of MDT- PR / 10000 population was 52 and deformity Rate was 9%.
- Leprosy Service was integrated in General Health Services in 2001.
- Today, MDT is available right from Medical Colleges to Health Sub-centers.
- Now Leprosy is diagnosed at routine Out Patient Department of all Health facilities without any discrimination.

Present Leprosy Situation in Bihar - March 2006
PR - 1.30 **ANCDR - 2.76**

Present Leprosy Situation in Bihar - August 2006
PR - 1.45

Reproduced from the PPT Presentation

Leprosy Epidemiological situation in Bihar:

Balance Cases as on 31st August 2006	13571
Cases detected from Apr. to Aug. 2006	10273
MB Cases as on 31st August 2006	3745 (36.45%)
PB Cases as on 31st August 2006	6528 (63.54%)
Child Cases as on 31st August 2006	1606 (15.63%)
Female Cases as on 31st August 2006	3732 (36.32%)
Deformity grade II as on 31st August 2006	173 (1.68%)
PR / 10000 population as on 31st August 2006	1.45/10000
Districts with PR less than 1/10000	5
Districts with PR between 1 & < 2 /10000	29
Districts with PR between 2 & <4 /10000	4

The decline of leprosy prevalence rate is uniform all over the state.

Status of Integration:

- Integration of leprosy was initiated in Bihar since October 2000 and it is satisfactory.
- Before integration there was great resentment among Doctors and Para Medical staffs of GHC system.
- 3 days training of all Medical Officers and Para Medical staff were organized.
- All MOs of GHC are attending to leprosy patients for diagnosis and give treatment on all working days without any discrimination.
- MDT drugs are available from the level of District Hospital to HSC.
- MDT drugs is kept in common store and issued through a common window.
- All centers are using SIS formats for reporting.
- The Health Sub Centers are providing subsequent doses of MDT to patients.
- Whenever in demand, A-MDT is being given with proper advice to the patients.

Success of Integration:

- Patients' friendly leprosy services through integrated health delivery system.
- Continuous effort to improve capacity of General Health Care System has helped to minimize operational factors.
- Intensive sustained awareness through campaign and round the year IPC.
- Special efforts to develop system for disability care with maximum stress on self care.
- Streamlining MDT management to ensure availability.
- Strong political and administrative commitment to deliver quality leprosy services to all, through regular involvement of community leaders like Members of Zilla Parisad, Mukhias etc.
- Excellent Coordination and Cooperation from all the partners i.e. WHO & ILEP (DFIT, LEPRA India, NLR and TLM).

Training to GHC staff:

- Three days leprosy training were given to all Medical Officers and Para Medical staff of GHC system.
- Management training of CMOs at NIHFW, New Delhi.
- Management training of DLOs at Patna
- Orientation training of public representative (i.e Mukhiyas, Surpanch & Members of Zilla Parisad)
- Orientation training of Under Graduates & Post Graduate Medical students, House Physicians, Nurses and trainees Nurses of all 8 Medical Colleges.
- Orientation training of School teachers, IMA members and private practitioners, ESI, CGHS, refinery Doctors and Para Medical staffs, AWW & ANM.

IEC / IPC activities:

- School IEC (No. of school covered) 3022
- No. of village covered by IEC 17687
- No. of persons contacted by IPC 177171

- Haat activities 672
- Village Group Meeting 794
- Pvt. Practitioner / RMP Doctors trained 966
- AWWs Training 1792
- No. NGO sensitized 11
- No. Banks sensitized 16

MLEC / BLAC / SAPEL / LEC:

- Conducted five MLECs in which more than 3.9 lacs cases detected and put on MDT treatment.
- Conducted 129 SAPELs and 31 LECs.
- 2 "Block level awareness" Campaigns in selected PHCs – (in 2004 & 2005)
- Two supervision month (in 2005 & 2006).
- One COMBI Activity (in 2003).

Supervision and Monitoring

- Annual meeting of Civil Surgeons, DLOs and DTST under chairmanship of Health Secretary in which WHO, Govt. of India, & ILEP representatives participated.
- DLOs and DTST meeting twice a year.
- Alternate month Zonal meeting of DLOs , DTSTs & NMS / NMA
- Quarterly meeting of SLO, WHO Coordinator & ILEP Coordinator
- Cleaning of Master register in alternate month in zonal meeting.
- Monthly meeting of PHC's MO I/c under chairmanship of Civil Surgeons in which DLOs review the program.
- Weekly / Fortnightly meeting of Para Medical staffs at PHC.
- Frequent visit of State Officials (SLO/ Addl. Directors), WHO
- Coordinator, ILEP Coordinator and Officials to district, PHC, Sub Centers and Patients Door.
- Implementation of all guide lines & activities issued from Govt. of India, WHO promptly & properly.

Support from ILEP Partners

- In Bihar four ILEP Partners supporting in Leprosy elimination Program with one Doctor, One NMA/ NMS, one vehicle and driver in each districts.
- DFIT supporting in – 22 Districts, NLR in – 5 Districts, LEPRA in – 9 Districts & TLM in – 1 District.
- DTST team supporting in planning, Implementation, Supervision, Monitoring, Case validation, training of MOs & Para Medical Staffs as well as IEC activities.
- ILEP Partners are also supporting in organizing of meeting, RCS and providing Office supports.
- POD training and Camps.
- Training of surgeons & Financial support for RCS.

Drug Management:

WHO (Sasakawa Memorial Health Foundation, The Nippon Foundation & The Novarties) providing Free MDT drugs through MSD to State.

GOI / MSD
↓
State Store
↓
Four Zonal Stores
↓
District Stores
↓
Primary Health Centers
↓
Central Govt. under taking Hospitals
Health Sub Centers NGOs etc.

Adequate stock through regular indenting and monitoring of MDT stock.

Storage of MDT drugs in common drug store and distribution through common window at PHCs.

Political and Adm. Commitment:

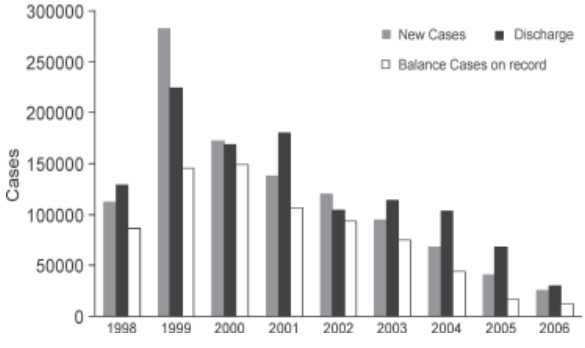
- Good will Ambassador Mr. Sasakawa visited twice in Bihar and met with Chief Minister / Governor, Health Minister and Health Officials.
- Chief Minister / Governor, Health Minister and Health Officials committed to all supports to achieve elimination of Leprosy from Bihar.
- Health Secretary / Minister attended meeting at Tokyo & Myanmar.

What has been achieved:

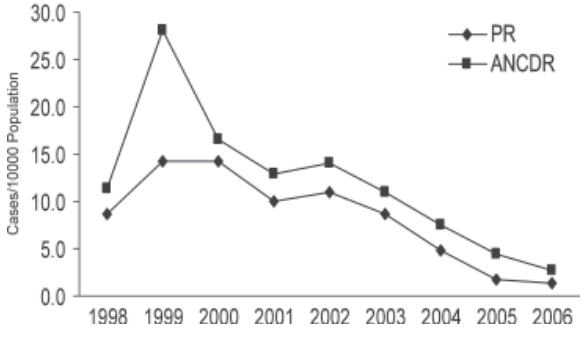
- More than 1.5 Million have been completely cured in Bihar.

- Presently 5 Districts have achieved elimination.
- More than 190 PHCs have achieved elimination.
- PR came down from 50.2 to 1.45/10000 population.
- Deformity came down from 8.9 to 1.6 % .
- Public awareness is about 67 %.
- Vertical Program integrated in General Health Systems successfully.
- MDT has prevented thousands persons from becoming disabled due to Leprosy.
- Daily availability of diagnosis and MDT services through all health facilities.

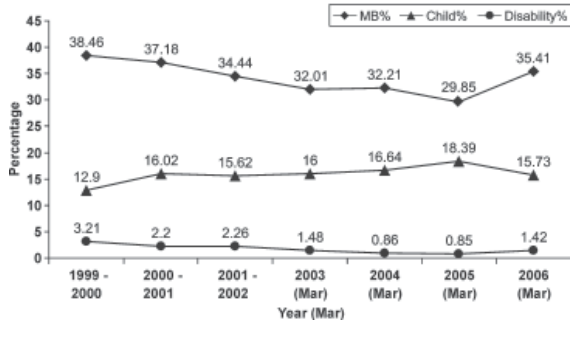
Case Detection & Discharge Trends 1998-06



ANCDR and PR Trends 1998-2006



Trend in MB %, Child % & Grade II disability % among New Cases-Bihar 1999-2006



Efforts and strategies adopted to achieve or sustain quality care in Leprosy

Capacity building:

Orientation Training Once in a year of -

- Medical officers & Para Medical workers of District Hospitals, Sub Div. Hospitals, Referral Hospitals, PHCs & Addl. PHCs.
- Medical Officers and PMW staff of Central Govt. under taking health facilities.
- Under Graduates, Post Graduates, Nurses, Trainees Nurses & House Physicians of Medical colleges.
- Orientation of Non Govt. Organisations.
- Advocacy of Public representatives.

Quality of Diagnosis:

- Availability of Medical Officers in all Govt.health facilities & correct diagnosis more than 95% at all working days without any discrimination.
- Validation before registration more than 90% cases.
- Discussion among doctors if there any suspicion in diagnosis.
- Strengthening of referral services.
- Re-registration, re-cycling, wrong diagnosis and over diagnosis < 5 %.

Quality of Treatment:

- Availability of sufficient MDT drugs from District Hospital PHCs and down to the HSCs.
- Treatment completion more than 95%.
- Timely RFT of leprosy cases more than 95%.
- Proper & regular Counseling of leprosy patients.
- Home visit of Patient's house to see whether patient is taking regular treatment and counseling of Patients.
- Back log cases to be made RFT.
- A campaigned MDT to migratory patients.
- Availability of Prednipack & timely treatment of patients of Lepra reaction.

MDT Stock Management:

- Availability of MDT drugs from district hospital to HSC in adequate amount.
- Adequate stock of MDT for all categories for two Patient's Month BCPs at all health facilities.
- Monthly & regular indenting of MDT in SIS format as per case load.
- Monitoring of MDT at each level on monthly basis.
- Storage of MDT Drugs to the common drug stores and distribution through common windows.

Quality of Referral Services:

- Establishment of referral system.
- Efficient referral system for suspects, Complications etc.
- Referral of suspect by ANMs, AWWs, ASHA & others PMWs.
- Timely referral of reactions / Complication cases.
- Referral for POD & RCS.

Quality of POD & Rehabilitation:

- Enlisting of Leprosy associated disabled persons & referring of the cases for RCS.
- Establishment of RCS in all 6 Medical colleges. At present RCS services are available at PMCH, DMCH & TLM Hospital Muzaffarpur.
- Enhancement of community participation.
- Leprosy effected disable persons get equal right & opportunities like other disabled persons.
- Two POD training cum Camps per PHC per year.

Quality of Community awareness:

Community members know about Availability of -

- Free of cost MDT drugs at all health facilities.
- Leprosy services at all PHC on all working days without any discrimination.
- Sign / Symptoms of Leprosy.
- Disease and its treatment.
- Availability of services.

Quality of Information:

- Completion of Patient Cards and updating of Master register.
- Timely sending of reports.
- Proper implementation of SIS and its use.
- New and under treatment cases as per register and MPR.
- Calculation and interpretation of indicators.

Counseling:

- Proportion of patients know about disease and its treatment.
- Proportion of patients know about side effects, residual signs & POD self-care.
- Insure the quality of Counseling provided to patients & families.
- Counseling for timely and full course treatment.
- Counseling for self POD care.

Quality of Supervision & Monitoring:

- DTST – All PHCs, Addl. PHCs & health Sub Centers at list once in 3 month.
- DLO – All PHCs & Addl. PHCs as well as 25% sub centers in two months.
- SLO / WHO Coordinators – 5 to 6 Districts,10 to 12 PHCs and 20 to 24 Patient's Door.
- Quarterly meeting of SLO/ Addl. Dir., WHO & ILEP Coordinators.
- Zonal Meeting of DLOs/ NMA & NMS in alternate month.
- DTST review meeting in alternate month at state head quarter.
- Up dating / cleaning of Master register in Zonal Meeting.
- Monitoring of MDT drugs during district / PHC / SHC visit.

❐ ❐ ❐

Is elimination a leap forward in Chhattisgarh?
Efforts and strategies adopted to achieve / sustain quality care in leprosy control.

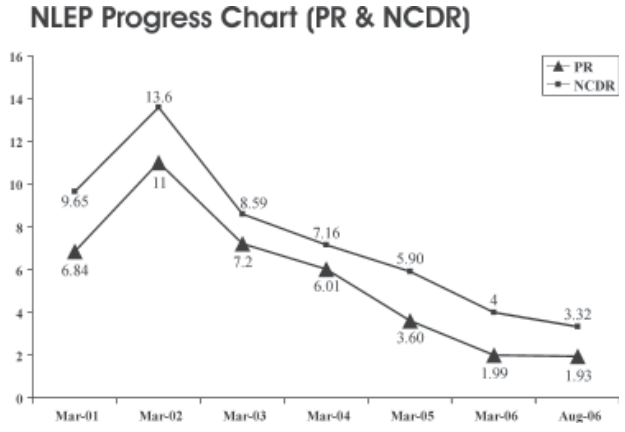
Dr. B. S. Sarwa,
Joint Director & State Leprosy Officer
Director of Health Services, Raipur, Chhattisgarh, India

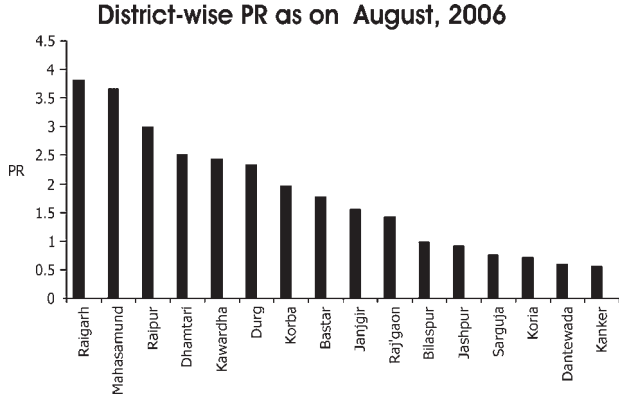
Chhattisgarh State profile:

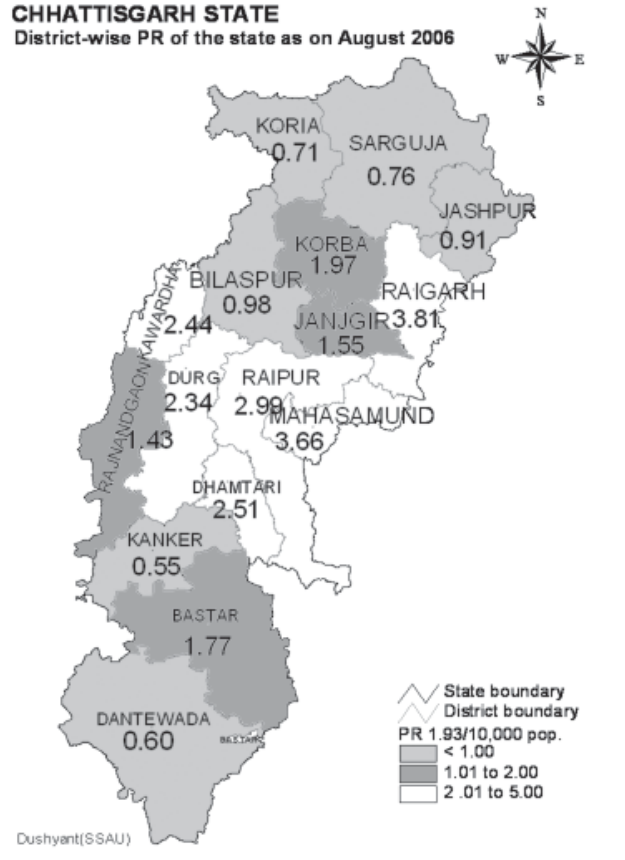
Area –	135191 Sq. Kms
Population –	2,25,80,282 (Estimated 2006)
SC Population –	26,30,602 (11.4%)
ST Population –	72,66,634 (32.17%)
No. of Districts –	16
No. of Blocks –	146
No. of Tribal Block –	85
District Hospital –	16
Community Health Centres –	116
Primary Health Centres –	516
Sub Health Centres –	4692
Ayurved & Homeopathy Dispensary –	69

Epidemiological Indicators of the state: 2001-2006:

Indicators	2001-02	2002-03	2003-04	2004-05	2005-06	Apr - Aug 06
PR	11.0	7.20	6.01	3.60	1.99	1.93
NCDR	13.6	8.59	7.16	5.90	4.00	3.22
PD Ratio	0.80	0.83	0.83	0.61	0.49	0.59
MB %	37	40.7	44.73	47.44	50.69	50.73
Child %	12.6	11.27	9.09	9.02	6.70	6.19
Disability %	2.7	2.65	2.07	2.49	2.32	2.23







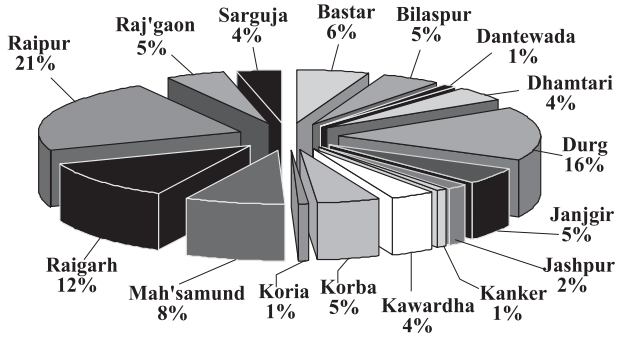
Distribution of districts according to PR as on August 2006

PR	01-02	02-03	03-04	04-05	05-06	Aug'06
< 1	0	0	0	3	5	6
1-2	0	0	2	1	5	4
2-5	5	7	5	9	6	6
5-10	8	6	7	3	0	0
>10	3	3	2	0	0	0

Change in the district wise PR

District	March 2006	August 2006
Raigarh	4.08	3.81
Mah'samund	3.26	3.66
Raipur	3.22	2.99
Dhamtari	2.98	2.51
Kawardha	1.93	2.44
Durg	2.38	2.34
Korba	2.02	1.97
Bastar	1.64	1.77
Janjgir	1.60	1.55
Raj'gaon	1.35	1.43
Bilaspur	1.28	0.98
Jashpur	0.99	0.91
Sarguja	0.68	0.76
Koria	0.75	0.71
Dantewada	0.69	0.60
Kanker	0.52	0.55

Proportion of Cases in Districts of Chhattisgarh Aug, '06



Operational factors responsible for declinig trend:

- Identified areas with PR>2, endemic districts, district with high disability with high child proportion and endemic urban locality.
- Increase awareness about leprosy among the masses.
- Capacity building of all categories of General Health Care Staff.
- Confirmation before Registration of new cases.
- Proper counseling at the time of 1st dose & whenever & wherever as per need.
- Weekly updating of treatment register (LF-02) at sector meetings by MPHW.
- Irregular retrieval within a fortnight by MPHW.
- Accompanied MDT (AMDT)
- Availability of MDT at sub-centre level. At any point of time, number of patients under treatment = number of BCPs.

Training of GHC personnel

Sr. No.	Categories of GHC personnel	No. Trained
1	Medical Officers	1362
2	Ayurvedic, Homeopathic & Unani MOs	237
3	Health Assistant	1084
4	MPWs	6137

Special strategies adopted for endemic blocks

Year	146 blocks distribution as per PR				
	>10	5 to 10	2 to 5	1 to 2	<1
2001-02	52	35	59	0	0
2002-03	28	43	56	19	0
2003-04	17	46	41	26	16
2004-05	3	22	52	24	45
2005-06	0	6	36	47	57

Intensive IEC activities were carried out:

- during BLAC – I in 2004 in Blocks having PR 5 & above.
- during BLAC – II in 2005 in Blocks having PR 3 & above.
- during every fortnight under Sustained Activity Plan-2006 at Block level through Inter Personal Communication (IPC) method.

Details of IEC activities carried out in the State

1	Wall Painting	14750
2	Hoardings	41
3	Tin Boards	7500
4	Folk Dances & Folk Shows	250
5	Revolving Display Panel	02
6	Global Appeal	1000
7	Mailer	100000
8	Learning Material on Leprosy to Medical Officers	7000
9	Guide book on Prevention of disabilities in Leprosy	5950
10	Plastic Coated Posters	30000
11	Stickers – 4 types	60000
12	Meri Diary (Pocket Diary)	20000
13	Rallies	17
14	Cinema Slides	400

Priority areas as on March'2006

Sr. No.	Category	PR/10,000		Total	Districts with high priority areas
		2-5	>5		
1	Districts	6	-	6	Dhamtari, Durg, Korba, Mahasamund, Raigarh, Raipur
2	Blocks	36	6	42	Dhamtari, Durg, Korba, Mahasamund, Raigarh, Raipur, Kawardha, Bastar, Rajnandgaon

Activities implemented at District level:

- Re-orientation training of MOs & including staff of District Nucleus
- Re-orientation training to all PHC staff (including urban areas)
- Re-allocation of DTST teams
- Blockwise situational analysis of indicators and action taken
- Regular supervision by state level & district level officers of priority areas
- District coordination meeting in all high priority district with situation analysis and micro planning for intensive IEC activities
- Referral slip is in use for suspect referral by MPHWs

Activities implemented at Block level:

- Posting of one NMS/ senior NMA to each priority Block.
- Training of GHC staff in respect of
  - Family counseling of MB patients
  - Retrieval of irregular patients
  - Close monitoring of MDT consumption by patients.
- Sectorwise situational analysis of indicators and action taken.
- Intensive supervision to all health facilities by District level supervising officers.
- Attendance of NMS/NMA in weekly sector meeting on rotation is a must.
- Involvement of ASHA (Mitanin), Aganwadi workers, PRI members & traditional healers.

Provision of quality care and referral services for POD after integration:

- MOs indicate in Patient Card (LF-01) about 'high risk' cases apt to develop reaction / neuritis.
- MPHWs trained to suspect cases of reaction and neuritis.
- Referral slips provided at sub-centre level.
- MOs are trained to treat simple complicated cases and refer severe complicated cases.

- Prednisolone and supportive medicines are made available at all health facilities
- Specialist in skin/medicine and a senior MO of Dist. Hospital have been trained to manage the referred cases
- Orientation training to 2 Laboratory Technicians in each district and all 13 Physiotherapy Technicians available in state. Steps are being taken to post one Physiotherapy Technician to each district in order of priority.

Details of POD camps organized :

Number of Model POD Camps organized	514
Number of patients learnt Self-care practices	8224
Number of GHC Staff including MOs provided on the job POD training	4023

Details of POD activities:

Number of RCS operations carried out	568
MCR Footwear distributed (By All centres & districts)	11254
Goggles distributed (By All centres & districts)	1083
Supporting Aids (Finger splints, Foot drop spring, etc.)	1387

32 surgery were performed on 17th & 18th August 2006 with active coordination of District Collector, CMO, DLO, Bilaspur & RLTRI under DPMR.

Care for the disabled patients in 2006-07:

1	Number of RCS operations carried out	96
2	MCR Foot Wear distributed (By All Centres & District)	702
3	Goggles distributed (By All Centres & Districts)	50

Operational factors that affect quality care:

At PHC level

- Out of 722 sectors in state, there are sector health institutions (PHC) only at 516 sectors
- There is vacancy of sector MOs post in 25 PHCs
- Full involvement of cent per cent MOs in the leprosy programme still awaited
- Hilly terrain and naxalite activity pose a constant problem
- Stigma still prevailing in 25-30% community
- List of leprosy affected persons with disability is yet to be completed

At District level

- In 12 out of 16 districts, DLO is having multiple duties like In- charge of other programmes, BMO, OPD and night emergencies in Dist. Hospital
- MO of District Nucleus although trained is not able to function full-fledged because of clinical duties in hospital and posting in peripheral health institution
- Laboratory in District Hospital for skin smear examination is lacking in 60% of the districts
- 13 Physiotherapy Technicians are clubbed in 3 adjacent districts including capital and yet to be redeployed.
- Urban leprosy strategy needs involvement of NGOs exclusively to work in the leprosy programme.

Suggestions:

1. Supports from partners like ILEP, WHO & NGOs should continue for another 2 years; i.e. at least 1 year after achieving elimination of leprosy as a public health problem.
2. Incentive in form of cash/reward should be introduced for PRI members, Community members, Private Practitioners & Volunteers for active involvement in programme.

Is elimination a leap forward in Jharkhand?
Efforts and strategies adopted to achieve / sustain quality care in leprosy control

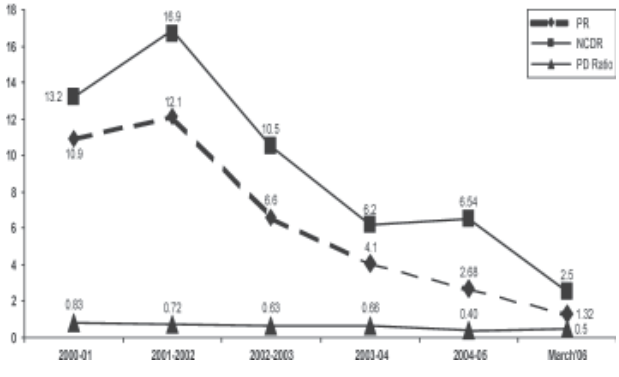
Dr. S. C. Nayak,
Dy. Director cum State Leprosy Officer, Jharkand

Introduction:

- Newly created small state with huge hilly and tribal area
- Surrounded by major endemic states like Bihar, West Bengal, UP, Chhattisgarh and Orissa
- 2.6 % Population of India
- 4.1 % leprosy case load of India
- PR: 13.1/10000 in 2000 (At the time of Separation from Bihar)
- PR 1.31/10000 as on 31st March 2006

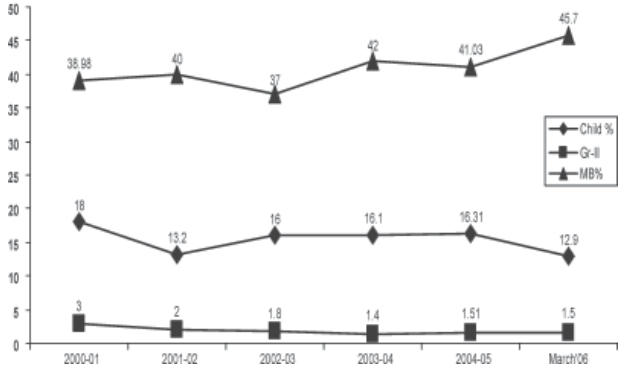
Jharkhand has not achieved elimination goal till date. But without doubt, the State is nearer to its goal.

Trends of PR, NCDR AND PD Ratio of Jharkhand



Reproduced from the PPT Presentation

Trends of MB%, Child% & Gr. II% of Jharkhand



Positive factors as per LEM – 2004 Report:

Correct Diagnosis:	90%
Correct Typing:	84.5%
PD-Ratio:	less than 1
Gr.II Disability:	1.4
Cure Rate:	91.2%
HCF providing MDT services:	96.4%

- Pre confirmation at PHC /APHC
- 100 % validation within two months
- Fixed day validation & counselling at PHC level
- Regular IPC by NMA in endemic villages
- NMS supervises 25%
- Sector Medical Officer supervises 10%

Negative factors as per LEM – 2004 Report:

Under reporting	:	10.7
Over reporting	:	14.2
Wrong diagnosis	:	6.7
Re-registration	:	8.3

Areas of concern:

- Internal Monitoring at PHC By MO I/c
- Internal Monitoring at district By CS
- Calculation of indictors the tool to monitor
- Buffer stock MDT — all categories
- Supervision
- Capacity building at GHCS for sustenance of integration

Efforts & Strategies adopted to achieve:

Regular I.E.C. in the State without any funds

An innovative strategy is going on in Jharkhand - *"Gram-Gosthi"*

- ***Every ANM / BHW is organizing group meeting to sensitize 8-10 persons, in a village, every week around the year.***

Leprosy Awareness through:

- Group meetings in all the villages
- Sensitization through *inter-personal communication*
- Total no. of ANM/BHW: 5338
- Total no. of Villages : 30628
- Beneficiaries (April'06 to Aug'06): 742974
- Suspected during the meeting: 1141
- Confirmed Cases during the meeting: 332

Strategy for Un-reached Population in urban slums:

- Urban Leprosy Control Plan
- A- MDT encouraged
- Involvement of Aganwadis
- Local Volunteers and Organized Health Sector

Reached office goers, factory workers, labourers in unorganized sector.

Strategy for Un-reached Population in rural areas

- Special IEC Drives
- Health camps in remote area
- IEC in local language
- Involvement of cured leprosy patients (Lokdut)
- AMDT – encouraged
- Involvement of AWW, Sahiyas

Reached the population in difficult to reach and law and order problem areas

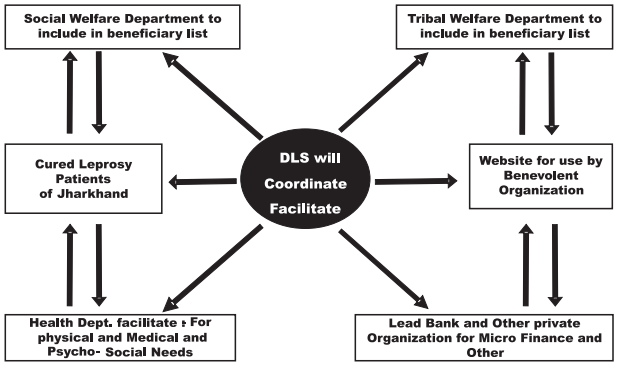
Provision for quality care for POD Services:

1. Regular training for Medical Officers in Reaction Management (Diagnosis, Treatment and Referral) at least 3 to 4 times.
2. Contractual Medical Officers were trained as above once.
3. Health Workers were oriented on the signs and symptoms of reaction and referral.
4. Districts authorized for procuring Prednisolone and supportive drugs.
5. POD Camps – Organized in all PHC & Urban area – Two times (Repeated this year).
6. Foot Care, Eye Care, Hand care (POD Materials, Provided to patients as per need).
7. MCR Chappals procured and supplied to patients through DLS.
8. IEC Materials related to POD has been distributed
   - Scroll Board at PHC & District
   - Flip chat at Sub Centre
9. DLOs are busy preparing disabled patient list PHC Wise.
10. Referral system for Reaction disability :-

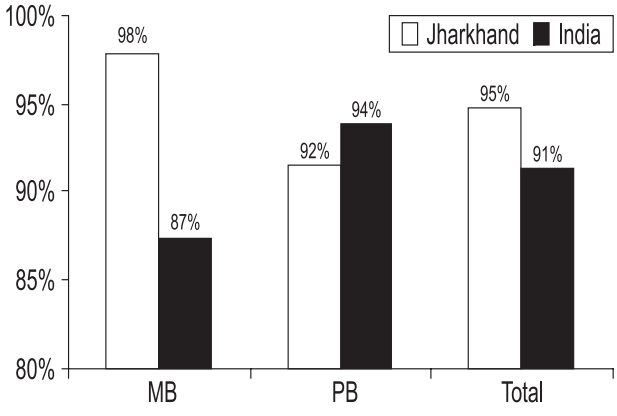
    Sub Centre ⇆ PHC ⇆ District ⇆ Medical College

11. Re Constructive Surgery at RIMS, Ranchi – Provision of RCS services established through ILEP Support.

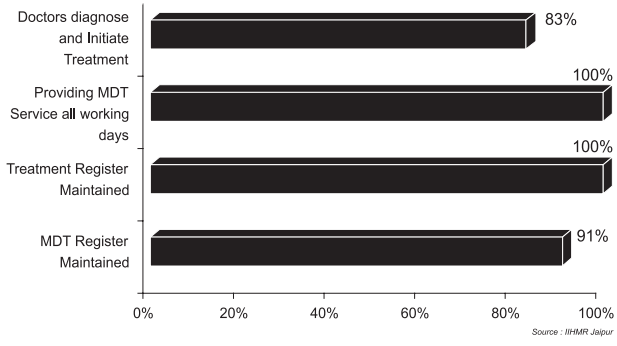
Networking for Rehabilitation



Cohort Cure rate Compared-IIHMR



Integration - MDT Services in Jharkhand



Competence of GHS:

Diagnosis	4/5
Classification	3.75/5
Diagnosing Complication	3.4/5
Managing Complication	3.2/5
POD	3.6/5
Diagnosing Relapse	3.5/5
On SIS	3/5
Calculation of Indicator	2.5/5

Source : IIHMR Jaipur

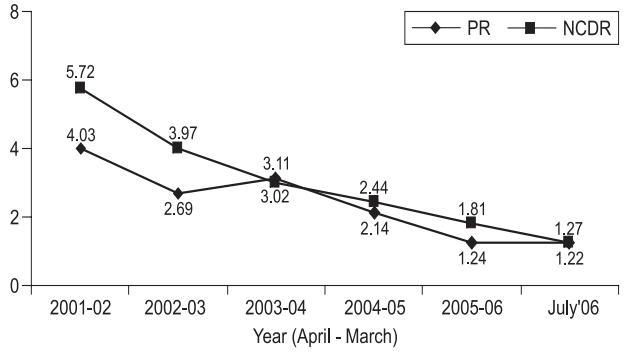
- Re-registration of Leprosy cases: 4.9%
- Improved accessibility : 3 Kms and Rs.2/-
- Satisfactory MDT service in terms of accessibility, User satisfaction and Cure rates

In conclusion, the distance between the success and failure can only be measured by ones desire.

Is elimination a leap forward in West Bengal?
Efforts and strategies adopted to achieve / sustain quality care in leprosy control

Dr. Aniruddha Kar
State Leprosy Officer,
Kolkata, West Bengal

Trend of PR & NCDR



Leprosy Status from April 1994 – July 2006

Year wise	Balance Regd. Cases beginning of year	New cases detected	Cases Discharged		Balance Regd. Cases end of year	Per 10,000 Population		PD Ratio
			Cured (RFT)	O.D		PR	NCDR	
94-95	1,49,427	48,465	78,495	23,795	95,602	12.76	6.47	1.97
95-96	95,602	41,379	58,846	7,198	70,937	9.26	5.40	1.71
96-97	70,937	42,092	36,137	25,226	51,666	6.63	5.40	1.23
97-98	51,666	38,607	44,654	8,197	37,422	4.72	4.80	0.98
98-99	37,422	73,832	44,528	12,610	54,116	6.64	8.88	0.75
99-00	54,116	55,347	55,250	11,747	42,466	5.25	6.73	0.78
00-01	42,466	36,331	46,558	9,843	22,396	2.72	4.33	0.63
01-02	22,396	46,620	33,175	2,970	32,871	4.03	5.72	0.70
02-03	32,871	32,374	40,578	2,772	21,895	2.69	3.97	0.68
03-04	21,895	25,050	18,765	2,423	25,757	3.11	3.02	1.03
04-05	25,757	20,908	19,779	8,565	18,321	2.14	2.44	0.86
05-06	18,321	15,755	18,115	5,167	10,794	1.24	1.81	0.69
July'06	10,794	5,094	4,487	760	10,641	1.22	1.27	0.96

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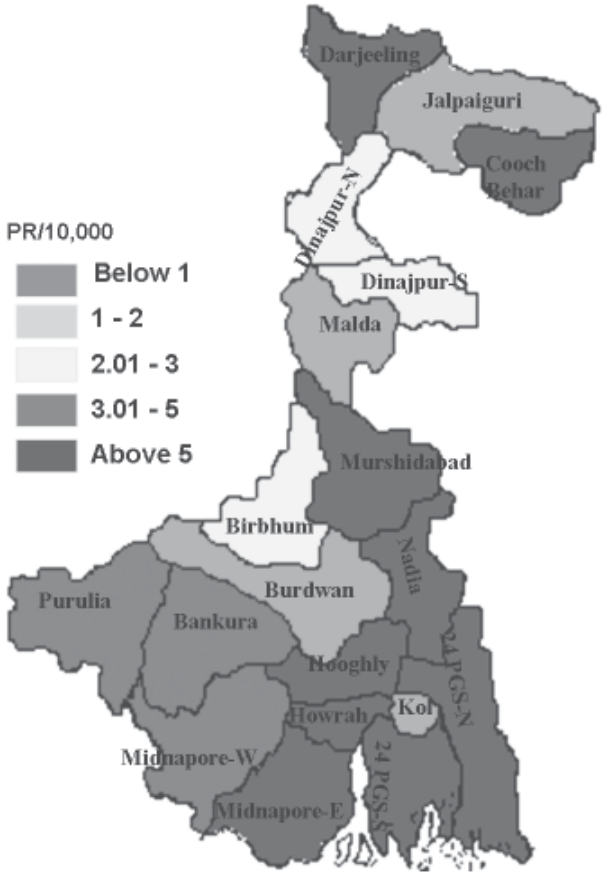
As on March, 2002 (PR 4.03)

As on March, 2006 (PR 1.24)



Change in epidemiological indicators

Indicators	March 2002	July 2006
PR	4.03	1.22
ANCDR	5.72	1.27
PD	0.70	0.96
Deformity %	2.74	2.83
Child %	13.29	9.11
Female %	NA	33.16
MB %	39.35	52.70

Current leprosy status:

- **State Level**
  - ñ Prevalence rate : 1.22 (1.88)
  - ñ Case Load : 10,641 (16,132)
  - ñ New Case detected in 4 months : 5,094 (5,796)
- **District Level**
  - ñ Districts achieved level of elimination : 9
  - ñ PR between 1 and 2 : 4
  - ñ PR between 2 and 3 : 4
  - ñ PR between 3 and 4 : 2
  - ñ PR above 4 : Nil

Fluctuations or steep reduction in the Prevalence:

- Reduction of PR in the different districts came down slowly:
  - ñ No steep fluctuation noted in any district.
  - ñ NCDR also came down gradually.
  - ñ The PD ratio is below 1 since 1997

Issues related to elimination:

- The State feels sustained quality care can only reduce the disease burden.
- Focussed attention given on POID, RCS, vocational training etc.
- To reduce operational short comings emphasis given on :
  - ñ Routine checking of the registers
  - ñ Routine validation
  - ñ Regular review meeting at block level, district level, and state level.
- Establishment of referral system.
- Elimination is not the priority, quality care will help eliminate in due course of time.

Cross Sectional Surveys:

- Cross sectional surveys are frequent and regular done by :
  - ñ CLD
  - ñ WHO
  - ñ ILEP
  - ñ State
- The reports received through such surveys are made into operational
- Changes are recorded and indicators are analyzed for preparing micro plan of the next year

Special strategy adopted to cover the unreached population:

- Conduction of BLAC
- SAPEL for hard to reach population
- Need based areas specific IEC
- Involvement of the PRIs, SHGs, ICDS & NGOs
- Organize GP level meeting
- Operational research / Health System Research to solve priority problems/evolve alternative strategy.

Plans to reduce the disease burden:

- Emphasis on early diagnosis.
- Management of reaction at all levels
- Availability of MDT and predinisolone at all levels.
- Defaulter follow up
- Routine monitoring and monthly GP based meeting
- Regular POID camps
- Organizing RCS
- To mobilize the PRIs, NGOs and SHG group.

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Tasks for Integration

Dr. S.K. Noordeen
President
International Leprosy Association
Ex. Director,
Special Action Programme for Leprosy, WHO, Switzerland

Integration Integration – Historical Historical Perspectives Perspectives:

- Communicable disease control through vertical specialized programmes Vs through general / primary health services has been debated for a long time (i.e.) since 1960's.
- Alma Ata Declaration gave fillip to primary health care and integrated approach.
- In India itself leprosy control through general health services had been discussed as early as the 1970's and introduced on an experimental basis in Karnataka.
- The strong resistance against integration then lead to the integration initiative being withdrawn.
- The interest in integration has been revived particularly in the last 10 years.

Arguments in favour favour of Vertical Programmes:

- Only way to deal with very heavy disease burden.
- Complexicity of control measures.
- Better quality of services including POD.
- Inability of GHS to handle.
- Possibilities for time bound strategies.
- Ability to raise disease specific funds.

Arguments in favour of Integrated Programmes:

- Widest possible coverage of services.
- Application of simplified procedures.
- Availability of referral chain.
- Optimization of resources.
- Mitigation of stigma.
- Acceptability by the community.

Integration issues in high endemic situations:

Although it is possible to integrate in high endemic situations problems exist in terms of:

- Ability of GHS to cope with the a large sized problem problem.
- Ensuring specialized activities.
- Coordinating with specialized supportive functions.
- Managing specialized Information Systems.

Integration issues in low endemic situations:

- Maintaining necessary skills for diagnosis and treatment.
- Drug logistics for very small number of cases.
- Maintaining the required priority for leprosy.
- Maintaining the information system.

Integration at different levels of health service:

Successful integration envisages integration at primary, secondary, and tertiary levels of care. This means capacity building of an appropriate nature will have to be organized for each level. In addition the referral mechanism and the feed back from higher to lower levels should be satisfactory.

Integration of essential activities at the primary level:

At the primary level the requirements to provide the essential services should be clearly identified and put into place. These include ability to suspect, ability to

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diagnose uncomplicated cases, ability to provide MDT, and ability to deal with minor complications. Besides these the services should be able to carry out necessary follow up of patients to ensure high levels treatment completion.

Integration of referral services:

The first and second level of referral services which is part of GHS should have the capacity to deal with diagnosis of all problem cases in terms of diagnosis, treatment, and management of complications. Facilities for rehabilitative surgery should be available at least at tertiary hospitals as part of the overall surgical service within GHS.

Integration of capacity building:

It is important that task oriented training on leprosy should be available as part of all training programmes of all types of health workers including physicians. This should include training in medical colleges, and other schools for health personnel. All on the job training programmes and refresher training programmes for health workers should include leprosy.

Integration of rehabilitation services:

While surgical rehabilitation should be integrated within general surgical care other aspects such as POD, physiotherapy, occupational therapy etc should become part of Community Based Rehabilitation programmes covering all disabilities.

Integration of Socio-economic support:

Socio economic support envisages inter-sectorial approach and this is best provided for leprosy affected persons as part of such support to all categories of disabled.

Integration of supervisory support:

In the integrated setting there will be no need for specialized leprosy supervisors, and the general health supervisors with proper training should be able to carry out the necessary supervisory tasks.

Integration of information system:

Integration of information system covering the minimum necessary information on leprosy is not only necessary but is inevitable.

Integration of IEC and advocacy activities:

Although leprosy requires intense IEC and advocacy efforts to combat social stigma it is likely to be more effective when it is presented as part of a package of several health messages.

Integration of surveillance:

Surveillance of the leprosy situation in different geographic areas is a very critical activity to ensure that there is no resurgence of the disease and that there is a steady and continued decline in the occurrence of leprosy. However this should be part of surveillance of all communicable diseases.

Integration of NGO and donor support:

This is an area which need careful evaluation so that the support available hitherto exclusively for leprosy continues to be available as part of the support of a communicable disease package such a package of neglected diseases.

Integration of research:

This is already happening in basic research. Other areas of research should also look at research issues in general and look at their relevance to the problem of leprosy.

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Views and opinions raised by the panel members and delegates

1. On registration of new leprosy cases for MDT

"I am rather struck by one finding that almost every speaker from all the States had highlighted. There is a steep decline in prevalence rate and annual new case detection rate following integration. We have been using the same MDT during the vertical programme and during the integrated programme. The steep decline during the last 4 to 5 years have been to the tune of 90% in the prevalence rate (PR) and almost the same with annual new case detection rate (ANCDR). If this has really happened, it is commendable and the States achieved should be complimented for that. If this is not so, we must find out the reasons for the same.

I wonder why this could not happen with the vertical programme with the same drug given for 13 to 14 years, whereas in just a matter of 4 to 5 years 90% reduction is achieved. This makes me think that we may be playing more with figures than the interest of leprosy patients. Whether it is because of decrease in reporting to primary health care or directions for what we call 'zero' registration are also to be looked into.

The consensus is that there are still new cases and there is need for strengthening the primary health care system, so that the emphasis could continue on leprosy like any other disease. We should keep making good effort."

Dr. B. K. Girdhar

"There is a big divide between 'haves' and 'have-nots' in leprosy. The 'haves' have seen tremendous changes and 'have-nots' are still struggling. The institutions run by The Leprosy Mission are not able to fill the wards with leprosy patients. Therefore leprosy institutions are being converted into general hospitals. There are surgical facilities, which are complaining that they are not getting enough leprosy cases. An Ophthalmic hospital exclusively built for dealing with ocular leprosy with 30 beds in Karigiri is not getting even a single case with ocular problems. So there is lot of changes taking place, which you can indirectly experience.

These are not as easy to measure as the number like PR, NCDR, deformity rate and other rates. Let us take the good developments in a very positive way. We are definitely seeing a huge change, certainly not enough, but we are in the right direction."

Dr. S. K. Noordeen

"Dr. Noordeen has rightly said that the profile of disease which we see now is not the same as we saw 20 or 30 years ago. This is true in Agra too. Twenty years ago, we would see about half a dozen lepromatous leprosy case with nodules every week and now we see one case in 2 weeks or so. Nevertheless, they are still present and that cannot be denied."

Dr. B. K. Girdhar

"I totally agree with Dr Noordeen and Dr Girdhar. As a measure to reduce the public health problem, the integration will work definitely, but over a long period of time. Having taken a plunge into integration, what are the interventions and techniques needed at this level? In a chronic disease like leprosy, nothing can be achieved over night."

Dr. R. Ganapati

A summary of views and opinions raised by the panel members and delegates are presented thematically to facilitate easy reading.

2. On setting targets

"I had the privilege of listening to about 17 speakers and keenly observing the proceedings. The title of this Workshop is, 'Is integration a leap forward?' There was some thought provoking statement as to whether it is backward or static by Dr KV Desikan. It sounded like government review meeting with everybody saying it is a success. The process of integration is a success as far as PR and NCDR is concerned. The emphasis on target of 1 per 10,000 is being interpreted by the lower level such as District Leprosy Officers and Medical Officers even now. This doesn't come to the surface. Unofficially it continues to happen. Even if you take the new cases into consideration, the MB ratio is high and cases with disabilities detected for the first time is 2% among the new cases. Is this acceptable? We need to be concerned about quality care and it will be vague to say that integration is a success"

Dr. R. Ganapati

"We are not setting any target for PR or NCDR. The system of setting target has been discontinued under NLEP. The term 'expected outcome' was just the outcome which we expect in the next 5 years. But we are not forcing anybody to achieve this outcome or target."

Dr. D. M. Thorat

"We do not want the word 'expected outcome' because it is considered equivalent of target. Today we heard some of the government officers categorically saying that the term 'expected outcome' or 'target' means one and the same. Hence, it is better to refrain from using the term. Today the officials down below think that the elimination is achieved at the national level, therefore they should now achieve one per 10,000 at the sub-national, district, block and PHC level. This will vitiate the ground situation. What about the 'zero' number registration?"

Mr. Antony Samy

"Regarding elimination, GOI was interested in elimination and they have achieved elimination. But there is no target set for elimination at sub-national, district and block level. In my opinion, none of the States have given such instructions to any staff that new cases should not be registered."

Dr. S. C. Nayak

"Regarding no registration of new patients, we have not asked not to register new patients. It is important not to register the patients unless diagnosis has been confirmed. One can register a patient after confirmation of diagnosis."

Dr. D. M. Thorat

"Everybody would like to register only after confirmation. Only in case of doubt a case can be kept under observation for one year. We are all scientific people and we do not want to say or label a person as leprosy unless the diagnosis of leprosy is established. I would not contest what you people are saying. I will be happy to hear such a statement from everybody that no such instructions have been passed on. In the last meeting of IAL, this issue was debated and the discussions went on almost for an hour. The most senior people who have put in more than 30 to 40 years in leprosy work, stood up in the presence of Government of India and WHO officials to say such instructions were given."

Dr. B. K. Girdhar

"A clear guideline is available from GOI and WHO. There is a declared programme implementation plan of 2006-07 issued by GOI. The direction is clear. GOI or WHO has not indicated any of this sorts. If any state is not following the guideline, the onus is on that state."

Dr. Aniruddha Kar

3. On establishing Leprosy Referral Centres

"Whatever we discussed, they are at the PHC level or little higher level. But a true referral centre, should be able to handle complications arising out of leprosy and also make accurate diagnosis. But how are they going to manage throughout the country. There may be some referral centre functioning but proliferating referral centres without an expertise being put into that, we are not going to do justice to patients. It is very well known that reactions and neuritis can also occur after care, after treatment. There was no discussion on referral centers? So to this extent, my reservations about the success of integration is, is it a reality at the grass-root level and is it going to be successful? If you look at the patient care, very little was discussed."

Dr. R. Ganapati

4. On providing POID & POD services

"In the era of integration, we are talking about referral centres for providing quality care and also looking at the prevalence rate. The deformity rate among the leprosy patients coming to JALMA is around 40% and out of them, 22 % are grade 1 and 18% are grade 2 and 3. If this is the situation in JALMA, why such phenomenon is not seen in any other leprosy treatment centres elsewhere needs to be debated."

Dr. Anil Kumar

"It is incorrect to state that the numbers of deformed patients are going up. In fact, the absolute numbers of patients are going down. If we had 10 cases with deformities in 1000 leprosy cases, you call it 1 % and now you have only 200 cases and even if you have less number of deformed cases, you have a higher rate.

Everybody is talking about the quantity of leprosy because the number is easy to crunch and put down. Some of us who lived through the worst days of leprosy will see that the quality of leprosy has completely changed and that's what makes a difference. When I joined leprosy and when I walked into the Ward, I could smell ulcerating lepromatous nodules from a distance. Of course, now we don't see them, it may be seen in some parts of Agra. By and large, most patients suffer from milder form of leprosy, with far fewer complications and living a better quality of life, irrespective of what facilities are available or not. We are not recognizing this aspect."

Dr. S. K. Noordeen

"My concern is about quality care. In the integrated set-up, can this be assured? People talk of human rights. Even WHO started talking of human rights issue and in today's discussion as Dr. Krishnamurthy said, a patient is treated as a 'case' for statistics and we don't look at the patient as a human being. It is the issue which is relating to the technology which the patient demands wherever he is in our country. Can we do justice to them in the process of integration? Moreover when you talk of disability, which is related to quality care, we should be concerned about new cases that come with disability and the cases who develop disability while under your care. According to statistics, almost 15 lakhs of visible disabled patients – grade 2 are there in the country and in our experience in small field experiment, we found the PR is 1 per 10,000, but the visible disability expressed as ratio of population is 10 times more, which means that over a long period in the chronic disease, this has not been prevented even by a vertical programme specialized in leprosy for so long. But how do we address this issue in an integrated set-up?"

Dr. R. Ganapati

5. On sample survey to determine epidemiological situation of leprosy

"Many of the speakers have expressed their concern about the achievement of elimination. We don't doubt the way we achieved elimination. Whatever arguments are there, let us be sure of that. We have to develop some mechanism. We have to follow the GOI guidelines, such as no active search and no case finding activities. In that situation, we are resorting to sample survey. I think we should go for some sample survey that would be applied to the entire country and not only the district or one State. That will give us some estimated prevalence and estimated figures that can be co-related. We have to find out a mechanism to find the interplay of different indicators, like the level of PR, NCDR, child rate and female rate. All these should be connected to develop an epidemiological model. This will be easier now with the integration because of the widespread support of the community and GHC. Efforts are to be undertaken at our level to be better informed and reach people with facts and figures. What will happen to leprosy after 25 years? When are we likely to eradicate leprosy? Can we answer that? We need to offer a date. A probable date of when we will get rid of this human scourge"

Dr. S. C. Gupta

"During the discussion, some have shown concern that after integration there is a sudden and large fall in PR and NCDR and there is a need to evaluate the same. On this account, there is a plan which will be proposed to study the quantum of hidden cases in the community and also the cases which are not detected and also determine over detection of cases."

Dr. D. M. Thorat

"I would like to ask Dr. Thorat, in the absence of active case detection, how are we going to detect all the hidden cases?"

Dr. Anil Kumar

"I just want to make a comment on the note by Dr.Thorat saying that there was a steep fall in the PR only recently. There were lot of presentations and statements saying that the present leprosy situation is near to the ground and it is almost eliminated. Whether it is true or not is the big question. Dr Gupta also suggested authenticating the present leprosy situation. In this background, we are trying to initiate some sort of activity in Mumbai to know the present PR in selected slum pockets. Out of 169 health posts in Mumbai, 22 were randomly selected for undertaking a sample survey in 25,000 population in each of these HPs. We have already planned based on the PR calculated at the health post level. There are 11 NLEP units: 6 or 7 NGOs, 4 government units and 1 municipal unit. We have approached everybody and all including NGOs and Brihanmumbai Municipal Corporation (BMC) have accepted to participate, except the government units. The BMC is taking a leading role and I take this opportunity to request Dr SC Gupta to instruct the government units in Mumbai to participate in this exercise. This survey will give information about the real leprosy situation in Mumbai and will be useful to plan programmes to achieve elimination in the future."

Dr. W. S. Bhatki

"Now, in any case, we are not resorting to active search. If it is only for authenticating of the reported figures, I think there should be no harm in doing on a sample basis."

Dr. S. C. Gupta

"Can we make the proposal for sample surveys as a general recommendation so that it will not only benefit Maharashra, but will benefit other States too? 90%

reduction in the case finding happened only in a particular point of time. The findings of sample survey will corroborate the figures reported by the government and it will also clear lot of doubts in the minds of people."

Dr. P. Narasimha Rao

"I think before making any recommendations, it is a treacherous territory to do a sample survey on a low frequency disease. The confidence interval is going to be so large. The sample size has to be huge. There is a sampling error. Non-sampling errors in sample survey is far greater than sampling errors. The specificity of diagnosis of early leprosy is so variable that if you send 2 different teams on 2 different days, you will get 2 different rates. Thirdly, the experience with sample survey assessment teams for the last 30 years established in all the states have not given any clear indications. In some sample survey units, they pick additional new cases and at the same time, they also miss lot of other cases. So the main reason is that the criteria for diagnosing leprosy are not specific enough. As an epidemiologist, I would recommend choosing a specific character of leprosy, like a patient with deformity and looking for those cases and comparing with the rates of published reports on deformity and then extrapolate it to find what the extent of under detection is. It is not an easy task."

Dr. S. K. Noordeen

"In a large city like Mumbai, covering 5.5 lakh population in 22 selected pockets and if the survey is done by the trained leprosy workers, I don't think there is any harm and we will definitely get fruitful information."

Dr. W. S. Bhatki

"Dr Thorat has already said there is a plan to study the quantum of hidden cases, which also includes validation of re-registration or duplication of cases. I see no problem in such a study being undertaken in Mumbai and I am sure that Government of Maharashra and the BMC should certainly agree to your proposal."

Dr. B. K. Girdhar

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

"We all agreed that integration has been the right step taken at the right time, when disease burden has decreased considerably. Integration which was undertaken 5 years back in most states and 9 years in Tamil Nadu is probably a right step. The achievements made during the MDT time under the vertical programmes have been sustained, more cases have been treated. My only concern is that integration is a leap forward, but without the focus on leprosy patients, which we must stress from now on. I was expecting Dr Noordeen's comments on 'reverse' integration and how that affected leprosy, because it is an important issue in today's context."

Dr. B. K. Girdhar

"The reverse integration is another myth created by leprosy NGOs. They think that they can handle all other health problems, because they are good in leprosy. This will never happen. They have to learn first before they plunge into general health services. Leprosy experience is unique and very limited. We should accept that."

Dr. S. K. Noordeen

"NGOs have to shoulder much more responsibility. We expect the NGOs to work very well because they are path-finders and our helpful partners. They should in their capacity become more empowered to tackle not only leprosy but other public health problems as well."

Dr. S. C. Gupta

7. On the need for skin smear in leprosy control

"The WHO operational guideline says that wherever, there is a proper smear technician, a proper microscope, skin smear can be taken. It is discontinued as a routine activity in India as all health centres are not equipped with good microscopy examination facility and a trained laboratory technician. As majority of the cases do not need skin smear, it is discontinued in the routine field programme as a policy. This policy is taken as a thumb rule and hit on one of the very important cardinal signs of leprosy as redundant even at the referral centres and hospitals where the facilities are available. This is inconsistent and needs to be corrected urgently. If we are not going to detect early lepromatous case who will continue to spread leprosy, how can we speak about control, elimination and quality care? This is a key question to our programme. We should have all the available tools in place if we have to sustain leprosy control work as it is directly relevant to quality care.

Recently, Dr. Desikan, Chairman, Gandhi Memorial Leprosy Foundation (GMLF), *(unable to come today because of his surgery)*, had sent a letter to the latest IAL meeting asking for a recommendation to the GOI as the DLO of Wardha district is objecting medical college at Sevagram to take skin smear. In November 2005, ALERT-India wrote to Dr. Dhillon for a clarification on the GOI policy regarding skin smear. He replied saying that skin smear can be taken at the leprosy referral centres. We will send that letter to Dr. Desikan. We definitely heard today some of the government officers giving their views about the skin smear and asking not to waste time on skin smear. If one has to diagnose an early lepromatous case, there is no other means or tool except to take skin smear. Thus, detecting infectious type of leprosy at an early stage is crucial for leprosy elimination."

Mr. A. Antony Samy

"Wherever feasible, skin smear should be taken. In fact that should be the approach and not the other way round. As doctors, we would like to use the available tools to confirm the diagnosis. I think there should be no ambiguity on that and we should re-emphasize that wherever feasible, skin smear should be taken to confirm the diagnosis. In JALMA, there is no patient who does not undergo skin smear. I cannot advocate it as a policy for others. As an institution, where the facilities exist, we take skin smear"

Dr. B. K. Girdhar

"A leprosy medical officer visited a leprosy referral centre at a teaching hospital and said that skin smear should not be taken. The person does not know that smears can be taken at the referral centre. Theoretically, it is said that the skin smears will be done at the referral centres. Where are these referral centres and how the patient from far distances and other states in India reach there? This is a human right issue and we need to rebel as the leprosy patients are unaware of their rights. It has been declared that skin smear should not be taken as though it is a crime.

I totally agree that the skin smear should not be done at the peripheral level as it is unreliable. The skin smear technique was useful for a long period of time even when the MDT was in trend. If we forego certain technologies, then how do we confirm the diagnosis in a LL patient? Recently, we examined a leprosy patient referred to us and found no classic evidence of leprosy though there was definite peripheral sensory loss. There was marginal thickening of ulnar nerve, which was debatable and

we subjected the patient to investigation such as EMG, nerve biopsy including skin smear. The simple skin smear examination from unsuspected sites showed BI 4+. If this patient had any knowledge about his rights, he will object to the way he received the treatment at the GHC system"

Dr. R. Ganapati

"In Jharkhand State, we are taking skin smears in cases wherever needed and where we have a doubt. We are not doing as a routine activity."

Dr. S. C. Nayak

"We have this confusion and contradictory statements are being made periodically. Is it possible to release a fresh circular mentioning all this what Dr. Thorat just mentioned as to explain when and where skin smear should be taken? But these guidelines are not known to everyone and often overlooked and misinterpreted by officials."

Dr. V. V. Pai

"The GOI guidelines are already issued and very clear in this regard. Skin smear should not be taken routinely and should be taken when there is some kind of doubt in diagnosis or in relapse cases or for some kind of research purpose you can take skin biopsy and facilities should be available for that purpose."

Dr. D. M. Thorat

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

"The capacity building was emphasized by most speakers and maintenance of the services at the secondary and tertiary level has to be monitored because when the disease prevalence comes down, some level of technical knowledge has to be maintained. Referral facilities have to be created at places where patients could be attended to. Supervision should be left with leprosy workers and must be shared and undertaken by general health care workers, so that they become instrumental in getting the things done rather than only by a leprosy worker or the doctor who supervises. It is the PHC doctor who should take a lead in that."

Dr. B. K. Girdhar

"One of the components of integration is training of the GHC staff. The GHC staffs are already busy with some training or the other. Therefore, under the National Rural Health Mission (NRHM), we are planning to integrate leprosy with other kind of training. This will probably solve this problem to some extent that the staff will not waste much of their time in attending different trainings."

Dr. D. M. Thorat

"I would like to submit one suggestion and request GOI to consider it. During integration, we find inhibition coming from the practicing doctors and the medical colleges. Neither have they followed the national guidelines nor the WHO guidelines. My humble suggestion is that the Central Leprosy Division should organize a meeting with MCI officials and the responsible persons of medical colleges and develop a new guideline that must be followed by the medical institutions. This is very crucial as the medical institutions set their own standards that are being followed by the junior doctors and paramedical students. It is really felt that the leprosy subject should be a part of the syllabus and should be taught at under-graduate level. The treatment protocol for RNTCP is now accepted but leprosy protocol is not in the standard medical textbooks. GOI should interact with the MCI, so that there is a common consensus and

recent treatment schedule for leprosy is included in the standard textbooks."

Dr. Aniruddha Kar

"We do endorse this suggestion as more and more leprosy patients are going to be treated by these young doctors."

Mr. Antony Samy

"Dr. Kar has made the right suggestion that GOI should have a meeting with MCI. This problem prevails in Jharkhand state too. All the doctors and the DLOs are adhering to GOI guideline for treatment, but the Professors and HODs of Skin department in medical colleges are not adhering. Hence they recycle the cases as the patients are reporting to them. Knowing that it is an old case, they enroll it as a new case. They say they are specialists and cases come to them and they will give medicines. There should be a clear cut guideline to all the skin HODs. GOI said that there should be 2 months drug stock, but they (Medical colleges) demand as much as they want. We have asked them just to diagnose the case and send back to the respective PHC but they are not listening to us."

Dr. S. C. Nayak

"Such problem is more in the states where MDT started rather late. In Tamil Nadu, Andhra Pradesh or Maharashtra, where MDT started early, I think it is gradually changing. There was some initial resistance and moreover government resolutions are very clear. Government medical colleges cannot afford to do it and they will have to conform to the government guidelines. A private medical college or a private medical practitioner or a dermatologist can do that, but we cannot have a control on that."

Dr. R. Ganapati

"Regarding Dr. Ganapati's observations on the private practitioners adopting different treatment regimen for leprosy, GOI tried to involve the private practitioners by giving special training on leprosy by the Indian Medical Association. We also tried to get the feedback from the private practitioners from various states who received this training. They were trained on how to diagnose a case of leprosy, the treatment procedure, where to refer the case of leprosy etc."

Dr. D. M. Thorat

"I had discussions with several doctors, consultants and pharmacologists. During 1985, not a single pharmacologist would agree to give Rifampicin once a month. You will find early WHO reports in Technical Series where Rifampicin was discussed and several pharmcologists of international repute in the international meetings of WHO have given quantitative assessments on how many molecules will be released by one capsule of Rifampcin and how many million organisms it will be able to tackle. You will still be left with a very large number of mycobacteria untouched by the Rifampicin. Therefore no one would know the number. Even if you give Penicillin once a day, we give at least for 3 to 4 days to complete the course. For Syphilis, it is given once in 12 days not less frequent than this. Now, in leprosy we give once a month. Secondly, the criteria of WHO and GOI guidelines are not followed by any Dermatologist. Nobody believes in the single dose therapy for single lesion leprosy and therefore, you cannot even logically convince them let aside force them."

Dr. K. K. Koticha

"It is a debatable issue. In the field, 90% of the patients are cured by WHO regimen. So why not stop the treatment. There is another perception. What is advocated is for a mass therapy programme and it is a means to spend a minimum quantity of drug to a large population to achieve a particular goal. But if it

was only one patient who had lepromatous leprosy with BI 5+ or 6 +, would we need to stop the treatment at one year? "

Dr. B. K. Girdhar

"The clinician of Dermatology department gives treatment for 2 years to a lepromatous case instead of 1 year. So that's why there should be a clear guideline on this matter."

Dr. S. C. Nayak

"There is nothing wrong in that and he is justified in doing it."

Dr. B. K. Girdhar

"We had a discussion with Dr. Pannikar of WHO, when he visited Hyderabad whether we can continue the treatment after 12 months. He said that he has incorporated in the latest WHO bulletin that if any treating clinician feels that he needed to continue the treatment, he can, provided he is qualified to do so. He has sent me an email and if somebody likes to see, I will forward it."

Dr. Narasimha Rao

"At this juncture, I would like to mention that Uniform MDT is already taken up in India and in 4 other places as a research trial and it is in progress in Tamil Nadu. Under this trial, we give MDT for 6 months to all cases, even MB cases. This trial is going on in 4 districts of Tamil Nadu as well as in Maharashtra and Andhra Pradesh. This trial is also started in China and Nepal and it is going to be recommended globally."

Dr. A. A. Jamesh

"I think we have digressed too much and we are talking something which is not in our purview. We will have many diverse issues and opinions on Uniform MDT and let us not discuss about that."

Dr. B. K. Girdhar

9. On legal and social problems

"We have been listening to integration all the time. Dr. Krishnamurthy said it is the human being in leprosy patients. Dr Ganapati has just mentioned the human rights. I always feel that integration may be a success, but what about the social and legal aspects which have to be given due importance. Statistical data and the figures may be deceptive. We don't have any statistical data of the patients who are legally handicapped. But connivance and provisions of the existing laws and acts pertaining to leprosy patients tantamount to its acceptance. It is time for us now to think about releasing these poor patients from the legal and social strangulations. From that point of view, nothing was said in this particular Workshop. What about the quality of life of patients in 300 self-settled colonies all over India? Has anybody gone and seen. Is it the only question for the social scientists and advocates? If it is so, is it not our duty to orient those particular social scientists and advocates doing justice to leprosy patients in the light of modern concepts of leprosy."

Dr. V. V. Dongre

"Even with regard to disabilities, the largest problem, as Dr Dongre mentioned, is our past patients living with disabilities in colonies and other places. Even in colonies, Dr Dongre will confirm, the number of new entrants to such colonies is steadily diminishing and also there are not many new colonies coming up. This means the depletion of deformed cases will take place over a period of time and these patients are not replaced in the same way as it used to happen before."

Dr. S. K. Noordeen

A summary of views and opinions raised by the panel members and delegates are presented thematically to facilitate easy reading.

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

"The overall leprosy profile has drastically changed and rightly so, we have a huge backlog of deformed individuals due to leprosy in the past. How many of these deformed patients actually need corrective surgery and how many would be benefited by it are not yet clear. In terms of quantum, these deformed individuals who do not want to have and do not seek corrective surgery would still keep adding to the figures. In other words, the patients needing corrective surgery is neither increasing nor decreasing."

Dr. B. K. Girdhar

"In these discussions, I find more emphasis was given to the surgical camps and instead the prevention of nerve damage, POID and POD should have been the main focus. If you do not include these at this crucial stage then it would be incomplete."

Dr. R. Ganapati

"In the DPMR plan, the interventions are not only for the leprosy patients who are deformed but also for the prevention of deformities in newly detected cases. These are included in the DPMR plan that was presented by Dr.T.Sreedhar."

Dr. D. M. Thorat

"Just a comment, DPMR is understood as only organizing surgery camps. It is not understood in the sense which you explained just now or outlined in the documents. In practice, it is limited to collecting patients, getting a surgeon and operating them. The pre operative selection and post operative care that are crucial is grossly ignored. Most surgeons would agree that the success of surgery depend largely on the role of Physiotherapists, who are not in place."

Mr. A. Antony Samy

Concluding Remarks

I am presenting the views and opinions expressed by several delegates at the Workshop including some ILEP representatives.

The first suggestion that emerged from the Mumbai group, specially LEAP related agencies and partner NGLOs in Mumbai is that a sample survey is required to ascertain the leprosy situation in Mumbai. Dr. Thorat said as a 'study of hidden cases' it can be done. The purpose of the study is to trace out hidden cases and know the situation in the community. Our first submission for the consensus statement is to adopt, a study of hidden cases in different places.

The second suggestion from many delegates including those from ILEP is that setting target for achieving the goal of elimination at the state, district and block level should be abolished altogether. If this is not done, we will be talking about achieving 1 case per 10,000 population at the block level etc. No target whatsoever should be given even in the name of 'outcome'. By setting outcome indicators target should not be set indirectly. Instead continuous monitoring of epidemiological trend at every level will yield better results and will take us somewhere close to elimination and eradication.

The third suggestion is the criteria for registering a new leprosy case should be strictly WHO criteria. There should not be a ban on registration of new cases. The practice of giving 'zero' number registration should be given up as it will give a false picture of the leprosy situation. The good part of it is that the patient with 'zero' number also gets treatment. Clear instruction to this effect can be given to all the states.

The fourth suggestion is about surgery camps. A target is given for organizing surgery camps and also for POD camps. Hence, the staff gathers leprosy patients, finds a surgeon and operates. Surgery is one of the solutions that can help a deformed patient functionally. This cannot substitute the need for physiotherapy care for all patients with disabilities and deformities. In order to bring this to the fore, we have reproduced the ILEP guidelines in Task Today released at this Workshop on the criteria for selecting patients for surgery. These criteria have to be made mandatory. Surgery should not be done without pre and post physiotherapy support. The decision of undergoing surgery should be left to the patient after proper counseling.

The fifth suggestion is on the need for LRCs at district and block levels as a sign post for new patients and the public. The LRCs must be located at the GHC level and should assist the GHC in diagnosing difficult cases, managing leprosy complications and providing services to all deformed leprosy patients. The details are also outlined in the special issue of Task Today on LRC. We do feel LRCs today can be manned by the leprosy workers and doctors at the GHC level. LRCs at the GHC in partnership with public health staff can help transfer the technical knowledge to GHC. If the present generation of leprosy specialist goes away, we have to start everything all over again and train people for providing quality services to leprosy patients.

The sixth suggestion is about the training of GHC staff formally with a proper training schedule to identify and refer the leprosy patients with complications. Or else in the next generation, we will not find people who are technically knowledgeable with clinical acumen to diagnose difficult cases and manage complications. Equipping them with knowledge and skills for follow-up services is essential.

Mr. Antony Samy

"We had discussions, comments, criticisms and exchanges on some issues related to integration, which have been dealt by several speakers from different states. We will now move on to finalizing the consensus statements. We have consolidated the views and opinions expressed by the delegates / panel members and formulated the recommendations related to policy issues and the programme specially on access to quality care. These will be forwarded to Dr. Dhillon, for consideration and necessary action. We would like these to be adopted and communicated to the state level programme managers. The ultimate aim is patient care and quality services in the integration phase.

I wish to thank the panelists, Dr. Thorat, Dr. Ganapati, Dr. Gupta, Dr. Rajan Babu, Dr. Krishnamurthy and thank you all for your patience and lively discussion of the real issues, which people face in the field. Thank you once again."

Dr. B. K. Girdhar

Recommendations

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

1. On registration of new leprosy cases for MDT.

We call upon GOI-CLD to issue specific directives to all the States on the criteria for diagnosing and registering new cases (WHO criteria for 'a case of leprosy') for MDT services at all GHC centres, Leprosy Referral centres, Public and Private Hospitals and Medical colleges. Registering new patients with 'Zero" number should be forbidden. Recording and reporting all new leprosy cases should be the norm.

2. On setting targets

We strongly advocate GOI-CLD to discontinue setting targets to achieve the goal of leprosy elimination at sub-national level (district and block level), even by way of 'expected outcome'. A clear and specific instruction to all the States to this effect is urgently needed.

3. On establishing Leprosy Referral Centres

We advise GOI-CLD to ensure sustainable leprosy control activities that are carried out within the integrated set up, which includes establishing leprosy referral centres at the block and district level mainly to manage leprosy-related complications including the cured leprosy patients with visible deformities.

4. On providing POID & POD services

We recommend GOI-CLD to develop a 'formal' and 'recognized' training course for Medical and Supervisory staff at GHC on the identification of leprosy-related complications and to treat / refer all new and cured leprosy cases with deformities. This should complement the training on diagnosis and treatment for leprosy undertaken for all GHC staff. This will help in identifying early nerve damage and provide appropriate care / necessary referral.

5. On sample survey to determine epidemiological situation of leprosy

We urge GOI-CLD to encourage as a policy for continuous monitoring of new case detection (Sample survey) using specific indicators as a part of routine supervision on sampling basis. Epidemiological data collected at the district / region level need to be validated without any prejudice and provide feedback to the programme.

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

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

7. On the need for skin smear in leprosy control

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

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

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

9. On legal and social problems

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

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

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

Mobilizing strong community support will promote social assimilation of the leprosy affected persons. This is a long drawn task; nevertheless it has to be consistently attempted, if we have to successfully conquer the disease.

Leprosy Elimination Action Programme (LEAP), promoted by ALERT-INDIA during integration phase, is a planned transition from the predominance of vertical leprosy programme to an action programme for the integration phase, focusing on community partnership strategies. The objective of LEAP is to meet all the need of leprosy affected persons by utilizing the best potentials available today with the NLEP and dovetail with the services and facilities in the public health system through a partnership approach.

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

from "A perspective for leprosy control beyond 2007"
National Workshop, October - 2006.

To make a success of the leprosy integration into General Health Services, the programme managers should keep note of past experiences and instances of failure in similar programmes after they were made non-priority and efforts diluted due to various reasons. It should not be assumed that integration of leprosy will automatically result in success of the programme and further elimination of leprosy would be achieved.

Dr. P. Narasimha Rao,

Dermatologist,
Gandhi Medical College Hyderabad, A.P.

Release of 'Task Today'series No. 3

Release of ALERT-INDIA's Annual Report 05-06

A section of the delegates at the National Workshop