SERIES NO. 2

LEAP

LEPROSY
ELIMINATION
ACTION
PROGRAMME

OCT 05

TASK TODAY

WHO :
sustaining leprosy services till 2010

GOI :
continuation of NLEP till 2007

LEAP :
leprosy referral centres

ALERT-INDIA'S
27th FOUNDATION DAY
SPECIAL ISSUE

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FOREWORD

Integration of leprosy into General Health Service is a major step forward in the fight against leprosy. As a vertical programme commendable work has been done under NLEP in India. It is under the vertical programme that there has been a drastic fall in the prevalence of leprosy and the disease has been brought to the level of elimination. Despite this remarkable success, a major draw back has been that leprosy was isolated and so discriminated. The general duty medical officers did not feel it their responsibility to deal with this major public health programme. Now with the integration, the entire health structure and the community in general are made to include leprosy in the control of all communicable diseases. The leprosy patient can now go to any PHC on any working day. Along with patients of other ailments he can avail treatment of not only leprosy but of any other medical problem.

While integration would bring several benefits to the leprosy patient, the quality of medical service cannot be as high as under vertical system. There are also certain special needs for a leprosy patient, apart from treatment of the disease. Therefore, for a few years more, there is a need to provide an additional support to the general health system. Establishment of Leprosy Referral Centres (LRC) would fully satisfy the need. Obviously, LRC should be manned by personnel with adequate knowledge and experience in leprosy.

The effort of ALERT-INDIA to come forward to establish or strengthen referral centres is a very welcome step. The LRC would be able to perform several important tasks. Leprosy does not normally pose difficult diagnostic problems. However, there can always be cases on which a PHC medical officer cannot make up his mind. Secondly the simple important investigation in leprosy, namely skin smear examination is not possible under the present set up. Management of some of the complications need the advice of a specialist. Care of the cured is another essential need which cannot be properly done in a peripheral dispensary. In this booklet, a very detailed information is given regarding the need, the purpose, the composition and the working of LRC. The plan of work proposed does not in anyway go against the national policy of integration. The LRC provides only those services not feasible in the PHC's, and that too for a limited period of a few years.

A referral centre is best managed by an NGO involved in leprosy work. The government should take the maximum advantage from the NGO's and encourage them to establish as many LRC's as possible. After all, the main intention of the Government and all institutions is to work in the best interest of the patient and the public.

Dr. K. V. Desikan
Chairman
Gandhi Memorial Leprosy Foundation

Sevagram, Wardha
6th October 2005

Task Today

'Task Today' is an effort to share information and gather informed support of one and all for Leprosy Elimination Action Programme (LEAP) during integration phase.

This issue of Task Today, focuses on the need to sustain leprosy services for the benefit of leprosy patients. Availability of MDT at all health facilities alone cannot fulfil the needs of patients. Since we promote integration as a long term solution, we need to attend to leprosy patient's immediate requirements. Leprosy patients require facilities for correct diagnosis, treatment and care today. They cannot wait until all the objectives of integration are actualised and the General Health Care (GHC) system is fully equipped to cater to the needs. Therefore, we need to take immediate steps to 'strengthen routine and referral services'.

Leprosy Referral Centre (LRC) is a specific proposal for sustaining leprosy services during integration phase. LRC is a 'signpost' for the public and for patients who seek treatment and care. From a practical point of view, when a leprosy patient gets lost in the vast network of services, LRC will serve as a signpost. Five decades of association with specialised vertical leprosy services, resulted in a mindset among people that will take another decade or so to change, provided we take steps that can alter the public perception towards the GHC System during the integration phase.

LRC's main objective is to provide comprehensive quality care. This issue of 'Task Today' includes the basic functions of LRC with tasks and task based activities along with an operational guideline for practical implementation.

Since leprosy is one of the new additions to the public health programme – the necessary knowledge and skills required for diagnosing the disease, specially in dealing with lepra reactions, neuritis and early disabilities may not exist with GHC medical personnel. Public health doctors can suspect leprosy and treat it, provided continued medical education, interaction and meaningful exchange of knowledge and expertise between the GHC and LRC personnel is undertaken consistently.

LEAP promotes LRCs as a part and parcel of its effort to strengthen integration and provide better care for leprosy patients. All are welcome to join this effort!

ALERT-INDIA
10th October 2005

A. Antony Samy
Chief Executive

I. WHO - Global Strategy

for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities : Plan period : 2006 - 2010

Executive Summary

The main principles of leprosy control, based on timely detection of new cases and their treatment with effective chemotherapy in the form of multidrug therapy, will not change over the coming years. The emphasis will remain on providing quality patient care that is equitably distributed, affordable and easily accessible. At the moment, there are no new technical tools or information that warrant any drastic changes in the strategy for leprosy control.

However, there is an urgent need to make decisive changes in the organization of leprosy control, in the attitude of health care providers and beneficiaries, and in the working arrangements between all partners.

The main elements of the strategy are as follows:

- sustain leprosy control activities in all endemic countries
- use case detection as the main indicator to monitor progress
- ensure high-quality diagnosis, case management, recording and reporting in all endemic communities
- strengthen routine and referral services
- discontinue the campaign approach
- develop tools and procedures that are home/community-based, integrated and locally appropriate for the prevention of disabilities/impairments and for the provision of rehabilitation services
- promote operational research in order to improve implementation of a sustainable strategy
- encourage supportive working arrangements with partners at all levels.

This strategy will require endorsement and commitment from everyone working towards the common goal of controlling leprosy, to ensure that the physical and social burden of the disease continues to decline throughout the world.

1. Introduction

The WHO Strategic Plan for Leprosy Elimination 2000–2005 encouraged commitment among endemic countries in dealing with the challenges posed by the disease. The most important component of the strategy was to ensure that leprosy control activities would be available and accessible to all affected individuals at their nearest health facility. (Leprosy control activities include diagnosis, treatment with multidrug therapy (MDT), patient and family counselling, community education, prevention of disabilities/impairments, rehabilitation and referral for complications.

The large-scale implementation of the Strategic Plan increased coverage for leprosy control activities and brought many undetected cases to health facilities for treatment. However, in many endemic countries, the Plan's implementation was slow. In addition, the continued reliance on specialized personnel and institutions inhibited the process of building up the capacity and competence of general health workers to take responsibility for leprosy control in their own area.

The Strategic Plan 2000-2005 had as its goal the elimination of leprosy as a public health problem, defined as reduction of prevalence to fewer than one case per 10 000 population nationally.

The Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities 2006-2010 is a natural evolution of the Strategic Plan, designed to address the remaining challenges and further reduce the disease burden due to leprosy.

The main principle of leprosy control is "morbidity control", i.e. timely detection of new cases, their treatment with effective chemotherapy in the form of multidrug therapy, prevention of disability and rehabilitation. This will not change over the coming years. The emphasis will remain on providing diagnostic and treatment services that are equitably distributed, affordable and easily accessible. At the moment, there are no new technical tools or information which warrant any significant changes in the strategy.

This document presents an overview of the Global Strategy. Together with the more detailed operational guidelines (to be published in the course of 2005) they will enable countries to develop their own country-specific strategy and plans of action.

Major Achievements of the Elimination Strategy

The significant achievements in reducing the global burden of leprosy over the last two decades are the result of two important events in the history of the fight against leprosy. The first event took place in 1981, when a WHO Study Group on Chemotherapy of Leprosy recommended the use of multidrug therapy as the standard treatment for leprosy. The success of multidrug therapy led to the second event in 1991, when the Forty-fourth World Health Assembly passed Resolution WHA44.9, declaring its commitment to eliminating leprosy as a public health problem by the end of 2000 – i.e. achieving a prevalence of less than one case per 10 000 population.

- Between 1985 and the beginning of 2005, more than 14 million leprosy cases were diagnosed and had completed treatment with multidrug therapy, with very few relapses reported.
- The number of countries reporting prevalence rates above one per 10 000 population has been reduced from 122 in 1985 to nine at the beginning of 2004.
- There has been a considerable increase in coverage of leprosy services in hard-to-reach areas and in underserved populations.
- Since 1995, the drugs required for multidrug therapy have been available free of charge in all endemic countries through WHO.
- There is now increased awareness and political commitment in all endemic countries.
- There is increased acceptance of the idea of integrating leprosy control services into general health services, and this is being implemented as a policy in most countries.

Background and Justification

In view of the need to sustain leprosy services for many years to come, there has to be a shift from a campaign-like elimination approach towards the long-term process of sustaining integrated, high-quality leprosy services which, in addition to case detection and treatment with multidrug therapy, also include prevention of disability and rehabilitation. There is an opportunity for this process to build on the gains made by the elimination campaign, such as increased awareness of leprosy, political commitment and the involvement of the general health services.

Even though the leprosy burden has been reduced substantially, new cases of leprosy will continue to appear for the foreseeable future in most of the currently endemic

countries. The basic principles for leprosy control beyond the year 2005 will continue to be based on early detection and treatment of leprosy patients. Health services must continue to provide quality services for leprosy control to these communities over a foreseeable period of time. Special expertise in leprosy and its control needs to be maintained at national and subnational levels. Such specialized leprosy units should serve as focal points for leprosy work, dealing with technical issues and coordinating activities as part of the overall national health plan. However, it is best to have these specialized units integrated within services provided for other endemic diseases.

A central unit, usually housed within the Ministry of Health, should be responsible for advocacy, policy formulation, technical guidance, technical training, planning, monitoring and evaluation. Specialized components must also be available within the general health service at intermediate levels for technical supervision, advice, referral services (including those in hospitals) and research.

Depending upon local conditions (e.g. the incidence and prevalence of leprosy; the availability and level of training of various categories of health staff), each country or region must decide at which level of the health system such specialized support should be available. In very low-prevalence endemic countries/areas, these units may be the only efficient way of providing leprosy services to the community.

The achievements so far need to be sustained, and there is a need for constant vigilance and surveillance to monitor and deal with relapses and the possible emergence of drug resistance, particularly to rifampicin. In addition, as the disease burden reduces further, it will become increasingly difficult to maintain public and government interest in leprosy control at current levels, especially as there are competing needs from other, more serious health issues.

The key will be to integrate all the essential components of leprosy control activities into the available primary health care system. This should include the utilization and strengthening of integrated referral facilities to deal with leprosy complications and issues related to chronic care.

Such a strategy will need careful planning and may require different approaches at the national and subnational levels within the same country, depending upon the local leprosy burden and the availability of appropriate health infrastructure.

Therefore, in close consultation with Member States, WHO regions and partners, a Global Strategy has been developed with the aim of sustaining leprosy control activities wherever leprosy exists. This will help to uphold the gains made by the elimination strategy and reduce the disease burden further in all endemic countries.

2. Current Situation

Major Challenges

- To continue progress towards the goal of <1 case per 10 000 population in those countries which have yet to reach it.
- To maintain quality of services in integrated systems and in low-endemic situations.
- To strengthen surveillance, drug supply logistics, information, education and communication (IEC), job-oriented capacity-building for general health workers and an efficient referral network.
- To assess the magnitude of the disability burden due to leprosy and develop appropriate tools and procedures to address issues related to prevention of disability and rehabilitation in integrated settings.
- To expand coverage of leprosy control activities in underserved/marginalized communities and areas.
- To further reduce stigma and discrimination against affected persons and their families and promote correction or deletions of outdated legislation.
- To reduce the gender imbalance seen in new case detection in some programmes.
- To build effective partnerships based on mutual trust, equality and unity of purpose.
- To ascertain the appropriate level of priority for leprosy relative to other more serious health and developmental challenges faced by the communities.
- To ensure an appropriate level of priority in the allocation of external resources in the context of a shift in priorities and resources to other challenges.

3. Basic concepts and guiding principles of the Global Strategy

Leprosy Control Activities

Disease control means reduction of the incidence and prevalence of the disease, and of the resulting morbidity and mortality, to a locally acceptable level as a result of deliberate efforts. Continued intervention is required to maintain the reduction. Leprosy control activities delivered by the health system include diagnosis, multidrug therapy, patient and family counselling, community education, prevention of disabilities/impairments, rehabilitation and referral for complications.

A direct translation of the word "services" may create confusion in some languages, as the term "leprosy services" may be wrongly interpreted as vertical leprosy programmes. Where this problem occurs, an alternative term may be used, such as "anti-leprosy activities".

Key Issues

- Opportunity to reduce disease burden by means of case-finding and treatment, BCG vaccination and improved socioeconomic conditions.
- Appropriate level of priority for leprosy relative to other, more serious health and developmental challenges faced by communities.
- Appropriate level of priority to be ensured with respect to external resources in the context of a shift in priorities and resources to other challenges.

Guiding Principles

- Early case detection and provision of multidrug therapy remain the cornerstone of leprosy control.
- An integrated approach using general health staff.
- Continued political commitment and adequate resources for leprosy control.
- Strong community acceptance, involvement and participation.
- Provision of high-quality leprosy control activities that are easily and equitably accessible to all, including referral services for complications and chronic care.
- Consensus and willingness to work together among all partners.
- The Global Strategy should maintain the momentum provided by the Strategic

Plan 2000-2005, and reduce disease incidence in endemic communities. Particular attention should be given to the nine countries still having a high disease burden.

- The Global Strategy calls for continued national commitment and resources, backed by international agencies, to ensure that leprosy services are sustained.
- The Global Strategy will succeed only if it is accepted by consensus and supported by a strong collaborative spirit of partnership between affected communities, national governments and international and local nongovernmental organizations.
- Given the heterogeneity of the leprosy situation in the world, the Global Strategy will encourage national governments to develop appropriate country-specific goals and targets and effective plans of action to ensure accessibility, timely case detection and completion of treatment. National authorities are encouraged to adapt the Global Strategy to suit their epidemiological situation, their own commitment, availability of resources and the capabilities of existing local health systems.

Goal

The goal of the Global Strategy is to reduce further the burden of leprosy and to provide access to quality leprosy control services for all affected communities, following the principles of equity and social justice.

Main Objectives

- Provide high-quality services for all persons affected by leprosy.
- Improve cost-effectiveness by integrating and/or decentralizing ongoing leprosy control activities within the existing local health infrastructure, including referral facilities and monitoring components.
- Sustain political commitment and increase collaborative activities with all partners at the global, national and regional levels.
- Enhance advocacy efforts in order to reduce stigma and discrimination against persons and families affected by leprosy.
- Strengthen the monitoring and supervision components of the surveillance system.
- Build capacity among health workers in the integrated setting.

4. Sustaining leprosy control activities

Sustainability is the capacity of a programme to maintain quality and coverage of services at a level that will provide continuing control and further reduction of a health problem at a cost that is affordable to the programme and the community.

Reasons to Sustain Leprosy Control Activities

- Achievements made to date must be protected.
- New cases will continue to occur, requiring diagnosis, treatment and care.
- There is a need for monitoring to detect reactions and relapses and prevent the emergence of drug resistance and resurgence.
- There are many people suffering from the consequences of leprosy and/or at risk of developing reactions and leprosy-related impairments.

Activities to Sustain Leprosy Control

In order to sustain the health benefits of leprosy control, "high-quality leprosy control activities" should include the following.

- Creating community awareness for self-reporting, IEC and capacity-building in health services:
- timely diagnosis at peripheral health facilities – simple cases with anaesthetic patches, both paucibacillary and multibacillary
- referral of other suspected cases for further examination.
- Patient management:
- free multidrug therapy, given in a user-friendly and flexible manner
- effective counselling and IEC for patients and family members
- recognition and management of complications
- referral for care of complications, when necessary
- correct handling of suspected relapses
- prevention of disability and self-care (including acceptably designed footwear) for those with nerve damage
- involvement in community-based rehabilitation programmes

- referral for specialist rehabilitation interventions, if indicated.
- Equity and social justice:
- people affected by leprosy treated in all health facilities like other patients
- respect for privacy and confidentiality
- advocacy and information for the public to reduce stigma and discrimination
- inclusion in any government provision for the disabled (e.g. disability pensions).

Mechanisms for Sustaining Leprosy Control Activities

- Integration into existing basic/general health services that are well supported by a referral network providing services for other diseases/conditions as well.
- Building capacity and competence among health care providers through education at medical/paramedical schools, motivation, on-the-job training and retraining and technical supervision. Increase awareness among the community and build up capacity through IEC and community involvement.

Importance of Integration in Relation to Sustainability

In the context of sustaining leprosy services, integration means active involvement of general health services in leprosy control activities. The general health services will take full responsibility for leprosy control in their areas, as part of their routine day-to-day activities. However, the nature of care and the category of staff involved will vary from country to country, depending on the structure and resources of the general health services.

The rationale behind this approach is that the general health services are widely distributed and have close and frequent contact with the local community, and involving them in leprosy control will improve case-finding, case-holding and the awareness of the local community about the disease. Apart from the costs needed to train the general health workers for their new tasks, over time the operational cost of an integrated programme is expected to be much less than that of a specialized, single-purpose leprosy programme.

Integration will improve efficiency and effectiveness, optimize the use of resources, promote greater equity, reduce stigma and discrimination and ensure long-term sustainability.

Activities which should be Integrated

- All leprosy related tasks and functions, which should be performed within the existing primary health care system at all times, avoiding segregation or special places or services for leprosy as far as possible.
- All management and support activities, e.g. planning, information systems, training and supervision.
- All organizational components, e.g. referral services, community support and awareness activities, and sharing of other resources.
- Promotion of basic and operational research in order to improve understanding of leprosy and its control.

definitions worth noting

What is meant by integration?

In most countries where leprosy is endemic, activities aimed at controlling the disease began as vertical programmes. A vertical programme is organised separately from other health services, from the national level down to the operational level, and has its own specialised staff and clinics. The underlying principle of integration is equity: optimal health care, including that for leprosy patients, consists of *general, continuous* and *comprehensive care*.

General health care means that a patient receives care for a broad spectrum of common health problems, contrary to the care offered by vertical services which only provide care in relation to specific health problems.

Continuous health care implies the constant (daily) accessibility of services, in contrast to the intermittent availability of vertical services (which may operate monthly clinics, for example).

Comprehensive health care means that the patient is cared for by health workers who know the personal history and (family) background of the patient. Such care can only be provided by multipurpose, permanent and decentralised health services.

Integration means that the general health service assumes responsibility for leprosy control activities. This will include case-finding, treatment, the prevention of disabilities and rehabilitation, all of which are implemented at the health services delivery level, but it also includes policymaking and planning, training, supervision and the identification of referral arrangements. It is therefore essential that capacity for the latter elements of leprosy control is retained at the intermediate and national level. **The local context will determine how these functions are integrated.**

***Source**: ILEP Technical Guide: Facilitating the Integration Process*
A Guide to the Integration of Leprosy Services within the General Health System, p.4, 2003, ISBN 0947543279

5. Strategic Issues

Epidemiological Situation

Countries that have not yet Achieved the Elimination Target

Countries that have not yet achieved the elimination target will need to continue their efforts to reduce the disease burden in the next few years, as recommended in the strategy laid down in this document. The countries that have included the elimination target in their long-term planning beyond 2005 can continue to pursue this target, including the use of "prevalence" as a major indicator in addition to those mentioned in Section 6 below. Several of these countries are facing severe challenges, in particular security problems in many of the African nations. These countries should also recognize the need to sustain leprosy services in the future, as the disease will continue to occur in appreciable numbers for many years after the elimination target has been achieved.

Low-endemic Countries

In situations where very few new cases are still occurring, e.g. in some countries in the Eastern Mediterranean and Western Pacific regions, maintaining the full spectrum of expertise to manage the disease at the peripheral level may be impractical, unsustainable and costly. Referral facilities with specialized leprosy care should be provided at the next level up, in order to cover a large area and thus be more cost-effective.

To make the programme more efficient, these referral facilities have to be integrated into the existing referral facilities supporting general health services e.g. departments of dermatology, neurology, (orthopaedic) surgery, etc. Proper referral facilities should be identified at district/provincial/state levels to support peripheral health workers in diagnosis and management. Supervision of activities at the peripheral level should be the responsibility of general health supervisors.

Difficult/disaster situations

Some countries face difficulties on account of social unrest and/or military operations. All health care functions become difficult to perform in such situations. There exist guidelines to tackle such difficulties during national and man-made disasters. Leprosy control activities may have to be performed using such approaches.

Operational Issues

Improving the quality of services

Each programme may have to define its own standards for quality of care, taking into consideration the capacity and competence of the general health staff and the availability of resources. This should be reflected by the targets set for quality indicators (see Section 6 below).

The quality of care can only be as good as the quality of technical supervision provided by the programme. In addition, the availability of strong backup from an effective referral system will improve the quality of care provided by the integrated leprosy services.

Free multidrug therapy

Early case detection and treatment with multidrug therapy will remain the key elements of the Global Strategy in the foreseeable future. There will therefore be a continuing need to maintain the quality and distribution of multidrug therapy at the global level, as well as in endemic countries. Since 1995, thanks to a generous donation from the Nippon Foundation and Novartis, WHO has become the world's leading supplier of multidrug therapy (MDT) drugs, free of charge. An increasing number of countries now rely upon WHO as the sole source of high-quality drugs for their leprosy elimination programmes. Novartis has committed itself to continuing the free supply of MDT drugs beyond 2005. The number of countries using WHO-supplied multidrug therapy has grown to over 100. Apart from the major endemic countries receiving regular shipments of MDT drugs every year, other lower-endemic countries have requested emergency supplies from WHO.

Good registration practices

These should include:

- adherence to WHO/national guidelines on treatment duration
- regular updating of the treatment register at primary health care level
- providing a choice of appropriate visiting schedules based on the needs of the patient, and taking the environment and available services into consideration
- routine counselling, defaulter retrieval and follow-up
- no reregistration (recycling) of any old case as a new case.

Building capacity and competence within integrated programmes

A key strategy for improving and sustaining leprosy services is to involve peripheral general health workers and community health volunteers in leprosy control tasks down to the village level. Simplified guidelines for general health workers should be made available in all health facilities providing leprosy services. Medical and paramedical training institutions for health workers in endemic countries should include leprosy in their curriculum, so that the new generation of workers will be able to sustain leprosy control services in the future.

Improving community awareness and involvement

The major theme of community awareness activities will be to provide accurate information about the disease, its curability and availability of services at the nearest health facility. The objective of such IEC efforts should be to encourage self-reporting of new cases and to reduce stigma and discrimination against affected individuals and their families. Most programmes have been using various communication approaches, including the mass media. Although there are claims for their effectiveness, there is limited published evidence to support this. There is some evidence that interpersonal communication is still the best way of conveying correct messages about leprosy.

Monitoring, supervision and evaluation

The amount of data that an integrated programme can provide for leprosy is limited, since it has to collect data and report on other diseases as well. Therefore, data collected for leprosy should be the basic minimum and should be an integral component of the monthly reporting formats used by the local health services, e.g. monthly mortality and morbidity reports (see Section 6 below).

However, special monitoring exercises may be carried out periodically to validate case-detection and quality-of-care indicators, as part of routine supervision or by independent teams on a sampling basis.

Equity and Social Justice

Leprosy and human rights

The basic human rights include: right to life, dignity of the person, equality before the law and freedom from inhuman or degrading treatment. These have been incorporated into constitutional rights by many nations. The main human rights issues for leprosy-affected persons are dignity of the person and equal access to adequate treatment.

The effectiveness of multidrug therapy in curing leprosy and intense advocacy activities in recent years have brought positive changes in public attitudes towards persons affected by leprosy in many communities. However, the stigma associated with leprosy has not disappeared completely in many countries. In some countries, the impact of discrimination is particularly severe among female leprosy patients. Any legal or statutory measures that are likely to compromise the rights of an individual affected by leprosy to employment, in his/her own country or elsewhere, should be abolished.

Gender

Although leprosy may affect relatively more males than females in some populations, this is not universally true. All programmes should ensure that all members of the community have easy and equitable access to leprosy services.

Reaching special population groups

It is important to reach patients living in difficult-to-access areas or special situations, or those belonging to underserved and marginalized population groups, since the most crucial element of the leprosy control programme is to reach every patient. Special initiatives should be aimed at finding people living in difficult areas or situations who are in need of treatment and, secondly, to ensure that they complete multidrug therapy. Innovative and practical strategies involving mainly operational solutions need to be developed in order to provide leprosy services for these patients. If a project operates in situations where the health infrastructure is weak or does not exist, there is a special need for strategies which promote self-reliance and self-help, and which involve the community and grassroots organizations so that the activities can be sustained.

Leprosy in urban areas

While the basic strategy for controlling leprosy in urban and periurban areas of all categories is similar to the strategy in rural areas, rapid industrialization and the increasing density of migrant populations in slums pose operational challenges.

Coordination between government and nongovernmental organizations, as well as local health authorities, dermatologists and general practitioners, should be encouraged; particularly to ensure that leprosy services are provided by all agencies and all new cases are treated with multidrug therapy.

Patient Care

Referral services and long-term care

Referral services to provide technical support and hospital facilities are essential in an integrated programme. The referral network must be part of the integrated system, providing referral services for other diseases and conditions in the area, e.g. district hospitals or medical colleges. The basic requirements are the availability of adequately trained staff and the necessary infrastructure. Referral services involving appropriate specialities will play a useful role in providing the necessary care.

One frequently neglected aspect is the provision of services for long-term care for patients suffering the sequelae of nerve damage, for example chronic foot ulcers or chronic leprosy reactions. These will need, besides medical and surgical interventions, support from proper counselling services.

Prevention and management of impairments and disabilities

The current situation with regard to the number of persons living with leprosy-related disabilities and impairments may need reassessment, particularly at national level. In addition, programmes should ensure that persons affected by leprosy have access to services provided by other programmes dealing with other disabling diseases or conditions.

Interventions aimed at preventing disabilities/impairments from occurring and/or worsening include early detection and effective management of leprosy-related reactions and nerve damage; proper counselling on self-care; participation of household members in home-based care; development and use of locally produced and culturally and aesthetically acceptable protective footwear and other appliances.

Rehabilitation

All societies are basically organized for nondisabled lifestyles, and expect disabled individuals to change, rather than making an effort to reorganize themselves to accommodate their disadvantaged members. The concept of rehabilitation encompasses issues that are directly linked to the socioeconomic situation of the country, and issues related to poverty, inequality and sustainable development. It is therefore important that society should include persons affected by leprosy in ongoing programmes for rehabilitation of other disadvantaged members of the community. Many projects have demonstrated the positive benefits and cost-effectiveness of using community-based rehabilitation approaches to deal with this issue.

Research

The Global Strategy will need input from ongoing and future research studies being conducted globally, in order to improve the quality and quantity of the tools and procedures available for leprosy control. The priority areas for research are prevention and management of nerve-function impairment and reactions, improving chemotherapy, developing and improving diagnostics to identify individuals in the community who are at high risk of developing leprosy and operational research to improve the sustainability and integration of leprosy services.

Partnership

Partnership is a joint working arrangement in which independent partners cooperate to achieve a common goal.

The term cooperation includes: planning, implementation, sharing information and equally sharing risks and rewards. The aim is to improve performance, avoid duplication, improve cost-effectiveness and prevent conflicts of ideology. The expected outcome is the delivery of high-quality services for persons affected with leprosy.

Partnerships are based on mutual trust, respect and understanding. They should be seen as a process of working together with the governments of the endemic countries to reach the common goal of sustaining high-quality leprosy control services for the affected communities. This will avoid duplication and wastage of resources and will therefore increase the effectiveness of the programme at all levels.

reasons for change

Why integration?

For decades leprosy control activities were undertaken by specially trained and highly dedicated and motivated individuals.The integration of leprosy control activities within existing general health services in endemic countries is now recognised as the best approach to bring about these changes. General health services are relatively widely distributed and close to the communities, they serve, and integration will improve MDT coverage and be more cost-effective and sustainable. It may also be expected that the age-old stigma attached to the disease will be reduced as persons affected by leprosy begin to use the general health service alongside other members of the community. This of course does not mean that all supportive components will disappear; it will be important to maintain an effective network of supportive and referral services within the health system to support peripheral general health workers in maintaining an acceptable quality of service.

Source: ILEP Technical Guide: Facilitating the Integration Process
A Guide to the Integration of Leprosy Services within the General Health System, p.5, 2003, ISBN 0947543279

6. Indicators for Monitoring and Evaluation

Indicators are tools for measuring the magnitude of the leprosy problem and progress towards achieving the objectives of the programme. They can be used to set targets for the quality of the programme (e.g., the proportion of patients with grade 2 disabilities among new cases as an indicator for the quality of case detection; treatment completion rate as an indicator for quality of patient management). In view of the different situations in the various countries, the targets for quality should be country-specific and based on recent trends.

Main indicators for monitoring progress

1. Number and rate per 100 000 population of new cases detected per year.
2. Treatment completion/cure rate.
3. Registered prevalence: for those countries yet to reach the elimination target, prevalence of registered cases will continue temporarily to be an indicator till the target has been reached (see Section 5.1.1 above).

Number and rate of new cases detected per year

The nature (e.g. type, grade of disability, etc) and number of new cases detected in a given area are mainly influenced by four factors:

- effectiveness of IEC activities in promoting awareness and self-reporting
- health workers' competence to make an accurate and timely diagnosis
- quality of monitoring and supervision by programme managers
- completeness of programme coverage, ensuring that all inhabitants are reached.

In order to ensure quality of new case detection, programmes should ensure that:

- case-finding is mainly focused on promoting self-reporting, with appropriate clinical examination and history-taking to avoid wrong diagnosis and reregistration
- case definitions are adhered to, as per national guidelines
- previously fully or partly treated cases are not registered as new cases – partly treated cases should be given treatment.

All national programmes should collect and report this information, distinguishing paucibacillary and multibacillary leprosy and child/adult patient (important for the calculation of MDT drug requirements).

Treatment completion/cure rate

The two most important components of the leprosy control programme are:

1. timely detection of new cases
2. ensuring that all new patients who start multidrug therapy complete the full course of treatment within a reasonable period of time.

A satisfactory treatment completion rate is indicative of efficient case-holding, counselling and patient satisfaction with the services. Completion of treatment means that a paucibacillary leprosy patient completes six monthly doses of PB-MDT within nine months and a multibacillary leprosy patient completes 12 monthly doses of MB-MDT within 18 months.

All national programmes should undertake cohort analysis for treatment completion rates for both paucibacillary and multibacillary leprosy. A reported unsatisfactory treatment completion rate indicates that the programme manager/supervisor should find more detailed information on the treatment outcome of the reporting clinic/ district in order to identify appropriate corrective action, including use of accompanied multidrug therapy as an option for certain category of patients who are unable to visit the health facility regularly.

Additional indicators for case detection

The following indicators may be collected as part of special monitoring exercises to evaluate the programme and to calculate MDT drug requirements.

1. Proportion of new cases presenting with grade 2 disabilities/impairments at the time of diagnosis.
2. Proportion of child cases among new cases.
3. Proportion of multibacillary cases among new cases.
4. Proportion of female patients among new cases.

Indicators for patient management and follow-up

The programme may collect the following indicators periodically on a sample basis, as part of an integrated supervision process.

1. Proportion of new cases verified as correctly diagnosed.
2. Proportion of treatment defaulters.
3. Number of relapses.
4. Proportion of patients who develop new/additional disability during multidrug therapy.

7. Leprosy Surveillance System

Reporting system

The existing simplified global information system should be adapted to be consistent with the indicators mentioned in Section 6.

Programme review

WHO will draw up guidelines to assist programme managers in determining priorities with regard to sustainability of leprosy control activities, and to suggest what specific actions might be taken. The review guidelines as developed under the elimination strategy are still valid and will, after some modifications, also be important for the strategy to sustain leprosy control activities. Programme reviews will continue to be organized and coordinated by the WHO global leprosy programme in selected endemic countries, and are based on information which can be collected by health staff under field conditions. Every leprosy programme is subjected to a periodic review by its manager and by WHO.

Drug supply database

WHO has developed an information database for monitoring the whole flow of drugs from the supplier to the recipient country. Spreadsheets and database management systems have also been produced as an aid to preparing the periodic reports, wherever computer facilities are available at the country level.

8. Expected Outcomes by 2010

- Further reduction of disease burden to very low levels.
- Improved quality of diagnosis, case management and registration practices and good management information system.
- Sustainable leprosy services in all endemic countries.
- Easy and equitable access to quality services through general health services, including an efficient integrated referral network.
- Adequate tools and resources for prevention of disability and rehabilitation.
- Strengthened partnerships and collaborative working arrangements with all partners.

We can expect a world with a reduced burden of leprosy, reduced stigma and discrimination, activities based on the principles of equity and social justice, and strong partnerships based on equality and mutual respect at all levels.

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II. Programme Implementation Plan (PIP) for continuation of NLEP

from 1st April 2005 to 31st March 2007

Ministry of Health and Family Welfare

1. Introduction

The second National Leprosy Elimination Project with World Bank assistance ends in December 2005. The programme is however to continue for the remaining part of the financial year i.e. till March 2005 with GOI funds. The National Leprosy Eradication programme activities are still required to be continued as a centrally sponsored scheme for a few more years as the goal of achieving leprosy elimination i.e. to reach the level of < 1 case per 10,000 population at the national/State/District level may take some more time. As per the WHO's extended time limit the elimination of leprosy at National level should be achieved by the end of the year 2005, which also been included in the National Health Policy of GOI. The period of the next 2 years i.e. 2005-2006 and 2006-2007 will be most crucial when the goal is to be achieved and then take it further down the level of all states/UTs and then districts. For reaching elimination of leprosy in most of the districts it is necessary to extend the National Leprosy Eradication Programme upto March 2007, i.e. till the end of 10th Plan. It is therefore proposed that the next 2 years programme under NLEP should be very strong with support from all NLEP partner organizations in India.

2. Concept Profile

The remaining 2 year period of 10th plan is proposed to be utilized with a programme designed to consolidate further on what has already been achieved in the National Leprosy Eradication Programme and towards that end more emphasis will be laid on:

(a) Information, Education and Communication (IEC):

Efforts on IEC carried out so far will be further intensified in a planned manner in the Rural and Outdoor areas of all States / UTs. Developing awareness among people in all nooks and corners of the country will be the aim. All media available in the States / Districts will be used in regional languages to derive maximum benefit. An IEC strategy has been framed based on which States / UTs will develop their own Action Plan and implement the same. Central Leprosy Division has already worked out a norm of IEC activities for districts with different level of endemicity and sent to the States / UTs for their guidance and support. Banishment of stigma attached to the disease in people's mind will be the basic aim of IEC.

(b) Training of GHC staff:

All GHC staff have already received training in leprosy, but due to turnover of staff, new entrants need training. This will be a continuous process to enhance the capabilities of the GHC staff in general and also specialists in Govt. Hospitals, so that they gain confidence for conducting RCS and can manage complicated cases of leprosy. Health services staff working in Municipalities and other organizations functioning in urban areas and Private Practitioners also will be given the benefit of training in a systematic way, so that patients covered by these centres receive proper treatment with free MDT.

(c) Quality improvement:

Now that programme has achieved considerable success in case reduction and availability of Anti-leprosy services in an Integrated way through the General Health Care System, the next logical step is to ensure that the new cases detected are definite cases of leprosy and case treatment with MDT is time bound and without any body leaving treatment midway. Case validation will be carried out by the District Technical Support Teams, District Nucleus staff

who will also ensure that cases under treatment are regularly followed up by the male and female Multi-Purpose Workers.

Similarly high quality will be maintained in all the other components of the programme like Record Maintenance and Reporting, MDT Stock Management, Prevention of Deformity and ulcer care services etc. Details of specific activities have been indicated under different components given at Sl. No. 4. MDT will continued to be supplied free of cost to each patient through all Health Centres.

(d) Elimination of duplication of activities:

The programme to be carried out in the next 2 years will be a joint effort of all the partners in NLEP in India. These are:

(i) Govt. of India

(ii) State / UT Governments

(iii) World Health Organization (along with donor agencies - The Sasakawa Memorial Health Foundation (SMHF), The Nippon Foundation (TNF) and NOVARTIS)

(iv) International Federation of Antileprosy Association (ILEP)

3. Objective

(a) To continue the efforts to achieve elimination of leprosy through existing MDT (Multi Drug Therapy) with focus on continuing current levels support in 10 States namely, Bihar, Jharkhand, Delhi, Uttar Pradesh, West Bengal, Chattisgarh, Andhra Pradesh, Goa, Maharashtra and Orissa. Additional clinic support is proposed to be provided in areas of Bihar, Chattisgarh, Orissa and Jharkhand, where the primary health infrastructure is not fully operational.

(b) To maintain the gains achieved in each of the States / UTs where elimination is achieved till March 2005 and to continue the efforts to achieve elimination at district and block level.

(c) To make quality leprosy services available through integrated general health system as well as other private and public health facilities.

4. Components Under Extended Leprosy Eradication Programme

Infrastructure:

(a) State Leprosy Societies were formed under the 2nd NLEP to decentralize the programme planning, execution and monitoring alongwith improved financial management in the States. These societies are providing very good support to the programme and should continue for next 2 years. A note on the State Leprosy Societies and State Leprosy Cell is given as Annexure - I. The additional staff support given under the 2nd Project will be there. The State Leprosy Cell will have to be managed with existing regular category staff of State Govt. WHO supported staff like Data Entry Operator will be there till December 2005 and may continue till March 2007.

(b) In each district a District Nucleus will be maintained under the district leprosy officer consisting of trained Medical Officer - 1, NMS - 1, PMW - 1 or 2 who will assist the General Health Care Staff in the periphery i.e. in PHC with case validation, record and report validation, hands on training (if required), capacity building of new staff, MDT stock supply and management, POD training through Organization of camps, IEC activities, conducting Special Action Plans etc. The existing District Leprosy Societies will remain.

(c) ILEP has been providing District Technical Support Teams consisting of one Medical Officer, 1-2 NMS / PMW and a driver with vehicle. From 1st April 2004, all the States and UTs are being covered by the DTSTs. In 10 States, viz. Bihar, Jharkhand, Delhi, Uttar Pradesh, West Bengal, Chhattisgarh, Andhra Pradesh, Goa, Maharashtra and Orissa, all the districts will be covered, where as in the remaining States / UTs State level teams and district teams in selected districts will be available. A total of 174 teams (165 district level + 9 State level teams) have been positioned. ILEP has agreed to continue these DTSTs during the extended programme period also. The teams will provide support to the districts and states as per agreed job responsibilities given. Monthly reports are submitted by each DTST to the State DTST Coordinator with copies to the District Leprosy Officers. The State Coordinator compiles the report and submit report to the State Leprosy Officer and Central Leprosy Division. Reporting formats have been prescribed and are being followed. District

nucleus and the District Technical Support Teams will continue to provide technical support to the General Health Care system.

(d) 27 Sample Survey cum Assessment Units (SSAU) were upgraded during the 2nd NLEP. Their working modalities were finalized. These teams have now started working and should continue. Under the project, post of Epidemiologist and DEO were provided on contract basis, which may be there during the extended period. The state should continue with this as surveillance unit at state HQ with regular Govt. staff.

(e) Project Financial Management System that was developed under 2nd NLEP to be continued to be followed with necessary modification in the software as required.

(f) The Central Leprosy Division (CLD) will have to be maintained at the present strength till all the states and majority of districts reach the level of leprosy elimination and the Programme achievement is consolidated. The World Health Organization has agreed to continue of the Sate / Zonal Coordinators (NLEP) and other supportive staff provided to the CLD till December 2005. Further requirement to be reassessed by end of the year 2005, to decide regarding extension of the support till March 2007. In addition CLD will have to maintain one Training Consultant, one Financial Consultant and one IEC Consultant with Govt. of India funds.

(g) The Central Leprosy Teaching and Research Institute, Chengalpattu and 3 Regional Leprosy Teaching & Research Institutes at Raipur, Aska and Gauripur are to continue and support the programme in Training of GHC staff in Rural areas, Training of Health functionaries in Urban areas, Management of complicated cases, POD care and RCS and Operational research. Each institute has been allotted jurisdiction of States / UTs each covering 8 - 9 States / UTs.

(h) Chandigarh, Delhi, Dadra & Nagar Haveli does not have any regular leprosy staff to form the District Nucleus. These 3 State / UTs also have high PR due to problem of migratory patients. During second Project these states were provided following manpower on contract basis.

	MO	NMS	PMW	Driver	Total
Delhi -	5	5	10	5	25
Chandigarh -	1	1	2	1	5
D&N Haveli -	1	1	2	1	5
Total -	**7**	**7**	**14**	**7**	**35**

In view of their difficulty in forming District Nucleus following staff support may be continued to be provided to these 3 States / UTs with contractual staff with programme funds:

	MO	NMS	PMW	Driver	Total
Delhi -	1	5	5	1	12
Chandigarh -	1	1	2	1	5
D&N Haveli -	1	1	1	1	4
Total -	**3**	**7**	**8**	**3**	**21**

MO, one NMS and Driver for Delhi is for maintaining a surveillance unit at state HQ. Remaining 9 NMS / PMW is for the 9 Districts Nuclei.

(i) Punjab & Haryana do not have regular vertical staff in the districts for which these two states were allowed to retain one PMW on contract in each district. These PMWs may be retained to form the district nucleus in the next 2 years also.

Integration

(a) Integrated leprosy service to be strengthened at all the Health Centres / Hospitals emphasing on quality of services delivered as detailed in 4.1 (b) above.

(b) Four states viz. Bihar, Jharkhand, Orissa and Chhattisgarh have areas under certain districts where Primary Health Care infrastructure is not adequately functioning due to various reasons. During the 1st and 2nd National Leprosy Elimination Project these states were provided with vertical field staff such as NMS and PMW on contract basis, who were responsible to cover these areas.

Such contractual staff were posted in the Leprosy Control Units / Modified Leprosy Control Units. Some such areas were also allotted to some local NGOs by the State Govt., which have now been withdrawn. After integration, these LCU / MLCU and also the contractural staff will not be available to cover these areas.

In a meeting held on 3rd June 2004 with the State Leprosy Officers of these 4 States the extent of the problem was discussed. It is found that this is a big problem for Bihar & Jharkhand where large numbers of Additional PHCs / Sector PHCs were not constructed and even wherever constructed Medical Officers are mostly not in position. In Orissa about 300 single doctor PHCs have no regular doctor filled up with doctors selected for PG courses for a 1 year stint of rural services. In about 80 of these PHCs there are no doctor at all. In chhattisgarh also about 113 PHCs in 14 districts have no regular Medical Officer. After discussion, all the 4 SLOs agreed that the component of leprosy case diagnosis and treatment services in these PHC areas need to be strengthened. Release of the old contractural leprosy staff and reduction of the regular leprosy staff at the end of the 2nd NLEP, has put these states at a disadvantage, so far as coverage of these deficient areas is concerned.

Statewise estimate of deficiency reported and proposed support required are as below:

	District	**Block PHC**	**Addl. PHC without MO**	**No. of Clinic support required**
Bihar	37	239	380	106
Chhattisgarh	14	55	104	30
Orissa	19	71	90	20
Jharkhand	13	43	58	20
Total	**83**	**408**	**632**	**176**

A note on the proposed clinic support is enclosed as Annexure - II

These non-functional Addl. PHC / Sector PHC will not be able to provide regular leprosy treatment with MDT to the patients near their house. In such situation it may be useful to provide some trained experienced staff on contract basis to the Block PHCs, from where these persons can visit the deficient

areas and run the MDT clinic on, say 1-2 days a week. Such clinic support should be provided in the deficient areas of the 4 states for next two years. These clinic support staff will be entirely different from the District Technical Support Team now working under ILEP support. WHO has however agreed to provide the support for the year 2005 only.

(c) Urban Leprosy Control through involvement of all existing health facilities under different organizations and their coordination through the District Leprosy Officer. Recently guidelines on the basis of a workshop held on Urban Leprosy Control has been circulated to all the States / UTs. States have been requested to develop their urban leprosy control plan for each city / town involving the municipalities and some local NGOs. To coordinate the activities of different partner organizations in the urban areas a Nodal Officer is to be identified and for its functioning some fund is required to be provided from the programme budget. Similarly for training the health personnel working under different organizations in the urban areas funds will be required to be provided out of programme budget of the concerned district. The CLTRI and 3 RLTRIs will be involved in assisting the district administration in conducting these trainings in the States / UTs under their jurisdiction.

MDT Services

(a) There is no need for any type of active search as Leprosy Services have been integrated with General Health Care System. The programme will encourage voluntary reporting of cases in the Health Centres through IEC efforts in the community and by referral through the multi-purpose workers (Male & Female) and other village level workers.

(b) Special Action Plans in identified localities may be required in very limited districts. Scrutiny of such project proposals will have to be more strict at Central Leprosy Division as funds will be limited out of programme budget.

(c) Emphasis on groups of patients like Female, Tribal, Migratory patients and other vulnerable groups should continue as at present.

(d) Develop a suitable referral system for providing services to complicated cases, reconstructive surgery services, capacity building of needy professional and supply of footwear by involving established NGO institutions.

IEC

Spreading awareness about leprosy, its complete curability with MDT, which is available free of cost at all Health Centres will have to be strengthened during the next 2 years to improve voluntary reporting of cases. This is a very important component which needs to be extended to all nooks and corners of the country. As the leprosy cases that have still remained untreated need to be brought out through heavy dose of persuasion and continued efforts, the programme will have to give more emphasis on Rural and Outdoor media activities to be carried out by the State/UT themselves.

Emphasis will remain at State & District level on -

(a) Interpersonal Communication (IPC) through the Health staff involving Panchayat leaders and NGOs through advocacy workshops.

(b) Mass media efforts through local Doordarshan channel, Radio and local Newspapers.

This may be quite costly but will give ample dividend subsequently. Further to conduct this IEC plan in a very efficient way an IEC Consultant at the Central Leprosy Division will be essential. WHO has agreed in principle to provide this support from January to December 2005 which may be extended till March 2007. IEC strategy for the years 2005-06 and 2006-07 has been indicated in **Annexure - III**. *(this annexure not included in this issue)* A norm for conducting IEC in districts with different endemicity and their costing pattern has been approved and sent to the states for implementation during 2004-05.

Leprosy Drug Supply & Management

(a) MDT supply assured till December 2005 by WHO. For further requirement from Jan. 2006 to March 2007 WHO is understood to be in the process of finalizing with donors. It is expected that free supply of MDT will be available for 5 years beyond 2005.

(b) Supportive drugs to be procured from programme funds. This will include Prednisolone, Antibiotics and dressing materials and Medicines. ILEP used to procure and supply some "Prednipack" for treatment of reaction cases. This resulted in districts not procuring Prednisolone, thinking that Prednipack will come from ILEP. Since Prednipack supply was limited, adequate stock was not available in the PHCs when required. To avoid this problem it is decided

after discussion with ILEP that the districts will procure Prednisolone for treatment of reaction cases and Prednipack will not be required to be supplied by the ILEP.

(c) MDT stock management has become a big issue because of wastage of large quantity of drugs due to overstocking. CLD is considering to develop a MDT management plan involving all partners for regular assessment of drugs availability and requirement starting from PHC upwards. It is proposed to provide one "Logistic Consultant" (contractual) in 5 major states to assist the State Leprosy Officer. These Consultants will be with State NLEP Coordinators in Bihar, Jharkhand, Chhattisgarh, Uttar Pradesh and Orissa. Who has agreed in principle to provide this support for short time of one year i.e. till 2005. This support will not be required during 2006-07, as the system should be streamlined by that time.

Disability Prevention and Care

(a) POD camps in blocks to continue in the next 2 years also with programme fund.

(b) Supply of MCR footwear to needy patients and provision of materials for ulcer care will continue. This support is also now being provided by many NGOs, which may be continued. Scheme of payment of Rs. 250/- for each pair of MCR footwear by the GOI to recognized ILEP institutions will be withdrawn.

(c) RCS operation in approved institution to continue. Capacity building to conduct RCS operations in Govt. Hospitals & Medical Colleges to continue. Continuation of scheme of payment of Rs. 2500/- per major RCS in the approved ILEP institute after December 2004 is not required. All institutions with RCS operation facilities whether Govt. or NGO will be requested to continue with their services for the benefit of the patients.

(d) ILEP has also been requested to provide referral services for complicated cases and also capacity building of surgeons of Govt. Hospitals for POD care and RCS services through ILEP supported 122 referral hospitals. Details are being worked out in consultation with ILEP India Coordinator, New Delhi.

Training

(a) 3 days leprosy / IEC training to be given regularly to the newly appointed GHC staff. The number will be quite small and may be continued with regular fund under the programme.

(b) On the spot capacity building for General Health Care Staff to continue as at present, with the help of the DTSTs, District Nucleus staff and State / Zonal Coordinators.

(c) 3 days training in leprosy may have to be imparted to Medical Officers and Health staff of Municipalities, other non-leprosy NGOs, some Private Practitioners etc. under the urban leprosy control plan with programme funds.

(d) Capacity building of the General Health Care Medical Officers in diagnosing early nerve involvement and management of such cases is an important requirement. This is to be worked out and done through the DTSTs in a planned way.

(e) Capacity building of specialist services in selected Medical colleges and district Hospitals in States / UTs where such facility is not available, to be taken up urgently. ILEP has agreed to provide such support in 5 Medical colleges of endemic states.

(f) Capacity building of 590 District nucleus staff eg. DLO, MO, NMS and 2 PMWs. Total number of persons to be trained are 2950. ILEP has agreed to carry out this activity by March 2005.

(g) Continue training of CM&HOS in Management of Leprosy Programme through the NIHFW with WHO support which started in 2003-04, to cover low endemic States or Regional basis.

(h) Training of Private Practitioners in leprosy and their involvement in the Programme activities has been taken up with the Indian Medical Association (IMA). Training has already started in selected districts of endemic states. The same is to be completed by 2005.

Simplified Information System

(a) Simplified Information System (SIS) was initiated from September 2002. The States / UTs took time in full implementation of SIS in all the districts and peripheral level. Proper implementation at all level to be streamlined.

(b) Record updating and case validation to be ensured routinely.

(c) Software for monthly report compilation and monitoring to be introduced & implemented at CLD and all states. WHO has been requested to provide support in developing and finalising the software, its supply to states and in organising training to the required staff which may need to be repeated.

(d) Printing of record and reporting forms - May be continued with the regular budget available with the SLS/DLS.

(e) In addition to the Monthly Progress Report of Epidemiological and MDT Logistic aspect available at present, a composite report covering all the components of the programme has been developed for submission by the States / UTs to the Central Leprosy Division.

Monitoring & Review

(a) Operational research on Integrated leprosy services through General Health Care Staff conducted by RLTRI, Raipur / Aska / Gauripur will be repeated during 2005-06. WHO has agreed to provide support for the same.

(b) LEM - 2005 to be conducted with WHO support through NIH&FW.

(c) Exercise of new case validation will also be done through the NIH&FW with WHO support alongwith the LEM - 2005.

(d) Routine validation of newly detected cases to continue through District Nucleus staff and DTST staff to ensure quality of diagnosis and treatment.

(e) Quarterly Review meetings at the State / UT level to continue with programme funds.

(f) Programme Review meetings at Central level and major endemic states to be done with WHO/ILEP support.

(g) Independent survey to assess the impact of IEC to be carried out with programme funds.

NGO Services

1. GOI has recently approved the Modified Voluntary Leprosy SET Scheme for the period 2004-07. Pattern of assistance under the scheme has been detailed and the same is under process of circulation. It is expected that with increased funding pattern more applicants will come forward for Grants-in-Aid. Yet, it is expected that the number of such NGOs may be around 40 with an estimated expenditure of Rs. 2.00 crore annually.

2. ILEP also support about 130 NGOs with an annual expenditure of about Rs. 17.00 crores. In the "National Workshop for redefining Roles and Responsibilities of NGOs / VOs in the context of leprosy elimination and integration with General Health Care System" held on 16-17 July 2002, it was decided that support to the state NLEP by NGO will be on recommended crucial areas of activity only. In addition to the activities allowed under GOI SET Schemes, NGOs can also continue to work for Rehabilitation, Research, Referral Services for RCS etc. under support from ILEP sources.

3. It has been agreed in the above workshop that all the proposals from NGOs for working in a specific areas for NLEP will be submitted to the concerned District Leprosy Officer, who will recommend the required one to the SLO. The State Leprosy Society will forward the approved proposals to the GOI or ILEP as the case may be for funding. Once approved the NGO will receive fund from the State Leprosy Society.

4. ILEP and GOI would continue to support local NGO's for NLEP work. Initially all existing NGO's of both ILEP and GOI would be automatically included for support so that there is no disruption in their activities.

5. Key Policy and Institutional Changes

(a) **Source of funding :** We may not seek a follow on World Bank Project after conclusion of NLEP II on 31.12.2004. Instead the programme should be supported through budgetary support of the Ministry, State Governments (through maintaining existing levels of manpower), the WHO and ILEP agencies.

(b) **Administrative structure for implementation :** The existing levels of staffing for Central Leprosy Division are proposed to be continued at least till the end of the Tenth Plan. The existing State Leprosy Societies and District Leprosy Societies may be retained for supervision and management of all cash assistance to states. The Sample Survey-cum-Assessment Units in 27 States may be continued.

(c) **SET Scheme :** The Government of India currently supports NGO's / NGO and hospitals working for detection and treatment of Leprosy affected patients. The scheme was revised with effect from 1.4.04. However it has not been popular and even with revised parameters, maximum utilisation of budget expected is approximately Rs. 2 crores / annum for 40 NGO's. The ILEP agencies support a similar scheme which has been largely popular and their expenditure under this scheme is approx. Rs. 17 crore / annum covering 130

NGOs. It is proposed that the two schemes may be merged. Proposals would be received by District Leprosy Officers and approved by District Leprosy Society for scrutiny and recommendation. Proposals may be forwarded to State Leprosy Society for approval. ILEP (and GOI) would place funds at the disposal of SLS for this purpose. Initially all existing NGO's of both ILEP and GOI would be automatically included for support so that there is no disruption in their activities.

(d) **Provision of MCR footwear :** This footwear is used by leprosy patients having leprosy related deformity in feet. Currently funding is provided under World Bank Project @ Rs.250 per pair. ILEP agencies also supply MCR footwear through their own factories.

It is proposed that provision of Rs. 250/- per pair of MCR footwear to the NGO institution of ILEP will be withdrawn.

GOI may continue to provide MCR footwear and other materials to states such as splints / crutches; printing costs etc.

(e) **SAPEL / LEC :** These cover specific areas and groups. SAPEL / LECs are not required now and therefore will not be carried out.

6. Targeted Milestones

The system of setting targets for Leprosy case detection, case treatment and discharge of patient is not being continued from the year 2003-04 onwards. Targeted milestones under the programme till March 2007 will be as under :-

Indicator	Achieved as on 3/04	To be achieved 3/05	12/05	3/06	3/07
PR/10,000 (National)	2.4	1.8	< 1	<1	< 1
PR<1/10,000 in Districts	42%	50%	60%	65%	80%
ANCDR/10,000 (National)	3.3	3.0	2.8	2.5	2.0
MB proportion of new cases	39%	41%	43%	45%	48%
Disability proportion	1.4%	1.3%	1.2%	1.1%	1%
Female Proportion	35%	38%	40%	44%	45%

III. L E A P
Leprosy Referral Centres

1. The Context

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

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

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

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

2. The Need

Despite bringing down the overall prevalence of leprosy, new cases continue to surface. Among the new cases, a substantial number of them are detected / reported with early disabilities and deformities. We also have backlog of cured patients with disabilities and deformities in addition to deformity prone patients. This calls for a

practical intervention strategy. In this context, the policy of GOI envisages to *"develop a suitable referral services for providing services to complicated cases, reconstructive surgery system, capacity building of needy professionals and supply of footwear by involving established NGO Institutions"*

3. Strengthening integration

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

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

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

4. LEAP *(Leprosy Elimination Action Programme)*

LEAP promoted by ALERT-INDIA, aims to bring together all the prospective partners, and to re-organize the existing manpower resources and to make best of the **potentials** and **opportunities** that are available today with the vertical leprosy agencies, and to assist the GHC services and to enhance the quality of the services to the leprosy-affected individuals. LRC is a strategic plan that can help promote integration on long-term basis coupled with Continuing Medical Education (CME). Following from the above, the immediate tasks are establishing / strengthening of LRCs to respond positively with appropriate interventions needed in different regions.

LRCs are proposed to be established in urban and semi-urban areas and at district levels and special endemic zones with an active collaboration of district level units, municipal councils, corporations, public and private hospitals (Dermatology departments), medical colleges, teaching hospitals, physical medicine and rehabilitation institutions, specialized leprosy institutions and hospitals, NGLOs and health NGOs.

5. Overall objective

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

6. Specific Objectives

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

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

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

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

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

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

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

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

Task Based Activities

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

(iii) Recruit / depute necessary personnel such as trained Medical Officer, trained Physiotherapist or Para-medical worker and an assistant.

(iv) Provide specialized services including counselling and education for leprosy patients and their families.

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

Task Based Activities

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

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

Task Based Activities

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

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

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

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

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

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

8. LRC should promote partnership with GHC

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

9. LRC: basic functions and operational guidelines

9.1. Confirming diagnosis of leprosy in difficult cases

Basic task:

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

Rationale:

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

Guidance is essential especially for patient presenting with uncertain cardinal signs such as early lepromatous cases, pure neural cases (without any skin patches). In order to confirm the diagnosis, these cases need to be subjected to a detailed clinical and laboratory examination* by trained health personnel. These laboratory investigations may also be required to diagnose 'relapse' in certain cases and will help to advise appropriate treatment (Refer box 1).

9.2. Ensuring prompt treatment at GHC

Basic tasks

1. Refer all new cases to the respective PHC / Health Post (HP) for MDT. with a proper referral note** LRC Referral Slip (LRS) (Refer Box 3).
2. Ensure that the patient is registered at the respective PHC / Health Post for MDT.
3. Advise the patient to take treatment regularly without any interruption.
4. Counsel the patient to report immediately if they develop any adverse effects.

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

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

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

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

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

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

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

Rationale:

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

Since many new leprosy patients might be reporting voluntarily to the existing leprosy

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

9.3. Management of leprosy related complications

Basic tasks:

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

Rationale:

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

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

9.4. Preventing disability among newly detected leprosy patients

Basic tasks:

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

Rationale:

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

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

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

Basic tasks:

1. In any given region or block or district enlist all patients with existing deformities and group them into i.e. Grade I & Grade II.
2. Maintain individual patient record and enter the type of deformities and other problems.
3. Prioritize them according to the frequency of follow-up needed (Refer box 2)
4. Provide relevant physiotherapy for patients with deformities and ulcers.

5. Teach self-care and provide information and demonstrate exercises to be carried out at home.
6. Maintain and update records for evaluation of patients under POID / POWD services.
7. Follow-up of all deformed patients as per the requirement/ frequency suggested.
8. Provide health education and counselling of all patients on every visit to LRC.
9. Liaise with GHC staff and ensure follow-up of all disabled patients periodically at LRC

Rationale:

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

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

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

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

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

9.6. Health Education /Counseling for self-care

Basic tasks:

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

Rationale:

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

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

9.7. Establishing linkages with GHC services and rehabilitation facilities

Basic tasks:

1. Prepare, maintain and regularly update a list of local hospitals / institutions / Vocational Training and Rehabilitation Centres that offer special services aids and appliances, vocational, surgical, rehabilitation services in the region for leprosy cured.
2. Liaise with those agencies who can offer care and services to leprosy patients.
3. Identify for referral those who need special services.
4. Refer displaced patients with socio-economic problems to specialized rehabilitation centre.
5. Keep an update of all Govt. schemes and welfare measures offered for the leprosy cured with specific eligibility criteria and the requisites for obtaining benefits under such schemes.
6. Maintain a record of patients referred to different agencies for follow-up and for feedback to the institutions / authorities offering rehabilitation services.

Rationale:

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

9.8. Monitoring and evaluation

Basic tasks

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

3. Undertake specific small analytical studies of special group of patients or specific interventions or results of special schemes promoted.

Rationale:

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

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

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

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

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

1. Known cases, 2. RFT cases, 3. Contact examination,

4. Suspects & observation 5. Patient follow-up notes

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

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

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

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

2. treatment

D. *Records to be kept :*

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

9.9. Health personnel required for LRC:

An ideal LRC should consist of GHC personnel and trained leprosy technicians / workers. The LRC team should consist of a minimum of one Medical Officer (M.O), one Physiotherapist (PT), two Paramedical Workers (PMW), one Health Educator (HE) and one Laboratory Technician (LT). Besides these health personnel one Programme Officer (PO), one Rehabilitation Officer (RO), one Dresser (DR), a Social Worker / Counsellor may be included wherever possible. It is recommended that all these personnel are leprosy oriented and have received elaborate training in providing comprehensive management of leprosy.

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

Promoting referrals to LRCs:

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

Promoting awareness in the community:

1. Health education and IEC in community

Involving general medical practitioners

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

Situation analysis and need based assessment

1. Visit all beneficiaries (leprosy cases: active/RFT/ RFC) & identify their

problems and needs.

2. Enlist cases from the area needing LRC services
3. Classify beneficiaries based on priority

Field level follow-up

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

10. Anticipated Outcome

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

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

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

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

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

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

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

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

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

LEAP : ALERT-INDIA

From :

LRC REFERAL SLIP (LRS)

To : Medical Officer,

_____

Municipal Dispensary / Health Post

Date_____

Referring Mr./Mrs/Miss_____Age_____

residing at_____for

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

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

_____

_____

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

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

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

Cutaneous Nerves :_____

Nerve Details : Thickened : Yes ☐ No ☐ Tender ☐

Nodules (Abscess) ☐

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

Muscle Weakness :_____

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

Foot Drop ☐ Lagophthalmos / Facial Palsy ☐ _____

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

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

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

Remarks :_____

_____

_____

_____

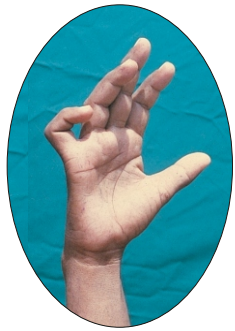
_____

Medical Officer

ALERT-INDIA:LEAP(04/05)

Splints for prevention and correction of hand deformities

Finger loops



Oponnens loop

Finger gutter

Adductor band

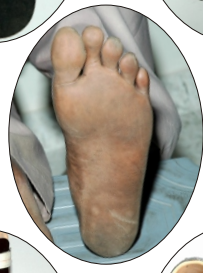
Available in different sizes
Durable and easy to use
Appropriate for hand exercises

Prosthesis and orthosis for foot deformities

MCR Insole

MCR sandal with
Foot drop spring

Malleoli cap



Foot prosthesis

Foot orthosis

Moulded shoe

'made-to-order' on 'no loss - no profit' basis

Policy Issues

Some questions that need to be answered

(this list does not exhaust the policy issues that may need to be debated and consensus arrived at)

Dr. H. Srinivasan

1. Who should take the responsibility for carrying out a rehabilitation programme in a given area ? Could we consider the district as a unit for this purpose? And in the context of the leprosy becoming integrated into the general medical / health services who will be best placed for carrying out rehabilitation work? Is rehabilitation a health issue?
2. To what extent the leprosy programme personnel may be involved in this kind of work?
3. What should be the community's role in this kind of work? In this context who constitute the "community" and who mobilizes this "community"?
4. What will be the source of funding for this work?
5. Should disability prevention activity be part of the rehabilitation programme? Or, should it be the part of a medical programme independent of the rehabilitation programme?
6. To what extent is CBR strategy likely to be helpful in the context of leprosy?
7. Which other kind of dehabilitated persons (with or without impairments/disabilities) could be clubbed along with leprosy-affected persons?
8. What should be the role of "patients' organizations" in the context of rehabilitation? And who will decide that?
9. How do we prioritise "rehabilitation needs"?
10. What proportion of affected persons is likely to really benefit from rehabilitation efforts?

Source: 'Rehabilitation of leprosy affected persons', Indian Journal of Leprosy, Vol. 75(2) 2003