SERIES NO. 3

LEAP
LEPROSY
ELIMINATION
ACTION
PROGRAMME

MAR, 05

# FOCUS

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## Focus on task based activities under Leprosy Elimination Action Programme (LEAP)




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# the purpose

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

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

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

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

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

Sion, Mumbai
28 March, 2005

A Antony Samy
Chief Executive,ALERT INDIA

# Role of Non Governmental Organizations (NGOs) towards Leprosy Elimination in India

**Dr P. S. S. Sundar Rao**
**Director, Schieffelin Leprosy Research and Training Centre, Karigiri, Tamil Nadu**

Leprosy elimination is the resposibility of all concerned including NGOs. The specific role of NGOs in this task can be broadly considered under health related NGOs and non-health NGOs such as educational institutions, industries etc. Some of the strengths of NGOs in complementing the work of the Government and in some instances even supplementing the work are briefly mentioned here.

**Health related NGOs:**

By virtue of the expertise available in many of the leprosy NGOs, (NGLO) and in terms of certain advantages in flexibility of working, resources available, networking possibilities, etc NGLOs can help in the following: increasing community awareness, train and CME, developing effective communication strategies, providing referral services including management of complications and reconstructive surgeries, provision of footwear and assistive devices, socio-economic rehabilitation, facilitation in drug compliance and early detection. Some of the NGLOs have excellent laboratory facilities that could be utilized for confirmation of diagnosis, effectiveness of drug regimens or drug resistance and confirmation of relapses. Above all these activities the NGLOs could also act as nodal agencies or co-ordinators of various stakeholders particularly in urban areas.

**Non-health NGOs**

With regard to non-health NGOs their roles could be primarily in several IEC related activities particularly in terms of removing various misconceptions, superstions and wrong information about leprosy and its treatment and also availability etc. In this connection they could also plan for screening camps of their own employees and families as well as act as role models for early detection and successful adherence etc. Thus the NGOs who have long background and experience in leprosy related activities could be strong partner with the Government of India and State Governments to achieve the national goal of elimination and eventually leprosy eradication.

For effective involvement of NGOs / Voluntary Organizations, it would, however, be necessary for the Government to clearly draw suitable MOU and provide necessary support, guidelines, resources where needed and suitable monitoring mechanisms. It is important that the urgency and the relevance of such combined efforts be emphasized for efficiency and success of the national goals.

# Integration : advantages & challenges

## The policy today . . .

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

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

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

## LEAP is possible . . .

### Rationale for LEAP

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

### Asset

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

### Potential

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

### Opportunity

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

# Basis for LEAP strategy

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

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

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

# LEAP : a strategy for integration

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

**LEAP is aimed …**

1. **To evolve a leprosy-affected persons' centric and community-oriented strategy and an action programme that would facilitate the changeover from vertical system to an integrated system.** ***Continuity of service to the leprosy affected persons during this transition is the prime concern. Programme is aimed to respond with positive interventions needed to strengthen the process of integration.***

2. **To formulate guidelines for action, for "vertical NLEP staff" (doctors/paramedicals/ multi-purpose workers) to actualise the goals of integration.** ***The different levels of expertise and specialisation available today with 'vertical staff' can adequately be reoriented to take up the tasks needed for actualisation of goals. This is an advantage, which needs to be utilised to realise the goals of integration.***

3. **To study the lacunae and to develop a feasible, replicable, supportive methodology for strengthening integration as well as to sustain the provision of leprosy care services in collaboration with the multiple partners (NGLOs/ Health NGOs/CBOs).** ***Such an effort alone can pave way for a long-term sustained strategy for work to achieve the target of elimination.***

4. **To assist the public health personnel by direct & indirect supportive actions and programmes to detect, treat and cure leprosy on par with any other diseases in the general health system.** ***Offering practical (technical) help in diagnosis, treatment, follow-up and care of leprosy-affected persons. This is the only way to strengthen integration.***

5. **To bring together leprosy NGLOs and other partners to work independently for a common strategy.** ***Pooling strengths and resources will definitely make a difference in the present context.*** *Take up tasks (relevant activities) for the benefit of leprosy-afflicted persons that can directly or indirectly promote integration.*

# Views. . .*that matter*

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

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

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

**The Holistic principle**

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

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

**Participation of the people**

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

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

**Need for a comprehensive approach**

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

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

# LEAP : GOALS

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

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

# LEAP : Specific Objectives

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

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

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

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

**Provide basic positive information**

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

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

**Case detection influenced by leprosy elimination campaigns**

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

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

**Easily accessible target group for education or intervention programmes**

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

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

## Specific Objective : 1

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

***Rationale***

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

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

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

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

***Tasks***

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

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

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

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

## Specific Objective : 1

## Task 1

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

### *Task Based Activities*

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

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

## Specific Objective : 1

## Task 2

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

### *Task Based Activities*

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

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

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

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

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

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

## Specific Objective : 1

## Task 3

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

### *Task Based Activities*

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

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

## Specific Objective : 1

## Task 4

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

### *Task Based Activities*

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

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

## Supervisory capabilities should be built up

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

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

## Disseminating appropriate information on leprosy elimination

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

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

## Training of PHC functionaries

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

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

## 'Captive Audience' in medical schools

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

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

## Specific Objective : 2

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

### *Rationale*

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

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

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

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

### *Tasks*

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

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

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

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

## Specific Objective : 2

### Task 1

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

### Task 2

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

### *Task Based Activities*

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

## Specific Objective : 2

### Task 3

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

### Task 4

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

### Task 5

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

### *Task Based Activities*

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

**Key Issue**

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

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

**Special action projects for the elimination of leprosy**

SAPEL were introduced with the objective of reaching patients living in difficult-to-access areas or among neglected population groups and thus to provide leprosy services, specifically MDT to those patients who otherwise would never have received treatment. They include those who are geographically inaccessible, politically neglected groups, ethnic minorities and certain population groups like nomads and refugees.

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

**Finding segments of the population left out**

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

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

**Tribal villages**

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

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

## Specific Objective : 3

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

### *Rationale*

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

### *Tasks*

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

## Specific Objective : 3

## Task 1

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

### *Task Based Activities*

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

## Specific Objective : 3

## Task 2

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

### *Task Based Activities*

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

## Specific Objective : 3

## Task 3

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

### *Task Based Activities*

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

**Identify the underlying epidemiological and operational reasons**

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

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

**Identification of leprosy pockets at sub-national level**

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

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

**Highlights of India's strategy for leprosy elimination**

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

*Excerpt from the article on "Leprosy elimination in India"*

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

## Specific Objective : 4

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

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

## Specific Objective : 4

### Task 1

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

### Task 2

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

### Task 3

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

***Task Based Activities***

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

## Specific Objective : 4

### Task 4

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

***Task Based Activities***

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

# Leprosy: too complex a disease for a simple elimination paradigm

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## Introduction

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

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

## The concept of elimination

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

## Prevalence and new-case detection rates

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

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

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

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

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

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

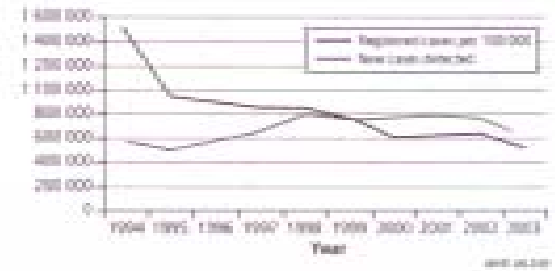



Fig. 2. Prevalence and new-case detection rate for leprosy in India, 1984–2002

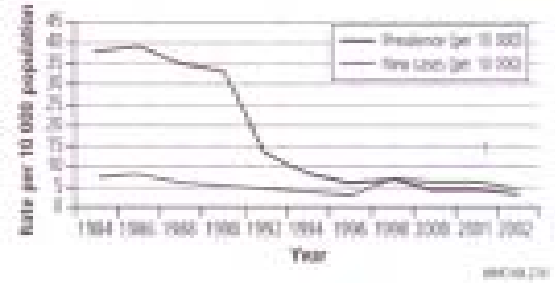
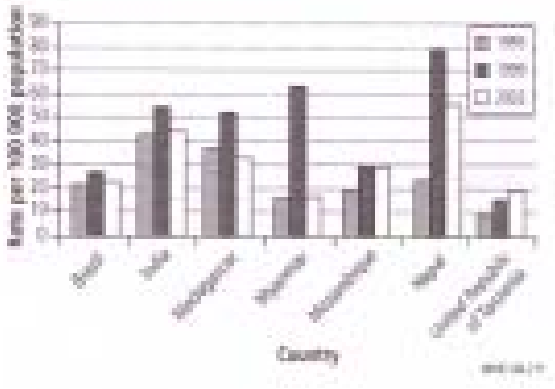



Fig. 3. Cases of leprosy detected in seven countries where rates of endemic leprosy are highest, 1995, 1998 and 2003




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

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

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

### Biological features of *Mycobacterium leprae*

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

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

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

### Vaccines

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

### Political effects of elimination

### Success of elimination

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

### Downsides

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

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

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

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

**Effects on partners**

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

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

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

**Contemporary challenges**

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

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

**Integration**

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

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

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

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

**Surveillance and training**

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

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

**Diagnosis**

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

**Treatment**

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

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

**Reactions and nerve damage**

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

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

**Preventing disability**

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

**Leprosy and stigma**

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

**Leprosy and poverty**

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

**Role of private practitioners and dermatologists**

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

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

**Research**

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

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

**Reflection on the leprosy elimination campaign**

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

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

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

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

## Recommendations of the NLEP : Good referral system

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

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

## Handing over

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

*The Final Push Towards Elimination of Leprosy, Strategic Plan : 2000 - 2005*
*WHO/CDS/CPE/CEE/2000.1/Page.7 & 12*

# You can be a LEAP Partner !

**(1) Who can be the LEAP partner?**

– Municipal Corporations, District NLEP Units, Non-Governmental Leprosy Organizations, Leprosy Institutions, Non-Government Organizations - Specialized in health and community based work, Medical Colleges or their units or departments involved in out-reach programmes.

**(2) How to take part in LEAP programmes?**

(a) Select a task or a group of tasks outlined in this booklet based on the present leprosy situation in your area of work.
(b) Prepare an action plan to undertake task based LEAP activities.
(c) Do get in touch with the LEAP Support Team of ALERT INDIA to discuss the same.

**(3) What is the role of the LEAP Support Team?**

(a) LST will visit the willing partners and will provide guidance regarding the specified tasks to be undertaken in your area and prepare proposals for the same with you.
(b) Support the training needs of your staff to implement the selected tasks.
(c) Provide necessary IEC materials and training aids to promote LEAP activities.
(d) Undertake monitoring and evaluation of activities implemented.
(e) LST will also help you to identify the local resources required for implementing the task based activities.
(f) Prepare estimates and ascertain the cost and help prepare an appeal for Project Support Fund (PSF) for the specific activities from the Nodal Agency (Maharashtra Lokhita Seva Mandal) for LEAP.

**(4) What is expected from the LEAP partners?**

(a) The eligibility for PSF from Nodal agency will be available only to those who are in total agreement with goals and objectives of LEAP.
(b) For each selected objective, identify task-based activities and present implementation plan in the area as per the defined methodology.
(c) Partners need to provide the following information / documents - A letter of acceptance by the Executive Head of the Institution / Corporation / Council to take up LEAP activities expressing willingness to become a LEAP partner. 3 years' activities supported by reports, Audited statement of Accounts, Names of Executive Committee members in addition to copies of Registration, Constitution, Memorandum.

**(5) Source of funds:** All the LEAP activities are supported by Anesvad Foundation.

**ALERT INDIA**

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

*ALERT-INDIA : VISION 2010*