SERIES NO. 3

LEAP

LEPROSY
ELIMINATION
ACTION
PROGRAMME

OCT 06

TASK TODAY

Integration :
Prospects

Integration and Referrals :
Operational Guidelines

Integration and Quality care :
Leprosy Referral Centres

ALERT-INDIA'S
28th FOUNDATION DAY
SPECIAL ISSUE

INDEX

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Foreword

Application of field program for control and later elimination of leprosy has been quite successful in most parts of the country as the elimination target have been achieved in January 2006. To achieve this, a special group of workers had focused on leprosy alone under the vertical program. This was the need all through as the case load was high. Now that the PR has come down considerably, the leprosy work has rightly been integrated into primary health care system. It is hoped that the general health care workers would shoulder the responsibility and be involved in control and care of leprosy sufferers in the same way as people suffering from other communicable diseases. The leprosy patients would benefit by treatment available near their homes and on all working days and without any stigma/ ostracism. This has indeed been so in many of the states where health awareness, set-up and commitment have been better.

It is expected that leprosy would continue to get due attention and further gradually decrease. However, continued appearance of new cases, some with advanced infectious leprosy, does indicate need for greater efforts with some midcourse support that are required in this direction lest a situation like malaria occurs. Continued support from established leprosy referral centers and experienced leprologists at the regional and state level is an important step in this direction. Not only diagnostic and therapeutic help, but more importantly, formal or informal training and support from these centers are also needed. NGO's are the right groups for carrying out these activities.

ALERT-INDIA has been involved in several anti-leprosy activities (in addition to TB and HIV) and has provided a lead and example to both NGO's and government units in organizing leprosy work and up-dating the skill of the workers through their publications. One of these, TASK TODAY has been a remarkable collection of *views and vision on leprosy* for workers who have spent almost their whole life in the fight against the disease.

This annual publication, the third in the series, details on issues and projections, which are relevant for the years to come in our efforts against leprosy. The directions for better output to sustain the pace of earlier achievement, the areas to be focused on and the line of planning for the future, detailed in the booklet, indicate the vision and the strength of the team at ALERT-INDIA. Important topics discussed in the current issue pertain to strengthening the primary health care units and at the same time establishing referral services for leprosy. Emphasis on community awareness, disability prevention and management are some of the other key issues are also discussed. Continued effort to educate the general health care staff and highlight the issues to the planners through such publications is indeed laudable.

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Agra
3 October 2006

Why Task Today ?

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

The country has achieved the intermediate target set for leprosy elimination. Today there is an urgent need to sustain leprosy control efforts and continue to provide quality care. The WHO has proposed a global strategy and operational guidelines for sustaining leprosy control work from 2006 to 2010. The Government of India (GOI) is in the process of formulating a new programme for the country to be implemented during the next 5 years (2007 – 2012) based on the Global strategy.

The 'Task Today' Series 3, in the first two parts, outlines all the key elements of this strategy and the essential details enshrined in them for sustaining leprosy control efforts and quality care. This issue is to bring forth the importance of these aspects and reach them to the grass root level workers and programme managers.

The third part outlines the crucial role of the field-based leprosy NGOs today. Translation of the strategy into action to an extent possible to meet the actual needs and situation is the need of the hour. This requires a practical application of the strategy at all levels by reorienting and redeploying the available manpower involving all the stakeholders.

This cannot be done alone by one organisation, but can easily be achieved if we pool together our strengths. This requires a common perception and a collective determination to respond to the needs of the leprosy patients of today and tomorrow.

This calls for a better planning and a concerted action by NGLOs / NLEP with all the public health personnel and other development workers in different communities.

Let us together learn, plan and work towards achieving a greater degree of leprosy control in our country !

Sion, Mumbai
11 October 2006

A. Antony Samy
Chief Executive

National Leprosy Eradication Programme

Sustained Activity Plan – 2006

Government of India

"States and districts that recorded > 2 % of deformed patients among new cases have to take special measures for early detection and treatment of patients, early diagnosis and management of reaction to prevent deformity and timely referral to the district hospitals for management of complications."

Sustained Activity Plan

SAP - 2006 is proposed to cover the 29 districts in 7 states (Chhattisgarh, Gujarat, Jharkhand, Orissa, Uttar Pradesh, West Bengal and Delhi) and 433 blocks in 14 states (Andhra Pradesh, Arunachal Pradesh, Bihar, Chhattisgarh, Gujarat, Himachal Pradesh, Jharkhand, Madhya Pradesh, Maharashtra, Orissa, Tamilnadu, Uttar Pradesh, West Bengal and D & N Haveli) that have been identified (See Table) as priority areas for the year 2006-2007.

NLEP – Focus during 2006-07

Post elimination at the National level, the country has still many areas in state, district and block level that need extra focus.

During the year 2006-07, NLEP will continue the efforts to achieve elimination of leprosy through existing MDT services in the remaining states/ UTs with focused attention on the endemic districts:

Endemic Districts

As on March 2006, district endemicity are:

PR	No. of Districts	(%)
< 1	439	(73.7)
1 - 2	128	(21.5)
2 - 5	28	(4.7)
> 5	1	(0.1)
Total	**596**	**(100)**

Sustained activity plan for the 29 districts and 433 blocks with PR > 2/10,000 population under priority areas are:

- Provision of quality services with proper referral for management of reactions, complications and correction of deformity will be the desired efforts in all the districts with PR > 1/10,000.
- District nucleus should be fully functional to monitor and supervise services being provided by the Health institutions.

Source: National Leprosy Eradication Programme, Sustained Activity Plan – 2006 (SAP-06)
Full document is available at http://mohfw.nic.in/nlep.htm

Endemic urban localities

In the urban localities prevalence is generally higher than the surrounding rural areas. Urban Leprosy Control Plan is already under operation in identified cities and towns. The activities will be further strengthened.

Districts showing high disability rate

At present disability grade II proportion in new leprosy cases is 1.9% at National level. Some of the State/ UTs having disability rate higher than the national level are Andhra Pradesh (2.4%), Chhattisgarh (2.3%), Gujarat (3.4%), Madhya Pradesh (3.9%), Orissa (3.2%), Tamilnadu (2.1%), West Bengal (2.4%) and Delhi (3.2%). State/UTs recording less than 100 deformed cases are not included in the above list.

On district-wise analysis of data, it is seen that a total of 201 districts (33.7%) out of 596 districts have recorded > 2 percent of deformed patients among new cases. The states and district concerned have to take special measures for early detection and treatment of patients, early diagnosis and management of reaction to prevent deformity and timely referral to the district hospitals for management of complications. Correction of deformity through Reconstructive Surgery (RCS) will also be given priority under the programme.

States with high child proportion

Child proportion among new cases detected stands at 10.0% at national level in March 2006. There is gradual reduction in the child proportion in the last 5 years (see table):

Years	Child % (among new cases)
2001-02	16.3%
2002-03	14.9%
2004-05	13.8%
2005-06	13.3%
2006-07	10.0%

The states having higher than national level child proportion are Tamilnadu (17.0%), Bihar (15.7%), Gujarat (13.0%), Jharkhand (12.5%), Andhra Pradesh (12.2%), Maharashtra (11.8%), Kerala (11.7%) and Karnataka (10.7%). These 8 states will have to analyse the position district-wise and study whether the higher rate is due to continued transmission potential in specific areas or otherwise some ‘operational factors’ are at play. Suitable action have to be taken in either case to remedy the present situation.

Disability Prevention and Medical Rehabilitation (DPMR)

A Disability Prevention and Medical Rehabilitation (DPMR) Plan is under consideration for implementation during the 11th Five Year Plan (2007 - 2012). However certain actions have already been initiated to increase institutions for providing RCS to leprosy disabled persons, to mobilize backlog of leprosy deformed patients through GHC staff for RCS in the identified institutes and to develop linkages with other social service organizations/ departments. ■

Leprosy and the General Health Services of India

Prospects for greater Integration

Yasir Al-Wakeel [*] and Terence J Ryan [**]

"Integration is not just about transforming a government approach from vertical to horizontal, rather it is a process that needs to incorporate full partnership in the health sector; bringing together the diverse 'set of actors' for a common goal."

Background: Leprosy

On the 30th of January 2006 India celebrated the elimination of leprosy as a public health problem. This success, however, is only part of the picture. India remains a stumbling block. Hence the best way to make the disease disappear is to stop looking for and registering new cases, or to cut the duration of treatment.

It was this slight of hand that has been employed, changing the 24 months MDT regimen for multibacillary (MB) cases to 12 and that of paucibacillary (PB) cases from 12 months to 6. Overnight the prevalence halved, with countries like Ethiopia suddenly attaining their goal of elimination [1]. To this may be added the instruction in 2005 not to register persons with single lesions (Rao PN, 2006).

Cutting the prevalence of leprosy by over 95% in the space of 20 years is still an impressive feat. Yet this has had little if any effect on incidence [1]. New cases are being detected almost as frequently as ever and because many of these are children the source of their infection is problematical. Yet before invoking an extra-human reservoir [2] or the infectious nature of sub-clinical cases, and whilst admitting that research on these topics is essential, one must further scrutinize whether there are many cases diagnosed correctly but never becoming part of the statistics.

Much has been made of over-reporting of leprosy in India, be it by re-registration, over-diagnosis [3] or the presence of non-existent cases on the register. On the other hand, under reporting exists, and it is possible that the scale is enormous. Sample surveys are an expensive epidemiological method for estimating the number of hidden cases. The few surveys conducted in India reveal a prevalence of 4-5 times the recorded prevalence [4, 5]. In addition, the number of hidden cases is not only accounted for by those with clinical leprosy not yet diagnosed, but includes those being treated, whether by

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Source: http://www.leprosyhistory.org/english/bulletindiscussion.htm (Extracts)

MDT or not, by those outside the government services such as private dermatologists many NGOs or practitioners of Indian systems of medicine.

Background: Integration

India is in need of an efficient and sustainable means of detecting leprosy early and providing access to MDT for as much of its population as possible. How to do it has evolved from a strategy using a focused vertical programme, to a drive to take leprosy elimination into a so called horizontal programme that amounts to relying on general health services to manage this disease.

It also requires a policy of integration of available resources for the promotion of health and the management of disease. It is not the only elimination programme to aspire to do this. Other major disease programmes for TB, Malaria or HIV/ AIDS, add to the burden and information overload of the general health services.

There is also the burden of the consequences of leprosy and the millions of disabled that attend for help. The Nippon Foundation estimate (Letter dated 30th January 2006) is that there are 700 colonies for leprosy in India. These disabilities are a consequence mainly of sensory loss.

In the long-term, leprosy as a cause of disability may disappear but trauma and diabetes will not. The provision of care at the level of the general health services is in need of integration.

It is now well recognized that in order to achieve the aforementioned aims of efficiency, sustainability, early detection and broad population coverage, an integrated approach is necessary[6.]. Government departments promoting Integration need strengthening. Integration refers both to the process of moving from a vertical system of healthcare to a horizontal one, but also the process of involving all systems and paradigms of health care.

Integration is not just about transforming a government approach from vertical to horizontal, rather it is a process that needs to incorporate full partnership in the health sector; bringing together the diverse ‘set of actors’ for a common goal[7]. In the context of India, with its vast and heterogeneous population seeking several different kinds of health practitioner, this is especially important. Heterogeneity and a failure of all systems charged with the delivery of health care to work as one, is also a problem still to be solved. As yet in India it is rare to find experts from several different disciplines problem-solving as a team. The “wound healing” team is increasingly popular elsewhere and Dermatologists are prominent members and often the leaders in solving chronic non –healing, as in foot ulcers.

Government Services: *Overworked, Unattractive and Unable to Meet Needs*

The Indian government has a long history of commitment towards leprosy. In 1955, it launched the Leprosy Control Programme, stressing the importance of education and rehabilitation. The programme was re-launched in 1982 as the National Leprosy Eradication Programe (NLEP) following the recommendation of the Swaminathan Commission in light of the efficacy of MDT[8]. Yet, commitment could not always bear fruit due to a variety of limitations.

There are 17,000 public hospitals in India and 24,000 primary health centres. Only 38% are adequately staffed. The primary health structure varies from place to place, with states such as Tamil Nadu having a well developed infrastructure as compared to states such as Bihar. India lies at 171st place of 175 countries for health care spending, contributing only 0.9% of its GDP.

Consequently, the government services that are free are overworked and unattractive. Even the poor try not to use them or to short circuit them and use the private sector, traditional medicine or NGOs. 40% of those faced with an acute disease or at a late stage in a chronic disease resort to borrowing or the selling of assets to pay for healthcare rather than make use of the available government services.

It is a scenario in which diseases that does not kill, such as leprosy, and diseases that make one unwelcome in a queue, also like leprosy, will be driven away from government services. There are also written reports[9] which show the difficulties experienced in the training and function of NLEP multipurpose paramedical workers and which suggest that midwives and government nurses of preschool children would be more appropriate for managing leprosy in women. Furthermore patients feel abandoned by Primary Health Centres in which their care has been thrust upon “an unwilling and apathetic staff”[10].

Those that do obtain their MDT from government services often find themselves spending under three minutes in a consultation with a doctor who is battling to see around 100 patients in a session. It is our belief that elimination of leprosy programmes does not effectively transfer into general health services for the very obvious reason that these services are desperately over-stretched, understaffed and by being general, are overloaded by the expectation that they will take on all aspects of health care.

The Private Sector: *Dermatology has great skills but being urban based it is also unenthusiastic about rural public health* **. . .**

Dermatology has the capacity and skill to play a leading role in India’s battle against leprosy. There are about 4000 members of the Indian Association of Dermatology, Venereology and Leprosy (IADVL), which adopted leprosy as a key component in 1973. Their curriculum for training, their exam, their membership of their association and their journal all indicate that they are well qualified in the field of leprosy.

Indeed the vast majority of dermatologists are in the private sector with academics and government appointments to government hospitals (1-3 per 475 districts), to the armed services or national organisations such as the railways or mining industry accounting for little more than 1000.

A feature of those trained as dermatologists is that when their diagnostic skills fail them they usually take a biopsy. At the individual level, dermatologists are playing an active part in the treatment of leprosy. Private practitioners are trusted and many offer free or concession rates for the poor. They mostly can offer consultations with no one else around, a degree of privacy rare in government services. As a result, they are well used by all strata of society and they well know that the look good feel good factor, unwelcomeness due to disfigurement and the prototype of stigma which is leprosy, require privacy not display. They have little involvement with the government services nor do they habitually refer their patients affected by leprosy to the Government services. Without so doing their patients do not receive MDT at no cost nor are they added to national statistics. This matters all the time targets are to be met.

A dermatologist with a mainly middle class clientele may see only three new cases in one year. A dermatologist with a busy clinic open to the poor in a state with a higher prevalence of leprosy may see seven new cases in one session and averages twenty new patients in one week. Questioning several dermatologists in urban practices gave a new case detection figure ranging from two to twenty per month. This is a substantial number of unrecorded new cases.

On the societal level, dermatology is not producing the leadership in the field of leprosy that is required, with more lucrative fields receiving greater support and co-ordination from the top. They are not producing the sort of visionaries that the government is looking for; rather, they are waiting for the government to take the lead. The teaching and examination is still good but what is depressing is that there is no investment in encouraging the young to take up research into leprosy and a lecture on leprosy at the Annual Meeting of the IADVL is one way to empty the hall. Sadly this is also the case at international dermatology congresses and no funding agency sees as one of its roles the recruitment of the young into the field.

Part of the dialectic between government and private practice revolves around guidelines for the treatment of leprosy. The government has adopted the WHO standpoint. Many private practitioners, however, are not happy with the shortened MDT regimens. An abolition of targets, the guidelines for MDT encouraging more flexible prescribing less tied to targets, and recognition of just how well qualified is the dermatologist in India to take a flexible approach to leprosy, would help.

Non-Governmental Organisations (NGOs): *Some models of effective solutions* . . .

NGOs are traditionally seen as non profit charitable organizations that fill gaps in provision. In India, NGOs have long played an active role in leprosy. The first known leprosarium in India was established in Calcutta in the early 19th century followed by another in Varanasi. Pioneering NGOs include the Indian Council of the British Empire Leprosy Relief Association (now LEPRA), established in 1925 and renamed Hind Kusht Nivaran Sangh in 1947, as well as the Gandhi Memorial Leprosy Foundation initiated in 1951.

The financial contribution from industrial countries is large, and leprosy appeals still generate much sympathy, most of which comes from voluntary agencies and not governments. These contributions are subject to the foreign contributions act of 1976, amended in 1985.

Currently, the number of NGOs engaged in leprosy work in India is diminishing from the 1991 estimate of 250[11]. The International Federation of Anti-Leprosy Associations (ILEP) has the task of co-coordinating the largest of the internationally most prestigious NGOs including the British Leprosy Relief Association (LEPRA) with its partner in India, Lepra India. Other ILEP members active in India are The Amici di Raoul Follereau Trust, The Leprosy Mission Trust India (TLMI), The Netherlands Leprosy Relief-India (NLRI), The Damien Foundation India Trust (DFIT), and The German Leprosy Relief Association India (GLRA).

Coordination is a difficult task. As the focus of elimination increasingly becomes directed towards fewer countries, the luxury of being able to geographically divide responsibility is no longer available. The result is that duplication of objectives is common.

Many NGOs, including those from the same religious denomination, are unaware of the other's existence. Hence, in a country where the poor travel only short distances, each NGO is an island in itself. Documents on the government's perception of the role of NGOs state that their main responsibility is capacity building in the prevention of impairments and deformity.

It is abundantly clear that the disease leprosy can still lead to destitution and it is the religious NGOs who are best at caring for the destitute. Indeed the love they give as well as the strength of the belief in salvation is a wonderful alternative to destitution.

However such love is not a substitute for the self-esteem of independence and income generation by those who are capable. A compound in which the majority are carrying out income generating activities is better than a ward filled with persons unwilling rather than unable to leave their beds.

Whether the NGOs provide another invisible pool of new case detection of significant size is questionable. Some we interviewed will not refer patients to government services and purchase MDT themselves so as to provide it free to patients. Another problem that the NGOs, in particular, are facing is the expansion of their mandates to include TB and HIV. This is a result of both the rising burden of TB and HIV/AIDS as well as economic pressure. Yet, the adjoining of multiple vertical programmes is not integration and as with other attempts to provide general health services, there are difficulties in quality control.

Integrated Medicine: *Giving access to all*

Leprosy remains a major public health problem in India and will likely remain so for decades to come. As we have seen there are a variety of actors in this drama; each is facing their own problems, and far from partnership, they currently see each other's failures. The patient with leprosy has a choice to take one or more of several routes to care. They include government services, the private sector and dermatologists. They can visit several other systems of medicine including Ayurveda, Siddha and Unani. Some may go for homeopathy.

There is also the route to NGOs which are often overtly religious and of questionable acceptance at locations where other religions are dominant. But there is no doubt about their value to the destitute and they are frequently the flagship of state prevention of deformity, reconstructive surgery and rehabilitation.

Box A

Advantages of reverse integration

Integration of leprosy control into general health services has gained much wider acceptance. Integration should be a gradual and slow process. At the same time it has some negative aspects like the quality of care may deteriorate, records and reports will be affected, there will be more re-cycling, and leprosy workers may relax if they feel that someone else is dealing with the problem.

Integration policies and efforts have usually been directed towards taking leprosy services to general health services and not bringing general health services into leprosy control.

"Reverse integration" means bringing other health care services into existing leprosy services.

The advantages include: accessibility of specialised services; affordability of specialised services; extended application of expert knowledge and skills; reduction in cost of training workers for leprosy work; integration of persons affected by leprosy; comprehensive health care for leprosy patients; additional sources of funds; effective utilization of personnel and facilities; springboard for other programmes; and interest of government functionaries and philanthropists.

Reverse integration will help to showcase the contribution of leprosy programmes to general health services.

Source: Fidelis T. Iyor. 'Reverse integration' in leprosy: lessons from Mkar, Nigeria, Asia Pacific Disability Rehabilitation Journal, 17, 1, 2006, 35-41

There is a great need for integration, bringing together the many actors, and providing an equitable service for all.

Proposals for leprosy in the GHS

The IADVL should set up a section on Public Health Dermatology to support those young dermatologists interested in epidemiology and community medicine inclusive of the gold standard for early diagnosis of leprosy and its management.

No other discipline knows the skin so well, understands the look good feel good factor and is so concerned with wound healing. Only this profession can make the expertise needed for one disease sharable in the management of other skin diseases[12, 13]. They need to take the initiative to help advise the government towards an integrated approach as well as co-coordinating within themselves their approach to leprosy.

Investment in experts among the younger generation of dermatologists is urgently needed and should be linked to research, both into the unknowns that characterize this disease but also into health service organisation.

Dermatology's textbooks and International congresses must continue to promote gold standards in diagnosis and management. But the aim to make all dermatologists expert in this field should give way to maintaining a small core of dermatologists practicing gold standards and giving a lead to the allied health professionals undertaking leprosy control. In turn, dermatology should receive the requisite advocacy for a job it has already begun, and in the disguise of many distinguished leprologists has proven to be effective[12, 13]. Such rewards and awards are a society's way of ensuring important activities take place at no added cost.

Communication between the different parties needs to be established at both the top and the bottom. This should initially be quarterly and should involve the heads of NLEP, ILEP, IADVL and the Ayurvedic trade unions or colleges.

Guidelines on how to take leprosy into general health services should focus on cheap and effective education programmes, especially recognising overload. These should not be unilateral. They should focus on procedures that are generalised i.e. management of common skin disease in a framework that picks up rarer diseases and is as effective for the prevention and management of the ulcerated diabetic foot as it is for leprosy.

We do not advise a full package of information about any one disease to be forced upon the general health services. However, for example, a comprehensive knowledge of how to wash and apply emollients to as important a barrier to infection as the skin, can be of benefit to the diabetic foot, the bedridden elderly, the lymphoedema of filariasis or cancer, the skin breakdown in HIV/AIDS as well as to common skin disease and to leprosy.

Stigma is a feature of all disfigurement and to be unwelcome because of ones appearance is one of the commonest presentations of skin failure. To focus only on one disease is negligent because it utilizes funding that could benefit at one and the same time common problems rather than rarities.

The Indian Government needs to work towards standardizing health care infrastructure and making such practice uniform throughout states. By standardization, variation in method is not negated, as needs will vary; rather standardization should be conducted with regards to a developed, manned, infrastructure for effective and accessible primary health.

Greater research is needed into Indian systems of Medicine. This will help provide credibility to a resource efficient method of sought after medicine; aiding the process of integration. NGOs need to ensure greater cooperation between themselves and other health care providers. A concerted effort needs to be made at generating funds without the need for adopting other parallel campaigns. Leprosy still needs a vertical programme at the top and diluting it with campaigns to control TB or HIV/AIDS will overwhelm it.

More NGOs need to adapt to the changing face of leprosy in India. Their role in filling gaps in provision requires a move away from the traditional leprosarium towards the development of education programmes, tertiary referral services or even research. Their passionate belief systems may be helpful to the destitute but require tact if they are to be integrated into local communities.

The abolition of targets would be welcome. They are inaccurate and achieving them is an expensive irritation for diverse practitioners who, realize more openly than NLEP that there are many unrecorded cases of leprosy seen in the Private Sector, and by Indian Systems of Medicine, by NGOs and lost in the Mega cities and in migrating populations.

Acknowledgement

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" leprosy is a lonely disease.. "

"The person with leprosy loses touch in more than one way. Not only does this horrible disease get into the nerves of his arms and destroys them and strangles them so that he can never again feel with his fingers, but somehow, and for some reason I cannot understand, this same germ gets between him and his friends, gets between him and his employer, gets between him and his community and builds a barrier so that a man who had experienced the loving warm greetings of his friends before, who had a job and could earn his living, finds that people turn away, that the children will run from him because they have been told by their parents they mustn't associate with this man who has leprosy.

He is treated with a superstitious kind of fear. And so it is that leprosy is a lonely disease."

- Dr. Paul Brand

Box B

Sustainability of leprosy services

Sustainability of leprosy services is no doubt very important. However, we need to clearly understand what we mean by that. Firstly, there is a general consensus that only through integrated services sustainability will be possible.

At the same time, it is important to define what services will be provided and at which level.

This will, to a large extent, depend upon two factors - capacity building at the peripheral level and the establishment of referral services at the appropriate level, which in turn would require capacity buidling at the referral level, networking and some infrastructure.

All these need to be built up within the ambit of general health services with only minimal vertical inputs. In short, leprosy patients will receive all services available to patients suffering from other problems.

The extent and quality of leprosy services should not be any higher or any lower than that is available to patients suffering from other ailments.

'Leprosy elimination' and 'sustainability of leprosy services' are two sides of the coin. They complement each other and do not compete. As long as one realizes this complimentarity there will be less confusion as to our future course of action.

Source: Editorial, 'The debate over leprosy elimination versus sustainability of leprosy services'. Indian Journal of Leprosy, 77 (4), 2005, 299-304.

Learning to manage leprosy after 2005

- Preserving critical knowledge and exploiting new technology

Dr. Paul Saunderson

"Health workers learn the foundations of their subject during basic training and it is important that leprosy remains in the curriculum and is taught by experienced and innovative staff."

Amidst the many challenges currently facing leprosy services, two key training issues stand out. Firstly, the struggle to maintain an adequate pool of appropriately knowledgeable and skilled health workers in endemic areas, in order to sustain leprosy services in an integrated setting.

The second major challenge is to utilize technology in the fields of training, communication and informatics, in a cost-effective manner. During the next few years, we may face the loss of knowledge and experience in the management of leprosy. Many experienced clinicians, from clinic level health workers to district supervisors, medical officers and specialists, will no longer be working with leprosy patients, for a variety of reasons. Many are retiring, or they are being re-assigned to other work; others are leaving to advance their careers elsewhere, either within the same country or abroad.

Thus, it will become more difficult for people with leprosy to access expert and timely care – both for the initial diagnosis and for the management of complications. Furthermore, these experienced clinicians have, until now, been responsible for the training and supervision of junior staff, who see and manage most cases.

Thus over time, one may predict that the quality of care for most new leprosy cases will deteriorate. While this may be inevitable in low endemic areas, it may also become a problem in areas where large numbers of new cases are still presenting.

A similar problem is occurring in the commercial world as large numbers of senior staff are expected to retire in the next five to ten years. This has led to further thinking about the kind of knowledge that is particularly at risk of being lost and how it can be preserved.

The converse of the problem of the loss of senior staff is the need to enable the many new health staff in integrated health

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Source: Excerpts from the Editorial article by Dr. Paul Saunderson. Learning to manage leprosy after 2005: preserving critical knowledge and exploiting new technology, Lepr Rev (2005) 76, 2–4

units to learn the clinical and counseling skills necessary to suspect and manage leprosy. There are large numbers of such staff and each one will see at most only a few cases of leprosy throughout their career. Nevertheless, appropriate training at each level (both the primary clinics and the referral centers) will be essential if people affected by leprosy are to be given the treatment they need.

The second major issue concerns the use of new technology to make learning more accessible and more easily managed. While this is being widely exploited in developed countries, leprosy endemic areas do not have the efficient and affordable Internet connectivity on which much of this development depends.

Preserving critical knowledge

In the health sector, knowledge is largely in the public domain and is accessible through books and journals. Health workers learn the foundations of their subject during basic training and it is important that leprosy remains in the curriculum and is taught by experienced and innovative staff.

Clinicians and specialists have a responsibility to ensure that their knowledge and experience is available to others by these means. Clinical and counseling skills and the attitudes towards patients that should accompany them, must be passed on directly in a process of mentoring, sharing knowledge, attitudes, skills and experience through a one-to-one relationship.

One way to tie these ideas together is to emphasize training in the person’s place of work, through what is known as on-the-job training (OJT). Clinical skills need to be taught in a clinical setting and the trainer is usually in a position to be able to help organize services and to negotiate with the people in charge.

Exploiting new technology

The Internet is still inaccessible in a practical sense in many leprosy endemic areas; another problem with the various online tools to assist learning is that, at present, they are generally in English, so even if a good connection were available, many health staff would not be able to take advantage of them.

There are, however, other developments that can be used in poorer areas. They can get material from different sources and thus compare and integrate different experiences and opinions.

A large amount of health information, including many medical journals, is available free of charge via the Internet in developing countries.

Empowerment of people to learn need not be limited to online learning. New technology is also changing the printing industry, so that it is now both convenient and cheap to produce learning materials locally.

Combined with well-organized on-the-job training, such a strategy will allow expertise in leprosy to be maintained and deployed when and where it is needed.■

Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities : 2006-2010

Operational Guidelines

World Health Organization 2006

"Our challenge is to sustain the quality of leprosy services and to ensure that all persons affected by leprosy, wherever they live, have an equal opportunity to be diagnosed and treated by competent health workers, without unnecessary delays and at an affordable cost."

Our challenge is to sustain the quality of leprosy services and to ensure that all persons affected by leprosy, wherever they live, have an equal opportunity to be diagnosed and treated by competent health workers, without unnecessary delays and at an affordable cost.

To achieve this goal, the major thrust of our efforts must focus on integrating leprosy into the general health services. Health workers at all levels must be taught the simple methods required to diagnose and manage leprosy.

This will improve access to leprosy services and reduce the stigma and discrimination faced by persons affected by the disease.

WHO's Global Strategy for further reducing the leprosy burden and sustaining leprosy control activities, 2006-2010, focuses on sustaining the gains made so far and on reducing the disease burden further in all endemic communities.

At the same time, particular attention should be given to ensuring that the quality of services is not compromised. Every person affected by leprosy should have easy access to diagnosis and free treatment with multi-drug therapy.

We need to ensure that sustainable activities are carried out and quality services provided within an integrated set up that includes an effective referral network to manage leprosy-related complications effectively.

Excerpts from the Foreword by
Dr. P. H. Samlee Plianbangchang, M.D.,
Regional Director, WHO, SEARO, New Delhi

Source: WHO, 'Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities : 2006-2010', Operational Guidelines - SEA/GLP/2006.2

Need for an effective referral system

Leprosy services are being integrated into the general health services throughout the world; a new emphasis is given here to the need for an effective referral system, as part of an integrated programme. Good communication between all involved in the management of a person with leprosy or leprosy-related complications is essential.

These Guidelines should help managers to choose which activities can be carried out at the primary health care level and for which aspects of care patients will have to be referred. This will depend on the nature of the complication and the capacity of the health workers to provide appropriate care at different levels of the health system.

The promotion of self-reporting is now crucial to case detection, as case-finding campaigns become less and less cost-effective. It is important to identify and remove barriers that may prevent new cases from coming forward.

The procedures for establishing the diagnosis of leprosy remain firmly linked to the cardinal signs of the disease, but the accuracy of diagnosis must be monitored.

The Guidelines suggest a greater emphasis on the assessment of disability at diagnosis, so that those at particular risk can be recognized and managed appropriately.

From the Executive Summary

1. Quality leprosy services

“Peripheral level guidelines” are given for the general health workers, working in integrated clinics, where they see and manage a wide range of health problems; leprosy is a relatively small part of their workload. “Referral level guidelines” are for those staff at referral units, including field supervisors, who have had more training and experience in leprosy and also for those with specialist skills to manage other leprosy-related consequences (ophthalmologist, orthopaedic surgeon etc). As part of the process of integration, referral services need to be strengthened.

Where leprosy is common and health workers are familiar with it, many of the routine activities of diagnosis, treatment and disability prevention can be carried out in the peripheral clinics and there should be a fairly good knowledge of leprosy at that level, even in an integrated setting; in this case, some activities mentioned in the “Referral level guidelines” may be appropriate for many peripheral clinics. Some issues may be laid down by the government, for example, who may diagnose and treat leprosy, and who may diagnose and treat reactions.

Referral will always be an essential component of an integrated health service and at any level, health staff must be ready to refer any patient who cannot be adequately managed where they are. Staff at selected health centres, district hospitals, or any other place identified as a referral unit, should be adequately trained and be ready to receive those patients and use such occasions as a training opportunity for peripheral staff. Global Strategy calls for increased efforts to reduce this "burden" by preventing disability in new cases, by helping to rehabilitate those with disability and by fighting stigma wherever it exists.

The Global Strategy emphasizes quality leprosy services as an essential component of an effective programme. Quality is based on appropriate training of staff at every level, regular technical supervision and monitoring of key indicators. The pursuit of quality assumes the willingness of staff to make changes aimed at improving their skills and the functioning of the health services in which they work.

Quality leprosy services:

- Are accessible to all who need them.
  - Coverage: MDT treatment can be provided at all health units.
  - No geographical, economic or gender barriers.
- Are patient-centred and observe patients' rights, including the rights to timely and appropriate treatment and to privacy and confidentiality.
- Address each aspect of case management, based on solid scientific evidence:
- Diagnosis is timely and accurate, with supportive counselling.
- Treatment with MDT is timely, free-of-charge and user-friendly.
- Prevention of disability interventions are carried out appropriately.
- Referral for complications and rehabilitation is done as needed.
- Maintain simple records and encourage review and evaluation.

2. Integration and referral

Effective leprosy control requires an integrated approach, which provides wider equity and accessibility, improved cost-effectiveness and long term sustainability. This implies that leprosy control activities should be implemented by the general health services, including integrated referral facilities. Integration not only improves accessibility to treatment, but also reduces the stigma and discrimination faced by persons affected by leprosy.

Integration means that day-to-day patient management, recording and reporting become the responsibility of general health staff. However, integration does not mean that specialist expertise disappears from the health service. On the contrary, this expertise must be available within the general health service at the central and intermediate levels for planning and evaluation, provision of training, technical supervision, advice, referral services (including those at hospitals) and research. A system should be in place for the referral of difficult or complicated cases to the hospitals or specialists (e.g., general medical officers with some additional training in leprosy, dermatologists or surgeons) and referral by specialists back to the peripheral health facilities for continuation of treatment. The specialized referral services for leprosy are part of the general health services, just like a surgeon in a district hospital is part of the general health services.

Depending upon local conditions (e.g. 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 specialist expertise should be made available. Peripheral general health workers should be capable of diagnosing and treating leprosy under the technical supervision of specialized health workers who are positioned at the intermediate level. This category of specialized staff will usually have responsibility for other diseases in addition to leprosy.

Where leprosy is less common, the ability to suspect leprosy and refer the patient to a referral unit is the most important skill required for peripheral general health workers. These referral units (including district hospitals and selected health centres) should diagnose leprosy and start treatment. Continuation of treatment could be delegated to the peripheral health facility serving the community in which the patient resides. The community should be informed about symptoms of leprosy and the availability of services. In areas with small patient loads, management of nerve damage will have to be concentrated in referral units. Centres treating the difficult complications of leprosy and providing rehabilitative surgical services will be even more centralized, but could also provide some referral services through mobile units.

An adequate referral system means that specialist services should be accessible and available to any patients who need them. The main obstacle to referral in many countries is the difficulty for the patient to reach the referral unit at the right time. In such situations, the visiting supervisor should prove useful in providing the necessary support services.

All peripheral health staff should know the clinics and health staff to whom they will refer patients, so that they can advise their patients accordingly, in order to minimize their difficulties.

Good communication should be maintained, to allow discussion of patients' progress and as an opportunity for further training. The convenience of mobile phones and text messaging can make this easy and timely.

Six basic principles for successful integration are advocated by WHO:

1. Every health facility in an endemic area should provide MDT services on all working days.
2. At least one trained staff member should be available in every health facility.
3. Adequate amounts of MDT drugs should be available, free of cost, for patients.
4. Information, Education and Communication (IEC) materials should be available for the patient and their family members.
5. A simple treatment register should be available.
6. Referral services should be available and accessible, and general health staff should know where and how to refer patients.

Peripheral level

Staff at the Peripheral level should develop good links with the referral units they are most likely to use regularly:

- The visiting technical supervisor.
- Nearest Health Centre (with staff with additional training in leprosy) or
- District Hospital.
- Eye clinic for anyone with eye problems.
- Leprosy or dermatology specialist: for diagnosis, skin smears, reactions.
- Local rehabilitation networks for anyone with long-term disability.

Referral level

Staff at the Referral level should know the specialist clinics and other professionals to whom they may refer patients, such as:

- Ophthalmology for significant eye pathology
- Dermatology for diagnosis of difficult skin conditions
- Laboratory for skin smears and histopathology
- Physiotherapy for assessment and management of reactions
- Podiatry for the feet and footwear
- Occupational therapy for rehabilitation and adaptations
- Reconstructive and plastic surgery
- Social worker for assessment and further referral
- Rehabilitation specialists and CBR programme

Conditions in leprosy that require referral . .

Staff should refer patients whose condition they are not able to deal with – this may be because they have not been trained to deal with it, or because they do not have the necessary resources (drugs, equipment, other staff, etc.) to manage the condition.

Routine referrals: non-urgent conditions include:

- Diagnosis: if leprosy is suspected but the diagnosis is uncertain
- Suspected relapse
- Any stable, long-standing disability which may be suitable for surgery or any other rehabilitation intervention
- Non-medical referrals, for example, to a social worker or to a CBR programme
- Other health problems, unrelated to leprosy

Emergency referrals: conditions that require urgent treatment such as:

- Severe leprosy reactions, including:
  - Severe reversal reactions
  - Reversal reactions overlying a major nerve trunk
  - Neuritis, including silent neuritis
  - Erythema Nodosum Leprosum (ENL) reactions
- Severe infection of the hand or foot (usually related to an ulcer with foul-smelling discharge); the hand or foot will be hot, red, swollen and probably painful.
- Eye involvement in leprosy – four specific problems which need urgent referral:
  - Recent loss of visual acuity
  - A painful red eye
  - Recent inability to close the eye (lagophthalmos)
  - A reaction in a leprosy skin patch on the face
- Serious adverse drug reactions

3. Case detection

Efforts to increase case detection are focused on facilitating self-referral by people who develop leprosy. This is done by increasing awareness of the early signs and symptoms of leprosy among the general public. Barriers which prevent people reporting for examination should be removed; they are considered here under five headings.

Barriers include a lack of awareness that leprosy is treatable and that treatment is free and available locally. This can be addressed most effectively by public information campaigns using a variety of media, including traditional means of communication.

Secondly, fear is also a common barrier. This may include fear of the diagnosis, fear of future deformity, fear of being exposed as having leprosy or fear that one's family will suffer. The latter two relate to negative attitudes or other forms of stigma and discrimination in society. Such fears may persist long after general attitudes have become more tolerant and instances of overt discrimination have become rare.

Fear and stigma are difficult to remove. They can only be addressed successfully through a combination of strategies that include factual information about leprosy and its treatment, context-specific media messages addressing misconceptions and traditional beliefs about leprosy, positive images of leprosy and testimonies of people successfully cured of leprosy. Contact between the community and treated patients, successful self-care, rehabilitation aimed at empowerment and counselling of patients to build up their self-esteem, also help to build a positive image of those affected by leprosy.

At the same time, any negative attitudes, structures or arrangements in the health services should be addressed as a matter of urgency. Assurance of privacy and confidentiality, and treatment with dignity are particularly important.

A third group of barriers include other disadvantages, some of which are culturally determined, such as gender, ethnic group and poverty. These require specific approaches, which include awareness raising and education, but also advocacy for supportive legislation and services, and general poverty alleviation measures.

Physical barriers, such as mountains, rivers or distance pose particular challenges, especially in areas with low health service coverage, and form a fourth category. These need flexible arrangements of diagnostic and treatment services.

The final group, issues of security in areas of war or civil unrest, is the most difficult to address, but is nevertheless a reality in several leprosy-endemic countries.

4. Diagnosis

Peripheral level

Examine: all the skin in a good light to identify all skin patches

- note the number of patches
- test for loss of sensation in the skin patches
- assess the disability grade

If there is definite loss of sensation in a skin lesion, make the diagnosis of leprosy, count the number of lesions to find the classification and start the person on MDT immediately. If there is no loss of sensation, do not start treatment, but refer the person for further examination.

Referral level

1. Examine the whole skin in a good light. Identify all the skin patches. Note the number of patches. Note if there are nodules around the face or ears, areas of plaque or infiltration of the skin.
2. Test for loss of sensation in the skin patches, as indicated above. Definite loss of sensation in a skin patch is diagnostic of leprosy.
3. Examine the nerves for enlargement and test for loss of feeling and muscle weakness: this is to be done only by those trained to do it.
4. If possible, arrange for a skin smear test, especially if there are nodular lesions, or if most of the skin is infiltrated with very indistinct lesions and if there is no obvious loss of sensation.

These features are more suggestive of MB disease, in which the skin smear is often positive and in an untreated individual, it is diagnostic of leprosy.

Nerves which are commonly enlarged:

- The great auricular nerve on the side of the neck, below the ear, is sometimes visibly enlarged: gently feel it to make sure it is the nerve and not one of the veins in the neck.
- The ulnar nerve at the elbow, the radial cutaneous nerve and median nerve at the wrist, common peroneal nerve at the knee and posterior tibial nerve at the ankle, should be gently palpated for enlargement.

Definite nerve enlargement, with loss of sensation or muscle weakness, is diagnostic of leprosy, but it requires experience to do this examination properly.

Assessment of disability in leprosy

Disability is a broad term covering any impairment, activity limitation or participation restriction affecting a person.

Peripheral level

1. Check for grade 1 disability by asking the patient for the presence of loss of sensation in the hands and the feet
2. Look for the signs of visible disability (Gr.2):
    - Wounds or ulcers on hands or feet
    - Marked redness of the eye
    - Muscle weakness, causing:
        - Incomplete eye closure
        - A claw hand
        - A drop foot

3. Loss of tissue, such as fingers or toes shortened or missing

Any patient showing the above signs should be referred to a referral unit where POD services are being provided. Visible disability should be recorded before referral.

Referral level

Examine carefully for any disability and recording the full results of the examination in the Patient Record Card for future reference:

Eyes

- Check the Visual Acuity of each eye separately, using a Snellen chart; if no chart is available, ask the person to count fingers at 6 metres; if the person cannot read the top line of the chart, or count fingers at 6 metres, they are visually impaired and have grade 2 disability in that eye.
- Look for an inability to close one or both eyes (lagophthalmos) and check for normal strength of eye closure
- Look for any redness of the eye

Sensation in hands and feet

Check the sensation in the palms of the hands and the soles of the feet, using a ballpoint pen:

- Explain the test to the patient
- Ask them to close or cover their eyes
- Touch the skin very lightly with the ballpoint
- Ask the patient to point to the place you touched
- Test a minimum of four points on each hand and foot
- Note areas where the pen is not felt

NB: In the palm of the hand, the side with the little finger is supplied by the ulnar nerve. The part with the thumb, index and middle fingers is supplied by the median nerve. The sole of the foot is supplied by the posterior tibial nerve.

Check for muscle weakness

The three key muscles are:

1. thumb up (tests the median nerve)
   - ask the person to put out their hand, palm up
   - support their hand in your hand
   - ask them to point the thumb towards their own nose
   - test the strength of the thumb to stay in that position
2. little finger out (tests the ulnar nerve)
   - ask the person to put out their hand, palm up
   - support their hand in your hand
   - ask to move the little finger out
   - test the strength of the little finger to stay in that position
3. foot up (tests the peroneal nerve)
   - ask the person to sit down
   - support the person's lower leg in your hand
   - ask them to point the foot up to the roof
   - test the strength of the foot to stay in that position

Muscle strength is recorded as : Strong (S) - means that the muscle being tested is of normal strength; Weak (W) - means that the muscle can move, but it is definitely weak; and Paralyzed (P) - means that muscle cannot move at all.

5. Treatment

MDT treatment is provided in blister packs, each containing four weeks' treatment. Specific blister packs are available for multibacillary (MB) and paucibacillary (PB) leprosy as well for adults and children.

As soon as someone misses an MDT appointment, action should be taken to find out why the patient has not attended and, if necessary, to remind the patient of the importance of taking treatment regularly and of finishing the full course of MDT.

If this proves insufficient, a home visit by a local community worker should be arranged to find out why the patient has stopped visiting the clinic and, if necessary, to motivate him or her to resume treatment. Such a home visit should be undertaken preferably within one month of the first missed visit date.

Peripheral level

Suspected relapses should be referred for further investigation at a referral centre.

Referral level

Suspected PB relapse: the diagnosis of a PB relapse can never be absolutely certain. A skin smear should be carried out, if at all possible, to ensure that an MB case is not being misclassified as PB. The evidence for either a relapse or a reaction must be weighed up and a decision made. If it is decided to treat someone as a PB relapse, they are given a normal six-month course of PB-MDT.

MB relapse: criteria for diagnosing a relapse are the presence of new skin lesions and an increase by two or more units of the Bacillary Index.

Management of leprosy reactions

Peripheral level

Reactions requiring treatment with steroids may be suspected when patients have symptoms suggestive of new nerve damage, such as numbness, or muscle weakness in the hands or feet; they should be referred to a specialist unit where they can be monitored and treated effectively.

The following signs also indicate that a reaction is severe and that the patient must be referred:

- Red, painful, single or multiple nodules in the skin with or without ulceration
- Pain or tenderness in one or more nerves, with or without loss of nerve function
- Silent neuritis – nerve function impairment, without skin inflammation
- A red, swollen skin patch on the face, or overlying another major nerve trunk
- A skin lesion that becomes ulcerated, or that is accompanied by a high fever
- Marked oedema of the hands, feet or face
- Pain and/or redness of the eyes, with or without loss of visual acuity
- Painful swelling of the joints with fever

Reactions which show none of these signs of severity, but which are limited to mildly inflamed skin lesions, may be treated symptomatically, with aspirin.

Referral level

MB patients with nerve damage present at the time of diagnosis are at high risk of further damage and should be examined regularly. Monitor nerve function on a monthly basis (or at least every three months). Recent nerve function impairment (appearing within the last six months) is the most important sign of a reaction requiring treatment with steroids.

There are two types of reaction: reversal reaction (or Type 1) and Erythema Nodosum Leprosum (ENL or Type 2). Both types can occur before the start of treatment, during treatment, or after treatment has been completed. Both types can be divided into mild or severe: only severe reactions are treated with corticosteroids. Patients with single skin lesions are unlikely to get reactions, but most other patients have some risk of getting a reversal reaction; only a much smaller group of MB patients with a high load of bacilli are at risk of developing an ENL reaction.

Distinguishing between the two types of reaction is usually not difficult: in a reversal reaction, the leprosy skin lesions themselves become inflamed, red and swollen; in an ENL reaction, new inflamed, red nodules appear under the skin of the limbs or trunk, while the original leprosy skin patches remain as they were. In addition, ENL reactions cause a general feeling of fever and malaise, while reversal reactions cause less systemic upset.

Signs of a severe reversal reaction

If any of the following signs occur, the reaction should be treated as severe:

- Loss of nerve function – that is, loss of sensation or muscle weakness
- Pain or tenderness in one or more nerves
- Silent neuritis
- A red, swollen skin patch on the face, or overlying another major nerve trunk
- A skin lesion that becomes ulcerated
- Marked oedema of hands, feet or face

Severe reversal reactions should be treated with a course of steroids, usually lasting 3–6 months. Steroids should be prescribed by someone properly trained in using these drugs. There are a number of important side-effects associated with steroids, so a careful assessment must be made of any patient requiring them.

Signs of a severe ENL reaction

If any of the following signs occur, the reaction should be treated as severe:

- Pain or tenderness in one or more nerves, with or without loss of nerve function
- Ulceration of ENL nodules
- Pain and or redness of the eyes, with or without loss of visual acuity
- Painful swelling of the testes (orchitis) or of the fingers (dactylitis)
- Marked arthritis or lymphadenitis

ENL reactions are complex medical problems requiring careful management by experienced clinicians. Short courses of steroids are often used, but other drugs are also useful.

Management of relapse cases

Peripheral level

Refer such patients for specialist assessment.

Referral level

The assessment of patient who has previously been treated for leprosy should be carried out as follows:

Take a full history of the current problem, including:

- The duration of previous treatment and the onset of the new symptoms
- Did new lesions appear quickly or over a long period?
- What is the relationship with old skin patches?
- Has there been pain, tenderness or swelling?
- Has there been any recent loss of function in any nerves?

Carry out a full examination of the skin and of nerve function, in order to identify any signs of a recent reaction.

Arrange for a skin smear test; an MB relapse is associated with an increase in the bacillary load. Obviously, if no previous smear has been done, it is impossible to identify an increase; in this case, the presence of solid staining bacilli in the smear gives support to the diagnosis of a relapse.

If no firm conclusion can be made after all these investigations, a trial of steroids may be considered; a reaction would begin to settle in 10-14 days, while a relapse would not be affected by such treatment.

6. Prevention of disability and self-care

Home level

Activities to prevent disability which can be done by the person at home:

- **Problems with eye closure:**
  - Inspect the eye in a mirror every day to look for redness
  - Learn to blink frequently to keep the eyes moist and exercise the lids
  - Wear a hat or sunglasses to prevent dust from getting into the eyes
  - Use a sheet or mosquito net to cover the head at night
- **Problems with the hand:**
  - Daily inspection for signs of injury
  - Loss of feeling is associated with dryness of the skin, so the insensitive hand must be soaked in water for about 30 minutes every day, to maintain skin elasticity. Use a rough stone to rub away callous, then use oil or Vaseline to prevent the skin from drying out
  - Use a clean cloth to cover any open wounds
  - If there is muscle weakness in the hand, passive stretching and active exercises will help to prevent contractures and may lead to some strengthening.
- **Problems with the foot:**
  - Daily inspection for signs of injury
  - Soak and oil the feet, as for the hands; use a rough stone to rub away callous
  - Walk as little as possible; walk slowly and take frequent rests
  - If ulcers are present, rest is essential: “All simple ulcers will

heal, if given sufficient rest no ulcers will heal if not rested sufficiently."
  - Use a clean cloth to cover open wounds
  - If there is a foot-drop, passive stretching will help to prevent a contracture of the Achilles tendon

Peripheral level

General health workers cannot be taught all of these interventions as a routine. When they have a patient with certain disability problems, however, they can arrange to see that person with their supervisor, so that specific interventions relevant to that person can be discussed.

Leprosy-related disabilities are long-term problems and individual health workers should learn how to manage the specific problems seen in their own patients.

Provide any help that may be needed by the person to carry out the home-based self-care tasks mentioned above.

- **Problems with eye closure:**
  - Provide saline drops for use if the eyes are very dry
  - Treat conjunctivitis with antibiotics and an eye pad
  - Refer serious eye problems to an eye clinic

- **Problems with the hand:**
  - Review, guide and refer if required.

- **Problems with the foot:**
  - Organize appropriate footwear
  - Review, guide and refer if required.

Referral level

Interventions which can usually only be done at a referral centre

- **Problems with the eyes:**
  - Any acute eye problem should be managed at an eye clinic
  - Corrective surgery may be helpful in severe cases of lagophthalmos

Remember that cataract is the most common cause of blindness in elderly people, whether or not they have leprosy; leprosy does not prevent routine cataract surgery

- **Problems with the hand:**
  - Help the person adapt tools to avoid injury to insensitive hands
  - Remove thick callous and trim ulcers with a scalpel blade
  - If there is weakness or a contracture, make a splint to wear at night
  - An invasive infection (hand is hot, red and swollen) is an emergency and must be referred for intensive treatment and surgery
  - Surgery may be appropriate in some cases of weakness or claw-hand, as long as the joints remain mobile
- **Problems with the foot:**
  - Remove thick callous and trim ulcers with a scalpel blade
  - Chronic ulcers may be helped by orthotics, or by surgery
  - For a foot-drop, make a spring-loaded device to keep the foot in the correct position while walking
  - An invasive infection (foot is hot, red and swollen) is an emergency and must be referred for intensive treatment and surgery
  - Foot-drop surgery

7. Rehabilitation

Role of health workers in rehabilitation

Peripheral level

Health staff may not have the time or expertise to be involved in rehabilitation activities. However, they need to be able to identify physical, functional or socio-economic problems resulting from disability and know about available services for rehabilitation and how to refer people to make use of such services.

Health workers may need to play an advocacy role to ensure that those affected by leprosy have access to health care services, including rehabilitation facilities, in the same way as other people.

Referral level

The following are examples of interventions that may be available.

Problems		**Interventions**
Anatomical:		
Deformity of hand	-	Reconstructive surgery and physiotherapy
Foot drop	-	Ankle-foot orthosis, reconstructive surgery
Amputation	-	Prosthesis
Psychological:		
Depression	-	Counselling
Functional:		
Limitation of fine hand movements	-	Occupational therapy
Mobility limitations	-	Crutches or wheel chairs
Social participation:		
Stigma in family	-	Counselling
Exclusion from social functions	-	Education and advocacy
Children with disability	-	Promoting inclusive education
Economic:		
Loss of employment	-	Vocational training and/or placement
Poverty	-	Micro-credit for self-employment

Training for general health workers

Training of general health workers should enable them to:

- correctly diagnose and classify a case of leprosy
- treat a leprosy patient with the appropriate MDT regimen
- manage or refer cases with complications
- maintain simple patient cards and a treatment register, and submit reports regularly
- keep adequate stocks of drugs for MDT
- provide appropriate information about the disease to patients, community members, and decision-makers
- recognize patients in need of rehabilitation and refer them to the appropriate services.

In an integrated setting, it is important to ensure that this training is included in the core curriculum of all health workers.

8. Monitoring

Additional indicators for monitoring

The information used to calculate these indicators is usually collected routinely, but in some countries with a large number of cases, it may be collected from a representative sample of cases:

Proportion of new cases presenting with grade 2 disability: Because disability and deformity occur late in the disease, the proportion of new cases with disability gives a rough indication of how early, on average, leprosy cases are coming forward for diagnosis.

Proportion of child cases (under 15 years of age) among new cases : If the transmission of leprosy is being reduced in an area, it is expected that the proportion of children affected will decrease. Monitoring this indicator over several years, may show a trend. It is also required for correctly replenishing the stock of child doses for MDT.

Proportion of multibacillary cases among new cases: The proportion of MB cases is a useful guide to the proportion of cases at risk of complications and is needed for replenishing the stock of MDT correctly.

Proportion of female patients among new cases: Many programmes diagnose leprosy more frequently in men than in women, but there is concern that women may have less access to health care in some situations. Thus, a ratio of 2 males to every 1 female is commonly seen. If the ratio is higher, steps should be taken to ensure that women have adequate access to diagnostic services.

Indicators for patient management:

The following indicators for quality of care and patient management may be collected, usually on a representative sample basis, as part of an integrated supervision process.

Proportion of new cases correctly diagnosed: The accuracy of diagnosis should be assessed through regular technical supervision. If there is any suggestion of significant over-diagnosis, a sample of new cases should be reviewed within three months of the diagnosis being made. This would identify problem areas where additional training and supervision are needed, but would not impede treatment at all.

Proportion of treatment defaulters: This only requires examination if the completion rate is low. The proportion of patients who default and who are transferred out are calculated in exactly the same way as the cure rate. If transfer out is the main reason for non-completion of treatment, the situation needs to be investigated to find out whether the transferred patients are really continuing treatment at a new clinic, or whether in fact they just stop taking treatment.

Number of relapses reported during the year: Relapse cases occur sporadically and are generally not part of any defined cohort, so these figures are difficult to analyze. If high numbers are reported from any particular area, further investigations must be carried out.

Proportion of patients who develop new or additional disability during MDT : EHF (eye-hand-foot) score is calculated from data already being recorded routinely. It is the sum of all the individual disability grades for the two Eyes, two Hands and two Feet.

Since the disability grade can be scored as either 0, 1 or 2, it follows that the EHF score ranges from 0 to 12. A score of 12 would indicate grade 2 disability of both eyes, both hands and both feet.

The EHF score has been shown to be more sensitive to change over time than the Disability Grade itself.

The simplest way to use the EHF score to measure the development of new or additional disability during MDT, is to calculate the score at diagnosis (this examination is already done in the initial assessment of Disability Grade) and then repeat the examination at the time treatment is completed.

The two scores can then be compared. When the cure rate is calculated for any cohort, the proportion in which the EHF score increased can be calculated at the same time – an increase in the score would indicate some new or additional disability.

9. Organizational issues

Technical supervision

Supervision is a way of ensuring staff competence and effectiveness through observation, discussion, support and on-the-job training. Its aim is to ensure that:

- the technical skills required for leprosy control activities are present;
- any obstacles faced by the peripheral health worker are identified and removed;
- plans for future work and improved performance are made;
- health workers are supported and motivated in their work; and
- additional information, not available under the routine reporting system, is collected and analyzed.

The central figure in supervision is a designated individual located at the first referral level (usually with other responsibilities in an integrated setting), who visits individual clinics on a regular basis, but the key element is a personal link with the staff of the peripheral clinics where the majority of patients are seen.

Training in supervisory skills and attitudes is essential for effective supervision. The supervisor should be aware of his own tasks and responsibilities, and also those of the people he has to supervise. ■

Acknowledgement:

We thank Dr V Pannikar, WHO-SEARO for permitting us to publish the extract from the WHO document.

Restoring function to prevent further disability in leprosy

Guidelines for identifying patients for referral for surgery

ILEP Medico-social Commission, UK

"The surgery should have the potential to make a difference to patients' acceptance in their society and to improve their socio-economic situation. Field workers should be aware of the criteria for selecting patients to refer and the optimal timing of referral."

These guidelines are designed for programme managers as a framework for training their staff in identifying individual patients affected by leprosy, who would benefit from reconstructive surgery or other forms of surgery. It is important that centres doing reconstructive surgery in leprosy liaise with field workers in developing local criteria and arrangements for the referral of appropriate patients.

A. Reconstructive Surgery

Reconstructive surgery aims to restore function and form as far as possible and to prevent further disability. It also plays an important role in the prevention of disability and rehabilitation process. Some patients can benefit from reconstructive surgery but not all patients are suitable.

It is important that field workers are aware of the criteria for referring patients for reconstructive surgery so that suitable patients are referred at the right time and that those not suitable are not referred. The reconstructive procedures considered here are tendon transfer procedures such temporalis transfers for lagophthalmos, foot-drop corrections, and corrections for paralysed fingers and thumb. Pre and post-operative physiotherapy is essential for a successful outcome of surgery and needs to be arranged in consultation with the surgical centre.

Criteria for referral for surgery

The detailed criteria will vary between reconstructive surgeons and it is important that surgeons make field workers aware of their local policy for referring people. The criteria have been grouped into three categories: social and motivation, physical and the leprosy treatment criteria. Patients and the health workers should be involved in the decision to refer.

Source: Medical Bulletin, **Issue No 15, March 1999,** International Federation of Anti-Leprosy Associations (ILEP), UK. Website: www.ilep.org.uk

a. Social and Motivational Criteria

1. All patients who will benefit socially, occupationally or economically should be considered. The surgery should have the potential to make a difference to patients' acceptance in their society and their family and to improve their socio-economic situation.
2. Patients must be well motivated and have demonstrated that they can be responsible for their own health and follow instructions on treatment and care of their eyes, hands, and feet before surgery. Patients who are not well motivated in self-care are not likely to be willing to participate in essential pre and post - operative physiotherapy.
3. Financial support or compensation for loss of income and travel may need to be considered for patients who may have dependent families. The surgery may involve loss of economic activity for a period of several months. Patients who are the main breadwinner in a household may be unable to undergo surgery unless assistance is provided.

b. Physical Criteria

1. The best age for referral for tendon transfer is between 15 - 45 years, but patients younger than 15 years or older than 45 years may be operated on depending upon the particular circumstance.
2. The muscle paralysis should be present for at least one year and preferably not longer that 3 years. There may be exceptional cases where there has been muscle paralysis for longer than 3 years and the individual has kept the joints supple through passive exercises. The patient may not remember accurately how long muscle paralysis has been present, so suppleness of the joints may be a more useful criterion.
3. Patients with severe contractures or stiff joints are not suitable, although physiotherapy or surgery can reverse some contractures.
4. There should be no infection of the skin such as scabies, and no deep cracks, wounds or ulcers at time of referral.

c. Leprosy Treatment Criteria

1. Patients should have completed the scheduled course of MDT or at least a minimum of 6 months MDT.
2. Patients should be free from reactions and symptomatic neuritis for at least 6 months.
3. Patients should not have taken steroids during the past 6 months unless the surgery is for neuritis.
4. There should be no tenderness of any major nerve trunk in the limbs.

Priorities for Reconstructive Surgery

Operations for lagophthalmos are usually considered as a high priority because of the possibility of secondary damage to the eye. Feet are usually considered the next priority followed by hands, but this may depend on the needs of individual patients.

For most patients there is a period of a few years in which surgery is most likely to be beneficial. This starts when the disease is stable (free of reactions and neuritis), MDT is established, and the muscle paralysis is not likely to progress or to recover.

Field workers should be aware of the criteria for selecting patients to refer and the optimal timing of referral. Motivation is a key factor as patients may need to be in hospital for at least 6 weeks and will have to work at physiotherapy. Patients in whom surgery will make a difference should be considered for referral.

The proposed surgical procedure and its positive consequences should be balanced against the consequences of not doing surgery. This should be discussed with the patient and the decision whether to undergo surgery should be taken by the patient.

Methods of managing to live with the deformities without causing further damages to the affected parts should be explained to patients who do not want or are not suitable for surgery.

B. Other surgical problems

Lagophthalmos is a sight-threatening condition because of the risk of recurrent conjunctivitis and corneal damage. Patients, irrespective of age, who have a lagophthalmos with lid gap, particularly when there is loss of corneal sensation, should be referred for surgery.

Patients with lagophthalmos but not fitting the criteria for reconstructive surgery can be considered for simple procedures such as tarsorrhaphy, which can be performed even on an outpatient basis.

Recurrent wounds of hands and feet

Patients who have recurrent wounds of the hand or foot should be referred for surgical advice. Such patients may have sequestra (dead bone) in the hand or foot which require removal.

Such procedures can be undertaken in general hospitals and an X-ray of the affected part can help confirm the diagnosis. Sometimes in severe cases of recurrent wounds, amputation is the only solution – this should only be considered as a last resort.

Chronic nerve pain and nerve abscess

Patients who have chronic pain and swelling in peripheral nerves which does not respond to analgesics and a course of steroids should be referred for consideration of nerve decompression. ■

Accelerate the patient's integration into society

Surgical management of deformities in Leprosy

Dr. G. A. Anderson

"We can cure, but must not forget that many cured patients still suffer the effects of the disease and experience its stigma. They still need care, even after cure".

Deformities in leprosy are the consequence of impairments of nerve function. The surgery in the hand is done for primary impairment leading to motor paralysis. Operations on nerves in attempts to regain sensation and autonomic function are now undertaken less often since there is no sound evidence to suggest that significant function returns to the hand.

A recent randomised controlled trial showed that conventional decompression of the ulnar nerve combined with steroid therapy had no additional benefit over steroid therapy alone. Unremitting nerve pain, despite adequate steroid therapy, and nerve abscesses are some of the remaining indications for neural surgery. However, there is a need for a multicentre controlled study of fascicular nerve decompression using standardised microsurgical techniques together with steroid therapy to provide a better chance for sensory restoration in early leprous neuritis.

The traditional safeguards for insensate hands continue to be the use of visual input to moderate functional activities, the prevention of injuries and health education on the vital function of the hand. Secondary impairments such as ulcerations, contracture and absorption arise as a result of the neural damage in the course of untreated leprosy and are indications for surgery when required. The aim of reconstructive surgery on the hand is to augment its capabilities for the activities of daily living (ADL) and for safe vocations, and to restore form and structure adequately in order to accelerate the patient's integration into society.

Prerequisites for surgical correction and pre-operative therapy

Before reconstruction, a full sensory and motor assessment and an occupational and functional appraisal are required. The deformities must be established and the disease quiescent. The multidrug therapy regime must have been completed. There must be no evidence of an acute neuritis

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Source: Anderson G. A. The surgical management of deformities of the hand in leprosy, J Bone Joint Surg [British], 2006; 88-B:290-4 (Excerpts).

or the use of steroids for some months preceding surgery. The skin smears must be negative and the patient must be sufficiently motivated and understand what surgery can accomplish and also its limitations.

Pre-operative hand therapy is mandatory in making stiff hands supple, isolating and strengthening the muscles identified for transfer and releasing myostatic and capsular contractures. All adverse features associated with primary paralytic deformities will negatively influence surgical correction if left unnoticed and untreated. A home self-care exercise programme and intermittent use of dynamic orthoses reduce severe contractures and allow easier post-operative re-education of tendon transfers for hand deformities when seen late.

Supervised post-operative therapy

This is essential after all reconstructive operations on the hands in patients with leprosy. After removal of the cast suitable protective/static splinting is provided. Post-operative re-education is provided in a staged manner, being easier for single tendon transfers. With combinations of transfers, which ideally complement one another, the re-education skills of experienced hand therapists are needed. With the diminished neuromuscular inhi- bition seen in hands with glove-type sensory loss, hand and occupational therapists must carefully supervise patients in order to coordinate their movements so that they perform purposeful, functional activities in the right sequence.

Brand pioneered reconstructive surgery for deformities of leprosy at the Christian Medical College Hospital, Vellore, India by performing the first correction of a claw hand in 1948. He had the foresight to introduce rehabilitation programmes concurrently tochannel reconstructed patients to safer vocations. Since then, several thousand surgical procedures have been carried out on patients at this centre, which is now recognised as the birthplace of hand rehabilitation and the first unit for hand surgery in India.

Rehabilitation

Rehabilitation is designed to ensure that the surgical procedures undertaken can help patients to achieve their full physical potential. Hands must be protected from injury and infection in order to prevent impairment and disability. Working aids and protective devices are provided whenever necessary in vulnerable patients, who bear scars of previous injury in the hand or have nerve impairment in other limbs. These patients must be placed in safe vocations which maximise visual feedback to protect the hands further.

As Brand pointed out a decade ago, “Our forebears cared for those they could not cure. We can cure, but must not forget that many cured patients still suffer the effects of the disease and experience its stigma. They still need care, even after cure”. ■

Absence of stigma and reasonable expectation of deformity-free future

Planning services for leprosy-affected persons

Dr. H. Srinivasan

"We should consider "disability management" as an integral part of management of leprosy, and not as an exotic component unrelated to the main aims of our work".

The phenomenal expansion in the coverage of the NLEP has necessarily led to bringing many persons not previously involved with leprosy to participate in the leprosy programme. Further, the success of the programme has also led to winding up its peripheral components in many places and transferring the responsibility of treating leprosy patients to the general health care services giving a foretaste of the future trend.

This is the best juncture to re-orient our thinking from the customary "preventive medicine" perspective to that of "curative medicine", in which the affected individual's concerns are fully addressed.

This means that, henceforth, we should consider "disability management" as an integral part of management of leprosy, and not as an exotic component unrelated to the main aims of our work.

It follows that health care providers at different levels should become familiar with the principles and practices relating to management and prevention of disabilities in leprosy-affected persons. The leprosy programme has the obligation to meet this requirement.

We have to collate and update the available demographic information about persons with leprosy-related impairments, identify their physical as well as psycho-socioeconomic needs in order to take positive measures to meet them to the possible extent.

The needs of most persons are not very demanding. The bulk of the problem will be solved if, like many issues related to leprosy, the backlog cases are dealt with and their problems cleared. In the new atmosphere (Integrated setting) of assured care, absence of stigma and reasonable expectation of deformity-free future, leprosy-affected persons can look forward to a stress-free and normal future.

In order to ensure that, we need to have two different kinds of workplans: one, a

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Source: Srinivasan H., Disabilities in leprosy - Current situation and some suggestions. (Invited lectures) Indian J Lepr, 76 (2), 2004, 164-165 (Excerpts).

short-term programme to deal with the various problems of the existing patient population (backlog cases); and two, an integrated long-term programme to meet the bodily as well as socio-economic needs of all disabled and handicapped persons, in which those with leprosy-related issues will also be included as a matter of course.

The goals will have to be achieved in piecemeal by breaking up the problem into numerous ‘solvable units’. It is eminently feasible to have a crash programme to provide deformity correction, for all fit and willing persons through reconstructive surgery, using a camp approach.

It should be possible to identify / foster the establishment of organizations at district and state levels to manufacture and provide protective footwear at prices that will be affordable to bulk of the users.■

“sustain leprosy service after 2005.”

> *“The Second NLEP also ensured a sense of ownership and commitment among different partners working for leprosy in India. ILEP supported institutions also provided good support in RCS and other POD care services. All this support helped in better monitoring and programme management from the centre. Also this support is helping the programme in developing a sustainable leprosy service even after the project ends and elimination goal is achieved by December 2005.”*
>
> *- from WB report, 2005*

Box C

Making a sustainable programme

Sustainability is one of the ‘buzz words’ continually heard and talked about. Usually we think of sustainability in financial terms and consider ways in which programmes can be less dependent on outside supporters. It is helpful to define more clearly what sustainability means.

Sustainable programmes are those whose internal and external methods of raising finance are likely to ensure their long-term survival. This does not mean these programmes are entirely self-sufficient, i.e. depending on their own resources alone.

Rather it means they are self-reliant, i.e. are able to assume responsibility for their own futures. All programmes must work towards self-reliance, always making sure that the poorest community members and subgroups have priority.

From a holistic viewpoint, there are ways in which the programmes must be sustainable. The ideal way is in terms of the culture and ethnic values of the population.

A correct approach is to ensure that we tackle the root causes of poverty in a variety of ways such as community transformation, the promotion of social justice and working towards behavioural change to establish good health practices.

Source: Ted Lankester, Chapter 20. How to make a programme sustainable?, Setting up Community health programmes - A practical manual for use in developing countries. Published by Voluntary Health Association of India, 2nd Edition, 2002, 292-300.

Reprint

Leprosy Referral Centres: An intervention vital to sustain elimination and support integration

Leprosy Elimination Action Programme

ALERT-INDIA, Mumbai

"Leprosy Referral Centres together with Continuing Medical Education, Information, Education & Communication, Selective Special Drives and Epidemiological Monitoring & Evaluation are identified as scheme of interventions under LEAP."

Summary:

LRC (Leprosy Referral Centre) centered activities are aimed to augment the services for leprosy affected persons by involving the GHC system to sustain leprosy elimination activities during integration phase.

The LRC activities are focused to promote the integration of MDT services within the general health services, strengthening surveillance and monitoring at the local level, supporting special surveys among specific groups of population, enhancing community participation and social communication to increase awareness, entwined with capacity building of the GHC personnel, promotion of prevention of disabilities and rehabilitation activities.

1. The context

The 'intermediate goal' for elimination of leprosy, defined as 'reducing the registered prevalence rate to less than 1 case per 10,000 population' by the end of December 2005, has been achieved at the national level. '*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 general health workers in maintaining an acceptable quality of services'* [1] assure the experts. This assurance needs to be translated into a policy driven action on the ground to benefit patients through out the length and breadth of the country.

After five decades of intensive specialised leprosy control efforts, the major thrust on elimination gave birth to the policy of integration. The structural integration of leprosy services into general health care (GHC) system has taken place. The entire GHC service in the country is made

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Source: A. Antony Samy, LRC: An intervention vital to sustain elimination and support integration. Journal of Communicable Diseases, 38, 1, 2006, 15-23

responsible to detect, treat and cure leprosy. The availability of MDT through a large network of Primary Health Centres (PHCs) and Urban Health Posts (UHPs) in most parts of the country is a boon to the leprosy patients and will help to reduce social ostracism in due course of time. Indeed, this is a reliable long-term process to achieve the goal of leprosy elimination, provided an active investment is made on priority for capacity building of the GHC personnel, both medical and paramedical to diagnose and treat leprosy.

The intermediate elimination target reached need to be ascertained and sustained in all regions of the country in the coming years. In this context, transfer of responsibility to the GHC system is only a partial solution. We also need to find ways and means to ***'maintain an acceptable quality of service'*** for all the leprosy afflicted. This is a monumental task yet to be realised. A serious consideration of this task from all 'points of view' is needed to arrive at a practical and viable answer.

2. Epidemiological point of view . . .

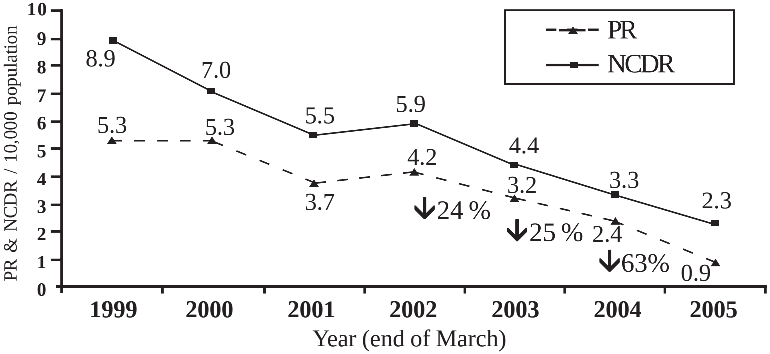
Experts say that *'mathematical modelling of leprosy indicators suggests* ***leprosy is slowly declining*** *but that the* ***rate of decline remains uncertain*** *and a sustained leprosy control is required'* [2]. However, *'the picture is different, when NCDR is used instead of PR figures. The NCDR is a better indicator of disease, because it is not affected by changing case definitions or duration of treatment* [3]. WHO presume that, *'from an epidemiological standpoint, an increase in new case detection is compatible with progress towards elimination, however sustaining leprosy control activities in the context of low prevalence conditions will continue to be a challenge in the coming years'* [4].

It is difficult to measure the leprosy incidence accurately due to operational and social factors, specially the effectiveness of case finding methods, social stigma and ignorance about leprosy. There may be areas reported 'zero' case detection, but it does not mean 'zero' incidence of leprosy. Whatsoever these indicators do not characterize the leprosy burden in a given population and must take into account disability related parameters to judge the efficacy of leprosy elimination programmes.

According to WHO, *a number of countries have demonstrated that a significant decline in the annual new case detection rates can be achieved after wide scale application of MDT for several years. The paradoxical trends with relatively stable detection rates reported in some major endemic countries (notably India, which contributes 78% of the global annual case detection) could be the result of several operational and administrative shortcomings, rather than epidemiological factor*[5].

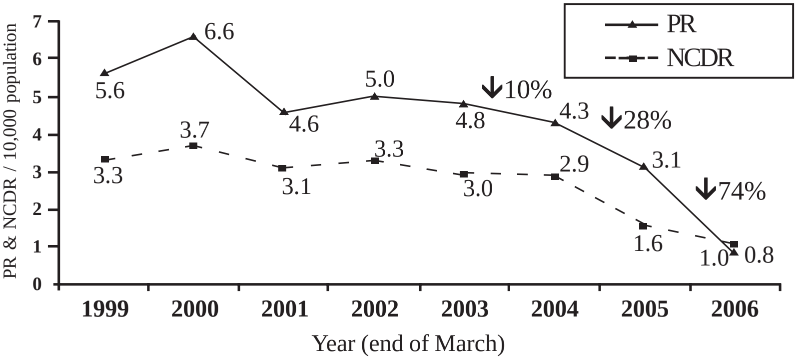
Granting operational and administrative shortcomings, one finds it extremely difficult to agree with the policy makers that the decline in epidemiological trend of the disease has fallen to the aspired

Chart 1: The trend of PR & NCDR in India [6]



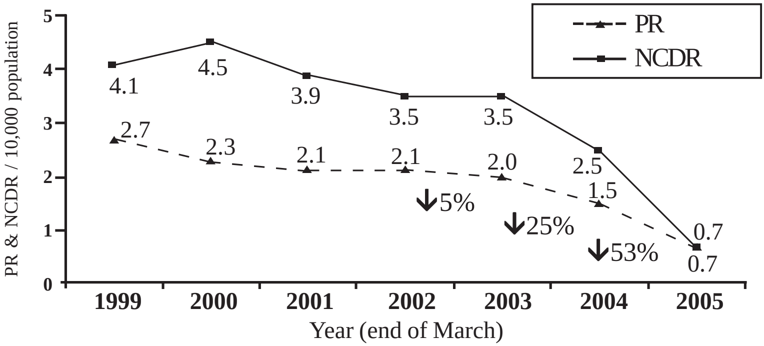
NB: Please note the sharp fall in Prevalence Rate (PR) between 2004 and 2005

Chart 2: The trend of PR & NCDR in Maharashtra state [7]



NB: Please note the sharp fall in Prevalence Rate (PR) between 2004 and 2005

Chart 3: The trend of PR & NCDR in Mumbai [8]



NB : Please note the sharp fall in Prevalence Rate (PR) between 2004 and 2005 limit in prescribed time span at all levels to meet the intermediate goal set for leprosy elimination.

The charts examine the policy driven decline of PR and NCDR from 2004 to the deadline of December 2005 in the country, Maharashtra and Mumbai. In an epidemiological situation, where the knowledge about the **specific clusters of population, where new cases occur** is limited, such a decline is unprecedented and sudden. This calls for an independent validation.

The possible empirical reasons for the sudden decline are (i) discontinuing active search for new leprosy cases and (ii) the policy directives, such as registering new leprosy cases only after the validation by the designated authority; not registering single lesion leprosy cases and deleting the patients name from the treatment register as soon as the patient receive the last pulse dose of MDT, issued to the health workers in several states.

a. Undetected new leprosy cases contribute to leprosy transmission

The incidence of new leprosy cases are geographically varying in different regions across the country. *'It is a fact that leprosy patients newly diagnosed may have transmitted the disease to others in their family or community long before the disease is detected'* [3]. WHO asserts that *'a lack of appropriate tools makes it impossible to measure the true incidence of leprosy, which would be the best indicator for monitoring the impact of elimination efforts on leprosy transmission in the community'* [4].

The GOI recommends intensive Information, Education and Communication (IEC) activities to promote voluntary reporting of new cases in the integration phase. However, lack of skills, manpower and education materials to carry out effective IEC campaigns defy easy answers to educate the community about leprosy.

This calls for special interventions during Integration phase in the absence of active case detection activities. However, one cannot expect voluntary reporting of new leprosy cases will happen to its fullest extent in the given socio-economic situation in which the rural and urban poor live.

Even with the entire anticipated positive outcome from integration, the GHC system is overloaded with number of other public health priorities and will take a long time to play a 'primary' role in timely detection of new leprosy cases in the community. Hence, the integration phase requires reliable intermediary steps that will help to sustain elimination.

LRC linked Selective Special Drives (SSDs) to reach out to all the latent cases among the new migrant population to the cities and towns, urban and rural pockets, remote tribal areas and other such population groups with high prevalence will ensure early detection, diagnosis and prompt treatment with MDT [9].

Table 1: A comparison of NCDR in general population and among healthy contacts in ALERT-INDIA Project areas

General population	**2003**	**2004**	**2005**
Population covered	2,80,036	2,85,746	2,23,085
New leprosy cases detected	279	310	113
NCDR / 10,000	**10**	**11**	**5**
Healthy Contacts of new cases	**2003**	**2004**	**2005**
Healthy contacts examined	5,654	4,687	2,686
New leprosy cases detected	62	43	19
NCDR / 10,000	**110**	**92**	**71**

Table 2: Comparision of disabled cases and NCDR trend in India

Year	NCDR per 10,000 (% of change)	Disabled among new cases
2000-01	5.5 (21%) ↓	12,955 (2.5%) ↓
2001-02	5.9 (0.07%) ↑	12,951 (2.1%) ↓
2002-03	4.4 (25%) ↓	8,545 (1.8%) ↓
2003-04	3.3 (25%) ↓	5,302 (1.4%) ↓
2004-05	2.3 (30%) ↓	4,145 (1.6%) ↑

b. Significant number of new leprosy cases detected among contacts

On examining the contacts of all new leprosy cases detected in 3 wards of Eastern suburbs of Mumbai (ALERT-INDIA's project area) during 2003 to 2005, it was revealed that more number of new leprosy cases are detected among the 'family contacts' than general population (Table 1). Although, the overall NCDR in the entire project area is only 0.9 / 10,000, the NCDR among the contacts is 71 / 10,000 during 2005.

LRC linked surveillance of all new leprosy cases and their contacts definitely help to unearth a reasonable number of new leprosy cases. LEAP plans to reach out to such known potential population group with the help of Mumbai Corporation, Government and Non-Governmental Organizations (NGLOs).

c. Accumulation of disabled persons due to leprosy

Government of India (GOI) reports that '*there are 6.7 lakhs (5.8%) out of 11.5 million leprosy patients registered during the last 3 decades (1984 to 2005) had visible (Grade II) disability in India*' [10] Increase in the proportion of disabled among the new cases detected during 2004-2005 (Table 2) is causing a concern.

The reason for the above situation is obvious. Even during decades of intensive surveys, the detection has been delayed due to reasons of inadequate coverage and persisting ignorance of early signs of disease in the community. Now the indications are that the disabled among the new cases would be higher in the coming years in the absence of active early case detection. '*It is vital to maintain continuing case detection, providing treatment and meeting the long term challenge of preventing disability*' [3]. Hence, the continuation of intensive public education linked to LRC is all the more necessary to promote early reporting of new cases voluntarily.

3. Operational point of view . . .

The WHO believes that, '*the problems facing disabled people at the community level need to be considered in their entirety, whatever the primary cause of the disability. Thus, access to all existing programmes that provide for the social and economic welfare of the disabled, including community-based rehabilitation, should also be available to leprosy-affected persons*' [12].

This is ideal, but the ground reality is different. Equipping the GHC personnel with adequate knowledge and skills especially at the district level hospitals and institutions is a long term objective to be accomplished.

Disabled leprosy patients today cannot wait until the GHC system is fully enabled to cater the needs of leprosy patients with disabilities and deformities. LRC will serve as a 'vehicle' located amidst GHC facilities as a 'reliable expertise' and 'multi-service unit' for prevention and care of deformities in addition to confirmation of diagnosis (when needed), smear facilities, management of complications (reactions / neuritis) today and equip the GHC personnel for tomorrow [2].

4. Integration point of view . . .

Effective partnership can help to sustain leprosy elimination during integration phase. Considering the huge magnitude of post-elimination problems to be tackled, there is a need for sharing the knowledge and resources. There is a need to end the legacy of vertical programme by strengthening the partnership with the public health system to sustain the leprosy elimination activities. Creating effective linkages with the existing institutions who offer specialised services such as surgery, aids & appliances and vocational rehabilitation will also substantially help to meet the needs of the leprosy affected persons. LRC can act as a 'catalyst' for partnership with medical, surgical & rehabilitation institutions, interact with GHC personnel, exchange the expertise available at GHC & private sector in to meet the special needs of leprosy afflicted persons [12].

5. Social commitment point of view...

From the social point of view, 'm*any leprosy patients are marginalised by their communities after being diagnosed. Stigmatization continues and it needs to be combated using community based approaches'* [3]. It is totally unjust to leave the leprosy disabled today at the 'mercy' of the presently available services in the public health system for disability prevention and care. The system is largely inadequate and unprepared. The public health system is already over burdened with multiple disability loads. The net result will be additions to the leprosy colonies and rehabilitation institutions. Hence, there is a need to create a network of referral services for long term care of all disabled due to leprosy to protect and restore functional abilities. LRCs are required to be established at regional and district levels to provide adequate care and services to a large number of leprosy patients living with disability today and the additions to the pool every passing day.

Leprosy patients must have equal access to appropriate treatment on par with other diseases. Services for early diagnosis, management of complications and disabilities through trained manpower are made available at places, easily accessible for patients. LRC can serve as a 'sign post' for the public and patients during integration phase, located in publicly known places, providing comprehensive and quality care to all leprosy patients in a patient-friendly environment [12].

6. Capacity building point of view...

Specialised centres in the public health system need to be fully utilized for the management of chronic reactions, plantar ulcers, ophthalmology and hospital care with appropriate orientation and training in leprosy. LRC can become the mainstay of an effective linkage between the leprosy patients and the specialists / institutions, located at the existing municipal, government and private health facilities. Departments of Dermatology in teaching Medical colleges can be enabled to function as LRCs with appropriate training and manpower. Capacity building through CME programmes with specific placement / exchange programmes at leprosy specialised centres is essential.

Physical and surgical needs can also be effectively met by the mainstream of Physical Medicine and Rehabilitation (PMR) department in medical colleges and government institutions in the country. However, the need to change the curriculum of rehabilitation professional courses in tune with leprosy disability services is yet to be realised. Following the recent interactions with PM&R professionals through a National Workshop at Mumbai in 2005, recommendations for curriculum change in medical education and related professional courses were suggested. The recommendations are likely to become part of Sixth Five Year Plan.

7. Policy point of view . . .

WHO recognizes the *'need for "referral" services to sustain quality services in the integrated setting'* [4]. GOI proposes *'to develop a suitable referral system for providing quality services by involving established NGO / Institutions'* [11]. One takes consolation by the fact that the GOI's policy is categorical in asserting that '*it is necessary to extend the NLEP up to March 2007 for reaching elimination of leprosy in most of the districts, i.e. till the end of 10th Plan and the programme will continue with NLEP partner organizations'* [11]. The activities proposed under this plan will be crucial to sustain the intermediate goal achieved with lot of extraordinarily active official policy changes and interventions.

Ideally, at least one LRC need to be established at regional and district level in the country. The existing NLEP units and NGOs working for leprosy can facilitate establishing new LRCs to offer timely, comprehensive & quality services to leprosy patients during integration phase and beyond.

Need for a practical intervention strategy

Despite bringing down the overall prevalence of leprosy, new cases continue to surface. Among the new leprosy cases, a significant number of them are detected / reported with early disabilities and deformities. There is a huge backlog of leprosy cured persons with residual disabilities and deformities in addition to leprosy patients prone to develop new disability and deformity.

WHO admits that *'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 multi-drug therapy (MDT), prevention of disability and rehabilitation. This will not change over the coming years. The emphasis will remain on providing diagnostic and treatment that are equitable distributed, affordable and easily accessible'* [12].

Therefore, *'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* [3]. Continuing transmission and increasing burden of disability due to leprosy will remain as a challenge for many years to come unless a renewed strategy with active approach to leprosy management is pursued by all stakeholders.

Leprosy Elimination Action Programme

This calls for a practical intervention strategy that supports integration and sustains leprosy elimination in a real sense of the term. Leprosy Eliminaton Action Programme (LEAP) promoted by ALERT-INDIA during integration phase, is a planned transition from the predominance of vertical leprosy programme and services to an action programme, focussing on community partnership strategies. The objective of LEAP is to meet all the needs of leprosy affected persons by utilising the best potentials available today with the NLEP and dovetail with the services and facilities in the public health system through a partnership approach.

Leprosy Referral Centres (LRCs) together with Continuing Medical Education (CME), Information, Education & Communication (IEC), Selective Special Drives (SSD) and Epidemiological Monitoring & Evaluation (EME) are identified as scheme of interventions under LEAP [13].

Establishing LRC in partnership with public and private health care providers, NGLOs and NLEP institutions is an immediate possibility to meet the needs of leprosy patients in the present phase. LEAP promotes such partnerships. LEAP promoted and assisted Government, Municipal Corporation and other NGLOs to establish seven LRCs in urban, rural and tribal areas of Mumbai, Thane and Raigad districts based on the principle of sharing resources, expertise and manpower.

In future, LEAP proposes to establish LRCs in four backward and tribal districts of Maharashtra in partnership with district NLEP units. ALERT-INDIA has also established, in its project areas at Mumbai and Navi Mumbai, six LRCs since 2004, out of which five are located in the municipal hospitals / dispensaries and medical colleges.

8. The Future

LRCs can help us make a difference for the patients of today and tomorrow. In places where such services do not exist, LRCs need to be established. LRC should be need based and can be located at block or district or regional level. All necessary infrastructures needed to offer specialised services should be ensured. At the district level, the facilities available with the existing general hospital should be availed.

LRC should promote partnership with GHC. The expertise of professionals such as surgeons, ophthalmologists, dermatologists, physiotherapists and rehabilitation experts available with GHC can be utilised for LRC by exchange and / or interaction programmes.

This will pave way for continuation of services to the leprosy affected in the general health sector and provide for sustainability. The dependence on specialised leprosy personnel should be eventually minimised.

In fine, LRCs can help us to make leprosy elimination sustainable and enduring.■

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Box D

Specialized element for leprosy

World Health Organisation (WHO) has accepted the principle of integrating leprosy control into general health services wherever possible, whilst at the same time, underlining the importance of maintaining a vertical specialised element at various levels of the programme, for supervision, referral facilities, drug supply and financing.

Integration will help in maintaining MDT services at the peripheral level, especially in areas where prevalence is declining. Several national programmes, even in countries with very high prevalence, have integrated leprosy services, mainly because of the urgent need to expand MDT coverage.

However, it is important to have an element of a specialized programme in all endemic countries, either at the central level or — in some larger countries — at intermediate level.

This specialized element for leprosy will be needed for providing technical guidance, for monitoring and evaluating the progress of elimination, for training and for research purposes.

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

Source: Handing Over. WHO, SEARO; New Delhi. Website: http://w3.whosea.org/leprosy/theplan.htm

Disabling conditions in South Asia : The hidden factors with implications for Leprosy

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"The specialists and referral centres that should have been developed to support the front line have often fallen victim to 'anti-institutional' rhetoric of the 1980s and 1990s."

Elimination of leprosy "as a public health problem" may be achievable in South Asia through Multi-Drug Therapy, within a few years. Management of disability in cured leprosy patients will nonetheless continue through the 21st century, probably with some stigma. Disabilities in leprosy are targeted for eradication or severe reduction, using affordable surgery or preventive measures; yet this have proved unexpectedly resilient. Experience suggests that technical solutions alone bring only partial success. They must be backed up by individual and family self-help, community participation in service provisions, and a redeployment of professional expertise.

In the current South Asian population of c. 1400 million, the WHO-backed target would be reached by bringing the number of registered 'active' leprosy cases down below 140,000. Yet even if that occurred, and the data were genuine, the visible human "problem" of leprosy would take at least a further century to disappear, with the eventual death of people who had leprosy-related disabilities and who could not, or did not wish to, gain access to rehabilitative care. Such outcomes, though feasible, are hardly the sharp, clear-cut, objectives that would be politically attractive.

Conflicts between vertical and horizontal approaches have appeared not only in the health field but also in disability services. Some people place Community Based Rehabilitation (CBR) in opposition to institutions or centres, though the WHO CBR scheme makes clear the need for referral centres with specialised skills.

After many futile struggles it has become clear that the knowledge, skills and design accumulated under careful scrutiny in the best of the specialised approaches are vital to the success of the best integrated community-based approaches, while the community resources and links are vital for disseminating knowledge, skills and design to people in the community. Thus, the expertise of people who have been

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Source: Miles. M., Knowledge and management of disabling conditions in South Asian Histories: Implications for leprosy futures. Indian J Lepr., 75 (2), 2003, 153-167 (Extracts)

working for 30 years in vertical leprosy schemes, for example, should neither be dispersed nor ignored.

It needs to be adapted and applied in the newer policy, so that people who have spent 30 years in primary health care schemes need not spend years discovering for themselves all the complexities and peculiarities of leprosy. Better results come by enlisting and sharing the existing information resources, and being open about the knowledge gaps.

"Leprosy-expert" staff and "CBR-expert" staff should observe, value and acquire one another's skills", and also makes clear that the cumulative experience of people with leprosy, and their own organisations, now make a valued contribution to the sum of "expertise".

The specialists and referral centres that should have been developed to support the front line have often fallen victim to 'anti-institutional' rhetoric of the 1980s and 1990s. In the long run it must be these human resources that tackle the social problems that continue after technical solutions have been applied to leprosy and other disabling diseases and conditions.

This has been seen elsewhere in the world where people often had narrower and shallower historical cultures on which to draw, but applied themselves successfully to improving the social context and facilitating inclusion of those with disabilities. ■

Box E

Perception of Quality Care

In recent years recognition has grown among researchers and policy makers that quality health care is determinant of the utility and success of the health servics.

Quality care has been defined by WHO as *"the extent to which the care provided within a given economic framework, achieves the most favourable outcome balancing risks and benefits"*.

However besides complicated technical definitions "consumer's satisfaction" is an important performance indicator.

Patient's satisfaction is commonly defined as the relationship between the perceived quality of care at the end of the process in relation to the expectations prior to its inception.

Health care system emphasizes on technical performance but mostly neglects consumers' needs that fall outside the biomedical definition of health.

Patients give high ratings to technical quality automatically, either because they feel they cannot judge it very well, or because it is threatening to admit that the technical care one has chosen is not of the highest quality. This implies that satisfaction expressed by patients reflect quality only for the non-technical aspects of care.

Further, satisfied consumers will have satisfied providers, as it is a vicious circle, supplementary & complementary.

Source: Shakuntala Chhabra., Sandhya Mishra., Perception of Quality care at Tertiary Care Facility, Health for the Millions, Vol.32, Issue 2: 2006; p 13-18.

Special attention to prevent deformities, blindness and damage to insensitive areas

Consultations for specialized care

Dr. Ramaratnam Sridharan

"Physiotherapy and occupational therapy are essential in patients with paralysis because of neural involvement. In patients who undergo rehabilitative surgery, such as tendon transfers, muscle-reeducation exercises are essential."

Surgical care

- A multidisciplinary team comprising a leprologist, a neurologist, physical and occupational therapists, and a surgeon with experience in peripheral nerve surgery is needed.
- Surgical treatment of an acute nerve abscess is careful incision of the nerve sheath and draining the abscess. Surgical neurolysis or even fascicular dissection has been advocated to relieve intraneural pressure.
- Surgical treatments for eliminating anatomically restricted areas (constrictions) improves sensation in selected patients and often prevents further deterioration. Optimal timing for nerve decompression needs to be established.
- Nerve decompression is used when signs of entrapment have not cleared after 3-4 weeks of steroid therapy, when function deteriorates despite steroid therapy, or when signs of nerve abscess or chronic entrapment are evident.
- Posterior tibial neurovascular decompression by release of flexor retinaculum with systemic administration of steroids may be beneficial in early acute or silent neuritis. Distal compression of plantar branches should be relieved by slitting the calcaneal bands and ensuring free passage of the plantar branches to the sole of the foot. Nerve function (particularly autonomic and sensory modalities) can recover considerably. In some cases vascular decompression may help heal chronic plantar ulcers and prevent recurrence.
- Peripheral nerve reconstruction performed by using denatured muscle autografts may help to restore protective sensation in hands and feet.
- Nerve grafts may be helpful for patients with localized nerve lesions.
- Cosmetic surgery may be contemplated after leprosy is medically controlled. Procedures include excision of redundant skin in ear lobes and

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Source: "Neuropathy of Leprosy" by Dr. Ramaratnam Sridharan, HOD, Neurology, Apollo Hospital, Chennai, India, http://www.emedicine.com/neuro/NEUROMUSCULAR_DISEASES.htm.

eyelids, excision of excessive breast tissue in gynecomastia, implantation of islands of scalp hair to replace lost eyebrows, and nasal reconstruction.

- Facial-nerve palsy with associated lagophthalmos may be corrected by performing tarsorrhaphy or canthoplasty to prevent exposure of cornea or by tunneling a slip of temporalis muscle attached to tendon through the lid and attaching it to the inner canthus. Re-education involves closing the jaws to effect eye closure.
- Tenodesis to stabilize joints, arthrodesis to correct clawing, and tendon-transfer surgery may be considered. Tendon-transfer procedures may be used to replace paralytic muscles with functioning ones, especially to restore action.

Consultations

Patients with leprosy are best referred to specialized centers with expertise in leprosy management.

- Consultation with an orthopedic surgeon is recommended for the management of trophic ulcers and for tendon-transfer surgery.
- Consultation with an ophthalmologist is recommended for the management of ocular complications.
- Consultation with an otorhinolaryngologist may be helpful for patients who have nasal symptoms.
- Reconstructive surgeon with special interest in leprosy and nerve surgery may be of assistance.
- Specialists in physical medicine and orthotics should be consulted.
  - Physiotherapy and occupational therapy are essential in patients with paralysis because of neural involvement. In patients who undergo rehabilitative surgery, such as tendon transfers, muscle-reeducation exercises are essential.
  - The most effective healing tools for plantar ulceration are the total contact cast and the posterior walking splint. Alternatively pressure-relieving or healing devices can be made, modified, or augmented to reduce loads on foot.
  - Heel ulcers are common in those with an insensitive foot and who need long-term bedrest or positioning during surgery. These ulcers can be located on the medial, lateral, or posterior aspect with a plantar component.
  - A boot is cut to appropriately relieve the area. When the wound closes, permanent footwear and orthotics are fitted to prevent reulceration.
  - All options used for the wound-healing phase and initial ambulation after wound closure must include use of an assistive device for partial weight bearing, preferably with crutches or a walker.
- Consult a psychologist to deal with the social aspects of the disease. ■

POID manuals
for health workers and leprosy affected persons

- ALERT-INDIA has designed three informative manuals on self-care with colourful illustrations and images with clear instructions to patients having disabilities and deformities due to leprosy.

- Another manual on prevention of deformity for service providers deals with assessment to detect early nerve damage in hands, feet and face, in addition to management of complications and deformities.

- These manuals are available in Marathi. Hindi version is under preparation.

LEAP EVENTS

Physiotherapy Technician of Govt. NLEP Unit explaining the role of aids & appliances in preventing deformity during training session on POID for GHCS staff at Vajreshwari, Thane district.

Skill Development Training to LRC Team of The Society for Eradication of Leprosy (SEL), Mumbai at St. George's Hospital.
SEL manages the LRC at St. George's Hospital.

Physiotherapy Technician explaining use of MCR footwear to Medical Officers of MCGM at LRC, S. K. Patil Hospital, Malad, Mumbai managed by Maharashtra Lokahita Seva Mandal (MLSM).

LEAP Support Team (LST) conducting sensitisation programme for NLEP staff of Gadchiroli District, prior to starting a LRC.

Have we won
the first battle against leprosy?

It seems like, we are entering
a new phase in leprosy control.
But without the largesse of governments,
without the consensus of stakeholders,
without the continued, unified effort of those in the programme,
and without the persistent pursuit of ‘quality’
as the centre-stage of all actions,
the “clear-sky” optimism will remain at best a self-indulgence and
we will be prevailed upon
to remain on the battle ground for a long, long time.

Dr. Krishnamurthy P., Have we won the first battle against leprosy?.
Indian J Lepr 78: 2, 2006, 103-104.